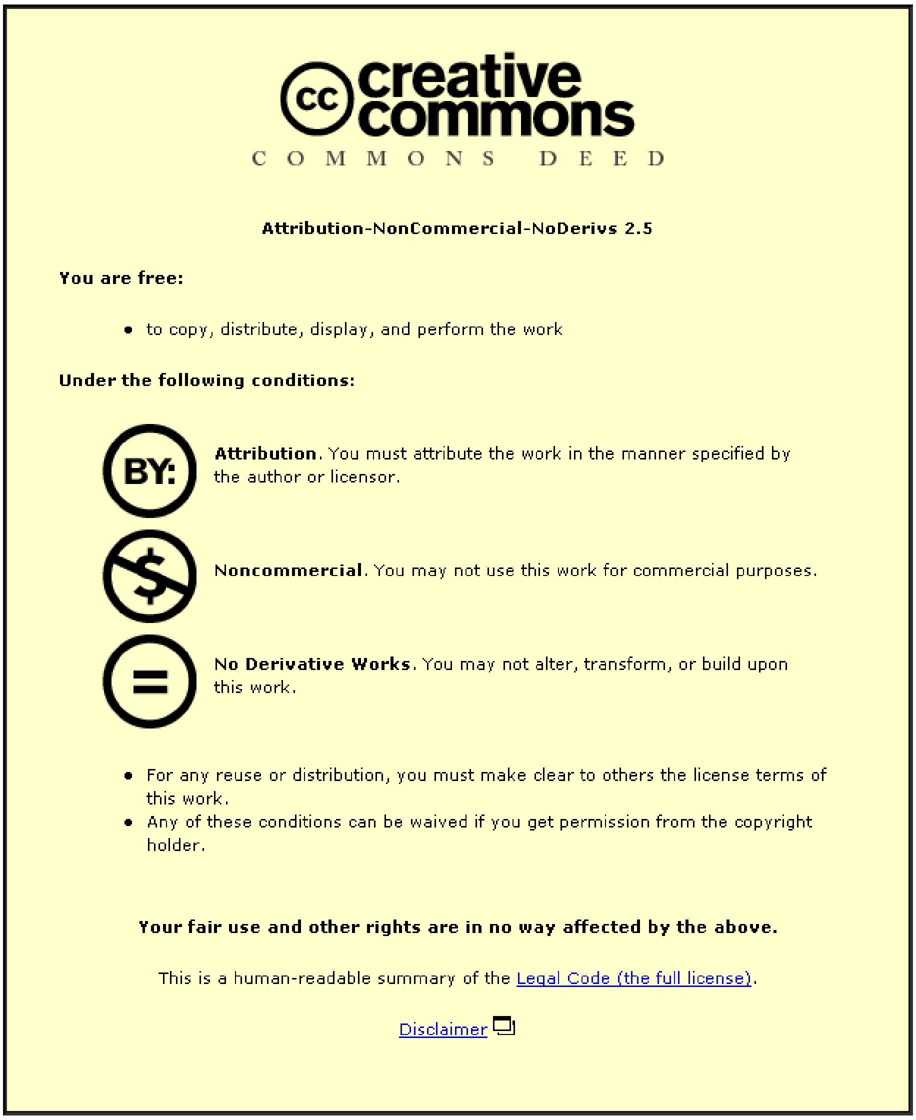

LOUGHBOROUGH UNIVERSITY

An Investigation of the NHS Service Provision of Prosthetic Limbs

Grace Smalley
2013

Abstract

This thesis explores the NHS Service provision of prosthetic limbs from a patient centred perspective. Amputation is the removal of a limb either for medical reasons or through trauma. The amputated limb can be replaced with a manufactured device to help the patient regain movement and as much function as possible. This device is known as a prosthesis and is given to the patient by the NHS at a Disablement Services Centre (DSC). There has been increasing negative media coverage of the NHS and the service it provides with specific reference to the 'Postcode lottery' which has allegedly become apparent. This research aims to ascertain whether the service being provided at DSCs across the UK is satisfactory to patients and how this service can be improved. The literature surrounding amputation rehabilitation and care pathways is reviewed (Chapter 2). Research philosophies and approaches are discussed (Chapter 3). A countrywide study of NHS Disablement Services Centres was conducted to ascertain how the centres functioned and the differences in service between centres (Chapter 4). The data collected from this study were used to create a questionnaire for amputees to ascertain their opinions on the service they received at their centre (Chapter 5). The data revealed that patients had many problems with the service they received, very few of which could readily be acted upon due to budget restrictions. An investigation into patient's opinions on information provision was conducted as information provision was a problem highlighted by patients that could be influenced by further research (Chapter 6). Data gathered from all three studies were used to produce a proposed clinical pathway for Disablement Services Centres to follow with a new patient (Chapter 7). The proposed pathway was critically evaluated by prosthetists at a clinical conference and improvements to the proposed pathway were made using their suggestions (Chapter 7). The benefits, drawbacks and threats to the use of the proposed pathway were discussed both from the patient and clinical perspective (Chapter 8). The work was completed by overall conclusions and a discussion of further work (Chapter 9).

Acknowledgments

There are several people I would like to thank for their help and support throughout this research. First and foremost I would like to thank Laurence Clift, without whom this research would not have been possible. Thank you does not seem adequate for all the time, support and encouragement he has given me. I must also thank Victoria Haines for her support and kind words when I needed them most. Her encouragement has helped me to finally believe in my own abilities.

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Publications

Smalley, G. J., Clift, L. 2010 “Continuity of Service within NHS Disablement Service Centres” Proceedings of the BAPO biannual conference, 4-6th March 2010, pp31.

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Contents

Glossary

AK – Above Knee Amputation: Transfemoral amputation.

BK – Below Knee Amputation: Transtibial amputation.

CCGs – Clinical Commissioning Groups: Local groups of doctors, mainly general practitioners, that are responsible for the planning, designing and payment for NHS services.

DSC – Disablement Services Centre: Centre at which patients receive rehabilitation and prosthetic care.

Dysvascularity: Problems with inadequate circulation in the legs.

MDT – Multi Disciplinary Team: Team consisting of a consultant, occupational therapist, prosthetist, nurse and physiotherapist that deal with prosthetic care.

Neoplasia: The abnormal growth of benign or malignant cells.

OT – Occupational Therapist: An allied health professional that uses purposeful activity and interventions to maximize the independence and health of any client who is limited by physical injury or illness, cognitive impairment, psychosocial dysfunction, mental illness, or a developmental or learning disability.

PALS – Patient Advice and Liaison Service: A service offering confidential advice, support and information to patients, their families and their carers.

PCT – Primary Care Trust: Local organisation that works with local authorities and other agencies to provide health and social care locally to ensure the needs of the community are being met.

Primary amputee: A patient that has recently had an amputation.

PVV – Patient Volunteer Visitor: An experienced amputee that volunteers their time to visit primary amputees in hospital or at the Disablement Services Centre to offer support and advice.

Chapter 1: Introduction

1.1 Amputation and NHS Care

Amputation is the removal of a limb or body part either surgically for medical reasons or through trauma. Lower limb amputations are more common than upper limb amputations, if fingers and non-mutilating hand injuries are excluded (Magee, 2008). Lower limb amputation affects around 4500 people in the United Kingdom every year, which has remained fairly constant between 1996 and 2007 (National Amputee Statistical Database, 2009). The figures published in the National Amputee Statistical Database (2009) do not include service personnel injured during active duty as their rehabilitation does not commence in NHS facilities. Following amputation, the most important outcome of rehabilitation for the patient and family is successful ambulation, with a view to returning to previous social connections and suitable accommodation (Pohjolainen et al., 1990). A prosthesis is a device which replaces the amputated limb and therefore, in the case of lower limb amputees, helps patients to regain ambulatory function.

There are 44 centres which provide prosthetic services in the UK, 35 in England, five in Scotland, three in Wales and one in Northern Ireland (The Douglas Bader Foundation, 2012). These centres are known as Disablement Services Centres (DSCs). There have been numerous news reports regarding ‘poor’ service being provided by the NHS prosthetic services (BBC, 2011; Salisbury Journal, 2011; BBC, 2010a; BBC, 2010b; Belfast Telegraph, 2010; Hicksville, 2008; Vasagar, 2003). The phrase ‘postcode lottery’ is frequently mentioned, implying that the service provision in one area of the UK is different to other areas (BBC, 2011; Salisbury Journal, 2011; BBC, 2010b). The news reports often detail the inability of the NHS to produce prostheses of sufficient comfort or quality which has an effect on the quality of life of the patients involved (BBC, 2011; BBC, 2010a; BBC, 2010b; Belfast Telegraph, 2010; Vasagar, 2003).

1.2 Aims and scope of thesis

The overall aim of this work was to evaluate, with respect to patient experience, the current prosthetic service provision for amputee patients provided by the NHS and provide suggestions for improving the service delivery. A number of research questions were addressed in order to fulfil the aim of the thesis.

1. How do Disablement Services Centres currently function and what are the constraints (if any) on service provision?
2. Is service provision uniform in centres across the country and if not, what are the differences?
3. If differences in service provision are present, why are they occurring?
4. Are the needs and expectations of amputees being met by the current NHS service provision?
5. What are the main issues patients currently have with the service provision?
6. Can the experience of amputees be improved without great cost to the NHS?
7. What are the implications of the work for the stakeholders, NHS and wider research arena?

The objectives of this research were:

1. To understand the current service provided to amputees in the UK by NHS Disablement Services Centres
2. To ascertain the differences in service provision between NHS centres
3. To understand whether the NHS service provision is fulfilling the needs of the amputee patients
4. To ascertain the shortfalls of the service provision from the patient perspective
5. To develop a patient pathway model that incorporates the needs of the patient as well as best practice for the clinicians
6. To evaluate the research findings and ascertain the wider implications of the work to allow for suggestions of further work.

This research includes NHS amputee patients only and focuses on the provision of prostheses for non-military patients. The research is focussed on lower limb amputation and the care provided to primary amputees.

1.3 Chapter Summary and Structure of Thesis

Chapter 1 – Introduction

This chapter introduces the general topics addressed within this thesis alongside relevant background information. The aims of this thesis are presented including the objectives and resulting research questions the work set out to answer. The structure of the thesis can be seen in Figure 1.1.

Chapter 2 – Literature Review

The main purpose of this literature review was to provide background knowledge on amputation and rehabilitation. Due to the direction of the work changing following results from previous studies, separate literature reviews for each chapter were created.

Chapter 3 – Research Philosophies and Approaches

This chapter introduces the research philosophies and approaches available for use within this work. Ethical considerations are also discussed and evaluated.

Chapter 4 – Study 1: A Countrywide study of NHS Disablement Services Centres

This chapter describes the interviews that were conducted at 12 NHS Disablement Services Centres to ascertain the differences in service provision between centres. The work was then used to inform a questionnaire study in the next chapter.

Chapter 5 – Study 2: What do Patients think?

This chapter describes a questionnaire study that was conducted involving amputees from across the country in order to ascertain their opinions on the service they were provided by their Disablement Services Centre. The results were used to inform a telephone interview detailed in the next chapter.

Chapter 6 – Study 3: The Importance of Information for Amputees

This chapter describes telephone interviews that were conducted with patients to ascertain the information they considered essential both pre- and post-amputation.

Chapter 7 – Study 4: Improved Rehabilitation Pathway

This chapter describes the process used to produce and evaluate a rehabilitation pathway for primary patients detailing the information to be provided and the members of the multidisciplinary team to be seen at each stage.

Chapter 8 – Overview and Synthesis

This chapter contains details of how the implementation of the proposed pathway could affect both patients and the NHS.

Chapter 9 – Conclusions and Further Work

This chapter details further work that is required in order to validate and continue the work detailed in this thesis.

