

# Developing consensus on what constitutes ‘success’ following upper limb loss rehabilitation

A thesis presented to Dublin City University for the Degree of Doctor of  
Philosophy

By

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## Table of Contents

Declaration.....	ii
Acknowledgements.....	iii
Table of contents.....	iv
List of tables.....	vi
List of figures.....	vii
List of Appendices.....	viii
Abbreviation List.....	x
Abstract.....	xi
Summary of thesis.....	xii

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## **Chapter 1 Literature Review.....1**

1.1 Literature review overview	3
1.2 ULA epidemiology	5
1.3 Outcomes and associated variables	10
1.4 Outcomes Assessment	65
1.5 Lessons from Disability Studies	68
1.6 Research Statement	72

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## **Chapter 2 Thesis Methodology.....74**

2.1 Mixed method design	76
2.2 Pragmatism	77
2.3 Present study design	78
2.4 Thematic analysis	82
2.5 Method of analysis	84
2.6 Reflexivity	86
2.7 Summary of methodology	87

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## **Chapter 3 Repertory Grid Interviews: Exploring perceptions of prosthetic devices.....88**

3.1 Introduction	90
3.2 Method	96
3.3 Results	101
3.4 Discussion	117

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<b>Chapter 4 Qualitative Studies: Identifying factors of importance to consider in ULA rehabilitation .....</b>	<b>123</b>
4.1 Introduction to qualitative studies 1 & 2	126
4.2 Method for study 1 & 2	135
4.3 Results for study 1 & 2	142
4.4 Discussion of Studies 1 & 2	199
<hr/>	
<b>Chapter 5 Delphi study: Reaching consensus on ‘success’ following ULA and factors of importance to consider in rehabilitation.....</b>	<b>222</b>
5.1 Introduction	225
5.2 Method	236
5.3 Results	245
5.4 Discussion	269
<hr/>	
<b>Chapter 6 Thesis Conclusion ... ..</b>	<b>283</b>
6.1 Review of the rationale for conducting this research	285
6.2 Summary of findings	287
6.3 Implications of research	292
6.4 Concluding comments	297
<b>References.....</b>	<b>298</b>
<b>Appendices.....</b>	<b>332</b>
<b>Research Dissemination.....</b>	<b>476</b>

## List of Tables

Table 1.1	Key studies that measure prosthesis use that are discussed in this review .....	40
Table 1.2	Overview of variables assessed by main studies in relation to prosthesis use .....	46
Table 3.1	List of elements for Repertory Grid .....	98
Table 3.2	Randomly generated sets of elements.....	98
Table 3.3	Jennifer's Grid.....	102
Table 3.4	Declan's Grid.....	109
Table 4.1	Demographic information for individuals with ULA .....	139
Table 5.1	Demographic information for all participants across 3 rounds.....	245
Table 5.2	Demographic information for all RP's across rounds.....	246
Table 5.3	Years experience working with people with ULA.....	247
Table 5.4	Demographic information for all individuals with ULA across rounds ....	248
Table 5.5	Further demographic information regarding individuals with ULA.....	249
Table 5.6	Demographic data for individuals who are RP's with ULA.....	250
Table 5.7	Further information regarding individuals who are RP's with ULA .....	250
Table 5.8	Analyses of differences between RP's (Group 1) and those with ULA (Group 2) across rounds.....	254
Table 5.9	Analyses for those who completed/ did not complete round 2 on their round 1 statements/ items .....	255
Table 5.10	Analyses for those who completed/ did not complete round 3 on their round 1 and round 2 statements/ items .....	256
Table 5.11	Means and standard deviations of 'Prosthesis use' statements.....	259
Table 5.12	Means and standard deviations of 'Activities and Participation' statements .....	261
Table 5.13	Means and standard deviation for 'Self image' statements .....	262
Table 5.14	Items that should be taken into consideration by RP's in rehabilitation....	264
Table 5.15	Section 2 items that were rejected by participants .....	266

## List of Figures

Figure 1.1 Levels of upper limb absence from NASD (2009).....	7
Figure 1.2. Cause of limb absence amongst individuals with ULA and lower limb absence from NASD (2009).....	8
Figure 2.1 Design of thesis.....	82
Figure 5.1. Overview of Delphi procedure.....	240

## List of Appendices

Appendix A	Exemplar of coded data extract from an interview with a psychologist.....	334
Appendix B	Information sheet for repertory grid study.....	336
Appendix C	Letter of invitation to participants for repertory grid study.....	341
Appendix D	Consent form for repertory grid study.....	343
Appendix E	Demographic questionnaire for repertory grid study.....	346
Appendix F	Interview guide for RP's qualitative interviews.....	349
Appendix G	Email invitation to RP's for participation in qualitative studies.....	351
Appendix H	Information sheet for RP's qualitative interviews.....	353
Appendix I	Consent form for RP's qualitative interviews.....	359
Appendix J	Interview guide for qualitative study with individuals with ULA.....	362
Appendix K	Letter of invitation to individuals with ULA for qualitative study.....	364
Appendix L	Information sheet for qualitative study with individuals with ULA....	366
Appendix M	Consent form for qualitative study with individuals with ULA.....	370
Appendix N	Brief questionnaire for qualitative study with individuals with ULA...	373
Appendix O	Poster for recruiting additional participants with ULA for qualitative study.....	376
Appendix P	List of Delphi items and how they were generated.....	378
Appendix Q	Text of email invitation to individuals with ULA to participate in round 1 of the Delphi study .....	385
Appendix R	Text of email invitation to RP's to participate in round 1 of the Delphi study.....	387
Appendix S	Information sheet for individuals with ULA for Delphi study.....	389
Appendix T	Information sheet for RP's for Delphi study.....	394
Appendix U	MS Word document version of Delphi questionnaire for round 1 for individuals with ULA.....	399
Appendix V	MS Word document version of Delphi questionnaire for round 1 for RP's .....	417



Appendix W	MS Word document version of Delphi questionnaire for round 2 for both groups.....	435
Appendix X	Word doc Delphi questionnaire for round 3.....	450
Appendix Y	Round 2 qualitative responses that were provided to participants in Round 3.....	465
Appendix Z	Frequency distribution of accepted and non-accepted items in Section 2.....	472

### Abbreviation List

<b>ADL</b>	Activities of Daily Living
<b>AT</b>	Assistive Technology
<b>BDI</b>	Beck Depression Inventory
<b>DASH</b>	Disability of arm, shoulder and hand
<b>GAS</b>	Goal Attainment Scaling
<b>GHQ</b>	General health Questionnaire
<b>HADS</b>	Hospital Anxiety and Depression Questionnaire
<b>HRQOL</b>	Health related quality of life
<b>ICF</b>	International Classification of Functioning and Disabilities
<b>IPA</b>	Interpretative Phenomenological Analysis
<b>MDT</b>	Multidisciplinary Team
<b>MPT</b>	Matching Person and Technology
<b>NASD</b>	National Amputee Statistical Database
<b>NHP</b>	Nottingham Health Profile
<b>NRH</b>	National Rehabilitation Hospital
<b>PCP</b>	Personal Construct Psychology
<b>PGI</b>	Patient Generated Index
<b>PLP</b>	Phantom Limb Pain
<b>PLS</b>	Phantom Limb Sensation
<b>PRS</b>	Prosthetic Rehabilitation Score
<b>PROMIS</b>	Patient Reported Outcomes Measurement Information System
<b>QOL</b>	Quality Of Life
<b>RGT</b>	Repertory Grid Technique
<b>RP</b>	Rehabilitation Professional
<b>RLP</b>	Residual Limb Pain
<b>TAPES</b>	Trinity Amputation and Prosthesis Experience Scale
<b>TMR</b>	Targeted Muscle Reinnervation
<b>TSR</b>	Targeted Sensory Reinnervation
<b>ULA</b>	Upper limb absence

## Abstract

The aim of this research is to explore what constitutes success following upper limb absence (ULA), and to reach consensus on which areas are important to consider in the rehabilitation of an individual following ULA.

Following a review of the literature on ULA, two case studies using the repertory grid technique (RGT) was undertaken with two prosthesis users in order to understand the unique requirements that upper limb prosthetic users may have. Following this, eleven interviews were conducted with Rehabilitation Professionals (RP's). Two focus groups were also conducted with a total of seven individuals with ULA and one to one interviews with four additional individuals were used to supplement these focus groups. These qualitative studies were conducted in order to determine prominent factors of importance following ULA from both perspectives. All data were analysed using thematic analysis. This study culminated in a Delphi study in order to reach consensus regarding what is considered successful outcomes in three key areas: 'Prosthesis use', Activities and Participation' and 'Self image' where there is currently little knowledge or agreement in the literature. The Delphi also aimed to identify the salient factors that are important for RP's to take into consideration following ULA.

The RGT produced a unique profile of preferences regarding prosthetic technologies for each participant. The qualitative analyses with RP's and individuals with ULA produced common themes such as 'Prosthesis Use', Activities and Participation', 'Psychological factors', 'Physical factors', 'Social factors', 'Satisfaction with the prosthesis' and 'Satisfaction with the service'. However, the emphasis within these themes differed amongst RP's and individuals with ULA. Consensus was reached in several areas following the Delphi study, which revealed core factors and items to consider.

This study identified what RP's and individuals with ULA believe constitutes success in three key areas and identified the most important factors that RP's should consider in the rehabilitation setting. These factors will provide a guide for RP's in assessing the progress of individuals with ULA and identifying the important areas to target in rehabilitation.

## Summary of Thesis

The majority of research concerned with major limb absence has focused on lower limb absence, with comparatively fewer studies concerned with the rehabilitation of individuals with upper limb absence (ULA). Chapter 1 discusses the differences between ULA and lower limb absence and argues that there is a need for more research to be conducted with individuals with ULA and to investigate these different populations separately in research. This review discusses how the bulk of research in ULA focuses on identifying the determinants of prosthesis use, and that there are few studies investigating the determinants of other rehabilitation outcomes, such as psychosocial and functional/physical outcomes where there are numerous gaps in the literature. A review of the literature also demonstrates how variances in how studies define ‘successful prosthesis use’ makes it difficult to compare across studies and reach consensus on the determinants of prosthesis use; as well as proposing that current definitions of ‘successful prosthesis use’ are quite restrictive and are not taking the patients perspective into account. This review discusses how it is important to identify all aspects of rehabilitation outcomes, while focusing on holistic care, in line with bio-psychosocial model and person centred care. The chapter concludes with a statement of the intentions of the research, which is to reach agreement on what constitutes a successful outcome following ULA and to identify the important factors to attend to in ULA rehabilitation.

Chapter 2 provides a rationale for using a mixed method design in the present study, which incorporates both qualitative and quantitative methods to achieve the studies aims. A mixed method design was chosen as it is commonly argued that the sum of qualitative and quantitative methods is greater than the individual parts (Barbour, 1999). Additionally, it can be particularly useful to use a mixed method design in areas where there is little knowledge on a particular subject as it expands the scope of enquiry by accessing a wider range of data (O’ Cathain & Thomas, 2006). There were two phases of study in this research, a qualitative phase, followed by a quantitative phase. The qualitative components (repertory grid, interviews and focus groups) are important because they allow a research problem or issue to be explored or a complex detailed

understanding needed. The data from the qualitative phases informed the quantitative Delphi phase which aimed to reach agreement on what has been elicited to date from the qualitative elements of this thesis.

The aim of Chapter 3 was to demonstrate the use of an individualised technique, the repertory grid, for exploring person-prosthetic fit amongst two upper limb prosthetic users, one of which used a conventional body powered prosthesis and another used a high tech prosthetic limb. The rationale for using the repertory grid was that when matching a person with a prosthetic device it is important to match the person's values and preferences with the prosthesis, therefore an appropriate personalised tool is needed to assess these needs. This study successfully demonstrated how the repertory grid is useful amongst two entirely different prosthesis users and gained access to what is important to them in terms of selecting a prosthesis and identified how they feel about alternative prosthetic devices.

The purpose of the study discussed in Chapter 4 was to elicit the factors of importance involved in the rehabilitation of individuals following upper limb loss from the perspective of RP's and individuals with ULA. This study also wished to use qualitative research techniques to demonstrate the importance of researching the perspective of the RP and the individual with limb absence. The study aims were achieved by using interviews with RP's and focus groups with individuals with ULA (supported by one to one interviews with additional participants). The analyses did not find the differences expected at the beginning of this study such as RP's being more likely to be far more concerned with the physical/ prosthetic aspect of disabilities and physical functioning in general compared to individuals with ULA, as all participants provided a discussion of diverse range, of psychological, social, and physical issues. However, the results showed that both groups shared common themes but they had different emphases within these themes. This study identified a general portfolio of issues of importance to both RP's and individuals with ULA, such as 'prosthesis use', 'function incorporating activities and participation', 'physical factors', 'psychological factors', 'self image', 'satisfaction with the service,' and 'satisfaction with the prosthesis'.

A three round Delphi questionnaire was used in Chapter 5 to reach consensus on what constitutes a successful outcome in three key areas, where the research literature and the qualitative phase demonstrated that there is limited knowledge or disagreement: 'prosthesis use', 'activities and participation' and self-image'. The Delphi also wished to seek a consensus on what factors should be considered by RP's for successful rehabilitation. The items for the Delphi study were identified through information from the literature on ULA and the qualitative data the repertory grid study in chapter 3 and the focus groups and interviews with RP's and individuals with ULA in chapter 4. The main results reached consensus on statements that suggest that successful outcomes of prosthesis use include when a person 'wears a prosthesis for specific activities', 'wears a prosthesis as often as they wish' and 'uses the prosthesis as intended'. In relation to 'activities and participation' consensus was reached on statements that indicate that a successful outcome is a person's ability to perform their own personal care and activities of daily living without help from other people. With regard to 'self-image', participants felt that a successful outcome included people not feeling self-conscious when in public with a prosthesis. This study also identified 46 items that are considered important for RP's to take into consideration when rehabilitating an individual with limb absence. These items belonged to seven major categories such as: 'Engagement in Activities and Participation', 'Physical factors', 'Prosthesis use', 'Psychological factors', 'Rehabilitation service', 'Self image', and 'Social factors'. The category of 'Demographic factors' which consisted of 'age at amputation', 'gender' and 'level of education' were not considered important by participants to take into consideration.

This thesis concludes with a final chapter which provides a summary of the study findings and how each of the chapters interacts. The chapter highlights the contribution that this study has made regarding clarification of what constitutes a successful prosthetic outcome, since consensus in this area has been lacking in the research literature. This study asserts that what RP's and individuals with ULA consider to be prosthesis success (can include an individual using a prosthesis for specific tasks; and that constant prosthetic use is not necessary for prosthesis success) contrasts with what is measured as success in the research literature (generally greater hours prosthesis use indicating greater success).

Additionally, this research has clarified what RP's and individuals with ULA consider to be success regarding 'activities and participation' and 'self-image', where there has been little research in ULA literature to date. This study suggests that a brief, more accessible individualized method to assess a person's own interpretation of what constitutes a successful outcome following absence of an upper limb is needed in order to ensure that individuals with ULA are meeting their own goals of importance. Another important contribution from this study is the identification of seven key areas that are important for RP's to attend to in the clinical setting, with specific items of importance also identified. These findings could be developed in future research to develop a screening tool for clinicians to use with individuals with ULA, to ensure all aspects important to the patients adjustment is attended to and to identify at risk areas of adjustment. Additionally the focus of both RP's and individuals with limb absence on the need to attend to the psychological care in the clinical setting regarding individuals with ULA, with both groups indicating throughout the research that psychological factors should be taken into consideration by RP's in rehabilitation. This study successfully demonstrated the usefulness of mixed methods design and including both RP's and individuals with ULA, as both groups contributed meaningfully to the study at every stage and elicited important factors that were unique and common to both perspectives.

## Chapter 1 Literature Review



<b>1.1 Literature review overview.....</b>	<b>3</b>
<b>1.2 Upper limb absence epidemiology.....</b>	<b>5</b>
1.2.1 Incidence and Prevalence.....	5
1.2.2 Conclusion.....	9
<b>1.3 Outcomes and associated variables.....</b>	<b>10</b>
1.3.1 Psychosocial outcomes.....	14
1.3.1.1 <i>Psychological Adjustment and Distress</i>	
1.3.1.2 <i>Body image</i>	
1.3.1.3 <i>Quality of life</i>	
1.3.1.4 <i>Qualitative research and psychosocial adjustment</i>	
1.3.1.5 <i>Summary of Psychosocial outcomes</i>	
1.3.2 Functional and Physical outcomes.....	26
1.3.2.1 <i>Functional outcomes</i>	
1.3.2.2 <i>Activities and Participation</i>	
1.3.2.3 <i>Phantom limb sensation and pain</i>	
1.3.2.4 <i>Summary of functional and physical outcomes</i>	
1.3.3 Prosthesis Use .....	37
1.3.3.1 <i>Factors associated with prosthesis use: Age</i>	
1.3.3.2 <i>Factors associated with prosthesis use: Gender</i>	
1.3.3.3 <i>Factors associated with prosthesis use: Cause of limb absence</i>	
1.3.3.4 <i>Factors associated with prosthesis use: Level of limb absence</i>	
1.3.3.5 <i>Factors associated with prosthesis use: Bilateral limb absence</i>	
1.3.3.6 <i>Factors associated with prosthesis use: Absence of dominant limb</i>	
1.3.3.7 <i>Factors associated with prosthesis use: Employment</i>	
1.3.3.8 <i>Factors associated with prosthesis use: Coping strategies</i>	
1.3.3.9 <i>Factors associated with prosthesis use: Fitting time of prosthesis</i>	
1.3.3.10 <i>Factors associated with prosthesis use: Satisfaction with prosthesis</i>	
1.3.3.11 <i>Factors associated with prosthesis use: Satisfaction with rehabilitation service</i>	
1.3.3.12 <i>Factors associated with prosthesis use: Choice</i>	
1.3.3.13 <i>Factors associated with prosthesis use: Co-morbidities</i>	
1.3.3.14 <i>Additional predictors</i>	
1.3.3.15 <i>Prosthesis use summary and conclusion</i>	
<b>1.4 Outcomes Assessment.....</b>	<b>65</b>
<b>1.5 Lessons from Disability Studies.....</b>	<b>68</b>
1.5.1 Conclusion.....	71
<b>1.6 Research Statement.....</b>	<b>72</b>

### Chapter 1.1 Literature review overview

The present chapter will provide a review of the available literature on ULA. The chapter begins by highlighting the lack of epidemiological data and research in general on ULA, explaining that this may be due to the lower incidence and prevalence of ULA compared to lower limb absence. Despite this, it is still essential to conduct more research with this population, given their documented younger age and general good physical health compared to people with lower limb amputations. This review also explains that due to distinct differences between people with upper and lower limb absence, it is not sufficient to assume that findings from lower limb absence literature apply to people with ULA.

This chapter will discuss the main psychosocial, functional, physical and prosthetic outcomes that have arisen for individuals following ULA. The specific psychosocial outcomes focused on will be psychological distress, body image and quality of life. However, some of these psychosocial outcomes are interrelated. The associated factors that have been investigated in relation to these outcomes will also be discussed. This chapter also draws attention to the lack of sufficient psychosocial research on upper limb amputation and highlights the merits of qualitative research in drawing attention to the under-researched areas.

This discussion will follow with a description of the functional outcomes of ULA and how function is usually operationalised in terms of achievement of goals and engagement in activities of interest and of personal need. The main physical co-morbidities, such as phantom limb pain and residual limb pain that are likely to arise as a result of upper limb amputation are discussed in relation to how they interact with other outcomes.

Additionally, this chapter highlights the main research in upper limb absence literature as focusing on identifying the predictors (largely demographic and physical) of prosthesis use and not sufficiently investigating the role of psychosocial factors in promoting prosthesis use, nor reaching any agreement on what is 'successful prosthesis use'. This

chapter also suggests that there is a need to identify further outcomes of rehabilitation following ULA other than prosthesis use.

This chapter suggests that there are valuable lessons we can learn from rehabilitation and disability literature, incorporating the ethos of the International Classification on Functioning and Disability (ICF), which emphasises the need to acknowledge personal, psychological and environmental factors into research designs in disability studies.

The chapter concludes with a description of the intentions of the research, while providing a brief overview of how the aims will be achieved through a mixed method research design.

Relevant literature for this study was identified through databases such as CINAHL, PsycInfo, Medline, PubMed, Web of Science, Journal of Prosthetics and Orthotics and Google Scholar. Search terms included 'upper and limb', 'upper and loss', 'upper and pros\*', 'upper and amp\*', and 'upper and absence'. Articles pertaining only to lower limb absence were excluded. The reference list of relevant studies were also examined.

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## Chapter 1.2 Upper limb absence epidemiology

### ***1.2.1 Incidence and Prevalence***

It is important for each country to have national records of upper limb amputations with the purpose of documenting incidence and prevalence of limb absence in order to adequately provide for those currently living with upper limb absence (ULA) and also in order to forecast future incidence of ULA and future need for services. However, as acknowledged by Esquenazi (2004) the exact number of people who have had amputations worldwide is difficult to ascertain, as many countries do not keep records of the number of people with limb amputations. Although there is the National Amputee Statistical Database (NASD) database in the UK, this database only documents annual referrals and not total national prevalence of limb absence. It also does not appear to have records of successful prosthesis provision, use or abandonment amongst those referred. Also, this data collection ceased in April 2007 due to lack of funding. A national record of provision of upper limb prostheses and rates of use or abandonment of prostheses will be useful in order to estimate the cost of the technology that is abandoned and to find ways to reduce future abandonment. It is essential that countries such as Ireland begin to keep such records. One study in Ireland (Johnstone, Walsh, Carton & Fish, 2008) did assess the number of patients accessing prosthetic services in Irelands National Rehabilitation Hospital (NRH) and reported that a total of 2328 patients were accessing their services. However, this is not the only limb fitting centre in Ireland and therefore this figure is not representative of number of people accessing prosthetic services in the entire country. Johnstone et al (2008) did not report any further information on possible number of attendees to these other centres. Johnstone et al (2008) also did not report the percentage of patients with amputations that were not accessing prosthetic services. However, Johnstone et al (2008) did acknowledge that the NRH admission data underestimates the total number of individuals with disabilities in Ireland as it includes only people who receive services at the hospital and that many if not most other individuals with disabilities receive rehabilitation services elsewhere. They also did not report how many of these patients had ULA. This lack of information on incidence of new amputations, numbers currently living with amputations and number of users of prosthetic devices for the whole

of Ireland, makes it difficult to know and adequately address the current or potentially changing needs of individuals with amputations in Ireland.

Johnstone et al (2008) recommended that research be conducted to determine how many individuals with disabilities live in Ireland to ascertain the type of disabilities of each individual. The 2006 Irish national census acquired information about the numbers of individuals with disabilities in Ireland and reported that approximately 9% of people living in Ireland have some type of disability (Central Statistics Office, 2006). However, the census did not report the specific type of disability. Therefore amongst the percentage of individuals claiming a physical disability in Ireland, there is no knowledge of the percentage of those that have an amputation and specifically an upper limb amputation.

The NASD provided Annual reports for 10 years (1997/1998 to 2006/2007) concerning referrals to prosthetic clinics in the UK. The publication presents information on new referrals to prosthetic service centres in the UK. There is currently no data on the prevalence of the entire population of individuals living with limb absence in the UK. Therefore, this chapter will be presenting data purely on new referrals in 2006/2007 from NASD. Between April 2006 and March 2007, there were a total of 4957 individuals referred to the 43 prosthetic services in England, Northern Ireland, Scotland and Wales. It is important to remember that this figure only includes those individuals that are eligible for referral or those who wish to be referred for prosthetic rehabilitation. According to NASD, referrals following lower limb amputation account for 92% of all individuals with amputation referred. Those patients following an upper limb amputation represent 4% and congenital absence cases account for 3% of all referrals. 2006/2007 reportedly had the lowest number of overall referrals to prosthetic services since data was first collected in 1997/1998. The number of upper limb referrals was also the lowest in 2006/ 2007 with 215 referrals (NASD, 2009). However, no statistically significant difference between previous years was calculated or reported in the NASD publication.

Upper limb referrals tend to be in the younger age groups reflecting the aetiology of the condition (mainly trauma). According to NASD (2009), almost three quarters of all upper

limb referrals were aged less than 55 years. As with lower limb referrals, the majority of upper limb referrals are male (67%). However, the percentage of all female referrals under 16 is higher (14%) than the percentage of male referrals (4%) in this age group. 43% of all upper limb referrals are following transhumeral or transradial amputations. Partial hand and upper digit amputees account for 41% of upper limb referrals (NASD, 2009). Figure 1.1, based on data from NASD, demonstrates the percentage breakdown of levels of ULA in 2006/ 2007.

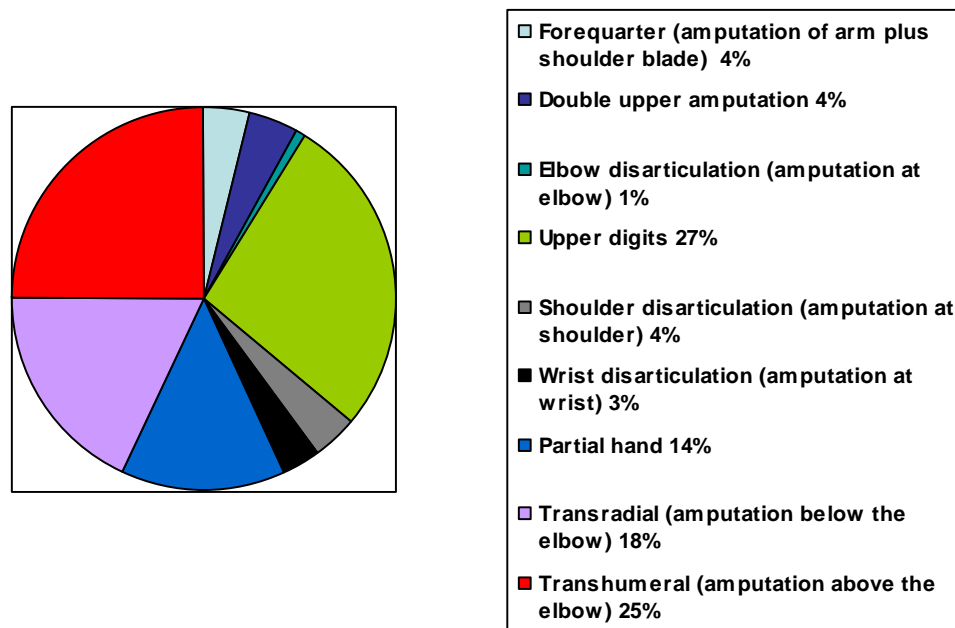


Figure 1.1 Levels of upper limb absence from NASD (2009).

NASD (2009) reported that a cause of ULA was recorded in 91% of the total referrals following upper limb amputation. Trauma accounted for 58% of all upper limb referrals, with mechanical trauma being the most common type. In terms of cause of ULA, dysvascularity (e.g. Peripheral Vascular Disease, diabetes) accounted for 11% of all upper limb referrals and neoplasia (usually a cause of tumours), 10%. Trauma is the most common cause of upper limb referrals and almost 75% of all trauma referrals are aged between 16-54. These data on cause of ULA can be compared to lower limb absence in Figure 1.2, which shows that in lower limb absence, trauma accounts for only 7% of amputations. However, dysvascularity is the most common cause of limb absence in lower

limb amputations and referrals from NASD (2009) show that 72% of all lower limb amputations were due to dysvascularity compared to only 11% in ULA (see figure 1.2).

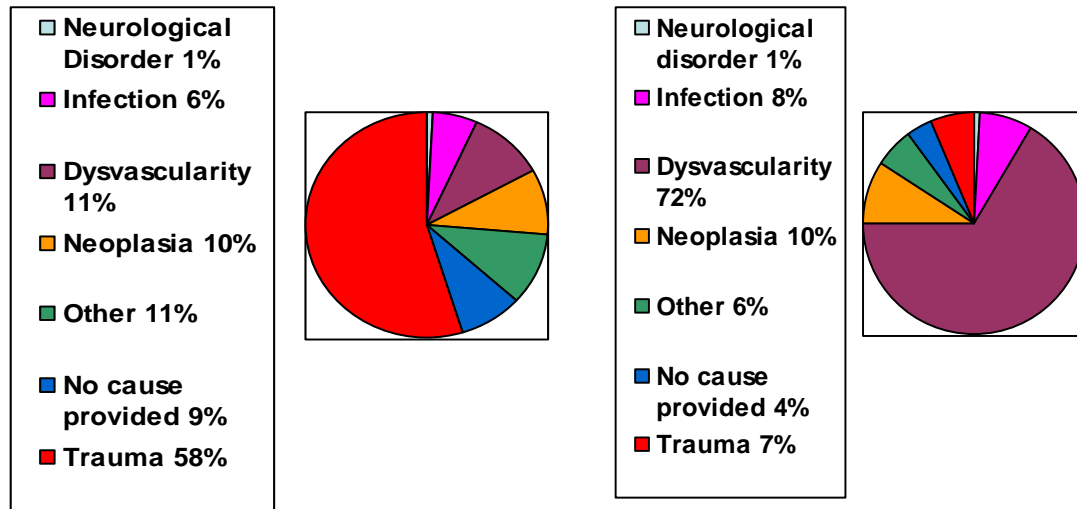


Figure 1.2 Cause of limb absence amongst individuals with ULA (left) and lower limb absence (right) from NASD (2009).

Although NASD (2009) reported only 4% of referrals to prosthetic clinics to be due to ULA, and information from the Committee of Veteran Affairs (2005) also acknowledges that incidence of ULA is generally approximately 4% in the public domain, it is important to note that this report from the Committee of Veteran Affairs (2005) observes that 35% of all amputations amongst U.S. service members from Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) involve the absence of an upper extremity. Technological advances in body armour, rapid evacuation and early medical attention in combat zones such as Iraq and Afghanistan are likely to be reason for the increased survival rate from combat situations (Pasquina, 2004), but in turn there has been an increase in the injuries of surviving service members. This dramatic proportionate increase in incidence provides support for the need to garner greater information on the needs of upper extremity amputees.

### ***1.2.2 Conclusion***

The dearth of epidemiological data on ULA reflects the general lack of research on major upper extremity limb absence. Indeed the majority of literature on major limb amputation has largely been concerned with the lower limb. Potentially, the primary reason for this is due to the relatively fewer numbers of individuals with ULA in the community in comparison to the amount with lower limb amputations. Although the data on incidence is important, due to the documented younger age of individuals with ULA, prevalence data is essential. This is because prevalence of individuals with upper limb amputations is reported to be much higher than incidence data suggests, at approximately 18% of all individuals living with amputations (NASD, 2002). This discrepancy between incidence and prevalence is due to the increased life expectancy of individuals with ULA as they tend to be younger and to lose their limbs due to trauma, in comparison to those with lower limb amputation, who tend to be older and lose their limbs as a result of illnesses such as diabetes and vascular disease. Therefore individuals that have ULA tend to require “whole life care” which may result in substantial costs to the health service. Thus, it is important that these individuals reach their full potential following rehabilitation and return to their original roles as soon as possible. In order for the rehabilitation professionals (RP's) to achieve this, it is essential to know what goals individuals with upper limb absence want to achieve and what factors will enable them to achieve them.



### Chapter 1.3 Outcomes and associated variables

It is important to be aware of how the current rehabilitation service for ULA are configured. According to the Murray Foundation, patient information leaflet, when an individual loses their limb, they will be referred to the limb fitting centre about 3-4 weeks after amputation, provided their stump is healing well. The rehabilitation team consists of the consultant, who specialises in vascular/ orthopaedics/ rehabilitation, the prosthetist, who will be responsible for provision of the prosthetic limb, the occupational therapist who will advise on daily living activities and the physiotherapist who will advise on general fitness and mobility. It should be noted that there is no explicit reference to any psychological therapists as part of the team.

The rehabilitation team will decide if the patient is ready for the limb fitting, as not all patients who undergo amputation will be fitted for an artificial limb. This may be because of other medical conditions, personal circumstances or choice. The rehabilitation team will also decide which type of prosthetic limb would be most suitable for the patient at that time, by taking into consideration, the patients' age, weight, fitness, build, lifestyle, range of activities, and patient's occupation. Once the patients has been measured and fitted with their new prosthetic limb, they will be taught how to use it, usually by the Occupational therapist. They will also be taught how to put it on, and take it off, and how to use their limb for daily functions. It is acknowledged that the new limb might be feeling awkward for a few weeks. During the first year post delivery of the new limb, the patient will continue to have appointments every few months to check their progress and also the fit of the limb (Murray Foundation Patient Information Leaflet).

In Ireland, according to the National Rehabilitation Hospital, Dun Laoghaire, patient information sheet, the patient will be assessed by an interdisciplinary team (however, it is not explicitly stated who are the members of the interdisciplinary team for initial assessment).

Team members will review the patient's assessment results with the patient and help the patient identify realistic goals for the patients' rehabilitation. Based on this assessment and your goals, specific targets are identified so treatment can begin. The rehabilitation team will develop an individualised Treatment Plan containing patients' goals. The outcomes of the Treatment Plan will be discussed with the patient to make sure they agree with the planned goals. The Treatment Plan is reviewed and updated to monitor progress towards achieving the patients' goals.

The treatment team will keep the patient and their family updated on progress and changes in goals. Every patient is offered the opportunity to invite their family to meet with select team members to discuss progress, goals and the discharge plan. This provides an opportunity for the patients' family to receive feedback and to have any concerns or questions addressed by the team. It would be beneficial to know if this process is followed routinely and what are the outcomes of this process, particularly with regard to patient satisfaction (National Rehabilitation Hospital, Patient Information Sheet).

As discussed in Chapter 1.2, there are comparatively fewer articles on ULA in the research literature compared to lower limb absence. Occasionally people with ULA and lower limb absence are investigated together in research with people with ULA serving as a comparative minority. However, often aspects of the research do not distinguish between the differing results between individuals with upper limb and lower limb absence (e.g. Gallagher & MacLachlan, 1999; Whyte & Niven, 2001; Ephraim, Wegener, MacKenzie, Dillingham, & Pezzin, 2005; Ephraim, MacKenzie, Wegener, Dillingham & Pezzin, 2006). It is important to differentiate between these two populations given their many differences. For example, Desmond (2007) acknowledged that findings from research involving people with lower limb amputations are of limited generalisability to those with ULA, due to differences in visibility/ concealability of amputation and prostheses and characteristics surrounding the circumstances of limb absence. Specifically, as described in Chapter 1.2, individuals with ULA are more likely to be young males of working age, which reflects the most common cause of ULA, trauma (NASD, 2009). In contrast, lower limb amputations tend to be caused by vascular and diabetes related issues associated with

increasing age which can affect both males and females equally. There are also differences between people with upper limb and lower limb amputations in their functional abilities following absence of their limb and upper limb prostheses have only limited function compared to the comparatively good function of lower limb prostheses (Gaine, Smart, & Bransby-Zachary, 1997). Also, Wright (1983) asserted that society has a tendency to hold more negative attitudes towards those with visible disabilities, with amputations of the lower limb having a less visible disability than amputations of the upper limb. It is also necessary to acknowledge the complex and diverse functions of hands and their importance in communication and self-presentation (Pillet & Didierjean-Pillet, 2001). All of these stark differences between upper limb and lower limb absence suggest that desired outcomes and the issues that might affect them may differ and therefore they should be investigated separately in research concerned with amputations.

The main focus in the ULA literature to date has been on identifying the determinants of the salient outcomes, particularly prosthesis use following ULA. According to Heinmann (2005), outcomes refer to the desired benefits of health care efforts and recently, health care outcomes have emerged as the focus of attention, given the recognition that good outcomes are the product of well organised and managed health care. Outcome indicators are used increasingly as the basis of quality measures and reflect efforts to improve quality of care and customer satisfaction (Heinemann, 2005). For example, the NIH roadmap PROMIS (Patient Reported Outcomes Measurement Information System) initiative ([www.nihpromis.org](http://www.nihpromis.org)) has focused on improving patient outcome measures specifically, how they are selected and employed in clinical research and practice evaluation. PROMIS aims to develop ways to measure patient reported symptoms such as pain and fatigue and aspects of health related quality of life across a wide variety of chronic diseases and conditions and therefore have used different chronic conditions to inform its measure such as with arthritis patients (e.g. Fries, Cella, & Rose, 2009; Callahan, DeVellis, & DeWalt, 2008). However, to date there does not appear to have been any research from the PROMIS study with a sample of participants with limb absence. Since the purpose of PROMIS is to develop an outcome measure that is useful for a variety of chronic diseases, it may be useful in the future for use with individuals with limb absence. However, given

the unique profile of individuals with ULA, such as the fact that there is a physical absence to the person (e.g. their arm), which also results in a functional and aesthetic absence, as well as the potential for other co-morbid health problems, and the important role of AT in their rehabilitation and potentially in their subsequent lives, it is important to assess individuals with ULA with a measure that is developed uniquely for them, to ensure that all potential outcomes of importance are considered. The literature review to follow will describe the outcomes of importance in relation to individuals with ULA that the research literature has focused on and the predictors that have been investigated in relation to them. The review to follow in Section 1.3.1., 1.3.2, and 1.3.3 will describe the most prominent outcomes following ULA, the most notable of which is ‘Prosthesis use’ and the factors that been investigated in relation to each outcome.

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### ***1.3.1 Psychosocial Outcomes***

Rybarczek, Edwards & Behel (2004) argue that the physical aspects of disability are much less central to the adaptation process than the psychological, developmental, social environment and the resources of the individual who acquires the disability. However, the psychological and social elements of limb absence are relatively understudied areas of upper limb amputation research. However, since the advent of much psychosocial research in lower limb amputation literature approximately ten years ago, this interest in psychosocial research has been extended to the ULA literature more recently. For example, psychosocial adjustment to ULA has been measured in recent studies. However, there is wide variation in what constitutes psychosocial adjustment, with some studies simply assessing psychological distress (characterized by depression and anxiety; Desmond, 2007; Whyte & Niven, 2001), and others using the TAPES (Gallagher & MacLachlan, 2000) to measure psychosocial adjustment encompassing general adjustment, social adjustment and optimal adjustment standardised for an ULA population (Desmond & MacLachlan, 2005; Desmond, 2007). Body image disturbance has been assessed in the lower limb literature but not quantitatively in the ULA literature. There also have been limited investigations regarding quality of life amongst individuals with ULA, with Hanley, Ehde, Jensen, Czierniecki, Smith, & Robinson (2009) incorporating it as part of their larger study of pain amongst those with ULA. It is important that when assessing psychosocial adjustment it is characterized by more than absence of psychological distress.

The Trinity Amputation and Prosthesis Experience Scales (TAPES; Gallagher & MacLachlan, 2000) is a measure of psychosocial adjustment designed specifically for use with individuals with lower limb absence. The TAPES subscales measure ‘satisfaction with the prosthesis’, ‘activity restriction’, and ‘psychosocial adjustment’. In the original TAPES, Gallagher & MacLachlan (2000) assert that the psychosocial adjustment subscale was designed to be the most comprehensive section and focused especially on the evaluation of adjustment and the impact of having an artificial limb on various aspects of the participant’s life. Although, since all subscales of the TAPES are largely concerned

with assessing adjustment, restriction and satisfaction to the prosthesis, it is therefore not ideally suitable for individuals who no longer wear their prosthesis or were never prescribed a prosthesis. A measure of psychosocial adjustment to amputation that is applicable to individuals with ULA regardless of whether they use a prosthesis is needed in order to be able to assess an individual's adjustment.

Desmond & MacLachlan (2005) investigated the suitability of the TAPES with individuals with ULA. Specifically regarding the psychosocial adjustment scale, Desmond & MacLachlan (2005) found that the subscale, adjustment to limitation accounted for 21.7% of variance in the psychosocial adjustment scale. This subscale refers to restriction experienced as a consequence of having an artificial limb. The general adjustment subscale incorporates items referring to adjustment to and acceptance of wearing an artificial limb and accounted for 19.6% of the variance. The third subscale, social adjustment accounted for 18.3% of the variance and incorporates items related to talking about the artificial limb and dealing with others reactions. The final subscale, optimal adjustment accounted for 12.7% of the variance explained and contained two items referring to dealing successfully with the challenges posed by amputation and leading a full life. Although, in their TAPES-upper, Desmond & MacLachlan (2005) took out items that were of no obvious relevance to ULA (such as an item referring to other people noticing the patient limping), there may still be other potential items of importance to ULA that are missed by using a lower limb derived measure, thus not reflecting a patient's true adjustment. This was acknowledged by Desmond & MacLachlan (2005) and they recommended developing an item pool relating specifically to activities involving bimanual upper limb dexterity. However, Desmond & MacLachlan (2005) found the TAPES to be reliable and valid amongst individuals with ULA.

#### 1.3.1.1 Psychological Adjustment and Distress

Desmond (2007) investigated the factors associated with psychosocial adjustment to prosthesis and affective distress in ULA. This study found that that age at amputation or time since amputation were not related to anxiety, depression (both measured by the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983; HADS) or

psychosocial adjustment (measured by the TAPES). However, Desmond (2007) did not report if anxiety and depression were related to psychosocial adjustment. Results from the HADS scores indicate that 28.3% of the sample met the criterion for possible clinical depression and 35.5% had possible clinical anxiety measured by the HADS. Desmond (2007) reports that the rates of depression in this sample were almost three times greater than a nonclinical sample broadly representative of UK adults (Crawford, Henry, Crombie, & Taylor, 2001). However, the clinical anxiety levels are generally consistent with the general population (Crawford et al, 2001).

Psychological distress has also been investigated amongst individuals with ULA by Whyte & Niven (2001) with phantom limb pain. Whyte & Niven (2001) assessed the psychological distress in 315 people with amputations, who reported phantom limb pain using two time points over a one year period. Phase 1 included the whole sample of 315 participants completing the General Health Questionnaire (GHQ; Goldberg, 1978), whereas phase 2 had a subset (n=89) of this sample who completed the Beck Depression Inventory (BDI; Beck, Ward, Mandelson, Mock, & Erbaugh, 1961). The BDI was used to specifically examine the role of depression in phantom limb pain. The subset of participants (n=89) that were selected in phase 2 to complete the BDI were selected to reflect an equal gender ratio and an equal number of individuals with varying health status' as the data from round 1 suggested that phantom limb pain and psychological factors vary as a function of gender and health status. However, only 10% of the sample had an upper limb amputation. Psychological distress was defined to include depression, anxiety and insomnia, somatic symptoms, and social dysfunction and was measured by the GHQ. Results of the first phase showed that over 50% of the sample had GHQ scores above the threshold to indicate depression. In the second phase, using the BDI, only 15% experienced moderate to severe symptoms of depression. Whyte & Niven (2001) also stated that the mean score was low indicating minimal level of depression in the sample. However, it is difficult to draw any relevant conclusions from this study as no analysis was provided regarding whether the individuals with lower and upper limb amputations in this sample differ.

Desmond (2007) investigated the role of three coping strategies, problem solving, seeking social support and avoidance measured by the Coping Strategy Indicator (CSI; Amirkhan, 1990) in relation to psychosocial adjustment (measured by TAPES, Gallagher & MacLachlan, 2000) and found avoidance to be significantly correlated with all aspects of psychosocial adjustment (adjustment to limitation, general adjustment, social adjustment and optimal adjustment) in a sample of participants with ULA. Also, all coping strategies significantly predicted 35.9% of variance in anxiety symptoms (measured by the anxiety subscale of the Hospital, Anxiety and Depression Scale; HADS, Zigmond & Snaith, 1983) with avoidance significantly relating to greater anxiety. All coping strategies (problem solving, avoidance, seeking social support) also significantly predicted 32.8% of the variance in depression (measured by depression subscale of HADS) with avoidance found to be significantly associated with higher depression and problem solving to be significantly associated with lower levels of depression (Desmond, 2007). It is important to note that the majority of participants in this study (72.5%) reported wearing a prosthesis, but average daily duration of prosthesis use varied from 46% using it more than 8 hours a day and 19% wearing it 2 to 8 hours a day and 35% reported occasional or task-specific use. Therefore in the prosthesis user group, 27.1% of variance in social adjustment was explained by the predictor variables, seeking social support, problem solving and avoidance. Specifically, avoidance was the strongest predictor of social adjustment, general adjustment and adjustment to limitation. Also, problem solving and avoidance contributed significantly to the variance explained in optimal adjustment. The limited evidence to date suggests that avoidance can have a strong influence on an individual's psychosocial adjustment. However, future investigations will be needed in order to understand the nature of this avoidance.

Previous studies have seen a similar influence of coping strategies on psychosocial adjustment amongst people with amputations. However, these studies identified different coping strategies as influential. Livneh, Antonak, & Gerhardt (1999) found that amongst a sample of participants with upper and lower limb amputations, that active problem solving (as measured by the COPE inventory; Carver, Schier, & Kumari Weintraub, 1989) as a coping strategy is negatively associated with the psychosocial reactions of depression and



internalised anger (measured by Reactions to Impairment and Disability Inventory (RIDI); Livneh & Antonak, 1990) but active problem solving is positively associated with adjustment (measured by RIDI) acceptance of disability (measured by Acceptance of Disability Scale; Lindowski, 1971). 14.5% of the sample had ULA and a further 3.5% had both upper and lower limb absence. Livneh et al (1999) also found emotion focused coping and cognitive disengagement (measured by COPE) to be positively related to adjustment and acceptance of disability. However, these results should be interpreted cautiously in comparison to Desmond (2007), as these studies had different measures of coping, and different measures of psychosocial adjustment. Also, no further information was given regarding specific results for individuals with upper limb absence. Therefore Desmond's (2007) study may be more applicable to a sample of individuals with ULA.

These findings suggest that anxiety and depression are more prevalent in ULA compared to the general population without limb absence. However, age at amputation and time since amputation are not related to anxiety or depression and that anxiety and depression are not related to psychosocial adjustment. Findings also suggest that avoidance coping is negatively related to psychosocial adjustment and that avoidance is positively related to anxiety and depression. Problem solving is also negatively associated with depression.

#### 1.3.1.2 Body image

Breakey (1997a) defined body image as the "mental picture a person forms of his or her physical self" (p.107). However, authors such as Orr, Reznikoff & Smith (1989) suggest that it is in part socially constructed as they have defined body image as a component of the self concept, which is formed from both sensory and social experiences with cultural and familial reactions to one's body having great importance in determining one's own attitude. Kolb (1959) asserted that each individual holds an image of the body that he or she considers the ideal in relation to his/ her own body. Additionally, Kolb (1975) suggested that absence of a limb through amputation will probably lead to a long term disorder in body experience. Wetterhahn, Hanson & Levy (2002) also assert that amputation, by definition, results in alteration of the body and this also results in distortion in body image. Gallagher, Horgan, Franchignoni, Giordano, & MacLachlan, (2007)

discuss how there are a number of images for the person who has experienced an amputation to adjust to: the “complete” or familiar body before the limb absence, the traumatized body, the healing body and the extended body (with prosthesis). It is important to know if individuals with limb absence have higher body image disturbance (BID) compared to individuals without limb absence in order to determine if it is a significant issue for these individuals. However, there is a lack of literature in amputation research in general and upper limb amputation specifically investigating the body image of individuals with ULA. Almost all of the research concerned with body image and amputation has been undertaken with people with lower limb amputations (Breakey, 1997b; Wetterhahn et al 2002; Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995; Fisher & Hanspal, 1998; Murray & Fox, 2002; Gallagher et al 2007). However, a qualitative investigation from Saradjian, Thompson, & Datta (2008) found that male participants with ULA described feelings of self-consciousness in social situations, which rendered them sensitive and a need to prove their self worth but that this feeling subsided over time. Since ULA is a more visible disfigurement and as pointed out by Desmond (2007) it is more difficult to conceal the absent limb compared to lower limb absence, ULA has the potential to have a greater impact on body image. Consequently, it is important that a specific quantitative study investigating body image disturbance in people with an upper limb amputation is conducted.

#### 1.3.1.3 Quality of Life

Over the last 30-40 years, quality of life (QOL) has increased in importance as a medical goal because it has become increasingly clear that mortality reduction is not enough for a person facing chronic and degenerative disease, but Sullivan (2003) suggests that it is the patient, not the physician, who has authority to judge their QOL. Despite this, few studies have investigated QOL amongst individuals with ULA. Demet, Martinet, Guillemin, Paysant, & Andre (2003) investigated health related quality of life (HRQOL) in a sample of 539 participants with upper and lower limb amputations. 77 participants reported ULA. Results showed that individuals with upper limb amputation had a better HRQOL than those with lower limb amputations, mostly for physical disability, pain and energy level scores. However, the measurement tool used, the Nottingham Health Profile (NHP; Hunt,

McKenna, McEwen, Backett, Wilkins, & Papp, 1980) considers the pain and disability categories mainly in terms of physical disability; with more than half of the items exploring standing, sitting, transfers or walking. Demet et al (2003) therefore concluded that the NHP is less well adapted for people with upper limb amputation than for lower limb amputations. This emphasises the need for care when using measurement tools that are standardised for use with patients with lower limb amputations, with individuals with ULA, as the nature of their disability and functional restrictions are entirely different. Devices standardised for individuals with some form of upper limb impairment in general are arguably better suited for this. Since there is no suitable QOL measurement tool for individuals with ULA, there is little information on the quality of life of individuals with upper limb amputations. However, a study by Biddiss & Chau (2008) that set out to develop a model for prediction of upper limb prosthesis use or rejection through distribution of a questionnaire exploring factors in prosthesis acceptance amongst 191 individuals with ULA asserted that they measured QOL in their study and reported it to be generally high and comparable between prosthesis users and rejecters in their study. However, they did not detail how QOL was measured or whether it was multidimensional or a singular item.

Hanley et al (2009) conducted a recent study investigating chronic pain in a sample of 104 individuals with ULA. This study also measured Global Health related quality of life with the Satisfaction with Life Scale (Diener, Emmons, Larsen, Griffin, 1985) and the Medical Outcomes Study Short form 12 (SF-12; Ware, Kosinski, & Keller, 1996). They found a slight majority (56%) of the sample had a score below the midpoint of 20, indicating that these respondents reported being more dissatisfied than satisfied with life, although reasons for dissatisfaction were not assessed. The mean score for the physical and mental component of the scale were significantly lower compared with the means for the general U.S. population (Ware, Kosinski & Keller, 1998). Hanley et al (2009) found that each of the QOL measures were significantly associated with all or almost all of the types of pain, with the exception that non-amputated limb pain was not significantly associated with life satisfaction or the mental component of the SF12. Although non-amputated limb pain was the least prevalent type of pain, pain interference, disability days and level of disability

(GCPS category) were high among the subset of individuals who reported this type of pain. Results also showed that self reported QOL was significantly lower for individuals with each type of pain (phantom limb pain (PLP), residual limb pain (RLP), back, neck, non-amputated limb pain) compared to those without any pain. Across the whole sample, PLP and RLP combined seem to cause the most interference in functioning and pain related disability, simply because they are the most common types of pain. However, for each type of pain in this study, a notable subset of individuals reported a moderate to severe level of pain intensity, interference and disability. Hanley et al (2009) hypothesised that pain in the remaining limb may be especially burdensome because use of the limb is so crucial for daily functioning.

As this review demonstrates, there is little information regarding QOL amongst individuals with ULA. Although Demet et al (2003) suggest that QOL is higher in people with upper limb amputation than lower limb amputation, since the measure they used was not suitable for ULA, further investigations are necessary to assess comparison between these two populations. Hanley et al's (2009) study provides support that reported QOL is slightly lower in individuals with ULA and results suggest that pain is a significant predictor of QOL with non-amputated limb pain causing the most interference and pain related disability. Given these findings, it is important to have further information on the factors associated with the QOL of individuals with ULA. It would also be useful to know whether individuals with traumatic versus congenital limb absence differ in their QOL, in order to understand if issues surrounding the cause of lower limb absence is responsible for a reduced QOL experienced by individuals. Also prosthesis users should be compared to non prosthesis users in their QOL in order to determine if use of the prosthesis promotes greater QOL, given the large emphasis on promoting prosthesis use in the literature and in practice.

#### 1.3.1.4 Qualitative research and psychosocial adjustment

Although there have been qualitative studies investigating the psychosocial outcomes of limb absence, they have largely focused on the experience of individuals with lower limb amputations (Gallagher & MacLachlan, 2001) or those people with amputations in general

(Murray, 2004, 2005, 2009). To date, only one study has focused on the specific experiences of individuals with ULA (Saradjian, Thompson, & Datta, 2008). Despite the lack of qualitative research solely amongst individuals with ULA, a review of the research concerning limb amputations can still provide an insight into the psychosocial outcomes and predictors that affect individuals after an upper limb amputation.

A series of qualitative studies using IPA from Murray (2004; 2005; 2009) demonstrate the unique personal and social meanings that using a prosthesis has for an individual. Each of these studies shared the same sample of participants and each study had both upper and lower limb prosthesis users in their sample. However, Murray (2004; 2005; 2009) didn't allude to whether there were any noticeable differences between the two groups, although since participants with ULA were in a minority (20%) in these studies, a comparison may not have been evident or perhaps was not investigated. These studies all incorporated a multi-method design using semi-structured email and face to face interviews and well as documentary analysis of an email discussion group of prosthesis users. Murray's (2004) study aimed to understand the embodied experience of successful prosthesis use and had six major themes concerned with 'adjusting to a prosthetic'; 'the balance of the body'; 'awareness of the prosthesis'; 'the knowing body'; 'the phantom becomes the prosthesis: extending the body'; and 'the prosthesis as tool or corporeal structure'.

Murray's (2005) study was conducted in order to ascertain the reason individuals become socially isolated following limb absence as quantitative research (Pell, Donnan, Fowkes, & Ruckely, 1993) had previously indicated a relationship between adjustment to amputation and a person's level of social isolation. The qualitative nature of this research allowed the opportunity to explore patients' experiences and found that many participants encounter negative reactions to their limb absence in social situations which may over time lead to social avoidance and isolation (Murray, 2005). The themes in this study consisted of 'prosthesis use and social rituals', 'being a leper: reaction of others'; 'social meanings of concealment and disclosure'; and 'feelings and experiences regarding romantic and sexual relationships'. Also, important discussions emerged in Murray (2005) regarding participants' experiences of eating in a restaurant. However, it emerged that the

prosthesis acted as a moderator of embarrassment in this situation through facilitating cutting of food for participants. These experiences in the restaurant are likely to be most prominent in individuals with ULA and potentially unique to them. Participants discussed how peoples' reactions to their limb absence or prosthesis could be 'offensive' such as distancing themselves from the individual with limb absence or being 'intrusive', such as asking direct questions. However, some participants accepted responsibility for how others react to their limb absence suggesting that if they are 'fine' about it, other people will be too. This study supports the use of qualitative research to provide a greater insight into the patient's perspective that is difficult for quantitative methods alone to achieve.

Murray (2009) also used IPA to gain an understanding of the lived experience of prosthesis use from a personal perspective. Important discussion emerged from this analysis concerning psychosocial factors such as the importance of independence such as travel, and participation in social activities in terms of 'being like everybody else'. The prosthesis also appeared to facilitate adjustment for participants especially in terms of concealing limb absence. However, since Murrays' studies focused on prosthesis use, individuals that did not use prostheses were not included in their study, thus limiting the applicability of some of the outcomes to other individuals with limb absence that do not use a prosthesis. Additionally, there was no discussion of whether individuals with ULA differed in any way from individuals with lower limb absence. Further discussions of Murray (2004, 2005, & 2009) will be discussed in Chapter 1.6 as a large component of their findings surround the prosthesis.

Additionally, a focus group study investigating the experiences of 11 male upper limb prosthesis users using IPA by Saradjian et al (2008) found that participants discussed psychosocial factors that appeared to facilitate adjustment for them such as having a positive attitude, motivation to achieve goals, external attributions, humour, downward social comparison, and support of others. Participants also mentioned that engagement in the treatment process and control over it was important to them. Since this qualitative study only had male prosthesis users in their sample, it is important to know if similar findings would be achieved in a qualitative study where females with ULA were included,

and especially individuals who chose not to wear a prosthesis. These discussions of qualitative studies demonstrate that qualitative analyses are successful in exposing issues of importance that may not have been investigated in quantitative analysis. The additional merit of qualitative data is the flexibility with which you can explore unanticipated findings and a greater awareness of the perspectives of participants (Weiss, 1998). Conversely quantitative research has the benefit of being able to generalise data to wider population, and analysing the findings relatively quickly. It is essential to use qualitative research in conjunction with quantitative data to identify the important outcomes and predictors both from the perspective of the user and the experts. Not only is it important to uncover the potential outcomes following upper limb rehabilitation, it is also important to attend to psychosocial outcomes of importance to the individual rather than focusing just on physical, functional or prosthesis related outcomes.

There are only limited studies involving psychosocial factors of importance to individuals with ULA (e.g. Desmond & MacLachlan, 2005; Desmond, 2007; Saradjian et al, 2008). The main focus of many studies of psychosocial outcomes has been adjustment to the prosthesis, also most qualitative studies had prosthesis users, so that was the main focus of their study, not limb absence. The role of the prosthesis is undoubtedly important to determine but it is necessary to be able to determine if use of a prosthesis is related to a better outcome compared to those who don't use a prosthesis. A greater relationship between prosthesis use and the psychosocial outcomes discussed should be investigated. More research is needed on identifying how non prosthesis users perform on many of the psychosocial outcomes given the number of individuals that do not use a prosthesis. Since many of these studies focus on the prosthesis and how it facilitates adjustment, the relationship between prosthesis use in these qualitative studies will be discussed in greater detail in Chapter 1.5 concerning prosthesis use.

Additionally, this review of qualitative research has highlighted the important influence social factors may play in an individuals adjustment to ULA. However, little quantitative research has been conducted in this area and the research that is available has only been conducted with paediatric populations looking mainly at how social factors relate to

prosthesis use (Hubbard, Kurtz, Heim, & Montgomery, 1997). However, there is evidence that strong social support networks have been shown to have a positive impact on a child's psycho-social health (Varni & Setoguchi, 1993) and negative perceptions of these social support systems, have been linked to depression, trait anxiety, and general self esteem (Varni & Setoguchi, 1993; Varni & Setoguchi, 1991; Tyc, 1992). A review of the literature from Biddiss & Chau (2007a) asserted that social context plays a formative role throughout the prosthetic experience and that familial and peer support networks help shape the overall psychosocial health of individuals with ULA. Biddiss & Chau, (2007a) also suggest that the potential benefit of peer support groups is worthy of further study. Since qualitative research suggests that social factors have an important role in adjustment amongst adults with ULA, it is important to expand this research from the paediatric population to the adult population.

#### 1.3.1.5 Summary of psychosocial outcomes

In summary, based on the scant available evidence, findings show that psychological distress is more prevalent in ULA compared to those without limb absence. It appears that certain coping strategies, such as avoidance may be related to increased psychological distress and reduced psychological adjustment. Body image has not been investigated in ULA. However, it is suggested that it is important to ascertain body image disruption in upper limb amputees and compare between those who use and do not use a prosthesis. There is also little research on QOL amongst those with ULA but some preliminary research suggests that QOL is slightly lower in people with upper limb amputations and results suggest that pain is a significant predictor of QOL. Although limited in number, qualitative studies are a perfect opportunity to expand our knowledge on the potential range of relevant psychosocial outcomes in this population, beyond the typically investigated outcomes in quantitative research.



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### ***1.3.2 Functional and Physical outcomes***

#### ***1.3.2.1 Functional outcomes***

Most studies that aim to investigate ‘function’ in the ULA literature measure it through assessment of involvement in activities. Hanley et al (2009) measured physical functioning through the physical functioning scale of the SF12 (Ware, Kosinski, & Keller, 1996), and found that the mean score of the sample (41.47) was significantly lower compared to the means for the general US population (50.12). Also, the physical functioning scale was significantly correlated with all types of pain (PLP, RLP, back, neck, non-amputated limb pain). These results suggest that physical functioning amongst individuals with ULA is impaired, and that presence of various types of pain are negatively related to physical functioning amongst individuals with ULA.

As discussed in Section 1.3.1, Desmond & MacLachlan (2005) validated the TAPES (Gallagher & MacLachlan, 2000) with a sample of male participants with ULA. The TAPES upper contains an activity restriction scale which measures 4 subscales. Desmond & MacLachlan (2005) found the ‘restriction of mobility’ subscale with items relating to walking, running, and climbing accounted for 37.3% of the variance in the activity restriction subscale. Athletic restriction accounted for 17.6% of the variance and included items requiring vigorous physical effort such as running for a bus and sport recreation. Social restriction accounted for 16.2% of variance and comprised maintaining friendships and visiting friends. The last subscale, Occupational restriction had 2 items; concerned with working on hobbies and going to work, which accounted for 13.8% of variance. Desmond & MacLachlan (2005) argued for the valid inclusion of several items, particularly on the Activity restriction subscale that make extensive use of the lower limb and do not essentially necessitate direct upper limb involvement, as they have the potential for involvement of the upper limb in maintaining balance and co-ordination. The average score for mobility restriction dimension was low, indicating relatively low levels of mobility impairment. As mentioned earlier Desmond & MacLachlan (2005) recommended developing an item pool relating specifically to activities involving bimanual upper limb

dexterity. More research is necessary using the TAPES upper activity restriction scale to assess the functional level of those individuals who have ULA.

Davidson (2004) used the DASH (Disability of the arm, shoulders and hand) questionnaire amongst a sample 274 patients who had varying disorders of the upper limb, 75 had upper limb amputation (26 of these had partial hand or digit amputation). Other diagnoses included complex regional pain syndrome, carpal tunnel syndrome, and brachial plexus injuries. The DASH is an evaluative outcome measure for patients with upper extremity musculoskeletal conditions. It is a region specific questionnaire as opposed to a diagnosis specific questionnaire. It measures function and symptoms of musculoskeletal disorders of the upper limb. The DASH asks about patients' ability to perform 21 physical activities for difficulty or severity. Items include writing, food preparation, transportation, recreational needs and changing a light bulb overhead. There are also three questions on psychosocial factors and 6 on symptomatology. This study reported a mean score of 51/100 for the entire sample on the DASH and reported that the highest DASH score (higher DASH scores represented greater disability) were for individuals with bilateral amputations (68/100), quadruple amputations (67/100), and complex regional pain syndrome (68/100). These scores were all significantly higher than the lowest DASH score for fractures (30/100).

Davidson (2004) found patients without compensation had significantly lower DASH scores (lower disability) compared to those with compensation. Specifically individuals that have amputation but do not have compensation had significantly lower DASH scores compared to individuals with amputation that do have compensation. Davidson (2004) also found significantly lower DASH scores for individuals with major upper limb amputation compared to those with partial hand amputation. Davidson (2004) attributed the findings on compensation to the potential 'anger' and 'blame' that a person may hold or the financial reward from litigation that may encourage increased perceived disability. It was also found that individuals with amputation had significantly lower DASH scores than individuals that do not have an amputation. Therefore this study indicates that individuals with ULA experience less disability than individuals with other upper limb

disorders. Since there was no mention of whether participants in this study wore a prosthesis, it is difficult to ascertain if this reduced disability was due to increased function from a prosthesis. This study also found a significant relationship between DASH scores and DASH work and leisure scores. There was no mention in this study whether participants' were prosthesis users.

These findings suggest that function of individuals with ULA is impaired compared to the general population. The review also suggests that functional level is related to reported pain. Findings indicate that individuals with amputations had lower disability compared to participants with other disorders such as complex regional pain syndrome, carpal tunnel syndrome and brachial plexus injuries, but should be interpreted with caution. Furthermore, findings suggest that whether an individual has compensation for their limb absence impacts on the level of disability experienced with those with compensation reporting greater disability.

#### 1.3.2.2 Activities and Participation

The World Health Organisation's (2001) International Classification on Functioning and Disabilities (ICF) was developed as a classification of health components of function and disability. A key point of this framework is the 'Activities' and 'Participation' components. The ICF defines participation as involvement in life situations at the societal level and recommends this as an essential outcome for rehabilitation. Participation is specifically considered the fulfilment of roles in society, such as worker student, friend, lover, spouse, parent, citizen etc. These are roles that are equally important to people with disabilities as the general population. Participation is now emerging as the gold standard of outcome measurement in disability and rehabilitation (Seekins, Ipsen & Arnold, 2007) and therefore should also be one of the most important outcomes considered for rehabilitation following ULA. This emphasis on participation is tied to the contextual or ecological model of disability that defines disability as the product of interaction between the individual and his/ her environment (Seekins et al, 2007). Activities are defined by the ICF as the execution of a task or action by an individual (WHO, 2001).

There is little research in the upper limb amputation literature that could fall under the term 'Participation' as defined by the ICF. Outcomes defined by 'Activities', such as employment or activities of daily living are more common.

Jones & Davidson (1995) surveyed 27 individuals with ULA who were treated at a hospital in Sydney, Australia between 1981-1990 in order to assess their long term rehabilitation outcome. They reported that of those in paid employment at the time of their amputation, 85% were in paid employment at the time of the survey. This suggests that some individuals were unable to return to paid employment following upper limb amputation. However, having compared the unemployment rate in their study to unemployment in the community at the time of the study, Jones & Davidson (1995) asserted that the absence of the limb does not make the person with an amputation more vulnerable to unemployment. Davidson (2002) surveyed 63 individuals with ULA to ascertain their satisfaction with their prostheses, their lifestyles and their abilities. However, this study found that an employment rate of 87% at the time of amputation had dropped to 54% at the time of the survey. 24% reported that they were unable to work, or unemployed and 16% were retired at the time of the survey. Davidson (2002) deduced that these findings suggest that ULA does make an individual more vulnerable to unemployment. However, regardless of whether the rates of employment differ post amputation, it is likely that occasionally some participants will have to change their jobs following ULA if they had worked in manual labour jobs (Jones & Davidson, 1995). There is no other data from studies which suggest that ULA leads to greater unemployment and there is no information regarding predictors of employment.

With regard to activities of daily living, a change in leisure activities because of the amputation was noted by 70% of people with an upper limb amputation in the study by Jones & Davidson (1995). Although there was no relationship between this change in leisure activities and prosthesis use, other studies suggest that individuals with ULA want the prosthesis for use in ADL. For example, Pylatiuk, Schulz, & Doderlein (2007) found that females wanted their prosthesis for use with handicrafts, personal hygiene, using cutlery, operation of electric and domestic devices, males wanted the prosthesis for using

cutlery, handicrafts, opening and closing door. The least wanted activity participants want the prosthesis for was writing. These results imply that the prosthesis is very useful for domestic and work tasks. However, Pylatiuk et al (2007) did not detail how many participants lost their dominant hand. It would also be useful to know if these identified tasks are significantly impaired in individuals that do not wear a prosthesis.

Jones & Davidson (1995) found that females reported significantly more difficulty with managing self care tasks than males. However, Jones & Davidson (1995) did not find a difference between prosthesis users and non-users prosthetic use regarding ability to manage self care tasks. Patients in Datta, Selvarajah & Davey (2004) found the prosthesis to be useful for personal care tasks (5%), DIY (18.3%), dressing (6.6%), cooking (13.3%), driving (25%), recreation (20%) and employment (15%).

Although it is now internationally agreed in the ICF that both personal and environmental factors contribute to levels of participation of an individual, the meaning of optimal participation is less clear (Rochette, Korner-Bitensky & Levasseur, 2006). It is proposed by Rochette et al (2006) that engagement is more appropriately used over the long term in individuals with chronic conditions who do not necessarily 'reintegrate' into the community after hospitalisation but instead attempt to remain engaged in community life in the face of changing body functions and structures (Rochette et al, 2006). Additionally, Rochette et al (2006) demonstrated that participation is a broad concept and that normality should not be defined as performing an activity without assistance but did not clarify if assistance is from others or from AT. Rochette et al (2006) suggested that the acceptance of doing activities and roles differently, perhaps with the use of an assistive device on a day to day basis without getting constantly frustrated, would constitute a change in the patient's internal standards. The change in value is a change in the importance of activities and roles that constitute participation (Rochette et al 2006). Typical mechanisms that help to trigger a positive response shift are thought to include; coping, social comparison, goal reordering, reframing expectations and spiritual practice (Rapkin & Schwartz, 2004).

### 1.3.2.3 Phantom Limb Sensations and Pain

Phantom limb sensation (PLS) has been described as all non-painful sensations in the amputated part of the limb, such as sensations of a certain position of the amputated part of the limb, of something touching, of warmth or cold, or of movements of the amputated part of the limb (Merskey & Bogduk, 1994). However, phantom limb pain (PLP) has been described as any phantom sensations or any feeling in the amputated part of the limb, which is so intense that it is experienced as pain (Merskey & Bogduk, 1994). Residual limb pain (RLP) refers to pain in the remaining part of the limb. It is also commonly referred to as stump pain, or the deficient limb, in the case of individuals with congenital limb absence. Research has suggested that pain, particularly PLP, (Dudkiewicz, Gabrielov, Seiv-ner, Zelig, & Heim, 2004; Kooijman, Dijkstra, Geertzen, Elzinga, & van der Schans et al (2000), RLP (Dudkiewicz et al, 2004) and back and neck pain (Hanley et al 2009) appear to be prevalent among individuals with ULA, with Hanley et al (2009) reporting that 85% of participants in their study experienced some form of pain. PLS's have also been commonly reported amongst individuals with ULA (Kooijman, et al (2000). However, rates of prevalence of these co-morbidities have varied widely in many studies. For example, reports of PLP in studies have ranged from 22% (Jones & Davidson, 1995), 32% (Biddiss & Chau (2007c), 35.71% (Dudkiewicz et al 2000), 51% (Kooijman et al, 2000); to 60% (Davidson, 2002). Also as many as 79% of participants in Hanley et al's (2009) study reported experiencing PLP. RLP also displays similar variations, with as little as 7.14% reporting RLP in Dudkiewicz et al (2000), 25% (Jones & Davidson, 1995), 32% (Biddiss & Chau, 2007c), 46% Davidson (2002), 49% (Kooijman et al 2000) and 71% in Hanley et al (2009). Other types of pain reported have been reported such as neck pain (43%; Hanley et al, 2009), back pain (Hanley et al, 2009), residual limb pain (7.14%; Dudkiewicz et al (2000), and pain from poorly fitting prosthesis (10%; Davidson, 2002). Other co-morbidities that have been reported are PLS's (43%; Davidson, 2002); irritation (46%; Biddiss & Chau, 2007c); blisters (23%; Biddiss & Chau, 2007c); and upper body pain (44%; Biddiss & Chau 2007c); and tingling (45%; Davidson 2002). However, Davidson (2002) didn't elaborate on 'tingling' and whether this was in the residual limb or the phantom limb. Despite gathering this important data on the prevalence of co-morbidities, neither Jones & Davidson (1995), Dudkiewicz et al (2000), Davidson (2002)

or Biddiss & Chau (2007c) reported the severity of these pains nor any consequences that arose for the individuals due to them. Variations in sample size in these studies (with many having particularly low numbers), differences in time since amputation of participants and differences recruitment procedures may be partly responsible for the wide differences in prevalence of co-morbidities.

Due to the documented prevalence of co-morbidities in ULA, it is especially important to understand the potential determinants of pain. These have been investigated previously by Wright et al (1995), Kooijman et al (2000), and Hanley et al (2009). Wright, Hagen & Wood (1995) assessed the prosthetic usage in major upper extremity amputations amongst a sample of 113 patients and stated that patients older than 30 years at amputation were more likely to complain of phantom pain. It was not reported whether this relationship was statistically tested. Wright et al (1995) also found that patients with wrist disarticulation had significantly less phantom pain than those with other levels of amputation (below elbow, above elbow, shoulder disarticulation, and forequarter). However, Wright et al (1995) did not investigate other types of pain in their analysis.

While Wright et al's (1995) findings suggest a role for age and level of limb absence, in contributing to PLP, a study by Kooijman et al (2000) that also investigated whether age (at amputation) and level of limb absence (above elbow/ below elbow) were related to PLP or PLS did not find a relationship. It is important to note that in this sample of participants by Kooijman et al (2000), PLP was not reported in the congenital group (n=27) and PLS was only reported once. RLP was only reported for three participants with congenital limb absence. Therefore all analyses from Kooijman et al (2000) referred to individuals with acquired limb absence (n=72). The study by Hanley et al (2009) also did not find any relationship between current age and type of pain (neck, back, PLP or pain in non-amputated limb).

In addition to assessing the role of age and level of limb absence with co-morbid problems, Kooijman et al (2000) also assessed whether gender, cause of amputation (accident), prosthetic use (less than 8 hours a day or greater than 8 hours a day), prosthetic

type (myo-electric)/ other) dominance, pain before amputation and follow up time were related to PLP and PLS. However, Kooijman et al (2000) only found RLP to be significantly related to PLP and PLS, and found PLP to be significantly related to PLS, and a significant difference between the time since amputation for those with and those without PLS, which suggests that PLS may fade away over time.

Hanley et al (2009) did not find time since amputation nor cause of amputation to be significantly associated with pain intensity (measured by Graded Chronic Pain Scale; GCPS, VonKorff, Ormel, Keefe, & Dworkin, 1992) or type of pain (neck, back, PLP or pain in non-amputated limb) in their study. However, this study did find a significant difference between males and females regarding the presence of certain types of pain. Specifically, men were significantly more likely to report PLP, RLP and neck pain but were not more likely to report back or non-amputated limb pain. However, Hanley et al (2009) did not report if this was different amongst those men who wore/ did not wear a prosthesis and since they did not gather information on types of prosthesis worn, there is no way to know if those who wore body-powered prostheses for example had more neck pain. Furthermore, both genders reported similar levels of pain intensity. Also, individuals who were married or living with a significant other were no more likely to report having any of the five types of pain or greater pain intensity compared with those who were divorced or widowed. Also, individuals with limb absence due to injury (compared to vascular, gangrene, diabetes, infection, congenital or other) were no more likely to report any of the types of pain examined. However, they did not report whether any of the other causes differ in types of pain reported. Hanley et al (2009) also found that individuals who reported pain before amputation were no more likely to report PLP, RLP or non-amputated limb pain but were more likely to report back and neck pain than those who did not report pain before amputation.

As discussed in chapter 1.3.1, Whyte & Niven (2001) found that psychological distress measured by GHQ was present in over 50% of their original sample. However, it was not significantly correlated to the intensity of phantom limb pain in their sample. Also, further results of phase two with a subset of the original sample indicate that BDI scores



accounted for only 4% of the variance in phantom limb pain. Whyte & Niven (2001) investigated the relationship of phantom pain with specific items of the BDI and found that performance difficulties were most related to phantom pain. Whyte & Niven (2001) concluded that negative affect in individuals with limb absence may be related to disability rather than pain. Although these findings are important, considering those with ULA only accounted for 10% of the sample, and that this study did not report any differences between participants who had ULA and lower limb absence in depression rates, it is difficult to ascertain if these findings can be applied to individuals with ULA.