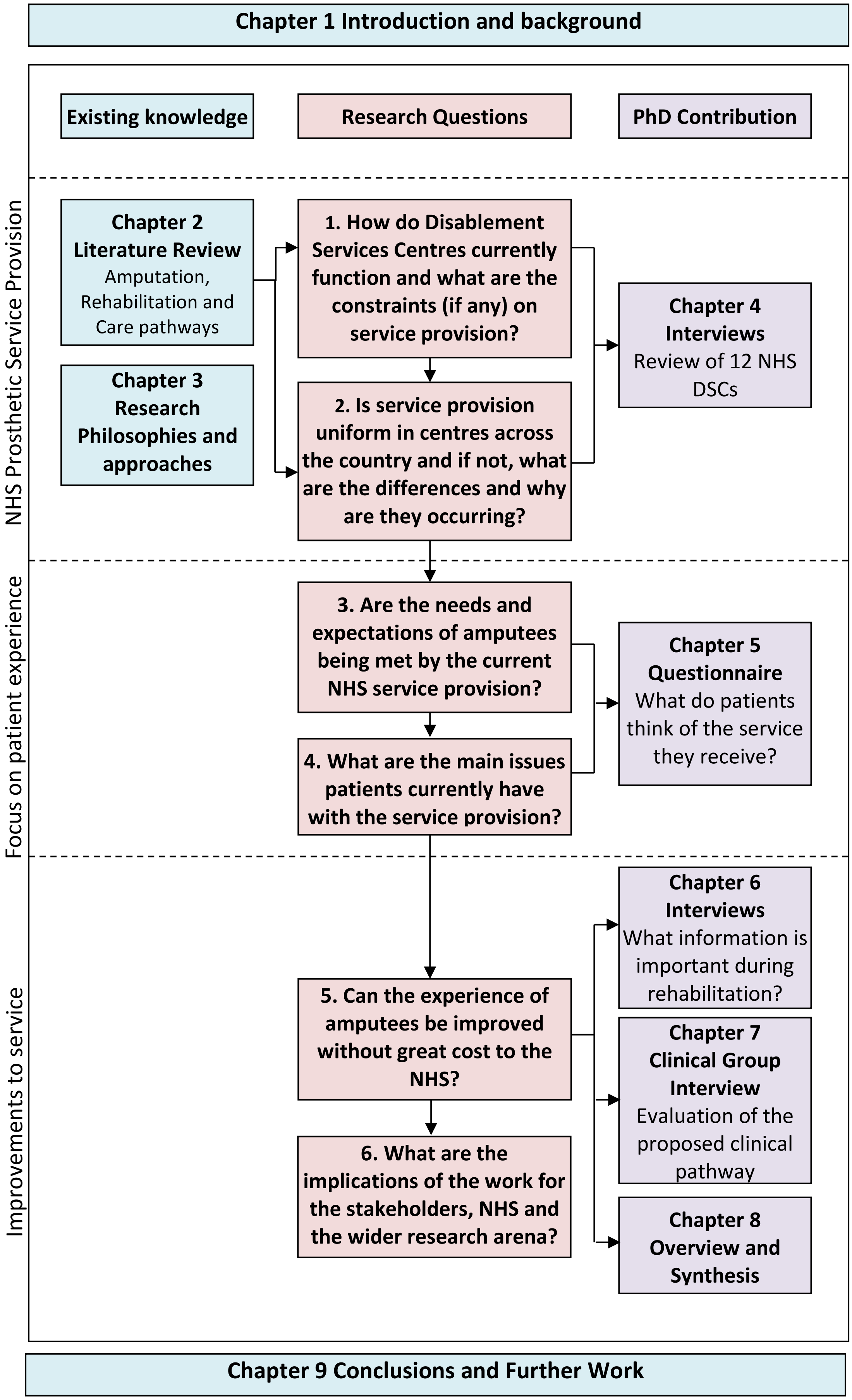


Figure 1.1: Thesis Structure

Chapter 2: Literature Review

The literature within this section covers amputation, patient rehabilitation and integrated care pathways in order to provide the background knowledge required for research within the rehabilitation arena. Separate literature reviews were conducted for each study and can be found at the beginning of each chapter. In order to evaluate appropriate literature, a number of different search terms and engines were used. An initial unrefined search using Google Scholar and the search term ‘Amputation’ was used to gain background information on the process of amputation. Science Direct, Medline plus, Go Pub Med, Web of Science and Springer Link were all used in sourcing academic literature for use in each literature review section. Searches were refined depending on the topic being reviewed. A broad search using the topic subject e.g. ‘Integrated Care Pathways’ was used before narrowing results down by adding more key words, such as ‘amputation’, ‘NHS service provision’ and ‘rehabilitation’. Initially no restriction was placed on the searches in terms of year of publication, however further searches restricting the year to 2000 and later were conducted in order to avoid out of date research without overly restricting the search results.

2.1 Amputation

Amputation should be considered a reconstructive procedure which leaves the patient with the best outcome possible. In order to achieve this, the goal of surgery is to create a well-balanced residual limb with good sensation and motor control (Magee, 2008). Statistics show that males are more likely to require an amputation than females and this has remained constant between 1997 and 2007 (National Amputee Statistical Database, 2009). In 2006 and 2007 more than two thirds of the total number of amputations were carried out on males (National Amputee Statistical Database, 2009).

2.1.1 Causes of Amputation

There are a large number of causes of amputation, with most falling under one of seven main headings which are discussed in order of prevalence.

2.1.1.1 Dysvascularity

Dysvascularity is the name given to conditions that cause inadequate circulation in the extremities and is currently the most common cause of amputation with 72% of all cases between 2006 and 2007 being dysvascular patients (National Amputee Statistical Database, 2009). There are ten circulatory restrictive conditions included in this group with Diabetes Mellitus being the most prevalent, accounting for almost 32% of all amputations in 2006 and 2007 (National Amputee Statistical Database, 2009). In contrast with trauma, the age group worst affected by Dysvascularity is 75 years and over, however there are more cases of Diabetes Mellitus recorded in 65-74 year olds. There has been an increase in amputations due to Dysvascularity from 1997 to 2007 however this could be due to better recording of cases as the number of referrals with no cause provided has decreased by a similar amount (National Amputee Statistical Database, 2009).

2.1.1.2 Diabetes

The two main types of diabetes are Type 1 and Type 2 which are very different from one another. Type 1 diabetes is a condition caused when the immune system attacks and effectively destroys the cells required for insulin production in the pancreas, leaving the pancreas unable to produce insulin (Rosenthal, 2009). The condition is irreversible and insulin injections are required for individuals to survive. In contrast, Type 2 diabetes can be managed, reversed and even prevented by a modification of lifestyle. Type 2 diabetes does not necessarily require insulin and many experts believe that a poor diet and sedentary lifestyle triggers the Type 2 gene in individuals who are predisposed to it (Rosenthal, 2009). It is estimated that 90% of cases of diabetes in adults are Type 2 diabetes (Diabetes UK, 2010). There are currently 2.6 million people in the UK who have been diagnosed with diabetes with an estimate of undiagnosed cases of half a million people (Diabetes UK, 2010). It is estimated that by 2025 there will be over 4 million people with diabetes in the UK (Diabetes UK, 2010). The incidence of diabetes in the UK has increased by 74% between 1997 and 2003 (González et al., 2009). This is almost entirely due to Type 2 diabetes as the incidence of Type 1 diabetes remained almost constant over the time period. The likelihood is that the increase in diabetes is related to the increase in obesity over the same time frame (González et al., 2009).

Individuals with diabetes are 15-40 times more likely to require a lower limb amputation than the general population which may be partly attributed to the occurrence of lower extremity disease, including peripheral neuropathy (damage to nerves of the peripheral nervous system) and peripheral arterial disease, being twice as high in individuals with diabetes than the general population (Vamos et al., 2010a). In 9-20% of cases, individuals with diabetes require a second amputation within 12 months and in 28-51% of cases within 5 years (Vamos et al., 2010a).

Amputations through or above the ankle due to Type 1 diabetes have reduced by 41% between 1996 and 2005, whereas the number of amputations due to Type 2 diabetes showed a consistent upward trend over the ten year period and have increased by 43% (Vamos et al., 2010a). This increase in the number of amputations is consistent with the increase in obesity and diabetes incidence, therefore it is likely that these figures will keep rising due to obesity in the UK being on the increase.

The figures also show that there was a considerable male predominance in amputations among people with diabetes. The male to female ratio was found to be more than twice that of people without diabetes (Vamos et al., 2010a).

The decrease in numbers of amputations due to Type 1 diabetes may be attributed to the more aggressive approach taken by the NHS, over the study time period, to peripheral arterial disease and the increase in preventative surgical interventions (McCaslin et al., 2007; Awad et al., 2006). Other interventions that could have impacted on this trend are better control of predisposing risk factors including tighter blood pressure and dietary control and reduced alcohol and tobacco consumption (Vamos et al., 2010a; Millett et al., 2007). In contrast the upward trend in amputations due to Type 2 diabetes could be caused by a number of possible factors including increases in the incidence and prevalence of the disease (Congdon, 2006). Improved survival of patients diagnosed with Type 2 diabetes and amputations being carried out on patients that would previously have died with an unhealed ulcer due to greater awareness of diabetic foot disease and improved specialist services could also contribute to the rise in the numbers of amputations (Vamos et al., 2010a; Jeffcoate and Van Houtum, 2004).

2.1.1.3 Trauma

Amputations due to trauma are split into four categories, mechanical, chemical, electrical and thermal with mechanical being by far the most common. Between 2006 and 2007 trauma cases only accounted for 7% of all amputations, with the age group 16-54 being the worst affected (National Amputee Statistical Database, 2009).

2.1.1.4 Infection

Infection is classed as either acute or chronic with chronic being the most common. Infection accounted for 8% of all amputations between 2006 and 2007 with 16-54 being the worst affected age group and very few cases in under 16s (National Amputee Statistical Database, 2009).

2.1.1.5 Other

Other causes accounted for 5% of all amputations between 2006 and 2007 and no cause was provided in 4% of cases (National Amputee Statistical Database, 2009).

2.1.1.6 Neoplasia

Neoplasia is the formation of an abnormal growth of tissue and accounted for 3% of all amputations between 2006 and 2007 with 16-54 year olds being the worst affected. Of the three conditions in this group primary malignant cases were the most common (National Amputee Statistical Database, 2009).

2.1.1.7 Neurological disorder

This group has the least amount of cases of all the groups accounting for just over 1% of all amputations between 2006 and 2007. There are five neurological disorders included in this group with diabetic neuropathy being the most prevalent. The worst affected age group is 16-54 years with every other age group having very similar numbers of cases to each other (National Amputee Statistical Database, 2009).

2.1.2 Amputation rates and trends

The number of lower limb amputations carried out in the UK has varied very little between 2003 and 2007 as seen in Figure 2.1. The year 2000 saw a sharp rise in lower limb amputations with rates reaching a high of 5298 between 2000 and 2001 (National Amputee Statistical Database, 2009). The most common age group for male amputation referrals between 1997 and 2007 was 65-74 compared to the over 75 age group for female referrals.

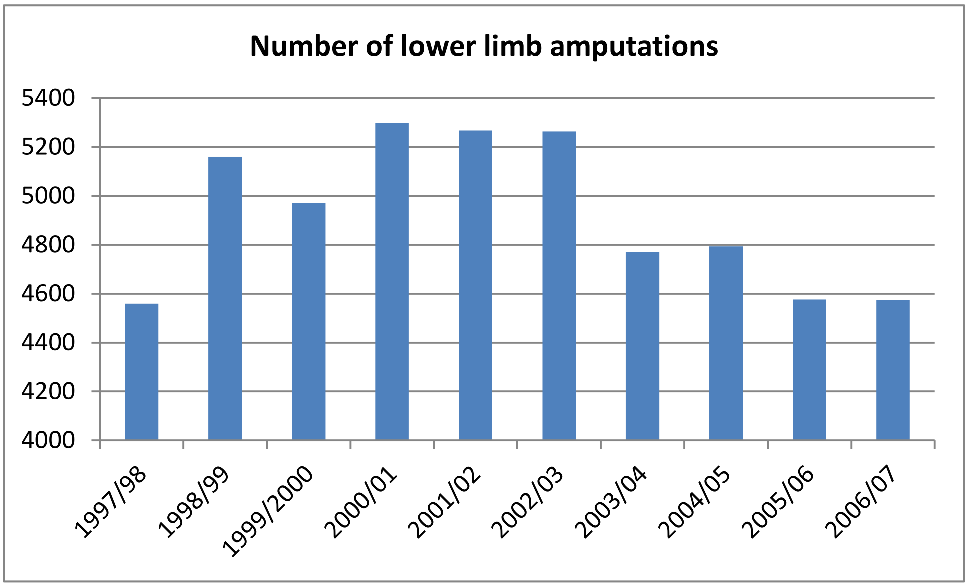


Figure 2.1: Number of lower limb amputations per year between 1997 and 2007 (National Amputee Statistical Database, 2009)

Studies have been published that show variations in incidence of amputation across the UK. Three studies showed age-adjusted incidences of first lower extremity amputation ranging between 5.1 and 176 per 100,000 people in different centres (Unwin, 2000; Canavan et al., 2008; Moxey et al., 2010). Recent work based upon Hospital Episode Statistic (HES) data has attempted to clarify the incidence of lower extremity amputations in England. Moxey et al. (2010) reported no change in the rate of major amputation (diabetes and no diabetes) between 2003 and 2008 (of 5.1 per 100,000) in England and Vamos et al. (2010b) report a reduction in the incidence of major amputation in patients with Type 1 diabetes from 1.3 per 100,000 in 1996 to 0.7 per 100,000 in 2005. There were large variations in incidence across the country and between PCTs found in 2008, with rates ranging from 11 per

10,000 people in Leicester to 44.6 per 10,000 people in Middlesbrough (Vamos et al., 2010b).

Some studies across Europe found that there were no significant changes in rates of all lower extremity amputations between 1990 and 1998 in both diabetic and non-diabetic patients (Stiegler et al., 1998; Trautner et al., 2001). These results are in contrast to other studies that suggest an increase in minor amputations as a result of introducing diabetic podiatry screening services (Ebskov and Ebskov, 1996; Calle-Pascual et al., 2001; Trautner et al., 2007; Larsson et al., 2008). Differences also exist across Asia and Australasia, with Australia showing similar trends to Europe in the fall in lower extremity amputation rates between 1980 and 1992 (Mattes et al., 1997; Lim et al., 2006)(Lim et al., 2006)(Lim et al., 2006). Japan has one of the lowest rates overall at 3.8 per 10^5, but Taiwan and East Asia are significantly worse with rates of 18.1 and 100 per 10^5, respectively (Unwin, 2000; Chaturvedi et al., 2001; Chen et al., 2002). Overall, the USA has the highest major amputation rate compared with the rest of the world at 23.6 vs. 14.2 per 10^5 males and 15.2 vs. 6.7 per 10^5 females (Renzi et al., 2006). Wrobel et al. (2001) report an incidence of 38 per 10^5 in the non-diabetic USA population based on an investigation of the Medicare administrative database, incorporating all ages and ethnicity.

International comparison of such rates is difficult due to the heterogeneity of the populations and different ways of reporting results. The results do highlight that compared with the rest of the world the incidence of amputation in the UK is relatively low, although considerable differences are found between areas of the UK, with some having rates higher than those found in the USA (Moxey et al., 2011).

2.1.3 Levels of Amputation

Lower limb amputations should, in most cases, be at the most distal site compatible with wound healing and with prosthetic fitting and rehabilitation in mind (Hunter, 1996). The selection of level of amputation should initially be based on a thorough physical examination and medical history with further radiographic and vascular studies if deemed necessary (Hunter, 1996). The behaviour, lifestyle and mental stability of the patient would also be considered extremely carefully when choosing the level of amputation (Levin et al., 2008). If a patient has a history of non-compliance with medical care the surgeon is likely to avoid an amputation level which will involve a high degree of patient compliance to try to ensure success (Levin et al., 2008). Behavioural factors, such as non-compliance and nicotine addiction, can profoundly affect outcome, therefore they should all be evaluated preoperatively and if possible corrected (Levin et al., 2008). Involving the patient and family in surgical decisions and follow up is extremely important to provide the best chance of optimum rehabilitation (Levin et al., 2008). The consequences of choosing the wrong level of amputation are one or more painful revision procedures causing trauma to the patient and their family, therefore it is extremely important that the decision made is the correct one (Hunter, 1996).

Figure 2.2 shows the most common levels of lower limb amputation. The most common are trans-tibial (below knee) and trans-femoral (above knee) with the other levels of amputation, collectively, only accounting for around 2% of all amputations in 2006-07 (National Amputee Statistical Database, 2009). The figure shows the percentages of each amputation level in 2006-07, with the total number of amputations conducted at all four levels being 4282.

2.1.3.1 Trans-femoral Amputation – Above Knee (AK)

The energy expenditure associated with walking at a regular walking speed with an above knee prosthesis is approximately 65% more than normal (Gottschalk, 1999). Trans-femoral amputees are unlikely to ever achieve a normal gait in terms of walking economy and velocity (Gottschalk, 1999). Dysvascularity is the highest cause of trans-femoral amputations (National Amputee Statistical Database, 2009) due to dysvascular patients having poor potential to heal at a lower level of amputation (Gottschalk, 1999). Older dysvascular patients often do not have the physical reserve required for prosthetic use and are usually limited to household walkers or totally unable to use a prosthesis (Gottschalk, 1999).

2.1.3.2 Trans-tibial Amputation – Below Knee (BK)

Trans-tibial is the most common level of amputation and due to the knee joint being intact it offers amputees the possibility of near normal function, regarding lifestyle and ambulation. Energy consumption for the transtibial amputee is considerably less than that of the transfemoral amputee and therefore older, dysvascular patients are more likely to be able to cope with using a prosthesis (Bowker et al., 1992).

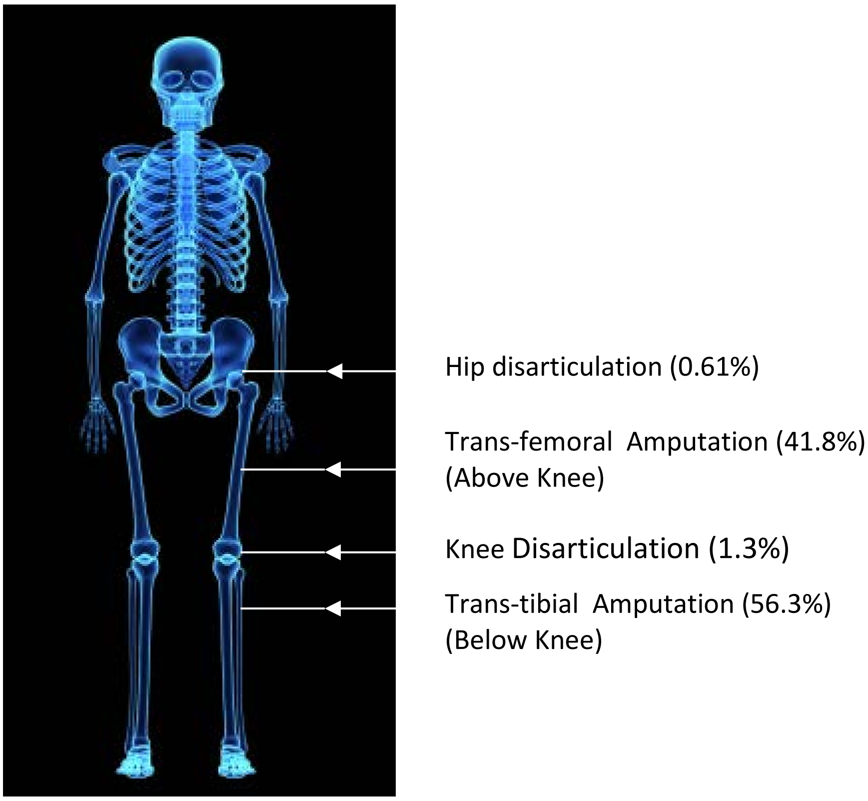


Figure 2.2: Levels of Amputation (iStock Photo)

2.1.3.3 Hip and Knee Disarticulation

Every effort is made by healthcare professionals to avoid a hip disarticulation due to the high morbidity and mortality associated with the procedure. Neoplasia and infection are the most common causes of this level of amputation (National Amputee Statistical Database, 2009). Knee disarticulations are rare due to the difficulties in prosthetic fitting inherent with this amputation level (Nelson et al., 2006). Incidences of knee disarticulations are increasing due to biomechanic and surgical advantages; however trans-femoral amputations are still favoured by surgeons (Stark, 2004).

2.1.4 Prosthetic Devices

Prosthetic prescription options have altered considerably over the past decade, giving prosthetists a much wider choice of componentry for patients (Garino and Beredjiklian, 2007). The prescription of such components is primarily based on empirical knowledge, however the advances in technology and increase in component costs has led to third party payers demanding scientific evidence to support the use of expensive components (Van der Linde et al., 2004). Ideally prosthetic prescription should fulfil the functional needs of the patient by adjusting the mechanical characteristics of a prosthesis (Van der Linde et al., 2004). This means that prescriptions must be individualised based on the functional capacity and goals of each amputee (Pasquina et al., 2006).

2.1.4.1 Sockets

Lower limb prostheses generally consist of three or more components, depending upon the level of amputation. Each prosthesis will have a foot, pylon and socket (shown in Figure 2.3) and a knee joint for transfemoral amputees (Figure 2.4). The socket component is custom made by a prosthetist using plaster casting or laser scanning technology. Plaster casting is the most common technique which involves a plaster cast being taken of the residual limb which is then used to produce a mould. This mould can be used to produce a number of different types of socket depending on the patient and the level of amputation. The most common materials used are plastic polymer laminates, the most frequently used being acrylic, epoxy and polyester (Figure 2.4). Carbon fibre is commonly used to reinforce laminate sockets but can be used to to create an entire socket as shown in Figure 2.3. Laser scanning involves a digital scan being taken of the residual limb and the resulting CAD model being edited by the prosthetist to increase thickness of the socket in the correct places. This data are sent to an automated carver which produces a test socket for the patient to try on and allows for adjustments to be made to the CAD model, following which a final socket is produced.

Figure 2.3: Below Knee (BK) Prosthesis

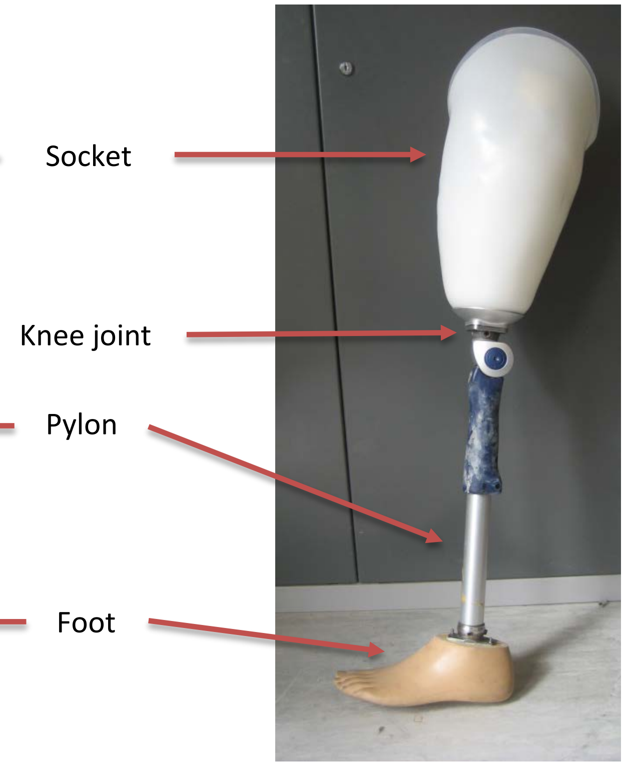


Figure 2.4: Above Knee (AK) Prosthesis

2.1.4.2 Design and production of knees and feet

There are a number of companies worldwide that design and manufacture prosthetic components. The aim of each component is to provide the user with as much functionality as possible without introducing too much weight to their prosthetic limb. A new component must pass rigorous mechanical tests before a trial with patients can take place. Trials with patients provide the manufacturers with invaluable information relating to the functionality of the new component and issues relating to its use. Due to there being a limited number of prosthetic users in the world, new components are extremely expensive as companies attempt to recoup their research and development costs from sales of the component. The choice of components is tailored to an individual patient therefore the cost of each prosthesis varies greatly. A below knee prosthesis using very basic components can cost the NHS as little as £200, however the use of an energy storing foot with an adjustable ankle can introduce costs of over £5000. A very basic above knee prosthesis could cost around £400, however above knee prostheses can be extremely expensive due to the need for a knee and foot component and can cost the NHS over £20,000.

Knee joints

There are a number of knee joints available to prescribers each with different benefits for individual amputees. Evidence suggests that the locked knee joint prosthesis is a sensible choice for geriatric vascular patients due to the stance-phase stability it provides; however this knee joint may not be suitable for more active patients (Van der Linde et al., 2004). Evidence suggests that an advanced mode of swing-phase control, either by a pneumatic or hydraulic knee unit is preferable for active prosthetic users (Van der Linde et al., 2004). Significant advances in technology have been made in prosthetic knee designs, with the latest available being microprocessor knees. These devices attempt to simulate the normal knee function by offering variable resistance control to the swing and/or stance phases of the gait cycle (Pasquina et al., 2006). Examples of such technology are the Otto Bock C-Leg (Figure 2.5) and the Ossur Rheo Knee (Figure 2.6). These components cost around £16,000 each and are usually only prescribed to patients with high activity levels for this reason (Pasquina et al., 2006).

Figure 2.5: Otto Bock C-Leg

Figure 2.6: Ossur Rheo Knee

Feet

Technical advances in materials technology combined with a better understanding of the biomechanics of human locomotion have led to new developments in feet components such as the systems known as energy storing or dynamic response feet (Desmond and MacLachlan, 2002). As with knees, the prescription of feet very much depends on the patient with evidence suggesting that the more active amputee would benefit from an energy storing device (Van der Linde et al., 2004). Energy storing feet are not always advised as they require a certain amount of energy to be supplied in order for the foot to function properly, which may not be possible for older amputees. The abilities and needs of the individual must be considered in order to prescribe the correct technology for each patient.