Some of these studies have also assessed the impact pain has on an individual. For example, Hanley et al (2009) assessed the prevalence, intensity and functional impact following types of pain associated with ULA. Average pain intensity (as measured by the GCPS) for all five types of pain (PLP, RLP, neck, back and pain in non-amputated limb) was in the moderate range, and pain interference scores (also measured by GCPS) were, on average, in the mild to moderate range (based on previous research on the classification of amputation-related pain; Jensen, Smith, Ehde, & Robinson, 2001). Although, Kooijman et al (2000) did not gather any further information concerning the intensity or consequences of pain for this sample, Hanley et al (2009) did gather this important data. Individuals with both PLP and RLP tended to report significantly greater pain intensity attributed to PLP but no significant differences between levels of pain interference or disability days were attributed to each type of pain. Although PLP on average was reported to be highest in intensity, it was also the lowest in terms of pain interference. Average pain interference and number of disability days were both highest for non-amputated limb pain. Mild disability as measured by the GCPS was the most common level for all pain types (Hanley et al 2009). Non painful limb sensations were reported by the majority of the sample (81%) and were reported as intermittent by 50% of those who had them. There was a significant association between non-painful limb sensations and phantom limb pain such that individuals who reported one were significantly more likely to report the other as well. In fact 86% of participants who reported having these sensations also reported having PLP (Hanley et al 2009). Hanley et al (2009)

acknowledged that the impact of non-painful limb sensations on participants functioning was not assessed.

However, an earlier study by Kooijman et al (2000) that determined the prevalence and factors associated with PLP and PLS in 124 individuals with ULA in the Netherlands did not investigate how pain or phantom sensations interfere with an individual's QOL. It is important that future studies investigate this relationship in order to ascertain the impact of pain.

This review of the research suggests that pain, such as PLP and RLP are largely prevalent amongst individuals with ULA, as is PLS and other types of pain, but that prevalence rates can widely vary across studies. Limited evidence suggests that RLP may be related to PLP and PLS (Kooijman et al, 2000) amongst individuals with acquired amputations. But that non-amputated limb pain causes the most pain interference and disability. Also, lower levels of limb absence may be related to less PLP (Wright et al, 1995) and that pain before an amputation may cause back and neck pain. Also males may be more likely to experience back and neck pain than females (Hanley et al, 2009).

#### 1.3.2.4 Summary of functional and physical outcomes

Based on the available evidence to date, this review of the functional and physical outcomes suggests that individuals with ULA might have reduced levels of function compared to individuals without ULA. In addition, it appears that individuals with ULA tend to change their leisure activities and employment following ULA. The literature shows that there is mixed evidence of whether absence of the upper limb renders an individual more vulnerable to unemployment. Additionally, the prosthesis is usually required for the purpose of performing ADL. The literature concerning co-morbidities suggests that levels of pain vary widely across studies in ULA studies. Although PLP appears to have the highest pain intensity for sufferers, it has the lowest reported interference. It also appears that PLP is related to PLS and RLP and that PLS may fade away over time but not PLP. However, it is important to note that these conclusions are

based on limited evidence and further research, in particular longitudinal research, is required to establish causal relationships.

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**Chapter 1.3.3 Prosthesis use**

Most studies in the ULA literature have been concerned with assessing prosthesis use and the factors that can predict prosthesis use. This large interest in prosthesis use is unsurprising given the high cost involved in developing, prescribing and rehabilitating an individual with a prosthetic limb. Additionally, the potential waste of resources if these individuals cease to use their prosthesis and the subsequent high rates of non-use make it important to understand the predictors of non-use. Rates of non-use of upper limb prostheses have been estimated at approximately 20% (Biddiss & Chau, 2007c; Hacking Van der Berg, Dahmen, & Post, 1997). However, constant prosthesis use in some studies has only been reported to be 37% (Jones & Davidson 1995). This indicates that although only 20% of individuals with ULA may completely reject their prosthesis, a much lower percentage of individuals may wear their prosthesis regularly. Therefore this indicates that participants may use their prosthesis sporadically or for specific activities. However, there is little discussion in the literature whether this sporadic or non-constant use of a prosthesis is satisfactory. Additionally, it is important to note that there are several options open to an individual when they have upper limb absence, they can have no prosthesis, a passive (sometimes referred to as a cosmetic) prosthesis, a body powered prosthesis, an electric prosthesis, a hybrid prosthesis or a task specific prosthesis (Gulick, 2007).

Due to the high rates of non-use or limited use of upper limb prostheses; prosthesis acceptance/ rejection, characterised by number of hours of prosthesis use, is the most commonly measured outcome in ULA research (e.g. Roeschlein & Domholdt, 1989; Hacking et al, 1997; Dudkiewicz, et al, 2004; Biddiss & Chau, 2007c). The reason for this focus on quantification of prosthesis use is to enable determination of factors which lead to 'successful prosthesis use'. However, there are inconsistencies within the ULA literature on the definition of successful prosthesis use. Some studies (e.g. Biddiss & Chau, 2007c) measure successful prosthesis use by dividing individuals as either prosthesis rejecters (i.e used a prosthesis once a year or less) or frequent wearers (described as either full time or part time use). Full time use was defined in Biddiss & Chau (2007c) as greater than 8 hours wear a day and part time use was considered less

than 8 hours wear a day. However, when reporting results in their study, Biddiss & Chau (2007c) did not report the differences between full and part time usage on the variables assessed. They only reported differences between prosthesis rejecters and frequent wearers, which means that there is no information analysed that may inform what promotes greater or lesser use of a prosthesis in their study. Jones & Davidson (1995) also divided prosthesis use in a similar fashion to Biddiss & Chau (2007c). Additionally, some studies use the number of daily hours the prosthesis is worn as a measure of successful prosthesis use, but the length of time worn that is considered success tends to differ across studies (e.g. Hacking et al, 1997; Roeschlein & Domholdt, 1989). Specifically, Hacking et al (1997) divided groups into 'greater than 4 hours prosthesis use' and 'less than 4 hours prosthesis use' and 'no prosthesis use'. Roeschlein & Domholdt (1989) considered successful prosthesis use to be when an individual wore and used a prosthesis at least once a day. Table 1.1 provides details of what several other studies defined as 'successful prosthesis use'. Additionally, Roeschlein & Domholdt, (1989) considered individuals who wore or used a prosthesis solely for certain tasks or hobbies to be 'partially successful users'. All these methods imply that 'successful prosthesis use' is frequent use of a prosthesis and 'prosthesis failure' is infrequent use. Also, Roeschlein & Domholdt (1989) categorize the use of a purely cosmetic prosthesis, without using it in a functional manner as unsuccessful prosthesis use. Other studies such as Malone, Fleming, Roberson, Whitesides, Leal, Poole, & Grodin (1984) defined successful prosthesis use as the use of the prosthesis for the patient's pre-amputation job or activities. However, Gaine, et al (1997) derived a prosthetic success score (PSS) which incorporated several elements such as patient satisfaction, daily wear of prosthesis, and function level. Participants received a certain number of points depending on how they scored on each domain, which combined to give a prosthetic success score. Depending on the number of points they received, a person may have a 'good', 'satisfactory', 'fair' or 'poor' PSS. However, Gaine et al's (1997) did not report what patient satisfaction specifically referred to and also did not give any details regarding how function level was assessed. Bhaskarand, Bhat, & Acharya (2003) also developed a 'Prosthetic Rehabilitation Score' (PRS) based on Gaine et al (1997) PSS. However, this scoring system assessed patients' acceptance, prosthetic usage and functional level but they did not state if it differed substantially from Gaine et al's

(1997) PSS or if it only differed in the names of the domains. See table 1.1 for a description of how prosthesis use was measured in the main studies that will be discussed in this section.

*Table 1.1 Key studies that measure prosthesis use that are discussed in this review*

<b><u>Author</u></b>	<b><u>Measure of prosthesis use</u></b>
Roeschlein & Domholdt (1989)	This study divided prosthesis users into three main groups: successful users (wore and used prosthesis at least one prosthesis everyday); partially successful users (wore or used a prosthesis solely for certain tasks or hobbies); unsuccessful users (did not use a prosthesis, or wore a prosthesis for cosmesis without using it in a functional manner)
Jones & Davidson (1995)	This study divided participants into three main groups: prosthesis users (wear their prosthesis for 8 hours a day or more and at least 5 days per week); occasional prosthesis users (wear their prosthesis for less than 8 hours per day and less than 5 days per week) and non prosthesis users (did not wear a prosthesis at time of study)
Wright, Hagen, & Wood (1995)	This was a retrospective study assessing the uptake of prosthesis following prosthetic rehabilitation. This study divided people by those who used a prosthesis or rejected a prosthesis. However, no further details were provided.
Gaine, Smart, & Bransby-Zachary (1997)	This study developed a Prosthetic Success Score which encompassed Patient satisfaction, Daily wear and function level. The results produced a score which indicated differing levels of success: good, satisfactory, fair and poor.
Hacking, Van der Berg, Dahman, & Post (1997)	This study divided groups based on their 'prosthesis wearing time': 1) patients who wear their prosthesis more than 4 hours per day; 2) patients who wear their prosthesis less than 4 hours per day; and 3) patients who do not use their prosthesis
Koojiman, Dijkstra, Geertzen, Elzinga, & van der Schans (2000)	This study divided prosthesis users into four categories: 1) prosthesis use for more than 8 hours per day; 2) prosthesis use for 4-8 hours per day 3) prosthesis use for less than 4 hours per day and not used on a daily basis; 4) prosthesis not used at all.
Davidson (2002)	This study assessed prosthesis wearing time as: 1) All the time; 2) A lot of the time; 3) Half the time; 4) Once in a while; 5) Never.
Bhaskarand, Bhat, Acharya (2003)	This study used a Prosthesis Rehabilitation Score (PRS), modified from the Prosthetic Success Score used by (Gaine et al, 1997). It was a combination of patient acceptance, prosthetic usage, and functional level, produced a score indicative of Good, Satisfactory or Poor prosthetic usage. They did not make clear what they meant by patient acceptance and how it was assessed.
Datta, Selvarajah, & Davey (2004)	This study divided participants into three groups: 1) regular prosthesis use (using prosthesis greater than 5 hours per day); 2) Occasional prosthesis use (not specified what this was) and 3) prosthesis rejection.
Dudkiewicz, Gabrielov, Seiv-ner, Zelig & Heim (2004)	This study divided participants into groups according to: 1) permanent use of the prosthesis; 2) temporal use of prosthesis; 3) non-use of prosthesis. However, they did not define further what they meant by these groups
Desmond (2007)	This study divided prosthesis users into 3 groups: 1) those who used prosthesis daily for more than 8 hours; 2) those who reported daily prosthesis use for 2-8 hours; 3) those who reported occasional or sporadic use. However, results only reported differences between prosthesis users and non-users.
Bidiss & Chau (2007c)	This study divided participants into 2 main groups: 1) Frequent wearers (either full time or part time consistent wear) a) Full time wearers (greater than 8 hours wear): b) Part time wearers (less than 8 hours wear) 2) Prosthesis rejecters (fitted with a prosthesis but used a prosthesis once a year or less)
Biddiss & Chau (2008)	This study divided participants into two main groups 1) Frequent wearers (wore a prosthesis greater than once a year) 2) Prosthesis rejecters (previously been prescribed a device but wore a prosthesis once a year or less)
Hanley, Ehde, Jensen, Czierniecki, Smith, & Robinson (2009)	This study considered successful prosthesis use to be greater than 8 hours per day and greater than 20 days per month

Hacking et al (1997) has argued that besides methodological differences, there are also differences in inclusion and exclusion criteria, measured variables and measuring methods used between studies in the literature. This makes it difficult to compare factors that predict successful prosthesis use across studies. Another concern is that some studies have been in survey format and do not always report statistical significance or statistical analysis methods or test interrelationships between outcomes measured (e.g. Hacking et al, 1997; Dudkiewicz et al, 2004; Davidson, 2002). A lot of these studies are also cross-sectional in design and there are no known longitudinal studies in the ULA literature.

Results from several studies have demonstrated further information on rates of prosthesis use. For example in Roeschlein & Domholdt's (1989) study of 40 participants, 65% of participants were reported to be 'successful prosthesis users' which indicated that they wore at least one prosthesis, every day, throughout most of the day. 25% of participants were 'partially successful users' which meant that they wore or used a prosthesis solely for certain tasks or hobbies. While 10% of participants were 'unsuccessful prosthesis users' did not use a prosthesis or wore a prosthesis for cosmesis without using it in a functional manner. Wright et al (1995) reported that 38% of patients fitted with a prosthesis discontinued its use. In Jones & Davidson (1995), 37% wore their prosthesis for 8 hours or more a day and at least 5 days per week. Prostheses were used occasionally by 19% of the sample, with them stating that they wore their prosthesis for specific purposes, such as to check the fit, for social occasions, or for shopping. Hacking et al (1997) reported that 13% of participants stopped using their prosthesis, 8% wore their prosthesis less than 4 hours a day and 40% used the prosthesis for more than 4 hours per day. However, Hacking et al (1997) did not account for the remaining participants in their sample. Kooijman et al (2000) reported usage rates for participants with acquired limb absence in their sample (n=72). They reported that 52 participants used the prosthesis for more than 8 hours per day, 3 used it for 4-8 hours per day, 7 used it for less than 4 hours per day, and 14 did not use the prosthesis on a daily basis or did not use it at all. When added up, this report accounts for 76 participants and not the 72 participants initially reported. It is not known where the error lies. Dudkiewicz, et al (2004) reported rates of 50% for 'daily use' of a prosthesis. Datta et al (2004) reported that 25% of their sample



had given up using the prosthesis. Although 71.6% of sample still used the prosthesis regularly and 3.3% wore the prosthesis occasionally. Of the participants that wear their prosthesis regularly, 65.1% of participants wore the prosthesis for greater than or equal to five hours per day. No further information was provided on how often other regular users wore the prosthesis. Desmond (2007) reported that 72.5% of their sample used a prosthesis; with 46% of prosthesis users using a prosthesis for more than 8 hours, 19% reporting daily prosthesis use for between 2 and 8 hours; and 35% reporting occasional sporadic or task specific use. However, when reporting results, Desmond (2007) only reported differences between prosthesis users and non users. Biddiss & Chau (2007c) reported that 28% of participants that had been fitted with a prosthesis were categorized as prosthesis rejecters (used a prosthesis once a year or less), whereas 64% were considered frequent wearers (either full time or part time consistent wear). They did not account for the further 8% of the sample. Biddiss & Chau (2008) reported that 31% of participants were identified as prosthesis rejecters (wore a prosthesis once a year or less), while 69% were identified as frequent wearers. Hanley et al (2009) reported that 57% of participants reported wearing a prosthesis compared to 42% who reported not using a prosthesis, one participant did not answer the question. Of those participants that reported using a prosthesis, 63% used a prosthesis for greater than 8 hours per day and 73% reported using the prosthesis for greater than 20 days per month.

Clearly it is important to have certain categories of prosthesis use when assessing prosthesis use in studies as patterns of use tend to vary substantially. However, consistency across studies in defining successful prosthesis use is needed. This categorization also needs to take into account the patient's perspective on what is successful to them. Specifically, an understanding is needed of what individuals use their prosthesis for, how often it is used, and what are the benefits of using the prosthesis to the individual. When this definition is agreed, then the predictors of 'successful prosthesis use' can be adequately investigated.

An ideal way of gaining access to these perspectives of successful prosthesis use may be through qualitative research. In support of this, Murray (2009) acknowledged there is

limited literature that attempts to address the wider issues implicated in use and non-use of prostheses as most research has taken a quantitative approach. Qualitative studies that have looked at upper and lower limb absence have provided a greater insight into what individuals want the prosthesis for. These studies were briefly introduced earlier in Section 1.3.1 in relation to psychological adjustment but are discussed in this section as an underlying theme of much of the research was how the prosthesis facilitates functional and psychosocial outcomes. Murray (2004) used IPA to gain an understanding of the embodied experience of successful prosthesis use amongst individuals with upper and lower limb absence. An important finding from this study was that participants who were regular prosthesis users found that at the beginning prosthesis use required a lot of thought and use was not intuitive but gradually the attention needed decreased over time and prosthesis use became more natural. Murray's (2004) results suggest that the reasons people often give for rejecting prostheses are frequently also experienced by 'successful users' early on. However, these individuals persist with using the prosthesis and find that these negative experiences subside and they begin to use the prosthesis more naturally. Murray (2008) suggests that the findings in Murray (2004) explain why there is an association between level of prosthesis use and satisfaction of prosthesis, in that, time with prosthesis leads to satisfaction. Additionally, there were some participants in this study that felt the prosthesis was part of them, whereas for others it was simply a tool that enabled achievement of a specified outcome. Both of these opposing experiences were also expressed by individuals with ULA in the study. However, since all participants were currently prosthesis users, Murray's (2004) finding demonstrates the individuality of prosthesis use for many participants.

As mentioned in Section 1.3.1, the prosthesis in Murray's (2005) study was useful in moderating outcomes such as awkwardness in restaurants. Participants in this study also appeared to wear the prosthesis for social reasons, for other's benefit (family, friends or public) in order to conceal disability. Also, Murray (2009) found that for participants with upper and lower limb absence that the prostheses were considered enabling devices and central to their personal and social identity. Prostheses enabled participation in work and in personally and socially valued activities such as driving and the prosthetic limb became

part of the person who used it (Murray 2009). Additionally, Murray (2009) found that a realistic looking passive limb with no functional use was sometimes preferred to a more functional but less aesthetically pleasing prosthetic limb. Therefore while such prosthetic limbs have no practical use, they were considered crucial for a person's psychological health and well-being. Most importantly, some participants discussed how they displayed their amputation and limb absence as a method of defiance to the notion of disability and even accentuated the visibility of the prosthesis use.

To date, the only qualitative study to focus exclusively on people with an ULA has been undertaken by Saradjian et al (2008). Participants in Saradjian et al's (2008) study confirmed many of the psychosocial outcomes identified in the quantitative literature. For example participants expressed achievement or disruption in the following outcomes: Return to active employment, fulfilment of activities of daily living, leisure activities (including driving a car) and performing roles of importance to them, good social relationships and prosthetic embodiment. Other outcomes mentioned included, regaining lost body image and function and constant awareness of difference from others. It was reported that all outcomes were facilitated by the prosthesis. However, all participants in this study were prosthesis users, so it can not be asserted whether or not individuals who do not wear a prosthesis would achieve these outcomes. However, participants also reported practical problems with the prosthesis, indicating that they did not think it was as good as a lower limb prosthesis. Saradjian et al (2008) findings support the suggestion that the prosthesis could moderate outcomes following ULA.

This qualitative literature has suggested that the focus of individuals with limb absence is not so much on the prosthesis itself but on what the prosthesis enables them to do. Consequently, prosthetic use as an outcome may be of secondary importance. More focus needs to be on ensuring that the individual reaches the goals they set for themselves.

A review of the literature has been previously conducted by Biddiss & Chau (2007a) concerning upper limb prosthesis use and abandonment over the past 25 years. This comprehensive review gave an insight into the factors that are likely to affect prosthesis

use/ abandonment and increase prosthesis wear. Biddiss & Chau (2007a) concluded in the review that there is insufficient evidence to clearly delineate the role of each variable discussed in their study on upper extremity use and abandonment. Also, they did acknowledge that prosthesis ‘acceptance’ is particularly difficult to measure as it incorporates a large number of dimensions from consumer satisfaction to extent of wear, and even more specifically extent of use. They argue that although rejection rates are more quantifiable, they are subject to varying definitions (complete abandonment or infrequent use) which make comparisons between studies difficult. However, Biddiss & Chau (2007a) did not provide any argument as to whether quantification of prosthesis use or measurement of prosthesis use is an appropriate method of measuring an individual’s progress following absence of the upper limb, especially considering the particular emphasis on it in the literature. Additionally, they included results from paediatric populations to support their assertions but did not discuss how this population differ from adults. Also several of the studies used in their review included individuals with both upper and lower limb absence in the sample. However, Biddiss & Chau, (2007a) did not acknowledge how the inclusion of these studies may affect their conclusions.

This review will discuss in each section, where the conclusions from this review, converge or diverge with the conclusions reached by Biddiss & Chau (2007a) review of the evidence. The following sections review the factors that have been investigated as associated with prosthesis use, such as age, gender, cause of limb absence, level of limb absence, bilateral limb absence, absence of dominant hand, coping strategies, employment, fitting time of a prosthesis, satisfaction with a prosthesis, satisfaction with rehabilitation service, choice, and co-morbidities, referring to studies published in the last 20 years (1989-2009) with adult populations, and with participants with upper limb absence only. This review also adds to findings by Biddiss & Chau (2007a) by inclusion of studies published since 2007. However, caution must be applied in interpreting the findings that follow, as there was much variation in how prosthesis use was assessed in these studies (see table 1.1). Table 1.2 provides a brief overview of which studies have investigated which variables. The following predictors have been investigated to date in relation to ‘successful prosthesis use’ as defined in each of the relevant studies:

Table 1.2 Overview of variables assessed by main studies in relation to prosthesis use

<u>Author</u>	<u>Age</u>	<u>Gender</u>	<u>Cause</u>	<u>Level</u>	<u>bilateral</u>	<u>Absence of dominant hand</u>	<u>Employ- ment</u>	<u>Coping strategies</u>	<u>Fitting time of prosthesis</u>	<u>Satisfaction with prosthesis</u>	<u>Satisfaction with Rehab service</u>	<u>Choice</u>	<u>Co- morbidi- ties</u>
Roeschlein & Domholdt (1989)	X			x		x	x		X				X
Jones & Davidson (1995)				x			x						X
Wright et al (1995)	X	x		x			x		X				X
Gaine et al (1997)			X			x			X				
Hacking et al (1997)	X			x		x	x		X				
Kooijman et al (2000)													X
Davidson (2002)													
Bhaskarand et al (2003)	X			x					X				
Datta et al (2004)													X
Dudkiewicz et al (2004)				x	x	x							X
Desmond (2007)								X					
Bidiss & Chau (2007c)	X	x	X	x	x	x	x		X	x	X	x	X
Biddiss & Chau (2008)	X	x		x					X	x	X	x	
Hanley et al (2009)													X

### 1.3.3.1 Factors associated with prosthesis use: Age

Chapter 1.2 gave an overview of the average age of individuals with ULA, indicating that they tend to be of younger age compared to individuals with lower limb absence. Several studies have investigated age at amputation as a potential predictor of prosthesis use. In a study assessing the factors related to successful use of an upper extremity prosthesis, Roeschlein & Domholdt (1989) assessed age at amputation and age at time of review for 40 participants with ULA. The mean age of participants in the study was 56.4 years (ranging from 19-81 years) and mean age at amputation was 30.8 years (range 35-62). However, the study found no statistically significant difference for age at amputation or age at time of study between successful (wore and used prosthesis at least one prosthesis everyday), partially successful users (wore or used a prosthesis solely for certain tasks or hobbies) and unsuccessful prosthesis users (did not use a prosthesis, or wore a prosthesis for cosmesis without using it in a functional manner). Additionally, in Wright et al's (1995) study of the prosthetic usage in major upper extremity amputations, the mean age at amputation for participants was 36 years and ranged from 2-73 years. However, this study only distinguished between those who were fitted with a prosthesis who continued with its use, and those who did not continue with its use. This study reported no correlation between age at amputation and discontinuation of use of the prosthesis. There were no further details reported concerning the statistical test used or significance levels. However, in another study by Hacking et al (1997) also assessing the factors influencing upper limb prosthesis use with 29 participants with amputation of the upper limbs, there was no correlation to a person's age at amputation and their wearing time of the prosthesis (that is, no hours prosthesis use, less than 4 hours prosthesis use, or greater than 4 hours reported prosthesis wear). Hacking et al (1997) gave no details on the statistical procedure used other than stating that there was 'no correlation' and did not report significance levels. This makes it difficult to interpret the suitability of the statistical analysis used. Also, Hacking et al (1997) reported that the mean age of 'separate groups' were 34 years (19-68 years) and 43 years (24-76 years). However, they did not make clear what the groups were referring to in this distinction of 'separate groups'. Bhaskarand et al (2003) assessed 71 patients with ULA in order to evaluate the success of prosthetic rehabilitation and determine reasons for non-compliance. The mean age for participants at the time of

amputation was 25.1 years (SD=11.6 years) and mean age at time of study was 39.5 years (SD=11.7). This study calculated a 'Prosthesis rehabilitation score' (which consisted of a patients acceptance, prosthetic usage and functional level) and correlated this score with a mean age at prosthesis fitting. However, there was no statistically significant relationship between mean age at amputation/ or mean age at time of study to the PRS. Additionally, Biddiss & Chau (2007c) analysed data from surveys with 242 individuals with ULA and found the mean age (at the time of the study) of prosthesis rejecters (used prosthesis once a year or less) and frequent wearers (used a prosthesis more than once a year) to not be significantly different. However, Biddiss & Chau (2007c) did not differentiate between frequent wearers who were full time or part time users in terms of age. The mean age of adults in Biddiss & Chau (2007c) study was 43 years (19-80 years) and the mean age of the paediatric group was 9.5 years (1-18 years).

Despite the lack of evidence that age at time of study is related to prosthesis use in Biddiss & Chau (2007c), this study did find rejection rates to be peaked markedly in three age groups, from 4 to 10 years from 24 to 35 years and for those greater than 65 years. These significant findings were irrespective of origin of limb absence (congenital or acquired). Biddiss & Chau (2008) assessed the factors that predict upper limb prosthesis use (wore a prosthesis greater than once a year) or rejection (previously been prescribed a device but wore a prosthesis once a year or less), through multivariate prediction. The mean age of adults in their study was 42 years (19-80 years) and the mean age in the paediatric group was 11 years (1-18 years). This study found there to be higher rates of rejection (>40%) between the ages of 4-10 years, 25-35 years and 50-60 years. Biddiss & Chau (2007c, 2008) believe that their results imply that age may reflect variations in functional needs and personal goals occurring at different life stages.

It can be concluded from these findings that age at amputation (Roeschlein & Domholdt, 1989; Wright et al 1995; Hacking et al, 1997), age at review (Roeschlein & Domholdt, 1989; Biddiss & Chau, 2007c) and age at prosthesis fitting (Bhaskarand et al, 2003) are not related to prosthesis use but that the current developmental stage of an individual may influence prosthesis use (Biddiss & Chau, 2007c; Biddiss & Chau, 2008). These findings

agree with the conclusions reached by Biddiss & Chau (2007a) who could not find any evidence that concluded that age is a risk factor for prosthesis abandonment in adult populations but that it may be a risk factor in maturing paediatric populations, and asserted that lifestyle is likely to have a more influential role as opposed to age in adults.

#### 1.3.3.2 Factors associated with prosthesis use: Gender

In general in amputation, there tends to be a lower proportion of females to males and this divide tends to be more prominent in ULA (NASD, 2009). Additionally, although there have been limited investigations of gender, there is some mixed evidence in the literature that gender may be a predisposing predictor of prosthesis use. In Wright et al's (1995) study, 16% of the sample were female and they observed that prosthesis rejection (reported discontinuation of prosthesis use) rates for males were 38% and for females were 35%. Wright et al (1995) therefore concluded that there was no gender difference for prosthesis rejection. However, Biddiss & Chau's (2007c) sample had 49% of females in their study and found that overall of the females, 39% were significantly more likely to reject a prosthesis than were males, where 23% rejected the prosthesis. However, for those with congenital limb absence, at any level (higher than elbow; lower than elbow to wrist) there were no significant gender differences in prosthesis use. However, amongst those individuals with acquired limb absence, females were significantly more likely to reject a prosthesis than were males at both the transradial (below the elbow) and high levels of limb absence. There was not enough data available to assess low-level limb absence. Results also found that females with high level, acquired limb absence rejected prostheses in 80% of cases. Biddiss & Chau (2008) had the same percentage gender breakdown as Biddiss & Chau (2007c) and also found that females displayed higher rates of prosthesis rejection particularly those with acquired limb absence.

These few studies suggest that females with acquired limb absence are more likely to reject the prosthesis than females with congenital limb absence and males. The larger sample size in Biddiss & Chau (2007c; 242) and Biddiss & Chau (2008; 191) compared to Wright et al (1995; 113) may account to some extent for the greater variation in rejection rates between males and females in Biddiss & Chau (2007c, 2008). Also given that Wright



et al (1995) did not test for any statistical differences, no further insights can be drawn. However, neither Wright et al (1995) nor Biddiss & Chau (2007c; 2008) assessed gender differences for frequency of prosthesis use. They just assessed the dichotomy of prosthesis use/ prosthesis rejection. Biddiss & Chau (2007a) did not find any evidence that gender is correlated with prosthesis use. However, the later studies by Biddiss & Chau (200c; 2008) have added to the literature suggesting that gender may have an influencing role in rejection of the prostheses.

#### 1.3.3.3 Factors associated with prosthesis use: Cause of limb absence

Gaine et al (1997) reported that when comparing the traumatic group (n=23) of individuals to the congenital group (n=27) there was a significant difference in terms of length of prosthetic wear, with individuals with congenital limb absence wearing the prosthesis longer, (6 hours versus 9.3 hours). In relation to the overall Prosthetic Success Score (PSS), participants with congenital limb absence received a score of 7 (which indicates a 'Good' value on the PSS) and individuals with traumatic limb absence received a score of 4 (which indicates a 'fair value on the PSS). However, it was acknowledged by Gaine et al (1997) that the individuals with congenital limb absence were also much younger and had more below elbow limb absence, which they suggested makes adaptation to prosthesis use easier. However, Gaine et al (1997) compared traumatic versus congenital cases, without taking into account other forms of acquired limb absence such as limb absence due to infection, cancer, or vascular disease.

Biddiss & Chau (2007c) compared individuals with acquired amputations to congenital cases and found that regardless of level of limb absence, individuals with acquired limb absence were more likely to be prosthetic users than those with congenital limb absence. Congenital limb absence was present in 91% of the paediatric population, but only 41% in the adult population. Since Biddiss & Chau (2007c) used prosthesis use/ rejection as the main outcome and Gaine et al (1997) was more concerned with frequency of use, it may explain the differences between the studies. Also, Biddiss & Chau (2007c) tested differences between acquired and congenital limb absence, whereas, Gaine et al (1997) assessed differences between congenital and traumatic cases. Therefore these data from

Biddiss & Chau, (2007c) suggest that individuals with acquired limb absence are more likely to be prosthesis users. Although, of those individuals that do wear a prosthesis, it has not been investigated whether they differ in hours of prosthesis use compared to individuals with acquired limb absence and based on Gaine et al (1997) findings, perhaps there would be a difference in hours use. Also, there is no data on whether other causes of acquired limb absence (infection, cancer, trauma, vascular disease) will differ amongst prosthesis users/ rejecters, or will differ in number of hours of prosthesis use. From their review of the literature, Biddiss & Chau (2007a) asserted that the relationship between cause of limb absence and prosthesis use is still unresolved.

#### 1.3.3.4 Factors associated with prosthesis use: Level of limb absence

In the Roeschlein & Domholdt (1989) study, 20% of participants had above elbow amputation, 10% had elbow disarticulation (amputation at the elbow), 42.5% had transradial (amputation below the elbow) and 27.5% had wrist disarticulation (amputation at the wrist). Roeschlein & Domholdt (1989) reported in a table in their study the types of prosthesis users (successful users, partially successful users and unsuccessful users) according to their level of amputation (above elbow, elbow disarticulation, below elbow and wrist disarticulation), which demonstrated that there were a greater number of successful users than partially successful or unsuccessful users for each level of limb absence. Roeschlein & Domholdt (1989) pointed out that at each level, at least half of the individuals with limb absence were classified as successful users, and that absence of elbow did not differentiate between successful and unsuccessful users. However, no further information was given regarding this analysis by Roeschlein & Domholdt (1989). Jones & Davidson's (1995) study reported that individuals with shoulder disarticulation (7.4%), partial hand amputation (3.7%), and transcarpal amputations (amputation just below the wrist; 3.7%) reported all day prosthesis use. Amongst individuals with amputation below the elbow (n=6, 22.2%), 3 reported all day use, 2 reported occasional use and one was a non prosthesis user. Amongst individuals with amputations above the elbow (n=11, 40.7%), 2 used the prosthesis all day, 3 used the prosthesis occasionally and 7 were non users. The individuals with fore quarter amputations (7.4%) did not report constant prosthetic use for over 8 hours. However, no statistical analyses were performed

so it is difficult to ascertain if there is any statistically significant relationship between level of amputation and prosthesis use. In the Hacking et al (1997) study, 3.5% had shoulder disarticulation, 27.5% had transhumeral, 6.9% had elbow disarticulation, 44.8% had a transradial amputation and 13.8% had a wrist disarticulation. They assessed the association between level of amputation (wrist, transradial, elbow, transhumeral, and shoulder) and prosthesis use (no prosthesis use, less than four hours prosthesis use, greater than 4 hours prosthesis use) and found that patients with an amputation lower than the elbow used their prosthesis relatively more often than patients with a high level of amputation (through or proximal to the elbow). It is not clear if these associations were statistically tested. Dudkiewicz et al (2004) had 7.1% of participants with amputation at the wrist, 11.9% with amputations below the elbow, 9.5% had amputations at the elbow, and 71.4% had amputations above the elbow. They reported that they found no significant effect of the amputation level except for those who had a wrist disarticulation who displayed 100% prosthesis use. However, they provided no information regarding what statistical analyses were used. Their study provided a table demonstrating prosthetic usage rates (non-use of prosthesis, temporal use of prosthesis, and permanent use of prosthesis) across 4 levels of limb absence (above elbow, trans-elbow, below-elbow, and transwrist). However, it is unclear how they deduced that there is no significant effect for all other amputation levels. The lack of transparency in the analyses used in Roeschlein & Domholdt (1989), Jones & Davidson, (1995), Hacking et al (1997), and Dudkiewicz et al (2004) makes it difficult to draw any valid conclusions from these studies.

In Wright et al's (1995) study, 11% had wrist disarticulation, 33% had an amputation below the elbow, 40% above the elbow and it was reported that 15% had either shoulder or forequarter amputation. They reported the usage rates of the prosthesis by amputation level, showing for those participants with wrist disarticulation, 54% used a prosthesis, for those with below elbow limb absence, 94% used a prosthesis, for those with above elbow limb absence, 43% used a prosthesis and for those with shoulder disarticulation or forequarter limb absence, 40% used a prosthesis. However, Wright et al (1995) reported no significant difference in hours of use of the prosthesis in relation to level of amputation. Bhaskarand et al (2003) conducted a chi square analysis to assess whether

there was a difference between individuals with amputations above the elbow and below elbow amputations in terms of Prosthesis Rehabilitation Score (PRS; patient acceptance, prosthesis usage, functional level) and found no significant difference between both groups who both received a PRS score of 'good'. There was one shoulder disarticulation patient who was rated 'poor' on the PRS.

However, recent evidence from Biddiss & Chau (2007c) found that individuals with limb absence proximal to the elbow, (high level) or to the wrist (low level) were significantly more likely to reject a prosthesis, than those with transradial limb absence (below elbow; medium level). 16% of participants in this sample had limb absence lower than the wrist, 54% had limb absence below the elbow, 21% had above elbow limb absence and 7% had shoulder disarticulation or higher. For participants in Biddiss & Chau (2008) 12% had limb absence below the wrist (low level), 59% had transradial (medium level) and 29% had above elbow (high level). Biddiss & Chau (2008) also found low and high levels of limb absence but not medium level to be significantly associated with prosthesis rejection.

Evidence from these studies suggests that below elbow amputation is the most common level of limb absence in these studies. Therefore, based on evidence from Wright et al (1995), there is no significant difference on prosthesis wearing time based on level of amputation. Neither is there a significant difference between amputation levels regarding a PRS (Bhaskarand et al 2003). However, Biddiss & Chau (2007c; 2008) results indicate that individuals with high and low amputation levels may be more likely to reject a prosthesis. This conclusion agrees with the review of the literature by Biddiss & Chau, (2007a) who suggested that level of limb absence is one of the most widely studied and definitive characteristics linked with prosthesis use, with most of their studies suggesting a particular role of below elbow limb absence in relating to prosthesis use.

#### 1.3.3.5 Factors associated with prosthesis use: Bilateral limb absence

Although bilateral upper limb absence has obvious extra difficulties for the individual than unilateral limb absence, there does not appear to be much evidence in the literature that suggests bilateral upper limb absence affects prosthetic use and no investigations appear to

have been conducted on how bilateral limb absence affects an individual's functional level and psychosocial outcome. Dudkiewicz et al (1995) reported that 9.5% of their sample had bilateral limb absence and that 58.9% of these used prostheses, compared to 66.6% of those with amputation of the non-dominant limb and 68.9% of dominant hand. However, they did not report if any statistical analysis had been conducted to assess this difference. Biddiss & Chau (2007c) found that those individuals with bilateral limb absence (15% of their sample) did not differ significantly with regard to prosthesis use compared to those with unilateral limb absence. However, Biddiss & Chau (2007c) did find that individuals with congenital, bilateral limb absence had significantly higher rates of rejection of prostheses (75%) in comparison with those with congenital unilateral limb absence (28%). The prevalence and impairment of bilateral limb amputation appears to be an understudied area of research. However, from limited number of studies Biddiss & Chau (2007c) found evidence that higher incidence of prosthesis wear by bilateral amputees. However, from these limited studies, it appears that those with congenital bilateral limb absence may be more likely not to use a prosthesis compared to those with congenital unilateral limb absence.

#### 1.3.3.6 Factors associated with prosthesis use: Absence of dominant limb

In the Roeschlein & Domholdt (1989) study 37.5% were reported to have lost their dominant limb. Roeschlein & Domholdt (1989) did not find absence of dominant hand to differentiate between successful, partially successful and unsuccessful prosthesis users. Once again, no details of the statistical analysis used were revealed. Dudkiewicz et al (1995) reported that 47.6% of the sample had amputation of the dominant limb. However, there was no significant difference in prosthesis usage (non-use of prosthesis; temporal use of prosthesis; permanent use of prosthesis) between sides in accordance to dominance. Biddiss & Chau (2007c) reported that of those with acquired limb absence, 54% lost their dominant limb and found amputation of the dominant limb to not be correlated with prosthesis use or prosthesis rejection.

Gaine et al (1997) reported that half of the individuals in their sample that had amputation as a result of traumatic causes lost their dominant limb but that absence of dominant limb

had no effect on the prosthetic success score (prosthetic wear, satisfaction with the prosthesis, and function). However, although not statistically significant, Gaine et al (1997) found that those patients who lost their dominant limb wore their prosthesis for an average of two and a half hours less each day than those who lost their non-dominant arm. However, they did not give any further details regarding how this was assessed. In contrast, Hacking et al (1997) found that of the 31% of their sample who lost their dominant limb, of these 89% wore the prosthesis for greater than four hours a day, but 50% of those who lost the non-dominant limb did not wear the prosthesis and only 40% wore it for greater than four hours. No statistical relationship was reported between dominancy and prosthesis use. It appears limb dominance is not related to prosthesis use but due to the lack of statistical evidence reported in these limited number of studies, it is difficult to draw any conclusions regarding the association between limb dominancy and prosthesis use. Additionally, Biddiss & Chau (2007a) also found mixed evidence of whether limb dominance is related to prosthesis use and asserted that based on the evidence, if it is correlated, it is probably only a minor factor.

#### 1.3.3.7 Factors associated with prosthesis use: Employment

Without a longitudinal study it is difficult to ascertain if prosthesis use is predictive of employment or whether employment is predictive of prosthesis use. Therefore this chapter can only discuss cross sectional correlational data. Data from Gaine et al (1997) found that at time of the study five participants of a total of 55 in their study lost the jobs they had at time of the amputation, and 11 participants in their study reported changing occupation after limb absence. Gaine et al (1997) also found that no patient fitted with a prosthesis after 12 weeks post amputation returned to gainful employment. No statistical analyses were reported for this study. Also, no analysis between employment and prosthesis use was conducted. Biddiss & Chau (2007c) reported that rates of unemployment and disability leave were low in their sample (but did not report the rates) and stated that they were not statistically different for prosthesis wearers and prosthesis rejecters. However, they did not give any indication as to whether there was a significant difference between full time or part time consistent wearers. Wright et al (1995) found no significant difference in hours of use of the prosthesis for those who were employed and there did not

appear to be a change in employment from pre-to post amputation (Wright et al, 1995). However, Jones & Davidson (1995) found that all unemployed people were non-prosthetic users. Roeschlein & Domholdt (1989) found that unsuccessful prosthetic users are less likely to have been employed at amputation or at time of review. This finding by Roeschlein & Domholdt (1989) may imply that employment could be a predisposing characteristic of prosthesis use. However, there were only three unemployed people in the sample and this association was not tested statistically. Hacking et al (1997) found that having or not having a job had no influence on wearing the prosthesis regularly, while no statistical relationship was reported. Biddiss & Chau (2007c) also found mixed evidence of the association between employment and prosthesis use but did not make any further assertions. This review shows a mix of evidence of whether employment status is related to prosthesis use.

#### 1.3.3.8 Factors associated with prosthesis use: Coping strategies

There was a wider discussion of coping strategies in Section 1.3.1 where Desmond (2007) found evidence to suggest that certain coping strategies such as avoidance may result in an individual not adjusting to the amputation. However, Desmond (2007) found that there was no significant difference between prosthetic users and non prosthetic users in coping strategies used. In order to ascertain if use of a prosthesis moderates the reported elevated psychological distress in this population compared to individuals without amputations (see discussion of Desmond, 2007 in Section 1.3.1), it would be useful to assess whether anxiety and depression scores differ between upper limb prosthetic users and non-prosthetic users. It is also necessary to investigate the role of coping strategies more in this population in terms of whether the prosthesis is a mechanism of coping, especially at earlier stages post amputation.

#### 1.3.3.9 Factors associated with prosthesis use: Fitting time of prosthesis

According to Esquenazi (2000), there is a direct relationship between the time of fitting and long term prosthesis use and a 1-6 month window of opportunity exists when there is a much greater rate of acceptance (use) and functional integration of the artificial arm for the individual with unilateral ULA. There is some evidence in the literature that supports

fitting an individual with a prosthesis early after amputation, as this may increase likelihood of increased prosthetic usage (Roeschlein & Domholdt, 1989; Biddiss & Chau, 2007c, Biddiss & Chau, 2008). Roeschlein & Domholdt (1989) reported that successful prosthesis users received their prosthesis sooner than the individuals with limb absence that are deemed unsuccessful. Although this was not tested statistically, nor was any indication given of how much sooner successful users received their prosthesis. Gaine et al (1997) reported that the average time from traumatic amputation to initial fitting of prosthesis was 6.5 months and this varied from 8 weeks to 2 years, but 10 of the 55 participants had initial fitting before 8 weeks. However, there was no analysis of whether fitting time was associated with the PSS. Biddiss & Chau (2007c) reported that the prosthesis fitting time frame was an important factor in prosthesis use for individuals with congenital limb absence. Prosthesis rejecters were fitted within a median of 3.9 years whereas frequent wearers were fitted within 11 months. Amongst those with acquired limb absence, prosthesis rejecters were fitted a median of 6 months after amputation whereas prosthesis wearers were fitted within a median of 3 months. Biddiss & Chau (2007c) found frequent wearers were fitted approximately 3 years more quickly with a prosthesis than rejecters. Biddiss & Chau (2008) found that fitting at greater than 0.5 years from amputation is significantly associated with higher rates of prosthesis rejection.

Despite evidence from these studies, there is also opposing evidence that that there is no link between time of fitting following amputation and prosthesis use (Wright et al, 1995). Wright et al (1995) found that 88% of participants in their sample received a prosthesis within the first year after amputation. There was no statistical correlation between time of fitting the prosthesis (greater or less than 1 year) and prosthetic use. Bhaskarand et al (2003) found that a delay in fitting had no relationship with successful prosthetic rehabilitation, as measured by the PRS. Although Hacking et al (1997) found that of the group that thought the prosthesis was provided at the right time, 82% used the prosthesis regularly, of the participants that thought it was prescribed too late, 25% used the prosthesis regularly. However, there is no report of the actual time of fitting by Hacking et al (1997). Since results by Roeschlein & Domholdt (1989) and Biddiss & Chau (2007c, 2008) suggest that early fitting is related to prosthesis use, and Wright et al (1995) and



Bhaskarand et al (2003) suggest that fitting time does relate to prosthesis use, therefore, there appears to be mixed evidence of the role of fitting time on prosthesis use, and most of the studies did not report what constitutes 'early fitting'. More definitive research is needed in this area. Similarly, Biddiss & Chau (2007a) found a mix of evidence but suggested that although early fitting with a prosthesis may increase acceptance, it will not necessarily increase skill or functional use. Ultimately they assert that the effect of time lapse between amputation and first fitting remains unresolved.

#### 1.3.3.10 Factors associated with prosthesis use: Satisfaction with prosthesis

Some research has suggested that satisfaction with the prosthesis is related to prosthesis use (Biddiss & Chau, 2007c; Biddiss & Chau, 2008). The most common areas of dissatisfaction with upper limb prostheses that have been reported have included weight (Dudkiewicz et al, 2004; Gaine et al, 1997; Pylatiuk, Schulz, & Doderlein, (2007); Hacking et al 1997; Datta et al 2004); and prosthesis causing sweating (Gaine et al, 1997; Dudkiewicz et al 2004; Jones & Davidson, 1995). Datta et al (2004) found that 76.6% of their sample of 60 participants were satisfied with the appearance of the prosthesis. However no data was provided regarding how often these participants wore their prosthesis.

Biddiss & Chau (2007c) found that individuals that have rejected their prosthesis were significantly less satisfied with all aspects of prosthesis design, including, appearance, comfort, function, ease of control, reliability, and cost than prosthesis users. Of prosthesis rejecters, 74% stated that they might reconsider prosthesis use if technological improvements were made at a reasonable cost. Biddiss & Chau (2008) found satisfaction with the prosthesis to be strongly correlated with prosthesis use. In general, the literature has reported many areas of dissatisfaction with the prosthesis experienced by individuals with ULA. These results highlight the growing need to address patients' areas of dissatisfaction with their prosthesis, in order to reduce prosthesis rejection and maximise prosthesis use and patient satisfaction. One of the scales of the TAPES is concerned with 'prosthesis satisfaction' (Gallagher & MacLachlan, 2000). The prosthesis satisfaction scale of the TAPES tested by (Desmond & MacLachlan, 2005) had 10 items and was

found to be significantly positively correlated with general adjustment and optimal adjustment as measured by the TAPES. Therefore, this scale could be used in future studies with ULA to assess prosthetic satisfaction.

#### 1.3.3.11 Factors associated with prosthesis use: Satisfaction with rehabilitation service

Biddiss & Chau (2007c) found that satisfaction with health care in all areas especially fitting; follow up, repair, training, and information provision was significantly lower for prosthesis rejecters. Prosthesis rejecters were also significantly less satisfied with the information provided with respect to prosthetic technology, sources of funding, use of multiple prostheses, level of expectations set, and overall knowledge and experience of health care providers. Both prosthesis rejecters and frequent wearers were interested in receiving better information on non-prosthetic options (i.e. strategies for accomplishing activities without use of a prosthesis) and resources for peer support (Biddiss & Chau, 2007c). Biddiss & Chau (2007c) acknowledge that these findings may be related to the fact that they found frequent wearers were fitted approximately 3 years more quickly with a prosthesis than rejecters. These findings suggested that dissatisfaction with the service may lead to prosthesis rejection. Biddiss & Chau (2008) also found greater satisfaction with service to be significantly associated with prosthesis use. However, there is no data from these studies investigating whether satisfaction with service is related to service uptake and if service uptake is related to prosthesis use. Further attention needs to be paid to areas of dissatisfaction amongst patients as suggested by Biddiss & Chau (2007c).

#### 1.3.3.12 Factors associated with prosthetic use: Choice

Biddiss & Chau (2007c, 2008) have provided evidence that provision of choice to the patient can be beneficial to the health service. For example, in Biddiss & Chau (2007c), frequent prosthesis wearers reported a significantly greater involvement in 'choice' regarding involvement in selection of their primary prosthesis. However, prosthesis rejection and involvement in prosthesis selection was not related to the type of device selected. Emphasising that it is simply having the choice of which prosthesis is chosen appears to predict prosthesis use.

#### 1.3.3.13 Factors associated with prosthesis use: Co-morbidities

In Section 1.3.2, the prevalence of co-morbidities such as PLP, and RLP were discussed and the impact these co-morbidities have on the individual with ULA. Koojiman et al (2000) and Roeschlein & Domholdt (1989) found results that suggested that those who suffer from PLP and PLS are less likely to wear a prosthesis. Specifically, Roeschlein & Domholdt (1989) reported that unsuccessful prosthesis users had more complications (visual handicaps, trauma to other limbs, heart problems, bone or joint problems, or phantom pain or sensations). However, there was no report of whether these findings were statistically calculated or simply an observation. Other studies have found support for that suggestion through patients citing reasons for why they ceased using their prosthesis. For example, Davidson (2002) reported that 85% of the sample had some pain, and that 42% of participants reported that pain interfered with their ability to wear a prosthesis. Participants in Datta et al (2004) cited pain as one of the reasons for prosthesis rejection. But there was no data nor any statistical relationship between how many individuals that currently wear a prosthesis and those who report pain.

Several other authors have found no link between PLP and prosthesis use (Biddiss & Chau, 2007c, Dudkiewicz et al 2004, Wright et al 1995, Jones & Davidson, 1995) or RLP and prosthesis use (Biddiss & Chau, 2007c, Dudkiewicz et al 2004, Jones & Davidson, 1995). Jones & Davidson (1995) stated that RLP or PLP did not affect prosthetic usage. However, they did not give any details of how they reached this conclusion. Wright et al (1995) found a significant correlation between PLP and shoulder stiffness but no correlation was found between PLP and discontinuation of the use of the prosthesis. Biddiss & Chau (2007c) reported no significant differences in RLP, PLP or upper body pain were observed between prosthesis rejecters and frequent wearers. However, no details were reported regarding differences between occasional users and frequent wearers or prosthesis rejecters in these domains. In Hanley et al's (2009) study, individuals who used a prosthesis were significantly more likely to report PLP, but they acknowledge that they do not know if using a prosthesis contributes to pain or is used to relieve it. The other pain types were not associated with prosthesis use.

These studies show a mix of evidence of a relationship between co-morbidities and prosthesis use. A similar mix of evidence was found by Biddiss & Chau (2007a) in their review of the literature and they concluded that the definitive role remains unresolved. Roeschlein & Domholdt (1989), Davidson, (2004), Datta et al (2004), and Hanley et al (2009) suggesting that co-morbidities are related to prosthesis use, whereas, Wright et al (1995), Jones and Davidson (1995), and Biddiss & Chau (2007c) suggest that they are unrelated. It is difficult to know without a longitudinal analysis if co-morbidities such as pain influence prosthesis use or if prosthesis use influences pain, particularly as the type of prosthesis used was not assessed in Hanley et al's (2009) study. Individuals who reported using a prosthesis were not significantly more likely to have neck, back or non-amputated limb pain. Prosthesis use demonstrated a non-significant trend to be associated with the presence of RLP. They did not report if any association was calculated between prosthesis use and QOL, despite gathering data on QOL.

#### 1.3.3.14 Additional predictors

There are other predictors that have been investigated in relation to prosthesis use, although not as commonly as the predictors already discussed. Participants in Roeschlein & Domholdt's (1989) study, who were prosthesis users, were found to have a higher level of education than unsuccessful users, although this finding was not tested statistically. Also, Roeschlein & Domholdt (1989) reported that those who were unsuccessful prosthetic users reported significantly less acceptance of amputation at time of review. Roeschlein & Domholdt (1989) did not detail how 'acceptance' was measured and they did not say if this difference was compared to partially successful users or successful users or both. In order to ascertain whether acceptance of amputation or educational level have any relationship with prosthesis use, it is necessary to test this relationship statistically in future research.

#### 1.3.3.15 Prosthesis use summary and conclusion

This section has discussed how studies differ in what they are defining as 'prosthesis success'. Some are referring to whether prosthesis use is used at all versus being outright rejected and others are assessing frequency of use. It is important to know how prosthesis

success was defined in a study before concluding if a factor is related to prosthesis 'success.' The methodological problems in assessing many of these studies were apparent with several studies drawing conclusions without statistically testing relationships or differences. In addition, to date no longitudinal study has been undertaken to explore the factors associated with prosthetic use. Additionally, this review is based on a small number of studies with individuals with ULA. Nevertheless, while taking into consideration the shortcomings and limited evidence, this review suggests that the following factors may be related to prosthesis rejection:

- Certain developmental stages may be associated with prosthesis rejection.
- Females with acquired limb absence may be more likely to reject a prosthesis compared to females with congenital limb absence or males.
- Those who lose a limb through congenital causes are more likely to reject a prosthesis compared to those who lose a limb through acquired causes.
- Those with higher and lower levels of limb absence are more likely to reject their prosthesis.
- Those with congenital bilateral limb absence are more likely to reject a prosthesis compared to those with congenital unilateral limb absence.
- Those who are less satisfied with their prosthesis may be more likely to reject a prosthesis.
- Those who are less satisfied with their service may be more likely to be prosthesis rejecters.

Although for other predictors, such as employment, co-morbidities and fitting time, the available evidence is mixed and inconclusive. The data also appears to suggest that coping strategies employed do not differ between prosthesis users and non users. However, caution is applied with this assertion as only one analysis with individuals with ULA has been conducted regarding coping strategies and ULA. Further analyses will enable a more definitive conclusion. This review could not find sufficient evidence of what factors may contribute to greater hours of prosthesis use.

As is evident from this review of the literature, most studies are concerned with

identifying the predictors of prosthesis use such as demographic, physical or amputation related factors and there are very few assessing the psychological or social factors that predict prosthesis use. For example, studies such as Biddiss & Chau (2007c) emphasised peer support and the need for information regarding non-prosthetic options and the state of technology, but did not investigate factors such as psychological state and coping strategies. Indeed Biddiss & Chau (2008) acknowledge that many of the internal motivating factors may not have been adequately captured in their study.

Although these factors have identified what might predict whether a prosthesis is used versus rejected, or what might promote greater hours of prosthesis use, whether this represents ‘prosthesis success’ or at least ‘rehabilitation success’ can be argued. It is important to identify predictors of ‘prosthesis success’, as defined by RP’s and individuals with ULA. It can be argued that, using pre-defined definitions of success are not taking into account the patient’s perspective and what is important to them in terms of prosthesis use and is not considering the possibility that a person who only uses their prosthesis for specific activities is as functional in other activities without the prosthesis as another individual is who wears the prosthesis all the time. It is argued that these outcomes are not taking a holistic view of the patient’s rehabilitation, by almost equating prosthetic use, as indicative of ‘the most important’ outcome of rehabilitation. This does not support the goals of rehabilitation which should consider more patient centred outcomes. However, it is acknowledged that Gaine et al (1997) ‘Prosthetic success score’ and Bhaskarands et al (2003) similar ‘Prosthetic rehabilitation score’ encapsulates this notion that prosthesis use defined by hours use is not enough to determine success.

Future research needs to understand the further impact many of these outcomes may have on an individual’s QOL. Although many studies have not investigated the outcomes other than prosthetic use, many of them acknowledge that it is needed. Davidson (2002) expressed that individuals with limb absence need not only prosthetic rehabilitation but also a program to assist in their return to vocational psychological, functional and social well-being. Biddiss & Chau (2008) acknowledge that their study does not address implications of prosthesis acceptance or rejection in terms of overall QOL. Biddiss &

Chau (2008) suggested that a study on QOL and incorporation of qualitative comments is needed.

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Chapter 1.4 Outcomes Assessment

Desmond & MacLachlan (2005) admit that relatively little is known about the outcomes of ULA. The desired outcome for each patient is application, training and integration of the prosthesis; however, quality rehabilitation goes beyond that outcome and accounts for individual variables that ultimately impact the entire calculus of successful rehabilitation (Yancosek, 2009). Livneh, et al (1999) recommend conceptualising psychosocial adjustment to disability as influenced by a host of interactive socio-demographic, disability-related, personality and environmental variables. The purpose of identifying outcomes of ULA is that ultimately knowing the important outcomes can enable the comparison of interventions and service delivery and contribute to cost effectiveness.

It needs to be agreed upon what should be the specific goals following the absence of an upper limb, whether it is prosthesis use or whether it is more than that. As Jones & Davidson (1995) posed, are the goals to enable a patient to function effectively at home, at work, and in leisure tasks? If it is found to be more than simply use of the prosthesis, then rehabilitation should focus on providing a patient with the ability to reintegrate functionally and socially to leisure and work activities (if desired by the individual), be it through the use of a prosthesis or not. Given that only limited function is possible with an upper limb prosthesis compared to the comparatively good function a lower limb prosthesis affords, as acknowledged by Gaine et al (1997), perhaps ability to perform a task through use of an upper limb prosthesis should not be considered more important than ability to perform the task in general by whatever means possible.

The proceeding discussion in Chapter 1.3 demonstrated the wide range of potential outcomes following ULA. Rehabilitation settings often use standardised outcome measures to assess patients' success following rehabilitation. However, it is important to ascertain if these measures used are relevant to the population and incorporate the necessary outcomes. For example, the outcome measures that have been reportedly used amongst individuals with ULA may not be adequately relevant to individuals with ULA.



For instance, most of the outcome measures available for use with individuals with ULA and used to measure outcomes in many research studies, are either designed to measure upper limb injury and not specifically amputation (e.g. Disability of the Arm Shoulder and Hand scale; DASH; Hudak, Amadio, Bombardier, & UECG (1996); were developed for individuals with lower limb absence first (e.g. Trinity Amputation and Prosthetic Experiences Scale; TAPES; Gallagher & MacLachlan, 2000); are meant for use with children (e.g. PUFi; Wright, Hubbard, Jutai & Naumann, 2001); or are mainly concerned with prosthetic function and satisfaction and do not measure psychosocial outcome (e.g. Prosthetic Profile of the Amputee; PPA; Grise, Gauthier-Gagnon, & Martineau, 1993). A measure that is developed solely for adult individuals with upper limb amputations, to assess their physical and psychosocial outcomes is needed.

However, in order for any outcome measure to be developed, an agreed set of outcomes is needed concerning physical, functional and psychosocial outcomes, reflective of the well accepted bio-psychosocial perspective (Engel, 1977). Rehabilitation is a broad field involving many areas of the functioning of a person, thus the bio-psychosocial model enables rehabilitation to address all aspects of the person. However, Mermis (2005) suggested that while the bio-psychosocial perspective provides a broad look at the person, it is useful to break the conceptualisation down into its domain levels and to define their relations in a meaningful way for measurement.

There is currently no agreement on which outcome should be measured in amputation rehabilitation. Deathe, Miller & Speechley (2002) observed that outcomes may be viewed as having a hierarchical order, ranging from the crude to the complex, as in prosthetic prescription, prosthetic wearing time, mobility performance and social activity, or community reintegration regardless of prosthetic use (Deathe et al, 2002). Deathe et al (2002) found that the majority of rehabilitation centres in Canada collected information on patient outcomes concerning amputation but most used informal measures. This suggests that there is no consensus regarding patient or program outcome measurement tools in the area of amputation rehabilitation in Canada. The most common outcome measure reportedly used is a non-standardised discharge checklist of activities in which

independence is believed to be important. Deathe et al (2002) recommend that amputation rehabilitation care providers reach a consensus as to which outcome measures are to be used. This will facilitate communication between centres and make possible collaboration in needed multicentre trials (Deathe et al (2002). In order to have one “gold standard” outcome measure, it is important to have one that encompasses all predictors and outcomes that are of relevance to all individuals with ULA and to all members of the multidisciplinary research team. These salient factors of importance to assess with individuals with ULA first need to be identified.

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Chapter 1.5 Lessons from Disability Studies

The functioning of persons with disabilities is affected by the entire network of biological, psychological, social, environmental, economic, legal, policy and political factors. However, disability research in psychology has been limited primarily to the first three factors. Psychology needs to go beyond an emphasis on the person with the disability to a broader-based approach that includes the family as well as the political and societal realms (Olkin & Pledger, 2003). It is essential that research on disability is embraced by psychology, and that the same principles (such as an emphasis on personal and environmental influences) that are based on disability studies in general are used by researchers in ULA/ absence.

The social model of disability focuses on the social and environmental barriers that oppress some impaired people. This model focuses on the social and institutional structures in which certain physical, emotional and intellectual ‘differences’ are identified and treated. The social model sees disability as the effect of an environment which discriminates against and disables certain ‘impaired’ individuals (Marks, 1999). Impairment only becomes disability because of social structures and organization (Marks, 1999). It is acknowledged within the disability literature that disability is multifaceted, and it is important to look beyond physical/ functional disability to the entire personal, social and environmental context of the individual.

Disability studies are grounded in the social model of disability and traditionally reject the medical model of which most disability research has been built (Olkin & Pledger, 2003). The importance of the social and contextual aspects of disability is reflected in the WHO's ICF (World Health Organisations International Classification on Functioning and Disability) framework. The ICF measures health and disability at both individual and population levels. The overall aim of the ICF classification is to provide a unified and standard language and framework for the description of health and health-related states.

The ICF model proposes that function is a positive outcome that arises out of the interaction among body structures, body functions, activity, and participation (Bartlett, Macnab, MacArthur, Mandich, Magill-Evans, Young, Beal, Conto-Becker & Polatajko, 2006). In contrast, disability is the negative outcome that arises out of the interaction among impairments, activity limitations and participation restrictions (Bartlett et al, 2006). Essentially, the ICF considers disability to be personally and environmentally constructed. Function and disability are modified by context, which is not only internal (personal) and external (environmental) factors but also the interaction among these components. Personal factors are thought to comprise the characteristics of the person independent of the health condition and environmental factors include the physical, social and attitudinal environments in which people live (Bartlett, et al, 2006).

ICF is based on an integration of both the medical and social models of disability, addressing the biological, individual and societal perspectives of health, reflective of the bio-psychosocial approach. The literature presented previously has demonstrated the essential role of physical, functional and prosthetic factors following amputation as well documented in the upper limb amputation literature. However, it is important to ensure that the literature on upper limb absence addresses the psychological, social, prosthetic, functional and physical factors that can all influence rehabilitation outcomes and assess how they interact.

The ICF also acknowledges the important role of personal factors, but they are not classified due to the large social and cultural variance associated with them. Personal factors are defined as the particular background of an individual's life and living and comprise features of the individual that are not part of a health condition or health states. These factors may include gender, race age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behaviour pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level (WHO, 2001). As was discussed in Chapter 1.3.3, many of these factors have been investigated in relation to prosthesis use.

However, there has been a stronger emphasis on personal demographic factors than more personal psychological factors, and these factors need to be investigated in relation to a wide range of outcomes following ULA.

Assistive technology (AT) is considered one of many environmental factors that affect the daily functioning of persons with disabilities, particularly their performance of activities and pursuit of vocational, social and community interests (Scherer, 2004, 2005). AT's are also considered to be a key component of the environmental factors domain of the ICF. Scherer & Glueckauf (2005) describe how AT's can improve the functioning of individuals with disabilities in community environments. Scherer & Glueckauf (2005) emphasise the need for comprehensive assessment of the individual before selecting AT's, particularly of their current goals, past experiences with the use of technologies and other supports, and predisposition to use the AT as well as alternative or additional supports (Scherer & Glueckauf, 2005). Assistive technology (AT) for many disabilities is considered an environmental factor that aids integration and facilitates participation in one's family, social and work life. The importance of the prosthesis in the rehabilitation of individuals with ULA can clearly be seen in the literature. However, as discussed in Chapter 1.3.3, prosthetic usage is the most common dependent variable investigated in the upper limb amputation literature, with many studies attempting to identify the most likely factors to predict their use. However, there is little research investigating how the prosthetic device benefits the individual in the long term, such as its relationship to psychosocial outcomes (such as body image, psychological distress, QOL) and functional outcomes (such as return to work, leisure activities, ADL) and co-morbidities. It is essential that prosthetic limbs also be considered environmental factors that for some individuals can enhance their rehabilitation outcomes rather than only measuring prosthetic "use" as the main rehabilitation outcome following ULA. As discussed in Chapter 1.4, there is a plea to move away from the medical model of rehabilitation, which focuses on the disability and the limitation of its effects to a social model, which emphasises the person and his/her participation in society beyond the provision of prosthetic limbs to consideration of how such limbs affect where that person can walk and the goals that can be achieved once he or she arrives there (Scherer, 2002a). Essentially,

wearing a prosthesis should not be the final or main outcome, but instead it is important to investigate the benefits wearing the prosthesis has for the individual.

### ***1.5.1 Conclusion***

Lessons from disability studies have been drawn on in this study, such as the importance of acknowledging that societal structures can impair an individual's ability to navigate their world, either socially or physically. Therefore, it is important to understand how we can remove these social barriers, by understanding how they impact on the individual with disability, in particular the individual with ULA. Disability studies also emphasise the importance of assessing personal and environmental factors (such as AT) in order to understand how each individual is affected by the loss of the limb. The present study intends to use these lessons from disability studies as a framework for this study. Much of the literature regarding ULA is still largely concerned with functional/ prosthetic outcomes and there has been very little investigation into psychosocial determining factors of prosthesis use and other outcomes. It is essential to rectify this and apply the philosophy of the ICF which incorporates the personal, social and environmental factors into research on upper limb amputation. Amputation can no longer be treated using the medical model of disability with the assumption that it only has physical repercussions. It is also affected by psychological and social influences and in turn impacts these aspects of the individual. Following the ethos of the ICF, it is important that the roles that personal and environmental factors play in all types of disability are acknowledged in research and are further investigated in research concerned with amputation of the upper limb.

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Chapter 1.6 Research Statement

This literature review has demonstrated that a considerable amount of research in the ULA literature has focused on identifying the salient predictors of upper limb prosthesis use. Much less research has been concerned with identifying the psychosocial, functional and physical outcomes of individuals with ULA. Lack of research on the likely outcomes to expect following ULA makes it difficult for RP's to ascertain if an individual is 'doing well' following ULA. It is important to determine what is important to assess in relation to individuals with ULA, in order to be able to determine any issues post amputation and any likely predictive variables. The literature has investigated an array of variables, with many deemed to have little impact on overall outcomes. It is important to know what factors are the most salient to investigate.

Additionally, the definition of successful prosthesis use is largely inconsistent across studies attempting to identify the determinants of successful prosthesis use. However, some studies consider successful prosthesis use to be whether a person uses a prosthesis at all, compared to others who completely cease using a prosthesis, while other studies consider successful prosthesis use to be determined by number of hours prostheses use. Consistency is clearly needed on this term. However, neither of these definitions are considering the patient's perspective on what constitutes successful prosthesis use. It was acknowledged by Fishman (1977) and Herberts, Korner, Caine (1980) and later re-stated by Saradjian et al (2008) that prosthesis use and acceptance is a complex process that lies within the psychology of the person more than any technical features of prosthesis itself. Therefore, arguably it is necessary to incorporate the patients' perspective, as well as the RP when defining the term 'successful prosthesis use' as well as defining success in other areas related to ULA.

The present thesis used a mixed method design in order to reach agreement on the factors of importance to take into consideration when assessing an individual following ULA. This design aimed to answer the two main research questions, which asked what the factors of importance to consider in ULA are and what constitutes a successful outcome in

these areas. There were two phases of study in this research, a qualitative phase, followed by a quantitative phase. The qualitative component is important because it allows a research problem or issue to be explored or where a complex detailed understanding needed. The qualitative phase began with a case study report that demonstrated a novel interview technique, the repertory grid interview technique, amongst both a high technology and low technology user in order to elicit their opinions of their starkly different prostheses while demonstrating a novel method that could be used in clinical practice. This RGT also revealed the individual nature of prosthesis use and the need to assess an individual's needs in their own terms. The RGT provided a foundation to begin the next qualitative part of the study, which involved interviews with RP's and focus groups with individuals with ULA in order to expand on the factors of importance regarding absence of the upper limb. The data from the qualitative phases informed the quantitative Delphi phase which aimed to reach agreement on what constitutes success following ULA and the factors that should be taken into consideration during rehabilitation of individuals with ULA.



## Chapter 2 Thesis methodology

<b>2.1 Mixed method design.....</b>	<b>76</b>
<b>2.2 Pragmatism.....</b>	<b>77</b>
<b>2.3 Present study design.....</b>	<b>78</b>
<b>2.4 Thematic analysis.....</b>	<b>82</b>
<b>2.5 Method of analysis.....</b>	<b>84</b>
<b>2.6 Reflexivity.....</b>	<b>86</b>
<b>2.7 Summary of methodology.....</b>	<b>87</b>

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Chapter 2 Thesis methodology**2.1 Mixed Method Design**

The present study will use a mixed method design to conduct this research. There are many different variations of the term ‘mixed method’ design such as multi-method designs and mixed model designs; and often these terms are used interchangeably. Therefore, when used, one may be referring to the use of various combinations of qualitative methods within a single study; or the combined use of different quantitative methods; or a mix of qualitative and quantitative methods in a study; or may mean borrowing a sampling an analysis technique associated with one methodology for use in another (O’Cathain & Thomas, 2006). However, it is argued that multi-method studies are more accurately referring to studies that use more than one research method in their study, such as two differing types of qualitative techniques. Johnson, Onwuegbuzie & Turner (2007) attempted to reach a definition of mixed method research by asking for its definition by leaders in the field. Once such definition provided by Al Hunter suggested that a multi-method study is when “...different styles of research may be combined in the same research project” (Johnson et al, 2007; p.119). There has been a move to standardise terminology and call ‘mixed method’ research that which combines qualitative and quantitative methods in the same study (Tashokkori & Teddlie, 2003). Therefore, specifically, this study wishes to conduct a mixed method research design, which will include quantitative and qualitative research. A suitable definition of mixed method research is drawn from John Creswell’s definition from Johnson et al (2007) as “a research design (or methodology) in which the researcher collects, analyzes, and mixes (integrates or connects) both quantitative and qualitative data in a single study or a multiphase program of inquiry” (p.119).

The use of mixed method research is a fairly recent development. Historically, the two standard research types in social scientific research are quantitative and qualitative research types. However, it has been suggested that mixed method research is the third research type (Johnson & Onwuegbuzie, 2004). There has been some objection to the use of mixed method research as it is claimed that quantitative and qualitative research cannot

and should not be mixed in the same study as the paradigms underlying them (positivism and constructivism respectively) are not compatible. This has been dubbed the incompatibility thesis (Howe, 1988).

## **2.2 Pragmatism**

However, a counter argument to these assertions is that under the philosophical paradigm, pragmatism, these two research approaches can be mixed as the basic philosophy of pragmatism is that you one can use multiple methods of data collection to best answer the research question (Robson, 2002). In addition, Howe (1988) posits that pragmatism as a paradigm allows for the simultaneous utilisation of quantitative and qualitative methods. Cherryholmes (1992) and Murphy (1990) asserted that pragmatism is not committed to any one system of philosophy or reality. Researchers have freedom of choice with regard to the methods, techniques, and procedures that best meet their needs and purposes. They also do not see the world in one view and pragmatists agree that research always occurs in social, historical, political and other contexts (Creswell, 2007). Therefore, based on pragmatism, mixed method research should use a method and philosophy that attempt to fit together the insights provided by qualitative and quantitative research into a workable solution (Johnson & Onwuegbuzie, 2004). Johnson & Onwuegbuzie (2004) suggest that research approaches should be mixed in ways that offer the best opportunities for answering important research questions.

Cornish & Gillespie (2009) argue that the pragmatic perspective is more suitable to health psychology research compared to realism or constructivism as it enables both critique and action that are needed in health research, which neither realism nor constructivism achieve alone. Pragmatism differs from realism in that pragmatism does not claim that knowledge reflects an underlying reality (Rorty, 1981). Pragmatism asserts that practical activity is the basis of knowledge. Specifically, that knowledge is judged according to its consequences in action and that knowledge is a tool for action. Knowledge is claimed by Rorty (1999) to mediate our relation to the physical and social world. According to Cornish & Gillespie (2009) pragmatism is pluralist, in that it accepts the variety of competing interests and forms of knowledge. It is also critical, in that its focus on the

interests served by knowledge invite questioning of whose interests are being served. However, it is also non-relativist, in that knowledge can be evaluated by reference to its ability to facilitate successful action. It is also action oriented in that everyday problems and actions are the primary reality and test of our knowledge.

Ultimately, Cornish & Gillespie (2009) argue against a hierarchy of methods in research. The pragmatist approach supports the assertion that there is no absolute best method of gathering knowledge, but each method is good at achieving particular goals (Baert, 2004). Additionally, Cornish & Gillespie (2009) suggest that health research that wishes to serve the practical interests of lay people or service users may appropriately begin with people's experiences and perspectives.

### ***2.3 Present study design***

There are two main reasons why a mixed method research design are chosen when conducting research. Firstly, it is commonly argued that the sum of both methods is greater than the individual parts (Barbour, 1999) and that the strengths of one method can be used to overcome the weaknesses of another method by using both in a research study (Johnson & Onwuegbuzie, 2004). Additionally, this research design is often useful in order to expand the scope of enquiry by accessing a wider range of data (O' Cathain & Thomas, 2006) and is ideal in areas where there is currently little information such as literature on ULA. There are additional advantages that have been suggested by Johnson & Onwuegbuzie (2004) to conducting mixed method research such as the ability to provide stronger evidence for a conclusion through convergence and corroboration of findings; increase generalisability of results; qualitative and quantitative research used together produce more complete knowledge necessary to inform theory and practice; and can add insights and understanding that might be missed when only a single method is used.

There are also several different types of designs that can be used within mixed method research. Firstly, it is important to ascertain the reason a mixed method design is being used. It can be used for several reasons such as complementarity (to get a greater picture),

development (one method used to aid another), triangulation (findings from two different methods are compared and agreement is sought) or crystallisation (a process of comparing data sets to explore convergence, divergence, and contradiction; O’Cathain & Thomas, 2006). The main reason the present study has chosen a mixed method design is for development purposes in order to gather a wide generation of data of importance in the qualitative phases and to use this data to develop items for the quantitative phase.

Secondly, it is necessary to decide in what order the different components of the study will be conducted. Methods can be taken concurrently, sequentially or iteratively. The present study intends to conduct the phases sequentially with a qualitative phase first, which aims to identify the important factors involved in the rehabilitation of individuals following ULA, the usefulness of qualitative techniques in achieving this aim; and the perspective of both RP’s and individual’s with limb absence. The qualitative interviews and focus groups will then inform the quantitative phase (O’Cathain & Thomas, 2006).

Thirdly, the priority of the methods to be undertaken is an important consideration. For the present study, it is difficult to ascertain which component takes priority as all phases are important in their own right. Without the qualitative phase, the quantitative phase would lack substance and without the quantitative phase, there would be little agreement as to the importance and applicability of the findings. Therefore it is argued that for the present study, the qualitative phase and quantitative phase each have equal priority (O’Cathain & Thomas, 2006).