2.1.5 Disablement Services Centres

Every centre which provides a prosthetic service is categorised as a Disablement Services Centre by the NHS. There is currently very little information available about Disablement Services Centres and the care they provide to the amputee community nationwide. There is little information widely available about how centres are run or the process an amputee follows in the first year of their rehabilitation. Due to the media coverage of the NHS the term 'postcode lottery' is being used more frequently, which implies that there may be large differences in prosthetic care around the country. Disablement services centres differ greatly in size and numbers of patients treated (National Amputee Statistical Database, 2009).

The number of referrals to the service differs greatly between centres; however numbers stay almost constant between years (National Amputee Statistical Database, 2009). Figure 2.7 illustrates the location of all 44 DSCs and Table 2.1 shows the number of referrals to each of the DSCs in 2006/2007. There are no up to date figures for referrals to DSCs due to the production of figures by the National Amputee Statistical Database being discontinued (National Amputee Statistical Database, 2009).

Figure 2.7: Illustration of the location of each DSC

Table 2.1: Number of referrals to each DSC between 2006/07 (National Amputee Statistical Database, 2009)

DSC	Referrals per year	DSC	Referrals per year
Manchester	298	Plymouth	99
Birmingham	279	Sussex	99
London:Harold Wood	231	Dundee	96
Glasgow	231	Stoke	92
Gillingham	200	Leicester	90
Sheffield	192	Norwich	83
Leeds	180	Hull	80
Preston	165	London: Bowley Close	79
Cardiff	159	Luton&Dunstable	78
Newcastle	149	Wirral	75
Exeter	145	Dorset	74
Nottingham	136	Edinburgh	69
Belfast	125	Northampton	69
Liverpool	124	Aberdeen	67
Cleveland	123	Portsmouth	62
Oxford	123	Wrexham	58
Wolverhampton	122	Derby	45
London:Stanmore	116	London:Charing Cross	40
Bristol	110	Carlisle	33
London: Roehampton	107	Inverness	31
Cambridge	105	Isle of Wight	15
Swansea	102		

2.1.6 Companies providing prosthetic care services to the NHS

There are currently four major companies that provide the NHS with prosthetic care services. Otto Bock is the largest of the four companies with bases in 49 countries and exporting products to 140 countries worldwide. The company was founded in Germany in 1919 and is still a family run business. The annual turnover is £560 million, mostly owing to the sale of highly innovative prosthetic and orthotic devices. Blatchford is the second largest company to provide prosthetic services to the NHS. The company was founded 120 years ago in the UK and manufactures prosthetic and orthotic devices as well as providing care at NHS DSCs. The company is only UK based which is reflected in the annual turnover of £34.5 million. RSL Steeper is the third largest company with an annual turnover of £28 million. It is the sister company to the larger US based Steeper USA and was founded in 2003. The company specialises in the research and development of upper limb prosthetic devices. The smallest of the four companies is Opcare which was founded in the UK in 1989 by a prosthetist in answer to a report of the prosthetic service commissioned by the government that stated that prosthetic care in the UK was inefficient. The company only provides services to the NHS and does not design or manufacture components such as knees and feet, however in 1995 the founder of the company introduced CAD modelling for the casting process to the UK. The annual turnover of the company is £15 million, which reflects its size compared with the other companies providing prosthetic services. Table 2.2 illustrates the number of NHS Disablement Services Centres each company supplied services to in 2013.

Table 2.2: Number of DSCs each company provides services for

Company	Otto Bock	Blatchford	RSL Steeper	Opcare
Number of DSCs	9	14	5	14

2.2 Rehabilitation

The universal aim of a rehabilitation process is to make the barrier between people with a disability and their physical and social circumstances as small as possible (Magee, 2008). Eldar and Jelic (2003) found that although rehabilitation has been developing for centuries, its growth and progress, to a considerable extent, can be traced to wars. This is evident today as limb fitting services for war veterans are now being used to treat elderly dysvascular patients (Eldar and Jelic, 2003).

The World Health Organization (2001) has produced a model known as the international classification of functioning, disability and health (ICF) the aim of which is to "provide a unified and standard language and framework for the description of health and health related states". The impact of a health condition on an individual can be described using this model due to a number of variables being considered. Changes in body structure and function are classified as well as consideration of the effects of the external environment and personal factors which ultimately leads to an emphasis on health and functioning rather than disability (Robinson et al., 2010).

ICF has two parts, each with two components (World Health Organisation, 2001) :

Part 1. Functioning and Disability

(a) Body Functions and Structures

(b) Activities and Participation

Part 2. Contextual Factors

(c) Environmental Factors

(d) Personal Factors

Table 2.3 gives an overview of ICF and its components. Figure 2.8 shows how these components are linked and interact.

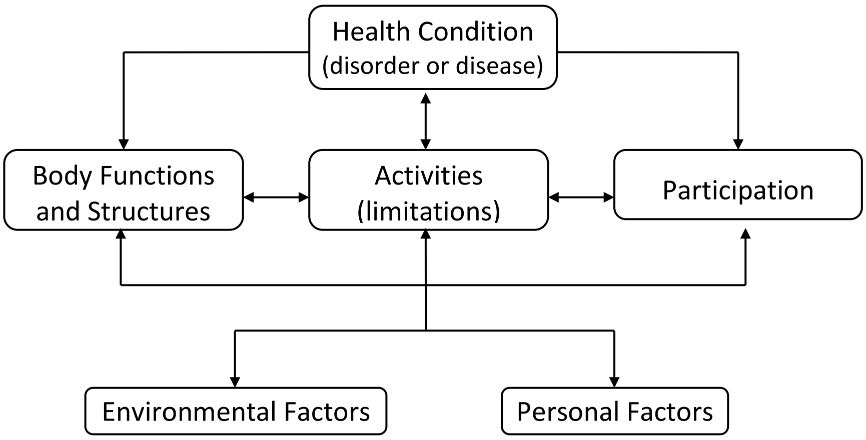


Figure 2.8: How ICF components are linked and interact (World Health Organisation, 2001)

Table 2.3: ICF and its components (World Health Organisation, 2001)

	Part 1: Functioning and Disability		**Part 2. Contextual Factors**	
Components	Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Domains	Body functions Body structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological) Change in body structures (anatomical)	Capacity Executing tasks in a standard environment Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person

Robinson et al. (2010) state that the implementation of this model by a multidisciplinary rehabilitation team leads to more effective outcomes for the patient by identifying pathological processes, functional limitation, impairments and disabilities. In order to achieve this and use the ICF to its full potential in clinical practice there is a need to develop appropriate ICF tools (Rauch et al., 2008). Rauch, et al. (2008) state that “ICF Tools allow the description of a functioning state, the illustration of the patient's experience of functioning and the relation between rehabilitation goals and appropriate intervention targets, an overview over required resources to improve specific aspects of human functioning and finally, the changes in functioning states following rehabilitative interventions.”

The tools are therefore extremely important in rehabilitation medicine and ICF tools are being developed for a number of health conditions. One of the tools developed to facilitate the use of the ICF in clinical practice is ICF core sets. Rauchet al. (2008) state that core sets are “generally-agreed-on lists of ICF categories, relevant for specific diseases or health care contexts, which can be used in clinical studies and health statistics or to guide multidisciplinary assessments”.

Kohler et al. (2009) began the process of developing ICF core sets for patients following amputation. It was hoped that the first version of the amputee core sets would be completed by 2011 with worldwide testing and validation commencing soon after (Kohler et al., 2009). The survey of clinical experts and focus group study of patients is currently in progress therefore the development is still in the preliminary stages (ICF Research Branch, 2012).

2.3 Integrated Care Pathways

Integrated care pathways (ICPs) are procedures detailing the critical steps in the care of patients with a specific health problem as well as their expected progress (Campbell et al., 1998). ICPs are also known as care protocols, critical care pathways, care profiles and multidisciplinary pathways of care (Hammond, 2002). They were introduced into the United Kingdom in the early 1990's and are used for treating patients in primary, secondary and tertiary care with a wide variety of health conditions (Kitchiner and Bundred, 1999).

De Luc has developed a handbook for developing care pathways and describes the reasons for developing ICP's as being:

- "To deliver consistent high-quality care
- To reduce unnecessary variation in practice and thereby reduce risk
- To get evidence based care into practice
- To provide integrated care across healthcare sectors, clinical disciplines and across agencies ('systems approach')
- A tool for concurrent audit
- A tool for communication between clinicians and with patients/users and carers
- Reinforces accountability of clinical staff
- Ensures care is focused
- Structures clinical documentation
- Can form a basis for benchmarking
- Informs the commissioning process
- Informs an organisation's management functions, e.g. resource planning, training and education, costing of services etc." (De Luc, 2000).

Poor quality healthcare is often associated with unjustifiable variation in clinical practice (Roycroft et al., 2004) therefore it is necessary to develop pathways which reduce or eliminate these variations. Kitchiner and Bundred (1999) found that standardisation of care improves outcomes which supports the development and implementation of ICPs. Rycroft-Malone et al. (2004) conducted a study on protocol based care and concluded that standardised care approaches were important to improve service delivery and reduce practice variation especially for new and/or inexperienced staff.

There have been a number of studies on the creation and implementation of ICP's with varying conclusions. Bick et al. (2009) found that implementation of a pathway resulted in a number of benefits however there were consequences which had not been anticipated. Introduction of the ICP had unintentionally had a negative impact on working relationships between clinical professionals (Bick et al., 2009). In contrast Calland et al. (2001) found that, following ICP implementation, there was a significant reduction in medical resource use, including decreased length of stay and total cost of care. The ICP was also described as being "successful, safe and satisfying for patients." (Calland et al., 2001).

Campbell et al. (1998) describe 12 steps which should be taken in order to develop an integrated care pathway once an area of importance has been chosen.

- Gather support for the project – locally and nationally
- Form a multidisciplinary team – compare current practice with established clinical guidelines
- Identify/ develop established guidelines – following national recommendations
- Review practice – current and past
- Involve local staff – develop a local protocol which focuses on best practice that is achievable locally
- Identify key areas for service development – document appropriate goals for the service
- Develop an integrated care pathway

- Prepare documentation
- Educate staff – how to use the integrated care pathway
- Pilot – implement the ICP and ensure regular reviews are completed
- Regularly analyse variances – investigate why current practice is different from that recommended in the ICP
- Discuss variations – differentiate between avoidable and unavoidable variances (Campbell et al., 1998).

A number of studies have been conducted on evaluating care pathways with varying results. Roycr(Roycroft et al., 2004)(Roycroft et al., 2004)oft et al. (2004) found that the development, use and impact of standardised care approaches are mainly professional, individual and context specific. Bick et al. (2009) state that ICP's are 'complex interventions which generate a number of consequences for practice.' They also recommended that all relevant stakeholders be engaged with the introduction of pathways and to develop robust assessment strategies to accompany implementation (Bick et al., 2009). Any development of care pathways must clearly involve each member of the multidisciplinary team involved in the care of amputees and must also have the approval of healthcare professionals in order to avoid rejection of suggestions.

2.4 International Best Practice

A review of the international best practice in amputee rehabilitation was conducted to ascertain the current level of provision across the world and to use this information to compare it with the provision provided by the NHS. The search strategy involved use of four databases: NARIC's REHABDATA database of disability and rehabilitation literature, the Cochrane Database of Systematic Reviews, the database of the Educational Resources Information Center (ERIC), and PubMed a database serving the National Library of Medicine and the National Institutes of Health. The key words used during searches were:

- Prosthetic
- Rehabilitation

- Amputee / Amputation
- Best practice
- Guidelines
- National
- Model
- International
- Interventions
- Provision

Each search produced a large amount of literature which was reduced down by reading each abstract and determining its relevance. The reports have been analysed and combined to produce an overview of the international best practice guidelines in important sections of rehabilitation.

Rehabilitation Treatment Plan

Evaluations from all key team members should be included in the development of the treatment plan. The initial treatment plan should be established early in the rehabilitation process and updated frequently based on patient progress, emerging needs, or problems and always indicate the anticipated next phase of rehabilitation care. The treatment plan must address identified rehabilitation, medical, mental health, and surgical problems as well as identifying realistic treatment goals. The treatment plan should identify and address plans for discharge at the initiation of the rehabilitation process. The discharge treatment plan should include needs for specialised equipment, evaluation of and required modifications of the discharge environment, needs for home assistance, and an evaluation of the patient's ability to drive. (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012)

Pain Management

Pain should be assessed at all phases of rehabilitation, preferably with a tool specific to pain assessment in patients with lower limb amputations. When possible, a postoperative treatment plan for pain control should be developed before surgery and be based on the preoperative pain assessment and treatment initiated. Measurement of the intensity of pain should be separately assessed at each site (i.e., phantom limb pain, residual limb pain, lower back pain) to achieve a thorough assessment of pain-related impairment. Treatment should target pain related to the residual/phantom limb and address pain in other body parts from a primary care approach (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

Interdisciplinary Consultation/Assessment

Key disciplines to be consulted during the preoperative (when possible) and postoperative phases of rehabilitation care include: surgery, physio therapy, occupational therapy, prosthetics, social work services, case management, mental health, nursing, nutrition, and recreation therapy. In addition, the following specialties should be available on a case-by-case basis: vascular surgery, plastic surgery, internal medicine, pain management and vocational therapy. The patient and family members (or other caregivers) should be an integral part of the interdisciplinary rehabilitation team. Interdisciplinary rehabilitation team meetings should be conducted on a regular basis within the institution to facilitate communication and integration of a comprehensive treatment plan. Outpatient amputation clinics should have interdisciplinary team participation for the periodic assessment of patients to ensure appropriate life-long care in order to preserve the quality of life, achievement of maximum function, and reduction of secondary complications (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

Medical Care

Medical status including laboratory studies should be assessed and monitored as indicated to screen for infection, anemia, electrolyte imbalances, nutrition, and liver and kidney diseases. Modifiable health risk factors should be assessed and education and treatment strategies to reduce their impact on morbidity and mortality should be implemented (e.g., smoking cessation, body weight management, diabetes management, hypertension control, substance abuse) (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

Residual Limb Management

The residual limb should be appropriately managed to prepare for prosthetic training and to enhance functional outcomes. Limb volume management is a critical issue throughout the lifespan of the individual. The patient should be educated about care and management of the residual limb including: proper application of external compressive devices, proper donning and doffing technique for the prosthesis, adjustment of prosthetic sock ply for limb volume change, if appropriate, proper hygiene of the residual limb and prosthesis, daily inspection of the residual limb for signs of abnormal pressure distribution, training with a long handled mirror to assist in the inspection of the residual limb. Interventions to prevent contracture at both the hip and the knee should be considered on an ongoing basis, especially in the early postoperative period and when the patient is an intermittent or marginal ambulator. Limb protection should be emphasized especially during the early phases when the risk of falls is greater. Skin and soft tissue should be monitored on a regular basis to detect any mechanical skin injury related to abnormal pressure distribution or signs and symptoms of infection (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

The Contralateral Limb

Comprehensive evaluation of the neurological, musculoskeletal, soft tissue and vascular status of the contralateral limb is necessary to initiate educational programmes and establish specialized footwear or orthotic needs. Comprehensive assessment of the contralateral limb should include: evaluating for the presence and severity of a sensory deficit, quantifying the presence and extent of a motor deficit, determining the arterial perfusion status of the extremity, evaluating the presence of deformity, evaluating for signs of acute or chronic abnormal pressure loading, including tissue redness, ulceration or callosity, inspecting the patient's footwear, including wear pattern. The patient and/or caregiver should be educated about strategies to protect the skin integrity of the foot. Appropriate foot care as indicated should provide: local foot care for callosities and nail care management by a health professional, especially in the context of sensory impairment or poor vision, footwear that can be adapted to meet a patient's mobility needs, and that can accommodate a foot deformity and/or an orthotic device, orthoses to optimize the pressure distribution on the foot or to substitute for muscle weakness. Regular follow-up to evaluate the adequacy of the footwear or orthosis should be established. Specialized foot protection devices and/or mattresses should be considered for patients that are confined to bed or spend a considerable amount of time in the recumbent position (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Hoffman, 2012).

Behavioural Health Assessment and Treatment

A psychological assessment should be completed in the preoperative phase, if possible and treat problems throughout all phases of rehabilitation. Psychosocial functioning should be assessed at each phase of amputation management and rehabilitation. Assessment should focus on current and past symptoms of psychopathology, particularly depression, anxiety, and post-traumatic stress symptoms. Interventions need to focus particularly on depressive, anxiety and post-traumatic stress disorder (PTSD) symptoms, using empirically supported medical and psychotherapeutic treatments for depression and PTSD. Effective coping goals/strategies should be developed during psychotherapeutic or counselling interventions. During the assessment, examples of effective and ineffective coping strategies should be discussed with the patient, such as enlisting sufficient social support versus social withdrawal and disengagement and problem solving difficulties versus helplessness and passivity. Specific structured interventions for problems such as depression, anxiety, sexual difficulties, substance abuse or drug overuse, and pain should be considered. Interventions may operate through individual, couple, family, or group therapy modalities. Significant others should be included in psychotherapeutic and/or psychoeducational interventions as needed. The use of validated tools for assessment should be considered; some examples may include: Prosthesis Evaluation Questionnaire (PEQ) for psychometric assessment is a self-report questionnaire, Trinity Amputation and Prosthetic Experience Scales (TAPES) for psychosocial evaluation, The Hospital Anxiety and Depression Scale (HAD), The SF-36 Health Survey measures the degree of burden or dysfunction a medical condition has in a patient's life. Psychological components to multidisciplinary approaches to chronic pain management should be included as needed (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

Social Environment (Support)

The social and physical support system that will be available to the patient during the rehabilitation process and help them cope with the challenges of limb loss, should be identified. A baseline assessment should be obtained and continuously updated throughout the rehabilitation phases. The assessment should include information about the existing social environment and support system:

- Interpersonal Social Environment: Family and extended family, Community - including workplace, employers/employees and co-workers, Spiritual, religious, and cultural support, Peer support system
- Physical Environment: Home environment – hazards and need for modification to address safety and accessibility, Workplace, Community – geographical location, distance from resources and services, and access to resources
- Economic Environment: Sources of income and/or financial support (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

Peer Support Interventions

Peer support should be considered, if available, throughout the course of amputation and rehabilitation. Peer visitation strategies may be considered throughout the rehabilitation cycle, particularly early when anxiety and adjustment problems may be most pronounced. Peer support interventions may be a particularly useful aspect of pre-procedural patient education interventions. Peer visitation volunteers should receive structured training prior to performing peer visitation services. Patients should be referred to peer support groups or similar resources, if available (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012)(Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

Patient Education

Patients scheduled for amputation should receive in-depth education regarding the procedure itself, and the various components of postoperative care and rehabilitation activities that will occur. A combination of information-giving and coping skills training should continue through all phases of the rehabilitation care. Pre-procedural educational interventions should be provided to the patient before amputation, if possible, in order to decrease his/her fear, anxiety, and distress and to improve his/her post-procedural recovery. All members of the rehabilitation team should be involved in patient education as part of their interaction with the patient. Pre-procedural educational interventions should generally include information and a description of the specific procedures and events the patient will experience at the various phases of treatments, and continue throughout the continuum of care. Educational interventions should also include sensory information, that is a description of sensations and other feelings/symptoms the patient may experience at various stages during and following the procedure. Educational interventions may also include coping skills training; cognitive behavioural coping strategies are likely to be the most effective strategies. General supportive counselling (e.g., eliciting and validating the patient's anxieties, fears, and concerns) may also be helpful. Open-ended questioning, active listening techniques, eliciting anticipation of future stressors, and eliciting and encouraging utilisation of the patient's social support resources are important strategies irrespective of whether information-giving or coping skills training interventions are being used (World Health Organisation, 2004; Department of Veterans Affairs, 2008; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

Learning Assessment

Prior to the learning assessment, the health professional should assess the patient with a lower limb amputation for core concerns, potential fears, support limitations, and cultural history. The best time to begin a learning assessment is determined on a case-by-case basis but often begins with the initial contact with the patient who has had a lower limb amputation and their family. The learning assessment should use open-ended questions to obtain the following and additional, information:

- Patient/family's ability to cope with the health status, plan of care, prognosis, and outcome
- Patient/family needs, concerns, roles, and responsibilities
- Specific learning needs (knowledge, attitudes, skills) and educational level
- Barriers to learning, including physical and/or cognitive limitations, language, emotional or psychological, and financial difficulties
- Readiness to learn
- Patient preferences regarding learning methods (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

Physical Rehabilitation

The aim of rehabilitation is to achieve maximum independence and function. The individual's rehabilitation programme takes into account their pre-amputation lifestyle, expectations, and medical limitations. The level of amputation, physical and psychological presentation, and social environment influence the expected level of functional independence. The rehabilitation team progresses the patient through a programme based on continuous assessment and evaluation. Through regular assessment, the team should identify when the individual has achieved optimum function with or without the prosthesis, facilitating discharge to a maintenance programme, and continue to follow-up as needed. Physical rehabilitation includes assessments and activities that improve the baseline status of the musculoskeletal system and include range of motion (ROM), strengthening, cardiovascular fitness, and balance (Rommers et al., 1997; World Health Organisation, 2004; Wan-Nar Wong, 2005b; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Greitemann, 2010; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

Functional Rehabilitation

Functional rehabilitation includes assessment and activities, such as activities of daily living (ADL), transfers, and mobility, which are performed to achieve a functional goal. Interventions to improve functional activities of daily living (ADL) should be initiated, measured and adjusted as needed during the postoperative phases. Mobility training to optimize the patient's ability to move from one location to another by means of adaptive equipment, assistive devices, and vehicle modifications is essential to prompt patient independence (World Health Organisation, 2004; Chiong and Lim, 2007; Greitemann, 2010; Statewide Rehabilitation Clinical Network, 2012a; Hoffman, 2012).

2.4.1 Charitable Organisations in the UK

There are a number of charitable organisations in the UK that support amputees and help promote healthy living and return to sport. The charities that currently operate in the UK are the Limbless Association, Limbcare, the Douglas Bader Foundation, LimbPower, Steps and Reach. Steps and Reach are charities specifically set up for children with congenital absence or acquired amputations. LimbPower is a charity that specifically aims at getting amputees back into sport and living a healthy lifestyle. Information on sports available in all areas of the UK can be supplied by LimbPower and there is a large online community for supporting new and established amputees.

Each charity has two common features, they all provide information and support for amputees thereby highlighting the importance of these services. There are no specific guidelines for best practice set out by each of the charities, however each one recognises the importance of thorough and comprehensive information as well as emotional support. Peer support is also highly regarded by each of the charities, with support groups and volunteers being available across the UK (Limbless Association, 2011; Limbcare, 2013; The Douglas Bader Foundation, 2013; Limb Power, 2012; Steps, 2012; Reach, 2012).

2.5 User Centred Research

When designing a system, if the users of that system are not considered, dissatisfaction and inefficiency can arise. This is due to the system not fitting the user and fulfilling their needs effectively (Norris, 2009). User centred design focusses on the needs and preferences of the user, ensuring that whatever is being designed fulfils their needs (Abras et al., 2004)(Abras et al., 2004). There can be multiple users of a product or system, each of whom must be considered during the design process. In the case of prosthetic care there are multiple users of the service, all of whom have different requirements. The patient is the the primary user, however for design purposes each of the clinicians that provide care to the patient, such as the prosthetist, consultant, nurse, OT and physiotherapist are also considered users of the service. Patients' families and carers are also users, as well as support services such as patient volunteer visitors who come and speak to primary amputees. If a user centred approach is to be utilised, each of these users must be considered during the design process.

According to Sanders (2002) the user is not seen as a member of the design team as their thoughts and opinions are determined by researchers working on the project. The data gathered by the researchers is then used by the designers to help inform the design process. The users are therefore consulted at the beginning of the process and towards the end during usability testing and evaluation. This process is laid out in British Standard EN ISO 9241 and represented in diagram form as shown in Figure 2.8.