An important element of mixed method research is not just conducting qualitative and quantitative components of a study, but integrating their findings. Integration in mixed method studies can take place at varying stages in the research design and data can be integrated back and forth through various stages. In the present study, the integration is built into the design of this study, as phase one (qualitative case study using repertory grid technique, interviews and focus groups) informs phase two (a quantitative Delphi study). O’Cathain & Thomas (2006) suggest that mixed methods research can involve qualitative research facilitating quantitative research by generating hypotheses for testing or

generating items for a questionnaire. O’Cathain & Thomas (2006) expand on this by suggesting that qualitative interviews or focus groups can be used to generate items and language for a questionnaire that will then be used in a survey. The qualitative component is considered to be a mark of quality, i.e. relevant and understandable for potential respondents. It has been recommended that the individual components of a mixed method study are of high quality (O’Cathain, Murphy & Nicholl, 2008); which is why the qualitative and quantitative components will be reported separately in this study. It has been suggested that if the qualitative and quantitative data are credible and valid then the mixed method study has high quality data (Teddlie & Tashakkor, 2009).

A mixed method design has been used recently in the amputation literature by Couture, Caron & Desrosiers (2010) to describe the leisure activities, satisfaction and constraints on participation amongst individuals with lower limb amputations. Their study involved assessing 15 individuals using a quantitative leisure profile questionnaire 2-3 months post discharge from rehabilitation to gain a general description of leisure activities, constraints and satisfaction. There were subsequent semi-structured interviews with a sub sample of 8 participants using semi-structured interviews to obtain the perspective of the participants regarding their experience of leisure activities since the amputation. This study showed that there were 12 different leisure activities on average, and that there was a reported decrease in participation in all categories of leisure activities, but overall satisfaction was high. Participants experienced constraint in participation in leisure activities due to lack of accessibility, material considerations, functional abilities, affective constraints and social constraints. Couture et al (2010) stated that the mixed method design was particularly helpful in studying leisure activities following lower limb amputation because both quantitative and qualitative data enriched their understanding of the phenomenon. The quantitative data provided information on the extent of participation in leisure activities and satisfaction with leisure activities and pinpointed the most important areas of constraint. The qualitative data provided an opportunity to discover how participants experienced their activities and how personal and external constraints influence their participation.

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This study has decided to use a mixed method approach for development purposes as this study wishes to reach agreement on the factors of importance following ULA. This design will answer the two main research questions, which asked what the factors of importance to consider after ULA are and what constitutes a successful outcome. As mentioned in previous paragraphs, the present study will use a sequential mixed method design with a repertory grid case study and two concurrent qualitative phases informing a subsequent quantitative phase. This study has decided that qualitative and quantitative methods are necessary to answer the research question because there is currently very little research which has identified the factors of importance following ULA. The qualitative phase (repertory grid, interviews, and focus groups) is necessary to identify the most salient factors that need to be considered in rehabilitation and the quantitative phase (Delphi study) will clarify their wider importance. The qualitative component is important because it allows a research problem or issue to be explored or a complex detailed understanding needed. Figure 2.1 details the overall design and method of the present thesis.

This thesis will commence with an analysis of two case studies of prosthesis users using an interview technique known as the repertory grid technique (RGT). This aspect of the study will demonstrate the individual nature of prosthesis use and the need to assess an individuals needs in their own terms. The RGT provides a foundation to pursue the next qualitative part of the study, which involves interviews with RP's and focus groups with individuals with ULA in order to expand on the factors of importance regarding absence of the upper limb. Finally, data gathered will inform the quantitative Delphi phase which aims to reach agreement on what has been elicited to date from the qualitative elements of this thesis.



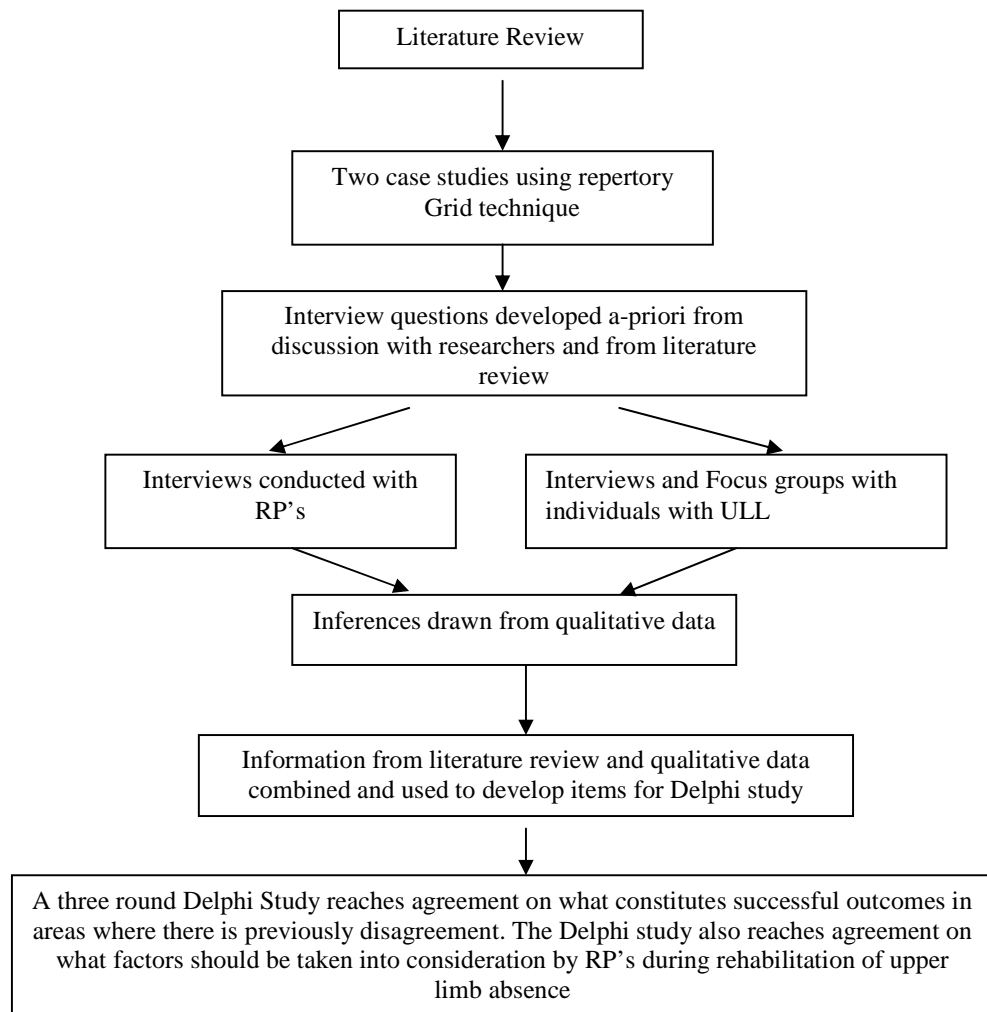


Figure 2.1 Design of thesis

## 2.4 Thematic analysis

Following the repertory grid interviews, interviews with RP's and the interviews and focus groups with individuals with ULA, thematic analysis was undertaken by analysing the transcript of the tape-recorded interviews. Thematic analysis was chosen as it offers an accessible and theoretically flexible approach to analysing qualitative data (Braun & Clarke, 2006). This was considered important as there were no hypotheses selected for this part of the study and it was felt this phase required a method of analysis that allowed the data to emerge in whatever direction was natural. The process of thematic analysis involves searching across a data set to find repeated patterns of meaning (Braun & Clarke,

2006). Joffe & Yardley (2004) state that there are few published guides concerning how to carry out thematic analysis and it is often used in published studies without clear report of the specific techniques that were engaged. Braun & Clarke (2006) rectified this lack of guidelines by providing a thorough discussion of the rationale, philosophy and process of using thematic analysis in psychology research. These guidelines were followed in the present study. Since thematic analysis was used in several aspects of this study, this chapter was deemed the most appropriate section for it to be discussed in this thesis. This section will detail why thematic analysis was chosen as an analytic technique and how the method was undertaken.

Boyatzis (1998) characterizes thematic analysis as a tool to use across different methods. Ryan & Bernard (2000) locate thematic coding as a process performed within ‘major’ analytic traditions (e.g. grounded theory), rather than a specific approach in its own right. However, Braun & Clarke (2006) state that thematic analysis should be considered a method in its own right and argue that one of the benefits of thematic analysis is its flexibility. Braun & Clarke (2006) also assert that there are two types of qualitative analytic methods, those that are tied to or stemming from, a particular epistemological position (such as Interpretative Phenomenological Analysis; IPA); and those that are essentially independent of theory and epistemology and can be applied across a range of theoretical and epistemological approaches. Braun & Clarke (2006) assert that thematic analysis is of the second type and is compatible with both essentialist (universal truth, not dependent on context) and constructionist (truth is constructed by our social world) paradigms within psychology. Through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and complex account of data (Braun & Clarke, 2006).

Braun & Clarke (2006) state that thematic analysis is a method for identifying, analyzing and reporting patterns within data. Braun & Clarke (2006) suggest that it is important that the theoretical framework and methods match what the researcher wants to know and that they acknowledge these decisions. Braun & Clarke (2006) argue that use of thematic analysis as opposed to IPA or grounded theory means that researchers do not need to

subscribe to the theoretical commitments of grounded theory if they do not want to produce a complete grounded theory analysis. Braun & Clarke (2006) acknowledge that thematic analysis does not have any particular reputation as an analytic method. However, they argue that this is because it is poorly demarcated and claimed, yet widely used. Braun & Clarke (2006) suggest that a rigorous thematic analysis can produce an insightful analysis that answers particular research questions. Essentially, Braun & Clarke (2006) consider it important to choose a method that is appropriate to the research question. The present study has chosen pragmatism as the theoretical basis of the present analysis, based on the previously stated suitability of pragmatism in the overall design of the study and its suitability for understanding health research (Cornish & Gillespie, 2009).

### ***2.5 Method of analysis***

According to Braun & Clarke (2006), a theme captures something important about the data in relation to the research question and represents some level of patterned response. There are two ways to identify themes or patterns within data, inductive or ‘bottom up’ (e.g. Frith & Gleeson, 2004) or in a theoretical or deductive, ‘top down’ way (e.g. Boyatzis, 1998). An inductive approach means the themes identified are strongly linked to the data themselves (Patton, 1990). This method of analysis has been used previously in relation to understanding how men’s feelings about their bodies influence their clothing practices (Frith & Gleeson, 2004); and the experiences of women with polycystic ovarian syndrome (Kitzinger & Willmott, 2002). Additionally, based on the article by Braun & Clarke (2006) several studies have followed their approach such as Harcourt & Frith (2008) who investigated women’s’ experience of altered appearance using thematic analysis. It has also been used to explore the barriers to rehabilitation and return to work for chronic pain patients (Patel, Greasely & Watson, 2007) and to assess patients and nurses’ perspectives on oxygen therapy (Eastwood, O’Connell, Gardner, & Considine, 2009).

Braun & Clarke (2006) also discuss the importance of identifying the ‘level’ at which themes are identified, that is, the semantic (explicit level) or latent (interpretative level) as suggested by Boyatzis (1998). The present study intends to analyze data in an inductive

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semantic level, meaning that data will be analysed independent of any theoretical presuppositions and the explicit or surface meaning of the data will be analysed and not anything beyond what the participant has written.

Braun & Clarke (2006) state that it is important to recognize that qualitative analysis guidelines should be applied flexibly to fit the research questions and data (Patton, 1990). Additionally, it is important to note that analysis is not a linear process of moving from one phase to another, it is actually recursive in that movement is back and forth between phases as needed. There are 6 basic steps of thematic analysis suggested by Braun & Clarke (2006). These steps are similar to many other qualitative analysis methods suggested by other authors such as Smith (1995) and Creswell (2007).

#### Phase 1: Familiarising self with data

Braun & Clarke (2006) recommend that the researcher immerses themselves in the data. This involves repeated reading of the data and reading in an ‘active way’, which means searching for meanings and patterns in the data. Braun & Clarke (2006) and Smith (1995) also suggest that it is a good idea to start taking notes or mark ideas for coding at this stage.

#### Phase 2: Generating initial codes

According to Braun & Clarke (2006), codes identify a feature of the data (semantic or latent) that appears interesting to the analyst. Braun & Clarke (2006) state that coding can be performed either manually or through a software programme. Due to the manageable amount of raw data, it was decided to manually code all data, to ensure full immersion and connection with the data. The present study coded the data by writing notes in the text to indicate potential patterns. Once the codes were identified, a ‘cut and paste technique’ on the word document (Miles and Huberman, 1994) was used in the present study to organize codes with their associated data extracts.

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*Phase 4 & 5: Searching for & reviewing themes*

Since the present study used a data driven approach to analysis, the themes depended on the codes that were produced from the data. After all data was coded, the codes were sorted to into potential themes that best represented each code. Themes were reviewed and refined until it was decided that the data within themes cohered together meaningfully and that there were clear and identifiable distinctions between themes.

*Phase 6: Defining and naming themes*

Braun & Clarke (2006) suggest that this phase involves identifying the essence of each theme and ensuring the themes are not too complex. This phase also involves writing a detailed analysis of each theme. Suitable quotations from participants are presented in the results section to demonstrate appropriate themes. Some participants' quotations may be used more than others as their feedback was the most appropriate for reflecting the focus of the particular theme. See Appendix A for examples of themes, codes and data extracts from an interview with a psychologist.

**2.6 Reflexivity**

The qualitative research paradigm suggests that reflexivity is important to understand the personal values and experiences that the researcher brings to the research process. "Reflexivity requires an awareness of the researcher's contribution to the construction of meanings throughout the research process, and an acknowledgment of the impossibility of remaining 'outside of' one's subject matter while conducting research. Reflexivity then, urges us "to explore the ways in which a researcher's involvement with a particular study influences, acts upon and informs such research." (Nightingale and Cromby, 1999, p. 228). The researcher that analysed the qualitative data was a young, able bodied, white, Irish female, who during the research phase was a postgraduate student. The researcher had an interest in health psychology research, with a particular focus and interest on disability and ULA rehabilitation. With relatively little personal knowledge of the research area of ULA, considering the dearth of research literature on the topic, the researcher was particularly interested in asking the questions 'Is the upper limb prosthesis useful to individuals with ULA?', 'If so, in what areas is it useful to the individual with limb

absence'?, 'Can these areas be useful in assessing the progress of all individuals with ULA?' and 'What is successful prosthesis use?'. The researcher was interested in assessing these questions from the perspective of individuals with ULA, whether they were prosthesis users or not and from the RP's perspective.

### ***2.7 Summary of methodology***

The present study has chosen a mixed method design incorporating a qualitative phase that informs a quantitative phase. This design has been chosen based on a pragmatic philosophy that suggests that the best methodology should be chosen for a study based on how best to answer the research question. Due to the scarcity of research investigating the factors of importance to consider in ULA research and the need for wider confirmation of any qualitative findings, a mixed method sequential design was considered ideal for this purpose. This pragmatic perspective is in line with recent suggestions from Cornish & Gillespie (2009) in health research. Further in line with this pragmatic perspective, it was chosen to analyse the qualitative aspect of this study using thematic analysis, due to its theoretical flexibility when analysing qualitative data. Due to the overlap in using this method in several different aspects of this study, it was decided to detail it in the present chapter to avoid repetition.

Chapter 3 Repertory Grid Interviews: Exploring perceptions of  
prosthetic devices

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<b>3.1 Introduction.....</b>	<b>90</b>
3.1.1 Recent developments in prosthetic technology.....	90
3.1.2 Matching person and technology.....	90
3.1.3 Assessing an individual's preferences.....	91
3.1.4 Personal Construct Psychology.....	92
3.1.5 Repertory Grid Technique.....	92
3.1.6 Conclusion.....	94
3.1.7 Aims of the study.....	95
<b>3.2 Method.....</b>	<b>96</b>
3.2.1 Participants.....	96
3.2.2 Materials.....	96
3.2.3 Procedure.....	96
3.2.4 Analysis.....	100
<b>3.3 Results.....</b>	<b>101</b>
3.3.1 Case Study 1.....	101
3.3.1.1 <i>Function</i>	
3.3.1.2 <i>Aesthetic indifference</i>	
3.3.1.3 <i>Acceptance</i>	
3.3.1.4 <i>Jennifer's view of the available prosthetic options</i>	
3.3.1.5 <i>Summary of Case Study 1</i>	
3.3.1 Case Study 2.....	108
3.3.2.1 <i>Function</i>	
3.3.2.2 <i>Standing out</i>	
3.3.2.3 <i>Reliability</i>	
3.3.2.4 <i>Happiness</i>	
3.3.2.5 <i>Declan's view of the available prosthetic options</i>	
3.3.2.6 <i>Summary of Case Study 2</i>	
<b>3.4 Discussion.....</b>	<b>117</b>
3.4.1 Themes.....	117
3.4.2 Methodological and theoretical strengths of the study .....	119
3.4.3 Limitations of the study.....	221
3.4.4 Conclusion.....	221



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### Chapter 3.1 Introduction

#### ***3.1.1 Recent developments in prosthetic technology***

There have been significant developments in upper limb prostheses in recent years, including myo-electric prostheses and more recently targeted reinnervation surgery aimed at enhancing prosthetic arm function (Kuiken, Miller, Lipschutz, Lock, Marasco, Zhou, & Dumanian, 2007a). Targeted Muscle Reinnervation (TMR) uses the residual nerves from an amputated limb and transfers them onto alternative muscle groups that are not biochemically functional since they are no longer attached to the missing arm (Kuiken et al, 2007a). Similarly, Targeted Sensory Reinnervation (TSR) is a method by which skin near or over the targeted muscle is denervated, then reinnervated with afferent fibres of the remaining hand nerves (Kuiken et al, 2007a). Therefore, when this piece of skin is touched, it provides the person with a sense of the missing arm or hand being touched (Kuiken et al, 2007a). TSR offers the possibility that a person with an amputation may one day be able to feel with an artificial limb as though it was their own (Kuiken, Marasco, Lock, Harden, & Dewald, 2007b). After TMR, patients have reported that their prosthesis is easier and more natural to use and the function of the prostheses has been shown to improve by an increase in speed and efficiency of motion (Kuiken et al, 2007a; Kuiken, Dumanian, Lipschutz, Miller, & Stubblefield, 2004). Kuiken et al (2007a) acknowledged the important psychological consequences of TSR; suggesting that enabling patients' perception of feeling what they are touching could help them incorporate their prosthesis into their self image in a more positive manner and to better connect with their physical and social environments. However, due to the considerable costs of producing this technology, a dilemma is posed about whom to prescribe such technology to and who will benefit most from such technology. This chapter describes an individualised technique for exploring the person- prosthetic fit and explores this in two people; one with a traditional body-powered prosthesis and one with a TMR facilitated prosthesis.

#### ***3.1.2 Matching person and technology***

In order to address the considerable rates of non-use of prosthetic devices discussed in Chapter 1.1, it is essential to understand the predictors of non-use of AT in general and

prosthetic devices in particular and also to ascertain what users require from prosthetic devices. Chapter 1.4 provided a description of the various studies that have attempted to identify these predictors in the ULA literature. However, according to Scherer (2002b), a good match between person and technology is achieved if the prosthetic device meets the users' performance expectations and is easy and comfortable to use. It has also been recommended that when selecting a prosthesis for an individual, attention should be directed at the specific needs of the individual (Brown-Triolo, 2002), that prosthetic users are provided with a choice of available options (Scherer (2002b), and are involved in prosthesis selection (Wielandt, McKenna, Tooth, & Strong, 2006; Philips & Zhao, 1993).

In order for prosthetic users to be able to get the greatest benefit from their prosthetic limbs, it is important to understand how the use of such technology affects how they see themselves and how they perceive themselves in relation to their broader social world (Gallagher, 2004; Gow, MacLachlan, & Aird, 2004; Gallagher & MacLachlan, 1999). Research has shown (Williamson, Schulz, Bridges, & Behan, 1994; Williamson, 1995) that prosthetic users may restrict their normal activities due to their fears about how society views them and reacts to them, which would in turn have an effect on their mobility and QOL.

### ***3.1.3 Assessing an individuals preferences***

In order to successfully integrate prosthetic devices into an individual's life, the individual values, preferences and meanings assigned to the device need to be explored (Pape, Kim & Weiner, 2002). Therefore, it is essential to develop methodological approaches to elicit and assess these meanings. Approaches such as the 'Patient Generated Index' (PGI; Callaghan & Condie, 2003) and 'Goal Attainment Scaling' (GAS: Rushton & Miller, 2002) have been used to assess the individual preferences, values and meanings of lower limb prosthesis users in prosthetic rehabilitation. Although these individualised assessment approaches have the advantage of consulting the consumer to determine which dimensions are most appropriate to them for evaluation in rehabilitation, they have not been used to determine preferences of alternative prosthetic options amongst users. Although, potentially these two approaches could be altered to be used to elicit

preferences for prosthetic options, the advantage of the RGT compared to the PGI or the GAS is that the RGT does not focus on eliciting negative outcomes. Both the PGI and GAS ask participants to nominate areas or activities that are affected (PGI) or problem areas (GAS) whereas the RGT does not draw references to any negative trait but instead asks participants to elicit ‘differences’ between elements. Additionally, the RGT has the advantage of eliciting concepts in a context such as comparing between two elements, whereas the GAS and PGI do not. Consequently, participants may have more difficulty in producing elements of relevance to them when asked questions using PGI or GAS.

#### ***3.1.4 Personal Construct Psychology***

This individualized approach is reflected in the basic theoretical assumptions of Personal Construct Psychology (PCP; Kelly, 1995) which states that a situation may be viewed differently by different people, or even differently by the same person at another time, as there are always alternative constructs available to choose from. PCP is centred on the notion that we construe our reality, and interpret our current experiences, based on our previous experiences. Subsequently, through experience, our theories or beliefs of reality are refined and consolidated (Borell, Espwall, Pryce, & Brenner, 2003). A personal construct is considered a particular way that the individual has of viewing, giving meaning to, or construing, the elements in their environment (Jankowicz, 1987). Elements can consist of individuals, institutions ideas, roles, activities and objects in the individual’s experience (Borell et al, 2003). Personal constructs are elicited directly from and are specific to the person studied. Kelly (1955) argued that in order to understand someone, we must do so in their own terms; which means identifying their personal constructs, otherwise, we run the risk of simply projecting our own thinking on to them (Jankowicz, 2004).

#### ***3.1.5 Repertory Grid Technique***

The method used to elicit an individual’s personal construct in relation to a predefined topic is the repertory grid technique (RGT). In this method, elements relating to the topic to be investigated are compared and contrasted by asking participants to indicate how elements are similar to and different from one another and thus eliciting their constructs

(this is known as the contrast method of triadic elicitation; Neimeyer, Bowman & Saferstein, 2005). The elements in a RGT were originally meant to include a variety of selves, such as ideal self and actual self (Kelly, 1955). These distinctions are especially relevant when used with an individual with limb absence as Shontz (1974) refers to the unique situation of persons with limb absence of having three body images, one with prosthesis, one without it, and pre-injury intact body. The RGT is an idiographic measure concerned with identifying and exploring the distinctive qualities of a single person and identifying patterns in how they construct meaning in relation to specific aspects of their life. It allows its users to explore a system of personal constructs which reveal the way they organise their social world (Giles, 2002). Devising a repertory grid is a unique way of guiding and documenting a conversation. The RGT has been shown to be a useful tool within the health sector to evaluate treatment preferences (Lambert, Rowe, Bowling, Ebrahim, Laurence, Dalrymple et al 2004; Frewer, Howard, & Shepherd, 2001) and services (Melrose & Shapiro, 1999), and to aid in medical decision making (Lambert et al 2004; MacCormick Macmillan & Parry, 2004). These findings suggest that techniques grounded in the RGT may be useful in situations where there is little medical basis for choosing amongst a variety of procedures allowing input of patient values into the treatment decision.

The Repertory grid was also used amongst a sample of 12 participants with upper and lower limb absence to determine how their self-image changed as a result of their amputation (Fisher, 1985). Participants were divided into successful and unsuccessful cases based on whether they needed frequent follow up appointments due to amputation related symptoms or whether the surgeon considered them able to employ their time usefully (returning to work or former household duties), with those needing follow up after a year or not employing their time usefully post amputation to be considered unsuccessful. The study showed that a person's 'actual self' is somewhat depressed following amputation, regardless of whether the physical outcome is successful. The ideal self is seen as happier and more independent in the successful group of individuals with limb absence. Additionally, the former selves are less successful, happy, and independent in the unsuccessful group. Results found that the unsuccessful group is more likely to

score ideal self perfectly, and Fisher (1985) suggested that one of the contributing factors to unsuccessful rehabilitation is holding unrealistic beliefs about what one should be like. Also it emerged that the unsuccessful group appear to have a lower opinion of themselves even before their accidents.

### **3.1.6 Conclusion**

This chapter wishes to demonstrate the usefulness of the RGT to understanding the needs of upper limb prosthetic technology users. The methodology of the RGT (Kelly, 1955) was chosen in order to give an opportunity to listen uncritically and to include the voices of upper limb prosthetic users in this research. Rowe, Lambert, Bowling, Ebrahim, Wakeling, & Thomson, (2005) proposed using a simplified version of the repertory grid technique without the statistical procedure. It is also important to ascertain how a patient who has undergone an innovative procedure such as TMR Surgery (Kuiken et al, 2007a) and who is a user of a prosthesis that uses the additional TMR sites, views their current abilities and their current prosthesis, and how they view alternative prosthetic options in order to assess the success of undergoing this procedure for the individual. It is also necessary to explore any other issues, especially psychosocial issues that may arise for the patient through the use of this experimental device. It is essential to understand what upper limb prosthetic users in general consider to be the important features of prosthetic devices and to determine what aspects, if any, that they are not satisfied with, in order to reduce the likelihood of rejection of prostheses. It is also important to qualitatively explore the views of upper limb users as qualitative research in this area has been limited to date. Incorporating Personal Construct Psychology provides the opportunity to appreciate its participants as shrewd individuals, and interpreters of their personal and social world (Bannister, & Fransella, 1986). This study has chosen two demographically different individuals to interview and report on in order to demonstrate the usefulness of the RGT in contrasting individuals.

***3.1.7 Aims of the study***

The aims of the present chapter are to:

- 1) Explore how upper limb prosthetic users (both high technology and conventional) perceive themselves and their prosthetic devices;
- 2) Investigate how the individual views alternative prosthetic options;
- 3) Demonstrate a novel, idiographic method for exploring these values and preferences.

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### Chapter 3.2 Method

#### **3.2.1 Participants**

The first participant was a young woman, Jennifer (pseudonym) who had an amputation at the transhumeral neck (shoulder). Jennifer underwent TMR surgery (Kuiken et al, 2007a) to improve prosthetic function and ease of use. Jennifer used a prosthesis that uses the additional TMR sites. It had been three years since her amputation and she had her current prosthesis for one year. She reported using her prosthesis approximately four days in the week and for about four hours of those days. The second participant, Declan (pseudonym) was a middle aged gentleman who had congenital transradial limb absence (below the elbow) and used a conventional body powered prosthesis. He reported wearing his prosthesis seven days per week and eighteen hours per day. The two participants were selected because of their contrasting backgrounds and experiences of prosthetic technologies. The first participant was recruited in consultation with Director of Rehabilitation Psychology at Johns Hopkins University, Baltimore, U.S.A and the second participant was recruited by staff from a private limb fitting centre in Dublin, Ireland.

#### **3.2.2 Materials**

The participants were interviewed using the repertory grid technique and a blank grid was used to facilitate this process. The elements that were presented to the participants are presented in Table 3.1.

#### **3.2.3 Procedure**

Ethics was sought and granted from The Institutional Review Board (IRB) of Johns Hopkins University, Baltimore. Purposive sampling was used to recruit participants for this study, as the study specifically required one user of a high tech upper limb prosthetic and one user of a conventional upper limb prosthesis. Potential participants in the U.S were contacted by the Rehabilitation Psychologist and provided with an information sheet (see Appendix B). An additional participant from Ireland was contacted by staff at a private limb fitting centre in Ireland and invited to participate. This participant was provided with a letter of invitation (see Appendix C) and information sheet by the research

team. Informed consent (See Appendix D) was also obtained from the participants prior to commencement of the interview. The participants were informed that the purpose of the interview was to find out how they feel about the elements (Table 3.1) and were told that they would be asked to compare the elements systematically. The interviews were conducted separately with each participant. The interviewer went through each element individually to ensure the participants understood them. Both interviews took place between September 2007 and October 2007. The first interview with Jennifer took place in a private room in a hospital local to Jennifer in Baltimore, MD. The second interview with Declan took place in a private room in a University in Ireland that was local to Declan. Both participants received \$50 and €50 respectively for their participation. The interviews lasted between one and two hours and were audio-taped and transcribed verbatim to facilitate later interpretation of the grids.

Each participant was asked to fill out a demographic questionnaire, which contained questions on marital status, education level, ethnicity, employment status, cause and level of limb absence and asking for information on prosthetic use (see Appendix E). As the focus of the study was to elicit the values and preferences of users of prostheses, the elements were predetermined by the research team. Each participant was given a list of prosthetic options and self referring items (e.g. Ideal self) to ensure that potential prosthetic options and rehabilitation relevant aspects of self perception were rated (see Table 3.1). These elements were chosen by professionals working in prosthetic rehabilitation and were based on a pilot study (NiMhurchadha et al, 2008). Not all prosthetic options chosen were available to each user due to financial, physical or technological reasons. These options were still included to gain further insight into how they were perceived.

For this particular procedure, constructs were elicited using the ‘Contrast Method’ of triadic elicitation. Triadic elicitation is the procedure used in all RGT studies to generate constructs on which to rate elements. In this method, elements are compared and contrasted by asking participants to indicate how elements are similar to and different from one another and thus eliciting their constructs. Elements from Table 3.1 were



grouped together into twelve randomly generated sets consisting of three different elements. These sets were generated using a random number generator at <http://www.randomizer.org>. See Table 3.2 for the list of the randomly generated sets.

**Table 3.1 List of elements for Repertory Grid**

1	My ideal Self
2	Self as I am now
3	Self as others see me
4	Intact arm
5	Own body
6	Myo-electric arm
7	Body powered prosthesis
8	Cosmetic arm
9	High tech prosthetic arm
10	Self before amputation*
11	Self after first prosthesis**
12	Transplanted arm

\* this was omitted for Declan as he has congenital limb absence

\*\*Declan specifically focused on the first prosthesis he had up until age 12, which was similar to a body powered prosthesis but had limited function and had a leather glove covering

**Table 3.2 Randomly generated sets of elements**

Set	Number combination	Elements
Set #1	8, 7, 12	Cosmetic arm, Body Powered Prosthesis, and Transplanted arm
Set #2	6, 10, 11	Myo-electric arm, Self before amputation*, Self after first prosthesis**
Set #3	7, 12, 5	(Body powered prosthesis, Transplanted arm, Own body
Set #4	8, 6, 9	Cosmetic arm, Myo-electric arm, High tech prosthetic arm
Set #5	9, 1, 6	High tech prosthetic arm, My ideal self, Myo-electric arm
Set #6	2, 8, 5	Self as I am now, Cosmetic arm, Own body
Set #7	9, 7, 4	High tech prosthetic arm, Body powered prosthesis, Intact arm
Set #8	10, 11, 12	Self before amputation*, Self after first prosthesis**, Transplanted arm
Set #9	4, 10, 8	Intact arm, Self before amputation*, Cosmetic arm
Set #10	7, 6, 11	Body powered prosthesis, Myo-electric arm, Self after first prosthesis**
Set #11	3, 12, 1	Self as others see me, Transplanted arm, My ideal self
Set #12	5, 9, 8	Own body, High tech prosthetic arm, Cosmetic arm

\* this was omitted for Declan as he has congenital limb absence. In this instance, this element was replaced with the element ideal self

\*\*Declan specifically focused on the first prosthesis he had up until age 12, which was similar to a body powered prosthesis but had limited function and had a leather glove covering

**Step 1** Jennifer and Declan were given three elements at a time, in the form of flashcards and asked to identify "how any two of these elements are alike in some way". Participants were told that the researcher was looking for a word or phrase that described how they were alike. The characterization created by the participants (e.g. functional) then formed one pole of the construct and was written on the first row on the left hand side of the grid. This process continued until twelve characterizations were obtained.

**Step 2** Participants were directed back to the first characterization and asked to provide a contrast for each of the twelve characterizations. This phrase was then written on the right side of the grid opposite the original phrase created, creating a completed construct. This process was continued until opposite poles for each separate dimension were elicited and written on the right hand side of the grid.

**Step 3** In the final phase, participants were asked to rate each of the elements, along each of the constructs in a step wise fashion, using a ten-point rating scale (1-10) to indicate an element's ratings along the construct dimension. Participants were told that the phrase on the left stood for '1' end of the scale and the phrase on the right stood for '10' and that the half way point was '5'. The participants were asked to rate the elements on the scale giving each of them a rating from 1 to 10 to say which end of the scale was nearest to each element. Participants were told that the same number could be used more than once.

**Step 4** Once completed, the interviewer discussed the ratings of the grid with the participant, as well as the constructs created to clarify meaning and ratings that arose from the whole process, in order to find out clearly what the participants meant with each dimension and each rating of the elements. During this process, it was ascertained which end of the construct was considered positive and which end was considered negative. A number of constructs were reverse scored so that a positive and negative end of the grid could be established for ease of analysis, meaning that '1' is considered 'positive' and '10' is considered 'negative'.

### **3.2.4 Analysis**

The repertory grid was analysed by firstly reviewing the data in the presence of the participant and discussing the various ratings with the participant as part of step 4 of the interview. Lambert, Kirksey, & McCarthy (1997) demonstrated the suitability of the RGT as a qualitative interviewing technique. Following the interviews, thematic analysis was undertaken with the grid and aided by the transcript of the tape-recorded interview. This method has been shown to be effective by Melrose & Shapiro (1999) and Shapiro (1991). Furthermore, a thematic analysis is particularly appropriate with individual case studies (Beaumont, 2006) as the grid is explored and interpreted using the participants own terms and language (Neimeyer, Bowman, & Saferstein, 2005). Further details of the nature of the analysis used are detailed in Chapter 2. The validity of the repertory grid analysis is safeguarded by the practice of going through the grid with the participant after its completion which is embedded in its method, to ensure that the participants agrees with the ratings that were produced in the grid and to gain further insight into what participants meant by their ratings.

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Chapter 3.3 Results**3.3.1 Case Study 1:**

There were three main themes that transpired from the elicitation of constructs and from analysing the transcript of the first interview with Jennifer (See Table 3.3 for Jennifer's grid).

**3.3.1.1 Function**

The main theme that emerged from the interview was that of function. For Jennifer, function was of utmost importance and featured three times in different forms as separate constructs: 'limited-fully capable'; 'functional-useless'; and 'capable-worthless'. It quickly became apparent that function was the most important aspect of prosthesis use for Jennifer.

*"If the functionality is great I'm down for anything that's gonna work"*

Notably, the main reason she gave for not liking particular prostheses was due to function, for example:

- Transplanted arm: *"I don't think it would be that functional"*
- Cosmetic arm: *"you can't function with them I mean they don't do anything"*
- Myo-electric arm: *"Yeah it didn't work"*

Furthermore, whether she liked a prosthesis was also usually driven by whether it was functional, for example:

- Her current high tech arm: *"em functionally and to work for certain things it works it does it's quite amazing"*
- Body-powered arm: *"it doesn't bother me as far as aesthetically appealing personally I don't care I don't care what they give me whatever works"*

*Table 3.3 Jennifer's Grid*

<b>Emergent construct</b>	My Ideal Self	Self as I am Now	Self as Others see me	Intact arm	Own body	Myoelectric arm	Body powered prosthesis	Cosmetic arm	High tech prosthetic arm	Self before amputation	Self after first prosthesis	Transplanted arm	<b>Contrasting construct</b>
Independent	1	4	3	1	1	6	5	10	4	1	9	8	Dependent
Kind	1	4	3	2	2	5	5	4	4	2	6	6	Mean
Fully capable	1	5	4	1	1	7	6	10	5	1	9	8	Limited
Functional	1	1	1	1	1	1	1	9	3	1	6	9	Useless
Enjoyable	1	4	3	1	2	10	7	9	3	3	9	9	Irritating
Aesthetically pleasing	1	4	3	1	4	8	9	2	8	4	4	9	Ugly
Outgoing	1	1	1	1	1	3	3	2	2	1	1	3	Shy
Determined	1	1	1	1	1	5	3	5	3	1	1	5	Non-caring
Capable	1	1	1	1	3	6	5	10	2	1	7	8	Worthless
Optimistic	1	5	3	2	2	4	3	4	3	1	9	7	Pessimistic
Amazing	1	5	4	1	5	7	4	5	1	5	5	3	Ridiculous
Needed	1	3	3	1	1	10	8	10	3	1	6	9	Unnecessary

Jennifer appeared to have a very positive view of her current functionality. However, she accepted that she had certain limitations and she feels that others see her as slightly more capable than she does. In relation to the ratings given to the 'limited-fully capable' construct, Jennifer sees her ideal self, her intact arm, her own physical body and her self before her amputation as fully capable. These positive functional ratings are reflected in her comments:

*"I'm functional though you know... I operate in life so it's not like I'm just completely useless"*

Comparing her self now to her self her after first prosthesis, she felt very limited after receiving her first prosthesis. She explained that this was because the myo-electric arm she was given at that time did not work for her.

Acknowledging that functionality appeared to be an important construct for her, Jennifer commented that:

*"function doesn't surprise me a bit and all the things that I picked were around you know capable, functional, limited, independent em because that's function is my number one when it comes to a prosthesis em that's what matters the most to me. Yeah if it helps great, if it doesn't don't bother me with it"*

Although the construct 'independent-dependent' relates to functionality, it relates more to a personality characteristic than a characteristic of the prosthesis. As in functionality, Jennifer accepts that there are certain areas where she cannot do everything she would like:

*"I'm as independent as I can be. However I do realise that I have physical limitations"*

Jennifer selected the construct 'independent-dependent' and rated cosmetic arm as affording her the least independence of all the options. This is supported by her admission that with cosmetic arms *"you can't function with them I mean they don't do anything so you would be just as you know dependent on whatever"*. Her 'self after first prosthesis' is also rated as high in dependence but it appears to have improved judging by the increasing

scores she attributed to 'self as I am now' and 'high tech arm'. Despite rating her independence as having declined since losing her arm, her attitude towards having lost her arm is very positive and she is still very confident of her ability to get on with things:

*"I think I'm capable with one arm I can make life work with one arm I don't have to have an arm to work, to live".*

Her positive outlook may be a consequence of her high tech prosthetic arm as she rates this as affording her the most independence of all the available prosthetic options.

#### 3.3.1.2 Aesthetic indifference

With regard to the 'aesthetically appealing-ugly' construct that she chose, 'ideal self' and 'intact arm' were the only elements to score 1, indicating that she considers these to be very aesthetically appealing. 'Cosmetic arm' received a rating of 2; her explanation for not awarding it a perfect score was that *"I guess I've never seen a really good one"*. 'Self as I am now', 'own body', 'self before amputation', 'self after first prosthesis' were all scored equally being given a 4 for aesthetically appealing. 'Self as others see me' was more aesthetically appealing than how she viewed herself, but the score for aesthetically appealing has not changed from before the amputation, to after the amputation to now. The 'myo-electric arm' and 'high tech prosthetic' both received a score of 8 and 'body powered prosthesis' and 'transplanted arm' received a score of 9, indicating that she views these as amongst the ugliest elements. However, her overall attitude towards aesthetics was that of indifference. For example, with regard to her current high tech arm, she states: *"I don't care about the way it looks"* and *"it's not that pretty but I don't really care"*.

#### 3.3.1.3 Acceptance

Although it was not a construct, another theme inherent throughout the interview was 'acceptance'. Jennifer made it quite clear that she has accepted her current situation and is very comfortable with who she is:

*"I feel like this is me this is who I am so if you don't like it don't look"*

*"I don't care who knows I don't have an arm"*

By examining constructs such as 'determined-non caring', and 'optimistic-pessimistic', her acceptance of her situation is evident. Her ratings for the determined construct show that she is as determined now as she was before her amputation. Jennifer does not rate her self now as optimistic as before her amputation, although her rating of optimism has dramatically improved since her first prosthesis.

She explains that her acceptance of her situation may be due to how she felt about herself before she lost her arm:

*“I think the fact that I did get comfortable in who I am, I was confident before my accident has a lot to do with look and cosmesis, aesthetic appealing, pleasantness isn't a big deal to me”*

#### 3.3.1.4 Jennifer's view of the available prosthetic options:

##### **High tech prosthetic arm (current arm)**

Jennifer reported overall satisfaction with her high tech prosthetic arm:

*“I have the best arm available... but it's still not this arm (intact arm) but you know it really helps a lot in a lot of things”.*

In aesthetic terms she feels that it looks like a robot arm. However it does not bother her - *“it's just not that pretty but I don't really care”*. She scored it highly on the outgoing construct explaining that it is a great conversation piece. She scored it highly in determination referring to her involvement in research projects *“is like a determination to get better arms for the next people who need them”*. She feels the difference between her current arm and her first arm is amazing. She also described her high tech arm as *‘needed but not mandatory’*. This supports her admission that *“...I can make life work with one arm I don't have to have an arm to work, to live”*.

##### **Cosmetic arms**

Her attitude towards cosmetic arms is unfavourable, she indicates that she would never pay for one, and if it was given to her she feels she would not wear it much, explaining that *“I am perfectly comfortable with myself the way I am right now”*. Jennifer is also not



that tolerant of other individuals who consistently wear cosmetic arms in public to conceal their limb absence. However, she feels it is fine if some one wants it once in a while for social occasions:

*“just someone who wants a cosmesis just to you know for photos you know for you know another reason I don’t think id have a problem with it, em because you know whatever, but if it was someone who was like oh I’m not ... I cant let people see me without it on I think that would be a little get under my skin”*

Summing up what she thinks of cosmetic arms, she scored it as completely unnecessary.

### **Myo-electric arm (first prosthesis) & Body powered prosthesis**

Myo-electric arm received favourable scores on the grid in terms of functionality. However, she also scored it as ‘irritating’. Due to the height of her amputation, she explained that it was difficult for her to use a myo-electric prosthesis and that her first myo-electric prosthesis *“didn’t work”*. Jennifer has never been offered a body powered prosthesis. However, she spoke quite favourably of them, commenting that she is aware they are quite functional and robust but she also rated it as aesthetically less appealing than a high tech prosthetic as there *“are more cables to deal with that are around and sometimes they are hooks instead of hands”*

### **Transplanted arm**

With respect to the transplanted arm, Jennifer admitted that she did not know much about transplanted arms but felt that:

*“I don’t think it would be that pretty... I see it as kind of science fiction as kind of monster ...”*

Her view of a transplanted arm’s functionality was not favourable, and this aspect of having an arm is most important to her. However, the idea of having an arm which belonged to someone else did not bother her:

*“The whole creep factor is not a big deal to me...I just think about function and em it would work or whether you know”.*

She also rated it as ‘pessimistic’ explaining that:

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*“If it was taking the time to do that, I think you would have to take those pills you know you have to take medication to keep your body from rejecting it you know, like if I went through all the trouble to do that and if it still wasn’t great, I would be really not optimistic about a lot of things”.*

She feels that the idea that a transplanted arm can happen is amazing and that the technology is there *“blows her away”*. When asked how she would feel if there was improved functionality, she responded: *“If the functionality was great I’m down for anything that’s gonna work”*.

#### 3.3.1.5 Summary of Case Study 1

Jennifer had an amputation at the transhumeral neck. She received a conventional myo-electric prosthesis to use after her amputation. However, she found it difficult to operate, and eventually ceased using the prosthesis. Therefore, she underwent TMR surgery to improve prosthetic function and ease of use. Jennifer used a prosthesis that uses the additional TMR sites. She reported using her prosthesis approximately four days in the week and for about four hours of those days. Jennifer rated her intact arm more positively than the prosthetic options. Jennifer considered the transplanted arm to be the most negative of all the prosthetic options, largely due to functionality being the most important construct in assessing prosthetic options for her and her anticipation that the transplanted arm would have poor functionality. While Jennifer rates cosmetic limbs as aesthetically appealing, her overall ratings of cosmetic arm are low reflecting her high value on functional performance. Overall, a myo-electric arm was not rated very favourably by Jennifer compared to her positive ratings of the high tech prosthetic arm and body powered prosthesis. While it received favourable scores on functionality, she also rated it as ‘irritating’ due to the height of her amputation, which made it difficult for her to use. Jennifer rated body powered prostheses favourably, because of her awareness of their functionality and robustness but she also rated them as aesthetically less appealing than a high tech prosthetic. Jennifer is particularly positive about the functionality of a high tech prosthesis. In aesthetic terms she feels that her high tech arm looks like a robot arm, but this aspect of prostheses emerged as unimportant through the interview.

### 3.3.2 Case Study 2

The constructs elicited for interview 2 are included in Table 3.4

#### 3.3.2.1 Function

For the second participant, Declan, functionality emerged as the most prominent theme arising from the repertory grid interview. Declan used six variations of the term: ‘useful-not being useful’, ‘no physical limitations-physical limitations’, ‘not very functional-functional’, ‘more capability-less capability’, ‘less capable-more capable’, ‘functional-not functional’. In several occasions throughout the interview, he emphasised his desire for functionality: *“because you have got to be functioning, you’ve gotta be as functioning as you can be”*. Declan's need for function is made further apparent in how satisfied he is with the functionality of his body powered prosthesis:

*“I think from my own opinion and it is em what I have with the body powered now it is very functional arm and I can do a lot of things I can play sport I can em drive a normal car I can carry and lift pc’s and lift and do my normal work as anyone else would do em with cosmetic you cannot really function properly”*.

It can be seen from Declan’s ratings that he was not satisfied with his first prosthesis, which was similar to a body powered but had limited function and had a leather glove covering. Through analyses of the grid and the interview transcript, one of the main reasons for his dissatisfaction was due to its poor functionality. The ‘self with first prosthesis’ received the most negative score across all functional constructs. This prosthesis was also considered to be the most unreliable, and most unappealing of all elements but especially of all available prosthetic options. Despite not liking his first prosthesis, Declan wore it explaining that *“I could do a lot more with it than without it”*. From Declan’s perspective, there was a vast improvement from his first to his second body-powered prosthesis:

*“em functionality improved greatly...you could actually hold something and still play football and stuff when I was before I was 12, but its just the hand basically was doing nothing so em to have something that could grip something hold a school bag or hold a briefcase was majorly an improvement you know”*

*Table 3.4 Declan's Grid*

<b>Emergent construct</b>	My Ideal Self	Self as I am now	Self as others see me	Intact arm	Own body	Myo-electric arm	Body powered prosthesis	Cosmetic arm	High tech prosthetic arm	Self with first prosthesis	Transplanted arm	<b>Contrasting construct</b>
Happy	1	2	2	2	2	2	2	4	2	5	3	Sad
Not standing out	1	3	3	1	3	3	3	4	4	7	1	Standing out
Useful	1	3	4	1	3	3	3	8	2	5	1	Not being useful
Truthful	1	1	2	1	2	2	2	4	2	4	6	Lying
May have no physical limitations	1	3	3	1	2	3	2	5	2	5	2	Having physical limitations
Functional	1	3	4	1	4	5	5	10	5	8	2	Not very functional
More capability	1	2	3	1	2	3	2	7	2	8	2	Less capability
Reliable	1	1	2	1	1	3	4	2	4	5	2	Unreliable
Aesthetically appealing	1	3	3	1	3	4	4	2	4	8	2	Unappealing
Confident	1	1	1	1	2	3	3	3	3	5	1	Not confident
More capable	1	2	3	1	4	4	4	9	4	9	1	Less capable
Functional	1	2	2	1	2	2	3	2	2	7	1	Not functional

Throughout the interview, Declan stressed the value from his perspective of having a prosthetic device

*“...you know it would certainly be something I would miss if I didn’t have a functioning arm you know so if I think maybe kids should be pointed towards using as much technology as they can take”*

If functionality had been better as a child, Declan feels it would have benefited him:

*"It would certainly have helped development em when your you know as em in national school and secondary school it would certainly have helped dramatically to have something better and more functional"*

Declan’s ratings with regard to the varying functional constructs in relation to the element 'self as others see me' compared to 'self as I am now' showed that he feels that other people see him as slightly less functional than he sees himself. Declan feels that: *"sometimes people that wouldn’t know you that well would so other people see me as less capable than I actually am..."*. He summarised how his friends and family see his functionality:

*"I would say people probably do see you as less able than you actually are you know em friends who might like to help out now and again help do something or whatever my family that know me quite well wouldn’t they know how capable I am and its not a problem you know but someone who doesn’t know you that well would say can I lift that for you or can I help you"*

### 3.3.2.2 Standing out

The issue of 'standing out' was an especially dominant theme for Declan. It permeated through most of the interview and he chose 'not standing-standing out' out as a construct. In terms of his grid, he rated his 'ideal self', the 'intact arm', and the 'transplanted arm' as 'not standing out', whereas he felt that 'self with first prosthesis' stood out most, attributing a score of 7 to this element:

*“...The first arm which stood out like a sore thumb em it does hold you back to a great extent if you are the one who stands out in the crowd so I would urge other*

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*parents to make sure they have the child has the best technology they can and which is suitable for them em so that they don't stand out too much ..."*

However, 'cosmetic arm' and 'high tech arm' were also considered to 'stand out' more than either the 'myo-electric arm' or the 'body powered prosthesis'. Declan explained why he did not feel the cosmetic arm aided integration:

*"I think it stands out a little bit more and I'll explain to you the reason why. If I got to lift something, ok X amount of people cop something but if you are using cosmetic because you have got no essentially you have got no very little body power in it, I have body powered I'm helping my left hand side with my right hand side but if I can't do that its gonna stand out a lot more"*

Emphasis on standing out also fed into Declan's belief that it is important to help the child to integrate into their surroundings "...the less kids stand out I think the better". He emphasises the need for not standing out mostly when it comes to children with a limb absence, and he feels this is a major parental role:

*"... I think its very important for parents I think growing up to approach it in the right manner you know that em I always played football when I was young I was always you know mixed in very well I think that's extremely important you know em if you are not one of the gang you're out of the gang if you know what I mean and kids will always be teased over everything em wearing glasses or pig tails or whatever the case may be so the less the more in the gang they are the better and the functioning they are the more they can be in the gang if you know what I mean in the 80% of people that you know play football or whatever the case may be you know"*

Declan also felt that when children reach the teenage years, standing out from the crowd due to not having an arm could have a negative psychological impact on the child.

*"Because when you get to the stage of 10/12/14 when you are mixing with the opposite sex anyway you know they want to be able to pass off as being as normal"*

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*as possible and to be the one kid that stands out I think could psychologically impact on the you know so having been there"*

Declan used techniques when he was younger to help him not stand out as much:

*"...being accepted into a group is very important I think you know and especially when your you have got a little bit which makes you stand out...what I used to find if I'd be walking somewhere I'd be wearing a bomber jacket with both hands tucked into the jacket pocket you know...it was me trying to change the body image or whatever em so I think its extremely important for children growing up they get as much em they stand out as little as possible you know"*

It emerged through the course of the interview that Declan did not like to be seen without his prosthetic by his friends or even members of his extended family. Only his wife and son would see him without it on. When asked does he mind people seeing it, he responded:

*"...I mind more for them than for me because I think it creates a (aagghh) (laugh)"*

He continued to explain that he would never take it off around people he knows. This revelation further reinforces his desire not to "stand out".

*"I wouldn't (take it off), call it shyness, call it whatever but it's I wouldn't no I wouldn't".*

In relation to functionality and the desire to not stand out, Declan felt it is important to strike a balance between the two;

*"Functionality with a balance not what I would say the hook aspect because I think my opinion I think you stand out too much when you go that way because em but cosmetics at one end and the hook at the other end. I think functionality with a certain amount of cosmetics is important because I think a better overall person if you know what I mean because it helps in the sense of if you have got the hook you are the odd one out but with the cosmetic you know somewhere in the middle it makes more sense to me"*

### 3.3.2.3 Reliability

The cosmetic arm and transplanted arm were both seen as quite reliable, receiving a score of 2 on the 'reliable-unreliable' construct. He viewed the cosmetic arm as reliable in that since it is not functional, it cannot let him down and is thus reliable.

*"It does nothing (laugh)...it can't break...there is no moving parts".*

However, the body powered prosthesis, the high tech prosthesis and the myo-electric arm were not rated as very reliable. Declan explains that he is concerned with the fact that high tech and conventional myo-electric prostheses are battery operated and thus batteries will wear out with use, possibly at inconvenient times.

*"and em reliability is a big issue you know so if a battery runs out maybe after 6 hours use and you're looking for somewhere to charge it it's a pretty big problem you know so em for that reason I have kind of settled with the technology I am used to"*

However, his body-powered prosthesis also tends to break on occasions.

*"if in the odd occasion reliability I think probably comes in there as well if on the odd occasion something breaks as I say like driving or whatever em it is a major issue so to have a cosmetic is no good to me to have something that's not reliable is no good to me. I need I need to be able to do certain things I need to be able to em lift certain things and hold things em so reliability"*

Declan gives an insight into the consequence of an unreliable prosthesis for him when he was younger:

*"...lets say when I was growing up and I was using this type of prosthesis em it could break once every six months right and that was a big issue because I only had one hand in terms of one I didn't have spare I only physically got the one and it would break and you would have to send it off ...and could take six months to get it back so I went from having something that was quite good be sent out for repair so I would have to use the old one again and the old one I was never happy with"*

Declan solved this issue by having additional spare prostheses.



### 3.3.2.4 Happiness

Overall, Declan acknowledged that he was "quite happy" but admitted that had he been born with his left arm, he may have been slightly happier:

*"Im quite happy in my own skin as I said before em the I suppose there there is that certain element missing where you said yourself ok I could have accomplished a certain amount but I could have accomplished X amount more em if I hadn't been in this situation that I was born into so I could be a little happier if em if that hadn't have happened but I am quite happy as I am"*

Declan disclosed that he would envisage himself striving for greater functionality through exploring new technologies at some stage despite his current satisfaction with his body powered prosthesis:

*"I am content but you would always like something you would always like new technology you would always like something better but em I would like to explore new technologies"*

The least favourable scores in the 'happy-sad' construct were attributed to transplanted arm, cosmetic arm and self with first prosthesis. The self with first prosthesis received a score of 5, indicating that he was least 'happy' with his first prosthesis. This is evident in most of his other ratings as he almost consistently scored the self with first prosthesis most negatively across all constructs and of all elements he labeled it as the one in which he felt least 'confident'. Therefore he may have felt least happy with it as it 'stood out', was not 'very functional', was not very 'reliable' and was not very 'aesthetically appealing'.

*"...I meant a physical glove like a physical em leather glove is what I wore when I was 12...so that really stuck out a lot"*

### 3.3.2.5 Declan's view of the available prosthetic options:

#### **Body-powered prosthesis (current arm), myo-electric prostheses & high tech prosthesis**

In general he viewed his current body powered prosthesis quite favourably.

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*"...what I have with the body powered now it is very functional arm and I can do a lot of things..."*

As far as Declan was concerned, myo-electric prostheses and high-tech prosthesis were considered unreliable due to the fact that they are both battery operated and therefore the batteries could die out.

### **Cosmetic Arms**

A cosmetic arm is considered the least useful prosthetic option and element to Declan. The cosmetic arm received a score indicating that it is considered the most physically limiting, and least capable construct.

*"em no I think what I have is quite good like because a cosmetic my opinion of a cosmetic is very purely cosmetic so its not useful its not functional em I wouldn't advise any children to use them unless its just for that one occasion..."*

However he does rate it as aesthetically appealing:

*"well yeah I had one em I it depends what you want to do with it it depends whether you want to look good if you know what I mean it does look good you can sit there and you know you would have to look at it quite closely to see is it real or not you know some of them they are quite good em but you know in terms of functionality they are zero"*

### **Transplanted arm**

Declan's knowledge of transplanted arm was limited. However, after briefly discussing the possible issues regarding a transplanted arm, his response was equivocal:

*"It would be useful; I don't know whether I would actually do it"*

*"I think the perception on rejection; the perception on using someone else's arm would be tempered by the fact that if it worked you have got something that is as useful as your other more functioning arm"*

From the grid, it can be seen that Declan would be more confident with the transplanted arm than any of the other prosthetic options. Declan viewed it quite favourably in terms of functionality as evidenced by the ratings he attributed to this element. In general, he views it as slightly less functional than his self now and a lot more functional than his current body powered prosthesis. His response to his favourable ratings of the transplanted arm:

*" yeah in an ideal world if it worked yeah...well if its a real arm and if the texture is right the skin is right its an actual body part and it worked it should be very useful you know it should be able to do everything..."*

However, his consensus was that if functionality was only equal to that of his body powered arm:

*"I wouldn't change sorry if it was just as functional...id expect it to be a lot more functional a lot more bells and whistles"*

#### 3.3.2.6 Summary of Case Study 2

Declan was a middle-aged gentleman who had congenital transradial limb absence and used a conventional body-powered prosthesis. The first limb he used as a child was also a body-powered prosthesis, but had limited function and had a leather glove covering. Declan reported wearing his prosthesis seven days per week and 18 hours per day. Declan rated his intact arm positively. A cosmetic arm is considered the least useful prosthetic option as cosmesis is an unimportant value for Declan. The cosmetic arm is also seen as the most physically limiting, least functional and least capable option. However, it is rated as the most reliable prosthetic option, explaining as "since it doesn't do anything, it cannot let me down". Overall, Declan viewed his current body-powered prosthesis, a myoelectric arm and a high tech arm quite favourably. The important differentiating constructs for Declan were functionality and 'not standing out', with 'functional' even appearing twice in his grid.

### Chapter 3.4 Discussion

The specific aims of the present study were to explore how a high technology user and conventional upper limb prosthetic user viewed the various choices of prosthetic limbs. The further aims of this study were to gain insight into the fundamental characteristics of prosthetic devices for these users, while demonstrating a novel, idiographic method for exploring these values and preferences. The results showed that a number of different features are important to individual prosthetic users when selecting a prosthetic option. While numerous papers suggest that individuals may vary in their prosthetic preferences, these case studies using a standardized assessment process provides evidence to support this assertion. Furthermore, these results suggest that the factors individuals use to evaluate a prosthetic option can be highly individualized, and that different prosthetic options are not held in the same regard among different prosthetic users.

#### **3.4.1 Themes**

The analyses revealed that for both Jennifer and Declan, function was of paramount significance. Jennifer was intolerant of prosthetic devices that did not aid her in terms of functionality and she viewed both cosmetic arms and transplanted arms as very limiting. This is not surprising given her admission that functionality is an essential component for her. However, Jennifer only reported wearing a prosthesis four days a week and only for three hours of each of those days. Perhaps for Jennifer her desired requirement of a prosthesis is purely for specific tasks. For example, she emphasised how much easier having her prosthesis has made cooking. This supports Jones & Davidson (1995) who found that domestic tasks affected women more than men after the absence of a limb. This finding shows that Jennifer has more specific functionality whereas from Declan's grid and the transcript of his interview, it can be seen that he has more general functionality requirements. This may be because Declan has congenital limb absence and therefore adapted to most tasks at a young age. It emerged that he is satisfied with the function of his current body powered prosthesis and being functional is very important to him. Both participants appeared to accept their limb absence and accept that they have functional limitations but they both rely heavily on having functional prostheses and their main need

for prostheses are defined by functional requirements. These findings support those of Biddiss & Chau (2007a) who found that established need is a primary factor in prosthesis acceptance.

Both Jenifer and Declan considered cosmetic limbs as virtually useless. Given that Jennifer is a female with a traumatic amputation at the humeral neck, her desire for purely functional prostheses with no regard for cosmetics is inconsistent with evidence from previous research. For example, Burger, Brezovar, & Marincek (2004) have found that most patients with higher levels of limb absence wear their prosthesis primarily for cosmetic reasons; therefore lightweight cosmetic limbs may be preferred to body powered prostheses in these patients (Datta et al, 2004). However, these findings may be due to the fact that individuals with higher level of amputations find it difficult to use conventional functional prostheses. Therefore, if TMR surgery was made available to more patients with high levels of amputations that traditionally find myo-electric prostheses difficult to operate, they may report wearing myo-electric functional prostheses more often. The present studies findings again challenge those of Biddiss & Chau (2007a) who indicated that females reportedly gravitate towards more aesthetic devices (Crandall, & Tomhave, 2002; Kruger, & Fishman, 1993), whereas Jennifer displayed contempt for purely aesthetic devices and showed no desire for cosmesis.

The findings from the present study challenge the observation by Fisher (1985) that suggested that participants with limb absence who were deemed to be unsuccessfully rehabilitated by their surgeons may be more likely to score 'ideal self' perfectly and that an individual holding unrealistic beliefs about their perfect self may contribute to an unsuccessful outcome. It appears that this finding may not hold true in the present study, as both participants scored their ideal selves as a perfect '1' for all elements. However, both participants rated their intact arm as near perfect. This suggests that for participants in the present study their aspirations for their ideal self is not unrealistic, as their unaffected arm is close to their ideal. Therefore this finding does not support Fisher's (1985) suggestion that unrealistic beliefs contribute to unsuccessful outcomes.

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### ***3.4.2 Methodological and theoretical strengths of the study***

This study successfully elicited individually meaningful constructs relevant to each of the participants to rate the different prosthetic options and an individuals different selves. The constructs that emerged managed to encompass how each participant thinks about aspects of themselves, their prosthesis and other prosthetic options. By rating the technology on these scales, we are essentially rating the technology under headings that are personally important to the prosthetic user. The unique perspective of each completed repertory grid provided a number of headings for rating prosthetics that may not have been identified using conventional questionnaire or interview techniques, and were exclusive to each individual. The RGT indicates what individuals' preferences are with regard to technology by offering ratings on different prosthetic options while showing why and how they arrived at these preferences. Each participant produced more than one construct referring to function, which is not surprising given that the purpose of a prosthesis is to restore some lost function to those with limb absence. A personal construct is considered a particular way that the individual has of viewing, giving meaning to, or construing, the elements in their environment (Jankowicz, 1987). Therefore it can be deduced that both participants mainly view their environments in functional terms. However, it is important to note that the purpose is not to generalise to the general population as these two participants potentially differ from the current population of individuals with limb absence whereby many other individuals may simply be content with having no prosthesis or purely cosmetic prostheses. Also, the other constructs elicited may have been quite specific to these particular individuals. However, these findings propose that the accepted norms of what prosthetic users want from a prosthesis do not apply uniformly to all individuals from the same demographic, emphasising the individuality of prosthetic users needs. Furthermore, the preference and choice of prostheses may not reflect what providers see as the most up-to-date and cutting edge available.

This study successfully incorporated the use of the contrast method of elicitation (Neimeyer et al, 2005), and recommends the future use of this approach in studies using the repertory grid and general standardization of the repertory grid method in research. The contrast method of elicitation (Neimeyer et al, 2005) was incorporated in this study

following recommendations by Neimeyer et al, (2005) that this method generated significantly more highly differentiated personal construct systems and more bipolar constructs than alternative methods of elicitation and this effect has been replicated repeatedly in subsequent research (Neimeyer, Neimeyer, Hagans, & Van Brunt, 2002; Hagans, Neimeyer, & Goodholm, 2000). The success of RGT was shown through the process of going through the grid with the participants and asking them to clarify and expand on the findings of the grid. When asked about the constructs and ratings that emerged from the grid, the participants agreed that they accurately reflected how they felt about prosthetic devices and went on to further elaborate what the grid had indicated.

The repertory grid method is favourably characterized by a considerable openness toward people's unique mental representations and the researchers own concepts are not forced on them and the risk of unnecessarily simplifying or complicating people's everyday constructions is reduced (Borell, et al, 2003). The RGT can help access important information regarding an individual's perspective and interpretation of reality. Such understanding better positions the practitioner to understand how and why individuals may be using specific coping strategies and in doing so unlocks potential avenues for change (Borell et al, 2003). Discovering the preferences of the patient and assessing them early in the treatment process is increasingly recognized as important in healthcare (Quill & Brody, 1996). In particular, client participation and client centred focus are central features in the ICF (WHO, 2001) and are highlighted in the widely accepted Matching Person and Technology (MPT) model used for prescribing assistive technology (Scherer, 2002b).

Furthermore, as demonstrated by Melrose & Shapiro (1999) tape recordings of the interviews from which the grid is developed, supplied valuable material to draw upon for further understanding. For example, from simply looking at the elicited constructs, it could be misinterpreted that the emergence of the construct 'aesthetically appealing' implies that aesthetics are important to Jennifer but aided by the ratings attributed to this construct and the transcript of the interview, it was clarified that she was indifferent to aesthetics. This example supports the use of tape-recording the interviews. This is also an interesting

example of how this type of interview can distinguish the aspects that are important to an individual.

#### ***3.4.3 Limitations of the study***

It must be taken into consideration that although every attempt is made for the interviewer to be impartial and to guide the respondent through the process, the technique does not completely protect against possible interviewer effects as in any qualitative study. The technique requires the interviewer to maintain a degree of sensitivity and openness to what is actually said and to limit the risk of influencing the respondent's options. It also needs to be considered that the interpretation relies upon the researcher's ability to accurately conceptualize the data and the ability of the data itself to mirror the respondent's mental concepts (Borell et al, 2003). However, by elucidating the data collected on the grid with each participant as part of the RGT process, there is little scope to misinterpret the data. It should also be acknowledged that the present study had a selection bias, whereby a convenience sample was used, comprising of one individual who has prior experience of involvement in research studies and is pro-active and enthusiastic about participating in research projects. However, the purpose of the RGT is not to generalize its findings to a wider population but to explore idiographic values and preferences in order to gain a deeper understanding of an individual's experience. It is appreciated that due to time constraints in clinical practice, a modified RGT would be more suitable for use within prosthetic prescription. Consequently, given that there are currently no standardised methods in which to measure patient preferences within the prosthetic prescription setting this study recommends a standardized method be created for clinical use which is based on a similar approach.

#### ***3.4.4 Conclusion***

This paper adds weight to the evidence that patient preferences need to be considered when prescribing prosthetic technology. Including individual's choices and opinions within the prescription process may increase patient satisfaction and decrease the likelihood of prosthetic abandonment. It emerged from the analysis that function was the most important construct for Jennifer and her current prosthesis that uses the additional



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targeted muscle reinnervation sites, successfully meets that need. Declan emphasized from his perspective that it is important to strike a balance between aesthetics and function. The results of this study have important implications for upper limb prosthetic users, as the results have given a unique insight into how prosthetic users may view the world post amputation and how they may view the prosthetic options available to them. This study supports suggestions from Scherer (2002b), Phillips & Zhao (1993) and Wielandt et al (2005) that the perspective of the user should be incorporated into device selection and that there is a need to provide prosthetic options to users. It appears from some sources (such as the Murray foundations patient information leaflet) that in many consultations, the prosthetic options are discussed with a patient. However, it is possible that the patient does not get much say in the final prosthesis chosen, due to medical, time, or economic constraints. It is proposed that there is a need to move away from the path of thinking of patients in general, but specifically prosthetic users as merely passive recipients of health care and rehabilitation. Prosthetic users need to be thought of as consumers who have preferences and expectations of the product or device they wish to use. This study demonstrates that the RGT was valuable in generating in depth information that may not have been achieved through a conventional interview. Chapter 4 will provide further evidence with a greater number of individuals that the perspective of the person with limb absence is essential to include in investigations concerned with identifying the broader outcomes associated with ULA and that qualitative research techniques are ideal methods to do this.

Chapter 4 Qualitative Studies: Identifying factors of importance to  
consider in ULA rehabilitation

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<b>4.1 Introduction to qualitative studies 1 &amp; 2 .....</b>	<b>126</b>
4.1.1 Lack of qualitative research in ULA literature.....	126
4.1.2 Focus groups and interviews.....	128
4.1.3 Rehabilitation professional and patient perspective.....	130
4.1.4 The present study.....	133
4.1.5 Aim of the study.....	134
<b>4.2 Method for study 1 &amp; 2 .....</b>	<b>135</b>
4.2.1 Method for qualitative study 1: Rehabilitation professionals.....	135
4.2.1.1 <i>Sample</i>	
4.2.1.2 <i>Materials</i>	
4.2.1.3 <i>Procedure</i>	
4.2.1.4 <i>Quality Control</i>	
4.2.2 Method for qualitative study 2: Individuals with ULA.....	138
4.2.2.1 <i>Sample</i>	
4.2.2.2 <i>Inclusion/ Exclusion Criteria</i>	
4.2.2.3 <i>Materials</i>	
4.2.2.4 <i>Procedure</i>	
4.2.2.5 <i>Quality Control</i>	
<b>4.3 Results for study 1 &amp; 2.....</b>	<b>142</b>
4.3.1 Results for Study 1: Rehabilitation Professionals.....	142
4.3.1.1 <i>Prosthesis use</i>	
4.3.1.2 <i>Goal Setting</i>	
4.3.1.3 <i>Function (incorporating activities and participation)</i>	
4.3.1.4 <i>Psychological factors</i>	
4.3.1.5 <i>Physical factors</i>	
4.3.1.6 <i>Social factors</i>	
4.3.1.7 <i>Satisfaction with prosthesis</i>	
4.3.1.8 <i>Satisfaction with the service</i>	
4.3.1.9 <i>Summary of findings</i>	
4.3.2 Results for Study 2: Individuals with ULA.....	168
4.3.2.1 <i>Prosthesis use</i>	
4.3.2.2 <i>Function (incorporating activities and participation)</i>	
4.3.2.3 <i>Psychological factors</i>	
4.3.2.4 <i>Self-image</i>	
4.3.2.5 <i>Physical factors</i>	
4.3.2.6 <i>Social factors</i>	
4.3.2.7 <i>Satisfaction with the prosthesis</i>	
4.3.2.8 <i>Satisfaction with the service</i>	
4.3.2.9 <i>Summary of findings</i>	

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<b>4.4 Discussion of Studies 1 &amp; 2.....</b>	<b>199</b>
4.4.1 Prosthesis use.....	200
4.4.2 Function (incorporating activities and participation).....	202
4.4.3 Psychological factors.....	204
4.4.4 Social factors.....	206
4.4.5 Physical factors.....	208
4.4.6 Satisfaction with prosthesis.....	210
4.4.7 Satisfaction with service.....	210
4.4.8 Self-image.....	213
4.4.9 Goal Setting.....	215
4.4.10 Limitations of the study.....	215
4.4.11 Strengths of the study.....	218
4.4.12 Conclusion.....	219

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### Chapter 4.1 Introduction to qualitative studies

The review of the ULA literature in Chapter 1 gave an insight into the distinct focus to date on identifying the predictors of upper limb prosthesis use. The chapter also demonstrated that despite this research, there is little agreement on the definitive predictors of prosthesis use amongst individuals' with ULA. There is also little knowledge on the other potential outcomes following ULA and what factors may predict achievement of a successful outcome and the role of prosthesis use specifically in achieving outcomes. This chapter aims to elicit the potential outcomes of ULA (including functional and psychosocial) and other factors that are associated with them.

#### ***4.1.1 Lack of qualitative research in ULA literature***

The literature review in Chapter 1 also highlights the dearth of qualitative research amongst individuals with ULA and demonstrates the merits of conducting research of this nature in the field of ULA, such that qualitative research can elicit factors that have not been considered in quantitative research to date. Gallagher & MacLachlan (2001) stated that most research involving people who have had an amputation has been concerned mainly with quantitative methodology, which largely ignores the perspective of the person who has had the amputation. The present study is an ideal opportunity to expand this research methodology in this field. Qualitative methods have also been deemed to be sensitive to the unique personal experiences, perceptions, beliefs and meanings related to individuals who experience ill health and its interventions (Sim, 1998). It has also been recommended that qualitative research can open up different research areas such as hospital consultant's views of their patients or general practitioners accounts of uncomfortable prescribing decisions (Britten, 1995). An ideal way to elicit the outcomes and predictors of ULA is through qualitative research.

The limited qualitative research to date in the field of amputation has mainly focused on individuals with lower limb amputation. Gallagher & MacLachlan's (2001) focus group study with individuals with lower limb absence, was one of the first qualitative studies amongst individuals with limb absence that provided data on psychosocial outcomes of

importance amongst 14 individuals with lower limb absence. The aim of their study was to identify the factors considered central to adjustment to amputation and wearing of a prosthetic limb from the perspective of the person who has the lower limb amputation. There was an array of themes indicative of psychosocial adjustment elicited in Gallagher & MacLachlan (2001) study pertaining to initial reactions to the amputation and the artificial limb and the long term effects of having a prosthesis. Additionally, discussion regarding self image, social interaction, support, effects on family and friends, acceptance, practical and physical issues and problems with the prosthesis also emerged. Findings of particular interest from this study was the psychological methods participants reported adopting that appeared to facilitate adjustment such as engaging a positive attitude and downward social comparison. Participants in this study discussed how they initially had a negative reaction to seeing their prosthetic limb the first time. Gallagher & MacLachlan (2001) interpreted this as a common response for individuals with limb absence. Participants in this study suggested that counselling should be obligatory and meeting and talking to others was useful and offered proof that rehabilitation was possible

However, additional qualitative studies that have been conducted such as Murray (2004, 2005, 2009) incorporated individuals with both upper and lower limb absence in the research. Additionally, Murray (2004, 2005, 2009) used a multi-method qualitative approach to investigate the personal and social meanings surrounding the use of prosthetic limbs. The data was collected using semi-structured email and face to face interviews with participants who had lower limb absence and ULA along with analyses of posts made in an internet discussion group. The qualitative nature of these studies allowed the opportunity to explore patient's experiences and found that many participants encounter negative reactions to their limb absence in social situations which may over time lead to social avoidance and isolation (Murray, 2005). These studies support the use of qualitative research to provide a greater insight into the patient's perspective that is difficult for quantitative methods alone to achieve. Saradjian et al (2008) conducted the only qualitative study to focus exclusively on ULA to date. They suggested the need for a psychological understanding of wearing a prosthesis in order to facilitate rehabilitation and understand the experience of having a prosthesis, how it affects a person's life, their

body image and their attitude towards the device. They also recommended that qualitative investigations could be a useful tool to explore these issues. However, this study only included male prosthesis users in their sample. Although fewer women tend to have ULA, their experiences are still valuable to gather, as well as those individuals that do not wear a prosthesis.

Frank (1984) found qualitative case studies a useful approach to describe the life history of a woman born without legs and with upper limb absence above the elbow. Frank collaborated with the participants to produce a holistic qualitative account. This qualitative case study described the themes of cultural normalcy and orientation to independent living and emphasised the participant's normal cultural development. The analyses showed the participant found the prosthetics more stigmatising than her current body form. Frank (1984) demonstrates that prosthetics will not be an aid for everyone and may be deemed limiting. Additionally Frank (1984) demonstrates how useful the qualitative case study is at accessing and reporting these experiences.

Most qualitative studies, in line with quantitative studies, have adjustment to prosthesis use at the forefront of their investigations and many have only used prosthesis users in their studies. However, in the same way as qualitative research has opened up a new understanding of adjustment to the prosthesis, qualitative research will be useful in facilitating a greater understanding of the outcomes associated with ULA and the associated factors. When choosing qualitative techniques in research, there are several different types to choose from such as observation, in depth interviews, or focus groups. In terms of interview techniques, a researcher may choose to conduct individual interviews or focus groups.