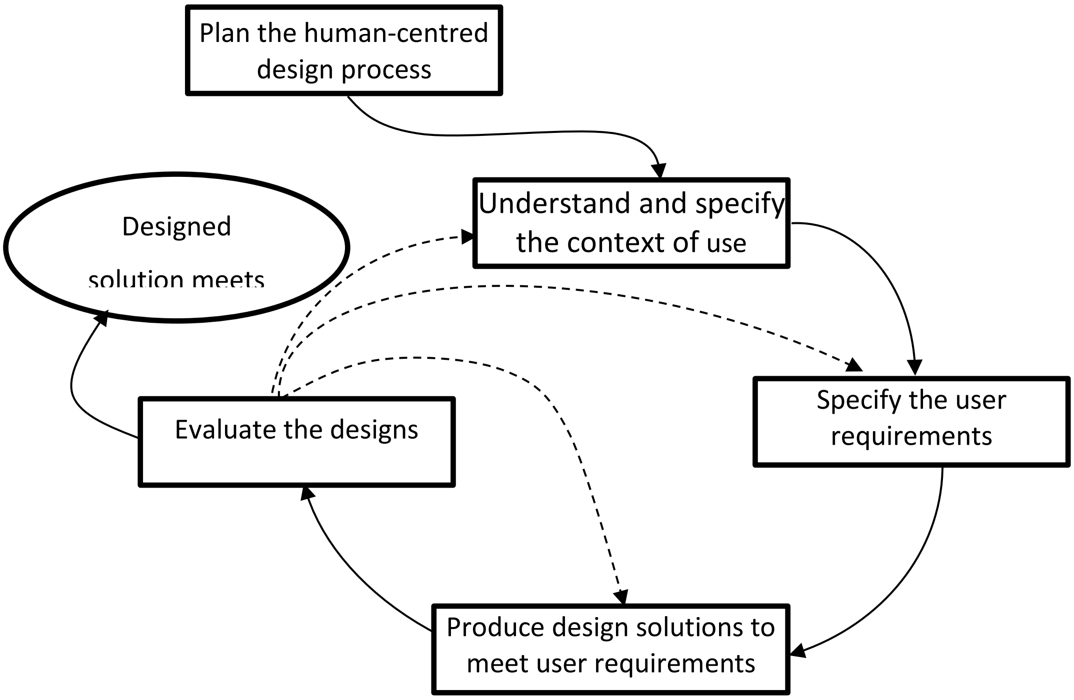


Figure 2.8: Interdependence of human design activities (BS EN ISO 9241)

The phases outlined in Figure 2.8 can be defined as discovery, design and development phases, each of which requires different methods for data gathering and user involvement. There are a number of methods that can be adopted at any or all of these phases, each with their own advantages and disadvantages:

1. Field studies (including contextual inquiry): These studies involve the researcher interacting and speaking with users in the environment the product or service is being designed for to understand the context and needs of the user. Watching the users carry out tasks with a certain product that is being redesigned or within a service system can help the researchers to understand how the product or system is currently being used and highlight any user difficulties. This method can be expensive and time consuming due to the necessity to spend a significant amount of time with users and transcribe all of the data collected. A study conducted by Mao et al. (2005) found that this method was the most highly regarded by teams of researchers carrying out user centred design however relatively infrequently used due to the cost.

2. User requirements analysis: This method involves speaking with users and understanding exactly what they require from a newly designed product or system. This helps inform the design process and focusses the designers when beginning to draft some design ideas. Data collection techniques that can be used during this process are focus groups, user interviews, surveys and card sorting. Card sorting is a process whereby users are presented with a number of cards each labelled with a piece of content or functionality. They are then asked to sort the cards into groups that they feel make sense. This technique is quick, inexpensive and reliable therefore can be used at the beginning of a project to ascertain how similar or different the needs of the users are. Each of the other techniques will be discussed in later chapters. The most utilised of these techniques was found to be focus groups with card sorting being the least frequently used. Cost-benefit analysis of each of these techniques is of great importance to researchers in industry, therefore surveys and interviews are not as widely used as focus groups (Mao et al., 2005; Vredenburg et al., 2002).
3. Iterative design: This methodology is based on a cyclical process of prototyping, testing, analysing and refining the product or system being designed. This process enables designers to improve the functionality and quality of the product or system. This was the second most important methodology used by designers as found by Mao et al. (2005). This was found to be the case due to the high return gained from implementing this methodology.
4. Usability evaluation: This method involved producing a prototype of the product or system being designed and allowing users to test and evaluate it. This technique allows designers to ascertain the issues, if any, users have with the product or system and also gain some insight into how these issues could be improved. Usability evaluation was the third most used method during user centred design projects as it allows the users to provide their opinion and the designers act upon these suggestions.
5. Task analysis: Task analysis is the analysis of how a task is accomplished, including a detailed description of both manual and mental activities, task and element durations, task frequency, task allocation, task complexity, environmental conditions, necessary clothing and equipment, and any other

unique factors involved in or required for one or more people to perform a given task (Kirwan and Ainsworth, 1992). This technique is used to provide designers with the detailed information of the tasks involved in using the product or system they are redesigning. This can help inform the design process and help designers understand where the current issues lie. This technique was found by Mao et al. (2005) to be the fourth most used technique by companies involved in user centred design projects. This highlights the importance of understanding the task before attempting to design for that task.

6. Formal heuristic evaluation: Heuristic evaluation involves having usability specialists judge whether each dialogue element follows established usability principles and is considered to be a very informal method to gather data. Formal evaluation uses a six-step procedure with strictly defined roles to combine heuristic evaluation and a simplified form of cognitive walkthroughs, whereby a detailed procedure is used to simulate a user's problem solving process at each step, checking if the simulated user's goals and memory content can be assumed to lead to the next correct action (Nielsen and Molich, 1990).
7. Prototyping: This method involves producing a prototype of the newly designed system or product that can be given to users or others to test and evaluate. This has been found to be a widely used method as costs can be minimal and return from data collection involving the prototype can be considerable in terms of imping the design (Sanders, 2002; Mao et al., 2005; Vredenburg et al., 2002).
8. Informal expert review: This method involves an expert, within the project subject area, being given a prototype of the system or product being designed and being asked to evaluate it based upon their expert knowledge. This informal procedure is highly utilised in user centred design projects, however is considered to provide little impact on the project as a whole (Mao et al., 2005).

These methodologies can be used independently or as part of a comprehensive project plan, however at least one of these techniques should be used during each of the three phases. Mao et al. (2005) found that there were many references to user involvement during discovery, design, or development phases by members of user centred design project teams, but only 13% of the projects engaged in a full

UCD approach in the sense of user involvement at all three stages of the development cycle. A technique has been developed to ensure user involvement at each stage as the user becomes a member of the design team and is involved in all critical decisions relating to design and development of the product or service (Sanders, 2002; Muller and Kuhn, 1993; Kensing and Blomberg, 1998)(Sanders, 2002; Muller and Kuhn, 1993; Kensing and Blomberg, 1998). This method is known as participatory design and is considered a highly useful method for designing products for specialist users (Sanders, 2002; Muller and Kuhn, 1993; Kensing and Blomberg, 1998). This method is not used in many projects due to the time and monetary investment required to involve the user at all stages of the design process (Mao et al., 2005; Vredenburg et al., 2002).

2.5.1 The NHS

A report published by the Department of Health (2005) states that in order to improve the NHS, care should become more patient oriented and therefore NHS staff would work with patients to provide support for their health needs. Designing new systems for patients could therefore improve patient experience and satisfaction and help the NHS to move towards patient centred care. In order to achieve this, careful consideration of patients' views and suggestions would be required, as without their input the system produced would provide no advantages over the old system. There have been a number of studies involving patients, to ascertain their views and use those views to help improve a system or provision of care. A study using a patient centred approach conducted by Dancet et al. (2011) found that infertility clinics were not sufficiently fulfilling patient's needs. These results were gained through the use of focus groups with patients and provided valuable information to the researchers about how to best improve infertility services (Dancet et al., 2011). Lee and Lin (2010) found, through the use of self-administered questionnaires, that Type 2 diabetes patients desired to be involved in their treatment choices and therefore assume some power over and responsibility for their condition. Involving chronic obstructive pulmonary disease (COPD) patients in their research allowed MacPherson et al. (2012) to establish that advance care planning could improve patient satisfaction and minimise distress. Homet et al.

(2009) state that due to patients having an increased participation in therapeutic decisions, their opinions on new treatments for cancer were imperative. Understanding the perceptions of patients about the new treatments available provided clinicians with the ability to discuss and organise treatment on the patient’s terms (Homet et al., 2009). A study conducted by Wheeler (2010) into patient perceptions of diagnostic ultrasound provided evidence that patients were very satisfied with this diagnostic technique and its use provided great value to the patient and clinicians. Each of these examples of the use of a patient centred approach has provided invaluable information for clinicians on shortcomings of their service and potential ways to improve them which could not have been gained through talking to clinicians or hospital staff alone. Asking the patient for their opinion of the service they are provided offers a biased view of the service, however this view is extremely important for clinicians to be aware of as patient satisfaction has become an important part of healthcare (Department of Health, 2005). Improvement of the systems already in place within the NHS requires the collection of data pertaining to the views and suggestions of the patients.

The core principles of the NHS have remained the same since its launch in 1948. These principles are, as stated by Aneurin Bevan in 1948:

- That it meets the needs of everyone
- That it be free at the point of delivery
- That it be based on clinical need, not ability to pay.

These principles were used to inform the creation of the NHS constitution, published in March 2011, which sets out the guiding principles of the NHS (Department of Health, 2011). Renewal of this document will be every 10 years and is stated as being with full involvement from staff, patients and the public. Quoting the constitution, the NHS website describes seven key principles that guide the NHS in all it does. In theory each sector of the NHS should be applying these principles to their practice on a regional and local level. These principles therefore apply to every NHS practice, therefore any practice not fulfilling these principles should be investigated and the issues amended.

- Principle 1: The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion or belief.
- Principle 2: Access to NHS services is based on clinical need, not an individual's ability to pay.
- Principle 3: The NHS aspires to the highest standards of excellence and professionalism.
- Principle 4: NHS services must reflect the needs and preferences of patients, their families and their carers.
- Principle 5: The NHS works across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population.
- Principle 6: The NHS is committed to providing best value for taxpayers, money and the most effective, fair and sustainable use of finite resources.
- Principle 7: The NHS is accountable to the public, communities and patients it serves.

On closer inspection of these seven defining principles, some interesting areas for further examination were found. In Principle 1 the NHS service is defined as comprehensive; however there is no definition given for "comprehensive service" therefore this phrase can be open to interpretation. This phrase could be interpreted as meaning that the NHS should be providing a service that offers treatment and care that covers all clinically relevant aspects of each illness. The classification of physical and mental health can lead to the compartmentalisation of illnesses where only the symptoms of the diagnosed ailment are addressed. Every illness has mental health consequences interlaced with the physical condition. Management of the mental health aspect of physical illnesses is instrumental in providing comprehensive care to patients and therefore fulfilling this principle. One view of this could be that if one centre is not providing comprehensive care then the NHS as a whole cannot be considered to be. This view could be considered unreasonable due to the NHS being a very large organisation with excellent services being overshadowed by poor service provision in other sectors. The NHS could therefore be considered as separate sectors rather than a whole when considering comprehensiveness of service provision. Principle 2 introduces the phrase “clinical needs” which is also ambiguous. The implication is that in order to provide a “comprehensive service” the clinical needs of every patient must be fulfilled. There cannot be one definition of patients clinical needs due to the diversity in illnesses and patient requirements therefore the clinical needs of each patient must be assessed and defined by a member of NHS staff. The phrase, “clinical needs” could mean that only the needs associated with the diagnosed illness are covered, not the overall needs of the patient. It is therefore evident that the comprehensive service is interlaced with the definition of the patients’ clinical needs; as if such needs are wrongly diagnosed the service cannot be considered to be comprehensive. Difficulties therefore arise in the appointment of an appropriate clinician to define the clinical needs of each patient, as each clinician should be aware of the psychological impact of illnesses as well as the physical symptoms requiring treatment. Clinicians can therefore encounter many problems in defining the needs of the patient, as the patient’s perception of their needs may be different to those of the clinicians treating them. If the needs of the patient, as defined by clinicians, are fulfilled but the patient is dissatisfied as their perceived needs have not been met, the service could not be described as comprehensive, unless the patient’s perceived needs have no clinical relevance to their condition. Principle 4 represents this as NHS services are required to reflect the “needs and preferences of the patients”; therefore, to fulfil this principle, clinical needs must be defined as: the treatment required to treat every aspect of an illness as outlined by the patient and clinician. Due to the way in which Principles 1 and 2 are connected it is clear that patient involvement in their treatment is essential in providing a comprehensive service.

Principle 6 describes the resources of the NHS as “finite”, therefore introducing the concept that the ideals defined by the seven principles must be delivered within financial constraints. Principle 7 outlines that the NHS is accountable to those that fund the service therefore must be seen to be providing excellent care for all patients within the boundaries of monetary constraints. Patient involvement is also required for constitutional changes, therefore patient opinions are considered to be of the upmost importance at the highest levels of decision making procedures.

Every principle defined by the NHS has involvement of patients embedded within it, therefore any research conducted pertaining to the NHS would necessitate patient involvement. When considering an overall theme for any work within the NHS a patient centred approach should be considered due to patient involvement being a key element in the NHS upholding its principles. In order to accurately define the “clinical needs” of patients, their opinions must be heard, as well as those of the clinicians involved in their treatment. The NHS cannot be considered to be fulfilling the first of its founding principles of fulfilling the needs of everyone, if patients are not involved in service research.

2.6 Conclusions

This literature review has shown a clear gap relating to the DSCs in the UK and the pathways they use to treat new (primary) patients. Research is therefore required to ascertain the current NHS service provision in order to fulfil the aims of this research. The principles of the NHS highlight the necessity to include patients in decisions relating to their healthcare needs, therefore any investigation into the NHS should include input from patients.

Chapter 3: Research Philosophies and Approaches

3.1 Introduction and Aims

This overall aim of this thesis is to focus on the patient experience of the NHS service provision of prosthetics. This chapter discusses the different approaches to research design and the applicability of these approaches to the work in this thesis. The objectives of this chapter are to:

- Outline the range of methodologies available for applied research
- Ascertain the principles of good practice generally accepted for research design
- Understand which methodologies are appropriate for the work in this thesis
- Identify possible limitations with the methodologies chosen

Due to the limited research conducted into the service provided to prosthetic patients by the NHS, methods used for other user centred applications were applied. It was accepted that there may be specific challenges with this subject area that would not be detailed in the literature; these challenges are discussed as they arise in the various studies (Chapters 4, 5 and 6). This chapter provides the overview to research approaches.

3.2 The Research Arena

Morse and Richards (2002) describe research design as being “a problem to be considered carefully at the beginning of the study and reconsidered throughout”. They express the research design as needing to fit and be drawn from the question, chosen method, selected topic and research goals. This implies that once the design has been finalised, it is not set in stone and can and should be changed following new developments or issues concerning the method, topic and research goals.

The interactive model of research design (Figure 3.1) offered by Maxwell (2005) shows research design having a number of components all grouped around a central component, the research question. This model emphasises the importance of the research question and how it will influence every other aspect of the research design. It also shows that no component in the design of a qualitative research project is completely independent from the other components and each has implications for the others. Maxwell (2005) describes this using his rubber band metaphor, which portrays each of the connections between components in this model as being rubber bands. Qualitative design is depicted as being considerably flexible in nature, however due to the constraints the different components impose on one another it can be rendered ineffective following violation of such constraints. Other authors have produced similar diagrams with different components feeding into the central research question. Robson's (2002) components for research design are purpose(s), theory, methods and sampling strategy. The differences and similarities of these two models show that some qualitative researchers have similar views on the design of research however they also have individual ideas about the importance of certain components.

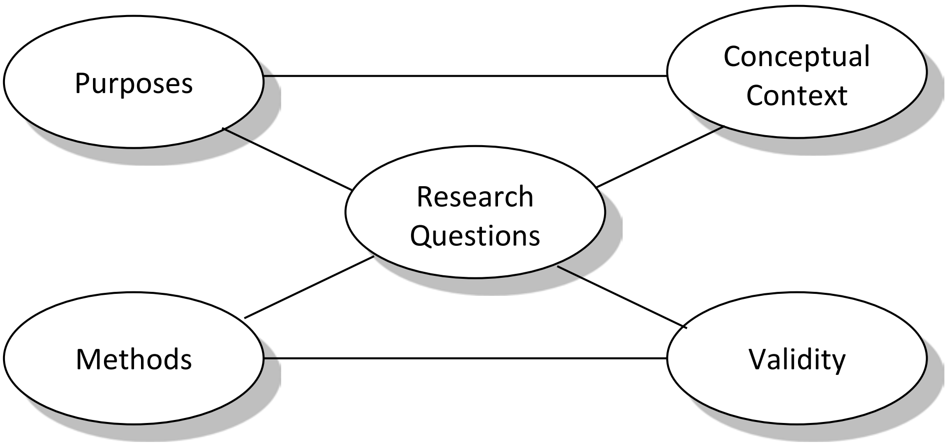


Figure 3.1: An interactive model of research design (Maxwell, 2005)

Maxwell (2005) develops his model further by adding subfactors that will influence research design (Figure 3.2). He states that the factors in this model are not part of the design of the study but rather the environment within which the research exists or are products of the research, however they are important to take into account during the design process.

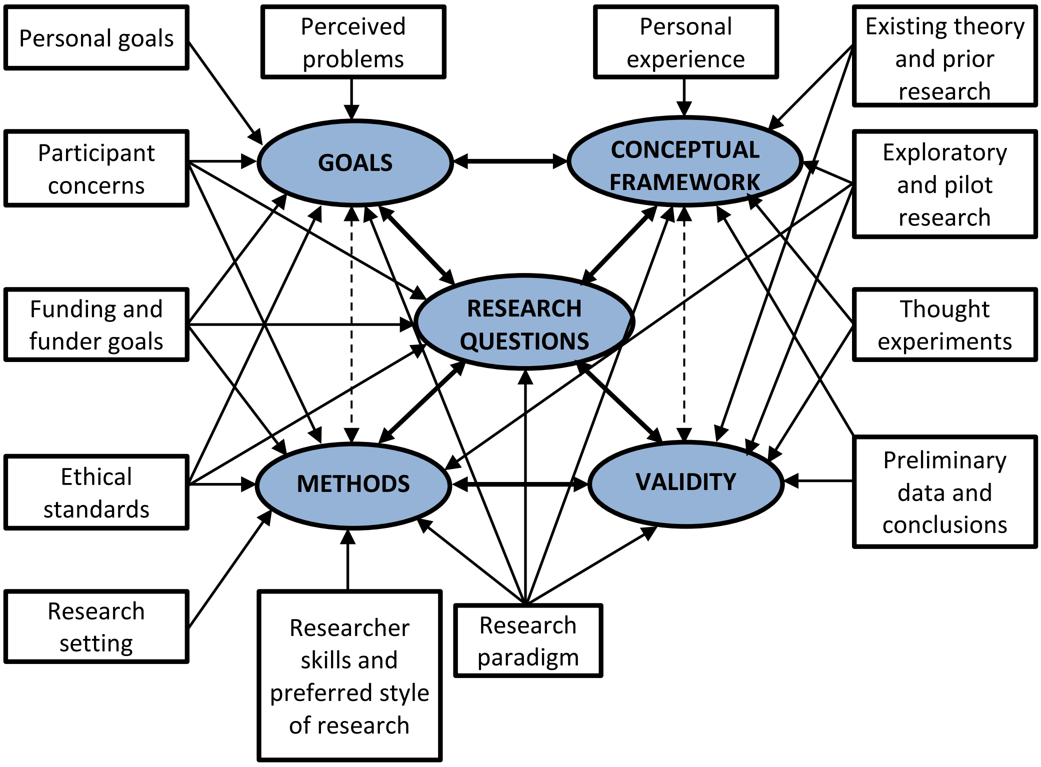


Figure 3.2: Contextual factors influencing Research Design (Maxwell, 2005)

As can be seen in Figure 3.2 there are numerous factors needing consideration when designing research, each of which has an impact on the next due to the connection between the five main components. In order to ensure validity of the research, each of these factors should be considered using varying forms of rigour depending on the impact they have on the design as a whole.

Research design clearly has many dimensions which a number of authors have described using various models. Saunders et al. (2007) have produced the research ‘onion’ which outlines the different layers involved in the research process. (Figure 3.3). The literature highlights the numerous factors requiring careful consideration when designing research, therefore further examination of such factors was required.

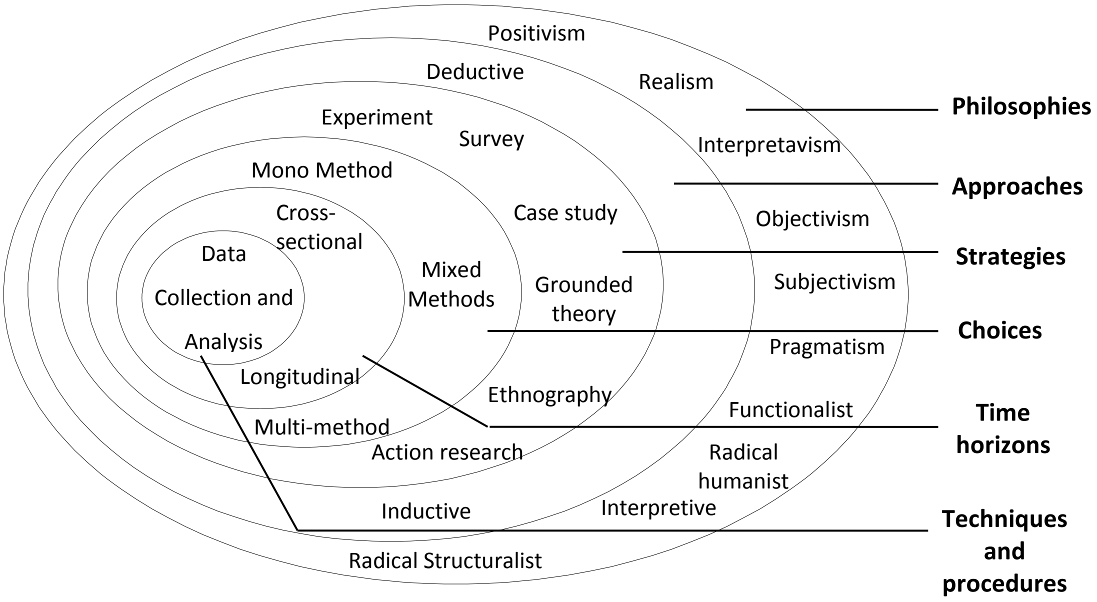


Figure 3.3: The research ‘onion’ (Saunders et al., 2007)

3.2.1 Research Philosophies

There is a clear distinction between research philosophies adopted in different subject areas due to the nature of the work being conducted. The two philosophies covered here are positivist and interpretivist. The positivist approach is very much the philosophical stance of the natural sciences. Progression of the natural sciences was seen only to be possible through the accumulation of facts about the world in order to produce scientific laws (Gray, 2009). Green and Thorogood (2009) state that “positivism assumes that there is a stable reality ‘out there’ and that phenomena (such as bacteria and disease) exist in exactly the same way whether we understand them or not”. An expansion of this is that although the human understanding of such phenomena may be flawed there is a possible correct explanation (Green and Thorogood, 2009). Positivism is difficult to define due to many different versions being produced which overlap but rarely agree exactly on the essential components (Green and Thorogood, 2009). Essentially, positivist research should be based upon scientific observation and aims to forward knowledge in the area through testing of a hypothesis using a defined methodology in order to allow reproduction of the results.

Interpretivist approaches have been developed due to the nature of human beings being unpredictable and complex. The behaviour of humans is not determined in law-like ways, therefore studying social behaviour requires a different approach which is concerned with people's interpretation of the world not the reality of it. Saunders et al. (2007) state that a crucial part of the interpretivist approach is that the researcher must assume an empathetic stance in order to enter the social world of the research subjects and understand it from their point of view. A summary of the positivist and interpretivist research approaches is shown in Table 3.1.

Table 3.1: Summary of positivist and interpretivist paradigms. (Adapted from(Gray, 2009)

	Positivist Paradigm	**Interpretivist Paradigm**
Basic Beliefs	The world is external and objective The observer is independent Science is driven by testing hypotheses and theories	The world is socially constructed and subjective The observer is party to what is being observed Science is driven by human interests
The researcher should	Focus on facts Locate causality between variables	Focus on meanings Try to understand what is happening
Methods include	Operationalising concepts so they can be measured Using large samples from which to generalise the population Quantitative methods	Using multiple methods to establish different views of a phenomenon Using small samples researched in-depth over time Qualitative methods

Positivism has come under scrutiny from many researchers and has even been described by Williams and May (1996) as being 'one of the heroic failures of modern philosophy'. Hughes and Sharrock (1997) show that one of the fundamental faults of the positivist view is some of the assumptions made about scientific enquiry. Science does not typically begin from observation, therefore theoretical explanations produced are not simply based on observation, but from theory in order to make the observations comprehensible (Gray, 2009). There are however researchers who believe and have stated that the positivist and interpretivist approaches are not mutually exclusive and can be used side by side. Lin (1998) states that qualitative research encompasses both positivist and interpretivist approaches and that the combination of both is more logically sound. The differences in approaches are stated by Lin (1998) as being the differences in questions asked of the data and the nature of the conclusions the researcher wishes to draw. The similarities stated are that both forms of qualitative work look for details about motivations, actions and preferences that are not easily made numeric. The distinction made by Lin (1998) is that positivist work seeks to identify qualitative data with propositions that can be tested or identified in other cases, while interpretive work seeks to combine those data into systems of belief whose manifestations are specific to a case. Both approaches are seen to comment about general principles or relationships, the difference being that positivist work does so by identifying general patterns whereas interpretivist work does so by showing how the general patterns look in practice (Lin, 1998). Lee (1991) also states that both approaches should be used to strengthen one another to form a truly collaborative research effort. Lee's (1991) framework for integrating the positivist and interpretivist approaches consists of three levels of understanding. The first is the subjective understanding, consisting of the 'everyday meanings and common sense' of the subjects under observation. The second is the interpretive understanding, consisting of the 'researcher's reading or interpretation' of the subjective understanding. The third and final understanding is positivist, consisting of the researcher's creation which is tested and used to explain the empirical reality being investigated (Lee, 1991). Both Lin (1998) and Lee (1991) put forward strong cases that positivist and interpretivist approaches can be used in conjunction in order to not only add substantive content that neither could add alone but also correct for biases that each approach suffers from separately.