#### ***4.1.2 Focus groups and interviews***

Dunn (2000) describes interviews as verbal interchanges where one person, the interviewer attempts to elicit information from another person, the participant. There are three types of interviews; structured (using pre-determined and standardised list of questions, followed rigidly), unstructured (questions directed mainly by the informant)

and semi-structured interviews where there is a predetermined list of questions that are roughly followed throughout the interview but allow the interviewer to probe anything of interest said by the interviewee (Longhurst, 2003). Longhurst (2003) suggests that semi-structured interviews and focus groups are similar in that they are conversational and informal in tone and both allow open responses in participants' own words. The key characteristic of focus groups that distinguish them from in depth interviews is the interaction between members of the group (Cameron, 2000) whereas semi structured interviews rely on the interaction between interviewer and interviewee. Focus groups also have the benefit of being able to gather opinions of a large number of people and for comparatively little time and expense (Longhurst, 2003). Additionally, The benefits of focus groups as suggested by Kroll, Barbour & Harris (2007) is that participants may enjoy their involvement in the group discussion and value the opportunity to share their experiences with individuals with similar characteristics and derive empowerment and stimulation from the experience (Kroll, Barbour & Harris, 2007). Kroll et al (2007) and Kitzinger (1995) also suggested that focus groups may be able to elicit information from people who are unable to write, as may be the case with some individuals with ULA. However, unlike focus groups, interviews allow more in depth analysis of an individual's responses.

However, it is argued that both semi-structured interviews and focus groups can be used as 'stand alone methods', as a supplement to other methods or as part of mixed methods research (Longhurst, 2003). When deciding whether to use a focus group or a semi structured interview in research, researchers often need to consider what is most suitable for the specific research. For example, it is vital to consider whether there is a need for complete confidentiality perhaps in a sensitive research area, as in these instances, semi-structured interviews may be more appropriate than focus groups. Additionally, the research time line needs to be taken into consideration as focus groups have the benefit of being able to interview more people at once but can be hard to schedule. Also, it is necessary to note the potential of certain participants to have dominant views in a focus group which can potentially intimidate or influence other participants (Lankshear, 1993).



This point is especially relevant with respect to health professionals as certain professionals may tend to dominate the focus groups with their views.

#### ***4.1.3 Rehabilitation professional and patient perspective***

In addition to using qualitative studies to gather information on the factors of importance following absence of an upper limb, it is worthwhile to consider the perspective of both the RP and the individual with limb absence in this investigation. Chapter 3 provided support for the inclusion of patients in research and also demonstrated the merits of qualitative research in accessing the unique perspective that individuals with limb absence provide. The need to assess patient outcomes is emphasised by Biddiss & Chau (2007b) who recommended the use of participatory research and that an emphasis on patient satisfaction is needed. Additional researchers have emphasised the importance of incorporating the perspectives of patients themselves in rehabilitation and prosthetics research (Bartlett et al, 2006; Van der Linde et al 2007).

Wright (2000) suggests that we should be focusing on what is important to patients in healthcare and that the decision can only be made by the patients themselves. A fundamental task for clinicians when evaluating patients or interpreting the results of clinical trials, is to decide if a particular outcome relates to an improvement in patients health. The choice of outcome in clinical trials is particularly pertinent when the primary purpose of treatment is to relieve symptoms or decrease disability. If the patient's main goals are not clearly determined and specified, the therapeutic accomplishments may be assessed with the wrong target or outcome (Rothwell, Mc Dowell, Wong & Dorman, 1997).

Despite this acknowledgement of the importance of the patient's perspective in research and the clinical rehabilitation setting, there tends to be a difference in a patient's and service provider's perspectives. This difference is noted by Scherer (2002b; p.3): 'Professionals have tended to define goals achieved (e.g. independence) in terms of physical functioning, whereas consumers more often equate independence with social and personal freedoms'. Biddiss & Chau (2007b) also suggested that in order to identify the

relevant outcomes, both the patient and the provider should be consulted. Additionally, previous studies in health that have used both health professionals and patients in their investigations have identified their differing perspectives. Studies investigating doctors and patients agreement on perceptions and assessments of disability in Multiple Sclerosis (MS) found that patients and clinicians often disagree (Rothwell McDowell, Wong, & Dorman, 1997). They concluded that patients with MS and possibly those with other chronic illnesses are less concerned than their clinicians about physical disability in their illness but that patients are more concerned with mental health and vitality. It has also been argued that doctors are not good at estimating the overall QOL of their patients (Slevin, Plant, Lynch, Drinkwater, & Gregory, 1988; Gerhardt, Koziol-McLain, Lowenstein, & Whiteneck, 1994). Additional research has shown that patients and health care providers (nurses) may have quite divergent views about a service (nurse led heart failure clinic) and its benefits (Lloyd-Williams, Beaton, Goldstein, Mair, May & Capewell, 2005), emphasising the potential value of consumer involvement and feedback when developing and delivering services.

The discrepancy between patients and health professional's opinions is supported by findings from Mortimer, MacDonald, Martin, MacMillan, Ravy & Steedman (2004) who conducted focus groups with health professionals on views of phantom pain, phantom sensation and need for patient information. They compared their findings to a parallel study of patient experiences of phantom pain and sensation following lower limb amputation (Mortimer, Steedman, McMillan, Martin & Ravey, 2002). Results found that professionals' opinions of the experiences of phantom sensation were largely similar to the patients reported experiences. However, not all professionals' fully appreciated patients potentially differing experiences of phantom pain. Mortimer et al (2004) suggested that professionals' understanding of phantom phenomena is gained mainly from their clinical experience which varies depending on their role in rehabilitation. It is suggested that it is also necessary to examine the views of all members of the rehabilitation team as the rehabilitation of individuals with limb absence is multidisciplinary and patients may receive conflicting information perhaps because of variations in the undergraduate training that health professionals undergo (Fields, 1995).

Schultz, Baade, & Kuiken (2007) also gathered the opinions of 51 prosthetic experts (including prosthetists, therapists, researchers, engineers, and physicians and one unknown profession) using a questionnaire which asked participants to rank comfort, function and cosmesis in order of importance for unilateral transhumeral amputees and bilateral transhumeral amputees. They then compared their results with those of prosthetic users from previous investigations such as Melendez & Le Blanc (1988), & Atkins, Heard, & Donovan (1996). Categories were subdivided into weight, socket interface comfort, power, agility, color and shape. Schultz et al's (2007) investigation found that the majority of prosthetic experts viewed comfort to be the most important factor for a person with a unilateral amputation and considered socket interface comfort to be more important than weight. Function was considered to be most important for an individual with bilateral limb absence, with agility considered more important than power. Cosmesis was consistently reported as less important than comfort and function and shape was considered more important than color. When they compared their results to Melendez & Le Blancs (1988) previous study with individuals with limb absence, they found that the rank orders were different, with unilateral prosthesis users ranking function first, comfort second and cosmesis third. However, those who did not use a prosthesis, rated comfort 1<sup>st</sup>, function 2<sup>nd</sup> and cosmesis third. However they didn't assess the opinions of those with bilateral limb absence. In Atkins et al (1996) study, participants' preferences were assessed according to the type of prosthesis they used. For body powered prostheses, function was most important, followed by comfort, then cosmesis. However, for myo-electric prosthesis users, function was also first, but it was followed by cosmesis and then comfort. These comparisons suggest that RP's and those with ULA do differ in what they value. However, they also show that there are differences amongst individuals with limb absence. Schultz et al (2007) suggested that the opinions of both prosthetic users and prosthetic experts should be consulted when studying the factors that affect prosthesis use and needs for improvement. They also argued that major contrasts between professionals' and user's opinions could indicate a lack of communication between both groups. Finally, they felt that it was vital that the needs of the population with ULA were understood in order for the health professionals' goals to coincide with theirs.

Van der Linde, Hofstad, Geertzen, Postema & Van Limbeek (2007) investigated the wishes and experiences of patients with a lower limb amputation using a cross sectional questionnaire with regard to prosthetic prescription and their exchange of information with the health care providers using a questionnaire. Van der Linde et al (2007) found a discrepancy between the patient's needs and what they experience in their contacts with clinical professionals. They compared their findings to that of Postema, van der Donk, van Limbeek, Rijken, & Poelma, (1999) who investigated prosthetic prescription and functioning with an upper limb prosthesis and concluded that the wishes and opinions of the patients did not match the opinions held by the clinicians. This study showed that the involvement of the patient was proportionate to the compliance of patients in relation to the use of upper limb prostheses. There was also no clear agreement between the wishes and opinions of patients and the ideas of the professionals about the compilation of prosthetic components and their functioning with the prosthesis. Therefore, patients did not use their prosthesis or there was disappointment for patients and professionals. These studies from the amputation literature, Mortimer et al (2004), Schultz et al (2007), Van der Linde et al (2007) provide further support that RP's and patients may differ in their perspectives.

#### ***4.1.4 The present study***

This chapter aims to use qualitative research to investigate the factors of importance in ULA. Due to the suggested differences in perspective, this study is incorporating both the RP's and individuals' with limb absence views on the factors associated with rehabilitation following ULA. The multidisciplinary team (MDT) was chosen as rehabilitation and prosthetic provision in patients with ULA is generally carried out by specialist MDT's involving prosthetists, physiotherapists, occupational therapists and rehabilitation physicians (Datta et al 2004). Both individuals with limb absence and RP's were chosen for inclusion in this study due to the evidence from health and limb absence research that health professionals and patients can disagree on the impact that an illness may have on a patient and on what is valued by the patient.

A qualitative approach was chosen in order to produce more in depth responses from participants and to allow exploration of unanticipated issues. Focus groups with individuals with limb absence were chosen as they provide opportunities to engage in the development and evaluation of health services for those service users who are often excluded from other forms of data collection (Kroll et al, 2007). It has been recommended by authors such as Mortimer et al (2004) that for exploratory studies such as the present one, it can be useful to use focus group methodology. Kitzinger (1995) suggested that group processes can help people to explore and clarify their views in ways that would be less accessible in a one to one interview. However, due to the busy schedules of RP's and the likelihood of dominant views occurring considering the hierarchies that exist within the different professions, it was decided to conduct face to face semi-structured interviews with the RP's instead of focus groups.

#### ***4.1.5 Aim of the study***

Due to the evidence that drawing on the perspective of both those with limb absence and the MDT is beneficial in disability research and specifically amputation research, the present study will conduct interviews with RP's and focus groups with individuals with ULA.

The aims of the present chapter are to

- 1) Elicit the factors of importance involved in the rehabilitation of individuals following ULA from the perspective of a) RP's and b) individuals with ULA.
- 2) Use qualitative research techniques to demonstrate the importance of researching the perspective of the RP and the individual with limb absence.

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Chapter 4.2.1 Method for qualitative study 1: Rehabilitation professionals**4.2.1.1 Sample**

A purposeful sample was used to recruit RP's for this study. Eleven participants were interviewed in detail using a semi structured interview approach. The only inclusion criteria for the present study were that RP's involved in various parts of the prescription and rehabilitation process working with individuals who have lost either an upper limb were eligible to participate in the interview. Participants consisted of five occupational therapists (OT's), three prosthetists, two consultants in rehabilitation medicine and one psychologist. Participants were from the UK, US and Europe. Participants consisted of seven females and four males.

**4.2.1.2 Materials**

An interview guide (see Appendix F) was prepared using eleven open ended questions. Questions were decided upon through literature reviews and brainstorming sessions with an advisory group. Questions were selected in order to best elicit the perceived outcomes and predictors of upper limb prosthesis use. To begin the interview and settle in the participant, they were firstly asked to detail what their job entailed. Interviews were concluded with participants being asked to discuss anything that was missed in the course of the interview. The same set of questions was posed for each participant. Semi structured interviewing allowed the opportunity to explore unanticipated issues that the participant raised. The first interview acted as a pilot but as no major changes were made to the questions, this interview was included in the final analysis.

**4.2.1.3 Procedure**

Ethics was sought and granted from Dublin City University Research Ethics Committee, and two of the participating hospital ethics committees for this particular phase of the study. Institutions were approached and permission was sought to interview staff. Eleven RP's from international institutions were approached via email (see Appendix G for content of email) and invited to participate in the interviews. Of these, two participants did not respond to the emails, a further two explained that they no longer worked with

individuals with ULA and three felt they had insufficient contact with ULA patients. Therefore out of the eleven RP's contacted, four of these participants took part in the interviews. Staff in one rehabilitation hospital were also approached and briefed about the study, and given an information sheet (Appendix H) by a member of staff in the hospital. Staff that were willing to participate in the study were asked to return consent forms (Appendix I) to the researcher. Five consent forms from those working with ULA patients were returned. All five RP's participated in the interviews. Two further RP's from a separate hospital were contacted directly and asked to participate in the study, which they accepted and they were subsequently interviewed. Interviews took place between August 2007 and April 2008. Interviews took between 30 and 60 minutes to complete.

When participants returned their consent forms or replied to emails sent by the research team, an interview was scheduled at a time and location convenient to each participant. Informed consent was also obtained from the participants prior to commencement of the interview. Nine participants were interviewed face to face. All face to face interviews were conducted in participant's places of work. For logistical reasons, two of the participants were interviewed via the internet using 'Skype' (a software programme which allows users to make telephone calls over the internet) to enable successful recording of the interview. The interviewer telephoned the participant from 'Skype' to their landline telephone. The interviews were audio-taped using an 'ipod' and 'italk', and were backed up using a conventional tape-recorder, with the permission of each participant. Following the interviews, the tapes were transcribed verbatim to facilitate analysis. The thematic analysis procedure was detailed in Chapter 2 (thesis methodology chapter).

#### ***4.2.1.4 Quality control***

Qualitative studies suggest it is crucial to ensure that the qualitative techniques have high standards of rigor applied. In order to check the coding and analysis of the focus group and interview transcripts, after the main researcher coded all the interview transcripts, an additional analyst, who was also a PhD student researching limb absence, coded one transcript randomly from the RP sample. There was a high degree of similarity in codes amongst the two analysts, which added to the validity of the first researcher's analysis.

However, the second analyst identified a few additional codes and these were used in conjunction with the initial codes to develop themes.



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### Chapter 4.2.2 Method for qualitative study 2: Individuals with ULA

#### **4.2.2.1 Sample**

Seven participants in total participated in two focus groups, with four participants in the first focus group and three participants in the second group. Four participants were interviewed for supplementary interviews. In total, participants consisted of seven males and four females. All participants had acquired amputations. Only ten out of the eleven participants completed a demographic questionnaire and one participant did not disclose their age. The mean age for the nine participants whose age was revealed was therefore 49.55 years (range: 21-72 years). One participant with below elbow amputations that was interviewed one on one, also had one below knee amputation and one above knee amputation. Mean time since amputation was 16.95 years (range: 1-48 years). Demographic information is displayed in Table 4.1. The names of participants in Table 4.1 are pseudonyms. Participants are referred to by these pseudonyms throughout the results section.

#### **4.2.2.2 Inclusion/exclusion criteria**

In order for individuals to be eligible to participate in the focus groups or interviews it was essential that they had major (i.e. through wrist and higher) upper limb absence; be over 18 years of age so they were legally able to consent for themselves; be at least one year post delivery of a prosthetic device; and have sufficient spoken English for the demands of the study, so that interaction can occur naturally within the group, without any need for interpretation. Those individuals with major psychotic illness; those currently receiving inpatient treatment for depression; those who were deemed suicidal; those with a severe head injury; those currently taking medication that severely impair cognitive capacity; and those who were deemed to have severely impaired cognitive or mental capacity, and were unable to give *informed* consent, were all excluded from the study.

**Table 4.1 Demographic information for individuals with ULA**

Names	Type	Age	Gender	Employment status	Reason for limb absence	Level of Limb absence	How often wear Prosthesis	Time since amputation	Pain
John	FG 1	59	Male	Retired	Trauma	Below elbow	7 days-10 hrs	7 years	PLP
James	FG 1	-	Male	Retired	Trauma	Shoulder disarticulation	7 days-all day	48 years	Occasional RLP and PLP
David	FG 1	59	Male	Full time employment	Trauma	Below elbow	7 days-16 hours	1 year	No
Andrew	FG 1	-	Male	-	-	-	-	-	-
Frank	FG 2	72	Male	Retired	Cancer	Shoulder disarticulation	7 days (shoulder cap)-always-apart from sleep	34 years	PLP
Paul	FG 2	21	Male	Student	Trauma	Below elbow	7 days-12 hours	1 year	No
Ann	FG 2	60	Female	Part-time employment	Trauma	Below elbow	7 days-10 hours	3.5 years	RLP and PLP
Elisabeth	Int	46	Female	Part time employment	Trauma	Below elbow	Social occasions	24 years	RLP and PLP
Catherine	Int	65	Female	Retired	Trauma	Below elbow	7 days –all day except sleeping	15 years	RLP and PLP
Jane	Int	29	Female	Full time employment	Trauma	Below elbow (also has below knee and above knee amputations)	5 days-14 hours	11 years	RLP and PLP and discomfort from prosthetics
Simon	Int	35	Male	Full time employment	Cancer	Shoulder disarticulation	7 days-11 hours	25 years	PLP

#### 4.2.2.3 Materials

The focus group topic guide was decided upon through literature reviews and brainstorming sessions with the research team. Questions were selected in order to best elicit the perceived outcomes and predictors of ULA (see Appendix J for interview guide). To begin the focus group and settle in the participants, they were first asked to introduce themselves to each other. Focus groups were concluded with participants being asked to discuss anything that they felt was missed in the course of the focus group. The same set of questions was posed for each focus group. A semi structured format to the focus group allowed the opportunity to explore unanticipated issues that arose during the group discussions. The first focus group acted as a pilot but as no major changes were made to the questions, this interview was included in the final analysis. The interview guide used the same questions as those outlined in the focus group topic guide.

#### **4.2.2.4 Procedure**

Ethics was sought and granted from Dublin City University Research Ethics Committee, and two participating hospital ethics committees for this phase of the study. Institutions were approached and permission was sought to recruit patients for participation in focus groups and potentially for interviews if required. Researchers didn't have access to patient files or names and addresses. Patients that met the inclusion criteria were identified through the database and contacted by post by hospital staff and invited to participate in the study. The letter of invitation (Appendix K) asked participants to read the information sheet (Appendix L) and to return the consent form (Appendix M) to the hospital if they wished to participate in the study. Participants' information was then passed on to the researcher. Participants that returned the consent form were then contacted by hospital staff or by a member of the research team to organise the focus groups at a time convenient to the participant.

#### **Focus groups**

Informed consent was obtained again prior to the commencement of the focus groups in the presence of a member of the research team. All patients from both focus groups were patients who had attended the same rehabilitation hospital and the focus groups took place in a room in the hospital that patients attended in February 2008. Participants were seated around a table to facilitate interaction. Before commencing the interviews, participants were asked to complete a brief demographic questionnaire (Appendix N). Most participants traveled independently to the focus group venue. Only one participant used hospital transport. All other participants were offered reimbursement for their traveling expenses. The focus groups and interviews were facilitated by S.N.M and assisted by another member of the research team, as recommended by Kroll et al (2007). The focus groups lasted approximately an hour for each group.

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#### **Interviews**

Additional participants were recruited from an Irish amputee support group, using a recruitment poster on the support group website (Appendix O). It was initially intended to recruit participants for further focus groups. However, due to limited responses, and

geographical spread of respondents, which would make organisation of focus groups difficult, it was decided to interview participants one on one. The interviews were conducted in order to supplement the data that arose from the focus groups. The interviews were conducted in the participants own homes except for one which was conducted in the interviewers home with the request of the participant as this was most convenient for them. All interviews were conducted by S.N.M, using the same sets of questions as the focus groups and were also tape-recorded. Interviews lasted between 40 minutes and 60 minutes and took place between April 2008 and July 2008.

The interviews were audio-taped using an “ipod” and “italk” and were backed up using a conventional tape-recorder, with the permission of each participant. Following the interviews, the tapes were transcribed verbatim to facilitate analysis. Data from the focus groups with individuals with limb absence and interviews with individuals with limb absence were analysed together. The thematic analyses of the interviews and focus groups are detailed in Chapter 2. The data from both the focus groups and interviews with patients were analysed together but are identifiable as either focus groups or interviews in the analysis.

#### ***4.2.2.5 Quality control***

The same methods of quality control were applied with the interviews and focus groups with individuals with ULA as with the interviews with RP’s. Namely, after the main researcher coded all the focus group and interview transcripts, an additional analyst (the same analyst as for the interviews with RP’s) coded one transcript randomly from the patient sample. Once again, there was a high degree of similarity in codes amongst the two analysts, which added to the validity of the first researcher’s analysis. A few additional codes were identified by the second analyst and these codes were used in conjunction with the initial codes to develop themes.

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### Chapter 4.3.1 Results for study 1: Rehabilitation Professional's

The questions asked to RP's in the present study were developed in order to elicit what issues need to be considered after ULA and what constitutes success following ULA. The particular quotations chosen were considered to best express the relevant theme.

#### **4.3.1.1 Prosthesis use**

Initially, most RP's vision of a participant 'doing well' referred to the prosthesis with some RP's specifically suggesting that wearing the prosthesis if given one, was favourable.

P7 (Prosthetist): *"If someone is doing well they will come in wearing their arm"*

However, many of the RP's did not rely purely on the patient's verbal report of whether they wore their prosthetic limb, but instead on the appearance of the prosthesis, which will reflect whether it is being used. This implies that self-reported use is not as important to RP's as objective evidence of use of the prosthesis. The need to ascertain how the prosthesis was used by the participant was also considered important.

P5 (OT): *"you know you can look at the state of it, if its pristine then you know they don't (wear it) but yeah you'd want to know how much they actually use the current prosthesis they have got em and you probably want to know what kind of things they use it for...what they use it for you know whether they actually functionally use the prosthesis for particular activities or whether you know they are just wearing it and its there"*

P5 (OT): *"em how do you determine they are doing well, they come in with a dirty prosthesis, need their gloves changed frequently, that is a bit facetious really but there is probably an element of truth in that em I think I think eh yeah yeah I mean it will be down to how much you perceive them to be using the prosthesis and how kind of like some people come in and they will be very focused on the prosthesis and what it can do and what they need to get from it in purely functional terms"*

The RP's also implied that they are satisfied if the patient is using the prosthesis as intended. For example, for patients who have been prescribed a functional prosthesis, it is essential that it is used functionally. However, for patients who wear a cosmetic prosthesis, it is sufficient that patients are satisfied with the prosthesis.

P7 (Prosthetist): *"its kinda a hard question because you know immediately if they are doing well and if they come in and they have got a myo-electric arm and come in and they are using it normally to do whatever em open their bags up whatever then you would see they are doing well em but then if someone was coming in wearing a cosmetic arm that doesn't do anything but you would still say they were doing well if they were happy with it"*

However, it is also acknowledged that prosthesis use is individual to each patient.

P5 (OT): *"it kinda relates to the whole idea about usage you know what how you define you know how well somebody uses the prosthesis is it you know is it you know a quantitative thing they get it out every day and use it every day or is it or they are happy with it and they have got it and they know its there if they need it sort of thing so I don't know so its very individual."*

Although not the focus of most RP's discussion of prosthesis use, it was also alluded to that the prosthesis can also be considered a method through which one can achieve their goals.

P5 (OT): *"they're kind of looking at their particular needs and what and how a prosthesis can meet those particular needs"*

In contrast to most RP's beliefs, one participant suggested that they feel a patient has more successfully adapted to their limb absence if they do not wear a prosthesis.

P11 (Consultant): *"...em I consider people going about very freely without a prosthesis, that's a well adapted person that's a person who has adjusted to not having an arm on that side and just working with one arm..."*

The above comment is reflective of his general view as overall, this participant was more concerned with psychological adjustment than prosthetic or functional restoration.

#### 4.3.1.2 Goal setting

Goal setting is essentially considered a critical precursor to successful achievement of and desired outcomes in the rehabilitation setting. There was a suggestion in the interviews with RP's that patients and RP's may have different opinions on what activities are necessary to achieve post amputation. An OT also acknowledged that while patients may be concerned with returning to their previous roles and employment, the RP's may have different concerns.

P1 (Psychologist): *"I think I think a lot of that goes on the goals they have set themselves and goal setting tends to be a big thing that is used generally in rehab so you know what we might think of a patient's progress would be might be very different from what they feel themselves em you know for example if they are able to if their goals are to be able to hold their cigarette or you know to be able to hold their own cup of coffee or whatever and they achieve that by using the prosthetic limb then that to them would be progress em we might see that they can do more with it but in terms of what they want themselves if they have achieved their goals and they are happy"*

P5 (OT): *"they might be always looking you know that bit higher at like I can get myself dressed but I need to be able to you know get my role back as bread winner and you know I think that would probably you know reclaiming their sort of original roles for an amputee patient I think that would be quite high up you know a value of if the success of succeeding which I might not necessarily I would be considering as a longer term goal but they might be considering it as a shorter term one"*

For this reason, it was considered vital that RP's and patients work together in the rehabilitation phase.

P10 (Consultant): *"...discuss it with the person themselves what their needs and wishes are because there is no point us setting goals which for us seem reasonable but for the person might seem unrealistic or pointless they have got to want to do it so we have got to try and take them with us we are you know for whatever we are"*

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*going to try and do for them we have to try and explain it and take them along with us and set reasonable goals which they can hope to attain that we can hope to attain”*

RP's added that a patient's motivation to achieve the goals is a key factor in whether the goals are achieved.

P10 (Consultant): *“if they had a very strong desire to do something that they couldn't do with the prosthesis they had then certainly would give that (upgrading their prosthesis) strong consideration...”*

P11 (Consultant): *“... those who are motivated, and adjusted have come to terms and are coping will want to get back to work quickly, those who aren't will not may not at all but if they say they do, they will make excuses and two years later they still haven't or tried it or even come up with thoughts about how they may achieve it they are not coping well or adapting”*

Patients having goals in their mind about wanting to return to pre-morbid quality of life to some extent, was considered an key factor in achieving what RP's consider rehabilitation success.

P1 (Psychologist): *“I think people who do better tend to be people who have very clear ideas of wanting to get back to quality of life again so if they have goals in their mind if they have thoughts about you know wanting to get back to work or getting back to functional tasks like walking or driving or work or whatever...”*

Ultimately, it appears that the existence of goals at the beginning of rehabilitation, the maintenance of these goals and their achievement will embody success following limb absence rehabilitation.

P9 (Prosthetist): *“if you achieve the aims you set out in the first place to do then yes its satisfactory yes”*



#### 4.3.1.3 Function (*incorporating activities & participation*)

A patient's ability to perform activities of daily living (ADL), especially their own personal care, and engagement in life activities, such as leisure activities and return to work, were all repeatedly mentioned as vital markers to "doing well".

P2 (OT): *" well I I don't know if they (pause) I think they have a sense of doing well as well as they can I think that would qualify as well because I think people carry around em issues related to limb absence for a long long long time I don't think it goes away but I think that they make an adjustment em and that's what we would call doing well they move on they are engaged in their previous interests em they're working or they're eh participating in family life I mean those are the things that I think reflect a degree of adjustment that we would hope for but I but I again I think its as well as they can em and I think it may take a lot of years before people eh say that they are doing well"*

Ability to perform Activities of Daily Living (ADL), incorporating personal care was considered by most RP's to define normality, and thus believed that patients should be able to perform these activities following successful rehabilitation.

P6 (Prosthetist): *"... probably getting their life back to what they would class as some form of normality em so be able to do everything that they have got to be able to do on a day to day basis whether that's with or without an arm so you know your general getting up, washed, dressed, cook, clean you know from that point of view just living you know just getting day by day getting everything done at a level that you feel comfortable"*

It is also recognised by RP's that it is fundamental for many patients that they achieve the ability to drive, as driving has a key role in giving the patient independence.

P8 (Prosthetist); *"em important outcomes getting a back to normal life em being able to do the job you were doing before hand em being able to drive being a bit independent em cause clearly driving is an issue for a lot of people em"*

It is also vital that patients are able to independently perform activities that are personally valued by the individual patient, especially personal care activities.

P6 (Prosthetist): *“not getting too much help from people because I think that that’s another thing that sometimes gets people down do you know everyone wants to help them do things but then they never learn to do things for themselves”*

P11 (Consultant): *“... its no good getting people to help you, you have got to do it yourself so that people who say they need help, they need carers they need their wife to shower them, they need their wife to put their shoes on, they are not doing well, there are ways to do that because we know that that can be achieved all other things being equal, em alone and independent...”*

An OT added that a valuable method of measuring whether a patient will be able to perform activities of daily living is through testing their ability to perform OT tasks.

P5 (OT): *“I would probably do a kind of assessment on them carrying out particular tasks that I’ve got a box that I use with activities like em opening up purse taking money various other things you know cutting paper and stuff like that so I would probably do that and just get an idea of how well they can use it functionally”*

As well as an ability to perform ADL, engagement in social and leisure interests were deemed markers of doing well for patients by RP’s.

P4 (OT): *“em so I think that the patients judge if they are doing well how they are em doing well socially if they have eh network of friends if they have nice house successful in terms of family or work I don’t think they judge doing well only by the prosthesis”*

P10 (Consultant): *“...em if they are able to pursue their leisure their work, their driving all those sort of interests you know what appears to us to be a reasonable upper limit of possibilities then em you know I would be quite encouraged...”*

Additionally, performing activities was not considered to be of sole importance to participants, regaining roles that had personal value were desired goals for many patients following rehabilitation.

P6 (Prosthetist): *“you know in terms of their roles and values because the majority of adult amputees you know probably have had a kind of working role at some point and obviously financial gain then so them getting back to work then or getting back to some kind of employment some kind of income em is probably, they would probably value that”*

However, linked to roles such as breadwinners, was returning to previous employment or new job as these are often key goals for many patients to achieve.

P8 (Prosthetist): *“...get back to job they were doing previously then I would say the patients would think that was quite a success for them...”*

One of the consultants interviewed also mentioned the significance of ascertaining the patient's pre-amputation occupation in order to tailor the rehabilitation to enable them to return to their job if possible.

P11 (Consultant): *“...in particular about their work because that's so important you know, what they actually do, the nature of the work, how manual it is or other wise is very important when determining whether they will be able to return to the same occupation or not in the future”*

A person's ability to do whatever they wish, regardless of whether the prosthesis was used is considered the most successful end result of rehabilitation following limb absence.

P4 (OT): *“and to me the most important outcome of me working with persons with upper limb deficiencies or amputations is that they feel they can live a full life whether with or not a prosthesis”*

Also, RP's considered it essential that patients are always trying to do better and are progressing within their capabilities.

P6 (OT): *“... achieve higher goals then I would view that as them doing well em because they are obviously happy at the level they are at and then seeking to achieve higher so that's what I would probably use as a guideline “*

P10 (Consultant): *“em if basically if they are progressing as one would hope I mean if they are hitting what we would think you know professionals would think to be reasonable goals but also if they're hitting goals that they you know want to be able to attain...”*

#### **4.3.1.4 Psychological factors**

Many RP's referred to the patient's psychological state as important to attend to following ULA, either as an important facet of an individual's wellbeing or as a potential predictor of further outcomes such as prosthesis use. Many RP's also referred to the fact that an upper limb amputation tends to arise out of a trauma and that this may be important in affecting the individual's psychological state and thus emphasizes the importance of attending to issues such as origin of limb absence in order to successfully rehabilitate a patient.

Several RP's from different professions, considered it crucial following ULA that patients were happy with themselves and their functional abilities.

P7 (Prosthetist): *“I think they think they are doing well when they have, when they are happy in themselves with what they can do at whatever level they have decided”*

P10 (Consultant): *“their mental health I suppose I mean how do they feel happy with things or are they concerned do they feel they are underperforming those kind of things”*

It was considered necessary that the patient returned to a feeling of satisfaction with themselves and their life.

P6 (OT): *"...but I would say getting back to a level that they were happy with in themselves..."*

It was also discussed how in order to adapt well to the absence of a limb, low levels, of anxiety are essential, as well as acknowledging the role life experiences play in adapting to the absence.

P4 (OT): *"some persons are more em stable and not em not so anxious not so concerned their looks and they are comfortable in their daily life they have friends and family and they have perhaps have seen amputations perhaps they have seen if its a family and they have a child with a limb deficiency and perhaps they have lived on the country side and they have animals... sometimes nature goes wrong"*

Particularly, certain causes of amputation may affect an individual's psychological adjustment to limb absence with traumatic causes tending to be the most difficult to adjust.

P6 (OT): *"I think it would depend on why the reason behind the amputation and how you know open they were to taking on information at that time"*

RP's suggested that the cause of limb absence can affect an individual's adjustment to limb absence, because very often people who lose their limbs due to trauma, may also have to deal with the loss of a family member or a friend.

P5 (OT): *"I think the circumstances of how they came by their amputation as well whether it was you know an accident at work or a road traffic accident or whatever it was you have to look at that as well because I think that that really does affect how people their kind of final outcome if you like is affected by how they came by their amputation... I can think of some people that we have had who have been in road traffic accidents where there has been other people involved who there has maybe been fatalities or whatever so as well as having to deal with the actual amputation and whatever kind of physical injuries they receive they're having to deal with you know the kind of psychological trauma of that as well ..."*

P1 (Psychologist): *"...I suppose the other thing I would say about upper limb users as well is that because its very often a traumatic cause of an amputation there*

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*tends to be a lot of issues of loss and bereavement around for them too and another part, a big big part of the work we do is working with the loss factor em you know, not loss of their of their limb but also loss of their maybe their dependents or it could be loss of their job or it could be loss of their you know where people have lost limbs in road traffic accident where other members of their family have been killed so very often its a double loss or a multiple loss for them so bereavement and loss tends to be another thing that very often has to be worked through with upper limb users"*

Therefore, for those who have lost their limb in traumatic accidents, they may first need to deal with post traumatic stress before they can tackle their rehabilitation.

P1 (Psychologist): *"but it does tend to be the more sort of traumatic victims that we would see and em therefore you do have to make a judgment as to whether they are psychologically ready or not and we would do that just by a combination of interviewing them em and looking at you know like the the trauma questionnaire to see whether there is anything outstanding in terms of posttraumatic stress symptomatology. If there is we wouldn't necessarily say no you are not ready for it but it might be something we would want to work on before hand..."*

Additionally, mood was suggested to be a potential predictor of rehabilitation success, implying that individuals with positive mood will have subsequent successful outcomes.

P1 (Psychologist): *"I think mood has to be the main one (outcome) because if your mood is good you know you are able to delve into your coping strategies much much more effectively"*

One RP felt a patient having a pleasant mood enabled them to integrate socially and was potentially more valued than other goals such as returning to work.

P11 (Consultant): *"...em I think that my main concern is that a patient adapt as necessary to their new situation and remain in a good frame of mind as opposed to being em depressed...if a patient fails to be able to work but nevertheless remains as it were happy or you know apparently happy and contented or actually happy"*

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*and contented thereby being pleasant to be with, fitting in well socially then that I think is more important than a person even getting back to doing some practical things but remaining morose and discontented and moody and irritable and frustrated and angry..."*

Additionally, it emerged that there are certain elements that the RP's may look for in an individual before proceeding with the fitting of the prosthetic limb, such as having a stable mood, being motivated, and not having depression or posttraumatic stress disorder.

P1 (psychologist): *"...so essentially I suppose I'm looking for someone whose mood is fairly stable, em who has goals in their mind em as to what they would like to achieve by by using a prosthetic limb em cause obviously if they don't have clear goals in their mind as to what they want to do it is much more difficult to rehabilitate them and get them the motivation to actually use the limbs because all of them would say that using upper limbs is much more difficult at times than actually using a lower limb prosthesis, it requires an awful lot more mental and physical effort em I'm led to believe anyway, so you know so I need to make sure that em they are well enough motivated that their mood is reasonable that they haven't got any outstanding depression or post traumatic stress symptoms or anything like that and if all that is clear and good family support and if they themselves want to wear the limb or want to think about wearing the limb then we generally go ahead and provided the medical criteria were fulfilled".*

It was recommended that if patients display any psychological issues, then these issues should be dealt with before the fitting of the artificial limb. As discussed previously, psychological issues may particularly occur with individuals with ULA who may have lost their limb due to trauma.

P1 (psychologist): *"I haven't come across anything (that would stop recommending someone be given a prosthesis), however, em if for example em I was talking to somebody and em in the course of the conversation it turned out that they were currently suicidal, em then we probably would you know say at the*

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*minute probably em you are not ready for this yet, we need to work through this particular crisis that you are having before you might be ready for rehab..."*

Individuals who have suffered from psychological problems in the past are also considered to be at greater risk of having difficulty adjusting to limb absence and prosthetic use.

P1 (psychologist): *"...I think that if somebody has a history of psychological problems pre-morbidly before their amputation it can be a bit more difficult for them to adjust to an amputation never mind using a limb.... "*

It was also mentioned that on certain occasions patients can dislike their prosthetic limbs which can hamper their acceptance of their prosthesis.

P10 (Consultant): *"...you know have a sort of a mixture of feelings maybe a love hate relationship they need it but they hate. And its you know its an obvious target for any sorts of problems the person is having and you know we do see people who have mental health problems personality disorders who you know will occasionally take out there feelings reactions or whatever on the prosthesis, being the most obvious kind of target..."*

RP's felt that in order for a patient to be ready to receive a prosthesis, it is essential that they have accepted their limb absence, which they asserted involves dealing with any outstanding issues the patient has, such as body image concerns, or any denial in relation to the limb absence and that they are focusing on their future.

P6 (OT): *"...I think you have got to...you know have dealt with what happened and have moved on from it not necessarily to have accepted it you have got to at least have addressed it"*

It is believed that in order for a patient to be able to adapt to using a prosthetic limb, it is important to assess whether they have the ability to cope with the lifestyle change that using a prosthetic limb involves. It emerged through the interview that this is not always assessed through formal testing but by "common sense" on behalf of the prosthetist.



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P9 (Prosthetist): *“whenever you meet a patient em you you assess their cognitive function as you are doing an assessment of them em you know you can be assessing this stump and em em things like that and you are getting an idea of how you think they would cope with with a limb because its not simply you know it should become second nature like brushing your teeth, putting on a limb and taking it off in the evening it should become second nature ...”*

Within this, the effective coping strategies that they will delve into need to be nurtured in order to cope with any difficult issues that may arise for them related to the absence of a limb.

P1 (Psychologist): *“as well em I think you know a good repertoire of coping strategies as well is quite important so that they are able to you know have a positive self talk on days when they are feeling a wee bit low or discouraged they have good cognitive strategies that they can tie into that you know can help to em improve or stabilize their mood and that they can help them access help if they need that”*

A patient’s rehabilitation expectations can potentially impact on achievement of further rehabilitation goals. For example, there is often a discrepancy between what patients expect an artificial limb to be like and what it is actually like and this can lead to disappointment on the patients’ behalf when they receive their prosthesis.

P6 (OT): *“often what their expectation of what an arm is and what is the reality and I think they don't always weigh that up and as much as we are very clear they only hear what they want to hear you know if because all they want is the arm back and I think that sometimes is difficult because you know if they have not come to terms with actually losing the arm then what their expectation of a cosmetic arm or you know a artificial arm is isn't gonna meet up to cause they just want their arm back”*

The role the media plays in shaping patients' expectations was mentioned and how this can be responsible for creating unrealistic expectations of what users can expect from a prosthesis.

P5 (OT): *"as well as the purely physical factors I think you need to look at what you need to find out what the patients want what the expectations are what their knowledge of a prostheses are, cause quite often people come in they have never had any experience of prosthetics before no understanding they might have seen something on telly and think they can get a bionic arm right away. So you have to kind of judge what the patients expectations are em and sometimes you might have to kind of gently explain to them that they are not going to get an arm that is gonna replace their you know original hand and that yeah sometimes you have to kind of you know help the patient understand that their expectations are not necessarily going to be met by a prosthesis"*

Although patients are often disappointed by high expectations, sometimes they have low expectations and are unexpectedly satisfied by the technology of the artificial limb.

P8 (Prosthetist): *"em unfortunately some new amputees come expecting em robotics and arms like Luke Skywalker got when he lost his arm in Star wars and its just not like that... eh the harshest thing for somebody is to come in and realise that actually it's not robotics and they cant feel the glass that they are picking up... think a common conception is that that is what its like and certainly the press don't realise what people are seeing, they are very positive which is good but the press produce things that aren't quite available yet ...for example its great it does all these things but its not quite available yet but the press never say its not available yet em so yeah I think that's part of it and also you sometimes get patients that come in expecting hook like captain hook and then you give them a cosmetic arm that looks quite nice and they go wow that does look like my hand that's great so em there is that side of it as well"*

#### 4.3.1.5 Physical factors

Two physical issues were discussed by participants in relation to how they can potentially interfere or affect the subsequent goals the individual wishes to achieve. These were the level of the amputation, and an individual experiencing some form of pain. Only one RP addressed the issue of the level of the amputation and the effect this can have on successful prosthetic use. The RP's view was the higher the level of amputation the more difficult it will be to use the prosthetic device.

P8 (prosthetist): *"...em perhaps the higher levels of upper limb prosthetics become a lot more difficult to use and things but generally well what we'll do is give people a shot with the limb to start with most people will get one and then sometimes sometimes afterwards they may decide actually its too much and they don't like it particularly at the higher levels of amputation em transhumeral, shoulder disarticulation, forequarter and things like these are quite high levels of amputation for people and the arms that they get can be quite em cumbersome so em but generally I would say most people would definitely get a shot at having one and see how well they progressed and then we can perhaps move the prescription on a little bit to something perhaps a lot more functional than the initial hand we would give them".*

The same RP also went on to clarify the importance of maintaining certain joints for the patient where possible and the difficulties that may arise for patients who do not have major joints such as the elbow or the shoulder joint.

P8 (prosthetist): *"level of amputations em I suppose eh some levels of amputations are better clearly if you go below the elbow its better if you go through the elbow it's a disaster its very difficult to make something cosmetically out of that..."*

Additionally, a few RP's discussed the role of significant health related co-morbidities such as pain that can interfere in a patients rehabilitation and their ability to use a prosthesis and this emphasises the importance of RP's ensuring individuals have a minimal amount of pain during rehabilitation and beyond.

P10 (Consultant): *"...minimizing their pain I mean again if you are in more pain before your amputation it is believed that you are more likely to get phantom limb pain that sort of thing so explaining those kind of things eh that's another thing I didn't mention is you know phantom limb sensation or pain stump pain neuromas those kind of things can cause difficulties for people em and some people find more pain when they wear their prosthesis or less when they wear their prosthesis..."*

P1 (Psychologist): *"I think having the minimal amount of phantom pain is important or pain that they can control themselves I think that tends to be a big outcome for a lot of people..."*

#### **4.3.1.6 Social Factors**

Social factors, such as the patient's family and friends providing support are believed to play a role in influencing a patient's adjustment to ULA.

P5 (OT): *"social networks again, like the social support people have before not got much in the way social support ah yeah I think the support of other people makes a huge difference as well"*

In particular, it needs to be considered how a patient's family may react to the prosthesis as this can influence whether the patient will use the prosthesis.

P2 (OT): *"em if the arm is not if its limiting their social em adjustment or their family adjustment I know I have a patient whose little girl just she despises his artificial arm"*

Several RP's mentioned the practice of introducing patients to another patient as beneficial to those individuals who have recently lost their limb, especially introducing them to an individual who has accepted their absence and perhaps has mastered the use of their prosthetic limb.

P1 (Psychologist): *"em I think I think meeting another patient in a similar set of circumstances can be very very important em I think you know if if the patients is matched in terms of not sex maybe age, em you know level of injury that sort of thing I think that can be very very beneficial particularly if the patient that we are*

*introducing them to is a very positive role model and is able to effectively use their limbs that they've been given em I think that can be really a very helpful thing"*

P8 (Prosthetist): *"meeting other amputees in the same situation as them is always good em they are able to see that there is life after amputation for some people and for the majority of people it is the worst thing that they can imagine happening to yourself and if you see somebody who is in the same situation as yourself getting on with their life and going to work and having a boyfriend or a girlfriend then meeting somebody in that situation I would say is probably really a really good thing if they are really struggling with the fact that they are now an upper limb amputee for sure"*.

#### **4.3.1.7 Satisfaction with prosthesis**

RP's in this study placed value on satisfaction with most aspects of the prosthesis such as the aesthetics and comfort of the prosthesis.

P1 (Psychologist): *"...obviously if the limb was comfortable and if it looked well and they were happy with the look and the feel of it then that again would be would be progress"*

P11 (Consultant): *"...there are so many aspects to a prosthesis and one is comfort you must have that..."*

Additionally, RP's suggested that the prosthesis should be doing what it needs to be doing and not breaking down.

P5 (OT): *"em well I mean I suppose in terms of the functional prosthesis that if they get a functional prosthesis I would want them to be able to subsequently be able to operate the prosthesis em and there would be no point in them having a myo if they couldn't actually operate it they couldn't open the hand so they would need to you know be physically able to operate the prosthesis em so yeah I mean purely practical physical terms I would want them to be able to operate the prosthesis and it to be able to demonstrate that they can use it in particular tasks whether they do then subsequently in their day to day lives do that or not I don't*

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*know and I don't know if that's for me to decide you know or to judge them on but yeah we would want them to be able to demonstrate to me that they could let's say operate it"*

P2 (OT): *"I think prosthesis working well is important too that piece of it because I think when it acts up and they can't make it do what for instance it did here in our clinic I think that's a frustration that makes people feel like they aren't doing well and I think the reliability of my myo-electric devices is a big issue for this because it always comes back to I'm not doing well when in fact it's the robot that's not doing well"*

P10 (Consultant): *"...em you know if the prosthesis is doing what they want it to do..."*

Particularly, it was considered that it is vital that the prosthesis is working well, as then the patient will not be worrying about the prosthesis.

P8 (Prosthetist): *"being able to get on with your life without having to worry too much about the prosthesis that we provided them with cause having to worry about and fiddle about with things then that's not been a very good outcome for them"*

P5 (OT): *"em probably if if they were coming back and you know if fittings or em you know for check up appointments and not coming up with problem areas"*

Elements particular to the prosthesis such as prosthesis breaking down and the weight of the device can have an impact on whether the prosthesis will be used and whether the patient will successfully adjust to the limb absence.

P2 (OT): *"oh yeah if if people's lifestyle changes or if they have a lot of issues with breakdowns or problems with the prosthesis that they have or if they are constantly breaking the hand tearing up the cosmesis em and it appears that they need something more durable or if it appears that they need something more"*

*cosmetic if they have overuse issues with their other extremities might want to look at myo-electric versus body powered”*

P7 (Prosthetist): *“I think weight is a big reason I think there is a lot of the upper limb amputees have been around a lot longer than I have been doing upper limb work and most of them tried myo-electrics in the past and have given it up for em cosmetic arms and an awful lot of them were congenital amputees and they just prefer cosmetic arms and they wont go out without one em and I think myo-electric is so heavy for the benefits you get from it”*

#### **4.3.1.8 Satisfaction with Service**

RP's were specifically asked if they felt the fitting service could be changed to improve patients' satisfaction with a prosthesis. Sub-themes emerged around the areas of 'access to services' and the 'rehabilitation process'.

##### Access to Services

The initial suggestions from several participants consisted more of issues regarding accessibility such as traveling distance to services be reduced for patients if possible.

P5 (OT): *“I think the sheer geographical distance that they have to cover to get to the service is an issue but then I don't know what else you can do I don't know what the kind of solution is to that em whether you have lots of little centres with people with very little experience or whether you have very experienced people in a few centres”*

Also, suggestions were made such that, having every member of the rehabilitation team in one location would make traveling to the services easier for the patient.

P2 (OT): *“em I know that here its the em chain the treatment chain for these patients its sort of complicated in that the prosthetist may be across town the therapist is on the east part of town and the doctor is in the north part of town and I think that makes it very challenging for people to get there just there services much less than make it work so I think I think it's the best possible scenario is all the people that are working with this patient are in the same place”*

Additionally, recommendations were made regarding having a good walk in service so patients can see their prosthetist when the need arises. Having a good appointment service was also considered essential, as well as reducing the waiting room times.

P10 (Consultant): *“eh we have a walk in service we try and make it as accessible as possible I mean if someone has a major problem they can potentially walk into the centre and say look I want to see my prosthetist...”*

P10 (Consultant): *“...making sure you have got good administration good appointment services making sure you have got lines of contact to the person you know up to date phone numbers and addresses...I think all of the staff are you know pretty open and approachable and if someone has a problem we will do our best to sort it out as quickly as we can em...”*

P4 (OT): *“but here locally we its a constant issue we try to improve the service in terms of em how long they need to wait when they come here, the wait in waiting room before they have a final prosthesis fit of the prosthesis and we em the service how we meet them how we address them*

#### Rehabilitation process

Several specific suggestions were made that related to the rehabilitation process, and one consultant recommended that it can be beneficial for a patient to have a consultation with the rehabilitation consultant early on, even if they are not yet ready to be fitted with a prosthesis.

P11 (Consultant): *“...of course because although some people some referrers will delay their referrals until they think the patient is ready for the prosthesis with the wound fully healed em I certainly think its advantageous to the patient to come and see us early to talk over with us their situation em to find out em what their potential is for wearing prosthesis, find out about the prosthesis, to ask questions, and eh I think that if they come quite early even if they aren't ready for a*



*prosthesis or for a cast particularly at that stage, I do think that's beneficial often to the patient rather than waiting"*

The consultant elaborated on this point when he recommended that communication should take place with the patient about the different treatment options and the implications of using a prosthesis.

P11: (Consultant) *"...but I think it is important to explain fully to the patient at the outset, the pros and cons advantages and disadvantages benefits or other wise of a prosthesis em again who does that discussion and who does that explanation is important..."*

Having other people present during the consultation was also recommended both for the benefit of the consultant and the patient.

P11 (Consultant): *"...I very like our occupational therapist to be there as well for some of it...but if she comes in in the beginning we can both talk to the patient and eh I think it probably helps the patient a lot and helps the whole process if more than one person our side and also more than one person on their side it was very helpful for the person to bring a relative or friend as well..."*

Patients seeing the prosthetic limbs early on, before they are ready to be fitted, can prepare them for what they should expect from their prosthetic device when they receive it.

P1 (Psychologist): *"...I think preparation is also very important and what we would try do here is to get them down you know so they could see the upper limbs em long before they are actually going to be using them so they can see what they look like so they can psychologically prepare themselves cause obviously the first time you see a limb its not a pretty thing necessarily ....and if your not your prepared for that it can be a big shock so on the assessment day even though we are not fitting them or even casting them necessarily at that stage we will take them along to meet the prosthetist and he or she will show them the sorts the sorts of limbs that they may be thinking about for them so they can have an idea of what they are going to look like and what they are going to feel like and what they are actually going to be able to do for them "*

RP's recommended a MDT approach which involves all providers working together for the benefit of the patient.

P5 (OT): *"em yeah I think I think a team approach works better..."*

RP's highlighted the benefits of having different members of the MDT available. They also added that it is essential the rehabilitation team do their job to the best of their ability in order for the rehabilitation to run smoothly and this includes having a skilled technician making the prosthetic limbs.

P8 (Prosthetist): *"eh em doing my job to the best of my ability and providing them with the best prosthesis that I possibly can to do what they want it to do eh inform them of what we are doing and why we are doing it and that kind of thing and I would always imagine that it would be reassuring if they are confident that I knew what I was doing em eh so or they knew what was going to happen or what might happen to them in the future and that kind of thing so"*

P11 (Consultant): *"...the standard of fitting is important the skill of technician doing the fitting is important..."*

The role of the OT as a valuable member for the team was also repeatedly mentioned by OT's themselves as well as the other team members, emphasizing their important role in rehabilitating the patient. It was also mentioned that the OT's need more input into the patient's rehabilitation.

P5 (OT): *"not always (see the patient if the prosthetist is seeing them) no, that I mean that is something that I want to look at that I basically want to change because I think at the moment there's are alot of people that are getting missed by an OT that are must have OT needs"*

P7 (Prosthetist): *"I don't know if we could I don't know if we have enough input from the OT's in the early stages"*

One OT described how she felt her role was viewed by others versus how she defined her role.

P5 (OT): *“yeah you know I mean I will quite happily talk about well not happily but I will talk to people about the circumstances of their amputation but I think a lot of people they see the OT as having a very practical role about providing equipment or whatever em and they're not that prepared to you know, some people are some people will open up you know quite freely and talk about their amputation and what kind of issues they are having dealing with it and other people I think that they think that that's maybe that's not my role to do that to look into that”*

P10 (Consultant): *“...occupational support em the occupational therapist obviously are very important and they will help the person hopefully learn what they can and cant do and adapt to the situation the whole of the team the prosthetist I mean we all have some input to that its not just any one person specifically, family support as well”*

Finally, psychological services were also considered essential for patients in general in order to help them deal with any issues that may lead to maladjustment or interfere with their rehabilitation. However, it was acknowledged that the resources may not be present in all facilities to provide this service.

P6 (OT): *“so maybe more clinical psychologists on site”*

P5 (OT): *“... need more psychologists definitely”*

P10 (Consultant): *“...em if you have the option then counselling before they have the amputation although that often isn't possible...”*

P1 (Psychologist): *“I certainly think being introduced to psychological or counselling services at an early stage is important you know because if you have you know outstanding psychological issues be it absence or bereavement or depression or just you know trauma then all of those factors can impede your progress and everybody at the clinic and least let people know can try to tell them*

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*that that is normal and certainly validate that at an early stage that that is normal then em you know I think that does make a difference"*

A strong theme running through the interviews was that of 'choice'. It was commonly emphasized that the patient's choice is the most critical factor when deciding if someone is ready for a prosthesis or whether they will get a prosthesis at all and they can decide this at any stage in their rehabilitation.

P1 (Psychologist): *"eh generally it would be the patients own decision themselves and we certainly we have had a number of people that I can think of who have gone through had their upper limb fitted and have gone through the training and then have opted not to wear it em that has happened a number of times and generally that would be because of either the amount of physical effort that's involved in it or simply because you know its not you know comfortable or its just too cumbersome for them".*

A patient's sense of control over the situation was also considered valuable to consider.

P10 (Consultant): *"...em also their coping you know have they got a robust coping type personality...very major mutilating horrible experience to go through and you know its coming back to you know locus of control kind of thing do they feel that they have some control over where their future lies what they are doing or do they feel they are being buffeted around by fate or what did they do to deserve this so those kind of factors basically and how we support them as well I mean we do our best but you know it's the bottom line its down to the person themselves"*

RP's stated that it was ultimately the patient's decision as to whether to receive a prosthetic limb. The RP's recommended that rehabilitation is pitched at the patient's pace and that the patient is in control, in order to help regain their possible lost sense of control following the absence of their limb.

P6 (Prosthetist): *"the thing is almost doing it at the speed they want doing it at and not pushing someone people will come to terms with it when they are good and ready and its almost trying to be patient and not not forcing your view on them and*

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*not forcing them in to treatment that's not what I mean but not putting pressure on them saying right you need to get a limb fitted now cause you know they're not maybe not ready but also taking on board they might they might think well if I get the arm its gonna be fine and you sometimes got to roll with that knowing that do you know they're not maybe ready for it"*

P6 (Prosthetist): *"em but its almost pitching it at the individuals level you know when they're ready for things and letting them take the responsibility usually because you are not always given the choice of whether you are gonna get your arm amputated you know if its a trauma that decisions been made without your sort of control so therefore some people just want that control back by saying I want the arm when they are maybe not ready to deal with they have not dealt with the amputation yet but you've sometimes gotta go with it em so its probably pitching it their pace and like giving them time to adjust to things"*

#### **4.3.1.9 Summary of findings**

A large value was placed on the use of the prosthesis by RP's in the present study, with several participants judging a patient as 'doing well' by evident use of the prosthesis. Many RP's described the value and importance of goal setting in rehabilitation and especially the need for RP's and patients to work together to achieve the goals of rehabilitation. RP's placed a particular emphasis on an individual's ability to perform their own personal care, and most importantly independently from other people. Additional activities of importance mentioned were work and leisure activities. The discussion of psychological factors was broad, with participants discussing the need for absence of psychological distress, such as anxiety, depression and PTSD, in addition to the presence of positive psychological traits such as a favourable mood, as these elements were important for general wellbeing as well as influencing subsequent rehabilitation goals such as prosthesis use. Additionally, the role of factors such as cause of limb absence, especially trauma and how it related to psychological difficulties was mentioned. Physical factors were only discussed briefly, suggesting that the level of limb absence can make prescription of prosthesis more challenging and that minimal pain is essential for an

individuals well-being. RP's also suggested that family and friends play a key role in facilitating adjustment for individuals and meeting individuals with limb absence can be helpful in some cases. Several participants felt that aesthetics, comfort, and reliability were important aspects of prostheses to improve. Lastly, service related factors of access and the rehabilitation process suggested that OT's need a greater input into the rehabilitation process and that there is a greater need for provision of psychological services.

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### Chapter 4.3.2 Results for study 2: Individuals with ULA

As with the interviews with RP's, the questions asked to patients were developed in order to elicit the important factors to consider following ULA and gaining further insight into what is 'success' following ULA.

#### **4.3.2.1 Prosthesis use**

From interviews and focus groups with individuals with limb absence, it emerged that the prosthesis had a facilitative role in achieving some functional tasks such as driving for several participants.

John (FG1): *"I wear mine (prosthesis) all the time I don't think it's a self conscious I wear it from practical I need it when I am driving you know"*

Participants in general discussed how the prosthetic device is helpful to them in performing some functional tasks that cannot be done with one hand.

Jane (Int): *"its fantastic, I mean the amount of things I can do with it, without it it would take a lot longer for me to get my legs on em I wouldn't be able to drive if I didn't have it I wouldn't be able to do certain things like you know those plastic folders putting paper into a plastic folder you cant do that without your myo-electric arm, its just impossible"*

Jane (Int): *"...so having a prosthetic arm is fantastic because you can hold it and you just devise all these different ways of doing things that you know is such a such a feeling of satisfaction to do something that you couldn't do yesterday like cooking, like holding a tomato in your fake hand without squishing it all over yourself although it sill does happen if you are not paying attention little things like that getting better with the arm being able to put on clothes quicker and easier you know because I had a silicone skin for a long time on my cosmetic arm and silicone attaches to all the clothes and all the material so it takes about four hours to get ready as opposed to 10 minutes so just getting used to different materials as well made a huge difference to me..."*

Additionally, for some participants, the prosthesis is worn only when it serves a purpose for them. Otherwise they take it off.

John (FG1): *“but I must admit as I soon as I go into the house I mean it’s basically just a dead weight when I go into my own house at home it comes off but when I’m outside”*

The prosthesis also served the purpose of minimising an individual’s feeling of self-consciousness and promoting an individual’s positive self image.

Jane (Int): *“nobody noticed the difference most people didn’t even notice that I had an arm whereas I hadn’t before do you know what I mean it was so nice just to almost blend in and the arm be part of me I really got to like that arm I still have it”*

Most participants in this study wore their prosthesis regularly; some wore it for functional purposes whereas others wore it for aesthetic purposes. The prosthesis itself, also serves to help conceal limb absence. One of the participants, who has two artificial legs as well as an artificial arm, feels the prosthetic arm serves an even greater social and aesthetic purpose than the legs.

Jane (Int): *“you can pretend, you can hide it...I’ve gotten such abuse and while that’s a horrible thing its kind of good that I can pretend because then it means that not everybody judges you and you know people treat me differently when I am in the wheelchair then they do when I am walking so I think having the legs have helped me adjust to being a different body shape...the arm probably more so the arm probably more so because it is exposed, so if when I didn’t have an arm people stared so much they stare more at the arm than they do at the leg you know like if the choice was you have one wish and you can either have both your legs or you can have your arm back, I would always say arm, always”*

The need to feel aesthetically balanced emerged as an influencing factor in prosthesis use.

Catherine (Int): *“I did it for balance as well, I needed it for balance and I needed it just to be kind of try to be the same as everyone else because I didn’t want to be*



*different, you are different enough in coping with it, so that was hard, I don't think they do enough for you on the emotional side of coping with it"*

Jane (Int): *"...that's the thing, whereas I take my legs off when I come home, even if my arm is sore I will keep it on, partly for balance and also partly for myself it's the bit of my body that I hate looking at the most I don't mind looking at myself with out my legs on but without my arm on I don't like it you know because I'm just unbalanced and it looks odd"*

#### **4.3.2.2 Function (incorporating activities and participation)**

##### Activities of daily living

An inability to perform basic daily tasks can cause great frustration for many individuals post amputation. The results show that there are certain tasks that participants find particularly difficult following the absence of their upper limb. In particular, the female participants expressed different functional frustrations than their male counterparts, with women finding it difficult to do more female specific functions such as put on jewellery or style their hair.

Jane (Int): *"...I suppose it is the things you cannot do you know whatever they may be like putting on earrings I have tried everything....but I can put on any necklace pretty much with one hand...but yeah the jewellery side of things and there is also certain tops that I have that I love that tie at the back or whatever..."*

Ann (FG2): *"...I mean I can't blow dry my hair now you know I cant put on my jewellery I know that's not a big thing to guys but it is a big thing to women I can put these earrings in but the ones with the butterflies I can't put them in..."*

Whereas, male participants in the first focus group found tying shoe laces difficult and shared ways they have learned to overcome this challenge.

Andrew (FG1): *"if you put your laces in the reverse way, like you can tie them with one hand no bother"*

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John (FG1): *“no I just go for slip ons I’ve got a list of instructions how to do it with one hand, no I’ll just buy slip ons Velcro”*

When participants were asked if there were challenging aspects of having a prosthesis, going to a restaurant raised issues for several participants. Participants described how they learn to adopt behaviours that make life easier, such as choosing to order foods in restaurants that are not difficult to cut with one hand, such as pasta, or choosing to wear a jumper to a restaurant that the individual does not need to take off, since individuals with ULA reported finding jackets hard to take off.

David (FG1): *I feel very self conscious just say going to a restaurant you put your jacket on put your jacket back on and you have to faff about with a plastic bag to me im very self conscious about that*

John (FG1): *“yeah well I would probably do the same as you rather than at the table not take the jacket off wear a jumper or something like that it’s the same if I go to restaurant and I want a steak, can you ask the chef to cut the steak up for me cause I cant cut it, apart from my jacket most of the things I wear are sleeveless jackets, coats whatever, just to save having to put this in and out just tears the lining”*

Participants learn to accept that certain things will take them longer to do than they had taken before.

Frank (FG2): *“so I have no bother cutting things might take me a wee bit longer, very very occasionally if it was a very tough steak or something I might have to ask somebody with me to cut up a wee bit but normally approximate to normality as far as eating is concerned em I would like to have that old arm back but its quite impossible”*

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### Leisure activities

Being able to participate in leisure activities, either established ones or new ones was very important to participants and factors such as motivation enabled them to return to these activities.

John (FG1): *“I wanted to get back I had golfed before and I before my accident and I was right handed so this hand did nothing and they had basically no, I still throw a ball like a girl but I wanted to build up the arm to the extent that I could golf and I have done so I’m and I compete with and I have got a usual Sunday four ball and I we win some weeks and lose other weeks but I’m golfing at a level that I feel like I enjoyed you know and I can compete with two armers of the same ability as me its one of those games as long as you play with people whether you have got one arm two arm or just a rubbish golfer you have got a level you are at and I enjoy that”*

Other participants are more ambitious and want to perform activities to the same standard they had before.

James (FG1): *“but my my aim or goal was always not to go to the one arm golfers but to go to the two armed golfers sort of thing I wouldn’t have wanted to be any different from anyone else...”*

Participants described being able to adapt and find ways to participate in their hobbies.

Frank (FG2): *“well I used to play table tennis when I lost my arm I found held the bat and the ball in the one hand through the ball up wacked it, I was just as good you know and eh so that didn’t there is not anything that I cant do that I used to do I just do it in a different way”*

Paul (FG2): *“basically cause I I’ve said I go to the gym, people say what did you do today, and I would say I was at the gym this morning and they would say were you really, how can you do that, and I feel like saying right I have got one missing limb, I have still got another three basically in fact I have got three and a half*

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*basically so actually I have got a bee in my bonnet about that people just assume because you have something missing that you cant do a thing for yourself"*

Some participants took up new hobbies following the absence of their limb, and one participant even found a talent she wasn't aware she had.

Catherine (Int): *"...oh another thing I did which I think has wonderful em was em I started painting...never held a paintbrush in my life till January and it was its something to do with the cross, I think anyway, you know the way you because I'm left handed, my non-dominant hand I have to force the creative, the right hand side of my brain to work and its fascinating to see what it can produce"*

#### Work activities

Occasionally, the absence of an upper limb results in some patients not being able to return to their pre-amputation jobs and may result in early retirement or a career change.

John (FG1): *"I was at sea all my working life I had an accident in 2001 which was a absence of my right arm that finished my sea faring career because any prosthetic was an automatic failure from a sea farers medical which you are required to go to see in any capacity"*

James (FG1): *"I had a motorcycle accident so I was in the army at the time and of course like you your sea faring my soldiering days were over em but eh I was just 17 at the time..."*

On the other occasions, participants were able to return to the same company but not specifically the same job as a result of their limb absence.

David (FG1): *"I didn't go back to the same job, I was a linesman climbing towers and poles and things, so after that I was restricted to ground level obviously and just inspecting things"*

For another participant, limb absence makes it difficult to get interviews for new jobs and invites the dilemma of whether to disclose her disability in an application for a job.

Jane (Int): *"...even just getting to the stage of interview em but basically career wise I suppose its just even getting to an interview most people think if you only have one arm you cant do anything its just the assumption"*

### Independence

Participation in activities of daily living, leisure activities and return to work, are all associated with the ultimate goal of achieving independence from others. Participants all valued their independence and did not wish to rely on other people. One participant in particular described how crucial it is for him to do things by himself and find other ways of doing things.

James (FG1): *"As far as I was concerned to be honest with you I just didn't feel I was any different from anybody else, there are more ways of skinning a cat and I would find different ways of doing it as I say my hobby was working on cars and I used to change engines and all sorts of things, but It didn't bother me if there was a different way of doing it"*

However, although other participants strived for independence, on occasions they accept that it is sometimes easier to ask for help.

John (FG1): *"I'm different, he is doing it the difficult way, I if there was something like tying a top button of my shirt I just don't if I need it buttoned I'll ask somebody to do it I'll give up, ok I'll persevere and try this but there is other things I'm not gonna bother going down that line too difficult, I'm not gonna waste my time"*

Frank (FG2): *"I didn't have that problem because I decided from the beginning this will be the way I am you know some people you cant conceal the fact you only have one arm in my case and some people want to help you I remember a lady at the checkout in the supermarket snatched the bag out of my hand and I thought wait a minute hold on I snatched it back again and I thought oh shouldn't have done that, that wasn't very, people offer help now I just accept that in the spirit of which it is offered you know I don't get angry or"*

Ann (FG2): *“some of the checkout ladies will say do you want your back packed and I would say yes please and if they want to pack the carrier bag they can pack it and I will just lift the bag out of the trolley and put it in the box in the boot of the car”*

Striving for independence is often associated with driving, as this is a mechanism by which most patients achieve their independence.

John (FG1): *“it was a goal to get a for me to get back driving because up until that point your relying even going to the golf course you were relying on somebody taking you there, coming picking you up you know you were at other peoples beck and call, availability whereas once you got behind the wheel you could go where you wanted you could come back when you wanted to”*

John (FG1): *“...being able to drive again has basically opened up, even coming up here today it’s a round trip for me 300 miles but I its not a problem being back driving and mobile and not having to wait on somebody else to pick you up or deliver you or anything like that”*

Participants who cannot drive due to other co-morbid health problems found that this impacted significantly on their independence.

Andrew (FG1): *“that’s the biggest problem I have you are dependent on other people whereas before I was an independent person but I have adapted to a lot of things especially gardening”*

#### **4.3.2.3 Psychological factors**

Participants’ discussed how their psychological state incorporating a positive attitude, sense of humour, and motivation, was a very central part of enabling them to adjust to their limb absence. In particular, several participants attributed their personality as an important factor in their recovery and adaptation. They believed that it allowed them to confidently enter social situations, but it also motivates them to succeed.

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Elisabeth (Int): *“I think I have often said I think I was blessed with an outgoing personality and I played a lot of sports, right so I had lots of team sports...touch wood that the man above gave me that personality...”*

Specifically, their personality enabled them to engage a positive attitude. Many participants adopt a positive attitude towards their situation and their disability and this has encouraged them not to pity themselves.

Catherine (Int): *“...oh definitely the type of person I am, I never sit down I mean I never sit down to let something get the better of me I mean my attitude in life is always you take a risk once its worth it and I think my positive attitude has done an awful lot for me”*

Frank (FG2): *“I tend to adopt the attitude there is no use getting angry or even self pity”*

Some participants took the attitude that they were lucky to be alive or that their injuries were not worse.

James (FG1): *“no I’ve just been trying to think there when It happened I was more I was really thankful firstly that I was still alive cause that was a miracle... but eh I was so thankful that it wasn’t my legs you know I said at least I can run and do this and I was thankful for that...”*

Frank (FG2): *“...em but I was so delighted to have em survived cancer that it seemed at the time almost a small price to pay for survival you know what I mean and I have had 30 odd years that I didn’t expect to get so I’m very deeply grateful to the medical profession and to (the rehabilitation centre) for all the help I have received”*

Another participant felt she had always been a happy individual and therefore she remained happy following the absence of her limbs.

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Jane (Int): *“...I have always been fairly fairly happy I mean if that if that’s the word, how can you be happy with you know absence of limbs but I suppose I have always been fairly content in myself...”*

Participants revealed that they adopt this positive attitude, not just for their own sake but also for their family.

Ann (FG2): *“if you are going to be miserable you are going to make your family miserable”*

Most importantly, one participant acknowledged the power of her own positive attitude in changing how other people relate to her.

Jane (Int): *“as long as I am positive I think a lot of people sort of bounce off my reaction or will react to my reaction as opposed to having their own reaction...”*

Additionally, having a sense of humour was considered useful when she meeting new people in order to make them feel more comfortable with the limb absence.

Jane (Int): *“...I thought it was really funny when people would come over and shake my hand and I would loosen it (the prosthesis) and it would fall off and they would be left with the arm in their hand...”*

Jane (Int): *“...but stuff like that I suppose joking about it and by me making it ok everyone else deals with it fine and I think that’s a good thing and I think that also shows the huge power of your own perception of how that makes other people perceive you, you know...”*

Additional psychological factors such as motivation to succeed enabled the achievement of goals.

Paul (FG2): *“...I don’t want to drive because I don’t remember the car crash but and that’s intimidating but the reason I chose to drive is because I’m not gonna let it dictate my life you know...”*



Participants also expressed how they had the self motivation to psychologically recover from the accident and therefore sought counselling

Catherine (Int): *“em well suppose I pushed my self all the time to go for counselling and that helped”*

Some participants also had the determination to succeed despite obstacles being present, and not letting the limb absence itself be any sort of an obstacle to success

James (FG1): *“...but my main aim or goal was not to go to the one arm golfers but to go to the two armed golfers sort of thing I wouldn’t have wanted to be different from anyone else”*

James (FG1): *“when I was younger I wouldn’t wear slip ons (shoes), I was determined I wouldn’t wear them, I just wanted to be like anybody else and I have got to say you know honestly I have had more people say I didn’t know you had the one arm...”*

The motivation to do things that she loved and return to normality following the accident was a strong driving factor for another participant

Elisabeth (Int): *“I played Gaelic (football) for Dublin with one arm, I have three county medals championship medals em what else have I done, but I didn’t like deliberately set out to do these things at least I didn’t think maybe I have em”*

Elisabeth (Int): *“yeah it would have been a motivation but it was also yeah I wanted to be back out playing something do you know what I mean I played soccer as well for a while because you didn’t need your hands...”*

Several participants discussed how when they initially lost their limbs they compared themselves to other patients in their wards and they were grateful that their injuries were not more severe. Participants engaging in downward social comparison in this way can aid them in their adaptation and disengaging any potential self pity.

John (FG1): *“when I had my accident, I was put in the plastic surgery, the burns place when you saw the burns people, thought there is nothing wrong with me in comparison”*

John (FG1): *“people lying in the next little private room where the sheet couldn’t touch any part of his body from burns and you think there is nothing wrong with me in comparison to that”*

Some participants still engage this attitude despite many years passing since losing their limb.

Frank (FG2): *“because I think there is a lot of people are so much worse than I am, gladly swap places with me if they could ...”*

Participants also realised that other people with similar limb absence can suffer more than them.

John (FG1): *“we have a young girl at home she is in her forties, she has lost her arm above the elbow, in the last 6 months she is at the stage now where she cannot sleep at night with the phantom pain I never had to go through that, the phantom pain I have ever had been easily controlled, you know oh bugger I have got a cramp in my pinky and you know its not there, she is two o clock in the morning you know”*

#### **4.3.2.4 Self- image**

For many of the participants, having a positive self image is imperative and in particular for the female participants, there was a strong desire to feel attractive. This desire may often mean them preferring not to show their residual limb in public or even look at it themselves.

Elisabeth (Int): *“It was weird, because I saw my arm it was naked, I just didn’t like the look of it at all, its quite gross underneath here you see from all cause literally the arm was amputated in the accident, it was under the wheel of a bus, you know so I was literally under the wheel...”*

Elisabeth (Int): *"I now know even though a bit contradictory I used to feel like I wasn't attractive and whatever and I know I would be attractive in other ways, but personally still for myself I don't like the image of having just one arm do you know what I mean I might as well be honest about that you know id want to be abnormal to say I do that its grand, cause you know its not grand, it not normal"*

Therefore, aesthetics are still very important when it comes to selecting a prosthesis, even to the detriment of function.

Elisabeth (Int): *"...I even remember when I got that hook thing, I had to have it all strapped up around you know and I might as well be honest, I'm very vain, I like to look well...I'm not going around wearing a hook, captain hook or whatever you call it, so em I'd be looking for something that would be light that looks real as well do you know again like you know if I do wear it a lot of people wouldn't know you know what I mean"*

Limb absence and the wearing of prosthetic devices make it difficult for some participants to wear the clothes they wish, and some find this challenging.

Catherine (Int): *"in the sense it's very difficult if you want to go get something nice and you go into the shops and you see all lovely summer things with short sleeves and you are always looking for something with long sleeves and it is very difficult I find that very challenging"*

Catherine (Int): *"it looks awful, its heavy its it's ungainly and its impossible to get I mean you know this big lump sticking up out of your arm like its bad enough having to wear long sleeves all the time because I wont wear short sleeves and I think from a feminine point of view it is all wrong"*

It appears to be very important to some participants that other people do not immediately notice that they are missing an arm or that they are wearing a prosthesis.

Ann (FG2): *"I don't think a lot of people at that wedding knew I had an artificial hand you know ...obviously it wasn't functional but it did the job you know it"*

*wasn't like maybe somebody going oh that woman's not got an arm or she's you know it does do the job that way you know although its cosmetic you know"*

Frank commented that he had not noticed initially that the other participants in the group, Ann or Paul had artificial arms. This comment was phrased in the form of a compliment, considering Frank didn't wear a prosthetic arm and his limb absence is clearly visible.

Frank (FG2): *"I must say visually I never guessed when you walked in that you had an artificial arm (directed to Ann) nor you Paul for that matter you know"*

Participants shared how not being able to cut their dinner in the restaurant and subsequently having to ask for help with this in public, causes them to feel self conscious, which leads some of them to adapt their eating choices to avoid this embarrassment.

Ann (FG2): *"...em being a bit self conscious as well like going into restaurants and having a meal cant use a knife and fork so don't know about you Paul and Frank, I tend to choose something I don't need to cut up you know cause I just don't like you know having to ask somebody to cut my dinner up for me, you know I don't know if you feel that way as well"*

Paul (FG2): *"I totally agree with that if I go out I tend to stick with things on the menu that"*

Ann (FG2): *"pasta or something you can cut with your fork"*

Paul (FG2): *"yeah basically"*

Ann (FG2): *"I know I do"*

Paul (FG2): *"and in the house I can ask my mum and dad If they will do it that's, out in public I would be a bit self conscious to say to the waitress excuse me I have a wee problem could you make sure the meal is cut up for me so I tend to stick go by the menu see if its easy to cut with one hand basically"*

While another participant revealed that other people staring makes him feel self conscious.

Frank (FG2): *"when I lost my arm as I said I was really pleased to have survived but I was conscious that I was minus an arm and people do look at you like when I*

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*walk along the road and I see someone kind of staring at me some people do stare as we know, what are they staring at, ah yes I only have one arm..."*

Certain prostheses can also increase an individuals feeling of self-consciousness such as hook prostheses.

James (FG1): *"...if you were out on a boat, and then all of a sudden you take your hand off and click this, they are all looking, you cant help but be a wee bit self conscious but I mean I'm older now and to be honest with you if I needed a hook I would have a hook..."*

However, attempts are often made to conceal the technical features of some prostheses as much as possible.

David (FG1): *"...and I get self conscious if somebody sees that one do you know what I mean, pull the sleeve down so you cant see it yet they tell me that there is people they don't even try to hide it they don't even wear, just use the hook"*

Practical issues with the prosthetic device itself can cause participants to feel self conscious.

David (FG1): *"I feel very self conscious just say going to a restaurant you put your jacket on put your jacket back on and you have to faff about with a plastic bag to me I'm very self conscious about that"*

Additionally, despite living 48 years with ULA, one participant described how he would still feel self conscious to be seen without a prosthetic limb.

James (FG1): *"oh no I wore it all the time I would never been without it and I would feel terribly awkward if I had to for example take it off and walk out here and even after all that time, you are still a bit self conscious you cant help that its just built in to me em"*

#### 4.3.2.5 Physical factors

Some participants commented on the difficulties they have encountered as a result of losing their dominant arm. One participant found that mastering tasks using her left (non-dominant hand) made things easier for her.

Jane (Int): *"...being able to get very good at being able to do certain things with my left hand you know the first couple of times I tried to butter toast I would just end up smashing you know the butter on the floor you know and like stomping off in a huff..."*

For participants who lose their dominant arm, writing can be a difficult obstacle to overcome.

John (FG1): *"that's one of the main problems I have had is learning to write with my left hand"*

Paul (FG2): *"I was right handed, I had to learn to write but see I was in a rehab unit for three weeks in my hospital experience and they had me writing from day one in there I think see when you haven't got an option it makes its easier for you my writing isn't brilliant but it wasn't that brilliant anyway"*

Participants who didn't lose their dominant arm also acknowledged that this would have made adaptation more difficult for them if they had lost their dominant hand.

Ann (FG2): *"...I was right handed because I think if you had to learn to write over again that's a big big thing"*

Frank (FG2): *"that would have been a big hurdle to get over, fortunately I was always left handed so that was saved me that"*

Additionally, PLP and PLS were discussed in both focus groups and by some of the interview participants in terms of how it impacts them and how they manage it. Participants described several different experiences of PLS, and for many individuals the feeling of the limb is quite vivid. For most of them, PLS was present all the time.

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Paul (FG2): *“... from the minute I wake up to the minute I go to sleep it feels like its there but its not a pain its just a sensation, I still wiggle my fingers and stuff”*

John (FG1): *“I can move all my fingers if the stump was there im moving my pinky now see a muscle moving there im closing all my fingers but the brain obviously still thinks its there”*

Andrew (FG1): *“it opens and shuts all the time you can feel it opening and shutting”*

John (FG1): *“I’m seven years down the line and I have got a hand there, that’s my permanent feeling is my fist is closed and somebody has wrapped it in a tight bandage and eventually someone bandage off and the fingers will do that (moving)... ”*

Heat and cold were also mentioned as common sensations occurring for individuals

Elizabeth (Int): *“phantom pain yeah in the winter terrible the cold yeah like I wear five socks in the winter tonight its warm I have two socks on”*

John (FG1): *“you don’t want to be landing in the stump end... my stump can be ice cold in the summer time and warm in the winter there is no rhyme nor reason to the circulation”*

Additionally, for one participant the PLS was related to the original injury before the limb was amputated.

James (FG1): *“ah yes well when I was in the hospital, they took my hand off here and then gangrene set in and then they take it away I can feel I have a hand I can just feel it I don’t not have a hand there I can feel it”*

Participants spoke about how sometimes the sensation in the hand increased to a feeling of pain, and this can come in many forms

James (FG1): *“cause that’s the last time I saw mine and it was black cause of the gangrene and that’s how I remember it and that’s how I feel it, if try to use what and it can get quite painful if I go too far with it”*

John (FG1): *“I have phantom sensation all the time but pain is now and again and its always two distinct types its cramp in the pinky or a burning sensation someone has put in the palm of your hand”*

Frank (FG2): *“I got phantom pains that were bad enough to need...pills painkillers and they gave me a rosey feeling there but they went away and it came to a point where I could probably do without these pills so I just threw them away I flushed them down and I have managed ever since but I can feel my arm and my fingers everything the old sensory equipment seems to be still there and occasionally I go hang on that’s the old nerves sounding off but it doesn’t bother me I live with it you know”*

Elisabeth: *“yeah it gets frustrating some times I accept like I said if I don’t think about it it its not there but I do know that if I if im stressed or if I feel down in my self its there I feel it I feel it there do you know what I mean, but nine times out of ten I would block it”*

Catherine (Int): *“em no but I mean its always there”*

For one individual, in particular, personal and environmental factors appear to trigger the pain such as cold, stress and attention.

Elisabeth (Int): *“stress is huge, another thing that drives it”*

Elisabeth (Int): *“right now I have it because we are talking about it...”*

Participants mentioned several things that they have tried to reduce their pain, some of which have been effective and others have not. The most commonly talked about



treatment was medication, with all participants adding that the painkillers were ineffective in reducing their pain and all participants appeared to be unsatisfied with relying on this form of pain management.

Ann (FG2): *“I was given cambamazapine, amytriptiline em something else there was like em cambamazapine em gapapentin em I was given them all and one of them went up to about 600 mg and it wasnt doing a thing for me. The doctors actually said to me... what about do you want to try do you want to try another and I said no I don’t want to try I don’t want to try the tablets again they didn’t do anything the first time oh just have to learn to live with it I just think basically you know”*

Although Catherine attended a pain clinic for treatment of severe PLP, she left after some time as she felt there was a reliance on providing her with pharmacological relief of the pain

Catherine (Int): *“...not really (effective) because I was drugged all they were giving you was drugs, drugs, drugs”*

One participant, who suffered quite badly from PLP, had tried numerous treatments over the years, with very little successful relief, however, most recently found massage to be slightly effective.

Ann (FG2): *“it worries me to a certain extent because I think to myself well em what I try to do when its really bad is I try to go and do something else to take my mind off it and ...one of the physios has been giving me massage for it and I feel as if its eased I was in all sorts of tablets and they weren’t doing a thing it was just making me kinda and I thought im not not taking it im not swallowing it because they are not doing me any good. I’ve tried raky, acupuncture, tensmachines, and em I feel as if I am getting a bit of relief with the massage”*

For Elisabeth, she found counselling to be particularly effective in relieving her phantom pain, through changing the position of the phantom limb.

Elisabeth (Int): *“yeah I used now, this is the other thing like I know from doing the*

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*counselling that when I started it was like in that position (very tight clenched fist) tightest fist you could ever make but even gradually its like this (loosening) so obviously I am releasing the protecting...*”

Other techniques such as the mirror box proved effective for Catherine after suggesting it to her OT.

Catherine (Int): “... *I was watching I don't know know how many years it was this stage, a program ... on where they were trying to get you to work on the phantom pains and muscles and all that and this program was that you would use a mirror a kind of one way mirror thing you probably know it you work on this when I had my accident, the fingers got stuck in the palm of my hand and when I am tense I till get that, that sensation is as real as and by trying to now I don't do it now because I kind of used to it but by working with I brought the information to... occupational therapist there, we rigged up a thing*”

However, one participant believed that being provided with a prosthesis early on after his limb absence may have helped relieve the initial PLP experienced.

Paul (FG1): “*mine went fairly quickly its just a sensation more than pain the only time I have pain when I am tired last thing at night before I go to sleep really so im lucky in that respect but apparently because I dont really remember much of it I suffered head injuries aswell I found I was quite miserable at first with the pain but I don't know maybe the prosthetic I got when I left hospital affected my brain psychologically yeah I have pain but my arms there kind of thing*”

Additionally many participants described how they simply ‘control’ their pain with their minds.

Elisabeth (Int): “*no no I block it out block the pain out most of the time, right now because we are talking about it I can feel my hand there and the pain, it's the phantom pain feel the hand is there*”

Catherine (Int): “*no I don't really do it but I know how to get my mind and work on*

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*it so that it works”*

John (FG1): *“I have been lucky phantom pain I have had is controllable by your mind”*

#### **4.3.2.6 Social factors**

Participants felt that social support such as the patience of people around them and their practical help with certain tasks was essential.

Paul (FG2): *“my mum and dad, their patience can you do us a favour and cut this up for me and the staff here have been out of this world basically eh the likes of the arm training they really really supportive and they have got a lot of patience”*

Jane (Int): *“...when I started to get better, they (family) all started to kind of pull together to help me have a life outside of hospital because that was always the fear that I would never get out of bed because of my burns mostly, not just the absence of the limbs...”*

However, this help can often involve not physically helping the patient and instead allowing the patient to do things for themselves.

James (FG1): *“...I can remember I got a lot of help from my mother because I used to be going to tie my laces and she would be like that going to help you, but shed say no like I’ll let you do it yourself and you know I learnt to do it myself it is really easy”*

Emotional support from family and friends was also valuable.

John (FG1): *“Aye from wanting to and encouragement from the people that I have golfed with before you know the folk that I had golfed with before were very encouraging”*

The importance of feeling loved by those close to them and not being treated differently was mentioned.

Jane (Int): *“by telling me it didn’t matter, by still loving me anyway, I suppose boyfriends in the past and I just I suppose being treated like a real person you know...”*

It was also acknowledged that the quality of the relationships the person had before losing the limb is also essential.

Jane (Int): *“and its something (good relationships) that’s often in place before anything happens you know and so no matter what happens to you in life you will always have, be alright, I have the best the best family, the best friends ever I am really lucky in that sense you know...”*

An emphasis was placed on meeting other people who have lost their limb which was reported to have helped participants, by being able to resolve issues that arise with limb absence.

John (FG1): *“the positive I have met a lot of people in the same position as myself through the golf side, and made a lot of friends and its handy when you go there because you find you are not the only one because everyone has basically got the same problems as you have especially in the one arm golf society cause we are all and you find out how different people have overcome some of the problems you are coming up against ...”*

Meeting others with limb absence was also another source of emotional support for participants by realising that they can overcome the absence of the limb.

Frank (FG2): *“em I remember the only person I spoke to was somebody who had had a absence of a limb had the limb but was useless hung on a sling there and they encouraged me to think that life wasn’t so bad after all with one arm and he was a teacher and eh I took a lot of courage from what he said...”*

Ann (FG2): *“I think when you see some people and they’re they’re an inspiration to you you know when you see what some of them have to go through...”*

Additionally, being stared at causes a lot of upset for participants.

Paul (FG2): *“you see some people and they walk towards you I’ve never seen people stare ahead so hard make it obvious when they are doing that cause I don’t mind people looking at me because its when you see the ones who do it its like a sly glance that doesn’t bother me its people who are there like that”*

Ann (FG2): *“I would rather they ask me rather than stare at me you know I think kids are more refreshing in that way you know because they will go oh what’s that you know oh is that not real and they will touch it you know”*

Jane (Int): *“cause often people just don’t realise how nasty it is for somebody to say that you know often mean I would retort with something...I think people wouldn’t be so nasty if they really realised what it felt like yeah so it just kind of depends...”*

Although, peoples’ reactions are not always negative and if new people they meet react positively to their disability this makes them feel more content.

Jane (Int): *“...probably the happiest time for me probably would have been in college you know when I was meeting new people and meeting new people outside of the sort of secure circle of friends that I had had which would have known me pre-and post accident was meeting people who had only ever known me using a wheelchair who had only ever known me without all my limbs and kind of getting good feedback from them you know and them seeing me for me as opposed to just my disability I think that helped”*

#### **4.3.2.7 Satisfaction with the prosthesis**

Issues participants have with the prosthesis such as the mechanics of the prosthesis and the prosthetic material used that affect their satisfaction with the prosthesis were evident through several discussions in the focus groups and the interviews, and were spontaneously mentioned by many of the participants.

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Mechanics of the prosthesis

Several participants were quite dissatisfied with the mechanics of the prosthetic limb and gave several suggestions for how they could be changed to improve their satisfaction with the prosthesis.

Andrew (FG1): *“... I think they could do quite a bit more with the hand really actually ah I don’t know if you ever eh seen a chicken turkey leg where you used to at Christmas time tie a piece of cord, open and shut like that would be a far better, the likes of that if you try to grip your trousers to hold them up it just slips out there is no pressure”*

Andrew (FG1): *“I find if they would do away with that finger there the hand would be made useful, just have the three fingers instead of the four”*

The weight of the prosthesis and its controllability are factors that affect the use of the prosthetic device.

Catherine (Int): *“em it doesn’t really work because it is too heavy now in the beginning it did but its it’s too awkward you cant really pick things up properly and you’ll pick up an orange and the next thing squeeze, you will take up an orange and you will squeeze it and you will get it up in your face”*

Jane (Int): *“its really heavy, it took a lot of getting used to and sometimes the batteries run down or id be sometimes, batteries run out when you are in the middle of doing something and like you dropped the pepper or you dropped whatever you are doing into the pot of boiling water...”*

Simon (Int): *“...the arm that’s sitting on me now at the moment is you know I’ve had trouble with it since day one since I got it but like you know there has always been something wrong with it in relation to its not sitting right the strap not right on it you know digging in to my kind of neck you know the weight of it you know what I mean sometimes you feel people don’t listen to you when you are telling them, this arm has gone back to them two and three times and it is still not right”*

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### Prosthetic material

Participants were also dissatisfied with prosthetic materials and described how this leads to frustration when they wear the prosthesis

David (FG1): *“two things that bug me about this I have got the wrong texture, I dunno, anybody else but when it comes time to put my jacket on I have got to cover this with a bag, surely there is a different material can be made, this is a mechanical one it could be more versatile for instance you can bend and once its there I mean to me that’s stupid surely in this day and age you can develop a more versatile version of that”*

An inability to clean the prosthesis also leads to hygiene problems and makes the prosthesis look dirty.

John (FG1): *“they are such fine material you cant rub them to clean them or you just abrase them to nothing it would be nice something that you could give a good wash to but you cant really with these and they do get a bit whiffy after a time”*

Jane (Int): *“...yes silicone looks good but it falls apart quicker in so far as it tears so it almost looks faker whereas the PVC it will stay in tact for longer it will get dirtier quicker the silicone stays clean but falls apart...”*

Jane (Int): *“I suppose in having a prosthesis its always for me anyway its always kind of a fine line between being comfortable and it being functional do you know...”*

#### **4.3.2.8 Satisfaction with the service**

One participant that was interviewed felt discriminated against that she did not get the same financial entitlements as other people with disabilities and those with lower limb absence or even those with double upper limb absence.

Elisabeth (Int): *“...definitely the government have let me down, discriminated against, not my friends, not my family, not in society, no em, the government*

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*everything that's the word I was telling you about, discriminated against all those other people who are able to get the VRT tax on their car..."*

Fortunately Jane does get her prosthetic limbs paid for, but she explained how she needs to fight each year to have them paid by the health board.

Jane (Int): *"If I ever got in trouble with the HSE (health board) and they didn't give me my medical card I would have to sit outside the Dail (parliament building) until they gave it to me, without my limbs on..."*

On the other hand, Elisabeth is not entitled to have her prosthetic limbs paid for by the health board and therefore she discloses that she cannot afford a new prosthetic limb.

Elisabeth (Int): *"...they are giving me a quotation but its three and a half grand and I don't have a medical card...I don't have a medical card, I cant afford a new arm..."*

All three participants in focus group two separately mentioned how favourably they view the staff and the service in their rehabilitation centre.

Frank (FG2): *"...I've nothing but praise for the national health service I must say I hear people complaining about it I've none at all I think its superb treatment over the years I must say for that and other things as well em so I couldn't say anything that displease me"*

Paul (FG2): *"eh the staff have been really really helpful with me and I have got nothing but praise for them and I have adapted quite quickly to an artificial limb and they are the reason for that basically"*

Ann (FG2): *"I think basically the help here, they are absolutely marvellous and they encourage you and you know I think the help you get down here..."*

The importance of a team approach was mentioned with one participant criticising that there was not enough consultation amongst other team members in her care.



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Catherine (Int): *“no but its just that I mean I would feel that it would have been much more of a help if there was more liaison with say doctors and the prosthesis people and the connections”*

However, for another participant, who received a great standard of multidisciplinary care, praised the quality of her care and the team approach used.

Jane (Int): *“It was all organised for em (the counselling) ...I had such good support I had like this multi-disciplinary team probably in the days before such a word was even invented...”*

Specifically the OT's received a lot of praise from participants in relation to the quality of their training.

Paul (FG2): *“the OT's here were really helpful I would come in for arm training and just when I was in hospital because they were trying to get me to do as much as possible the likes of cooking and stuff like that when I was in a rehabilitation ward that's when people say I have come on leaps and bounds in dealing with this but there has been a lot of factors that help me deal with it basically”*

The OT's also played a role as a patient advocate when they needed them

Catherine (Int): *“...I was very lucky in that in the sense that...the occupational therapist knew me from (the hospital) so I was able to contact her get her to intervene with the people who made the prosthesis...”*

Catherine (Int): *“well I was new to them I suppose so then she suggested em like had I ever gone back driving and I hadn't I had never sat in a drivers seat since the day I was lifted out of it and em so then she said would I talk to somebody you know avail of that service so I did”*

However, not all participants felt that their OT training was of a good standard, and ultimately this participant rejected her initial functional prosthesis and now uses a cosmetic prosthesis for social occasions mainly.

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Elisabeth (Int): *"...I was in the rehab and that's when I got the hook and I was in there for a month and it was actually I spent the whole month literally lifted sticks with a claw for the whole month from there to there, that's all I did for the whole month..."*

However, some participants reported being dissatisfied with the skill of the prosthetist making their artificial limb and felt that their concerns regarding the prosthesis were not being acknowledged.

Simon (Int): *"yeah telling them this you know telling them its not right,...but like em I got the last arm, basically just fell apart on me you know what I mean the hand fell off and whatever, got this arm made the guy that was making it, was leaving and go the trainee and she wasn't great and kind of left it up to her...he kind of finished up and when the arm came, it wasn't sitting right, it wasn't sitting well, you know there was a lot of errors with it and then there was another guy an English guy and he was trying to fix it for me and I felt like we were crammed into the place (fitting centre) you know what I mean like we are nearly sitting on top of each other I don't know if you have ever been in it".*

Simon (Int): *"I have mentioned it a few times up there but you know water off a ducks back, it doesn't go down... they are only interested in doing the job that's in front of them I suppose they have a budget that they work to you know what I mean..."*

Many participants felt that psychological support is essential in order to deal with the issues they had relating to the absence of their limb, although most of them never received this support despite feeling that they needed counselling.

Catherine (Int): *"cause em at that stage well I suppose I was dealing with the emotional side of the whole thing and they don't do it they don't really do that at all I mean its it's a thing of you're your just a your arms out there (away from you) your not, the emotional side of you isn't dealt with"*

Catherine (Int): *"I didn't feel when you went to the prosthesis place they don't look at that side"*

Simon (Int): *"no I didn't like after I lost my arm I didn't get any counselling or anything like that it was just arm off get back to normal that's it"*

Simon (Int): *"I suppose I would have had a lot of anger in me because of it you know in relation to that you know, 'why me', I didn't get to express my feelings or how I felt about what was happening or how to adjust for life, it was all kind of left up to me to find my own way you know in relation to it I suppose..."*

Elisabeth (Int): *"...the staff were lovely and everything but even looking back, no-one offered me counselling then unfortunately..."*

Some participants who fail to adapt initially to their limb absence, may engage in maladaptive behaviours in order to cope with absence of the limb.

Elisabeth (Int): *"...eh I would be quite outgoing so I would put on this image that everything was fine and you know everything was grand but what I was actually doing was I was drinking my way through the pain you know..."*

Elisabeth (Int): *"...I only went into counselling 6 years ago, following a huge break up or break down I should say and I've been up and down with depression I would say ever since because of it because of not getting proper support, being isolated really in it you know a lot of isolation in it maybe part of it was my own fault because I protected myself in it because I didn't want anyone you know..."*

One of the participants, who received psychological support after the accident, spoke very highly of that experience.

Jane (Int): *"...great psychological support, my psychologist...been fantastic for me in the beginning just to let me grieve and to let me get all my emotions out you*

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*know the whole why me attitude and all that just kind of to get it out of my system...”*

Jane (Int): *“yeah I just got really sad and upset and she came along to see me and sat there writing notes and because I had been used to having a psychologist, I thought she was there to talk to me, I didn’t realise that it was all about drugs, drugs, drugs, that’s kind of what it seemed to me, the psychologist was there to help me through talk the psychiatrist was there to drug me out of my mind and apparently she said to the nurses afterwards that I was fine, I was just sad.*

Despite not being offered counselling at the time of the limb absence, some participants sought that help themselves and feel that they have benefited from the counselling.

Elisabeth (Int): *“the thing about it, its not like today, there was no support like I got no support like there was nobody there there was no one there I had nobody, I had support in my family and my friends but from a professional body, no I worked it out all myself basically do you know I mean I had to hit serious rock bottom, I’m talking about serious rock bottom before...”*

Elisabeth (Int): *“yeah I used now, this is the other thing like I know from doing the counselling that when I started it (phantom hand) was like in that position (very tight clenched fist) tightest fist you could ever make but even gradually its like this (loosening)...”*

One participant feels that it is not acceptable that they do not consider the ‘whole person’ when rehabilitating them following ULA.

Catherine (Int): *“well that’s what It was, now it doesn’t matter to me, now it doesn’t make any difference I don’t bother anymore, I mean I just go up and get it changed if I need to but you know looking back I think for anybody who has similar I think you need to be viewed from a holistic point of view, every aspect of you”*

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#### ***4.3.2.9 Summary of findings***

The qualitative results from the perspective of individuals with limb absence described the facilitative role the prosthesis plays in several key outcomes for individuals with limb absence, such as engagement in activities and promoting positive self image by reducing self-consciousness. Additional factors which were found to enable individuals to adjust to the absence of a limb were psychological factors such as attitude, motivation, and humour. Participants discussed how physical factors such as absence of dominant limb cause additional difficulty in performing certain essential activities especially, writing and the co-morbid conditions such as PLP that can interfere with participants sense of well being, while describing the varied experiences of PLS and PLP. Additionally emotional and practical support from family and friends was highly valued as well as meeting other individuals with limb absence, especially at an early stage following limb absence. Participants shared their dissatisfaction with the mechanics of the prosthesis and prosthetic material, especially in relation to hygiene issues. There were also varied experiences of satisfaction with service. However, the important role of OT and psychological services were emphasised throughout.

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#### Chapter 4.4 Discussion of qualitative studies

From the analyses of the qualitative studies with RP's and individuals with ULA, codes were elicited that provided an insight into what both groups believe to be the key factors following rehabilitation of upper limb amputation, while giving insight into what is deemed 'successful' in certain areas. These themes were elicited inductively from the data. Themes were identified and labeled to represent the coded data, and most of these themes have been previously identified to be important by the research literature. These findings acknowledge that what constitutes 'success' will invariably differ from person to person. There were a few similar themes found amongst the factors elicited by RP's and individuals with ULA which will be discussed together in relation to the current literature and the implications for future research in order to demonstrate where perspectives from both groups converge and diverge.

The common themes that emerged between both groups of participants consisted of *Prosthesis use*, where RP's were more concerned that the prosthesis was used, whereas patients focused on what the prosthesis enabled them to achieve. Both groups also discussed the importance of *function, operationalised through activities and participation*. RP's emphasised that they know a patient is doing well by their engagement in activities and valued need for independence. Performing ADL, leisure and work activities were considered essential. Participants with limb absence focused on their functional limitations and discussed the frustration it caused them. A further theme from both groups was *psychological factors*. RP's referred to how psychological factors such as mood are important outcomes following ULA, what factors can affect psychological state such as cause of limb absence and how psychological state is vital in helping further factors of importance such as prosthesis use. On the other hand, those with limb absence were very concerned with how certain personality traits such as attitude, humour and downward social comparison, were essential in enabling them to adjust to the limb absence.

The fourth theme in common for RP's and individuals with limb absence was *physical factors*. RP's discussed how the level of the amputation can cause difficulty with

prosthesis prescription and use and emphasised the importance of minimising PLP, whereas individuals with limb absence described the differing experiences of PLS and PLP and how it can cause significant distress for some participants and none to others. Individuals with limb absence also discussed how limb dominance effects their lives, especially in relation to writing. The fifth theme in common was social factors. RP's emphasised the benefits of family and friends providing support and benefits of introducing individuals with limb absence to other successfully rehabilitated individuals. Both of these aspects were also mentioned by those with limb absence as important.

Satisfaction with the prosthesis for RP's focused around aesthetics, comfort, reliability, and weight. Whereas, those with limb absence criticised the design, weight, controllability and material of the prostheses. The final theme in common was satisfaction with service, with RP's emphasising the importance of communication with the patient and preparing them for what to expect. Additionally, the importance of MDT care and particularly the importance of OT's and psychological services were emphasised. Similarly, many patients highlighted the role of OT's and psychological services and emphasised the need for counselling following limb absence.

Additional themes were suggested by those with limb absence that were not suggested by RP's such as self image and how aesthetics are valued by the person with ULA and how a prosthesis reduces self consciousness. RP's also discussed how goal setting is a key part of the rehabilitation process.

#### ***4.4.1 Prosthesis Use***

In the present study, persons with ULA characterised the prosthesis as an enabling factor in achieving functional tasks such as driving and ADL. It also appeared to have a role in promoting an individual's self-image, and reducing self consciousness by concealing limb absence. However, the prosthesis was often worn only when it served a particular purpose for the person. In Saradjian et al (2008), patients also reported a similar role for the prosthesis as a facilitative tool to functional and psychosocial adjustment. The findings of Murray (2009) suggest that individuals with upper or lower limb amputation require a

prosthesis to enable them to drive, participate in social activities and sometimes to conceal limb absence. However, Murray (2004) found that not everyone considers a prosthesis to be purely a 'tool' and that for some people the prosthesis is integrated into 'part' of them. These findings also support Biddiss & Chau's (2007a) assertion that the need for a prosthesis is often justified by its enabling of participation in life activities and achievement of personal goals. The literature in general indicates that prostheses are mostly used for work and social activities (Millstein, Heger & Hunter, 1986; Scotland & Galway; Durance O'Shea, 1988); while home use is generally less frequent (Millstein et al, 1986). The functional importance of prosthetic devices in recreational activities and hobbies (Webster, Levy, Bryant, & Prusakowski, 2001) has been emphasized (Millstein, et al 1986) and the demand of specialized devices to facilitate these pursuits is significant. Also, as in Saradjian et al (2008) the prosthesis was considered to facilitate completion of desired functional tasks such as driving.

In contrast to patients emphasis on what the prosthesis allows them to achieve, RP's were more concerned that patients wear a prosthesis and RP's emphasized that 'prosthesis use' is a successful outcome following upper limb amputation. Considering the literature has been largely concerned with identifying the predictors of prosthesis use amongst individuals with ULA (e.g. Hacking et al, 1997; Roeschlein & Domholdt, 1989), it is not surprising that 'prosthesis use' emerged from RP's interviews as a desired goal to achieve following limb absence. However, the main contribution this part of the study provides is the further insight in to what is considered 'successful prosthesis use'. For RP's, this comprises patients wearing a prosthesis to consultations, and using it as necessary during the consultation. In particular, it was expressed that 'successful prosthesis use' is when the patient is using the prosthesis as intended. However, the individual nature of prosthesis use was also emphasised. Essentially, these findings along with one consultants view that when an individual is content not to wear a prosthesis is a success, opposes the common held belief in the literature that successful rehabilitation involves wearing a prosthesis and that prosthesis success in particular, consists of a fixed number of hours of prosthesis use (e.g. Jones & Davidson, 1995; Hacking et al, 1997; Datta et al, 2004). Although it is



important to measure prosthesis use, the individuality of the type and extent of prosthetic usage needs to be taken into consideration.

RP's discussed how crucial it is that the prosthesis is worn and along with the emphasis in the literature, it appears that there are a few factors that potentially can predict prosthesis use, such as the developmental stage of an individual (Biddiss & Chau, 2007c, 2008) and in some instances female gender can be a predisposing characteristic of prosthesis rejection (Biddiss & Chau, 2007c, 2008). However, this study showed that prosthesis can facilitate achievement of outcomes such as performing ADL, therefore it is proposed that prosthesis use should be considered a moderator of (facilitates) adjustment between certain variables and potential outcomes of ULA. This supports Scherer (2004a, 2005) argument that AT is an environmental factor that can affect a persons' performance in activities and their achievement of vocational, social and community interests.

#### ***4.4.2 Function (incorporating activities and participation)***

Both individuals with limb absence and RP's emphasized the importance of performing certain functional tasks post amputation and several patients expressed frustration at not being able to do some of their pre-amputation activities, with household tasks and ADL being the primary source of frustration for patients. Many female participants with limb absence found some female specific tasks more difficult. Similarly, Jones & Davidson (1995) found the ability to manage self care tasks appeared to be related to gender rather than prosthesis use, with more females reporting difficulty compared to males. Although, Jones & Davidson (1995) findings were not tested statistically. In this study, achieving independence was important to most participants with ULA and driving emerged as the main tool by which this could be achieved. Independence also emerged in the qualitative study by Saradjian et al (2008), as participants in their study expressed a wish to not be reliant on others.

There is little knowledge of the specific activity restriction that individuals with ULA experience. The theme of 'Function (incorporating activities and participation)' emerged as important through RP's and individuals with ULA emphasizing the patient's need to

participate in life roles, return to work, and engage in some form of leisure activity. The RP's and individuals with ULA both considered the ability to perform activities of daily living, including personal care tasks as essential. The RP's also emphasised the importance of performing these activities independent of help from other people. Particularly, an individuals' participation in life roles, such as breadwinner was emphasized in the present study by RP's. However, it is possible that this importance is related more to esteem needs than financial needs. This emphasis reflects that of the ICF (WHO, 2001) in relation to the essential outcome of rehabilitation for an individual to have involvement in life situations specifically, worker, student, friend, lover, etc.

For some patients, work activities were affected following limb absence, with some people not being able to return to work and others having to change jobs. One third of the participants in Wright et al's (1995) study also had to change jobs post amputation and Datta et al (2004) reported that 66% of participants had to change to a different job following limb absence. West et al (2005) noted higher levels of workplace discrimination, aimed at individuals with limb absence, particularly with regard to hiring promotion and job training. Similar difficulties were discussed by one individual with limb absence in the present study with regard to getting an interview for a job because she felt that potential employers underestimated her functional competence.

This study suggests that it is not the fulfillment of particular activities that is important but the ability to perform activities of importance to each individual that is essential. However, these activities will usually fall under the broader headings of ability to perform personal care, activities of daily living, and leisure activities and participation in life roles. This supports findings by Hammel, Magasi, Heinemann, Whiteneck, Bogner, & Rodriguez (2008), where individuals with disabilities defined what was meant by participation and emphasized that participation is individual and is the fulfillment of activities of interest to the individual. Hammel et al (2008) concluded that a measurement of objective participation needs to acknowledge that different people value different aspects of participation and that different patterns of participation can still be defined as 'full participation'.

Both groups of participants suggested that independence from others is essential to obtain; and driving is linked to this independence. Participation in activities of daily living, leisure activities and returning to work was important to patients. This was similar to the finding of Saradjian et al (2008), where the majority of participants reported very little restriction in leisure activities and several participants took up new activities following their limb absence. This supports findings by Wright et al (1995) who found that although 38% of participants had to give up a hobby because of the amputation, 46% took on a new activity and one half of these patients used the prosthesis in pursuit of this new activity.

#### ***4.4.3 Psychological factors***

Psychological factors emerged as vital considerations of RP's and individuals with ULA following ULA. The importance of psychological factors such as psychological distress and positive adjustment indicators such as mood as outcomes of importance following ULA were suggested by RP's. As well as these psychological factors, psychological traits, such as attitude and humour in predicting further successful outcomes were emphasised. Individuals with ULA did not refer to negative mood states in the same way as RP's. Specifically, the findings suggest that RP's feel it is important for individuals to have absence of PTSD, depression and to display a positive mood, whereas, individuals with limb absence focused on personality attributes that can contribute to their successful outcomes. RP's suggested that the cause of the amputation may have a direct affect on an individuals' psychological state. This is due to the likelihood that traumatic causes may potentially result in associated bereavements. The cause of the limb absence and an individuals' psychological state, therefore need to be taken into consideration before the fitting of an artificial limb. There was no assertion by RP's regarding prosthesis use in particular as being effected by traumatic causes. However, previous research (Gaine et al, 1997) has indicated that participants with limb absence due to traumatic causes are likely to wear their prosthesis significantly less often than participants with congenital limb absence. Potentially, this finding by Gaine et al (1997) is as a result of unresolved psychological issues due to the traumatic causes of limb absence, that result in reduced use of a prosthesis.

The important role of psychological state suggested in this study highlights the need for more research on the psychological adjustment amongst individuals with ULA as there is a dearth of research in this area (Davidson, 2004), despite Desmond (2007) and Datta et al (2004) showing that individuals with ULA appear to display higher depression levels than the normal population. RP's in the present study also suggested that in order for a patient to adapt to a prosthetic limb, it is important to assess whether they have the ability to cope with the lifestyle change that using a prosthetic limb involves, but that it is currently not assessed through formal tests but by "common sense" on behalf of the prosthetist. However, there is no evidence to date that there is a difference between prosthesis users and non-users in coping strategies used (Desmond, 2007). As a result of the knowledge that coping strategies such as avoidance strategies are significantly related to psychosocial adjustment (measured by the TAPES), and coping strategies such as problem solving, seeking social support, and avoidance are related to anxiety and depression (Desmond, 2007), along with suggestions from the present study that psychological factors can impact on prosthesis use, it is important that more attention is paid to an individuals coping strategies early on in the rehabilitation process and their assessment by formal methods should be considered. More research needs to be conducted on the most adaptive coping strategies employed by patients who have undergone an upper limb amputation. These qualitative studies suggested that as well as promoting adaptive coping strategies, it is essential to ensure the patient is motivated to achieve the goals they set and that the patient has realistic expectations regarding their rehabilitation and what they can expect from the prosthesis.

RP's revealed how sometimes patients' unrealistic expectations can influence their reaction to an artificial limb and high expectations of what a prosthesis will be like, often shaped by media portrayal, can lead to disappointment when the limb is received. Previous research has supported the importance of nurturing accurate and realistic expectations on prosthesis use in order to prevent prosthesis rejection due to disappointment (Balance, Wilson & Harder, 1989; Postema, et al 1999). These findings support the need for RP's to provide realistic expectations to patients prior to fitting of a prosthesis to avoid

disappointment for the patient. As suggested by one RP, early consultation and seeing limbs early on may rectify this. The suggested role of a patient's psychological state, coping style, expectations, motivation, and social support in shaping patient's outcomes endorse the introduction of support groups for all patients and perhaps psychological counseling for at risk patients as part of their early rehabilitation. There was no discussion from individuals with ULA regarding expectations.

However, individuals with limb absence in the present study emphasised how certain psychological factors incorporating a positive attitude, sense of humour, and motivation were important for them to achieve a successful outcome. Individuals with limb absence in the present study also described engaging in downward social comparison, by comparing themselves to other patients that they have met, either with other injuries like severe burns, or just other patients with ULA that are suffering more with phantom pain. Engaging a positive attitude, sense of humour and downward social comparison, were also techniques used by participants in Saradjian et al's (2008) study to facilitate adjustment following ULA, but have also been equally demonstrated in qualitative investigations in lower limb absence such as Gallagher & MacLachlan (2001) where participants acknowledged that there are people that are worse off than them. These personality traits have not been investigated quantitatively in any research study in ULA literature. However, Rybarczyk et al (2004) suggest that findings such as these coincide with the message of positive psychology where positive meaning and optimism, value of humour and spirituality are among positive psychological factors that are notable in successful adjustment to leg amputation. Rybarczyk et al (2004) also asserted that medical and disability related factors have been shown to predict less of the variance in psychological adjustment than body image concerns, perceived social stigma, perceived vulnerability, social support and optimism. The distinct focus on roles of varying psychological factors from both groups highlight the need for further psychological research in this area.

#### **4.4.4 Social factors**

Evidence from RP's analysis suggest that social factors such as how a patient's family may react to the limb absence or the prosthesis can impact on whether the prosthesis is

worn. This reflects similar findings from Murray's (2005) study where participants often wore their prostheses for the benefit of their friends and family, thus highlighting the important social influence on prosthesis use. Differing types of social influences, especially social support were discussed in the present study, with one individual with limb absence mentioning that sometimes it was most helpful when their family/friends didn't help them and allowed them to learn to do things for themselves. However, other participants with limb absence acknowledged that on other occasions' persons with limb absence need more practical help and appreciated it when they received the help. More emotionally driven support such as encouragement also helped individuals with limb absence return to leisure activities and feeling loved and accepted, improved their feelings of self worth. These findings support those of Saradjian et al (2008) where participants also emphasized the importance the support of their family played in their adjustment. It is recommended based on the findings of this study, that the role emotional and practical support play in the adjustment to amputation amongst individuals with ULA be investigated further. These findings also support the inclusion of the family in rehabilitation and counselling process given the influence the families' reaction to limb absence can have on the patients' adjustment. The present study recommends that the family also be involved in the training of the prosthesis and rehabilitation in general in order to encourage the family to give the patient the opportunity to find new ways to do things.

RP's suggested that meeting other people who have also lost their upper limb can be helpful for patients. This practice was also considered important by individuals with limb absence, in order to resolve issues that may have arisen due to ULA. It was also considered beneficial in that it allowed them to see that they will lead a meaningful life after the absence of a limb. However, none of these meetings were arranged by the service, most of these people were met by chance or by searching for them themselves. There is currently a considerable lack of research on the role of social factors in adjustment to ULA and especially there is no research concerning the benefits of meeting other people with ULA, however, drawing on the positive experience that most individuals with limb absence in this study had, the effect of meeting other people in same

situation needs to be investigated further. Additionally meeting and talking to others with limb absence was recommended by participants in Gallagher & MacLachlan's (2001) study as it provided participants with evidence that rehabilitation was possible. Those individuals with limb absence in this study expressed anger at how they are treated sometimes by other people, either by assuming that they cannot do many things or insulting them or staring at them. This supports the need for further public awareness campaigns promoting the abilities of individuals with disabilities with the aim of reducing discrimination. It also supports the usefulness of social skills training similar to that used with people with disfigurements (Robinson, Rumsey & Partridge, 1996) as suggested by Saradjian et al (2008). Saradjian et al (2008) also suggested providing cognitive behaviour therapy in order to encourage patients to identify and challenge maladaptive thoughts about disability and their sense of worth, which would also help participants to cope in social situations.

#### ***4.4.5 Physical factors***

RP's in the present study also discussed how physical issues relating to the amputation such as presence of pain from either phantom limb pain or residual limb pain can interfere with patient's rehabilitation and their ability to use a prosthetic limb. In the ULA literature, the role of how pain can affect the use of the prosthesis is inconclusive (Biddiss & Chau, 2007a). The literature suggests that absence of phantom pain and stump pain is often linked with increased prosthesis wear or ability to return to work (Dudkiewicz, 2004; Gaine et al 1997; Datta et al, 2004, Koojiman et al, 2000). However, Wright et al (1995) found no correlation between phantom pain and discontinuation of use of the prosthesis and Hanley et al (2008) suggested that individuals with phantom limb pain were more likely to use a prosthesis. It is essential that research be conducted to ascertain the role, if any, pain (both phantom and residual) play in upper limb prosthesis use and a patients overall rehabilitation.

Although PLP did not feature much in RP's accounts, individuals with limb absence gave a rich and varied description of their differing experiences of PLS and PLP with some participants being affected greatly by PLP and others not at all. Individuals with limb

absence shared the various treatments they have tried for PLP, with many having little effect. Despite this most individuals criticised the medical profession's reliance on medication as none of the participants found medication to be useful in affecting their pain. The most effective pain management technique was reported as the 'power of the mind' in reducing the pain.

One RP suggested that the higher the level of amputation and absence of certain joints, the more difficult it may be for an individual to use the prosthesis. These suggestions are supported by Davidson (2002; 2004); Jones & Davidson (1995) and Hacking et al (1997) who found participants with more distal amputations to use their prosthesis more. However, recent evidence from Biddiss & Chau (2007c; 2008) has found that level of limb absence is significantly related to prosthesis use, and specifically that individuals with either very high or very low limb absence are more likely to reject their prosthesis. In particular, Biddiss & Chau (2007c) found amongst those with congenital limb absence, that prosthesis rejection was more likely for those with low or high amputation levels than for participants with transradial amputations. For those with acquired amputations, higher levels of rejection were found for those with higher amputation levels (Biddiss & Chau, 2007c). Based on the literature and the suggestions from this study, the role of level of limb absence and prosthesis use needs further investigation.

Some individuals with ULA commented that losing their dominant hand can cause additional difficulties. However, learning to master tasks with the non-dominant hand assisted one participant. Writing, in particular can be a difficult obstacle to overcome and individuals who hadn't lost their dominant hand, acknowledged that this would have caused additional problems for them. Although there is some evidence from the literature (Gaine et al, 1997; Hacking et al, 1997) that suggests that hand dominance can effect prosthesis use, no relationship between prosthesis use and hand dominance was asserted in the study. Furthermore, since limb dominance was not mentioned by RP's, it appears that this may be an issue that is overlooked by RP's in rehabilitation. It is recommended that future research assess if hand dominance affects an individual's ability to engage in activities of importance.



#### **4.4.6 Satisfaction with prosthesis**

Individuals with ULA and RP's shared similar perceptions on the areas of dissatisfaction with the prosthesis. Particularly, aspects of the prosthesis breaking such as the silicone tearing and the weight of the prosthetic were emphasised by individuals with ULA. RP's detailed the importance of the aesthetics, functionality, comfort and weight of the prosthesis to promote an individuals satisfaction with a prosthesis. Previous studies have also found these to be areas of satisfaction amongst upper limb amputations (Dudkiewicz, et al (2004); Gaine et al, (1997); Pylantiuk et al (2007); Hacking et al (1997); Datta et al (2004), Biddiss & Chau, (2007c); Postema et al (1999). These results highlight the growing need to address patients' areas of dissatisfaction with their prosthesis, in order to reduce prosthesis rejection and maximise prosthesis use as the findings from the present study suggest that satisfaction with prosthetic device, and issues such as the prosthesis breaking down and its weight can effect whether the prosthesis itself is worn.

Some individuals with ULA focused more on the dissatisfaction with the prosthetic materials and how this lead to frustrations when they wear a prosthesis and they explained that an inability to clean the prosthesis also caused frustration. Many patients had criticisms regarding their prosthetic limb and these mainly concerned the mechanics of the hand and the prosthetic material used. Patients were also critical of silicone as it sticks to everything and makes getting dressed a difficult task. Female patients with limb absence expressed that the weight of the prosthesis was one of the main driving reasons that lead them to not use functional prostheses or to at least use them minimally. These findings support Hacking et al (1997) and Kyberd, Davey, & Dougall Morrison (1998) who suggested that patients desire a lightweight prosthesis. In order to increase patient's satisfaction with their limbs, these issues need to be addressed. It appears that more attention should be paid to the specific areas of dissatisfaction mentioned by individuals with ULA as their emphasis differed from that of RP's.

#### **4.4.7 Satisfaction with service**

RP's suggestions on how to improve the service were insightful and can be used to deliver a more patient focused service and potentially any shortcomings in these areas may effect

some of the factors such as prosthesis use. Since studies such as Biddiss & Chau (2007c) have found satisfaction with health care in all aspects especially fitting, follow up, repair, training and information provision are higher amongst prosthesis users, it is very important to ensure patients are satisfied with the service and perhaps attending to the recommendations of the RP's in this study is an avenue by which this can be achieved. Specifically, the recommendations that rehabilitation should be multidisciplinary, with all team members working together in the same facility and particular attention needing to be paid to the role of occupational therapists (OT's) and psychologists as their valued roles were emphasized by the multidisciplinary team and those participants with limb absence. Many of these recommendations have not been supported by any evidence in the literature that they will improve satisfaction with services, although an investigation into their role is recommended. These findings have direct relevance to promoting prosthesis use because individuals who are not satisfied with a service may cease attending and ultimately cease prosthesis use. Further attention needs to be paid to areas of dissatisfaction amongst patients.

An important theme throughout the interviews with RP's was the importance of providing choice to the patient and maintaining an individuals' sense of control. Biddiss & Chau (2007c, 2008) has provided evidence that provision of choice to the patient can be beneficial to the health service. For example, in Biddiss & Chau (2007c), frequent prosthesis wearers reported a significantly greater involvement in 'choice' regarding involvement in selection of the primary prosthesis but not related to the type of prosthesis. Degree of involvement in choice of prosthetics was also found to be related to health care and enabling resources, with those patients who are actively involved being more likely to continue prosthetic use (Biddiss & Chau, 2008). Scherer (2002) believes that individuals with disabilities who are involved in rehabilitation decisions in a meaningful way will generally be more satisfied with services overall. Scherer (2002) also recommends that in order to reduce non-use of AT, more attention should be paid to the person as a unique user of a particular device (Scherer & Frisina, 1998). The fact that RP's felt that their goals and the patients can differ reiterates the importance of taking the patients'

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perspective into consideration when choosing the goals of rehabilitation in the clinical setting.

Service related factors that transpired through the conversations with individuals with limb absence showed that overall participants in the focus groups were relatively satisfied with the service they received. The OT's were praised by both groups of participants and it emerged that they appeared to have played a valued role in the patient's rehabilitation. This was supported by Melendez & Le Blanc (1988) who asserted that OT's are particularly well suited to educate individuals with limb absence regarding a variety of aids and techniques that can be used with or without a prosthesis. Most RP's considered the OT's to have a particularly valuable role in rehabilitating the patient. Also, OT's themselves and other team members felt there was a greater need for more input from them into the patient's rehabilitation. One OT felt their role involved more than just improving a patient's functional adjustment but they were also important in providing emotional support for patients. This was also suggested by patients, who praised the OT's in relation to the quality of their training and for the OT's support in other areas relating to their rehabilitation. It is therefore important to nurture the role of the OT and their prominent role in the rehabilitation process.

Lack of psychological support was an important area of dissatisfaction for both groups, with many individuals with limb absence stating that they had to seek their own psychological support many years after their accident due to self perceived maladjustment. Also another participant, who was never offered support but never sought it himself, still feels 24 years later, he should have been offered some sort of support. There may still be benefits to offering these patients support now, even though they may feel that they have dealt with any issues. Biddiss & Chau (2007a) propose that ongoing psychological care and counseling appear to be important aspects of rehabilitation follow up. There doesn't appear to be much investigation in the literature for the importance of psychological support for individuals following acquired upper limb amputations, despite the strong consensus amongst patients that counseling is necessary and desired. This need for psychological counseling was also recommended by those with limb absence in Gallagher

& MacLachlan's (2001) study, adding that it should be obligatory. Melendez & Le Blanc (1988) suggested that interdisciplinary service provision has been shown to be an effective approach in prosthetic rehabilitation of individuals with limb absence.

Discrimination emerged as a factor related to the financing of limbs and other financial issues. This was only relevant to those individuals that currently do not get financial support from the health service in relation to their prosthesis and therefore struggle to afford new limbs. One participant felt very strongly that this was a discriminatory practice. Although this inequality in provision of limbs is usually evident in developing countries (e.g. Bhaskarand, et al 2003), several developed countries such as the Republic of Ireland do not appear to provide artificial limbs to all patients with ULA. In the Republic of Ireland, whether a participant will have an artificial limb paid for by their health board can often depend on their geographical location in the country and the resources available to the health board. This finding is not surprising considering a similar finding was found in Gallagher & MacLachlan's (2001) focus group sample from Ireland. Gallagher & MacLachlan (2001) found expense of prostheses to be a prevalent issue in their sample and participants asserted that they should get them for free as they are a basic living right. In the National Health Service (NHS; the UK health service) all participants with limb absence are provided with a limb if it is felt that they will benefit from one and if they wish to have one. All of the participants in the focus groups in this study were from the NHS, UK, whereas all of the participants from the interviews were from the Irish health service. This division in the sample may explain the relative dissatisfaction of the service and prosthetic limbs amongst the interview participants with limb absence in comparison to individuals with limb absence in the focus groups.

#### **4.4.8 Self image**

Considering that ULA is a more visible disability than lower limb absence and the assertion that society has a tendency to hold more negative attributions towards those with visible disabilities (Wright, 1983) along with the suggestion by Orr et al (1989) that body image is socially constructed, it is surprising that there is no research on this subject in the ULA literature. It is equally surprising that RP's did not discuss the disruptions of body

image of patients or potential self-consciousness that may arise as a result of ULA. Perhaps this is because they underestimate the extent to which it impacts or effects individuals with ULA or they feel they do not have the skills or resources to change it so do not focus on it. However, for individuals with ULA in the present study, they expressed that their self image is important, in particular, a desire to be attractive. This may lead people with ULA to conceal their residual limb from themselves and others and this desire for an attractive self image may lead patients to want aesthetically appealing prostheses. Not being able to do certain things or needing help makes individuals self-conscious of their limb absence, thus threatening their self-image. The issue of self consciousness also emerged as a theme in Saradjian et al's (2008) qualitative study where male participants with ULA described feeling self conscious in social situations, which rendered them sensitive and a need to prove their self worth, but that this subsided over time. While self consciousness in the present study influenced individual's use of their prosthesis with participants more inclined to wear it in social situations, it did not appear to subside over time. These findings differ markedly to findings by Murray (2009) that some participants displayed their amputation, their limb absence and prosthesis use as a method of defiance, resistance and to challenge notions of disability. Murray (2009) asserted that prosthetic display held profound personal significance and meaning to self and social identity and rather than trying to avoid the stares of others, these participants recognized that people would stare and accentuated the visibility of prosthesis use (Murray, 2009).

A negative self image could also potentially lead to additional undesirable outcomes for a patient as demonstrated by Rybarczyk (1992) and Williamson (1995) who found that social discomfort, perceived social stigma and public self consciousness have also been found to independently predict depressed affect in people with lower limb amputations. Particularly, in the present study being aesthetically attractive in terms of their entire body image was important for participants with limb absence. One individual in particular found it difficult to accept her body image despite twenty-four years passing since she lost her limb. Research needs to be conducted on body image as an outcome amongst people with ULA, especially amongst women, considering this absence tends to be more visible than lower limb absence. This is important in order to determine if aesthetics is the main

driving reason for some women to chose to abandon their prosthesis or in fact is a driving reason to want to 'fit in' and therefore wear a prosthesis. Losing a limb has been found to dramatically change a person's sense of body image and consequently self image, which has in turn been associated with a person's satisfaction with life (Breakey, 1997a). It was very important for participants in the present study that they can conceal their limb absence, and often this is achieved through wearing an artificial arm. However, participants also wish for other people not to immediately notice that they have prosthetic arm. People not noticing limb absence/ artificial arm also emerged in Saradjian et al (2008) study where participants felt that the prosthesis aids adaptation through helping to conceal limb absence ultimately participants didn't want others to notice they were missing a limb. This may be due to a desire to not stand out from the crowd. This reflects a similar finding in a case study by Rybarczyk et al (2004) that showed one participant actively avoided looking at their stump and Rybarczyk et al (2004) interpreted this as reflecting discomfort and distress with altered appearance.

#### ***4.4.9. Goal setting***

Goal setting was a theme unique to the interviews with RP's and appeared to have a valued role in the rehabilitation process. The RP's acknowledged that what they consider to be goals of importance might be different than what a patient would consider important. This further emphasizes the need for patient centered rehabilitation where patients and RP's are working together to set the goals to be achieved and devise ways to achieve these goals. Goal setting has not been referred to sufficiently in ULA research. However, this study emphasises the need to identify goals particular to each individual and rate their progress in their own terms, such as was demonstrated by the RGT in chapter 3. However, similar principles have been advocated in lower limb research using GAS (Rushton & Miller, 2002).

#### ***4.4.9 Limitations of the study***

This study included the perspective of most members of the multi-disciplinary team (such as prosthetists, psychologists, consultants, and OT's) that work with patients with ULA (as described by Datta et al, 2004). However, although this study was unable to recruit a

physiotherapist, who is also a member of the rehabilitation team, it is believed that this omission is unlikely to bias the research considering the physiotherapists have a lesser role to play in the rehabilitation of individuals with ULA in comparison to individuals with lower limb absence. Instead, the inclusion of five OT's who have an essential role in the rehabilitation of patients with ULA is a more important inclusion.

It is acknowledged that the current study in general had limited participants with limb absence. Perhaps this is a reflection of the small numbers of ULA patients in general. However, it has been acknowledged previously by Datta et al (2004) that since there are relatively small numbers of individuals with ULA, published reports and reviews regarding the outcome of prosthetic and rehabilitation programmes have had small study samples, as with the sample in the present study.

Arguably, the sample sizes in the focus group were small with four participants in the first focus group and three participants in the second group. However, guidelines proposed by Kitzinger (1995) recommended that focus group sizes can be as small as 4 participants. Hsueh, Hu & Clarke –Ekong (2008) provide support for these small group sizes as they also conducted focus group studies where they assigned three participants to one focus group and four to another focus group. Gallagher & MacLachlan (2001) also used the focus group method to assess the adjustment of patients with a lower limb amputation to an artificial limb. Gallagher & MacLachlan (2001) had 14 participants participate overall, divided into three focus groups, with 4 to 5 participants in each. Gallagher & MacLachlan (2001) emphasised the importance of the small groups to enable everyone to share insights and have the opportunity to talk, but equally, large enough to provide diversity of perceptions.

Despite the relatively small number of people with ULA, every effort was made to recruit more participants. Therefore, two participants who were contacted through a rehabilitation centre and showed a keen interest in participating were interviewed individually, in order to gain their opinions. The inclusion of two further interviews with participants, who were recruited from a support group for people with limb absence, strengthened the use of

interviews in addition to the focus groups. Hsueh, et al (2008) also supplemented their focus groups with interviews in order to draw on the strengths and overcome the limitations of each method. They believed that focus groups allowed them to assess common beliefs within the group and allowed participants to express their own views fully, using cues from others ideas. Individual interviews then gained further insights into personal views. The individual interviews also provided an opportunity to obtain details in a private setting in which participants were not influenced by others opinions. Although this was not an intended method from the outset, and even though the numbers in each focus group were small, there was intense discussion with all participants contributing in both groups, with discussions lasting over an hour. The moderator felt the discussion had reached saturation as all participants were satisfied that all issues had been explored. Furthermore, there was also much similarity in themes and issues that emerged spontaneously between groups. Similar themes also were produced in the individual interviews as emerged in the focus groups.

A potential limitation that may arise from the use of focus groups is that the articulation of group norms may silence individual voices of dissent (Kitzinger, 1995). Due to the small sample size in the present study, it is believed that this issue did not arise and every participant spoke freely and had the opportunity to voice their opinions within the group. Kitzinger (1995) suggests that some participants who may not be able to sustain a one to one interview may be able to take part in a group and contribute intermittently. Kitzinger (1995) also suggested that communication difficulties should not rule out group work and that sometimes group participants can help to translate for each other. This supports the inclusion of Andrew in focus group 1, who had hearing and sight difficulties but he still contributed meaningfully to the group.

Additionally, the general limitations that apply to qualitative research must be considered in the present study. According to Mays & Pope (1995), qualitative research is often criticized for lacking scientific rigor and that is often considered to consist of anecdotal assertions and personal opinions, which are often subject to researcher bias. These limitations were acknowledged and taken into consideration in the present study;



therefore, this study wishes to clarify the findings of this study through a further investigation with the goal of achieving consensus on these factors, using a Delphi study (Chapter 5).

#### ***4.4.10 Strengths of the study***

This study has added to the limited body of literature on ULA, particularly qualitative research in this area. The reliability of the analysis of qualitative data was enhanced by organizing an independent assessment of transcripts by an additional researcher and comparing agreement between the raters as suggested by Mays, & Pope (1995). The social and contextual aspects of disability were inherent within this research as recommended by the WHO's ICF framework. Considering the ICF's proposition that disability is personally and environmentally constructed, it was essential for this study to consider both personal and environmental factors that affect the outcome and not just the traditional amputation related factors and demographically fixed factors. The present study endorsed the use of a qualitative investigation to allow a relatively open-ended investigation to ultimately determine the broad range of factors of importance to the population of individuals with ULA.

Additionally, this study successfully included RP's and individuals with limb absence in the present study and successfully demonstrated their common themes but their different emphases on similar topics. Despite assertions by Rothwell et al (1997) and Scherer (2002b) that health professionals have a tendency to be over concerned with the physical aspect of disabilities and physical functioning in general, this was not apparent in the present study; with both groups of participants providing a diverse range, of psychological, social, and physical predictors that impact the individual following ULA. As suggested by Britten (1995), the use of qualitative research in the present study provided the opportunity to open up different research areas by giving greater insight into the role of the prosthesis in ULA and highlighting additional psychosocial factors of interest.

Given the relatively sparse research amongst individuals with ULA, the addition of a qualitative investigation is an important contribution to the literature as it successfully provides a voice to individuals with ULA regarding what factors they consider important following limb absence. Richards & Emslie (2000) illustrated how contextual details of the interview such as the gender and age of the interviewer and respondent and where the interview takes place, can interact and influence the interview process. Richards & Emslie (2000) showed how participants may hold back on negative views of the medical professional if the interviewer is a medical professional such as GP, whereas, if the interviewer is simply 'a researcher' with no medical qualifications participants will express any negative views. The interviewer in the present study was not a member of the rehabilitation team nor was she a medical or RP and this was disclosed to the participants at the beginning of the focus groups and interviews, therefore it is believed that participants did not intentionally hold back on any potential negative comments.

#### ***4.4.11 Conclusion***

This study provided a forum for patients who have experienced the absence of an upper limb to voice their opinions in what they believe to be the important factors involved in their successful rehabilitation. The results show that many patients have many issues that put them at risk for poor adjustment following limb absence such as, many being frustrated with their functional abilities and not all patients achieving their desired level of independence; with other participants having issues with their self-image. However, most individuals with ULA that participated in the study appeared positive and well adjusted and have given good insight into the factors that they deem important, essentially engagement in activities and satisfaction with life. There were between the themes that arose between RP's and patient interviews, such as 'prosthesis use'; 'engagement in activities and participation'; 'psychological factors', 'satisfaction with prosthesis' and 'satisfaction with the service'. However, there was slight variation within these themes between the RP's emphasis and the patients' emphasis. It also emerged that the prosthesis plays an important role in facilitating adjustment for patients. However, patients all engage in other behaviours such as using humour, downward social comparison along with the social support of their family and friends to facilitate their adjustment. However,

issues with financial discrimination, and problems with their prostheses make use of the prosthesis itself difficult which may in turn impact on the outcomes that wearing a prosthesis facilitates. These results support the importance that rehabilitation moves away from the ethos that its sole purpose is just to functionally rehabilitate a patient and instead equip each patient with the personal and social skills, along with the functional skills, to engage meaningfully in all aspects of life following ULA. A key method of achieving this should be through the provision of psychological support to all patients. Most of the themes that emerged in this study reflect what has been investigated in the literature, such as Prosthesis use, and to a lesser extent functional and psychological factors, satisfaction with prosthesis and physical issues. However, social factors, satisfaction with service and self image have received little focus on research in ULA. The findings from the present study support the need for future emphasis on these areas.

It is important to focus on upper limb amputation research despite the lower prevalence of this injury compared to lower limb amputation, as these individuals are likely to be of working age and if they manage to reach their full potential following rehabilitation, they can live a meaningful life and contribute to society. However, firstly it is important to know what a successful outcome consists of and how these can be achieved. The present study has identified a general portfolio of factors of importance to assess, consisting of prosthesis use; involvement in activities and participation; and psychological, social, physical, prosthesis and service related factors.

Although this is not the first study within the amputation literature that has investigated the views of the multidisciplinary team (e.g. Mortimer et al, 2004), it is the first study to qualitatively explore the views of the multidisciplinary team concerning their views of the factors associated with the rehabilitation of patients with ULA from the physical, functional and psychosocial perspective. The next step is to gather consensus from a broader range of RP's and individuals with ULA to ascertain if they agree with these judgements. This consensus will be reached via a Delphi study which gathers consensus from a group of experts on a topic where there is little knowledge. These qualitative studies provided the foundation for the items and statements that will form the basis of the

Delphi study. Ultimately, by identifying the important factors following ULA, it will be possible to conduct future studies that will identify whether these variables interact so that any predisposing characteristics can be nurtured or any potential problems identified and resolved at the time of rehabilitation.

Chapter 5 Delphi study: Reaching consensus on ‘success’ following  
ULA and factors of importance to consider in rehabilitation

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<b>5.1 Delphi Introduction.....</b>	<b>225</b>
5.1.1 Introduction to Delphi.....	226
5.1.2 Usefulness of Delphi.....	227
5.1.3 Modified Delphi.....	228
5.1.4 Consensus.....	230
5.1.5 Use of the Delphi in limb absence research.....	233
5.1.6 Present study.....	234
5.1.7 Aims of the study.....	235
 <b>5.2. Delphi Method.....</b>	 <b>236</b>
5.2.1 Study Design.....	236
5.2.2 Participants.....	236
5.2.3 Sample size.....	238
5.2.4 Materials.....	239
5.2.4.1 Item generation for round 1	
5.2.5 Procedure.....	241
5.2.5.1 Consensus	
5.2.5.2 Round 1	
5.2.5.3 Round 2	
5.2.5.4 Round 3	
5.2.6 Statistical analysis.....	244
 <b>5.3 Results.....</b>	 <b>245</b>
5.3.1 Descriptive statistics for all rounds.....	245
5.3.2 RP's results.....	246
5.3.3 Individuals with ULA results.....	247
5.3.4 Combined RP's and individuals with ULA results.....	249
5.3.5 Main analyses.....	251
5.3.5.1 Round 1 ratings	
5.3.5.2 Round 2 ratings	
5.3.5.3 Round 3 ratings	
5.3.5.4 Test of differences in ratings for RP's and individuals with ULA	
5.3.5.5 Test of differences in rating for those who dropped out and those who did not drop out.	
5.3.6 Section 1: Successful outcomes of rehabilitation following ULA..	257
5.3.6.1 Prosthesis use	
5.3.6.2 Activities and Participation	
5.3.6.3 Self-image	
5.3.7 Section 2: Important areas to consider in rehabilitation.....	264
5.3.8 Change between rounds.....	268

<b>5.4 Delphi Discussion.....</b>	<b>269</b>
5.4.1 Successful prosthesis use.....	269
5.4.2 Successful outcomes regarding ‘activities and participation’.....	272
5.4.3 Successful outcomes regarding ‘self image’.....	273
5.4.4 Important areas to consider in rehabilitation.....	274
5.4.5 The present study.....	277
5.4.6 Useful applications of the findings.....	278
5.4.7 Limitations of the study.....	278
5.4.8 Strengths of the study.....	279
5.4.9 Conclusion.....	281

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### Chapter 5.1 Delphi Introduction

As discussed in Chapter 1, there is currently no agreement in the literature regarding the successful outcomes for individuals who have been rehabilitated following the absence of the upper limb. Neither is there agreement on the definitive predictors of these outcomes. Agreement on the most important factors to assess following ULA will allow the construction of a core set of factors of importance related to ULA rehabilitation that can be used by RP's for use with individuals with upper limb amputation. Also, in conjunction with the literature review in Chapter 1, the case studies using the repertory grid technique in Chapter 3, and the results of the qualitative phase of this research (chapter 4) highlighted that in areas such as 'prosthesis use', 'self image' and 'activities and participation' there is much disagreement and inconsistency on what is specifically 'successful' in these areas. It is important to reach agreement on what is important to consider during rehabilitation and what is considered a 'successful outcome' in key areas in order to maintain consistency in research.

Consensus methods such as the Delphi technique have been used in health research for a broad spectrum of purposes. For example, Miro, Nieto, Haguët (2008) used the Delphi technique to identify the specific domains that should be assessed in predicting which individuals are at risk of developing chronic pain and disability following initial whiplash associated disorders sustained in a crash. Esmaily, Savage, Vahidi, Amini, Zarrintan & Wahlstrom (2008) wished to identify specific outcome based indicators regarding rational prescription for GP's which were then used in developing the content for a course in rational prescribing, the assessment of what participants had learned during the course as well as prescribing behaviour after the course. Scott, Treacy, MacNeela, Hyde, Morris, Drennan et al (2006) used the Delphi to identify the core elements of a minimum data set for Irish nursing. Kirchberger, Cieza & Stucki (2008) used the Delphi to validate the ICF core set for rheumatoid arthritis; and Petry, Maes, & Vlaskamp (2007) operationalised quality of life amongst individuals with profound multiple disabilities. Of particular relevance to the present study, Van der Linde et al (2005) developed evidence and consensus based clinical practice guidelines for lower limb prosthetic prescription using



the Delphi. Although all of these studies used the Delphi technique in their research, the formats of the studies wildly differed, with Van der Linde et al (2005), for example, reaching consensus at a consensus development conference whereas a specially assigned panel of experts reached consensus after a two round Delphi study in Esmaily et al's (2008) study.

### ***5.1.1 Introduction to Delphi***

The Delphi technique involves a series of sequential questionnaires or 'rounds' interspersed by controlled feedback that seek to gain the most reliable consensus of opinion of a group of 'experts' (Linstone & Turoff, 1975). It has been deemed useful for situations where individual judgements must be tapped and combined in order to address a lack of agreement or incomplete state of knowledge (Delbecq, Van de Ven, & Gustafson, 1975). The current lack of consensus on the outcomes and predictors in upper limb amputation has been discussed in Chapter 1 and due to this lack of consensus, it is deemed that the Delphi is an ideal method to aid agreement as the Delphi draws on the opinions of experts and since we do not have sufficient evidence from the literature in this area, the combined experience of those who have ULA and those who work with them may provide the insight that is needed. Also, Delphi's use as a tool for solving problems in health care is well recognised (Fink, Kosecoff, Chassin, & Brook, 1991).

Consensus studies are intended to correct for the lack of conclusive data by putting the knowledge and experience of practitioners and other 'experts' in touch with the available information (Fink, Kosecoff, Chassin, & Brook, 1984). Specifically, the Delphi is a survey method of research which aims to structure group opinion and discussion, but is distinguished by the fact that the discussions are anonymous. The Delphi method is one of several types of consensus methods, the others being, nominal group technique (NGT) (face to face meeting) and RAND techniques (a combination of a delphi and the NGT). The Delphi method evolved as a response to the limitations of traditional methods employed to obtain specific groups' opinions or judgement for policy development, such as the use of committees, where they can be prone to domination by powerful individuals (Murphy, Black, Lamping, McKee, Sanderson & Askham, 1998). Dalkey & Helmer

(1963) stated that the Delphi technique was a research method suitable for any problem and subsequent policy making that required expert judgement as a necessary input. Rowe, Wright, & Bolger (1991) suggested that for the Delphi to be useful it should provide more accurate assessments or judgements than those obtained either by individuals or by interacting groups. Rowe et al (1991) who acknowledge the principle that groups perform better than their best member, also recognise that the presence and actions of others in group situations may inhibit the ability to resolve ambiguous issues. Murphy et al (1998) note that the Delphi technique and other consensus development methods should not be viewed as scientific methods for creating knowledge, but rather as processes for making the best use of available information, be that scientific data or the collective wisdom of participants.

### ***5.1.2 Usefulness of Delphi***

The Delphi process involves the presentation of a questionnaire to a panel of informed individuals in a specific field of application in order to seek their opinion or judgement on a particular issue (Mc Kenna, 1994a). After questionnaires are returned, the data are summarised and a new questionnaire is designed based on the responses from the first round. Subsequent rounds are returned to each participant showing the overall group response from the previous round. Participants are asked to reconsider their initial response in the light of the first round's overall results. Repeat rounds of this process are carried out until consensus has been reached (Beretta, 1996; Green, Jones, Hughes, & Williams, 1999). It is through this essentially democratic process that Delphi aims to facilitate a group opinion or judgement that can claim to be representative. Delphi provides a statistical summary of the groups' views on specific items. This is often achieved by ranking items according to their descriptive statistics scores such as mean, medians, standard deviations as decided by group responses on Likert-type scales. The individual can then see where their opinion lies in relation to that of the total group (Goodman, 1987). It is important to ascertain differences between those who drop out and those who did not drop out in order to ensure that it is consensus that is being reached and not just that those who had differing responses did not continue with the study, as

Bardecki (1984) has suggested that those with extreme views may drop out and that consensus is then due to attrition and not to any change in views.

The feedback between rounds in the Delphi method can widen knowledge and stimulate new ideas (Pill, 1971). The Delphi provides a sharing of responsibility that releases the participants from group inhibition (Lindeman, 1975). It provides an opportunity for 'experts' to communicate their opinions and knowledge anonymously about a complex problem and to see how their evaluation of the issue aligns with others, and to change their opinion, if desired, after reconsideration of the findings of the group's work (Powell-Kennedy, 2004). Hornsby, Smith, & Gupta (1994) further indicated that the Delphi method is superior to the focus group approach because it allows the greatest degree of anonymity in reaching a group consensus (Vasquez-Ramos, Leahy & Hernandez, 2007). The Delphi method solves potential geographic limitations associated with achieving agreement in areas with limited knowledge (Jones, Sanderson, & Black, 1992; Alder & Ziglio 1996). This is particularly useful in the field of upper limb amputation research where there are limited individual 'experts' working in this field. The Delphi also has the added advantage of often being a highly motivating experience for participants (Vasquez-Ramos et al, 2007).

### ***5.1.3 Modified Delphi***

The traditional Delphi approach which generally involves an open-ended first round, a purposively selected panel, iteration, controlled feedback (up to five rounds) and technical forecasting or future prediction (Dalkey, 1969) is seldom used. However, the various Delphi hybrids that have emerged have been criticised by Sachman (1975) for their differing formats, and the fact that the approaches within these formats differ. Although what constitutes a modified Delphi has not been explicitly defined in the literature, it appears that the modified Delphi study is any study which deviates from the traditional Delphi in terms of not including an open-ended format, and includes studies that have as little as two questionnaire rounds but still retains the most important characteristics which are anonymity, iteration, controlled feedback and statistical aggregation of group scores (Rowe & Wright, 1999). Modified Delphi studies such as those by Keeney (2000) and Hasson, Keeney & McKenna (2000) used focus groups/ interviews in their first round

Delphi and used the literature to inform the questions for the qualitative sections. Although Keeney, Hasson & McKenna (2006) argue that this approach gives round one participants ample opportunity to raise fresh issues to avoid early closure on ideas. They noted that this action could introduce bias by making participants feel psychologically pressured to alter their views according to the recognised literature. Therefore Keeney et al (2006) recommend allowing participants freedom to bring their views to the first round. In support of the modified Delphi, Fink et al (1984) acknowledge that the major challenge in a consensus process is to pull from existing sources all appropriate information and to synthesize it into a form that can be used. Otherwise participants will rely on their own possibly limited experience and reading. Custer, Scarcella, & Stewart (1999) suggested that a modified Delphi that begins with a set of carefully selected items has the advantages of typically improving initial round response rates and providing a solid grounding in previously developed work. In the modified Delphi, it has been suggested that the number of rounds can also be decreased to two if panellists have been provided with an event list and if early group consensus has been achieved (Martino, 1983).

Although Rowe & Wright (1999) stated that the Delphi is typically used as a quantitative technique, Skulmoski, Hartman & Krahn (2007) suggested that a researcher can use qualitative techniques with the Delphi method. An alternative modified Delphi using semi structured interviews after the Delphi to explore the factors that influenced the ratings of panellists has been conducted by Campbell, Shield, Rogers & Gask (2004). In addition the qualitative component of Delphi is very important where participants are encouraged to feedback on the statements or are given the opportunity to add new statements. These newly proposed statements can be fed back to the participants in a quantitative form through a second round questionnaire. Murphy et al (1998) recommended that where possible feedback in each round should include qualitative comments as well as statistical measures (Campbell, & Cantrill, 2001). The final results of the consensus method should also be fed back to respondents.

Many contemporary studies using the Delphi have begun to use the internet to distribute the Delphi rounds instead of the traditional postal rounds (e.g. Miro et al 2008; Van der

Linde et al 2005). There are several advantages to using this method of distribution. As Devane, Begley, Clarke, Horey, & O'Boyle (2007) pointed out, the Delphi online allows a) international participation b) relatively low cost structure c) data collection efficiencies and d) potential for a higher response rate through rapid communication with participants.

Despite many studies gathering participants opinions in numeric form, only one (Miro et al, 2008) reported statistical analysis of their results, particularly if any groups differ in their responses. Miro et al (2008) studied whether the proportion of panelists who categorized each item as a predictor of chronic pain and disability were compared. The independent samples analysis showed that for two items, the percentage of experts who thought these items were important to predict the development of chronic pain were higher than the percentage who thought they were important to predict disability. Miro et al (2008) also examined the predictive power that experts had attributed to items using paired t-tests for independent samples to determine if the items mean values on the development of chronic pain and disability were different or the same. Results showed that only 3 items had different predictive power. These analyses show the usefulness of statistically comparing results in Delphi studies.

#### **5.1.4 Consensus**

Williams & Webb (1994) argue that consensus is poorly explained in studies. It has also been suggested that the definition of consensus and how it is measured changes considerably between studies (Hasson et al, 2000). Mc Kenna (1994b) drew on Loughlin & Moore's (1979) work and suggested that consensus should be equalled with 51% agreement among respondents. Sumsion (1998) recommends 70%, while Green et al (1999) opted for 80%. Crisp, Pelletier, Duffield, Adams, & Nagy (1997) questioned the value of using percentage measures, suggesting that the stability of response through series of rounds is a more reliable indicator of consensus. This variation in consensus levels and lack of transparency of the method is evident in various Delphi studies in health care.

Most notably, one study by Esmaily et al (2008) did not report consensus levels in their published article. They reported having a subsequent meeting following the Delphi where consensus was reportedly reached, but they did not report the consensus level. In another study by Miro et al (2008), participants were asked whether or not an item was related to chronicity/ disability. However, they gave no further detail of how this was measured, that is, whether it was a 2 item-yes/ no scale. Additionally, items that were thought to impact chronicity/ disability, participants were asked to what extent they did so on a scale ranging from -100 to +100. Miro et al (2008) explained that confidence interval of percentage of experts was used to determine consensus, rather than discrete estimation, because the confidence interval has lower amounts of error. No more information on actual consensus cut offs were provided.

However, other studies have been much clearer in how consensus is defined with Petry et al (2007) and Telford, Boote, Cooper (2004) stating that consensus was reached when there was 80% agreement amongst participants on a particular item. Whereas other studies such as Elwyn, O'Connor, Stacey, Volk, Edwards, Coulter, et al (2006) and Campbell, Cantrill, & Roberts (2000) have defined consensus in a different way. Both defined disagreement in their study as 30% of ratings being in upper 3<sup>rd</sup>, and 30% in lower third of a 1-9 rating scale of importance. Items that had an overall rating between 7 to 9 without disagreement were considered important. Items with 4 to 6 ratings were considered equivocal. In a study by Scott et al (2006), an item was considered core to nursing work when it achieved a 25<sup>th</sup> percentile score of 4 or above on importance, frequency, relevance or agreement on a 7-point Likert scale. Additionally, Van der Linde et al (2005) defined consensus as when an item had general agreement, which was greater than 75%. However, they did not say with what type of scale agreement was measured. Items that reached agreement were included in a set of draft guidelines and items with less than 75% agreement were re-rated in round 2. Items that did not reach agreement after round 2 were included in a Consensus Development Conference. Another reported method by White (1991) used standard deviation as measure of consensus, claiming that a larger standard deviation is associated with weaker consensus because the distribution of scores around the mean is relatively great. Similarly, a study by Whitehead (2008) considered consensus

in their study to be if the mean was greater than 4, and standard deviation less than 1. As this review of Delphi studies in health research demonstrates, there is little agreement on how consensus should be measured.

It is important to consider when setting consensus levels that Jones & Hunter (1995) clarified that agreement takes two forms. Firstly, the extent to which each respondent agrees with the issues under consideration (determined by mean/ median rating in some studies). Secondly, the extent to which respondents agree with each other, the consensus elements of these studies (often measured by standard deviation). Therefore parameters such as White (1991) and Whitehead (2008) are useful as they make both forms of agreement easy to measure.

When considering consensus, it is also necessary to keep in mind that studies also differ considerably on how they deal with items that have reached consensus. It has been argued often that consensus should be set prior to commencement of the study (Williams & Webb, 1994). Therefore, if items reach the predefined consensus level in round 1, it is argued that there is no need to continue to ask participants to rate these items in round 2. However, some studies such as Scott et al (2006) and Petry et al (2007) continue to ask participants to rate them. In addition, other studies delete items after round 1 that do not reach consensus in round 1 (Hoppestad, 2006), rather than giving participants an opportunity to see other participants perspectives and re-rate the previously rated items. On the other hand, Groatorex & Dexter (2000) argue that many studies do not report what happens between the rounds of a study, with only consensus reached by the panel reported.

Miro et al (2008) included most of the items that were in round 1, in the round 2 questionnaire, including new items, but items considered difficult to assess were deleted. However, only items that had been newly proposed in round 2 were rated in round 3. However, they do not say how many items that had reached a pre-defined consensus in round 1 were rated in round 2, nor why items that had reached consensus, were re-rated. In Esmaily et al (2008), round 2 consisted of all items in round 1 plus newly proposed

items from round 1. They did not report if results from round 1 were fed back to respondents in round 2. However, they did report that only a smaller panel from the original reached ultimate consensus, but did not reveal why consensus was reached this way. In Petry et al (2007), those items that had consensus or relevance were re-rated in Round 2. Many of these studies do not explain the reason for asking panellists' to re-rate items that had already reached the pre-defined level of consensus.

Further studies such as Elwyn et al (2008) did not detail whether all items were represented in Round 2 and Whitehead (2008) did not discuss what happened to items between rounds. Additionally, a study by Campbell et al (2000) stated that no indicators were discarded between rounds and they used the second round to achieve consensus. Also in Scott et al (2006), all items were rated in each of the three rounds. After the first round, items were presented as core items (consensus), non core (mixed consensus) and new items. Asking participants to rate all items in each round could lead to fatigue and drop out. If prior consensus and agreement levels are set before hand and reached in round 1, there is no need to ask participants to re-rate them in subsequent rounds.

In a study by Telford et al (2004), participants were requested to rate the original principles and indicators again that had not reached consensus in the light of the provided median and distribution data relating to round 1. They were also asked to rate any new principles and indicators proposed in round 1. In Van der Linde et al (2005) items that received consensus in round 1 were entered into accepted draft clinical guidelines. Round 2 only rated modified postulates. Items with no agreement were discussed at a Consensus Development Conference. These studies by Telford et al (2004) and Van der Linde et al (2005) both have accepted items that reach a pre-defined level of consensus, and items that are yet to reach consensus are rated again, with information on participants scores provided to participants in order to aid them to reach consensus.

### ***5.1.5 Use of the Delphi in limb absence research***

The Delphi method has been used to develop national clinical guidelines for prescription of lower limb prostheses in order to achieve “transparency and consensus among



clinicians, manufacturers, and insurance companies” (Van der Linde et al, 2005). Van der Linde et al (2005) adopted the modified Delphi approach by gathering data through systematic review, survey of national clinical practice on prosthetic prescription, and interviews with experts in order to determine postulates about prosthesis prescription. This was followed by a 2 round Delphi method with 32 participants representing physicians, prosthetists, and physiotherapists but there were no individuals with limb absence in their sample. This Delphi method culminated in the views of the national expert panel being presented at a Consensus Development Conference. In the Consensus Development Conference, there were 19 of the 32 participants from the expert panel, with enough participants representing each group as the expert panel. They argue that many options exist for prosthetic components and that prescription criteria can be derived from the experiences of physicians, therapists, prosthetists and patients. Van der Linde et al’s (2005) study produced draft clinical guidelines comprising guidance for prescribing prosthesis for lower limb absence. However, they acknowledged that it is also necessary to include patients in the Delphi sample which they did not include in their study, as they recognise the importance of consumer opinions and the potential for there to be differences in opinion from those of clinical professionals. However, they stated the reason they didn’t include them in their present study was that their aim was simply to produce first draft guidelines. This study was also not an international study with the expert panel being restricted to the Netherlands only. Given the importance of developing guidelines for prescribing prostheses in lower limb absence literature, it is also important to identify what factors are important to attend to during rehabilitation of individuals with ULA. The present study intends to identify these factors.

#### **5.1.6 Present study**

The present Delphi study will form the quantitative element of the overall mixed method design of this thesis. It is intended that the present study will reach consensus through an international online Delphi study that includes international experts that are representative of the multi-disciplinary team involved in the rehabilitation of individuals who have absence of an upper limb, including individuals with limb absence. This study will take the form of a ‘Modified Delphi’, as data for the first round will be gathered from the

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available literature on upper limb absence and from repertory grids, interviews and focus groups with individuals with limb absence and the RP's involved in their care. As previous research has suggested that RP's and patients differ in their opinions (Mortimer et al, 2004; Schultz et al, 2007; Van der Linde et al, 2007; chapter 4), the present study will test the differences between these groups across all rounds. Rowe & Wright (1999) characterise the classical Delphi by four key features: anonymity; iteration; controlled feedback; and statistical aggregation of group responses, all of which have been retained in the present study. Rowe & Wright (1999) suggest that only those studies that have their origins in the four characteristics should be classified as Delphi studies.

#### ***5.1.7 Aims of the study***

The aims for the present study are:

- 1) To reach group consensus concerning successful outcomes of rehabilitation following upper limb absence, in areas where there is currently disagreement.
- 2) To identify the most important factors to assess during rehabilitation of ULA.

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### Chapter 5.2 Delphi Method

#### **5.2.1 Study Design**

The present study used the 'Modified Delphi' technique to reach group consensus concerning the 'successful outcomes' following rehabilitation of ULA and to identify the most important factors to assess following ULA. This study used the outcomes and predictors identified through the literature in conjunction with the outcomes and predictors generated from interviews with RP's, and repertory grids, interviews and focus groups with individuals with ULA to develop items for a first round Delphi questionnaire that was distributed to a panel of 'informed individuals'. There were three questionnaire rounds in total. The results from each round informed the next questionnaire round.

#### **5.2.2 Participants**

Participants are referred to as 'informed individuals' (Mc Kenna, 1994a) in the present study and not the term 'experts' as is usually used in other studies as Goodman (1987) asserts that the term 'expert' can be misleading. Goodman (1987) recommends recruiting individuals who have knowledge of a particular topic or who are consequently willing to engage in discussion upon it. According to Fink et al (1984) an expert should be a representative of their professional group with either sufficient expertise not to be disputed or the power required to instigate the findings. This study recruited 'informed individuals' that fit these criteria. As recommended by Keeney et al (2006), the inclusion criteria were defined for the expert panel prior to commencement of the study. Firstly, it was agreed that the panel would consist of a heterogeneous group of informed individuals (Delbecq et al 1975, Murphy et al 1998), from several disciplines involved in the rehabilitation of patients with ULA. Secondly, it was agreed that the panel would include individuals with ULA as 'experts' of their own condition (Mayers, 1998). The inclusion of patients or service users within the panel has been considered to provide valuable insights and is deemed to be undoubtedly important (Fink et al, 1984). To develop the initial list of participants, this study employed purposive sampling so that people are selected not to represent the general population, rather their ability to answer the research questions (Fink & Kosecoff, 1985).

The present study identified RP participants by:

- Undertaking a database search of 'psycInfo' and 'Medline using the keyword search terms 'upper', 'amput' and 'prosth' in order to identify journal articles and books published within the years 1999 to 2009 concerned with upper limb amputation or prosthetics. The authors of these articles and books (where valid email addresses were provided) were contacted by the research team and invited to participate. This approach has been used and supported by other studies (e.g. Baker, Lovell & Harris, 2006; Hoppestad, 2006).
- Contacting delegates at the Trent International Prosthetic Symposium (TIPS; an international upper extremity prosthetic conference) 2005 and the delegates that presented at TIPS 2009.
- Identifying and contacting people who presented oral or poster presentations concerned with the upper extremity at the ISPO (International Society for Prosthetics and Orthotics) international conference 2007 through the conference proceedings.
- Reviewing contact lists on the UTAH arm and Touch Bionics websites.
- 'Snowballing' where participants were encouraged to pass the questionnaire onto other eligible participants (Demonstrated by Butterworth, 1991).

The inclusion criteria for RP's to be eligible to participate in this study were that:

- 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 between 1999 and 2009;
- they must be working as part of a rehabilitation team concerned with individuals with ULA for at least 3 years;
- or both.

RP's were told that if they did not fulfil these criteria but felt that they were an 'informed individual' that should participate in this study, to contact the researcher with their details.

Individuals with ULA were recruited by emailing several international support groups for individuals with limb absence (lists found on

<http://www.upperex.com/supportGroups.html>) that listed email addresses and requesting that they distribute the information sheet to their support group members. Another support group ([www.arm-amp.com](http://www.arm-amp.com)) also distributed information sheets to their list of members. Private prosthetic limb fitting clinics in Ireland were also contacted and asked to distribute the information sheet to their patients. In addition, individuals who attended the Amputee Coalition of America (ACA) annual conference 2009 were referred to the study. Participants were also encouraged to pass the questionnaire onto other individuals that may wish to complete the questionnaire. The inclusion criteria required participants to be at least one year post amputation; be over 18 years of age and have major upper limb absence.

### **5.2.3 Sample size**

There is no set recommended sample size for Delphi studies. Previous research suggests that the size of the panel is at the discretion of the researcher (Hasson et al, 2000). Given the iterative nature of the Delphi study, it is important to cater for a low response rate and high rates of attrition when recruiting. Sumsion (1998) recommends catering for a response rate of 70% for each round of the Delphi technique. Therefore, this study aims to target approximately twice the number of participants required for participation in the final round to allow for poor response rates and high attrition at each questionnaire round.

The Delphi does not call for expert panels to be representative samples for statistical purposes (Powell 2003). While some studies have employed as many as 1685 participants (Reid, 1988), others have involved as few as 15 participants (Burns, 1998). However, the benefit of a larger sample size is the greater the generation of data (Hasson et al, 2000). The sample size for a Delphi appears to be more of a resource issue than a conceptual issue (Campbell et al 2001). A similar study conducted by Van der Linde et al (2005) with experts working with individuals with lower limb prosthetics recruited 32 participants. However, no individuals with limb absence were included in Van der Linde et al's study. The present study wished to include individuals with limb absence and a representative proportion of RP's including OT's, prosthetists, psychologists, engineers and consultants

in rehabilitation medicine while accounting for poor response rates and high attrition. This study therefore wished to have 60 participants in the final round.

#### 5.2.4 Materials

The questionnaire rounds were conducted electronically via email through a software program called 'Question Pro' ([www.questionpro.com](http://www.questionpro.com)) as used in a previous Delphi study (Devane et al, 2007).

##### 5.2.4.1 Item generation for round 1

For a step by step overview of the Delphi procedure, see figure 5.1. The first round questionnaire contained 3 sections; Section A, 1 & 2. Section A contained demographic questions, with separate questions tailored specifically for RP's and individuals with limb absence. Statements/items for Section 1 & 2 for the first round of the Delphi survey were developed through a review of the literature on ULA (Chapter 1), findings from the repertory grids (Chapter 3) and interviews with RP's and interviews and focus groups with individuals with limb absence (Chapter 4). See Appendix P for a list of the Delphi items and how they were generated. 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 'body image'. Therefore Section 1 presented **statements** with the aim of reaching agreement in these areas. For Section 1, participants were asked to rate each statement on a 5 point scale for their agreement as to whether they were a 'successful outcome'. At the end of each section, participants were given the opportunity to add to the list any other 'successful outcomes' that they felt were important but had not been included.

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 section 2, sought to reach agreement on the most important items to consider. For Section 2, participants were asked to rate the importance of assessing each **item** on a 5 point Likert type scale. In addition, participants were asked to list any additional factors that they deemed important.

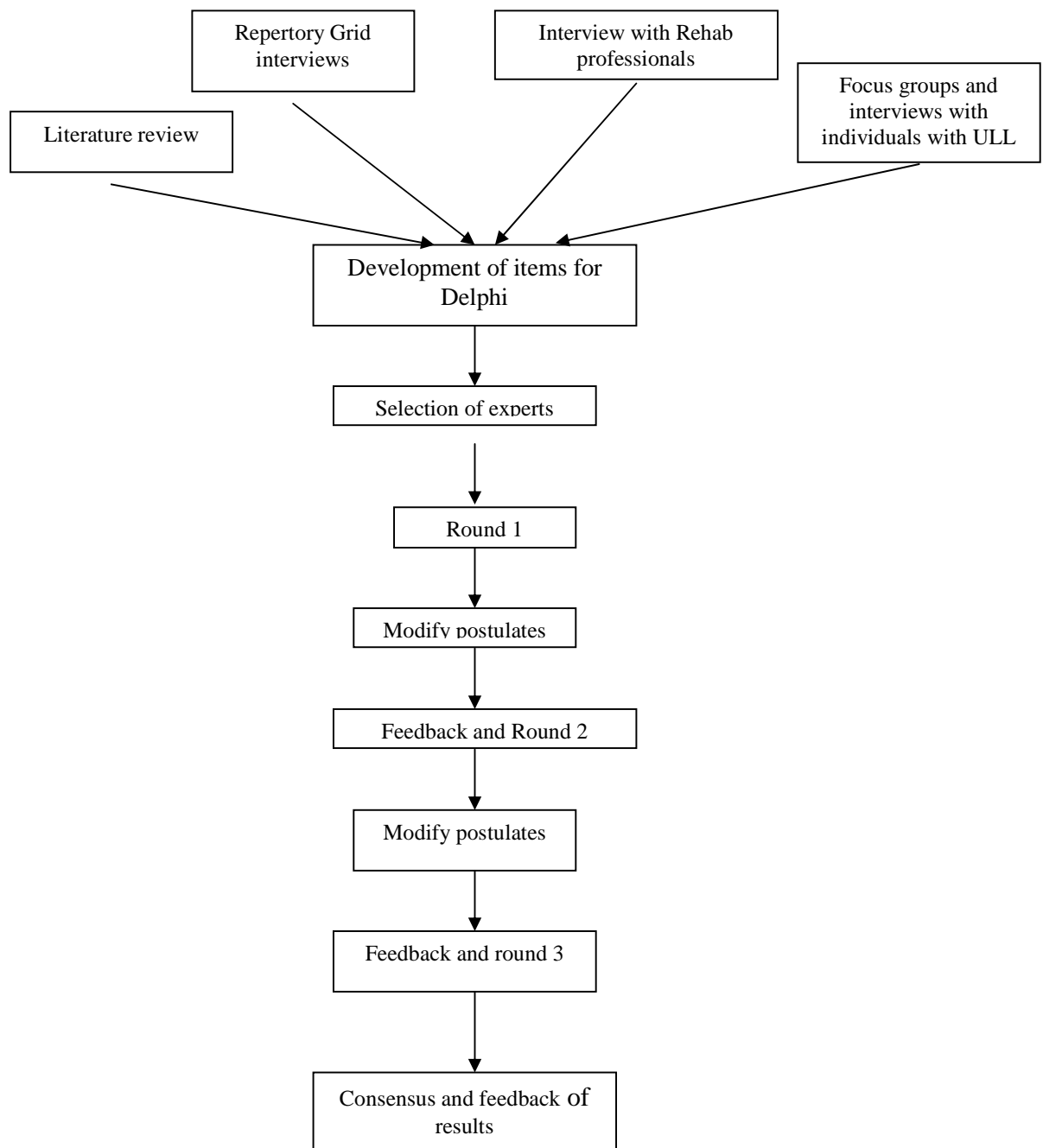


Figure 5.1 Overview of Delphi procedure

### 5.2.5 Procedure

Ethical approval was sought and granted from Dublin City University Research Ethics Committee to conduct an international internet Delphi study. Although optional, pilot testing of questionnaires with a small group has been previously recommended as it may help to identify ambiguities and improve the feasibility of administration (Jairath & Weinstein, 1994; Hasson et al 2000). Therefore in this study the first round was pilot tested with 2 rehabilitation professionals and 2 individuals with ULA. The Delphi questionnaires were distributed to participants between June & August 2009. Feedback from the pilot study demonstrated that participants found the instructions and structure of the questionnaire easy to follow and to complete. It also demonstrated how long participants may take to complete the questionnaire.

#### 5.2.5.1 Consensus

Means, ranges and standard deviations were calculated for all questions in Section A, Section 1 & 2. As recommended by Williams & Webb (1994), consensus on a statement was defined from the outset of the study. A statement/ item was considered to have reached **consensus** (agreement) if it possessed a standard deviation of less than 1.0. This means that there is relatively small variation in the responses amongst participants. A statement/ item was **accepted** to be a successful outcome in Section 1 if the mean score was greater than 4 (on 5 point agreement scale; 1-5) and to be an important factor in Section 2 if the mean score was greater than 4 on a 5 point importance scale (1-5). An item was **rejected** if it did not fulfil either of these criteria. If items/ statements did not have a standard deviation less than 1 or a mean greater than 4, they were rated again in the next round to ensure they are not rejected prematurely. However, if in the next round, it was still unimportant, it was rejected for good. The reason mean and standard deviation were chosen for consensus, was to ensure both types of agreement were measured (as discussed in Delphi introduction). The mean was chosen as a measure of central tendency to represent the group opinion of the panel. The standard deviation was chosen as a measure of spread, representing the amount of disagreement in panel (Greatorix & Dexter, 2000).



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### 5.2.5.2 Round 1

Email invitations were sent out to Individuals with ULA (see Appendix Q for text content) and RP's (see Appendix R for text content) detailing the aims and method of the study and requesting their participation over three rounds and emphasising the importance of their commitment in each round. Attached to the email was an information sheet for individuals with ULA (see Appendix S) and for RP's (see Appendix T). Participants were asked to read the information sheet and if they wanted to participate to complete the questionnaire via the link provided. Consent was obtained by asking participants to tick a statement that confirmed that they consented to participate in the study. Participants were unable to complete the study if they did not confirm their consent. If participants did not want to participate, they were asked to respond to the email explaining the reason they would not like to participate.

The round 1 Delphi questionnaire was attached to the email via a link <http://round1p.questionpro.com/> (individuals with limb absence; see Appendix U for word document) <http://round1rp.questionpro.com/> (RP's; see Appendix V for an MS word document version of the questionnaire) which once filled in was automatically saved for ease of access and analysis of the results.

The round 1 Delphi contained Section A which had several demographic questions. For RP's, the questionnaire asked them questions concerning their gender, country of residence, profession, years professional experience, and educational qualifications. For the individuals with limb absence, they were asked their age, gender, country of residence, cause for limb absence, level of limb absence and time since limb absence and questions regarding prosthesis use. In addition, all participants were asked to give their email address so that the next round questionnaire could be sent to them. This resulted in 'quasi anonymity', which meant that although the identity and judgements were known to the researchers, they were not known to other participants (McKenna, 1994a).

Participants were told that there was a deadline of 3 weeks to complete round 1. Non – responders were sent a reminder 2 weeks before the deadline and a further reminder 2

days before the deadline. Once the deadline had passed, participants scores were analysed and incorporated into the 'round 2' questionnaire. The investigator analysed the newly proposed items and chose 15 items/ statements that were relevant to the research questions to be rated as part of round 2.

#### 5.2.5.3 Round 2

The round 2 questionnaire (<http://round2p.questionpro.com>) was sent to participants by email approximately 4 weeks after the round 1 questionnaire was sent (see appendix W for an MS word document version of the round 2 questionnaire). In this round, the same questionnaire was sent to RP's and individuals with limb absence. The round 2 questionnaire contained Section 1 & Section 2. As in Round 1, Section 1 asked participants to identify the important indicators of a successful outcome and Section 2 asked participants to determine the important factors to consider in rehabilitation. In round 2, participants were presented with the items that did not reach consensus in round 1 (had  $SD > 1$ ), and those items that did reach consensus but received an average score of less than 4 on the 5 point Likert scale. Participants were presented with the average score from participants in round 1 and their frequency of scores on the Likert scales and asked to rate the items again. In this round, participants were given the opportunity to provide reasons for their responses to these items/ statements that had either been rejected in round 1 or had not reached consensus. Participants were also presented with 15 newly proposed items/statements from round 1 and asked to rate them. On this occasion, participants were given two weeks to complete the questionnaire and non responders were sent a reminder one week before the deadline and another reminder 2 days before the deadline.

#### 5.2.5.4 Round 3

Participants were sent the final round questionnaire (<http://round3.questionpro.com>) via email approximately four weeks after receiving the round 2 questionnaire (see appendix X or an MS word document version of the round 3 questionnaire).

Several points were clarified to participants in round 3 that required explanation. Firstly, participants were reminded that the statements were not the opinions of the research team;

that the team was not wishing to force agreement, but would like to give them a final opportunity to reach agreement in light of thoughts of other participants. Additionally, it was mentioned that the research team was interested in all aspects of rehabilitation and not just prosthetic rehabilitation; that the team acknowledge that rehabilitation is often individual, but wished to determine if a statement indicates one of the important indicators of success. Participants were also told that they would not be provided with their own ratings from the previous round as the research team would like them to rate the statement how they feel now, rather than be influenced by their previous rating.

For Section 1 in the final round questionnaire, participants were asked to rate 4 of the original round 1 statements that had not yet reached consensus. Each participant was provided with participants round 2 ratings and participants reasons for these ratings (see Appendix Y). In Section 2, participants were asked to rate 7 of newly proposed items/ statements that had reached consensus in round 2 but were not considered important. They were also provided with all participants ratings for these items/ statements. Participants were also asked to rate 3 of the newly proposed items/ statements that had not reached consensus in round 2 and were provided with participants ratings for these items/ statements. Participants were also given the opportunity to provide reasons for their answers if they wished. Once again participants were given two weeks to return the questionnaire and non responders were sent a reminder one week before the deadline and another 2 days before the deadline. Once the feedback from round 3 was analysed, participants were sent a final report and thanked for their participation.

#### **5.2.6 Statistical Analysis**

Statistical analyses were carried out with SPSS for Windows (version 14) statistical software package. Descriptive analyses of the data were generated for participant characteristics and statement ratings.

### Chapter 5.3 Delphi Results

#### ***5.3.1 Descriptive statistics for all rounds***

In total for round 1 of the Delphi survey, there were 73 participants. The number of participants reduced to 58 in round 2 and 53 in round 3. Therefore this means there was an attrition (participant drop out) rate of 20.6 % from round 1 to round 2 and the attrition rate from round 2 to round 3 was only 8.62%. This means that both round 2 and round 3 exceeded the minimum recommended participation rate of 70% suggested by Sumsion (1998). One additional participant who never completed round 1, completed round 2 and an additional participant who had not completed round 2, completed round 3, but these participants were not included in the final analyses.

Table 5.1 details the gender breakdown and the number of RP's and individuals with limb absence for all rounds. As can be seen, there was virtually an even number of males and females across all rounds. However, the majority of participants in all rounds were RP's. This reflects the fact that substantially more RP's were targeted to participate in the study than individuals with limb absence.

***Table 5.1. Demographic information for all participants across 3 rounds.***

Characteristics	Details	Round 1 (n)	Round 1 (%)	Round 2 (n)	Round 2 (%)	Round 3 (n)	Round 3 (%)
<i>Total Participants</i>		73	100	58	100	53	100
<i>Total Group Gender</i>	Male	36	49.3%	29	50%	26	49.1%
	Female	37	50.7%	29	50%	27	50.9%
<i>Total group representation</i>	RP's	47	64.4%	41	70.7%	38	71.7%
	Individuals with ULA	22	30.1%	15	25.9%	13	25.5%
	Both RP's and individuals with ULA	4	5.5%	2	3.4%	2	3.8%

### 5.3.2 RP's results

In order to recruit RP's for round 1, emails were sent to 131 RP's inviting them to participate in the study with a link to the study provided. Sixteen mails were undelivered. 23 of the initial 131 RP's that were emailed completed the questionnaire. Of the RP's, that were sent the questionnaire one emailed to say that he was not eligible to participate due to insufficient contact with individuals with ULA. In addition, 5 of the 131 RP's that were emailed the questionnaire by the research team started the questionnaire but did not complete it. RP's were also given permission to send the questionnaire onto suitably qualified colleagues. Through this method, an additional 25 RP's sent the questionnaire back to the research team. A further five RP's who received the questionnaire from another source, started it but did not complete it. There was a total of 47 RP's who completed round 1, and there was 41 RP's in round 2 and 39 RP's in round 3. Table 5.2 provides information on all the RP's across all three rounds.

*Table 5.2. Demographic information for all RP's across rounds.*

Characteristics	Detail	Round 1 (n)	Round 1 (%)	Round 2 (n)	Round 2 (%)	Round 3 (n)	Round 3 (%)
Gender	Male	20	42.6%	18	43.9	16	42.1
	Female	27	57.4%	23	56.1	22	57.9
Country	USA	29	67.6%	26	63.4	23	60.5
	UK	10	21%	9	21.1	9	23.7
	Canada	3	6.4%	3	7.3	3	7.9
	Australia	1	2.1%	1	2.4	1	2.6
	Japan	1	2.1%	1	2.4	1	2.6
	Jordan	1	2.1%	0	0	0	0
	Netherlands	1	2.1%	1	2.4	1	2.6
Professions	OT's	18	38.3%	14	34.2	13	34.2
	Prosthetists	13	21.7%	12	29.3	12	31.6
	Engineer	5	10.6	4	9.8	3	34.2
	Psychologist	4	8.5	4	9.8	4	10.5
	Consultant in rehab medicine	1	2.1	1	2.4	1	2.6
	Physiotherapist	1	2.1	1	2.4	1	2.6
	Researcher	1	2.1	1	2.4	0	0
	Surgeon	1	2.1	1	2.4	1	2.6
	Consultant in pain medicine	1	2.1	1	2.4	1	2.6
	Social worker	1	2.1	1	2.4	1	2.6
	MD	1	2.1	1	2.4	1	2.6

It is evident from this table that there are slightly more females amongst RP's across all rounds. The majority of RP's were from USA; with the second largest group representing the UK. OT's and Prosthetists were the most represented professions. Table 5.3 details the participants' mean years experience working with individuals with upper limb absence. It is shown that there is a wide range of experience and a mean years experience of working with individuals with ULA is approximately 13 years across all rounds.

*Table 5.3 Years of experience working with people with ULA*

Characteristics	Round	N	Mean	SD	Min	Max
Years experience	1	47	13.62	9.86	2	35
	2	41	13.38	9.65	2	35
	3	38	13.25	9.50	2	35

### **5.3.3 Individuals with ULA results**

A total of thirteen individuals with ULA were emailed an invitation to participate in the survey, of which seven completed it and one emailed the research team to say he was ineligible to participate as he had partial absence of the hand. A further fifteen participants who were sent the questionnaire via another source completed the questionnaire and a further two left it incomplete. These other sources may have been support groups for individuals with limb absence or perhaps other participants with limb absence. In total, there were 22 individuals that completed the first round questionnaire. Table 5.4 outlines the gender, country of residence of participants as well as the cause and level of limb absence. Participants' use of the prosthesis is also detailed. 22 individuals' with upper limb absence completed round 1, 15 completed round 2 and 13 completed round 3. Proportionately, there were a greater number of individuals with ULA that dropped out from round 1 to round 2, compared to the number of RP's that dropped out from round 1 to round 2.

*Table 5.4. Demographic information for all individuals with ULA across rounds.*

Characteristics	Detail	Round 1 (n)	Round 1 (%)	Round 2 (n)	Round 2 (%)	Round 3 (n)	Round 3 (%)
<i>Total Participants</i>		22	100	15	100	13	100
<i>Gender</i>	Male	13	59.1%	9	60	8	61.5
	Female	9	40.9%	6	40	5	38.5
<i>Country</i>	US	20	91%	14	93.3	12	92.3
	Switzerland	1	4.5%	1	6.6	1	7.7
	Canada	1	4.5%	0	0	0	0
<i>Cause</i>	Trauma	12	54.5%	8	53.3	7	53.9
	Congenital	3	13.6%	2	13.3	2	15.4
	Cancer	3	13.6%	3	20	3	23.1
	Infection	2	9.1%	2	13.3	1	7.7
	Blood clot	1	4.5%	0	0	0	0
<i>Level</i>	Shoulder Disarticulation	2	9.1%	1	6.6	1	7.7
	Forequarter	1	4.5%	0	0	0	0
	Above elbow	9	40.9%	5	33.3	4	30.8
	Below elbow	9	40.9%	8	53.3	7	53.9
	Through wrist	1	4.5%	1	6.6	1	7.7
<i>Prosthesis Use</i>	Yes	15	68.2	11	73.3	10	76.9
	No	6	27.3	4	26.6	3	23.1

Throughout the three rounds, there were slightly more males than females with ULA participating. The majority of participants were from the US. Most participants had limb absence due to trauma and there were equal numbers of participants with below elbow and above elbow amputations in round 1. However, more participants with above elbow amputations dropped out from round 1 to round 2 compared to participants with below elbow amputations. 15 out of 22 participants reported wearing a prosthesis and as can be seen from Table 5.5, the mean hours of prosthesis use for all rounds was approximately 10 hours and approximately 5 days wear per week. Participants also had an average age between approximately 52 and 54 years across all rounds. The mean time since amputation ranged from 23 years in round 1 to 29 years in round 3.

*Table 5.5. Further demographic information regarding individuals with ULA*

Characteristics	Round	N	Mean	SD	Min	Max
Age (years)	1	22	52.14	9.95	42	71
	2	15	52.53	10.73	42	71
	3	13	54.85	10.97	42	71
Time since amputation (months)	1	21	276.24 months (23.02 years)	258.08	14	861 months (71 yrs, 9 months)
	2	15	321.4 (26.78 years)	276.7	14	861
	3	13	354.15 (29.51 years)	283.40	14	861
Hours per day of prosthetic use	1	10	10.01 hrs	4.38	1	16
	2	8	10.88	4.32	1	16
	3	7	10.71	4.65	1	16
Days per week of prosthetic use	1	12	5.08	2.84	1	7
	2	9	5.66	2.65	1	7
	3	8	5.5	2.77	1	7

#### **5.3.4 Combined RP's and individuals with ULA results**

In addition, there were four RP's in round 1 who also had ULA. However, only two continued to participate in the study up to round 3. Only 3 filled out patient demographic questions. These demographic details are provided in Table 5.6 & 5.7. on the next page, and demonstrate that in the final round, both participants were male, from USA, one was an engineer while another was a special registrar in rehabilitation, both had below elbow limb absence from trauma and used prostheses.



*Table 5.6 Demographic data for individuals who are RP's with ULA*

Characteristics	Details	Round 1 (n)	Round 1 (%)	Round 2 (n)	Round 2 (%)	Round 3 (n)	Round 3 (%)
<i>Gender (n=4)</i>	Male	3	75	2	100	2	100
	Female	1	25	0	0	0	0
<i>Country (n=4)</i>	USA	4	100	2	100	2	100
<i>Profession (n=4)</i>	OT's	1	25	0	0	0	0
	Engineer	2	50	1	50	1	50
	Special registrar rehabilitation	1	25	1	50	1	50
<i>Cause (n=3)</i>	Trauma	2	50	2	100	2	100
	Congenital	1	25	0	0	0	0
<i>Level (n=3)</i>	Below elbow	3	75	2	100	2	100
<i>Prosthesis user (n=3)</i>	Yes	3	75	2	100	2	100
	No	0	0	0	0	0	0

*Table 5.7. Further information regarding individuals who are RP's with ULA*

Characteristics	Round	N	Mean	SD	Min	Max
Age (years)	1	3	50.67	12.66	37	62
	2	2	43.5	17.68	37	62
	3	2	49.5	17.68	37	62
Time since amputation (months)	1	3	243.66	341.59	39	638
	2	2	46.5	10.61	39	54
	3	2	46.5	10.61	39	54
Hours per day of prosthetic use	1	3	13.66	1.53	12	15
	2	2	14.5	0.71	14	15
	3	2	14.5	0.71	14	15
Days per week of prosthetic use	1	3	6.66	0.58	6	7
	2	2	6.5	0.71	6	7
	3	2	6.5	0.71	6	7
Years experience working with individuals with ULA	1	4	13	12.57	3	30
	2	2	3.5	0.71	3	4
	3	2	3.5	0.71	3	4

### 5.3.5 Main analyses

#### 5.3.5.1 Round 1 ratings

There was a total of 68 statements/ items to be rated in round 1 by all participants. There were twenty two statements in section 1 and forty six items in section 2. **Section 1** asked for participants opinions regarding what constitutes a successful outcome in three domains; 'prosthesis use'; 'activities and participation'; and 'self-image'. These statements can be found in the round 1 questionnaire (see Appendix U). Consensus ( $SD < 1$ ) was reached on 16 statements in Section 1, with 10 of those statements with consensus achieving score of 4 or greater which means they were accepted as important (based on criteria set prior to beginning the study), so participants would not be asked to rate them again in the next round. Of the remaining statements that reached consensus (had  $SD < 1$ ), 6 did not reach the accepted score of a mean greater than 4 and so were given a second chance to be rated in round 2. Of the 5 statements that did not reach consensus (had  $SD > 1$ ), these were also given a second chance in round 2. Six additional statements were chosen as newly proposed for Section 1 in round 1 and participants were asked to rate these in round 2.

In **Section 2**, participants were asked to rate which items should be taken into consideration by RP's in rehabilitation (see Appendix U questionnaire containing the items). In round 1, all 46 items in Section 2 achieved consensus (had  $SD < 1$ ) and 40 items achieved a score greater than 4. These items were therefore accepted as important, so participants would not be asked to re-rate them. A further 6 items reached consensus (had  $SD < 1$ ) but had means less than 4. These items were given a second chance in round 2 to enable them to score a mean greater than 4 before they were rejected. Also, eight additional items were newly proposed for Section 2 in round 1 and participants rated these in round 2 for the first time.

#### 5.3.5.2 Round 2 ratings

In **Section 1**, out of the 11 original statements from round 1 that were re-rated, 7 statements did reach consensus (had  $SD < 1$ ) and had means less than 4. Therefore these statements were rejected and were not re-presented to participants for a third time.

However, for four of the 11 original statements, there was still no consensus (had  $SD > 1$ ) and all had means less than 4. These statements were given a final opportunity to reach agreement in round 3.

Out of the 6 newly proposed statements from round 1, no statements had consensus (had  $SD < 1$ ) and had a mean greater than 4. However, 4 of the newly proposed statements from round 1 reached consensus (had  $SD < 1$ ) but did not have mean greater than 4 and 2 statements had not reached consensus (had  $SD > 1$ ). These 6 statements were all given a second chance to be rated in round 3.

**In Section 2**, 6 out of the 6 original items reached consensus (had  $SD < 1$ ) but had means less than 4 for the second time so they were rejected and were not presented to participants again in round 3. Of the 8 newly proposed items from round 1, 4 reached consensus (had  $SD < 1$ ) and had means greater than 4. These 4 items were accepted and not re-presented in round 3. One newly proposed item from round 1 did not reach consensus (had  $SD > 1$ ), and 3 reached consensus (had  $SD < 1$ ) but had means less than 4. Therefore these 4 newly proposed items from round 1 were given a second chance to be rated in round 3.

#### 5.3.5.3 Round 3 ratings

With regard to statements seeking to define successful outcomes, round 3 contained 4 original statements from Round 1 that had not reached consensus (had  $SD > 1$ ) in the previous two rounds. Two out of the four statements reached consensus in the final round but both had means less than 4 so they were rejected. The remaining two items did not reach consensus and had means less than 4, so they were also rejected. Round 3 also had one newly proposed statement from round 1, but this statement did not reach agreement, and had a mean of 3.23, which is well below the minimum required value of 4.

With regard to items aiming to ascertain what should be considered by RP's in rehabilitation, all 9 newly proposed items from round 1 reached consensus (had  $SD < 1$ ). However, all items had means less than 4 and were therefore rejected.

#### 5.3.5.4 Test of differences in ratings for RP's and individuals with ULA

Independent t-tests were used to ascertain if there was any difference between RP's (group 1), individuals with limb absence (group 2). The third group which included individuals with limb absence who were also RP's, were not included in this analysis as there were only 2 participants in this group in the final round.

Results showed that there was a significant difference between both groups on some items across all rounds. Table 5.8 reports the t-test results for those statements/ items that had significant differences. The table also reports their mean scores, and standard deviations which shows which groups rated significantly higher than the other. Statements/ items marked with an asterisk (\*), indicate that one group accepted an item/ statement, whereas another group didn't. Table 5.8 shows that the statement 'a successful outcome is when a person is confident to show their residual limb (stump) in public' received significantly higher scores from individuals with limb absence compared to RP's in each round. By looking at the separate mean scores and standard deviations of individuals with limb absence and RP's it can be seen that in round 1 and round 2, individuals with limb absence accepted the item, whereas RP's didn't accept the item. However, by round 3, both groups had a SD below 1 and a mean below 4 for this item, thus rejecting it. It is possible that providing the individuals with limb absence with the participants open ended qualitative feedback influenced their change in responses.

Interestingly, seven items that were all accepted in their first round rating, were scored significantly higher by those with limb absence than RP's with individuals with limb absence accepting the items and RP's not accepting them. These items were: 'Getting along with other people', 'Patients sense of humour', 'Pre-amputation life experiences and skills (E.g. experience of disability or limb absence in the family)', 'Phantom limb sensation', 'Time since amputation' and 'The social skills of the individual with limb absence'. These findings demonstrate that there are certain items are not considered important by RP's that are by individuals with limb absence.

*Table 5.8. Analyses of differences between RP's (Group1) and those with ULA (Group 2) across rounds*

Round	Statement/ Item	Sig	Mean Group 1 (SD)	Mean Group 2 (SD)
Round 1	A successful outcome is use of a non-functional cosmetic prosthesis	0.001	3.47 (0.93)	2.27 (1.32)
	*A successful outcome is when a person is confident to show their residual limb in public	0.005	3.43 (0.97)	4.14 (0.89)
	*A successful outcome is when a person is not feeling self-conscious when in public without a prosthesis	0.016	3.72 (0.90)	4.27 (0.77)
	*Getting along with other people	0.050	3.94 (0.87)	4.36 (0.73)
	Getting around	0.002	4.28 (0.65)	4.73 (0.46)
	*Patient's sense of humour	0.009	3.83 (0.79)	4.36 (0.73)
	*Pre-amputation life experiences and skills. E.g experience of disability or limb absence in the family	0.034	3.85 (0.88)	4.32 (0.72)
	*Phantom limb sensation	0.000	3.81 (0.77)	4.59 (0.59)
	*Time since amputation	0.000	3.96 (0.72)	4.64 (0.49)
	Type of limb absence (bilateral or unilateral)	0.000	4.72 (0.54)	4.05 (0.72)
	Emotional support from family/ friends	0.016	4.68 (0.52)	4.23 (0.75)
	Reaction of family to the prosthesis	0.021	4.51 (0.62)	4.09 (0.81)
	*A successful outcome is when a person is confident to show their residual limb (stump) in public	0.000	2.95 (0.97)	4.13 (0.95)
Round 2	A successful outcome is a persons ability to perform activities to the same standard they had before the limb absence	0.009	3.22 (0.96)	3.47 (1.06)
	A successful outcome is use of a non functional (cosmetic) prosthesis	0.007	3.44 (0.71)	2.733 (1.10)
	Cost of prosthesis	0.049	3.66 (0.965)	4.23 (1.10)
	*The social skills of the individual with limb absence	0.029	3.90 (0.66)	4.40 (0.91)
Round 3	A successful outcome is when a person is confident to show their residual limb (stump) in public	0.005	3.13 (0.62)	3.77 (0.83)
	A successful outcome is when a person feels grateful when the prosthesis is initially delivered	0.029	2.45 (0.60)	2.92 (0.64)

### 5.3.5.5 Test of differences in ratings for those who dropped out and those who did not drop out

Independent t-tests were conducted to ascertain if there was a significant difference in round 1 statements/ items for those who completed round 2 and those who did not. Results show that out of the 68 statements/ items in round 1, two had significant differences between those who completed the next round and those who did not. Higher mean scores indicate a higher mean rating for participants. The statements/ items that had significant differences are detailed in Table 5.9, with the statement ‘a successful outcome is when a person is not feeling self conscious when in public with a prosthesis’ being accepted by those who dropped out of the study after round 1, but not those who completed round 2.

*Table 5.9 Analysis for those who completed/ did not complete round 2 on their round 1 statements/items*

Round	Statement/ Item	Sig	Mean score for those who completed round 2 (n=58)	Mean score for those who did not complete round 2 (n=15)
Round 1 statements	*A successful outcome is when a person is not feeling self-conscious in public with a prosthesis	0.036	3.90 (0.85)	4.40 (0.63)
	Engagement in leisure activities	0.021	4.48 (0.57)	4.80 (0.14)

Analyses were also conducted to see if those who completed round 3 and those who didn't complete round 3 had significant difference in their round 1 statements. Three statements/ items were found to be significantly different, with one item ‘Getting along with other people’ being accepted by those who did not complete round 3, and not accepted by those who did complete round 3. Whereas, ‘cause of limb absence (acquired or congenital) was rejected by those participants who did not complete round 3, but accepted by those who did complete round 3. These statements and their means are shown in table 5.10

*Table 5.10 Analyses for those who completed/ did not complete round 3 on their round 1 and round 2 statements/ items*

Round	Statement/ item	Sig	Mean completed round 3 (n=53)	Mean did not complete round 3 (n=20)
Round 1 statements	*Getting along with other people	0.028	3.96 (0.89)	4.45 (0.61)
	*Cause of limb absence acquired or congenital	0.045	4.13 (0.83)	3.70 (0.73)
	Satisfaction with the prosthesis	0.023	4.58 (0.57)	4.85 (0.37)
Round 2 statements	*A successful outcome is when a person is not feeling self conscious when in public without a prosthesis	0.054	3.76 (0.88)	4.14 (0.38)
	A successful outcome is when a person does not feel they stand out	0.050	3.49 (0.61)	3.86 (0.38)

There were 33 statements/ items that participants were asked to rate in round 2, t-tests found that two of these statements were significantly higher for those who did not complete round 3 compared to those who did. The results showed that the statement ‘a successful outcome is when a person is not feeling self conscious when in public without a prosthesis’ was accepted by those participants who did not complete round 3, but was rejected by those participants who did complete round 3. Results are presented in Table 5.10.

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### 5.3.6 Section 1: Successful outcomes of rehabilitation following ULA

#### 5.3.6.1 Prosthesis Use

From the final round survey, a greater insight into what is considered a ‘successful outcome’ regarding prosthesis use is provided and can be seen in Table 5.11. The final rating reported is the final rating taken into consideration. The colour coding for each table is explained below the table. Qualitative comments from participants provide an illustration of participants thought processes while rating these items. It appears that only three items that reached agreement regarding successful prosthesis use were accepted. Two of these reached agreement in the first round, therefore no open-ended comments are available for these items. The third statement, ‘A successful outcome is when a person wears their prosthesis for specific activities’ initially reached agreement in round 1, but had an average rating below four. However, when given a second opportunity to be rated in round 2, it reached agreement (standard deviation (SD) <1) and had a mean greater than 4, so the statement was accepted. The comments from round 2 provided insight into the many different views regarding this statement. Several participants clarified that they believed the prosthesis is a “*tool*” and that a person should not be expected to wear a prosthesis all the time. Specifically one participant that rated this statement ‘agree’ commented “*...using the prosthesis is the short term goal-the higher goal is performing the desired activities*”. However, in contrast, another participant who rated ‘neither agree nor disagree’ commented that “*wearing a prosthesis just for activities isn’t living a full life*”. These contrasting comments reflect why this statement had difficulty reaching agreement in round 1. However, overall the majority of participants consider a successful outcome to include wearing a prosthesis for specific activities.

With regard to all accepted items, these data suggest that a successful prosthetic outcome is when a person uses the prosthesis as often as they wish and use of the prosthesis as it was intended. A person wearing a prosthesis for specific activities is also considered a successful outcome.

Following all three rounds, two statements could still not reach agreement. Analysis of the mean of 3.08 for the statement concerning ‘wearing the prosthesis all day every day’,



suggests that had the statement reached agreement, it still would not have been accepted. Considering the standard deviation for this item was 1.02, implying that it was very close to agreement, suggests that (in conjunction) with the low mean that it is very unlikely that this statement would have had a mean of 4, which is necessary for it to be accepted. Qualitative comments from round 3 reiterate that participants believe that the prosthesis does not need to be worn all day every day for success. In the same way the second statement that couldn't reach agreement concerning the 'person feels the prosthesis is part of them', also appears to have a mean rating well below 4 indicating that it had reached a standard deviation below 1, it still may have been rejected. Round 3 comments for those who 'strongly agreed' suggested that *"they will be more likely to wear it regularly if it doesn't feel like a foreign body attached to their being"*. More specifically, another participant stated that *"I don't think this is necessary, but it would certainly represent success..."*. However, further participants who rated 'agree' and 'strongly agree' stated that they believe the prosthesis is a tool, clarifying *"it is no more a part of me than my shoes"*.

Seven further statements reached agreement but were rejected on the basis of their mean score being below 4. One statement, 'a successful outcome is when a person is content not to wear a prosthesis' received a particularly low mean score of 2.40 in round 2. One participant who 'agreed' with this statement commented that it is *"a possible successful outcome. If there are things that they would like to do but can't and are content to give up, then not"*. Also many participants commented that 'content' is the essential word here describing the individual. However, very few participants provided comments as to why they disagreed with this outcome, with most comments provided by those who rated 'agree' or 'strongly agree'. However, one participant who rated this statement 'neither agree nor disagree' stated that *"a person who is happy to take their limb off and show their stump may indicate that they have adjusted to their limb absence"*. Four statements that had been suggested by participants in round 1 were subsequently rejected by all participants by round 3, indicating the participants that proposed them were in the minority in their views.

*Table 5.11. Means and standard deviations of 'Prosthesis use' statements*

Heading	Statement	R1 Mean	R1 SD	R2 Mean	R2 SD	R3 Mean	R3 SD	
Prosthesis use	1. A successful outcome is use of a prosthesis for a persons pre-amputation job or activities	3.99	.94	3.79	0.91			Item rejected in round 2
Prosthesis use	2. A successful outcome is use of a non-functional cosmetic prosthesis	3.08	1.16	3.26	0.87			Item rejected in round 2
Prosthesis use	3. A successful outcome is when a person is content not to wear a prosthesis	3.42	1.01	2.40	0.88			Item rejected in round 2
Prosthesis use	4. 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 could still not be reached in round 3.
Prosthesis use	5. A successful outcome is when a person wears their prosthesis for specific activities	3.97	0.82	4.02	0.61			Item accepted in round 2
Prosthesis use	6. 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 could still not be reached in round 3
Prosthesis use	7. A successful outcome is when a person uses the prosthesis as often as they wish	4.38	.680					Item accepted in round 1
Prosthesis use	8. A successful outcome is when a person uses the prosthesis as intended (e.g. a functional prosthesis uses functionally)	4.08	.89					Item accepted in round 1
Prosthesis use	9. A successful outcome is when a person uses the prosthesis for both functional and cosmetic purposes			3.80	0.89	3.53	0.93	Item rejected in round 3
Prosthesis use	10. A successful outcome is when a patient is satisfied with the cosmetic appearance of the prosthesis			3.88	0.80	3.94	0.41	Item rejected in round 3
Prosthesis use	11. A successful outcome is when a person feels grateful when the prosthesis is initially delivered			2.86	0.98	2.62	0.71	Item rejected in round 3
Prosthesis use	12. A successful outcome is when a person uses the prosthesis to feel socially accepted			3.31	0.98	3.04	0.94	Item rejected in round 3

**Green** highlight items accepted items after all rounds

**Red** highlight items rejected items after all rounds

**Yellow** highlighted items that did not reach agreement after all rounds

### 5.3.6.2 Activities and Participation

Table 5.12 details the means and standard deviation of statements concerned with ‘Activities and Participation’. The ‘activities and participation’ section had more accepted statements than either the ‘prosthesis use’ or ‘self image’ section. The statement ‘a successful outcome is a person’s ability to perform activities to the same standard as they had before the limb absence’ reached agreement in the final round but had a mean less than 4, which means that it was not an accepted statement. Open ended comments suggest that although this is an ideal goal, it is unrealistic and not necessary in order to achieve a ‘successful outcome’. Similarly, the statement ‘a successful outcome is a person’s ability to perform activities within the same time parameters as prior to their injury’ was a newly proposed item by a participant in round 1 and was rejected as not important in round 3. Participants’ objections to this statement were similar to the previous one. For example, a participant who ‘strongly agreed’ to this statement said it “...*represents a high degree of success, but I doubt it ever happens...*”. As can be seen from table 9, one newly proposed statement from round 1 could still not reach agreement after 2 rounds of rating. The mean for this statement in round 2 (3.23) ‘a successful outcome is when a prosthetic user can perform an activity bi-laterally to an equal standard as a 2 handed person’, was not near the cut off mean of 4, therefore this implies that participants did not believe it was a true statement. Participants once again agreed that although this would be “*an excellent result*”, it is “*highly unlikely*”. Particularly one participant who “agreed” added that it would be “*a great outcome if and when achievable, but absolutely not a requirement and frequently unrealistic*”. All statements for ‘Activities and Participation’ that were accepted, reached consensus in the first round and therefore open-ended responses were not gathered for these statements.

Overall, these statements imply that participants feel that a ‘successful outcome regarding ‘Activities and Participation’ is a person’s ability to perform their own personal care and activities of daily living without help from other people. It is also important for a person to be satisfied with their functional abilities and to perform to the best of their ability. Participants also agreed on more specific statements such as persons being able to drive if they desire and returning to active employment but perhaps having to change jobs.

*Table 5.12. Means and standard deviations of 'Activities and Participation' statements.*

Heading	Statement	R1 Mean	R1 SD	R2 Mean	R2 SD	R3 Mean	R3 SD	
Activities and Participation	1. A successful outcome is a person's ability to perform their own personal care without help from other people	4.37	0.81					Item accepted in round 1
Activities and Participation	2. A successful outcome is a person's ability to complete activities of daily living without help from other people	4.34	0.82					Item accepted in round 1
Activities and Participation	3. A successful outcome is a person's ability to drive if they desire	4.29	0.72					Item accepted in round 1
Activities and Participation	4. A successful outcome is when a person is satisfied with their functional abilities	4.51	0.75					Item accepted in round 1
Activities and Participation	5. A successful outcome is when a person has returned to active employment (but may have to change jobs)	4.21	0.65					Item accepted in round 1
Activities and Participation	6. A successful outcome is when a person is performing to the best of their ability	4.51	0.71					Item accepted in round 1
Activities and Participation	7. 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	Item rejected in round 3
Activities and Participation	8. A successful outcome is when a prosthetic user can perform an activity bi-laterally to an equal standard as a 2 handed person			3.41	1.30	3.23	1.17	Item did not reach agreement in round 2.
Activities and participation	9. 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	Item rejected in round 3

**Green** highlight items accepted items after all rounds

**Red** highlight items rejected items after all rounds

**Yellow** highlighted items that did not reach agreement after all rounds

### 5.3.6.3 Self image

Table 5.13 provides information on what items were accepted and rejected with regard to ‘self image’.

*Table 5.13. Means and standard deviation for ‘Self image’ statements*

Heading	Statement	R1 Mean	R1 SD	R2 Mean	R2 SD	R3 Mean	R3 SD	
Self image	1. A successful outcome is when a person reports having a positive body image (feeling attractive)	4.30	.811					Item accepted in round 1
Self image	2. 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	Item rejected in round 3
Self image	3. A successful outcome is when a person does not feel they stand out	3.66	0.98	3.54	0.60			Item rejected in round 2
Self image	4. A successful outcome is when a person does not mind looking at their residual limb (stump)	3.96	0.89	3.93	0.95			Item rejected in round 2
Self image	5. A successful outcome is when a person feels that they look balanced	3.71	0.84	3.50	0.73			Item rejected in round 2
Self image	6. A successful outcome is when a person is not feeling self-conscious when in public with a prosthesis	4.00	0.83					Item accepted in round 1
Self image	7. 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			Item rejected in round 2

**Green** highlight items accepted items after all rounds

**Red** highlight items rejected items after all rounds

**Yellow** highlighted items that did not reach agreement after all rounds

Although there was little disagreement in ratings for ‘self image’, 5 of the 7 statements originally proposed were not accepted by participants. Participants considered a successful outcome to be ‘when a person reports having a positive body image’ and ‘not feeling self conscious in public with a prosthesis’. These two statements were both accepted in Round 1. Therefore there are no open-ended responses for them. A further four statements were rejected in round 2. The statement pertaining to a successful outcome being when a person does not feel they stand out, received comments about the individualist nature of this question, suggesting that some people want to stand out. This opinion was shared by participants ranging from those who scored agree to disagree on this statement. One participant stated that a successful outcome should not be determined by standing out or

not. However, other participants acknowledged that most people want to look “normal” and not different. This statement shares a lot in common with the statement ‘...an individual does not mind looking at their residual limb’. Participants, who rated this statement ‘strongly agree’, commented that *“a person has to come to terms with the amputation and as such, must be able to look at their residuum”*. Ultimately, participants who scored ‘strongly agree’ felt it related to successful psychological adjustment. Many who commented ‘agree’ felt it related to ‘self acceptance’. Some who scored ‘disagree’ felt that this statement encompassed an individual choice rather than an ‘outcome’. Similarly for the statement ‘... not feeling self conscious when in public without a prosthesis’, those who scored ‘strongly agree’ to this statement, commented that *“to be able to be seen in public without one on, indicates good psychological adjustment”*. Once again, those who scored ‘Agree’, felt that this is indicative of ‘self acceptance’ and that it relates to others accepting them. Other participants suggested that *“Acceptance with or without the limb”* is a successful outcome. Participants who scored ‘neither agree nor disagree’ stated that *“as long as person is comfortable in public, doesn’t matter if this is achieved with a prosthesis or without”*. Another participant who ‘disagreed’ felt this was a personal choice rather than an ‘outcome’. Regarding the statement about balance, for one participant who strongly agreed, *“feeling”* in balance was a strong indicator of successful rehabilitation outcomes. However, the majority of comments were given from those who scored ‘neither agree nor disagree’ and many commented that they were not really sure why this statement matters.

The statement ‘A successful outcome is when a person is confident to show their residual limb (stump) in public’ did not reach agreement until the final round. One participant who ‘agreed’ with this statement indicated that *“it is a success if a patient is comfortable in their own skin, with or without their arm on”*. Some participants who rated it ‘neither agree nor disagree’ stated that *“it is very personal and shouldn’t be a successful or unsuccessful outcome either way”*

### 5.3.7 Section 2 items: Important items to consider in rehabilitation

These items in Section 2 refer to what participants rated to be important to consider in rehabilitation across 7 main categories. Table 5.14 lists the accepted items. The final score recorded is the final rating taken into consideration.

*Table 5.14. Items that should be taken into consideration by RP's in rehabilitation*

Heading	Item	R1 Mean	R1 SD	R2 Mean	R2 SD	R3 Mean	R3 SD
Engagement in Activities and Participation	Achieving set goals	4.48	.56				
	Engagement in activities of daily Living	4.74	.47				
	Engagement in leisure activities	4.55	.55				
	Getting along with other people	4.10	.85				
	Getting around	4.44	.62				
	Perceived environmental barriers	4.16	.75				
	Performing self care	4.70	.55				
	Performing social/ family roles of importance (e.g. breadwinner/ spouse/ student/ parent)	4.66	.53				
	The achievement of tasks set by the individual with ULA			4.50	0.84		
Physical factors	Cause of limb absence (congenital or acquired)	4.01	.83				
	General physical health	4.14	.71				
	Level of amputation	4.44	.67				
	Absence of dominant or non-dominant arm	4.26	.71				
	Phantom limb pain	4.41	.68				
	Phantom limb sensation	4.03	.80				
	Presence/ absence of certain joints	4.40	.60				
	Residual limb pain	4.38	.64				
	State of residual limb	4.53	.53				
Prosthesis use	Type of limb absence (bilateral or unilateral)	4.52	.70				
	Time since amputation	4.15	.72				
	Purpose of prosthesis use	4.47	.69				

Heading	Item	R1 Mean	R1 SD	R2 Mean	R2 SD	R3 Mean	R3 SD
	A patient's feeling of control over the rehabilitation			4.38	0.83		
	A patient's resilience			4.31	0.82		
	Anxiety	4.51	.57				
	Coping Strategies	4.64	.51				
	Depression	4.59	.55				
	Patient's attitude	4.66	.58				
	Patient's expectations	4.77	.49				
	Patient's mood	4.29	.66				
	Patient's motivation	4.74	.47				
	Patient's sense of humour	4.03	.82				
	Pre-amputation life experiences and skills (e.g. experience of disability or limb absence in the family)	4.03	.87				
	Post traumatic stress disorder (PTSD)	4.48	.58				
	The social skills of the individual With limb absence			4.03	0.75		
Rehabilitation service	Access to services (for example making appointments/ physical access)	4.44	.58				
	Satisfaction with the prosthesis	4.66	.53				
	Satisfaction with the rehabilitation Service	4.66	.48				
Self image	Body image	4.41	.57				
	Public self-consciousness (feeling self-conscious around other people)	4.36	.61				
Social Factors	Emotional support from family/ Friends	4.52	.63				
	Meeting another individual with limb absence	4.26	.75				
	Practical support form family/ friends	4.37	.61				
	Reaction of family to the prosthesis	4.37	.70				

There are no comments from participants for these statements as they were all accepted on their first round of rating. See appendix Z for the frequency distribution of accepted and non accepted items.



*Table 5.15. Section 2 items that were rejected by participants*

Heading	Item	R1 Mean	R1 SD	R2 Mean	R2 SD	R3 Mean	R3 SD
Demographic factors	Age at amputation	3.90	.93	3.85	0.77		
Demographic factors	Gender	3.34	.99	3.45	0.75		
Demographic factors	Level of education	3.16	.83	3.24	0.66		
Engagement in Activities and Participation	The achievement of tasks set by rehabilitation professional			3.78	0.73	3.76	0.59
Physical factors	Cause of acquired limb absence (trauma v malignancy/ disease)			3.90	0.79	3.89	0.70
Prosthesis use	Frequency of prosthesis use	3.99	.86	3.93	0.90		
Psychological factors	The extent to which people compare themselves to other people who are better or worse off	3.73	.84	3.41	0.75		
Rehabilitation service	Cost of prosthesis			3.83	1.01	3.91	0.66
Rehabilitation service	Whether individual is entitled to compensation			3.43	0.84	3.11	0.78
Social factors	Reactions from public	3.88	.71	3.74	0.61		

Table 5.15 shows the items that were rejected (had means less than 4). All demographic factors were rejected in Round 2. Regarding the demographic items, participants who scored strongly agree and agree argued that age at amputation is important and several participants implied that individuals that are younger, mostly referring to children, will be able to adjust better. However, it was also added by participants who scored ‘neither agree nor disagree’ that “*experience shows success and failure at all ages*”. With regard to gender, the comments provided were mixed with several participants suggesting that gender is not important and specifically that “*reactions to amputation and prostheses are not gender specific*” and that cosmesis can be just as important to men as it appears to be for women. However, other participants who scored ‘agree’ suggested that absence of an arm may be harder for females than males and that women may have more appearance concerns. Although most participants felt that level of education was not very important, it was suggested that “*cognition skills and visual motor skills are also very important*”. Also, level of education was suggested to influence how the professional communicates with the client. However, most comments suggest that participants felt it had little effect on outcomes.

Participants in round one were asked to rate whether ‘achieving set goals’ is important to take into consideration in rehabilitation, and they accepted this statement. However, participants made suggestions in round 1 that an individual achieving their own goals is important to take into consideration. Therefore, in round 2 participants were asked to rate whether ‘the achievement of tasks set by the individual with ULA’ was important to take into consideration as well as the item ‘the achievement of tasks set by the Rehabilitation Professionals. The findings suggest that achieving goals set by patient are more important to take into consideration than goals set by RP. One participant commented that there are two sets of goals “*patient’s (very important) and clinician’s (less so). These should be agreed together*”. For those who rated this item ‘important’ some comments reflected that RP’s have the experience to know what the patient will need beyond rehabilitation.

Ratings for frequency of prosthesis use suggested that participants did not feel it was on average ‘very important’. However, one participant who rated it ‘very important’ suggested that “*rehabilitation professionals should be asking if the patient is wearing the prosthesis as much as they would like to. That should be the directive criteria*”. Additionally, several participants suggested that frequency of use is linked to justification for the cost. Incidentally, the cost of prosthesis and whether an individual was entitled to compensation was not considered important by participants. In general, this finding reflects the findings in section 1 regarding prosthesis use.

As can be seen the item ‘extent to which people compare themselves to other people who are better or worse off’ was rejected. Most participants felt that ‘reactions from public’ was important, and this was reflected in most of the comments but their ratings weren’t strongly enough in favour to give this item a mean rating above 4.

From the open ended text comments it is apparent that in general participants wished to be clear that they considered an item indicative of ‘one of many successful outcomes’ and not indicative of the only one. Additionally, participants were given the opportunity in round 3 to provide any final comments they wished on the overall Delphi study. Some participants found some of the questions to be unrealistic, specifically suggested that questions such as

‘A successful outcome is when a prosthetic user can perform an activity bi-laterally to an equal standard as a 2 handed person’ was not at all possible given today’s prosthetic technology. This statement was initially suggested by one participant in round 1. This is an example of the idealism of some of the suggestions or ratings by some participants in this study. Also an important distinction was made by many participants that although they may consider a statement to indicate a successful outcome, it is not successful in isolation. Fundamentally, it constitutes one of many successful outcomes.

The importance of the perspective of the individual with limb absence was emphasized throughout the comments. Additionally, one participant suggested that *“prosthetic restoration or functional replacement is a tool to achieve success, but not the definition of success. Satisfactory completion of tasks important to the amputee, however, he or she achieves them should be the gauge of success, not whether or not they chose to wear a prosthesis to do so”*. Also, several participants expressed content at being given the opportunity to read other participants responses.

### **5.3.8 Change between rounds**

It is important to note how the ratings of statements/ items changed across rounds. Of the 12 statements/ items that had SD <1 in round 1 but had means less than 4 (meaning they had reached consensus but were not accepted), that were given a second chance in round 2, only one of these 12 went from round 1 (m=3.97; SD 0.816) to round 2 (m=4.02; SD 0.61). This means that this item/statement went from being rejected in round 1 to being accepted in round 2. 11 of the 12 remained the same from round 1 to round 2 (had SD <1 and means less than 4), 10 of those 11 had the mean scores reduce slightly from round 1 to round 2. Of the 6 items in round 1 that initially had no consensus (had SD>1), 4 of them still had no consensus in round 2. The other 2 reached consensus (had SD <1) in round 2, but were subsequently rejected (means <4). No item/ statement in round 3 reached a standard deviation less than one and mean greater than 4, therefore, no new items were accepted in this round. Also, looking at the standard deviations from most rounds, the standard deviation tends to reduce, from the previous round to the next showing greater agreement between rounds.

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### Chapter 5.4 Delphi Discussion

This chapter will begin with a discussion of the two main aims of the Delphi study. The first aim of this study was to reach consensus concerning successful outcomes of rehabilitation following upper limb absence across the areas of ‘prosthesis use’, ‘activities and participation’ and ‘self image’. The results suggest that successful outcomes of prosthesis use include when a person ‘wears a prosthesis for specific activities’, ‘wears a prosthesis as often as they wish’ and ‘uses the prosthesis as intended’. In relation to ‘activities and participation’ accepted statements included that a successful outcome is a person’s ability to perform their own personal care and activities of daily living without help from other people. With regard to ‘self-image’, participants felt that a successful outcome included people not feeling self-conscious when in public with a prosthesis.

The second aim of this study was to identify the most important items to assess or take into consideration during rehabilitation of ULA. Although this study may not have greatly narrowed down the number of important items, it has identified a comprehensive list of the potentially important items that are needed to be taken into consideration within the realm of ULA rehabilitation. Additionally within these 46 items, the study identified the seven major categories that are considered important. These were: ‘Engagement in Activities and Participation’, ‘Physical factors’, ‘Prosthesis use’, ‘Psychological factors’, ‘Rehabilitation service’, ‘Self image’, and ‘Social factors’.

#### **5.4.1 Successful prosthesis use**

This study identified statements that participants agreed described successful outcomes concerning ‘prosthesis use’. Only 3 of 12 statements concerning prosthesis use were accepted. The statement ‘a successful outcome is when a person wears their prosthesis for specific activities’ was accepted. This statement along with another accepted statement ‘a successful outcome is when a person uses the prosthesis as often as they wish’ contrast with the definition that normally constitutes successful prosthesis use in the literature such as greater hours of use indicating greater success (Roeschlein & Domholdt, 1989; Hacking et al, 1997; Datta et al, 2004; Biddiss & Chau, 2007c, 2008). As stated in Chapter 1, there

is a lack of consistency in ULA literature on the definition of successful prosthesis use, with hours of use per day being the most frequent measurement of prosthesis success, and greater hours of use implying greater success. However, there is no agreement on how many hours constitutes success. However, many studies suggest greater than 8 hours prosthesis use a day is success. But no study has provided justification for why they chose a particular number of hours use as their measurement of success. Additionally, the third statement accepted was ‘a successful outcome is when a person uses the prosthesis as intended (e.g. a functional prosthesis used functionally)’. This statement refers to the fact that individuals who may wear a functional prosthesis often but are not actually ‘using’ it on a regular basis, are in fact not achieving a successful outcome. This is an important differentiation as the cost of prescribing functional prosthesis is considerably more than a non-functional prosthesis, therefore it is important to know how a person is using their prosthesis and if it is used as intended.

The basic tenet for accepted statements in the present study appeared to be that successful prosthesis use is indicative of a person achieving their own goals for their prosthesis. The fact that the statement referring to wearing a prosthesis all day every day to be a successful outcome was rejected, adds weight to the argument that greater use is not the same as greater success. This raises questions about the appropriateness of the research and literature to date to predominantly employ hours of use as the main method of assessing success. Also, in the second section of the questionnaire where participants were asked to rate items that should be taken into consideration during rehabilitation, ‘frequency of prosthesis use’ was rejected, providing further support for the need to find an alternative method of measuring prosthesis success. The findings from the Delphi support the type of development by Gaine et al (1997) of the ‘Prosthetic success score’ (constituting daily wear, patient satisfaction, and function level) and Bhaskarand’s (2003) ‘Prosthetic rehabilitation score’ (patient acceptance, prosthetic usage and function level) as alternative measures of prosthesis success beyond the limited ‘greater hours, greater success’ notion of most studies. Gaine et al’s (1997) and Bhaskarand’s (2003) measures appear to be more all encompassing measures of prosthetic success.

It is important to acknowledge that participants were made aware that statements receiving a mean score of less than 4 would not be accepted. The items that participants didn't accept encompass what RP's and individuals with limb absence in this study feel do not represent successful outcomes concerning prosthesis use. Participants did not think that 'a successful outcome is use of a non-functional cosmetic prosthesis'. Although this finding is surprising given the seemingly individual approach most participants appeared to take regarding prosthesis use, it is in keeping with Roeschlein & Domholdt's (1989) assertion that use of a purely cosmetic prosthesis is considered indicative of unsuccessful prosthesis use. Additionally, examination of the differences between RP's and those with limb absence revealed that RP's scored this statement significantly higher than individuals with limb absence in both round 1 and round 2. However, the mean and standard deviation scores for each group reveals that neither RP's nor individuals with limb absence accepted the item. This is a potentially surprising difference that those with limb absence don't seem to think that cosmetic prosthesis use is successful. However, it is possible that the individuals with limb absence that participate in studies such as this are inclined to desire greater functionality and participate in studies in the hope of contributing to greater success in prosthetics. This is reflected in the comments from several individuals with limb absence that suggest that their greatest frustration is what the prosthesis cannot do and one participant referred to the prostheses that are currently on offer as simply no more than "toys".

Similarly to the statement above, it appears the statement 'a successful outcome is when a person is content not to wear a prosthesis' was also not favoured by participants. This statement implies that if a person chooses not to wear a prosthesis it is not a 'successful outcome'. The reasoning behind this choice may be influenced by the number of prosthesis wearers in the sample, with 68% of the participants that had ULA reporting prosthesis use. Additionally, RP's may be concerned that if individuals cease to wear a prosthesis once it has been prescribed that this is a waste of resources, as well as potentially functionally restricting some individuals in some areas. Furthermore, the statement 'a successful outcome is when a patient is satisfied with the cosmetic appearance of the prosthesis' was rejected. Considering evidence shows that satisfaction

with the prosthesis is related to prosthesis use (Biddiss & Chau, 2007c, Biddiss & Chau, 2008) and general and optimal adjustment (TAPES; Desmond & MacLachlan, 2005). It is surprising that RP's and individuals with ULA didn't consider that it constitutes success. Finally, the statement 'a successful outcome is when a person feels their prosthesis is part of them' did not reach agreement amongst participants. The standard deviation showed that there was almost agreement (1.08), but the mean was not near the accepted score of 4. The rejection of this statement and disagreement amongst participants perhaps reflects Murrays (2009) assertion that prosthesis will feel 'part' of them for some individuals and simply be a tool for others. It is important that this dichotomy of experiences is acknowledged in research and practice, to understand that both conceptualisations can equally constitute success for different individuals following ULA.

#### ***5.4.2 Successful outcomes regarding 'activities and participation'***

The outcomes referring to 'activities and participation' implied that success for an individual with ULA is performing their personal care and ADL independently from other people and an ability to drive, if an individual wishes. These findings reflect the importance of independence. Similar findings have been shown in the qualitative literature such as Saradjian et al (2008) and in Murray (2009).

The statements 'a successful outcome is a person's ability to perform activities within the same time parameters as prior to their injury', and 'a successful outcome is a persons ability to perform activities to the same standard as they had before the limb absence' were rejected by participants. Both of these statements appear to have been rejected on the basis that they were too idealistic and current prostheses do not allow for this level of function. These findings suggest a response shift is required from participants regarding what is acceptable after limb absence. Its purpose is believed to be to keep a person's feeling of well being within a narrow positive range despite considerable health difficulties and it has been ascertained that response shift may be especially important in situations where symptoms and functions may not improve dramatically but better QOL is desired (Schwartz & Fairclough, 2004). This is particularly relevant amongst individuals with ULA, where their physical situation cannot be changed (Barclay-Goddard & Epstein

& Mayo, 2009). This reflects what Rochette et al (2006) suggested regarding the acceptance of doing activities and roles differently, perhaps with the use of an assistive device on a day to day basis without getting constantly frustrated, would constitute a change in the patient's internal standards. However with regards to the latter statement, 'a successful outcome is a persons ability to perform activities to the same standard as they had before the limb absence', it is important to note that in the second round of questions, individuals with limb absence scored this statement significantly higher than RP's, implying that those with limb absence think a successful outcome does require activities to be the same standard as before the limb absence. However, the statement was not accepted by either group. This finding signals a disparity between the goals of RP's and the desires of those with limb absence. Similarly, agreement could not be reached on the statement 'a successful outcome is when a prosthetic user can perform an activity bi-laterally to an equal standard as a 2 handed person'. This statement is likely to have the same issues as the previous statement in that it is ideal but not achievable.

#### ***5.4.3 Successful outcomes regarding 'self image'***

Given the limited data on body image amongst individuals with ULA in the literature, these findings from the Delphi data make an important contribution to the literature. Findings suggest that 'a successful outcome is when a person reports having a positive body image (feeling attractive). Furthermore, a person not feeling self-conscious when in public with a prosthesis was considered important to achieve. However, the statement 'a successful outcome is when a person is confident to show their residual limb (stump) in public' was rejected but scored significantly higher by the participants with limb absence in each round compared to RP's. This suggests that individuals with limb absence believe this to be more important than RP's and therefore despite not being accepted by the entire range of participants, person centered care would suggest that if participants consider it to be important, it should be target of rehabilitation to address an individual's feeling of self-consciousness in public. Additionally, the statement 'a successful outcome is when a person does not mind looking at their residual limb (stump)' is quite similar to the previous statement as is the statement 'a successful outcome is when a person is not feeling self conscious when in public without a prosthesis. However, the implied



difference between them is that in the former, 'residual limb' is referring to showing the bare limb whereas in the latter statement it is referring to simply not wearing a prosthesis, and perhaps having clothes covering the stump.

Of the 14 items/ statements in presented in round 3, only 3 items did not reach consensus (had SD >1). Two of these were the original statements in round 1, and the third was a newly proposed statement from round 1.

- A successful outcome is when a person wears their prosthesis all day every day (mean =3.08)
- A successful outcome is when a person feels their prosthesis is part of them (mean=3.64)
- A successful outcome is when a prosthetic user can perform an activity bi-laterally to an equal standard as a 2 handed person (mean 3.23)

As can be seen, all items that did not reach agreement were statements referring to defining a 'successful outcome'. Although following examples from previous rounds, the third item which was a newly proposed item from round 1 should have had one final chance to reach agreement. However, it was felt that there was little justification for a 4<sup>th</sup> round just for one item. Also considering the mean reduced from 3.41 in round 2 to 3.23 in round 3, even if it had reached agreement in round 4, it is likely that it would have remained unimportant (mean <4).

#### ***5.4.4 Important areas to consider in rehabilitation.***

This study has identified 46 key items to take into consideration or assess in rehabilitation and they fall within 7 major domains consisting of; 'Engagement in Activities and Participation'; 'Physical factors'; 'Prosthesis use'; 'Psychological factors'; 'Rehabilitation Service'; 'Self image' and 'Social factors'. One domain 'Demographic Factors' incorporating age, gender, and education level was not deemed sufficiently important to consider by the average rating attributed to these items by participants. The rejection of age at amputation as important is not surprising since no evidence from the literature has suggested it plays a role in any of the major outcomes such as prosthesis use (Roeschlein & Domholdt, 1989; Wright et al, 1995; Hacking et al, 1997); psychosocial adjustment or psychological distress (Desmond, 2007; PLP or PLS (Kooijman et al, 2000). Equally, although Roeschlein & Domholdt (1989) found prosthesis users to have a higher level of education than non-users (not tested statistically), participants in the present study did not

consider it important to take into consideration. There has been no further support or investigation of this in the literature or justification for why it may influence outcomes. The third demographic item that was rejected referred to gender. This is slightly surprising because although the literature suggests that there is no gender difference for levels of PLP or PLS (Kooijman et al, 2000), findings in relation to prosthesis use suggest that females with acquired amputations may be more vulnerable to rejection of prostheses than males or females with congenital limb absence (Biddiss & Chau, 2007c). However, the present study asserts that while there may be some differences in gender reactions, it is not deemed an important factor to take into consideration during rehabilitation.

With regard to items concerning goal setting, in the section on 'Engagement in Activities and Participation', the findings in this study are of relevance considering it emerged that participants considered it important to take into consideration the achievement of set goals. When further broken down, into two separate items, items pertaining to goals set by the person with limb absence; and goals set by RP, the former was accepted, while the latter was rejected. This finding provides evidence that both RP's and individuals with limb absence consider patients' goals to be more important than RP's and supports patient centred goal setting at the beginning of rehabilitation and ensure re-evaluation of whether these goals have been achieved at regular intervals. This was the only item in this section that was rejected.

For the section referring to 'Physical factors', 11 out of 12 items were accepted. Although the item cause of limb absence in terms of whether it was congenital or acquired was thought to be important to take into consideration, the distinction between trauma versus malignancy/ disease was not. However, open ended text responses did not provide any insight into why the item concerning congenital versus acquired was accepted and not trauma versus malignancy disease. The literature supports the suggestion that individuals with acquired limb absence may be more likely to use a prosthesis than those with congenital limb absence (Biddiss & Chau, 2007c). However, differentiating between whether acquired limb absence was due to trauma or malignancy/disease although not investigated previously in the literature was not considered important to consider.

In the section referring to 'Prosthesis use', participants rejected the item 'frequency of prosthesis use' but included 'purpose of prosthesis use' as important for RP's to take into consideration. This provides quite clear evidence of what both individuals with limb absence and RP's consider more important. This finding supports the earlier results with regard to successful prosthesis use.

The only psychological factor to be rejected in the Delphi study was the one referring to social comparison 'the extent to which people compare themselves to other people who are better or worse off'. This item was included in the list of items, as previous qualitative research (Saradjian et al 2008) and results from the qualitative investigations (Chapter 4) suggested that participants were likely to engage in downward social comparison.

However, despite items from the psychological factors domain such as 'the extent to which people compare themselves to other people who are better or worse off' being rejected, other similar items relating to 'social factors' such as 'emotional support from family/ friends' and 'practical support from family/ friends' and 'meeting another individual with limb absence' were considered important as well as the reaction of the family to the prosthesis. These findings once again provide further support for the value of incorporating the family into the rehabilitation process to enable them to understand their valued role in the patient's adjustment.

In relation to the domain concerning 'Satisfaction with rehabilitation service, items referring to 'access to services', 'satisfaction with prosthesis' and 'satisfaction with rehabilitation service'; were all accepted as important, while the items 'cost of prosthesis' and 'whether an individual is entitled to compensation' were rejected. The open-ended responses suggest that although many individuals believed that cost/ compensation can interfere with outcomes, it is important as much as possible, to not let cost/ compensation issues influence the decisions they make that are in the best interest of the patients.

#### ***5.4.5 The present study***

This study employed a 'Modified Delphi' approach, incorporating previous qualitative research (chapter 3 and 4) with RP's and individuals with limb absence to inform the first round of the Delphi in lieu of a traditional open ended first round Delphi. This has been done in several previous studies in health research such as Evans, Rogers, McGraw, Battle & Furniss (2004) and Petry et al (2007). Although Evans et al (2004) did not employ an identical technique, they initially used a nominal group technique with health professionals. Then, in conjunction with a prior literature review, they attempted to gain consensus with the Delphi technique. Petry et al (2007) conducted interviews with patients and experts, then conducted a two round Delphi study. The advantages of having interviews and literature to inform the first round Delphi is that it provides a solid grounding in previously developed work (Custer et al, 1999). Although researchers such as Hasson et al (2000) and Keeney et al (2000) called the interview and focus group part of their research in the first round, the present study considers them separate research phases (Chapter 3 and 4) while also informing the first round Delphi, representative of the mixed method design of the overall thesis.

It is important to note items/ statements that were rejected were not necessarily considered 'unimportant' by participants and may still have an important role to play, they were just not considered important enough to reach the predefined level to be accepted. It appears for many of the statements defining 'successful outcomes', participants rejected them as they were unrealistic or not necessary to achieve. Therefore it is proposed that the items that were accepted were 'realistic' and necessary.

#### ***5.4.6 Useful applications of the findings***

A review of the literature has highlighted that there is a need for a brief instrument to assess areas of concern amongst individuals with limb absence, so that RP's can identify issues quickly in consultation with a patient and therefore address it. There are several brief screening tools available, some of which assess psychological distress such as the HADS (Zigmond & Snaith, 1983) and the Brief Symptom Inventory (BSI-18), but others such as the SF-12 (Ware et al, 1998) are useful as general measures of health status.

As this study has identified the 7 main domains that are important to consider amongst individuals with ULA, and 46 related items that relate to these domains, it would be useful to use these to form a screening tool with individuals with ULA in a rehabilitation setting. These domains and items that were identified through the Delphi study provide a guide for clinicians to know the most salient issues to attend to amongst individuals with ULA, and the likely areas of concern. A screening instrument using the principles of the Distress Thermometer (Roth, Kornblith, Batel-Copel, Peabody, Scher & Holland, 1998) could be suitable. The Distress Thermometer works on the principle that it calls attention to the distressed patient and allows the conversation about distress to begin. It works by asking the patient on a scale of 0-10 (from no distress to extreme distress) “How distressed have you been in this past week, including today?” with scores of 5 or above indicative of significant level of distress that should be evaluated further. A problem list accompanies the thermometer, which asks the patient to indicate the causes of their distress from 34 issues, as to whether they are practical, family, emotional, spiritual or physical. If a patient checks “yes” to an item under emotional problems” one could consider giving them to Hospital Anxiety and Depression Scale (HADS) for more specific assessment (The American Psychological Oncology Society (APOS; 2006). It is proposed that the items developed from the Delphi study can serve as a form of checklist for practitioners in ULA rehabilitation in the same way as the Distress Thermometer. However, instead of the checklist simply referring to psychological distress, it will allow quick 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 is an area that warrants further research.

#### ***5.4.7 Limitations of the Study***

It is important to acknowledge the limitations of the present study. The round 1 Delphi did not give participants the opportunity to give reasons for their responses to each particular statement/ item as it may have caused participant fatigue and cause participants to drop out due to the amount of items in round 1. However, participants were given the opportunity in round 2 to give reasons for their response to statements/ items that had not reached consensus, or had mean scores less than 4 in round 1. This method meant that

only items/ statements that had disagreement or were at risk of being rejected had responses gathered. Therefore, there are several items that were accepted by participants on the first time they were rated, that there are no open ended responses. Therefore the researcher has no further insight into why they were believed to be important.

It could be argued that that since there were no new items accepted in round 3, whether there should have been a third round. However, it is felt that the inclusion of the third round is justified as three of the items had no agreement in round 2, reached agreement in round 3, but were subsequently rejected due to having means less than 4. Also the addition of further qualitative comments from round 3, gives greater insight into participants reasons for their ratings.

Due to the wide range of professions participating in this study but a small number of participants representing some professional groups, the differences between professions were not assessed. However, it is important to note that differences between RP's and individuals with ULA were assessed, which demonstrated that the mean ratings attributed by both groups differed significantly on some items. However, only a minority differed to the extent that some items were accepted by one group but rejected by another.

#### ***5.4.8 Strengths of the study***

Despite the above limitations, there were several advantages to the present Delphi study. Firstly, the recruitment method of snowballing was effective as an additional 25 RP's were recruited from the first round through this method. This technique has been used in other studies using the Delphi (Hartman & Baldwin, 1995; Mason, 1996). Also, the attrition rates of participants between each round was low, (particularly in round 3) with each round exceeding the recommended response rate of 70% suggested by Sumsion (1998). Therefore, the 'response exhaustion' found by Mc Kenna (1994b) after two rounds was not apparent in the present study. Also, taking into consideration that the rounds were conducted over summer months, when some panel members may have been on holidays, some level of attrition was expected and was taken into consideration from the outset. Sending two reminders to participants to complete each round appears to have influenced

the response rate, with many respondents completing the questionnaires soon after receiving the prompt.

Bardecki (1984) reported that those with extreme views will drop out of a Delphi study and that consensus will therefore be due to attrition and not to any change in views. To ascertain if this was the case in the present study, those who completed round 2 were compared to those who did not, and those who completed round 3 were compared to those who did not in relation to their round 1 scores to assess any differences. Similarly, those who completed round 3 were compared to those who did not complete round 3 in relation to their round 2 scores. Although a few items in each analysis were significantly different, these were only a minor amount compared to all the scores the participants had to rate. Therefore, it appears that consensus was reached as a result of participants changing their views between rounds in line with the opinions of others that were presented to them and not the result of attrition. Also, participants who dropped out after round 1 (i.e. completed round 1 but not round 2), had not yet seen the other participants scores, as they couldn't progress through each page of the study without answering each question, so it is therefore unlikely that they dropped out due to dissatisfaction that their scores were not represented by the mean scores. These findings add to the validity of the results from this study.

Although the panel size in the final round ( $n=53$ ) did not reach the desired panel size of 60 at the outset of the study, the number still exceeds the recommended panel size of 15-30 participants suggested by Ladetta (1999). The panel size also exceeded the number of participants in Van der Linde et al's (2005) Delphi study of experts working with individuals with lower limb prosthetics. Although, sample size can and does vary widely amongst Delphi studies, it has been suggested that having a slightly larger sample size is beneficial as there will be a greater the generation of data (Hasson et al, 2000). Also, Van der Linde et al's (2005) study did not include individuals with limb absence in their sample as this study did.

The use of the internet to distribute questionnaires in general and specifically Delphi questionnaires is becoming more common (e.g. Miro et al 2008; Van der Linde et al

2005). Its use in the present study proved convenient, with potentially less burden on participants compared to needing to post several rounds of a questionnaire back to the research team. This method therefore may have influenced the good participation rates observed. It also enabled a relatively quick turnaround time between questionnaires, enabling inputting of data conveniently for the researcher. The internet Delphi method also provided an opportunity for a geographically diverse group of RP's and individuals with limb absence to consider each others responses and opinions and reach consensus (Jones et al, 1992, Ziglio 1996). Additionally, some participants in this study expressed appreciation at the research being conducted and others stated that they liked having the opportunity to read others responses.

Although there were some issues associated with RP's and individuals with limb absence (discussed in the section on limitations), in all their contribution outweighed the disadvantages. With regard to including two distinct groups of participants in this study, RP's and those with limb absence, it is acknowledged that although there appeared to be some differences between RP's and individuals with limb absence in the present study with regard to some statements/ items, their inclusion enabled an insight into what specific areas RP's and individuals with limb absence differ. It has enabled us to build on and confirm what both RP and individuals with limb suggested in the qualitative studies. Although the participation of RP's who also have ULA was unanticipated, this sample gave an interesting perspective, as in some areas they have a very unique ability to see both perspectives. Ultimately, it needs to be considered that individuals with ULA are integral members of the MDT alongside RP's and therefore their inclusion is important in this research. The value of including individuals with ULA in Delphi research was also highlighted by Van der Linde et al (2007).

#### **5.4.9 Conclusion**

This study provided an opportunity for 'experts' to communicate their opinions and knowledge anonymously regarding the important areas to consider in rehabilitation and to see how their evaluation of the issue aligns with others, and to change their opinion, if desired, after reconsideration of the findings of the groups work (Powell-Kennedy, 2004).



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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 RP's and individuals with limb absence consider important, such as specific use of the prosthesis, as often as an individual wishes, while using it as intended. Additionally, this study clarified how individuals consider performing activities of importance independently is of key importance and an individuals feeling attractive is part of a successful outcome. The successful clarification of seven key domains of importance to consider in rehabilitation, along with 46 specific items pertaining to these domains is useful, as well as providing support for the key themes identified in the qualitative studies and their acceptance from a wider audience.

Chapter 6 Thesis Conclusion

<b>6.1 Review of the rationale for conducting this research .....</b>	<b>285</b>
<b>6.2 Summary of findings.....</b>	<b>287</b>
6.2.1 Repertory Grid Case Studies.....	287
6.2.2 Qualitative Studies.....	288
6.2.3 Delphi Study.....	290
<b>6.2 Implications of research.....</b>	<b>292</b>
<b>6.3 Concluding comments.....</b>	<b>297</b>

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Chapter 6 Thesis Conclusion***6.1 Review of the rationale for conducting this research***

This research was conducted in order to expand the research literature on ULA through a mixed method design of qualitative and quantitative research. As stated in Chapter 1.1, it is not sufficient to simply look to lower limb amputation research and assume the findings from research with individuals with lower limb absence will apply equally to those with ULA, as there are distinct differences between these two populations such as differences in causes and incidence; age, gender, visibility, and functionality of these two conditions and this study argues that there is a particular need to expand research with individuals with ULA given their documented younger age and general good physical health compared to people with lower limb absence.

The review in Chapter 1 demonstrated that much of the literature involving individuals with ULA is largely concerned with identifying the likely predictors of ‘prosthesis use’, with the definition of ‘successful prosthesis use’ varying across studies which makes it difficult to compare between studies in order to reach consensus regarding the likely determinants of prosthesis use. Specifically, many studies differ in what they are defining as ‘prosthesis success’ with some referring to whether the prosthesis is used at all versus being outright rejected and others assessing frequency of use. Also, for those studies assessing frequency of prosthesis use as indicative of prosthesis success, most studies consider greater than 8 hours use to be success, whereas some consider greater than 4 hours to be success. Additionally some studies have considered that use of a cosmetic prosthesis or sporadic use of a prosthesis is unsuccessful. Additionally, this review questioned whether measuring prosthesis success in terms of hours use is in the best interest of the individual and asserts that the patient should be involved in determining what constitutes successful prosthesis use. Ultimately, the limited studies that exist in the ULA literature and the lack of transparency in how some of the studies are conducted add to the difficulty in drawing valid conclusions from those studies.

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While taking into consideration the shortcomings and limited evidence, regarding the predictors of successful prosthesis use, the literature review suggested that the following factors may be related to prosthesis rejection: females with acquired limb absence may be more likely to reject a prosthesis compared to females with congenital limb absence or males; those who lose a limb through congenital causes, are more likely to reject a prosthesis compared to those who lose a limb through acquired causes; those with higher and lower levels of limb absence are more likely to reject their prosthesis; those with congenital bilateral limb absence are more likely to reject a prosthesis compared to those with congenital unilateral limb absence; those who are less satisfied with their prosthesis may be more likely to reject a prosthesis; and those who are less satisfied with their service may be more likely to be prosthesis rejecters. However, this review could not find sufficient evidence of what factors may contribute to greater hours of prosthesis use.

Most studies to date have been largely 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 psychosocial research is evident in general in research concerning ULA as was demonstrated by the literature review concerning psychosocial outcomes of importance in ULA. The literature review also highlighted the lack of sufficient psychosocial research on upper limb amputation, especially in areas such as body image; but highlighted the merits of qualitative research in drawing attention to the under-researched areas.

The review also described how most studies measure an individual's functional capabilities in terms of achievement of goals and engagement in activities of interest and of personal need. Based on the available evidence to date, this review of the functional and physical outcomes suggested that individuals with ULA might have reduced levels of function compared to individuals without ULA. In addition, it appears that individuals with ULA tend to change their leisure activities and employment following ULA. The research also suggested that the prosthesis is usually wanted or needed for the purpose of performing ADL. The literature concerning co-morbidities suggested that levels of pain

vary widely across studies in ULA studies. Although PLP appears to have the highest pain intensity of sufferers, it has the lowest reported interference. However, it was asserted that these conclusions were based on limited evidence and further research, in particular longitudinal research, will be required to establish causal relationships.

Ultimately, the literature review demonstrated that less research space has been reserved for outcomes other than prosthesis use following ULA, such as the functional, physical and psychosocial outcomes, which makes ‘success’ in these areas difficult to define. Therefore this study wished to use a mixed method design to answer the two main research questions, which asks what are the factors of importance to consider after ULA and what constitutes a successful outcome in these areas.

## ***6.2 Summary of findings***

### ***6.2.1 Repertory Grid Case Studies***

This mixed methods study had 3 major research phases. The first was the repertory grid analysis which explored the values and preferences that upper limb prosthesis users have of themselves and different potential prosthetic options; and demonstrated a novel application of a method for exploring the needs of prosthesis users. The results showed that a number of different features are important to individual prosthesis users when selecting a prosthesis. For the first participant, Jennifer who was using a technologically advanced prosthesis, the most prominent feature was function, and she admitted to having little interest in aesthetics, which was evident from her repertory grid. Whereas, for the second participant Declan, who used a conventional body-powered prosthesis function, reliability and not standing out were the most prominent constructs that emerged from his grid. The results showed that both Jennifer and Declan valued function the most, using several different constructs concerned with function to demonstrate this. However, Jennifer appeared to desire her prosthesis for task specific activities such as cooking. In contrast, Declan wore his prosthesis all day, mainly for functional reasons, but also in order to not stand out, but he emphasised that in his opinion it is important for an individual to strike a balance between aesthetics and function following ULA. While

numerous papers suggest that individuals may vary in their prosthetic preferences, these case studies using a standardized assessment process provide evidence to support this assertion. Also, this study demonstrates that an individualized technique such as the RGT is valuable in generating in depth information that may not have been achieved through a conventional interview. Additionally, these case studies support suggestions from Scherer (2002), Phillips & Zhao (1993) and Wielandt et al (2005) that the perspective of the user should be incorporated into device selection and that there is a need to provide prosthetic options to users. By rating the technology on these scales, we are essentially rating the technology under headings that are personally important to the prosthetic user. The findings from this study partly informed the data that contributed to the items for the Delphi study.

#### 6.2.2 Qualitative studies

The second phase of this mixed methods research used focus groups and interviews with RP's and individuals with limb absence that provided a detailed insight and comparison into how both groups consider 'success' following absence of the upper limb. There were several common themes between both groups, such as 'prosthesis use', where individuals with limb absence characterised prosthesis use in terms of its benefits, especially in relation to how it facilitates function and minimises a person's feeling of self-consciousness and promotes a positive self image. In particular the social and aesthetic role of the prosthesis was also emphasised by participants. However, this study found that in contrast to patients emphasis on what the prosthetic allows them to achieve, the RP's were more concerned with patients wearing a prosthesis and they suggested that they know someone is 'doing well' by whether they are wearing the prosthesis. The theme of 'function' was also common for both groups, with both RP's and individuals with limb absence suggesting that the ability to perform ADL, personal care, leisure and work activities usually constituted a favoured outcome for an individual. The theme of 'psychological factors', although constituting a theme in both studies, differed in its emphasis between RP's and individuals with ULA, as RP's were concerned with a patients mood and the potential for psychological distress and how these factors in turn can interfere with a persons rehabilitation. Whereas individuals with ULA were more

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focused on the importance of character traits such as positive attitude and humour and how adoption of these characteristics can positively influence their adjustment. ‘Physical factors’ mentioned in common between both groups was the impact that presence of pain can have on an individual. However, RP’s emphasised that it is important to ensure patients have minimal pain, whereas most individuals with limb absence that suffered from PLP, discussed how few treatments have been effective in reducing their pain and they now rely on the ‘power of their mind’ to manage their pain. Additionally, the themes of ‘satisfaction with the prosthesis’ and ‘satisfaction with the rehabilitation service’ provide an important contribution to future developments of prostheses and the services provided to individuals with ULA, and suggested it is important to focus on improving the materials used in prosthesis development; and to focus on the important contributions of the entire multidisciplinary team, especially OT’s and psychological services. The additional themes suggested by individuals with ULA such as ‘self image’ and ‘goal setting’ by RP’s provide additional support for the investigations of these aspects in future studies.

The inclusion of interviews with RP’s in this study was valuable in assessing their perspective on the issues of importance following ULA and has not been investigated in this area to date. Furthermore, given the relatively sparse research amongst individuals with ULA, the addition of a qualitative investigation is an important contribution to the literature as it successfully provides a voice to individuals with ULA regarding what factors they consider important following limb absence. The use of focus groups and interviews facilitated the emergence of a broad range of factors of importance to the population of individuals with ULA.

Although some previous studies within the amputation literature have investigated the views of the multidisciplinary team, this study was the first to qualitatively explore the views of the multidisciplinary team concerning their views of the factors associated with the rehabilitation of patients with ULA from the physical, functional and psychosocial perspective. A considerable merit of this study was the comparison of the RP’s perspective with that of the individual with ULA, as previous research has acknowledged



that both perspectives are equally important but can often differ. Despite assertions by Rothwell et al (1997) and Scherer (2002) that health professionals have a tendency to be over concerned with the physical aspect of disabilities and physical functioning in general, this was not overly apparent in the present study; with both groups of participants providing a diverse range, of psychological, social, and physical predictors that impact the individual following ULA.

Of particular note, the use of qualitative research in the present study provided the opportunity to open up different research areas by giving greater insight into the role of the prosthesis in ULA and highlighting additional psychosocial factors of interest. It also should be emphasized how the social and contextual aspects of disability were inherent within this research as recommended by the WHO's ICF framework. This qualitative investigation identified an array of themes of importance that represent a holistic view of the outcomes of importance to individuals with ULA and RP's in relation to rehabilitation. The qualitative results in conjunction with the findings from the literature and the repertory grid analysis provided items and statements with which to begin the final phase of analysis, the Delphi study, in order to reach consensus.

### 6.2.3 Delphi Study

The final stage of the mixed method study incorporated a Delphi study. Indeed, the international online Delphi study conducted with a sample of RP's and individuals with ULA enabled a thorough analysis of all findings from the literature review, repertory grid, and qualitative analyses to attempt to gather opinions from those most knowledgeable of the area of upper limb absence and reach agreement on what constitutes 'success' in three key areas, where the literature and the qualitative phase demonstrated that there is limited knowledge or disagreement: 'prosthesis use', 'activities and participation' and self-image'. Results showed that participants reached consensus (agreement amongst panel members; having a standard deviation <1) over the three rounds on 25 of 28 statements concerned with defining successful outcomes in these three areas. Only 11 statements reached a mean score of 4 on the 5 point (1-5) Likert scale (these items were accepted as being successful outcomes) and 14 statements were rejected as successful outcomes for having a

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mean score below 4. The accepted items indicated that successful ‘prosthesis use’ is ‘wearing a prosthesis for specific activities; using a prosthesis as often as they wish; and using a prosthesis as intended. Regarding ‘activities and participation’, the accepted items indicate that a successful outcome is an ability to perform their own personal care and ADL without help from other people. Also, a successful outcome includes that a person has returned to active employment (but may have to change jobs). A further successful outcome ‘is a person performing to the best of their ability’. Lastly, for ‘self image’, accepted items indicated that a successful outcome was considered when ‘a person reports a positive body image (feeling attractive)’ and ‘not feeling self-conscious in public with a prosthesis’.

This study also identified what is important for RP’s to take into consideration when rehabilitating an individual with limb absence. All of the 53 items concerned with identifying what is important for RP’s to take into consideration in rehabilitation reached consensus. However, the consensus reached on 10 of these items was that they were unimportant as they did not have a mean rating above four and so they were rejected. Additionally within the items that emerged as important, seven major categories were identified. These were: ‘Engagement in Activities and Participation’, ‘Physical factors’, ‘Prosthesis use’, ‘Psychological factors’, ‘Rehabilitation service’, ‘Self image’, and ‘Social factors’. The category of ‘Demographic factors’ which consisted of ‘age at amputation’, ‘gender’ and ‘level of education’ had had all three items rejected by participants.

This study recommends that findings from the Delphi study can help form the basis for a screening tool, for clinicians to be able to identify areas of concern for a patient in their care and to subsequently treat them. This study successfully included both RP’s and individuals with ULA in the Delphi study, providing further support for their future inclusion in research in this area

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### **6.3 Implications of research**

The main contribution this series of studies has achieved is the defining of what constitutes success in three key outcomes: ‘prosthesis use’, ‘activities and participation’ and ‘self image’. Clarification of these areas allows a clearer evaluation of what should be the focus of rehabilitation in these areas. The results in the Delphi study highlighted that there is a difference between knowing an ‘ideal’ outcome versus an ‘achievable’ outcome. It is therefore important to identify the realistic outcomes that constitute success.

All three phases of this mixed methods study gained a particular insight into the issue of ‘successful prosthesis use’ and challenged the ‘status quo’ of how it is measured in research. The repertory grid analyses in Chapter 3 with Jennifer demonstrated that, hours use is not a sufficient measure of prosthesis success. For example, Jennifer had undergone major pioneering surgery as a research participant and was using a high tech prosthesis, which was facilitated as an outcome from her surgery. Jennifer was highly satisfied with her functionality and her current prosthesis, and her self image. However, by standard measures of prosthetic success, she would be classed as moderately successful, due to her use of a prosthesis, 4 hours a day and 4 days a week. This notion challenges how adequate this measure of successful prosthesis use is. What is more important in terms of measuring hours of prosthesis use is if there is any dissonance between a users desired hours use versus actual hours use. Additionally, it is also important to consider that hours ‘wear’ does not necessarily equal hours ‘use’ as one individual may wear their prosthesis all the time but only functionally “use” it for cooking, whereas another person might only put the prosthesis on to cook. Individuals representing these two scenarios are no different in success.

Additionally, findings from the qualitative analyses from the RP’s indicated that a successful outcome is when the prosthesis is used as intended, while acknowledging that prosthesis use is individual to each patient. This emphasis contrasts to that of individuals with limb absence who focused on the prosthesis as a facilitator of activities or personal and social adjustment. Both groups of participants in the Delphi study also emphasised the importance of performing specific activities. This finding suggests that the prosthesis is

not necessarily important in its own right, but it is important through what it does. This quantification of prosthesis use that is widely evident in ULA literature is likely to be influenced by this practice from lower limb research, where frequency of prosthesis use is more likely to be important. This may be because if an individual is not wearing a lower limb prosthesis, they are more likely to have restriction of mobility. This is unlikely to be the case in ULA. This study challenges the notion that prosthesis use is ‘best’ and that use of a prosthesis equates to a successful outcome. ‘Prosthesis use’ has in many studies become synonymous with ‘prosthetic ‘success’ without questioning are they the same thing.

In a similar way as the repertory grid was used in the present study to assess what an individual wants from a prosthesis, perhaps a brief, more accessible individualized method to assess a persons own interpretation of what constitutes a successful outcome following absence of an upper limb is needed. This principle has been used in quality of life measures such as the Schedule for the Evaluation of Individuals Quality of Life (SEIQoL; McGee, 1991; O’Boyle, McGee, Hickey, O’Malley & Joyce, 1992) and the Patient Generated Index (PGI; Ruta, Garratt, Leng, Russell, & MacDonald, 1994). For example, the SEIQoL asks patients to nominate 5 aspects of their lives (not specifically health related) which most contribute to their overall quality of life at the time of assessment and the PGI which uses a similar concept but is specifically health related. Additionally, Carr & Higginson (2001) suggested a weighting system be employed when assessing individualized quality of life to ensure what is being measured is important to the individual. Additionally, Gallagher & Desmond (2007) argue that individualized measures of quality of life allow the respondent to nominate and weight the importance of aspects of their own lives rather than imposing an external, potentially less individually relevant standard through administration of a fixed predetermined set of questions. Arguably, this ethos could be usefully applied in the clinical setting when assessing the outcomes of importance to individuals with ULA.

The second contribution of this research is that it has identified seven key domains to consider in rehabilitation; and is the first study in the ULA literature to undertake this task.

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The fact that it was developed in consultation with RP's and individuals with limb absence gives weight to its applicability and validity for use with this population. Additionally, this study has provided a core set of 46 factors to consider when assessing the progress of an individual with ULA during a consultation or rehabilitation. These domains as well as the specific items complement the lessons from disability studies in that they incorporate the personal, social and environmental factors that affect the life of an individual with ULA, and emphasise the importance of attending to these highlighted areas from disability studies during rehabilitation. The identification of these core set of factors may also be an appropriate starting point for development of a screening tool to assess areas of concern in an individual undergoing rehabilitation for ULA. This is an important area for future research in this area.

As stated in Chapter 1, literature on limb absence in general has largely used quantitative methods in their studies, which is a limitation acknowledged by Gallagher & MacLachlan, 2001; Murray, 2009, as particularly in ULA research, there is a scarcity of qualitative research. This research has demonstrated the usefulness of three qualitative techniques, repertory grid, interviews and focus groups and shown their applicability to unearth data of relevance beyond what most quantitative data has investigated (such as importance of a patients attitude and humour) and incorporate the perspective of the two important populations in rehabilitation, the individuals with limb absence and the RP's who work with them. Qualitative research is important to carry out in areas where there is little data, in order to help focus where most research is needed. However, the inclusion of mixed methods, incorporating quantitative methods in the Delphi study with the purpose of verifying the findings of the qualitative stages with a larger sample, was successful, as consensus was reached on most items, thereby supporting the validity of the qualitative data.

The stated need for greater psychological support from both RP's and those with ULA, and suggestions that the social support they received along with meeting another individual with limb absence are important in the rehabilitation process provide compelling support that individuals with limb absence should be involved in support

groups as part of their rehabilitation. In particular, these findings provide support for the move towards intervention research such as the PALS intervention. PALS (Promoting Amputee Life Skills) was developed by Wegener, MacKenzie, Ephraim, Ehde, & Williams (2009) which involves self management promoting techniques and teaching skills and problem solving to individuals with limb absence which are facilitated by an individual with limb absence in a support group context. Wegener et al (2009) assessed the acceptance and effectiveness of a community based self management intervention designed to improve outcomes after limb absence by comparing the PALS technique to control support groups. This study found that participation in a self management support group resulted in improved outcomes such as depression, positive cognitions, improved functional limitations and quality of life for individuals with limb absence compared to a control group of individuals in a conventional support group. These outcomes were also more successful amongst individuals less than three years post amputation, providing further support for early intervention. This study included individuals with both upper and lower limb absence in the study but did not allude to the specific findings for individuals with ULA. However, given the purported differences between these two groups, further research should focus on the appropriateness of such interventions for people with ULA specifically and explore whether aspects of such interventions require tailoring for specific target groups.

From information received from the qualitative investigations with RP's and those with limb absence, suggestions for improving the service were provided. The main categories suggested were approved by participants in the Delphi study as important to consider in rehabilitation; such as 'access to services (for example, making appointments/ physical access)', 'satisfaction with the prosthesis' and 'satisfaction with the rehabilitation service'. Additionally, it is especially important that attention is paid to areas of dissatisfaction with the service as research has found that satisfaction with the health service is significantly lower for prosthesis rejecters (Biddiss & Chau, 2007c). The specific suggestions from the qualitative studies such as provision of psychological support should be addressed considering the large support for the need for psychological factors to be addressed in the present study, by both RP's and individuals with limb absence. Both groups discussed an

array of important psychological factors in the qualitative analyses as well as confirming their importance in the Delphi study. Additionally, RP's expressed a need for greater psychological services for individuals with limb absence in the qualitative studies as well as individuals with limb absence that valuing its important role in facilitating adjustment. .

Findings in this mixed methods study from both the qualitative and quantitative investigations suggest that certain positive personality traits (such as humour and positive attitude) can aid adjustment to ULA. Additionally, Rybarczyk et al (2004) suggest that findings such as these coincide with the message of positive psychology where positive meaning and optimism, value of humour and spirituality are among positive psychological factors that are notable in successful adjustment to leg amputation. These assertions have received support previously from other qualitative literature on limb absence (Saradjian et al, 2008; Gallagher & MacLachlan 2001) as well as similar support in a quantitative study amongst 138 individuals with amputations, where 14% of the sample had ULA (Dunn, 1996). Dunn (1996) found that finding positive meaning following an amputation and perceiving control over the disability was linked to lower levels of depression (measured by CES-D; Radloff, 1977). Dispositional optimism and perceived control over disability were also related to higher self esteem (measured by Rosenberg self Esteem scale; Rosenberg, 1965). However, there was no report if whether any of these findings were evident particularly amongst individuals with ULA Identification of psychological traits 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 humour' and 'social skills' suggest that the role these traits play in adjustment to ULA need to be assessed. Although RP's may claim they assess these intuitively, formal measurement of these traits could prove informative to clinicians and add greater support for the value of promoting these psychological traits in individuals with limb absence. Most of these personality traits have not been investigated quantitatively in any research study in ULA literature.

According to Biddiss, et al (2007), consumer feedback is vital to the successful development of products and services that address user wants and needs. Feedback is

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particularly valuable in tracking user's satisfaction of new technology in upper limb prosthetics (Biddiss et al, 2007). Bartlett et al (2006) also suggested that health policy and program development needs to be based on solid research through a variety of both qualitative and quantitative methods. This study provides a foundation for future outcome measures described by Wright (2000) as patient specific measures that allow patients to state their individual concerns, and weight their relative importance. Wright (2000) 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 (Wright, 2000). Our contribution of patient specific outcomes, in conjunction with agreement from RP's is a suitable foundation for any future production of a patient specific outcome measure.

#### ***6.4 Concluding comments***

This research contributes to the literature on ULA by providing a greater insight to the needs of individuals with ULA, and the beliefs of the RP's who work with them, while demonstrating a middle ground where they can both meet. Findings suggest that from both the RP's and patient perspective it is essential that a patient's rehabilitation is holistic and incorporates the important elements to target to achieve this holistic care, such as psychological, functional, physical, social, service and prosthesis issues. It is important for all these areas of importance to be targeted in order for the individual to live an optimum life, thus contributing to society and perhaps returning to the workforce and contributing financially, vocationally and avocationally to the State, their community and their family.



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## Appendices

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List of Appendices

Appendix A	Exemplar of coded data extract from an interview with a psychologist
Appendix B	Information sheet for repertory grid study
Appendix C	Letter of invitation to participants for repertory grid study
Appendix D	Consent form for repertory grid study
Appendix E	Demographic questionnaire for repertory grid study
Appendix F	Interview guide for RP's qualitative interviews
Appendix G	Email invitation to RP's for participation in qualitative studies
Appendix H	Information sheet for RP's qualitative interviews
Appendix I	Consent form for RP's qualitative interviews
Appendix J	Interview guide for qualitative study with individuals with ULA
Appendix K	Letter of invitation to individuals with ULA for qualitative study
Appendix L	Information sheet for qualitative study with individuals with ULA
Appendix M	Consent form for qualitative study with individuals with ULA
Appendix N	Brief questionnaire for qualitative study with individuals with ULA
Appendix O	Poster for recruiting additional participants with ULA for qualitative study
Appendix P	List of Delphi items and how they were generated
Appendix Q	Text of email invitation to individuals with ULA to participate in round 1 of the Delphi study
Appendix R	Text of email invitation to RP's to participate in round 1 of the Delphi study
Appendix S	Information sheet for individuals with ULA for Delphi study
Appendix T	Information sheet for RP's for Delphi study
Appendix U	MS Word document version of Delphi questionnaire for round 1 for individuals with ULA
Appendix V	MS Word document version of Delphi questionnaire for round 1 for RP's
Appendix W	MS Word document version of Delphi questionnaire for round 2 for both groups
Appendix X	Word doc Delphi questionnaire for round 3
Appendix Y	Round 2 qualitative responses that were provided to participants in Round 3
Appendix Z	Frequency distribution of accepted and non-accepted items in Section 2

Appendix A

Exemplar of coded data extract from an interview with a psychologist

Code	Extract	Line
Mood	<i>"I think mood has to be the main one (outcome) because if your mood is good you know you are able to delve into your coping strategies much much more effectively"</i>	10-11 P.10
Cause of limb absence/ trauma	<i>"...I suppose the other thing I would say about upper limb users as well is that because its very often a traumatic cause of an amputation there tends to be a lot of issues of loss and bereavement around for them too and another part, a big big part of the work we do is working with the loss factor em you know, not loss of their of their limb but also loss of their maybe their dependents or it could be loss of their job or it could be loss of their you know where people have lost limbs in road traffic accident where other members of their family have been killed so very often its a double loss or a multiple loss for them so bereavement and loss tends to be another thing that very often has to be worked through with upper limb users"</i>	12-20 P.10
PTSD	<i>"but it does tend to be the more sort of traumatic victims that we would see and em therefore you do have to make a judgment as to whether they are psychologically ready or not and we would do that just by a combination of interviewing them em and looking at you know like the the trauma questionnaire to see whether there is anything outstanding in terms of posttraumatic stress symptomatology. If there is we wouldn't necessarily say no you are not ready for it but it might be something we would want to work on before hand..."</i>	18-24 P.2
Depression	<i>"I haven't come across anything (that would stop recommending someone be given a prosthesis), however, em if for example em I was talking to somebody and em in the course of the conversation it turned out that they were currently suicidal, em then we probably would you know say at the minute probably em you are not ready for this yet, we need to work through this particular crisis that you are having before you might be ready for rehab..."</i>	10-14 P.3
	<i>"...I think that if somebody has a history of psychological problems pre-morbidly before their amputation it can be a bit more difficult for them to adjust to an amputation never mind using a limb.... "</i>	21-23 P.8
Coping ability	<i>"as well em I think you know a good repertoire of coping strategies as well is quite important so that they are able to you know have a positive self talk on days when they are feeling a wee bit low or discouraged they have good cognitive strategies that they can tie into that you know can help to em improve or stabilize their mood and that they can help them access help if they need that"</i>	31 P.9- 5 P.10

Appendix B

Information sheet for repertory grid study

### **Participant Information Sheet**

**Title:** An Investigation into the Thoughts and Views of Prosthetic Users

Researchers: Professor Stephen Wegener, Ms. Sinéad Ní Mhurchadha, Dr. Pamela Gallagher, Professor Malcolm Mac Lachlan,

#### **Introduction**

You are being invited to take part in a research study. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please take time to read the following information carefully and feel free to discuss it with others. Ask us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### **What is the purpose of the study?**

The overall aim of this study is to explore the attitudes, beliefs, and perceptions of users of a prosthetic limb towards their current prosthetic, as well as their attitudes, beliefs and perceptions towards other rehabilitation options.

It is important for clinicians and researchers to understand how the experience of using a certain prosthesis affects self-perception and how the prosthesis is viewed in relation to alternative prosthetic options.

In this study, an interview technique, known as the repertory grid method, will be used to explore prosthetic users' views regarding this. The repertory grid is simply a structured method of doing an interview, where the interviewer and interviewee are guided through a systematic procedure by recording responses to questions using a standardized grid.



**Why have I been invited?**

This study aims to investigate the experiences of a person with either a high-technology prosthetic limb or the more standard issue prosthetic limb. You have been chosen to take part in this study as you use one of the above types of prosthetic limb.

**Do I have to take part?**

No, it is completely up to you whether you take part or not. If you decide to take part, you will be given this information sheet, and asked to sign a consent form to show you have agreed to take part. You are free to withdraw at ANY time without giving a reason.

**What will happen to me if I take part?**

You are being asked to take part in a face-to-face interview on how you feel about your prosthetic limb. This interview will last approximately 60-90 minutes. The interview will take place at a time convenient to you. This interview will be tape-recorded and transcribed so that the data can be analysed. During this interview you will be asked to complete a grid. This grid will also be retained by the interviewer for further analysis. No one will listen to the tapes except the members of the research team listed above. Information will be kept confidential at all times. If you are willing to take part, you will be asked to sign and return a consent form. This form will indicate that you have agreed to take part and for the session to be aided by a webcam. When we receive your consent form, we will contact you to arrange the interview.

People who agree to participate will be sent a participant information sheet and step by step written guidelines of the interview process and will also be given an incomplete grid.

**What are the possible risks of taking part?**

There are minimal risks involved in taking part in the interview. We are asking you to discuss your experiences and feelings of using your prosthesis, or other rehabilitation options, which may be unpleasant for some people. If you feel uncomfortable or distressed

at any stage, you can withdraw without any consequences. In addition, the research team will support you in accessing suitable support systems, if required.

**What are the possible benefits of taking part?**

There are no direct benefits to you from taking part in this study. However, it is expected that the research will increase our knowledge of how people feel about different prosthetic prescriptions. Having a better understanding of this may be helpful in managing issues that arise while deciding on the most appropriate prosthesis. Therefore it may benefit other people using or requiring a prosthetic limb.

**What information will be held about me?**

If you agree to take part, all information collected will be kept strictly confidential within the limitations of the law. All information will have your name and address removed so as to preserve confidentiality. Any information that will identify you in any way will also be removed. The procedures for handling, processing, storage and destruction of your data will be compliant with Data Protection (Amendment) Act 2003.

**What will happen to the results of the research study?**

The results of the research study will form the basis for preparation of reports, academic publications, conference papers and other scientific publications.

**What will happen if I don't want to carry on with the study?**

Your participation in the research is entirely voluntary. You are free to decline to enter or to withdraw from the study any time without having to give a reason. If you choose not to participate, or to withdraw once entered, you will not be penalised. It will not affect your health service provision in any way. Any participation you had in the study previous to your departure from the study will be stricken from the record and destroyed if you so wish. Participation in this study will in no way affect your legal rights.

**Who is organising and funding the research?**

This research is organised by John Hopkins University, Baltimore, Dublin City University and Trinity College Dublin.

### **Complaints**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions

Ms. Sinéad Ní Mhurchadha.

Email: [Sinead.Nimhurchadha@dcu.ie](mailto:Sinead.Nimhurchadha@dcu.ie)

Dr. Pamela Gallagher.

Email: [Pamela.Gallagher@dcu.ie](mailto:Pamela.Gallagher@dcu.ie)

Prof. Malcolm Mac Lachlan.

Email: [Malcolm.MacLachlan@tcd.ie](mailto:Malcolm.MacLachlan@tcd.ie)

**Date: 27<sup>th</sup> September 2007**

**You will be given a copy of the Information sheet and a signed consent form to keep.**

**Thank you for taking time to read this sheet.**

Appendix C

Letter of invitation to participants for repertory grid study

Dear \_\_\_\_\_

I would like to invite you to take part in a research project on prosthetic limb use. The aim of the research is to learn more about the thoughts and views prosthetic limb users. In the research study, we wish to interview people who have been recently fitted with High-Tech prosthetic arms as well as the more standardized limbs.

This research was devised by a research team consisting of staff from John Hopkins University Hospital, Dublin City University, and Trinity College Dublin. You are being contacted as a prosthetic user through Dublin City University.

The research will involve a face-to-face interview with the aim of filling out a grid to explore your thoughts and views on different prosthetic options, as well as your adjustment to the prosthetic limb. The interview will last approximately 1.5 hours and will be tape-recorded. The research will be conducted by the interviewer Sinéad Ní Mhurchadha, based in Dublin City University. These interviews will take place in a place suitable for you.

You will find an Information leaflet, Consent Form and 'Guide to the interview' enclosed with this letter. If you would like to take part, please sign the consent form and post it back Dublin City University, using the stamped addressed envelope enclosed, as soon as possible. When we receive your signed consent form, I will forward details about the location, time and date for the interview to take place.

Participation is on a voluntary basis – you are under no obligation to take part in this research study. All information collected will be kept strictly confidential. Your choice to take part in this study will not affect the care you receive.

I would be very grateful for your support.

Yours sincerely,

---

Sinéad Ní Mhurchadha

Appendix D

Consent form for repertory grid study

**Consent Form**

Date: 27<sup>th</sup> September 2007

**Title of Project: An Investigation In to the Thoughts and Views of Prosthetic Users**

Researchers: Ms. Sinéad Ní Mhurchadha, Dr. Pamela Gallagher, Professor Malcolm Mac Lachlan, Professor Stephen Wegener.

**Please read the following statements and initial box**

1. I confirm that I have read and understand the information sheet dated 27<sup>th</sup> September 2007 for the above study and have had the opportunity to ask questions and have had these answered satisfactorily. ☐
2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
4. I understand that the repertory grid interview will be tape recorded and that direct quotations may be used in future publications. ☐
5. I understand that my repertory grid will be kept for future analysis and publications ☐
6. I agree to take part in the above study ☐

Continued on next page/

1 form for patient

1 to be kept as part of the study documentation

### Consent Form

Date: 27<sup>th</sup> September 2007

**Title of project: An Investigation into the Thoughts and Views of Prosthetic Users**

Researchers: Ms. Sinéad Ní Mhurchadha, Dr. Pamela Gallagher, Professor Malcolm Mac Lachlan, Professor Stephen Wegener.

_____	_____	_____
Name of patient	Date	Signature

_____	_____	_____
Name of person taking consent	Date	Signature
(If different from researcher)		

_____	_____	_____
Researcher (to be contacted	Date	Signature
If there are any problems)		

1 form for Patient

1 to be kept as part of the study documentation



Appendix E

Demographic questionnaire for repertory grid study

### Demographic Questionnaire

Subject ID#\_\_\_\_\_

Date\_\_\_\_\_

Age\_\_\_\_\_

Gender: Male ☐ Female ☐

---

Please indicate your Marital Status

Single ☐ Living w/partner ☐

Married ☐ Divorced ☐

Widowed ☐

---

Please indicate your education level:

Less than High School ☐ High School Diploma/GED ☐

Some College ☐ 4 year college degree ☐

Graduate college ☐

---

Please indicate your ethnicity

Caucasian ☐ African American ☐

Hispanic ☐ Asian ☐

Native American ☐ Other\_\_\_\_\_

---

Please indicate your employment status

Full time employment ☐ Part time employment ☐

Student ☐ Unemployed ☐

Retired ☐ Disability Leave ☐

Other ☐ Please state\_\_\_\_\_

---

Please indicate your income level:

<\$20,000 ☐

\$20,000-\$40,000 ☐

\$40,000-\$60,000 ☐

\$60,000-\$80,000 ☐

\$80,000-\$100,000 ☐

>\$100,000 ☐

---

Please indicate your primary reason for limb loss:

Acquired ☐

Congenital ☐

For individuals with acquired limb loss, please specify the reason for your limb loss:

Trauma ☐

Cancer ☐

Dysvascular/ Diabetes ☐

Infection ☐

Other ☐ Please state \_\_\_\_\_

---

Please indicate the type of level of you limb loss

Upper limb ☐

Through wrist ☐

Below elbow ☐

Above elbow ☐

Shoulder disarticulation ☐

Lower limb ☐

Through ankle ☐

Below knee ☐

Above knee ☐

Hip disarticulation ☐

---

Questions of prosthesis use:

How long has it been since your amputation? \_\_\_\_\_ years

How long have you had your current prosthetic limb? \_\_\_\_\_ years

How often do you wear your prosthesis? Days per week \_\_\_\_\_ Hours per day \_\_\_\_\_

Appendix F

Interview guide for RP's qualitative interviews

The interview guide was developed using the following questions:

- 1) How do you decide when someone is ready for an upper limb prosthesis?
- 2) Is there anything that would stop you prescribing a prosthetic limb to an individual?
- 3) Is there anything that would lead to advise someone to give up their upper limb prosthetic?
- 4) Are there any factors that may influence choosing to upgrade an individual's prosthesis?
- 5) How do you know/determine when someone is doing well?
- 6) How do patients judge they are doing well?
- 7) From your experience, do you believe there are any premorbid characteristics, other than the physical ones, that can influence adjustment to amputation?
- 8) As a (insert profession) what do you feel are the important outcomes of using a prosthesis for the patient?
- 9) Do you think there is anything that could make adjustment easier for the patient?
- 10) Do you feel the fitting service could be changed to improve patients' satisfaction with their prosthesis?

Appendix G

Text from Email invitation to RP's for participation in qualitative studies

Dear \_\_\_\_\_,

I would like to invite you to take part in a research project on upper limb prosthetic use. The aim of this study is to gain a better understanding of what individual users and service providers consider to be important outcomes of having an upper limb prosthesis and the issues involved in getting used to it. In the research study, we wish to involve people who require upper limb prosthetics and the people who provide the service, so that any improvements in this area can be made.

This research is funded by the Health Research Board, Ireland and has received ethical approval from Dublin City University Research Ethics Committee. This research is part of a wider project organised by the Dublin Psychoprosthetics Group ([www.tcd.ie/psychoprosthetics](http://www.tcd.ie/psychoprosthetics)) and under the direction of Dr. Pamela Gallagher and Professor Malcolm Mac Lachlan.

The research will involve both focus groups with patients and individual interviews with professionals working within the upper limb fitting service. You are being asked to take part in an individual interview and talk about your experiences of working within the prosthesis-fitting services and your opinions on patient outcomes and care. The interview will take place at a time and location convenient to you. The interview will be tape-recorded.

You will find an Information Leaflet and a Consent Form attached with this email. If you would like to take part, please reply to this email and we will contact you to organise the interview. Participation is on a voluntary basis – you are under no obligation to take part in this research study. All information collected will be kept strictly confidential.

If you have any queries, please contact any member of the research team on the contact details provided on the information sheet

I would be very grateful for your support.

Yours sincerely,

Sinéad NíMhurchadha

Appendix H

Information sheet for RP's qualitative interviews



## **INFORMATION SHEET FOR SERVICE PROVIDERS**

**5<sup>TH</sup> JULY 2007**

Researchers: Dr. Brian O'Neill, Ms. Sinéad NíMhurchadha, Ms. Elisabeth Schaffalitzky, Dr. Pamela Gallagher, Professor Malcolm Mac Lachlan.

### **Introduction**

You are being invited to take part in a research study. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please take time to read the following information carefully and feel free to discuss it with others. Ask us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### **What is the purpose of the study?**

The overall aim of this study is to gain a better understanding of what individual users consider to be important outcomes of having a prosthetic limb, and the issues involved in getting used to it. Not everyone benefits from getting a prosthetic limb, or will be able to use it as expected and therefore, a more detailed understanding will be an important step in ensuring that people benefit from the prosthetic limb that they are prescribed. People who have experienced limb absence and wear/ require prosthetics and the people who provide the service will be involved in the research so that any improvement in this area can be made.

### **Why have I been invited?**

This study aims to investigate the experiences of a person with a prosthetic limb and the people providing the service of prosthetic limbs. You have been chosen to take part in this study as you are a member of the team working with people with a prosthetic limb.

### **Do I have to take part?**

No, it is completely up to you whether you take part or not. If you decide to take part, you will be given this information sheet, and asked to sign a consent form to show you have agreed to take part. You are free to withdraw at ANY time without giving a reason.

**What will happen to me if I take part?**

You are being asked to take part in an interview about your experiences as a professional working with prosthetic limbs. This will involve a number of questions about the outcomes and predictors of prosthetic use and will last approximately 60 minutes. The interview will take place at a time and location convenient to you. This interview will be tape-recorded and transcribed so that the data can be analysed. No one will listen to these tapes except the members of the research team listed above. Information will be kept confidential at all times. If you are willing to take part, you are asked to sign and return a consent form informing you of the research, indicating that you agree to take part and for the session to be tape-recorded. When we receive your consent form, we will contact you to arrange the interview.

**What are the possible risks of taking part?**

There are minimal risks involved in taking part in the interview. However, if you feel uncomfortable or distressed at any stage, you can withdraw without any consequences. In addition, the research team will support you in accessing suitable support systems, if required.

**What are the possible benefits of taking part?**

There are no direct benefits from taking part in this study. However, it is expected that the research will increase our knowledge of the factors that contribute to successful rehabilitation and adjustment to prosthetic limbs. Having a better understanding of these issues may be helpful in managing issues that arise while deciding on the most appropriate prosthesis. Therefore, it may benefit the people who provide prosthetic services by providing appropriate helpful information for their profession.

**What information will be held about me?**

If you agree to take part, all information collected will be kept strictly confidential within the limitations of the law. All information will have your name and address removed so as to preserve confidentiality. Any information that will identify you in any way will also be removed. Tapes of the interview discussions will be destroyed by the principal investigators when the study is completed. The researchers, Ms. Sinéad NíMhurchadha and Ms Elisabeth Schaffalitzky, will be responsible for safety and security of the data. The procedures for handling, processing, storage and destruction of your data will be compliant with the Data Protection (Amendment) Act 2003.

**What will happen to the results of the research study?**

The results of the research study will form the basis for preparation of policy documents, reports, academic publications, conference papers and other scientific publications

**What will happen if I don't want to carry on with the study?**

Your participation in the research is entirely voluntary. You are free to decline to enter or to withdraw from the study any time without having to give a reason. If you choose not to participate, or to withdraw once entered, you will not be penalised. It will not affect your professional position and you will not give up any benefits you had before entering the study. Any participation you had in the study previous to your departure from the study will be stricken from the record and destroyed if you so wish. Participation in this study will in no way affect your legal rights.

**Who is organising and funding the research?**

This study is organised by a research team from the Dublin City University and Trinity College Dublin. This research is being funded by the Health Research Board, Ireland.

### **Complaints**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions

[Sinead.Nimhurchadha@dcu.ie](mailto:Sinead.Nimhurchadha@dcu.ie) (researcher)

[Liz.Schaffalitzky@dcu.ie](mailto:Liz.Schaffalitzky@dcu.ie) (researcher)

[Pamela.Gallagher@dcu.ie](mailto:Pamela.Gallagher@dcu.ie) (co-investigator)

[Malcolm.MacLachlan@tcd.ie](mailto:Malcolm.MacLachlan@tcd.ie) (co-investigator)

If you have concerns about this study and wish to contact someone independent, you may contact: The Secretary, South Glasgow & Clyde Research Ethics Committee.

*This research has been reviewed by the South Glasgow & Clyde Research Ethics Committee.*

**Date:** 7<sup>th</sup> July 2007

**You will be given a copy of the Information sheet and a signed consent form to keep.**

**Thank you for taking time to read this sheet.**

**If you wish to contact us our details are on the following page:**

**Name:** Sinéad NíMhurchadha  
**Address:** School of Nursing  
Dublin City University  
Glasnevin  
Dublin 9  
Ireland  
**Phone:** (003531) 7008527  
**Email:** Sinead.Nimhurchadha@dcu.ie

**Name:** Elisabeth Schaffalitzky

**Address:** School of Nursing  
Dublin City University  
Glasnevin  
Dublin 9  
Ireland

**Phone:** (003531) 7007582

**Email:** Liz.Schaffalitzky@dcu.ie

Appendix I

Consent form for RP's qualitative interviews

Date: 7<sup>th</sup> July 2007

CONSENT FORM

**For interviews with Service providers**

Title of project: Improving outcomes of prosthetic limb prescription

Researchers: Dr. Brian O'Neill, Ms. Sinéad NíMhurchadha, Ms. Elisabeth Schaffalitzky,  
Dr. Pamela Gallagher, Professor Mac Lachlan

**Please read the following statements and initial box**

1. I confirm that I have read and understand the information sheet dated 7<sup>th</sup> July 2007 (Version 1.1) for the above study and have had the opportunity to ask questions and have had these answered satisfactorily. ☐
2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
4. I understand that the interview will be tape recorded and that direct quotations may be used in future publications. ☐
5. I agree to take part in the above study. ☐

Continued on next page/

1 form for participant

1 to be kept as part of the study documentation

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Date: 7<sup>th</sup> July 2007

CONSENT FORM

**For interviews with Service providers**

Title of project: Improving outcomes of prosthetic limb prescription

Researchers: Dr. Brian O'Neill, Ms. Sinéad NíMhurchadha, Ms. Elisabeth Schaffalitzky,  
Dr. Pamela Gallagher, Professor Mac Lachlan

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of person taking consent (If different from researcher)	Date	Signature
_____	_____	_____
Researcher (to be contacted If there are any problems)	Date	Signature

Comments or concerns during the study

If you have concerns about this study and wish to contact someone independent, you may contact: The Secretary, South Glasgow & Clyde Research Ethics Committee.

1 form for Participant

1 to be kept as part of the study documentation



Appendix J

Interview guide for qualitative study with individuals with ULA

The focus group session was structured based on the following questions

- 1) What was your initial reaction to your first prosthesis? Were your expectations met?
- 2) What goals/ achievements did you set yourselves when you lost your limb?
  - Have you been able to reach these goals?
  - If you were not able to, why do you think that was?
  - was the reason related to your own personal circumstances?
- 3) If you did reach your goals, what helped you to achieve them?
- 4) What are the most common issues, if any, that arise because of having a prosthesis?
  - What are the most challenging aspects, if any of having a prosthesis?

Appendix K

Letter of invitation for qualitative study with individuals with ULA

Dear

We would like to invite you to take part in a research project on limb prostheses. The aim of this study is to gain a better understanding of what individual users and service providers consider to be important outcomes of having a prosthesis and the issues involved in getting used to it. In the research study, we wish to involve individuals who require prosthetic limbs and the people who provide the service, so that any improvements in this area can be made.

This research is funded by the Health Research Board, Ireland and will be conducted by a research team from the Southern General Hospital, Glasgow, Dublin City University and Trinity College Dublin. This study has also received ethical approval from the South Glasgow & Clyde Research Ethics Committee.

The research will involve a group discussion. You are being asked to take part in this group discussion and talk about your experiences of using a prosthetic limb and the prosthesis-fitting services. The group will consist of 8-10 people who have had an amputation and will last between 1.5 to 2 hours. The session will be tape-recorded.

You will find an Information Leaflet and a Consent Form enclosed with this letter. If you would like to take part, please sign the consent form and post it back to Dublin City University, using the stamped addressed envelope enclosed, as soon as possible. When we receive your signed consent form, details will be forwarded about the location, time and date of the group discussion.

Participation is on a voluntary basis – you are under no obligation to take part in this research study. All information collected will be kept strictly confidential. Your choice to take part in this study will not affect the care you receive.

If you have any queries, please contact any member of the research team on the contact details provided on the information sheet.

We would be very grateful for your support.

Yours sincerely,

Appendix L

Information sheet for qualitative study with individuals with ULA

Improving Outcomes of Prosthetic Limb Users

10<sup>th</sup> December 2007

**Participant Information Sheet**

*Researchers: Ms. Sinéad NíMhurchadha, Dr. Pamela Gallagher, Professor Malcolm Mac Lachlan.*

You are being invited to take part in a research study. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please take time to read the following information carefully and feel free to discuss it with others. Ask us if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**What is the purpose of the study?**

To gain a better understanding of what upper limb prosthetic users consider to be important outcomes of having a prosthetic limb, and the issues involved in getting used to it. A more detailed understanding of prosthetic use will be an important step in ensuring that people benefit from the prosthetic that they are prescribed.

**Why have I been invited?**

You have been chosen to take part in this study as you have upper limb absence/absence with a number of other individuals with upper limb absence/absence

**Do I have to take part?**

No, it is completely up to you whether you take part or not.

**What will happen to me if I take part?**

You are being asked to take part in a group discussion about your experiences of having a limb absence/absence. The group will consist of 8-10 people who have an upper limb absence/absence and will last approximately 1.5- 2 hours. This discussion will be tape-

recorded and transcribed so that the data can be analysed. No one will listen to these tapes except the members of the research team listed above. Information will be kept confidential at all times. If you wish to participate, you will be sent information regarding your scheduled session.

**What are the possible risks of taking part?**

Remembering your experiences and feelings of limb absence and/or prosthetic fitting may bring back unpleasant or distressing memories. If you feel uncomfortable or distressed at any stage, you can withdraw. The research team will support you in accessing suitable support systems if required.

**What are the possible benefits of taking part?**

There are no direct benefits from taking part in this study. However, it is expected the research will increase our knowledge of successful rehabilitation with prosthetic limbs, and therefore may benefit those requiring a prosthetic limb.

**What information will be held about me?**

All information collected will be kept strictly confidential within the limitations of the law. All information will have your name and address removed for confidentiality. Any information that identifies you will be removed. Tapes of the discussion will be destroyed when the study is finished. The principal investigators are responsible for the safety and security of the data. The procedures for handling, processing, storage and destruction of your data will comply with the Data Protection (Amendment) Act 2003.

**What will happen to the results of the research study?**

The results of the research study will form the basis for preparation of policy documents, reports, academic publications, conference papers and other scientific publications

**What will happen if I don't want to carry on with the study?**

You are free to withdraw from the study at ANY time without giving a reason. Choosing to not enter, or to withdraw once entered, will not affect your medical health care and you will not give up any benefits you had before entering the study. Any participation you had in the study before leaving will be stricken from the record and destroyed if you so wish. Participation in this study in no way affects your legal rights.

***This research has been reviewed Dublin City University Research Ethics Committee and is funded by the Health Research Board, Ireland***

**Thank you for taking time to read this sheet.**

### **Complaints**

If you have a concern about any aspect of this study, or would like more information, you should ask to speak to the researchers who will do their best to answer your questions

[Sinead.nimhurchadha@dcu.ie](mailto:Sinead.nimhurchadha@dcu.ie) (researcher)

[Pamela.Gallagher@dcu.ie](mailto:Pamela.Gallagher@dcu.ie) (co-investigator)

[Malcolm.MacLachlan@tcd.ie](mailto:Malcolm.MacLachlan@tcd.ie) (co-investigator)

If you have any further concerns about this study and wish to contact someone independent, you may contact: The secretary, Dublin City University Ethics Committee, Dublin City University, Glasnevin, Dublin 9.



Appendix M

Consent form for qualitative study with individuals with ULA

**Consent form for focus groups with prosthetic users and non-users**

10<sup>th</sup> December 2007

Title of Project: Improving outcomes of prosthetic limb prescription

Researchers: *Researchers: Ms. Sinéad NíMhurchadha, Dr. Pamela Gallagher, Professor Malcolm Mac Lachlan.*

**Please read the following statements and initial box**

1. I confirm that I have read and understand the information sheet dated 10<sup>th</sup> December 2007 for the above study and have had the opportunity to ask questions and have had these answered satisfactorily. ☐
2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
4. I understand that the conversations in the focus group will be tape recorded and that direct quotations may be used in future publications. ☐
5. I agree to take part in the above study. ☐

_____	_____	_____
Name of patient	Date	Signature

_____	_____	_____
Name of person taking consent (If different from researcher)	Date	Signature

_____	_____	_____
Researcher (to be contacted If there are any problems)	Date	Signature

Comments or concerns during the study

If you have any further concerns about this study and wish to contact someone independent, you may contact: The secretary, Dublin City University Ethics Committee, Dublin City University, Glasnevin, Dublin 9.

Appendix N

Brief questionnaire for qualitative study with individuals with ULA

**Improving Outcomes for Prosthetic Limb Prescription**

25<sup>th</sup> June 2007

**Please fill in the spaces or tick the boxes where appropriate**

Age: \_\_\_\_

Gender: Male ☐ Female ☐

**Please indicate your employment status:**

Full-time Employment ☐ Part-time Employment ☐

Student ☐ Unemployed ☐

Retired ☐ Disability Leave ☐

Other ☐ Please state \_\_\_\_\_

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**Please indicate the primary reason for your limb absence:**

Acquired ☐ Congenital ☐

**For individuals with acquired limb absence, please specify the reason for your limb absence:**

Trauma ☐ Cancer ☐

Dysvascular/ Diabetes ☐ Infection ☐

Other ☐ Please state \_\_\_\_\_

---

*Shoulder Disarticulation* ☐

*Hip Disarticulation* ☐

Hours per day\_\_\_\_\_

Do you suffer from another type of pain?    YES   ☐    NO   ☐

Please state

Appendix O

Poster for recruiting additional participants with ULA for qualitative study

# Can you help us?

We are looking to recruit a number of people with upper limb absence/ absence to take part in a focus group. The aim of the group is to discuss ideas regarding how you feel about your limb absence and/or prosthetic limb and the way it affects your life.

The information from these focus groups will be used to help the development of more effective prescription methods for prosthetic limbs. Any contribution you can make and opinions you have will be greatly appreciated!

To take part, you need to be over 18 years of age and have a major upper limb amputation i.e. through wrist or higher

The focus group will take place over the next few weeks at a time and location convenient to all participants.

If you are interested, please contact us on the details below. Expressing interest does not mean you have to take part.

Thank you!!

*This research is being conducted by investigators from Dublin City University and Trinity College Dublin and is funded by the Health Research Board, Ireland.*

**Contact details:**

Email: Email: [sinead.nimhurchadha@dcu.ie](mailto:sinead.nimhurchadha@dcu.ie). Phone: +353 1 700 8527



Appendix P

List of Delphi items and how they were generated

'Prosthesis use' statements

Heading	Statement		Source
Prosthesis use	1. A successful outcome is use of a prosthesis for a persons pre-amputation job or activities	Item rejected in round 2	Interviews with RP's
Prosthesis use	2. A successful outcome is use of a non-functional cosmetic prosthesis	Item rejected in round 2	Literature
Prosthesis use	3. A successful outcome is when a person is content not to wear a prosthesis	Item rejected in round 2	Interviews with RP's
Prosthesis use	4. A successful outcome is when a person wears their prosthesis all day every day	Agreement could still not be reached in round 3.	Interviews with RP's
Prosthesis use	5. A successful outcome is when a person wears their prosthesis for specific activities	Item accepted in round 2	Repertory Grid/ Qual studies with individuals with ULA
Prosthesis use	6. A successful outcome is when a person feels their prosthesis is part of them	Agreement could still not be reached in round 3	Literature
Prosthesis use	7. A successful outcome is when a person uses the prosthesis as often as they wish	Item accepted in round 1	Interviews with RP's
Prosthesis use	8. A successful outcome is when a person uses the prosthesis as intended (e.g. a functional prosthesis uses functionally)	Item accepted in round 1	Interviews with RP's
Prosthesis use	9. A successful outcome is when a person uses the prosthesis for both functional and cosmetic purposes	Item rejected in round 3	Suggested by participants in Round 1 Delphi
Prosthesis use	10. A successful outcome is when a patient is satisfied with the cosmetic appearance of the prosthesis	Item rejected in round 3	Suggested by participants in round 1 Delphi
Prosthesis use	11. A successful outcome is when a person feels grateful when the prosthesis is initially delivered	Item rejected in round 3	Suggested by participants in round 1 Delphi
Prosthesis use	12. A successful outcome is when a person uses the prosthesis to feel socially accepted	Item rejected in round 3	Suggested by participants in round 1 Delphi

Green highlight items accepted items after all rounds

Red highlight items rejected items after all rounds

Yellow highlighted items that did not reach agreement after all rounds

'Activities and Participation' statements.

Heading	Statement		Source
Activities and Participation	1. A successful outcome is a person's ability to perform their own personal care without help from other people	Item accepted in round 1	Interviews with RP's
Activities and Participation	2. A successful outcome is a person's ability to complete activities of daily living without help from other people	Item accepted in round 1	Interviews with RP's
Activities and Participation	3. A successful outcome is a person's ability to drive if they desire	Item accepted in round 1	Interviews with RP's, literature, Focus groups
Activities and Participation	4. A successful outcome is when a person is satisfied with their functional abilities	Item accepted in round 1	
Activities and Participation	5. A successful outcome is when a person has returned to active employment (but may have to change jobs)	Item accepted in round 1	Interviews with RP's, focus groups
Activities and Participation	6. A successful outcome is when a person is performing to the best of their ability	Item accepted in round 1	Interviews with RP's
Activities and Participation	7. A successful outcome is a person's ability to perform activities to the same standard as they had before the limb absence.	Item rejected in round 3	Interviews with RP's
Activities and Participation	8. A successful outcome is when a prosthetic user can perform an activity bi-laterally to an equal standard as a 2 handed person	Item did not reach agreement in round 2.	Suggested by participants in round 1 Delphi
Activities and participation	9. A successful outcome is a person's ability to perform activities within the same time parameters as prior to their injury	Item rejected in round 3	Suggested by participants in round 1 Delphi

**Green** highlight items accepted items after all rounds

**Red** highlight items rejected items after all rounds

**Yellow** highlighted items that did not reach agreement after all rounds

'Self image' statements

Heading	Statement		Source
Self image	1. A successful outcome is when a person reports having a positive body image (feeling attractive)	Item accepted in round 1	Interviews with RP's
Self image	2. A successful outcome is when a person is confident to show their residual limb (stump) in public	Item rejected in round 3	Qual studies with individuals with ULA
Self image	3. A successful outcome is when a person does not feel they stand out	Item rejected in round 2	Repertory grid
Self image	4. A successful outcome is when a person does not mind looking at their residual limb (stump)	Item rejected in round 2	Interviews with individuals with ULA
Self image	5. A successful outcome is when a person feels that they look balanced	Item rejected in round 2	Interviews with individuals with ULA
Self image	6. A successful outcome is when a person is not feeling self-conscious when in public with a prosthesis	Item accepted in round 1	Focus groups with individuals with ULA
Self image	7. A successful outcome is when a person is not feeling self conscious when in public without a prosthesis	Item rejected in round 2	Interviews with individuals with ULA

**Green** highlight items accepted items after all rounds

**Red** highlight items rejected items after all rounds

**Yellow** highlighted items that did not reach agreement after all rounds

*Items that should be taken into consideration by RP's in rehabilitation*

Heading	Item	Source
Engagement in Activities and Participation	Achieving set goals	Interviews with RP's
	Engagement in activities of daily Living	Interviews with RP's, literature, qual studies with individuals with ULA
	Engagement in leisure activities	Interviews with RP's, literature, qual studies with individuals with ULA
	Getting along with other people	Literature
	Getting around	Literature
	Perceived environmental barriers	Literature
	Performing self care	Literature
	Performing social/ family roles of importance (e.g. breadwinner/ spouse/ student/ parent)	Literature
	The achievement of tasks set by the individual with ULA	Suggested by participants in round 1 Delphi
Physical factors	Cause of limb absence (congenital or acquired)	Literature
	General physical health	Literature
	Level of amputation	Literature, Interviews with RP's, rep grid, qual studies with individuals with ULA
	Absence of dominant or non-dominant arm	Literature
	Phantom limb pain	Literature, Interviews with RP's, qual studies with individuals with ULA
	Phantom limb sensation	Literature
	Presence/ absence of certain joints	Interviews with RP's
	Residual limb pain	Literature, Interviews with RP's
	State of residual limb	Interviews with RP's
	Type of limb absence (bilateral or unilateral)	Literature
	Time since amputation	Literature
Prosthesis use	Purpose of prosthesis use	Interviews with individuals with ULA

Heading	Item	Source
	A patient's feeling of control over the rehabilitation	Suggested by participants in round 1 Delphi
	A patient's resilience	Suggested by participants in round 1 Delphi
	Anxiety	Literature, Interviews with RP's
	Coping Strategies	Literature, Interviews with RP's
	Depression	Literature, Interviews with RP's
	Patient's attitude	Interviews with individuals with ULA
	Patient's expectations	Interviews with RP's
	Patient's mood	Interviews with RP's
	Patient's motivation	Interviews with RP's, repertory grid, focus groups with individuals with RP's
	Patient's sense of humour	Qual studies with individuals with ULA
	Pre-amputation life experiences and skills (e.g. experience of disability or limb absence in the family)	Interviews with individuals with ULA
	Post traumatic stress disorder (PTSD)	Interviews with RP's
	The social skills of the individual with limb absence	Suggested by participants in round 1 Delphi
Rehabilitation service	Access to services (for example making appointments/ physical access)	Literature, Interviews with RP's
	Satisfaction with the prosthesis	Literature, Interviews with RP's, Qual studies with individuals with ULA
	Satisfaction with the rehabilitation Service	Literature, Interviews with RP's
Self image	Body image	Interviews with RP's
	Public self-consciousness (feeling self-conscious around other people)	Qual studies with individuals with ULA
Social Factors	Emotional support from family/ Friends	Qual studies with individuals with ULA
	Meeting another individual with limb absence	Qual studies with individuals with ULA, Interviews with RP's
	Practical support form family/ friends	Focus groups with individuals with ULA
	Reaction of family to the prosthesis	Interviews with RP's

*Items that were rejected by participants*

Heading	Item	Source
Demographic factors	Age at amputation	Literature
Demographic factors	Gender	Literature
Demographic factors	Level of education	Literature
Engagement in Activities and Participation	The achievement of tasks set by rehabilitation professional	Suggested by participants in round 1 Delphi
Physical factors	Cause of acquired limb absence (trauma v malignancy/ disease)	Suggested by participants in round 1 Delphi
Prosthesis use	Frequency of prosthesis use	Literature
Psychological factors	The extent to which people compare themselves to other people who are better or worse off	Qual studies with individuals with ULA
Rehabilitation service	Cost of prosthesis	Suggested by participants in round 1 Delphi
Rehabilitation service	Whether individual is entitled to compensation	Suggested by participants in round 1 Delphi
Social factors	Reactions from public	Qual studies with individuals with ULA

Appendix Q

Text of email invitation to individuals with ULA to participate in round 1 of the Delphi study



Dear member of the amputee community,

I would like to invite you to participate in a research study that is investigating what contributes to successful outcomes in **upper limb absence** rehabilitation. This study is being conducted by an international group of researchers based at Dublin City University, Ireland. We are inviting people with upper limb absence to participate from Ireland, Great Britain, Canada and the United States. To do this, the study uses a brief internet questionnaire completed on three separate occasions.

**You will find an information leaflet attached that will detail what the study involves.**

**In order to be eligible to participate, you must have major upper limb absence (ie. through wrist of above) and be at least one year post amputation.**

**If you wish to participate, the questionnaire can be found at the following link**

**<http://round1p.questionpro.com/>**

If you do not wish to participate, we request that you reply to this email indicating your reason for not participating.

The first round questionnaire will be available until **20<sup>th</sup> July 2009**. I recommend that you complete the questionnaire as soon as possible. I would be very grateful for your support.

Yours sincerely,

Sinéad NíMhurchadha,

If you have any questions regarding this study you can contact me at [sinead.nimhurchadha@dcu.ie](mailto:sinead.nimhurchadha@dcu.ie) Or alternatively you can call me on **+35387-6224707 or +353 1 7008527**

Research team: Ms. Sinéad NíMhurchadha, Dr. Pamela Gallagher, Prof. Stephen Wegener, Prof. Malcolm MacLachlan

Appendix R

Text of email invitation to Rehabilitation Professionals to participate in round 1 of the Delphi study.

Good Morning,

I am writing to invite you to participate in a research study concerned with gaining a better understanding of what individuals with upper limb absence and Rehabilitation professionals consider to be important in rehabilitation following upper limb absence. This research study intends to gather information through a research method known as the 'Delphi' technique, involving a brief internet questionnaire completed on three separate occasions.

**You will find an Information Leaflet attached with this email that will detail what the study involves.**

**If you would like to take part, please complete the questionnaire at the following link: [http://delphi\\_round1\\_rehabprofessionals.questionpro.com](http://delphi_round1_rehabprofessionals.questionpro.com).**

**If you wish to participate, the questionnaire can be found at the following link**

**<http://round1rp.questionpro.com/>**

If you do not wish to participate, we request that you reply to this email indicating your reason for not participating.

The first round questionnaire will be available until **20<sup>th</sup> July 2009**. I recommend that you complete the questionnaire as soon as possible. I would be very grateful for your support.

Yours sincerely,

Sinéad NíMhurchadha,

If you have any questions regarding this study you can contact me at [sinead.nimhurchadha@dcu.ie](mailto:sinead.nimhurchadha@dcu.ie) Or alternatively you can call me on **+35387-6224707 or +353 1 7008527**

Research team: Ms. Sinéad NíMhurchadha, Dr. Pamela Gallagher, Prof. Stephen Wegener, Prof. Malcolm MacLachlan

Appendix S

Information sheet for individuals with ULA for Delphi study.

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**INFORMATION SHEET FOR INDIVIDUALS WITH UPPER LIMB ABSENCE**  
**25<sup>TH</sup> JUNE 2009**

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Researchers: Ms. Sinéad NíMhurchadha, Dr. Pamela Gallagher, Professor Stephen Wegener, Professor Malcolm Mac Lachlan.

**Introduction**

You are invited to take part in a research study. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please take time to read the following information carefully and to decide if you wish to take part. You can contact the research team if you have any questions (sinead.nimhurchadha@dcu.ie).

**What is the purpose of the study?**

The aim of this study is to gain a better understanding of what individuals with upper limb absence and Rehabilitation professionals consider to be important factors of rehabilitation following upper limb amputation, so that any improvements in this area can be made.

This study will use the 'Delphi method' to help obtain agreement on an issue where there is currently no agreement, this is done by asking the 'experts' or 'informed individuals' in the area to share their knowledge with other 'informed individuals' and to reach agreement together.

This method was chosen for this study as there is currently no definitive agreement in the literature on the outcomes for a patient following upper limb absence and there is also no agreement (and some contradiction) on the factors that predict them. This study hopes to reach a agreement on this area. Agreement on these issues will help to allow the eventual construction of a core set of factors that can be used by rehabilitation professionals working with this population.

**Why have I been invited?**

This study aims to investigate the experiences of a person with absence of an upper limb. You have been chosen to take part in this study as you have absence of an upper limb, along with a number of individuals with upper limb amputation.

In order to be eligible to participate, you must have a major upper limb amputation (ie. through wrist of above) and be at least one year post amputation.

**Do I have to take part?**

No, it is completely up to you whether you take part or not. If you decide to take part, you are asked to fill in the attached consent form, and return it by email to the research team. You are free to withdraw at any time from this study without giving a reason.

**What will happen to me if I take part?**

This study involves you completing a series of three questionnaires over a period of a few weeks.

The first questionnaire is available at the internet link:

<http://round1p.questionpro.com/>

You will be asked to rate a series of statements on the extent to which you agree them to be a successful outcome following upper limb amputation on a 1 to 5 scale. You will also be asked to rate the importance of measuring a set of factors of rehabilitation on a 1 to 5 scale. You will also be asked to add anything to these lists of statements that you feel are important. Your anonymous ratings will be sent back to the research team through the website. You are asked to complete the questionnaire by the **20<sup>th</sup> July 2009**

After approximately a week from the round 1 deadline, the research team will report your ratings back to you and those of other participants (anonymously) in order for you to see what other participants consider important. You will also receive a second questionnaire (which will be similar to the first questionnaire) and you will be asked to re-rate each statement again and some new statements from the previous round and you will be given the opportunity to change your ratings from the previous round in the light of other participants responses if you wish. The same process will apply for the third and final questionnaire.

Each questionnaire round will take approximately 15 minutes to complete and it is anticipated that there will be three rounds in total, sent approximately every three weeks. Information will be kept confidential at all times. It is important that if you agree to take part that you participate in all rounds.

**What are the possible risks of taking part?**

There are minimal risks to taking part. However, if you feel uncomfortable or distressed at any stage, you can withdraw without any consequences.

**What are the possible benefits of taking part?**

There are no direct benefits from taking part in this study. However, it is expected that the research will increase our knowledge of the factors that contribute to successful rehabilitation following upper limb absence. Having a better understanding of these issues may be helpful in managing issues that arise while deciding on the most appropriate rehabilitation. Therefore, it may also benefit the people who have lost an upper limb.

**What information will be held about me?**

If you agree to take part, all information collected will be kept strictly confidential within the limitations of the law. All information will have your name removed so as to preserve confidentiality. Any information that will identify you in any way will also be removed. The researcher, Ms. Sinéad NíMhurchadha will be responsible for safety and security of

the data. The procedures for handling, processing, storage and destruction of your data will be compliant with the Data Protection (Amendment) Act 2003.

**What will happen to the results of the research study?**

The results of the research study will form the basis for the preparation of policy documents, reports, academic publications, conference papers and other scientific publications.

**What will happen if I don't want to carry on with the study?**

Your participation in the study is entirely voluntary. You are free to decline to enter or to withdraw from the study any time without having to give a reason. If you choose not to enter the study, or to withdraw once entered, you will not be penalised. Any participation you had in the study previous to your departure from the study will be stricken from the record and destroyed if you so wish. Participation in this study will in no way affect your legal rights.

**Who is organising and funding the research?**

This study is organised by a research team from Dublin City University and Trinity College Dublin, Ireland. This research is being funded by the Health Research Board, Ireland.

**Complaints**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions

[Sinead.Nimhurchadha@dcu.ie](mailto:Sinead.Nimhurchadha@dcu.ie) (researcher)

[Pamela.Gallagher@dcu.ie](mailto:Pamela.Gallagher@dcu.ie) (co-investigator)

[Malcolm.MacLachlan@tcd.ie](mailto:Malcolm.MacLachlan@tcd.ie) (co-investigator)

If you have concerns about this study and wish to contact someone independent, you may contact: The Secretary, Research Ethics Committee, Dublin City University, Dublin, Ireland. Ph. +353 (0) 1 700 8000

***This research has been reviewed by the Dublin City University Research Ethics Committee.***

**Thank you for taking time to read this sheet.**

**Feel free to pass this survey link and information sheet on to other individuals with upper limb absence that are eligible to participate and that may wish to participate.**

**If you wish to contact me, my details are below:**

**Name:** Ms. Sinéad NíMhurchadha

**Address:** School of Nursing  
Dublin City University  
Glasnevin  
Dublin 9  
Ireland

**Phone:** +353 (0) 1 700 8527

**Email:** [Sinead.Nimhurchadha@dcu.ie](mailto:Sinead.Nimhurchadha@dcu.ie)



Appendix T

Information sheet for RP's for Delphi study.

**INFORMATION SHEET FOR REHABILITATION PROFESSIONALS**  
**25<sup>TH</sup> JUNE 2009**

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Researchers: Ms. Sinéad NíMhurchadha, Dr. Pamela Gallagher, Prof. Stephen Wegener, Prof. Malcolm Mac Lachlan.

**Introduction**

You are invited to take part in a research study. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please take time to read the following information carefully and to decide if you wish to take part. You can contact the research team if you have any questions (sinead.nimhurchadha@dcu.ie).

**What is the purpose of the study?**

The aim of this study is to gain a better understanding of what people with upper limb absence and rehabilitation professionals consider to be important in rehabilitation following upper limb absence. Having a better understanding will help us make ongoing improvements in this area.

This study will use the 'Delphi method' to help obtain agreement on an issue where there is currently no agreement. This is done through asking the 'experts' or 'informed individuals' in the area to share their knowledge with other 'informed individuals' and to reach agreement together. This method was chosen for this study as there is currently no definitive agreement in the literature on the 'successful' outcomes for a patient following upper limb absence and there is also no agreement (and some contradiction) on the factors that predict them. This study hopes to reach a agreement on this area. Agreement on these issues will help to allow the eventual construction of a core set of factors that can be used by Rehabilitation professionals working with this population.

**Why have I been invited?**

This study aims to investigate the experiences of a person with upper limb absence and the rehabilitation professionals. You have been chosen to take part in this study as you are a member of the rehabilitation team working with people with upper limb absence.

In order to participate, you 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 between 1998 and 2008; or to be working as part of a rehabilitation team concerned with individuals with upper limb absence for at least 3 years; or both. If you do not fulfil either of these criteria but feel that you are an 'informed individual' that should participate in this study, please contact the research team with your details (Sinead.nimhurchadha@dcu.ie).

**Do I have to take part?**

No, it is completely up to you whether you take part or not. If you decide to take part, you are asked to fill in the attached consent form and return it by email to the research team. You are free to withdraw at any time from this study without giving a reason.

**What will happen to me if I take part?**

This study involves you completing three questionnaires over a period of a few weeks.

The first questionnaire is available at

<http://round1rp.questionpro.com/>

Here you will be asked to consider what are the successful outcomes following upper limb absence and what factors are important to consider during rehabilitation. All your responses will be confidential and they are sent back to the research team through the website. You are asked to complete the questionnaire by the **20<sup>th</sup> July 2009**.

After approximately a week from the round 1 deadline, the research team will send you back your responses and also the responses of other people who completed the questionnaire. You will not know the names of other people who took part but you will know what they considered to be important. You will also be sent a second questionnaire and you will be asked to respond to each statement again and some new statements from the previous round. You will be given the opportunity to change your ratings from the previous round in the light of other participants responses if you wish. The same process will apply for the third and final questionnaire.

Each questionnaire round will take approximately 15 minutes to complete and it is anticipated that there will be three rounds in total, sent approximately every three weeks. Information will be kept confidential at all times. It is important that if you agree to take part that you participate in all rounds.

**What are the possible risks of taking part?**

There are minimal risks involved in taking part in this study. However, if you feel uncomfortable at any stage, you can withdraw without any consequences.

**What are the possible benefits of taking part?**

There are no direct benefits from taking part in this study. However, it is expected that the research will increase our knowledge of the factors that contribute to successful rehabilitation following upper limb absence. Having a better understanding of these issues may be helpful in managing issues that arise while deciding on the most appropriate rehabilitation and prosthesis for patients. Therefore, it may benefit the people who provide the rehabilitation services by providing appropriate helpful information for their profession.

**What information will be held about me?**

If you agree to take part, all information collected will be kept strictly confidential within the limitations of the law. All information will have your name removed so as to preserve confidentiality. Any information that will identify you in any way will also be removed. The researcher, Ms. Sinéad NíMhurchadha will be responsible for safety and security of the data. The procedures for handling, processing, storage and destruction of your data will be compliant with the Data Protection (Amendment) Act 2003.

**What will happen to the results of the research study?**

The results of the research study will form the basis for the preparation of policy documents, reports, academic publications, conference papers and other scientific publications

**What will happen if I don't want to carry on with the study?**

Your participation in this study is entirely voluntary. You are free to decline to enter or to withdraw from the study any time without having to give a reason. If you choose not to participate, or to withdraw once entered, you will not be penalised. It will not affect your professional position and you will not give up any benefits you had before entering the study. Any participation you had in the study previous to your departure from the study will be stricken from the record and destroyed if you wish. Participation in this study will in no way affect your legal rights.

**Who is organising and funding the research?**

This study is organised by a research team from Dublin City University and Trinity College Dublin, Ireland. This research is being funded by the Health Research Board, Ireland.

**Complaints**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions

[Sinead.Nimhurchadha@dcu.ie](mailto:Sinead.Nimhurchadha@dcu.ie) (researcher)

[Pamela.Gallagher@dcu.ie](mailto:Pamela.Gallagher@dcu.ie) (co-investigator)

[Malcolm.MacLachlan@tcd.ie](mailto:Malcolm.MacLachlan@tcd.ie) (co-investigator)

If you have concerns about this study and wish to contact someone independent, you may contact: The Secretary, Research Ethics Committee, Dublin City University, Dublin, Ireland. Ph. +353 (0) 1 700 8000.

***This research has been reviewed by the Dublin City University Research Ethics Committee.***

**Thank you for taking time to read this sheet.**

**Feel free to pass this survey link and information sheet on to other suitably qualified colleagues that may wish to participate.**

**If you wish to contact me, my details are below:**

**Name:** Ms. Sinéad NíMhurchadha

**Address:** School of Nursing  
Dublin City University  
Glasnevin  
Dublin 9  
Ireland

**Phone:** +353 (0) 1 700 8527

**Email:** Sinead.Nimhurchadha@dcu.ie

Appendix U

MS Word document version of Delphi questionnaire for round 1 for individuals with  
ULA.

Round 1 Delphi survey (for individuals with upper limb absence)  
Health Research Board (Ireland) funded.

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Welcome to the Delphi survey! Thank you for agreeing to participate in this study, your contribution is important. To begin, click the continue button below.

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**What is the purpose of the study?**

The aim of this study is to gain a better understanding of what people with upper limb absence and rehabilitation professionals consider to be important in rehabilitation following upper limb absence. Having a better understanding will help us make ongoing improvements in this area.

**What will happen to me if I take part?**

We will use the Delphi method for the research study. This method involves ‘experts’ or ‘informed individuals’ sharing their knowledge using three rounds of information gathering. The first questionnaire is available at a link at the end of this page. You will be asked to consider what are successful outcomes following rehabilitation of upper limb absence and what factors are important to consider during rehabilitation. The first round questionnaire will be available until the 17th July 2009. All your responses will be confidential and they are sent back to the research team through the website. After approximately a week from the deadline of the 1st round questionnaire, the research team will send you a second questionnaire. You will be asked to respond to each statement again along with some new statements based on how other people responded. You will not know the names of the other people who took part but you will know what they consider to be important. You will have the opportunity to change your ratings from the previous round in the light of other participants responses. Each questionnaire round will take approximately 15 minutes to complete.

For more detailed information on the present study, see the information sheet attached with the email you received from the research team.

This study is designed to gather information on successful outcomes of rehabilitation following upper limb absence and their predictors. Your participation will allow us to identify the important factors from the perspective of rehabilitation professionals.

This questionnaire is divided into three sections:

Section A: background information

Section 1: asks you to identify what are the important indicators of successful outcomes

Section 2: asks you what are important factors to consider in rehabilitation

To participate, you must have major upper limb absence (that is through wrist or above) and be at least one year post amputation.

Please tick the box to confirm that you are eligible to participate in this study

	<input type="checkbox"/>

Please tick the box to indicate your consent to take part in the present study.

	<input type="checkbox"/>

We need your email address to enable us to contact you for the next round of the study. This information will only be made available to the research team and will not be used for any other purpose. Your confidentiality will be maintained at all times.

Please insert your email address (If you do not complete your email address we will be unable to provide feedback on the results from each round or send the 2nd round questionnaire)

--

### **Section A: Background information**

Please complete each section

Please state your age

--

Are you...

1. Male
2. Female

Country of residence:

--

Please indicate your employment status:

1. Full-time Employment
2. Part-time Employment
3. Student
4. Unemployed
5. Retired
6. Disability Leave
7. Other



Please indicate the reason for your limb absence:

1. Congenital (from birth)
2. Trauma
3. Cancer
4. Dysvascular/ Diabetes
5. Infection
6. Other

Please indicate the type and level of your limb absence:

1. Through Wrist
2. Below Elbow
3. Above Elbow
4. Shoulder Disarticulation
5. Through Ankle
6. Below Knee
7. Above Knee
8. Hip Disarticulation

How long has it been since your amputation? (years & months)

### Questions on prosthetic use

How long have you had your current prosthetic limb? (years & months)

How many hours per day do you wear your prosthesis?

How often do you wear your prosthesis? (Days per week, weeks per month, months per year)

What is the main reason/ purpose you wear your prosthesis?

Please complete Section 1 on the next page

### **Section 1: Successful outcomes of rehabilitation following upper limb absence**

The statements in Section 1 are designed to clarify what defines a successful outcome following upper limb absence rehabilitation. The statements presented here have been gathered through a review of the literature, focus groups and interviews with patients who have upper limb absence and rehabilitation professionals. While there is agreement on what constitutes a successful outcome in some domains such as positive psychological wellbeing or being pain free, there is less agreement in other areas such as prosthesis use or self image. Please indicate the extent to which you agree that each statement is a 'successful outcome' following upper limb absence rehabilitation.

#### **Prosthesis Use**

1. A successful outcome is use of a prosthesis for a persons pre-amputation job or activities
  - 5 = Strongly Agree
  - 4 = Agree
  - 3 = Neither agree nor disagree
  - 2 = Disagree
  - 1 = Strongly Disagree
  
2. A successful outcome is use of a non-functional (cosmetic) prosthesis
  - 5 = Strongly Agree
  - 4 = Agree
  - 3 = Neither agree nor disagree
  - 2 = Disagree
  - 1 = Strongly Disagree
  
3. A successful outcome is when a person is content not to wear a prosthesis
  - 5 = Strongly Agree
  - 4 = Agree
  - 3 = Neither agree nor disagree
  - 2 = Disagree
  - 1 = Strongly Disagree
  
4. A successful outcome is when a person wears their prosthesis all day every day.
  - 5 = Strongly Agree
  - 4 = Agree
  - 3 = Neither agree nor disagree
  - 2 = Disagree
  - 1 = Strongly Disagree

5. A successful outcome is when a person wears their prosthesis for specific activities

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

6. A successful outcome is when a person feels their prosthesis is part of them

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

7. A successful outcome is when a person uses the prosthesis as often as they wish

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

8. A successful outcome is when a person uses the prosthesis as intended (e.g. functional prosthesis used functionally)

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Think of your experience. Are there any other outcomes relating to prosthesis use that you think should be included in this list? Please list any you would like to see included below.

--

### **Activities and Participation**

1. A successful outcome is a persons ability to perform their own personal care without help from other people

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

2. A successful outcome is a persons ability to complete activities of daily living without help from other people

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

3. A successful outcome is a persons ability to drive (if they desire)

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

4. A successful outcome is when a person is satisfied with their functional abilities

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

5. A successful outcome is when a person has returned to active employment (but may have to change jobs)

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

6. A successful outcome is when a person is performing to the best of their ability

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

7. A successful outcome is a persons ability to perform activities to the same standard they had before the limb absence

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Think of your experience. Are there any other outcomes relating to activities and participation that you think should be included in this list? Please list any you would like to see included below.

### **Self Image**

1. A successful outcome is when a person reports having a positive body image (feeling attractive)

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

2. A successful outcome is when a person is confident to show their residual limb (stump) in public

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

3. A successful outcome is when a person does not feel they stand out

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

4. A successful outcome is when a person does not mind looking at their residual limb (stump)

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

5. A successful outcome is when a person feels that they look balanced

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

6. A successful outcome is when a person is not feeling self-conscious when in public with a prosthesis

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

7. A successful outcome is when a person is not feeling self-conscious when in public without a prosthesis

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Think of your experience. Are there any other outcomes relating to self image that you think should be included in this list? Please list any you would like to see included below.

--

Please complete Section 2 on the next page

## **Section 2: Important areas to consider**

There are many possible factors that may contribute to successful rehabilitation following upper limb absence. On some factors there is significant agreement and for others there is less agreement. The following factors have been suggested in the literature and by patients and rehabilitation professionals; however agreement is lacking. How important do you think each factor is to consider for individuals with upper limb absence?

### **Demographic Factors**

For successful rehabilitation, how important do you think it is to consider...

1. Age at amputation
  - 5 = Very Important
  - 4 = Important
  - 3 = Neither important nor unimportant
  - 2 = Unimportant
  - 1 = Very unimportant
2. Gender
  - 5 = Very Important
  - 4 = Important
  - 3 = Neither important nor unimportant
  - 2 = Unimportant
  - 1 = Very unimportant
3. Level of education
  - 5 = Very Important
  - 4 = Important
  - 3 = Neither important nor unimportant
  - 2 = Unimportant
  - 1 = Very unimportant

### **Engagement in Activities and Participation**

For successful rehabilitation, how important do you think it is to consider...

1. Engagement in activities of daily living
  - 5 = Very Important
  - 4 = Important
  - 3 = Neither important nor unimportant
  - 2 = Unimportant
  - 1 = Very unimportant

2. Achieving set goals

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

3. Engagement in leisure activities

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

4. Getting along with other people

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

5. Getting around

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

6. Perceived environmental barriers

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

7. Performing social/ family roles of importance (e.g. breadwinner, spouse, student, parent)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant



8. Performing self care

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

9. Understanding and communicating

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

**Psychological Factors**

For successful rehabilitation, how important do you think it is to consider...

1. Anxiety

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. Coping strategies

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

3. Depression

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

4. Patients attitude

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

5. Patients expectations

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

6. Patients mood

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

7. Patients motivation

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

8. Patients sense of humour

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

9. Post Traumatic Stress Disorder (PTSD)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

10. Pre-amputation life experiences and skills (e.g. experience of disability or limb absence in the family)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

11. The extent to which people compare themselves to other people who are better/ worse off

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

### **Self-image**

For successful rehabilitation, how important do you think it is to consider...

1. Body image

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. Public self-consciousness (feeling self-conscious around other people)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

### **Prosthesis use**

For successful rehabilitation, how important do you think it is to consider...

1. Purpose of prosthesis use

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. Frequency of prosthesis use

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

### **Physical Factors**

For successful rehabilitation, how important do you think it is to consider...

1. Cause of limb absence (congenital or acquired)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. General physical health

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

3. Level of amputation

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

4. Absence of dominant or non-dominant arm

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

5. Presence/ absence of certain joints

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

6. Phantom limb pain

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

7. Phantom limb sensation

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

8. Residual limb pain

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

9. State of residual limb

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

10. Time since amputation

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

11. Type of limb absence (Bilateral or unilateral)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

**Social Factors**

For successful rehabilitation, how important do you think it is to consider...

1. Emotional support from family/ friends

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. Meeting another individual with limb absence

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

3. Practical support from family/ friends

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

4. Reaction of family to the prosthesis

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

5. Reactions from public

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

**Rehabilitation service**

For successful rehabilitation, how important do you think it is to consider...

1. Access to services (for example, making appointments, physical access)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. Satisfaction with the rehabilitation service

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant

- 1 = Very unimportant
3. Satisfaction with the prosthesis
- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

Think of your experience. Are there any other factors that you would like to be included in these lists of important factors to consider in rehabilitation? Please list any you would like to see included below.

--

Thank you for your participation. By clicking the continue button, you are submitting your responses to the research team.

Appendix V

MS Word document version of Delphi questionnaire for round 1 RP's



Round 1 Delphi survey (For Rehabilitation Professionals)  
Health Research Board (Ireland) funded.

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Welcome to the Delphi survey! Thank you for agreeing to participate in this study, your contribution is important. To begin, click the continue button below.

---

**What is the purpose of the study?**

The aim of this study is to gain a better understanding of what people with upper limb absence and rehabilitation professionals consider to be important in rehabilitation following upper limb absence. Having a better understanding will help us make ongoing improvements in this area.

**What will happen to me if I take part?**

We will use the Delphi method for the research study. This method involves ‘experts’ or ‘informed individuals’ sharing their knowledge using three rounds of information gathering. The first questionnaire is available at a link at the end of this page. You will be asked to consider what are successful outcomes following rehabilitation of upper limb absence and what factors are important to consider during rehabilitation. The first round questionnaire will be available until the 17th July 2009. All your responses will be confidential and they are sent back to the research team through the website. After approximately a week from the deadline of the 1st round questionnaire, the research team will send you a second questionnaire. You will be asked to respond to each statement again along with some new statements based on how other people responded. You will not know the names of the other people who took part but you will know what they consider to be important. You will have the opportunity to change your ratings from the previous round in the light of other participants’ responses. Each questionnaire round will take approximately 15 minutes to complete.

For more detailed information on the present study, see the information sheet attached with the email you received from the research team.

This study is designed to gather information on successful outcomes of rehabilitation following upper limb absence and their predictors. Your participation will allow us to identify the important factors from the perspective of rehabilitation professionals.

This questionnaire is divided into three sections:

Section A: background information

Section 1: asks you to identify what are the important indicators of successful outcomes

Section 2: asks you what are important factors to consider in rehabilitation

To participate in this study, you must be either

(1) a researcher who has authored an article on upper limb absence, prosthetics or rehabilitation that has been published in a peer reviewed or professional journal between 1999 and 2009; or

(2) working as part of a rehabilitation team concerned with individuals with upper limb absence for at least 3 years; (3) or both.

If you do not fulfil either of these criteria but feel that you are an ‘informed individual’ that should participate in this study, please contact the research team (sinead.nimhurchadha@dcu.ie) with your details.

Please tick the box to confirm that you are eligible to participate in this study

	<input type="checkbox"/>

Please tick the box to indicate your consent to take part in the present study.

	<input type="checkbox"/>

We need your email address to enable us to contact you for the next round of the study. This information will only be made available to the research team and will not be used for any other purpose. Your confidentiality will be maintained at all times.

Please insert your email address (If you do not complete your email address we will be unable to provide feedback on the results from each round or send the 2nd round questionnaire)

--

**Section A: Background information**

Please complete each section

Are you...

1. Male
2. Female

Country of residence

Please indicate what profession you belong to

1. Prosthetist
2. Occupational therapist
3. Physiotherapist
4. Consultant in rehabilitation medicine
5. Engineer
6. Psychologist
7. Researcher
8. Other

How many years professional experience do you have working with patients with upper limb absence?

Please list your educational/ professional qualifications

Please complete Section 1 on the next page

### **Section 1: Successful outcomes of rehabilitation following upper limb absence**

The statements in Section 1 are designed to clarify what defines a successful outcome following upper limb absence rehabilitation. The statements presented here have been gathered through a review of the literature, focus groups and interviews with patients who have upper limb absence and rehabilitation professionals. While there is agreement on what constitutes a successful outcome in some domains such as positive psychological wellbeing or being pain free, there is less agreement in other areas such as prosthesis use or self image. Please indicate the extent to which you agree that each statement is a 'successful outcome' following upper limb absence rehabilitation.

#### **Prosthesis Use**

1. A successful outcome is use of a prosthesis for a persons pre-amputation job or activities
  - 5 = Strongly Agree
  - 4 = Agree
  - 3 = Neither agree nor disagree
  - 2 = Disagree
  - 1 = Strongly Disagree
  
2. A successful outcome is use of a non-functional (cosmetic) prosthesis
  - 5 = Strongly Agree
  - 4 = Agree
  - 3 = Neither agree nor disagree
  - 2 = Disagree
  - 1 = Strongly Disagree
  
3. A successful outcome is when a person is content not to wear a prosthesis
  - 5 = Strongly Agree
  - 4 = Agree
  - 3 = Neither agree nor disagree
  - 2 = Disagree
  - 1 = Strongly Disagree
  
4. A successful outcome is when a person wears their prosthesis all day every day.
  - 5 = Strongly Agree
  - 4 = Agree
  - 3 = Neither agree nor disagree
  - 2 = Disagree
  - 1 = Strongly Disagree

5. A successful outcome is when a person wears their prosthesis for specific activities

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

6. A successful outcome is when a person feels their prosthesis is part of them

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

7. A successful outcome is when a person uses the prosthesis as often as they wish

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

8. A successful outcome is when a person uses the prosthesis as intended (e.g. functional prosthesis used functionally)

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Think of your experience. Are there any other outcomes relating to prosthesis use that you think should be included in this list? Please list any you would like to see included below.

--

### **Activities and Participation**

1. A successful outcome is a persons ability to perform their own personal care without help from other people

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

2. A successful outcome is a persons ability to complete activities of daily living without help from other people

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

3. A successful outcome is a persons ability to drive (if they desire)

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

4. A successful outcome is when a person is satisfied with their functional abilities

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

5. A successful outcome is when a person has returned to active employment (but may have to change jobs)

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

6. A successful outcome is when a person is performing to the best of their ability

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

7. A successful outcome is a persons ability to perform activities to the same standard they had before the limb absence

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Think of your experience. Are there any other outcomes relating to activities and participation that you think should be included in this list? Please list any you would like to see included below.

### **Self Image**

1. A successful outcome is when a person reports having a positive body image (feeling attractive)

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

2. A successful outcome is when a person is confident to show their residual limb (stump) in public

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

3. A successful outcome is when a person does not feel they stand out

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

4. A successful outcome is when a person does not mind looking at their residual limb (stump)

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

5. A successful outcome is when a person feels that they look balanced

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

6. A successful outcome is when a person is not feeling self-conscious when in public with a prosthesis

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

7. A successful outcome is when a person is not feeling self-conscious when in public without a prosthesis

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Think of your experience. Are there any other outcomes relating to self image that you think should be included in this list? Please list any you would like to see included below.

--

Please complete Section 2 on the next page



## **Section 2: Important areas to consider**

There are many possible factors that may contribute to successful rehabilitation following upper limb absence. On some factors there is significant agreement and for others there is less agreement. The following factors have been suggested in the literature and by patients and rehabilitation professionals; however agreement is lacking. How important do you think each factor is to consider for individuals with upper limb absence?

### **Demographic Factors**

For successful rehabilitation, how important do you think it is to consider...

1. Age at amputation
  - 5 = Very Important
  - 4 = Important
  - 3 = Neither important nor unimportant
  - 2 = Unimportant
  - 1 = Very unimportant
2. Gender
  - 5 = Very Important
  - 4 = Important
  - 3 = Neither important nor unimportant
  - 2 = Unimportant
  - 1 = Very unimportant
3. Level of education
  - 5 = Very Important
  - 4 = Important
  - 3 = Neither important nor unimportant
  - 2 = Unimportant
  - 1 = Very unimportant

### **Engagement in Activities and Participation**

For successful rehabilitation, how important do you think it is to consider...

1. Engagement in activities of daily living
  - 5 = Very Important
  - 4 = Important
  - 3 = Neither important nor unimportant
  - 2 = Unimportant
  - 1 = Very unimportant

2. Achieving set goals

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

3. Engagement in leisure activities

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

4. Getting along with other people

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

5. Getting around

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

6. Perceived environmental barriers

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

7. Performing social/ family roles of importance (e.g. breadwinner, spouse, student, parent)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

8. Performing self care

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

9. Understanding and communicating

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

**Psychological Factors**

For successful rehabilitation, how important do you think it is to consider...

1. Anxiety

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. Coping strategies

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

3. Depression

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

4. Patients attitude

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

5. Patients expectations

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

6. Patients mood

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

7. Patients motivation

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

8. Patients sense of humour

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

9. Post Traumatic Stress Disorder (PTSD)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

10. Pre-amputation life experiences and skills (e.g. experience of disability or limb absence in the family)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

11. The extent to which people compare themselves to other people who are better/ worse off

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

### **Self-image**

For successful rehabilitation, how important do you think it is to consider...

1. Body image

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. Public self-consciousness (feeling self-conscious around other people)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

### **Prosthesis use**

For successful rehabilitation, how important do you think it is to consider...

1. Purpose of prosthesis use

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. Frequency of prosthesis use

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

### **Physical Factors**

For successful rehabilitation, how important do you think it is to consider...

1. Cause of limb absence (congenital or acquired)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. General physical health

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

3. Level of amputation

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

4. Absence of dominant or non-dominant arm

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

5. Presence/ absence of certain joints

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

6. Phantom limb pain

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

7. Phantom limb sensation

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

8. Residual limb pain

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

9. State of residual limb

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

10. Time since amputation

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

11. Type of limb absence (Bilateral or unilateral)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

**Social Factors**

For successful rehabilitation, how important do you think it is to consider...

1. Emotional support from family/ friends

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. Meeting another individual with limb absence

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

3. Practical support from family/ friends

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

4. Reaction of family to the prosthesis

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

5. Reactions from public

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

**Rehabilitation service**

For successful rehabilitation, how important do you think it is to consider...

1. Access to services (for example, making appointments, physical access)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

2. Satisfaction with the rehabilitation service

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant



3. Satisfaction with the prosthesis

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

Think of your experience. Are there any other factors that you would like to be included in these lists of important factors to consider in rehabilitation? Please list any you would like to see included below.

--

Thank you for your participation. By clicking the continue button, you are submitting your responses to the research team.

Appendix W

MS Word document version of the Delphi Questionnaire for round 2 for both groups

## Round 2 Delphi survey Health Research Board (Ireland) funded.

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Thank you for completing round 1 of the Delphi survey

The purpose of the round 2 survey is to reach consensus agreement) on items in Section 1 and Section 2. This study is designed to gather information on successful outcomes of rehabilitation following upper limb absence and their predictors. Your participation will allow us to identify the important factors from the perspective of rehabilitation professionals and individuals with upper limb absence. This questionnaire is divided into two sections:

Section 1: asks you to identify what are the important indicators of successful outcomes

Section 2: asks you what are important factors to consider in rehabilitation.

In round 1, there were 73 participants in total (48 Rehabilitation professionals and 21 individuals with upper limb absence, and an additional 4 Rehabilitation professionals who also have upper limb absence). All participants rated the extent to which they agreed with the statements presented in Section 1 and Section 2. In this round, you will be presented with items that did not reach agreement in round 1. You will also be provided with the average rating from all participants in round 1 and asked to re-rate these items again. You do not have to agree with the average rating. You will also be asked to rate some newly proposed items from round 1.

Please insert your email address (If you do not complete your email address we will be unable to provide feedback on the results from each round or send the final questionnaire)

---

### Section 1: Successful outcomes of rehabilitation following upper limb absence

Agreement was reached on 62 out of 68 items in round 1. In round 2, you will be presented with the items where there wasn't sufficient agreement to automatically keep them in and also the items that were not considered as successful outcomes. Only items that receive an average rating of greater than 4 will be considered as successful outcomes. Feedback on the responses for the entire group of participants are provided in this round. You are given the opportunity to rate these items again and are given information on how other participants rated items. You are also given the opportunity to provide a reason for your response. There were also some newly proposed items in round 1 which you are asked to rate. As in round 1, the statements in Section 1 are designed to clarify what defines a successful outcome following upper limb absence rehabilitation. Please indicate the extent to which you agree that each statement is a 'successful outcome' following

upper limb absence rehabilitation.

In round 1, the following items had small variation in response range from participants, that means there was agreement, but the average rating was less than 4 which indicates that they were not considered indicative of successful outcomes.

1. A successful outcome is use of a prosthesis for a persons pre-amputation job or activities

Average rating by all 73 participants 3.99 (range 1-5)

Range of ratings from all 73 participants in round 1:

34.2% Strongly Agree

38.4% Agree

19.2% Neither agree nor disagree

8.2% Disagree

0% Strongly Disagree

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Strongly Agree

4 = Agree

3 = Neither agree nor disagree

2 = Disagree

1 = Strongly Disagree

Reason for answer

--

2. A successful outcome is when a person wears their prosthesis for specific activities

Average round 1 rating by all 73 participants 3.97(range 1-5)

Range of ratings from all 73 participants in round 1:

26% strongly agreed

50.7% Agreed

17.8% Neither agreed nor disagreed

5.5% Disagreed

0% Strongly disagreed

PLEASE RE-RATE THE UNDELINED STATEMENT ABOVE

5 = Strongly Agree

4 = Agree

3 = Neither agree nor disagree

2 = Disagree

1 = Strongly Disagree

Reason for answer

3. A successful outcome is when a person does not mind looking at their residual limb (stump)

Average round 1 rating by all 73 participants 3.96 (range 1-5)

Range of ratings from all 73 participants in round 1:

31.5% Strongly agreed  
 38.4% Agreed  
 24.7% Neither agreed nor disagreed  
 5.5% Disagreed  
 0% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer

4. A successful outcome is when a person is not feeling self-conscious when in public without a prosthesis

Average round 1 rating by all 73 participants 3.90 (range 1-5)

Range of ratings from all 73 participants in round 1:

27.4% Strongly agreed  
 42.5% Agreed  
 23.3% Neither agreed nor disagreed  
 6.8% Disagreed  
 0% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer

5. A successful outcome is when a person feels that they look balanced

Average round 1 rating by all 73 participants 3.71 (range 1-5)

Range of ratings from all 73 participants in round 1:

17.8% Strongly agreed  
 42.5% Agreed  
 32.9% Neither agreed nor disagreed  
 6.8% Disagreed  
 0% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer

6. A successful outcome is when a person does not feel they stand out

Average round 1 rating by all 73 participants 3.66 (range 1-5)

Range of ratings from all 73 participants in round 1:

20.5% Strongly agreed  
 38.4% Agreed  
 28.8% Neither agreed nor disagreed  
 11% Disagreed  
 1.4% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer

The following are items that had with wide variation in ratings from participants in round 1, that means there wasn't sufficient agreement to automatically keep them in

1. A successful outcome is when a person feels their prosthesis is part of them

Average round 1 rating by all 73 participants 4.08 (range 1-5)

Range of ratings from all 73 participants in round 1:

45.2% Strongly agreed

27.4% Agreed

19.2% Neither agreed nor disagreed

6.8% Disagreed

1.4% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Strongly Agree

4 = Agree

3 = Neither agree nor disagree

2 = Disagree

1 = Strongly Disagree

Reason for answer

2. A successful outcome is when a person is confident to show their residual limb (stump) in public

Average round 1 rating by all 73 participants 3.63 (range 1-5)

Range of ratings from all 73 participants in round 1:

24.7% Strongly agreed

27.4% Agreed

28.8% Neither agreed nor disagreed

34.2% Disagreed

13.7% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Strongly Agree

4 = Agree

3 = Neither agree nor disagree

2 = Disagree

1 = Strongly Disagree

Reason for answer

3. A successful outcome is a persons ability to perform activities to the same standard they had before the limb absence

Average round 1 rating by all 73 participants 3.52 (range 1-5)

Range of ratings from all 73 participants in round 1:

24.7% Strongly agreed  
 27.4% Agreed  
 26% Neither agreed nor disagreed  
 19.2% Disagreed  
 2.7% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

- 5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer

4. A successful outcome is when a person wears their prosthesis all day every day.

Average round 1 rating by all 73 participants 3.44

Range of ratings from all 73 participants in round 1:

17.8% Strongly agreed  
 34.2% Agreed  
 27.4% Neither agreed nor disagreed  
 15.1% Disagreed  
 5.5% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

- 5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer



5. A successful outcome is when a person is content not to wear a prosthesis

Average round 1 rating by all 73 participants 3.42 (range 1-5)

Range of ratings from all 73 participants in round 1:

17.8% Strongly agreed  
 26% Agreed  
 38.4% Neither agreed nor disagreed  
 16.4% Disagreed  
 1.4% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5=Strongly Agree  
 4=Agree  
 3=Neither agree nor disagree  
 2=Disagree  
 1=Strongly Disagree

Reason for answer

--

1. A successful outcome is use of a non-functional (cosmetic) prosthesis

Average round 1 rating by all 73 participants 3.08

Range of ratings from all 73 participants in round 1:

9.6% Strongly agreed  
 28.8% Agreed  
 35.6% Neither agreed nor disagreed  
 12.3% Disagreed  
 13.7% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer

--

Please rate the newly proposed items from participants in Round 1

1. A successful outcome is when a person uses the prosthesis for both functional and cosmetic purposes

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

2. A successful outcome is when a prosthetic user can perform an activity bi-laterally to an equal standard as a 2 handed person.

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

3. A successful outcome is when a patient is satisfied with the cosmetic appearance of the prosthesis

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

4. A successful outcome is when a person feels grateful when the prosthesis is initially delivered

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

5. A successful outcome is when a person uses the prosthesis to feel socially accepted

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

6. A successful outcome is a persons ability to perform activities within the same time parameters as prior to their injury

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

7. A successful outcome is when an individual has a high level of function regardless of whether they use a prosthesis or not

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Please complete Section 2 on the next page

---

## Section 2: Important areas to consider

As in Round 1, the statements in Section 2 are designed to clarify what factors you think are important to consider in the rehabilitation of individuals with upper limb absence. Feedback from round 1 In round 1, agreement was reached on all items in Section 2. However, for items presented here, although there was agreement, participants did not rate them on average to be important to consider in rehabilitation (they had an average rating less than 4). You are given the opportunity to rate these items again and are given information on how other participants rated items. You are also given the opportunity to provide a reason for your response. There were also some newly proposed items in round 1 which you are asked to rate in this round.

---

For successful rehabilitation, how important do you think is it for rehabilitation professionals to consider...

### 1. Frequency of prosthesis use

Average round 1 rating by all 73 participants 3.99 (range 1-5)

Range of ratings from all 73 participants in round 1:

31.5% Very Important  
 39.7% Important  
 24.7% Neither important nor unimportant  
 4.1% Unimportant  
 0% Very unimportant

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Very Important  
 4 = Important  
 3 = Neither important nor unimportant  
 2 = Unimportant  
 1 = Very unimportant

Reason for answer

2. Age at amputation

Average round 1 rating by all 73 participants 3.90 (range 1-5)

Range of ratings from all 73 participants in round 1:

28.8% Very Important

41.4% Important

23.3% Neither important nor unimportant

5.5% Unimportant

1% Very unimportant

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Very Important

4 = Important

3 = Neither important nor unimportant

2 = Unimportant

1 = Very unimportant

Reason for answer

--

3. Reactions from public

Average round 1 rating by all 73 participants 3.88 (range 1-5)

Range of ratings from all 73 participants in round 1:

15.1% Very Important

61.6% Important

19.2% Neither important nor unimportant

4.1% Unimportant

0% Very unimportant

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Very Important

4 = Important

3 = Neither important nor unimportant

2 = Unimportant

1 = Very unimportant

Reason for answer

--

4. The extent to which people compare themselves to other people who are better/worse off

Average round 1 rating by all 73 participants 3.73 (range 1-5)

Range of ratings from all 73 participants in round 1:

21.9% Very Important

31.5% Important

43.8% Neither important nor unimportant

2.7% Unimportant

0% Very unimportant

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Very Important

4 = Important

3 = Neither important nor unimportant

2 = Unimportant

1 = Very unimportant

Reason for answer

--

5. Gender

Average round 1 rating by all 73 participants 3.34 (range 1-5)

Range of ratings from all 73 participants in round 1:

9.6% Very Important

38.4% Important

32.9% Neither important nor unimportant

15.1% Unimportant

4.1% Very unimportant

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Very Important

4 = Important

3 = Neither important nor unimportant

2 = Unimportant

1 = Very unimportant

Reason for answer

--

## 6. Level of education

Average round 1 rating by all 73 participants 3.16 (range 1-5)

Range of ratings from all 73 participants in round 1:

5.5% Very Important  
 24.7% Important  
 53.4% Neither important nor unimportant  
 13.7% Unimportant  
 2.7% Very unimportant

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE

5 = Very Important  
 4 = Important  
 3 = Neither important nor unimportant  
 2 = Unimportant  
 1 = Very unimportant

Reason for answer

---

Newly proposed items from Round 1

For successful rehabilitation, how important do you think it is to consider...

1. The achievement of tasks set by the individual with upper limb absence

5 = Very Important  
 4 = Important  
 3 = Neither important nor unimportant  
 2 = Unimportant  
 1 = Very unimportant

2. The achievement of tasks set by Rehab professionals

5 = Very Important  
 4 = Important  
 3 = Neither important nor unimportant  
 2 = Unimportant  
 1 = Very unimportant

3. A patients feeling of control over the rehabilitation

5 = Very Important  
 4 = Important  
 3 = Neither important nor unimportant  
 2 = Unimportant  
 1 = Very unimportant

4. A patients resilience

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

5. Cost of prosthesis

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

6. Cause of acquired limb absence (trauma vs malignancy/ disease)

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

7. Whether individual is entitled to compensation

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

8. The social skills of the individual with limb absence

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

Thank you for your participation. By clicking the submit responses button, you are sending your responses to the research team.



Appendix X

MS Word document version of Delphi Questionnaire for round 3 for both groups

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Final round Delphi survey  
Health Research Board (Ireland) funded.

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Thank you for your participation in the previous 2 rounds of the Delphi survey. So far, we have reached agreement on 76 out of 83 statements. Some of these statements have been deemed important and some have been deemed unimportant by all participants.

We have made a lot of progress. However, there are some final statements where there is a high level of disagreement amongst participants. We are aware that agreement may not always be possible amongst participants. But it is important that we offer one final opportunity for you to consider these statements.

You do not have to change your ratings. However, some participants may wish to change them. This questionnaire is divided into two sections with only 14 statements in all to rate.

---

There are a few things that we would like you to note:

- The statements are not the opinions of the research team. They are a reflection of previous research and interviews from rehabilitation professionals and individuals with upper limb absence. The research team seeks your opinion on the statements.
  - We are not attempting to force agreement amongst participants. We are providing you with a final opportunity to reach agreement amongst each other in light of the thoughts of other rehabilitation professionals and individuals with limb absence.
  - We are concerned with all aspects of rehabilitation involved with upper limb absence, not just prosthetic rehabilitation.
  - We acknowledge that rehabilitation is often individual and are not suggesting that any item is the sole indicator of success. What we wish to determine is if a statement indicates one of the important indicators of success.
  - We are not providing you with your previous ratings as we would like you to rate the statements as you feel now, rather than be influenced by your previous rating.
- 

Please insert your email address (If you do not complete your email address we will be unable to provide the results of this round to you)

--

---

**Section 1: Original items presented to you in round 1**

In this round, you are presented with the original statements from round 1 where there still isn't sufficient agreement to automatically keep them in.

You are given the opportunity to rate these items again for the final time. You are also given information on how other participants rated these items and their reasons for these ratings. (**\*These reasons are attached in the email you received from the research team**). You can also provide a comment after each statement if you wish.

Please indicate the extent to which you agree that each statement is a 'successful outcome' following upper limb absence rehabilitation.

---

**1. A successful outcome is when a person feels their prosthesis is part of them**

Average round 2 rating by all 58 participants **3.83**

Range of ratings from all 58 participants in round 2:

39.7% Strongly agreed  
 29.3% Agreed  
 12.1% Neither agreed nor disagreed  
 12.1% Disagreed  
 6.9% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
 BESIDE YOUR ANSWER

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Comment

**2. A successful outcome is when a person is confident to show their residual limb (stump) in public**

Average round 2 rating by all 58 participants **3.28**

Range of ratings from all 58 participants in round 2:

15.5% Strongly agreed

22.4% Agreed

41.4% Neither agreed nor disagreed

15.5% Disagreed

5.2% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X BESIDE YOUR ANSWER

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Comment

**3. A successful outcome is a persons ability to perform activities to the same standard they had before the limb absence**

Average round 2 rating by all 58 participants **3.60**

Range of ratings from all 58 participants in round 2:

22.4% Strongly agreed

32.8% Agreed

29.3% Neither agreed nor disagreed

13.8% Disagreed

1.7% Strongly disagreed

P PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X BESIDE YOUR ANSWER

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Comment

**4. A successful outcome is when a person wears their prosthesis all day every day.**

Average round 2 rating by all 58 participants **3.12**

Range of ratings from all 58 participants in round 2:

5.2% Strongly agreed

39.7% Agreed

25.9% Neither agreed nor disagreed

20.7% Disagreed

8.6% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
BESIDE YOUR ANSWER

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Comment

---

**Section 2: Items proposed by participants in the first round of the survey**

There were 15 statements proposed by participants in round 1, which you rated in round 2. Seven of these statements reached agreement amongst participants (had small variation in scores) but had an average rating below 4, indicating that they were not considered important. In order for these statements to be considered important, they will need an average rating above 4.

We would like to provide you with a final opportunity to rate whether you consider these statements important. You are also provided with the ratings of participants from the previous round. You may also wish to provide a reason for your response.

---

**For successful rehabilitation, how important do you think it is for rehabilitation professionals to consider...**

**1. The achievement of tasks sets by rehab professionals**

Average round 2 rating by all 58 participants **3.78**  
Range of ratings from all 58 participants in round 2:

8.6% Very important  
67.2% Important  
19% Neither important nor unimportant  
3.4% Unimportant  
1.7% Very unimportant

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
BESIDE YOUR ANSWER

5 = Very Important  
4 = Important  
3 = Neither important nor unimportant  
2 = Unimportant  
1 = Very unimportant

Reason for answer

--

**For successful rehabilitation, how important do you think it is for rehabilitation professionals to consider...**

**2. Cause of acquired limb absence (trauma vs malignancy/ disease)**

Average round 2 rating by all 58 participants **3.90**

Range of ratings from all 58 participants in round 2:

20.7% Very important  
 53.4% Important  
 20.7% Neither important nor unimportant  
 5.2% Unimportant  
 0% Very unimportant

**PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
 BESIDE YOUR ANSWER**

5 = Very Important  
 4 = Important  
 3 = Neither important nor unimportant  
 2 = Unimportant  
 1 = Very unimportant

Reason for answer

**For successful rehabilitation, how important do you think it is for rehabilitation professionals to consider...**

**3. Whether individual is entitled to compensation**

Average round 2 rating by all 58 participants **3.43**

Range of ratings from all 58 participants in round 2:

8.6% Very important

37.9% Important

43.1% Neither important nor unimportant

8.6% Unimportant

1.7% Very unimportant

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
BESIDE YOUR ANSWER

- 5 = Very Important
- 4 = Important
- 3 = Neither important nor unimportant
- 2 = Unimportant
- 1 = Very unimportant

Reason for answer



**Please indicate your level of agreement with this statement**

**4. A successful outcome is when a person uses the prosthesis for both functional and cosmetic purposes**

Average round 2 rating by all 58 participants **3.80**

Range of ratings from all 58 participants in round 2:

22.4% Strongly agreed  
 41.4% Agreed  
 31.0% Neither agreed nor disagreed  
 3.4% Disagreed  
 1.7% Strongly disagreed

**PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
 BESIDE YOUR ANSWER**

5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer

--

**Please indicate your level of agreement with this statement**

**5. A successful outcome is when a patient is satisfied with the cosmetic appearance of the prosthesis**

Average round 2 rating by all 58 participants **3.88**

Range of ratings from all 58 participants in round 2:

17.2% Strongly agreed  
 60.3% Agreed  
 17.2% Neither agreed nor disagreed  
 3.4% Disagreed  
 1.7% Strongly disagreed

**PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
 BESIDE YOUR ANSWER**

5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer

--

Please indicate your level of agreement with this statement

**6. A successful outcome is when a person uses the prosthesis to feel socially accepted**

Average round 2 rating by all 58 participants **3.31**

Range of ratings from all 58 participants in round 2:

8.6% Strongly agreed  
 37.9% Agreed  
 32.8% Neither agreed nor disagreed  
 17.2% Disagreed  
 3.4% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
 BESIDE YOUR ANSWER

5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer

--

Please indicate your level of agreement with this statement

**1. A successful outcome is when a person feels grateful when the prosthesis is initially delivered**

Average round 2 rating by all 58 participants **2.86**

Range of ratings from all 58 participants in round 2:

6.9% Strongly agreed

15.5% Agreed

39.7% Neither agreed nor disagreed

32.8% Disagreed

5.2% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
BESIDE YOUR ANSWER

- 5 = Strongly Agree
- 4 = Agree
- 3 = Neither agree nor disagree
- 2 = Disagree
- 1 = Strongly Disagree

Reason for answer

Out of the 15 statements that were proposed by participants in Round 1 and rated by you in Round 2, three of them had wide variation in responses amongst participants. This means they have not reached agreement on whether they are important or unimportant.

We would like to provide you with a final opportunity to rate whether you consider these statements important. You are also provided with the ratings of participants from the previous round. You may also wish to provide a reason for your response.

Please indicate your level of agreement with this statement

1. A successful outcome is when a prosthetic user can perform an activity bilaterally to an equal standard as a 2 handed person.

Average round 2 ratings from all 58 participants: **3.41**

Range of ratings from all 58 participants in round 2:

22.4% Strongly Agree

36.2% Agree

10.3% Neither Agree nor disagree

22.4% Disagree

8.6% Strongly Disagree

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
BESIDE YOUR ANSWER

- |   |                              |
|---|------------------------------|
| 5 | = Strongly Agree             |
| 4 | = Agree                      |
| 3 | = Neither agree nor disagree |
| 2 | = Disagree                   |
| 1 | = Strongly Disagree          |

Reason for answer

Please indicate your level of agreement with this statement

**2. A successful outcome is a persons ability to perform activities within the same TIME parameters as prior to their injury**

Average round 2 rating by all 58 participants **3.33**

Range of ratings from all 58 participants in round 2:

12.1% Strongly agreed  
 32.8% Agreed  
 32.8% Neither agreed nor disagreed  
 20.7% Disagreed  
 1.7% Strongly disagreed

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
 BESIDE YOUR ANSWER

5 = Strongly Agree  
 4 = Agree  
 3 = Neither agree nor disagree  
 2 = Disagree  
 1 = Strongly Disagree

Reason for answer

---

**For successful rehabilitation, how important do you think is it for rehabilitation professionals to consider...**

**2. Cost of prosthesis**

Average round 2 rating by all 58 participants **3.83**

Range of ratings from all 58 participants in round 2:

24.1% Very important  
48.3% Important  
19.0% Neither important nor unimportant  
3.4% Unimportant  
5.2% Very unimportant

PLEASE RE-RATE THE UNDERLINED STATEMENT ABOVE BY PLACING AN X  
BESIDE YOUR ANSWER

5 = Very Important  
4 = Important  
3 = Neither important nor unimportant  
2 = Unimportant  
1 = Very unimportant

Reason for answer

---

Thank you! We really appreciate you participating in all three rounds of the delphi study.

If you would like to make any comments on this study, please do so below

Appendix Y

Round 2 qualitative responses that were provided to participants in Round 3



1. **A successful outcome is when a person feels their prosthesis is part of them**

*Average round 2 rating by all 57 participants 3.83*

**39.7% Strongly agreed**

- ❖ I just \*feel\* that way about myself but it is not true for everyone. A non-self part can be a very successfully accepted tool
- ❖ Person may accept prosthesis but still feel whole when not wearing it
- ❖ As a therapist, you want the prosthesis to feel natural, more a part of them. They will be more likely to wear and use it regularly
- ❖ More likely to wear and use regularly
- ❖ Aids in effective use
- ❖ Self acceptance moving on to considering activities not the device
- ❖ High correlation with function
- ❖ If the person chooses to wear a prosthesis, outcomes tend to be better when they feel it is part of them
- ❖ It reinforces a nice result when patients say this to me

**29.3% Agreed**

- ❖ This is ONE example of a successful outcome
- ❖ A good outcome
- ❖ Being comfortable with the prosthesis is important but it still remains an addition
- ❖ This certainly improves the overall chance of success
- ❖ A noble goal, but one would never feel a failure if the client feels the prosthesis is not part of them
- ❖ They can sort of feel apart from you, but mostly they are hot, heavy, painful, cumbersome, downright uncomfortable and they will never feel natural
- ❖ A prosthesis could be considered a "tool" for some people, a "helping" hand/device, not necessarily a part of them

**12.1% Neither agreed nor disagreed**

- ❖ Not sure why this is important
- ❖ Generally agree but this may not relate to people who see their prosthesis as tool for specific activities (you wouldn't feel that a knife or fork belonged to you)
- ❖ The use should be comfortable and automatic. But shoes are not part of me, and neither is a prosthesis

**12.1% Disagreed**

- ❖ An upper extremity prosthesis is a tool. As a prosthetist, I would never be so arrogant as to presume that a device has become part of a client
- ❖ The prosthesis may be useful for many activities but may never feel to be part of them
- ❖ I have the habit of referring to prosthesis in third person ie. the arm of the leg, instead of my arm/ leg even though they are part of me
- ❖ A prosthesis is not skin and bone

### **6.9% Strongly disagreed**

- ❖ I feel sorry for anyone who feels a mechanical component is part of their body. A prosthesis is a tool, even if it is just used to conceal the amputation
- ❖ It is a tool. Does anyone truly believe it is part of them?
- ❖ If someone manages functionally with or without a prosthesis is the important factor not if it feels part of them
- ❖ It can be a successful outcome without being THE successful outcome
- ❖ A successful outcome can be when a person views their prosthesis as a useful and functional tool, but does not think of it as a part of them that is required to constitute wholeness. But, they may choose to think of their prosthesis as a part of them as well, or instead. One cannot be judged by the other

## **2. A successful outcome is when a person is confident to show their residual limb**

*Average round 2 rating by all 57 participants 3.28*

### **15.5% Strongly agreed**

- ❖ Means that the amp has accepted themselves as an amputee
- ❖ Self acceptance
- ❖ I always do
- ❖ Yes but people will always stare

### **22.4% Agreed**

- ❖ A successful outcome. Not the only one.
- ❖ This is one example of a successful outcome
- ❖ Concealing anything that works against self confidence. Self confidence should be the goal of any rehabilitation
- ❖ They are more likely to return to normal 'pre-amputation' community activities if they do not feel embarrassed or awkward about the amputation.
- ❖ Part of self image
- ❖ Confidence, comfortable
- ❖ Again, this most probably relates to adjustment to limb absence
- ❖ A persons ability to be comfortable in his/ her body is a very positive outcome.
- ❖ As the individual is comfortable with their own body, the increased opportunity to allow for 'normality' is important

### **41.4% Neither agreed nor disagreed**

- ❖ Some amputees flaunt their disability-not really a successful outcome
- ❖ Some are naturally more concerned about how they look than others
- ❖ This is right for some and not for others
- ❖ Really it depends on the injury and the individual....thus the wide range of answers you got
- ❖ I feel that they should be comfortable enough to go in public without their prosthesis but I am not in this position

- ❖ Not everyone is confident to show what they might consider a private part of themselves
- ❖ Especially for this one-a very successful prosthetic rehabilitation can be accomplished without this result-some life long wearers are never comfortable with their residual limb shown in public
- ❖ I hesitate about someone making a point of demonstrating their residuum in public.
- ❖ Personal level of comfort and being

#### **15.5% Disagreed**

- ❖ Why would that be a requirement?
- ❖ This is an individual choice not an outcome
- ❖ There are many and complex reasons (psychosocial) involved here
- ❖ I don't think that really matters
- ❖ Showing stump does not matter on prosthetic use
- ❖ Confidently showing ones limb does not constitute success

#### **5.2% Strongly disagreed**

- ❖ Again, this is a psychological issue, not a prosthetic issue
- ❖ With this question, again we return to personal preference. If a person is phobic about being seen in public or displaying their stump in public, I would conclude psycho-social adaptation work is in order. But if a person chooses not to display their amputation in public to avoid stares or unwanted increase in public attention, this should be their choice. The amputee may have a strong sense of personal self or body image, but simply not want to attract increased interest or looks by others

### **3. A successful outcome is a person's ability to perform activities to the same standard they**

*Average round 2 rating by all 57 participants 3.60*

#### **22.4% Strongly agreed**

- ❖ This is ideal but hard to achieve
- ❖ The same or better would be the goal. No?
- ❖ I would say that would be the ideal!
- ❖ Their limb loss has not changed their performance in life too much
- ❖ Great, if possible but perfection is not required for a good outcome.
- ❖ It is vitally important to be able to do all of the same things
- ❖ This is almost certainly the case; in fact, a very successful outcome

#### **32.8% Agreed**

- ❖ Tasks may be performed differently now and it will take more effort but the goal is to get on with life
- ❖ Probably wont happen
- ❖ Helps in regaining confidence
- ❖ Even below the standard can be successful
- ❖ This is a good goal, but does not mean rehabilitation is not reached if prior

functional levels have not been reached.

**29.3% Neither agreed nor disagreed**

- ❖ What was wrong with admitting that ‘disability’ entails loss of some abilities
- ❖ Standard set by the patient may be influenced by disability experience-may just be glad to be alive!
- ❖ Upper extremity amputees will likely not perform all activities to the same standard as pre-amputation
- ❖ This is a good aim but may need to be altered depending on the persons previous activity level and their loss
- ❖ Yes that would be a great option but wake us up in a 100 years or so when prosthetics are pretty good. These things we have now are cosmetics and toys. Are you trying to bait me into going off on *[Name of manufacturing company deleted]* and how bad they are ripping off the amputee community and insurance companies?
- ❖ Even if the person cannot do everything as well, it can still be a good outcome
- ❖ Depends too much on their own goals and how realistic they are.
- ❖ Congenital
- ❖ This may not be particularly important to them
- ❖ Performance is important to the individual and aiming for exactly the same prior to limb loss may lead to distorted expectations.
- ❖ There may be a change in activities and performance; level of amputation is important; they may perform it with a different method

**13.8% Disagreed**

- ❖ The persons life pre limb loss may or may not be relevant. I really know of no-one with acquired amputation who can perform all activities to pre-limb loss standards... some activities will be acceptable to still be productive or fun, some not. It becomes a balancing act between quality standards, level of hassle vs. results, etc.
- ❖ This statement leaves no room for modifying expectations down in cases where the same standard is not a realistic possibility.
- ❖ It is pretty uncommon to be able to perform activities exactly as well as one could with a sound limb
- ❖ This would be nice but may not be possible due to the level of amputation or function of the prosthesis
- ❖ New condition-new standard, what is my new ‘good enough’
- ❖ What is the standard you are talking about? Post amputation, the person may not be able to do the same things. A swimmer could swim post amputation, but perhaps not to the same standard.
- ❖ Although this would be a success it is not essential to do these activities to be successful.

**1.7% Strongly disagreed**

I strongly disagree with the statement. “Successful outcome” is when the person performs activities to the standard that pleases them, whether that level is higher or lower than they believe it was before their amputation. Again, we have the opportunity to apply adaptation

of goals and motivators evolving to fit new life circumstance. It may be that successful outcome may be described as discovering other things to do or perform to the same standard they had before limb loss is a better way to achieve happiness, that returning to exactly the same activities

**4. A successful outcome is when a person wears their prosthesis all day**

*Average round 2 rating by all 57 participants 3.12*

**5.2% Strongly agreed**

- ❖ No matter how crappy they be, they sure beat the hell out of nothing

**39.7% Agreed**

- ❖ If its necessary to do what they want to do, then yes. Not the only successful outcome. If they would like to wear it more but can't, then unsuccessful
- ❖ ONE example of a successful outcome, although ALL day every day may be overly excessive/ compulsive
- ❖ Full time wear is a lovely goal, but not realistic for many patients who are still successful wearers/ users
- ❖ A better goal might be to wear their prosthesis as tolerated and as needed
- ❖ More use means better competence with it
- ❖ Not excluding persons who wear it less
- ❖ This indicates that the prosthesis is comfortable enough for them to use all the time and does, to some extent do what it was designed to do, give a satisfactory cosmetic look or function in an appropriate way or both.
- ❖ Good but not exclusively so
- ❖ All day usage, is not the higher goal, return to desired activities is the higher goal
- ❖ Ultimately, you should be able to function better with, and be comfortable in your prosthetics
- ❖ Generally, yes, it would be a good sign
- ❖ It does not have to be all day; every day

**25.9% Neither agreed nor disagreed**

- ❖ Prosthesis is a complicated issue, don't generalize like that!!!
- ❖ When they wear it to suit their needs
- ❖ Duration of wear of prosthesis does not equal successful outcome
- ❖ Never had a prosthesis

**20.7% Disagreed**

- ❖ Absolutely not, A successful outcome is when a person wears a prosthesis when they perceive a need
- ❖ Once again, there are many reasons people don't wear their prostheses, this is a simplistic question
- ❖ One should only see their prosthesis as a useful tool, not as an essential part of their life
- ❖ ALL day, EVERY day is a nit much, maybe every day for a portion of the day.
- ❖ Still a success if prosthesis is used part of the day

- ❖ Physical limitations
- ❖ They may not need to wear it for ADL's so why wear it?
- ❖ A person who is happy to take their limb off and show their stump may indicate that they have adjusted to their limb loss
- ❖ A prosthetic arm is a tool, not a replacement. They are uncomfortable and heavy. If someone thinks they need to use it all day every day with no positive function, it serves to hide the residual limb or divert attention
- ❖ It is preferable to be comfortable with the limb according to individual needs
- ❖ Although this would be a success, it is not essential to do these activities to be successful

**8.6% Strongly disagreed**

- ❖ Few upper extremity amputees do this and I can see no benefit to making that a goal. You use a tool when its needed, not carry it around all the time in case you need it
- ❖ Someone may be successful without wearing a prosthesis
- ❖ This will rarely happen and is not necessary in many instances. Factors such as heat, discomfort, will affect this. People kick their shoes off, or don't wear shoes for these reasons.
- ❖ They should use it when they need it
- ❖ The extension of this question is that the amputee must sleep with the thing on...? Personal choice again. Let the organism decide what gives them the most successful outcome.

Appendix Z

Frequency distribution of accepted and non accepted items in Section 2.

## Accepted Items

	n	Very important	Important	Neither important nor unimportant	unimportant	Very unimportant
Achieving set goals	73	37 (50.7%)	34 (46.7%)	2 (2.7%)		
Engagement in Activities of daily living	73	55 (75.3%)	17 (23.3%)	1 (1.4%)		
Engagement in leisure activities	73	42 (57.5%)	29 (39.7%)	2 (2.7%)		
Getting along with other people	73	26 (35.6%)	32 (43.8%)	11 (15.1%)	4 (5.5%)	
Getting around	73	37 (50.7%)	31 (42.5%)	5 (6.8%)		
Perceived environmental barriers	73	26 (13.5%)	34 (46.6%)	12 (16.4%)	1 (1.4%)	
Performing social/ family roles of importance (e.g. breadwinner/ spouse/ student/ parent)	73	50 (68.5%)	21 (28.8%)	2 (2.7%)		
Performing self care	73	54 (74.0%)	16 (21.9%)	3 (4.1%)		
The achievement of tasks set by the individual with upper limb absence	58	36 (62.1%)	19 (32.8%)	1 (1.7%)	2 (3.4%)	
Cause of limb absence (congenital or acquired)	73	23 (31.5%)	30 (41.1%)	18 (24.7%)	2 (2.7%)	
General physical health	73	22 (30.1%)	41 (56.2%)	8 (11.0%)	2 (2.7%)	
Level of amputation	73	38 (52.1%)	30 (41.1%)	4 (5.5%)	1 (1.4%)	
Absence of dominant or non-dominant Arm	73	29 (39.7%)	35 (47.9%)	8 (11.0%)	1 (1.4%)	
Phantom limb pain	73	37 (50.7%)	30 (41.1%)	5 (6.8%)	1 (1.4%)	
Phantom limb sensation	73	24 (32.9%)	27 (37.0%)	22 (30.1%)		
Presence/ absence of certain joints	73	33 (45.2%)	36 (49.3%)	3 (5.5%)		
Residual limb pain	73	33 (45.2%)	36 (49.3%)	3 (4.1%)	1 (1.4%)	
State of residual limb	73	40 (54.8%)	32 (43.8%)	1 (1.4%)		
Time since amputation	73	24(32.9%)	37 (32.9%)	11 (15.1%)	1 (1.4%)	
Type of limb absence (bilateral or unilateral)	73	45 (61.6%)	21 (28.8%)	7 (9.6%)		
Purpose of prosthesis use	73	42 (57.5%)	23 (31.5%)	8 (11.0%)		
A patients feeling of control over the rehabilitation	58	31 (53.4%)	21 (36.2%)	4 (6.9%)	1 (1.7%)	1 (1.7%)
A patients resilience	58	27 (46.6%)	25 (43.1%)	4 (6.9%)	1 (1.7%)	1 (1.7%)
Anxiety	73	39 (53.4%)	32 (43.8%)	2 (2.7%)		
Coping Strategies	73	48 (65.8%)	24 (32.9%)	1 (1.4%)		
Depression	73	45 (61.6%)	26 (35.6%)	2 (2.7%)		
Patients attitude	73	52 (71.2%)	17 (23.3%)	3 (5.5%)		
Patients expectations	73	58 (79.5%)	13 (17.8%)	2 (2.7%)		
Patients mood	73	29 (39.7%)	36 (49.3%)	8 (11.0%)		
Patients motivation	73	55 (75.3%)	17 (23.3%)	1 (1.4%)		
Patients sense of humour	73	24 (32.9%)	28 (38.4%)	20 (27.4%)	1 (1.4%)	
Pre-amputation life experiences and skills (e.g. experience of disability or limb	73	25 (34.2%)	28 (38.4%)	17 (23.3%)	3 (4.1%)	



absence in the family)						
Post traumatic stress disorder (PTSD)	73	38 (52.1%)	32 (43.8%)	3 (4.1%)		
The social skills of the individual with limb absence	58	14 (24.1%)	35 (60.3%)	6 (10.3%)	3 (5.2%)	
Access to services (for example making appointments/ physical access)	73	35 (47.9%)	35 (47.9%)	3 (4.1%)		
Satisfaction with the prosthesis	73	50 (68.5%)	21 (28.8%)	2 (2.7%)		
Satisfaction with the rehabilitation service	73	48 (65.8%)	25 (34.2%)			
Body image	73	33 (45.2%)	37 (50.7%)	3 (4.1%)		
Emotional support from family/ friends	73	43 (58.9%)	25 (34.2%)	5 (6.8%)		
Public self-consciousness (feeling self-conscious around other people)	73	31 (42.5%)	37 (50.7%)	5 (6.8%)		
Meeting another individual with limb absence	73	32 (43.8%)	28 (38.4%)	13 (17.8%)		
Practical support from family/ friends	73	32 (43.8%)	36 (49.3%)	5 (6.8%)		
Reaction of family to the prosthesis	73	35 (47.9%)	31 (42.5%)	6 (8.2%)	1 (1.4%)	

### Non-accepted items

		n	Very important	Important	Neither important nor unimportant	unimportant	Very unimportant
1. Age at amputation	Round 1	73	21 (28.8%)	30 (41.1%)	17 (23.3%)	4 (5.5%)	1 (1.4%)
	Round 2	58	9 (15.5%)	35 (60.3%)	10 (17.2%)	4 (6.9%)	
2. Gender	Round 1	73	7 (9.6%)	28 (38.4%)	24 (32.9%)	11 (15.1%)	3 (4.1%)
	Round 2	58	3 (5.2%)	26 (44.8%)	23 (39.7%)	6 (10.3%)	
3. Level of education	Round 1	73	4 (5.5%)	18 (24.7%)	39 (53.4%)	10 (13.7%)	2 (2.7%)
	Round 2	58	2 (3.4%)	14 (24.1%)	39 (67.2%)	2 (3.4%)	1 (1.7%)
The achievement of tasks set by rehabilitation professional	Round 2	58	5 (8.6%)	39 (67.2%)	11 (19.0%)	2 (3.4%)	1 (1.7%)
	Round 3	53	2 (3.8%)	38 (71.7%)	11 (20.8%)	2 (3.8%)	
Cause of acquired limb absence (trauma v malignancy/ disease)	Round 2	58	12 (20.7%)	31 (53.4%)	12 (20.7%)	3 (5.2%)	
	Round 3	53	7 (13.2%)	36 (67.9%)	7 (13.2%)	3 (5.7%)	
Frequency of prosthesis use	Round 1	73	23 (31.5%)	29 (39.7%)	18 (24.7%)	3 (4.1%)	
	Round 2	58	13 (22.4%)	34 (58.6%)	7 (12.1%)	2 (3.4%)	2 (3.4%)
11. The extent to which people compare themselves to other people who are better or worse off	Round 1	73	16 (21.9%)	23 (31.5%)	32 (43.8%)	2 (2.7%)	
	Round 2	58	6 (10.3%)	15 (25.9%)	34 (58.6%)	3 (5.2%)	
Reactions from public	Round 1	73	11 (15.1%)	45 (61.6%)	14 (19.2%)	3 (4.1%)	
	Round 2	58	3 (5.2%)	39 (67.2%)	14 (24.1%)	2 (3.4%)	
Cost of prosthesis	Round 2	58	14 (24.1%)	28 (48.3%)	11 (19.0%)	2 (3.4%)	3 (5.2%)
	Round 3	53	7 (13.2%)	36 (67.9%)	8 (15.1%)	2 (3.8%)	
Whether individual is entitled to compensation	Round 2	58	5 (8.6%)	22 (37.9%)	25 (43.1%)	5 (8.6%)	1 (1.7%)
	Round 3	53	1 (1.9%)	14 (26.4%)	30 (56.6%)	6 (11.3%)	2 (3.8%)

Research Dissemination

### **Publications**

Schaffalitzky, E., **NiMhurchadha, S.,\*** Gallagher, P., Hofkamp, S. MacLachlan, M., Wegener, S. (2009) *Identifying the values and preferences of prosthetic users: A Case Study Series Using the Repertory Grid Technique*. Prosthetics and Orthotics International. 33 (2), 157-166.

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### **Conference Proceedings**

**NiMhurchadha, S.,** Gallagher, P., MacLachlan, M. & O' Neill, B. (2009). *Identifying the outcomes of upper prosthetic limb rehabilitation and their predictors: The patients' and rehabilitation professionals' perspective*. Trent International Prosthetic Symposium, Loughborough, UK, May, 2009.

**NiMhurchadha, S.,** Gallagher, P., Mac Lachlan, M., Hoffkamp, S. & Wegener, S. (2008). *Getting the right fit: what upper limb prosthetic users want*. International Society for Prosthetics and Orthotics (ISPO) UK National Member Society Annual Conference, Chester, 2008.

**NiMhurchadha, S.,** Gallagher P., MacLachlan, M., & O'Neill, B. (2008) *Identifying the Factors and Outcomes associated with upper limb prosthetic use: the patients' perspective*. Joint BPS Division of Health Psychology and European Health Psychology Society Conference-Behaviour, Health & Healthcare: From Physiology to Policy, Bath, UK, 2008

**NiMhurchadha, S.,** Gallagher, P., Mac Lachlan, M., Hoffkamp, S. & Wegener, S. (2008). *Getting the right fit: Using the Repertory Grid to determine what upper limb prosthetic users want*. British Psychological Society Annual Conference, Dublin, 2008.

**NiMhurchadha, S.,** Gallagher, P., MacLachlan, M. & O' Neill, B. (2008). *Identifying the factors and outcomes associated with upper limb prosthetic use: The Rehabilitation Professionals Perspective*. Psychology Health & Medicine Conference, Derry, 2008.

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