3.2.2 Deductive and Inductive Research Approaches

Following the research onion model in Figure 3.3 the next consideration for a qualitative research project is whether to adopt a deductive or inductive approach. A deductive research approach is described by Saunders et al. (2007) as involving development of a theory which is then subjected to rigorous testing. Gray (2009) takes this one step further by describing deduction as beginning with a universal view of a situation and working back to the particulars. The stages of the deduction process are described by Robson (2002) as being:

1. Production of a hypothesis from the theory. The hypothesis is a "testable proposition about the relationship between two or more concepts".
2. Indicate exactly how the concepts or variables are to be measured (operational hypothesis).
3. Test the operational hypothesis.
4. Examine the outcomes of the enquiry
5. If necessary modify the theory in light of the findings.

In contrast to this, the inductive approach involves planning data collection and analysing that data for emerging patterns that suggest relationships between variables (Gray, 2009). It is possible, using the observations made to construct generalisations, relationships and at times theories. Gray (2009) states that in order to ensure a degree of reliability, researchers often multiply observations rather than base conclusions on one case.

Table 3.1 shows the major differences between the deductive and inductive approaches. The table represents the important elements of each approach.

Gray (2009) states that deductive and inductive approaches are not mutually exclusive. Saunders et al. (2007) agree with this statement in saying that it is possible to combine the two approaches and is often advantageous to do so.

Table 3.1: The major differences between deductive and inductive approaches (Saunders et al., 2007)

Deduction Emphasis	**Induction Emphasis**
• Scientific principles • Moving from theory to data • The need to explain casual relationships between variables • The collection of quantitative data • The application of controls to ensure validity of data • The operationalisation of concepts to ensure clarity of definition • A highly structured approach • Researcher independence of what is being researched • The necessity to select samples of sufficient size in order to generalise conclusions	• Gaining an understanding of the meanings humans attach to events • A close understanding of the research context • The collection of qualitative data • A more flexible structure to permit changes of research emphasis as the research progresses • Less concern with the need to generalise

3.2.3 Research Approaches

There are a number of research strategies that can be employed when designing research, each of which can be used for explanatory, descriptive or exploratory research (Yin, 2003). These strategies are experiment; survey; case study; action research; grounded theory and ethnography. Saunders et al. (2007) describe some of these strategies as clearly belonging to the inductive approach and others to the deductive approach, however also stated that allocating strategies to one approach or another is “unduly simplistic”. It is not thought that any particular strategy is superior or inferior to the other, just that when chosen carefully the appropriate strategy can yield good results and enable the research question(s) to be answered and objectives attained. Saunders et al. (2007) also emphasise that the strategies are not “mutually exclusive” and can be used in conjunction with one another to produce valid and reliable results.

3.2.3.1 Experiment

Experiments are used to determine whether an intervention or change in an independent variable will have an impact on the outcome or dependent variable being studied. This is usually achieved by randomly dividing participants into two groups, the control group and the experimental group. The control group does not receive any intervention and the dependent variable being studied will be observed. The experimental group will receive the intervention and when compared, the differences (if any) between the dependent variables of both groups is attributed to the intervention (2007; Gray, 2009).

3.2.3.2 Survey

Saunders et al. (2007) describe survey research as most frequently used to “answer who, what, where, how much and how many”. Surveys tend to use questionnaires to gain quantitative data on trends, attitudes or opinions of a population by studying a representative sample of that population (Lee, 1991). Structured observation and structured interviews are data collection techniques also associated with survey research (Saunders et al., 2007).

3.2.3.3 Case Study

Stake (1995) describes case studies as an inquiry strategy involving in-depth exploration of “a programme, event, activity, process or one or more individuals”. Data are collected over a sustained period of time using a number of data collection procedures. The data gained can be qualitative i.e. diary studies, or quantitative i.e. coding of events (Boynton, 2005).

3.2.3.4 Action Research

Action research was first used as a term in 1946 (Saunders et al., 2007) however since then it has been used to describe a large range of methods and activities (Gray, 2009). Coghlan and Brannick (2004) describe action research as an approach that focuses on action and research simultaneously in a participative manner. There are varied methodologies within this approach which each have their own priorities and modes of inquiry (Gray, 2009). Gray (2009) identifies three common themes amongst the approaches to action research:

- Research subjects are themselves researchers or involved in a democratic partnership with a researcher
- Research is seen as an agent of change
- Data are generated from the direct experiences of research participants

3.2.3.5 Grounded Theory

Strauss and Corbin (1998) describe grounded theory as a theory that is “discovered, developed and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon”. This approach can be used to help research and predict behaviour with the emphasis being on developing and building theory (Saunders et al., 2007). Data collection begins with no formation of an initial theoretical framework as the theory is developed from data generated by a series of observations (Saunders et al., 2007). Predictions are then generated which are tested through further observations which will either confirm or disprove the predictions. Gray (2009) states that the grounded theory researcher works with their participants to actively construct the data.

3.2.3.6 Ethnography

Ethnography was first associated with anthropological studies, however it is now used to describe participant observation studies in social and organisational settings (Gray, 2009). The researcher becomes immersed in the field of study, often for long periods, in order to understand the social processes present. This makes ethnography extremely time consuming and flexibility is a necessity due to new patterns constantly emerging from what is being observed (Saunders et al., 2007). Observation may be carried out overtly so that participants are aware that they are being observed, or covertly where participants are unaware of the observation taking place (Gray, 2009). Covert observation can be thought of as unethical due to participants not having the choice to participate in the research or not. One strong argument in its favour is that people may change their behaviour when they know they are being observed and therefore taint the results (Gray, 2009).

Each of these strategies has its merits and each should be considered. However some strategies are more appropriate for certain work than others. Ethnography, for example, is not always possible due to time and budget constraints. Choosing a strategy is a very important step in designing research and should be done so cautiously and with appropriate knowledge of the theory.

3.2.4 Reliability and Validity

The credibility of research findings is extremely important when designing research of any nature. In order to produce credible research, attention must be paid to the reliability and validity of the research tools used. Research may be carried out and the results analysed, however if it is not possible to prove steps have been taken to avoid coming to the wrong conclusions, the work cannot be considered credible.

3.2.4.1 Reliability

Reliability is described by Saunders et al. (2007) as referring to the extent to which the data collection techniques or analysis procedures used will produce consistent findings. Easterby-Smith et al. (2008) state that reliability can be assessed by posing three questions:

1. Will the measures yield the same results on other occasions?

2. Will similar observations be reached by other observers?
3. Is there any transparency in how sense was made from the raw data?

A reliable research tool would be expected to produce the same results when something is being measured on two consecutive days, providing the underlying traits being measured have not changed (Gray, 2009). Differences found in traits between individuals would be expected to be based on real differences in the individuals and not due to inconsistencies in the measuring instrument (Gray, 2009). Gray (2009) states that 'reliability is never perfect' and is therefore measured using a correlation coefficient. If the research tool being used is not reliable it cannot be valid.

There are a number of ways in which reliability can be measured, five of which have been described by Black (1993).

Stability

Stability is the measure of scores achieved on the same test on two separate occasions. Any difference found is known as the 'subject error' (Gray, 2009). An example is the attitudes of employees to their workplace may be different when taken on Monday and Friday, therefore the survey should be conducted mid-week to avoid this (Gray, 2009).

Equivalence

Equivalence is the comparison of responses of the same set of subjects using two different measurement techniques, preferably on the same day. This procedure is useful for evaluating the equivalence of a new test compared with an existing one (Black, 1993).

Internal Consistency

Internal consistency allows a reliability coefficient to be calculated as it measures the extent to which a test or questionnaire is homogeneous (Black, 1993). Sekaran (2007) states that the items in the measuring instrument should hang together as a set in order to produce higher reliability coefficient values.

Inter-judge reliability

Inter-judge reliability compares the consistency of observations when more than one person is judging the same event. The degree to which the scores of each judge correlate provides the reliability of the observation (Black, 1993). In order to reduce observer error the research requires a high degree of structure. This can be achieved by using structured questionnaires or a structured observation schedule (Black, 1993).

Intra-judge ability

When a large amount of data has been collected, over time the consistency of results can be checked by taking a sample set of observations or scores and repeating them (Gray, 2009). This may show up inconsistencies due to participant bias. Threats to reliability such as this are discussed below.

Threats to reliability

Robson (2002) suggests that there are four main threats to reliability, the first being ‘subject or participant error’. This is mainly down to timing of the study and can easily be controlled by choosing to conduct the study at a time when there would be no emotional bias i.e. the start of the week or just before the weekend (Robson, 2002). The second threat to validity is ‘subject or participant bias’. This is when participants answer questions in a way that they believe they should either to please the researcher or their manager, depending on the research (Robson, 2002). This could potentially be a problem and therefore should be considered carefully when designing the research (Saunders et al., 2007). Steps should be taken to ensure anonymity of respondents for questionnaires and interviews as far as possible in written reports (Saunders et al., 2007). Careful analysis is also necessary so that the true meaning of the results is understood. ‘Observer error’ is the third threat to reliability. This is when there are a number of researchers all working on the same project (Robson, 2002). It is possible that they all have different ways of asking questions and therefore elicit different answers from the participants. Reducing the risk of observer error can be attempted by having a high degree of rigidity to the interview schedule (Saunders et al., 2007). The final threat to reliability is ‘observer bias’. This occurs when there is more than one researcher analysing the results (Robson, 2002). Different people will interpret the same results completely differently therefore it is important to correlate findings and ensure that researchers agree on the results being produced before all of the analysis has been completed.

3.2.4.2 Validity

Gray (2009) states that to ensure validity "a research instrument must measure what it is intended to measure." It is possible to conduct reliable research without it being valid. If the methods being used are correct but the results being collected are not relevant to the study then the research has no validity and is therefore of no use. Gray (2009) defines validity as having seven subtypes which must be considered.

Internal Validity

Internal validity refers to correlation questions and to the extent to which causal conclusions can be drawn. In order to reduce the risk to the internal validity, steps should be taken to control possible confounding variables by ensuring that appropriate participants are chosen (Gray, 2009).

External Validity

External validity relates to the extent to which it is possible to generalise from the results collected to a larger population (Gray, 2009). Generalising from a study can be problematic due to cynics arguing that the results can only be correct for the setting in which they were collected (Gray, 2009). Robson (2002) states that there are two ways in which to argue the case for generalisation; making a case or direct demonstration. Making a case simply involves constructing a reasoned argument that the findings can be generalised (Robson, 2002). This is done by showing that the group, setting or period being studied, share certain essential characteristics with other groups, settings or periods (Robson, 2002). Direct demonstration involves conducting the same study but using different participants in different settings (Robson, 2002). If a series of demonstrations show that the findings can be replicated then the argument for generalising becomes stronger (Gray, 2009).

Criterion Validity

Criterion validity involves comparing how people have answered a new measure of a concept with widely accepted measures of a concept (Robson, 2002). If the answers are highly correlated on the new and existing measures it is usually assumed that the new measure possesses criterion validity (Gray, 2009). It would be wrong to assume that if there is a low correlation that the new measure is invalid. De Vaus (2002) suggests that low correlation may mean that the old measure was wrong. However many concepts do not have well established measures against which to test the new measure (Gray, 2009).

Construct Validity

Construct validity is concerned with the measurement of abstract concepts and traits, for example attitude and knowledge (Robson, 2002). Each of these traits must be operationally designed before it can be measured, this is done by taking the trait and elaborating on all of the characteristics that are present. This is a very useful exercise when designing a questionnaire (Gray, 2009).

Content Validity

Content validity is related to validation of the content of examinations or tests (Robson, 2002). It is important to create a match between what is taught and what is examined therefore content validity may involve comparing the cognitive level of an achievement test with the original specifications in the syllabus (Gray, 2009).

Predictive Validity

Predictive validity demonstrates how well a test can predict a future trait such as job attainment (Robson, 2002). If a test has construct and content validity but fails to identify those who are ‘high performers’ it is of no use (Gray, 2009).

Statistical Validity

Statistical validity refers to the extent to which a study has made use of the appropriate design and statistical methods to allow for detection of effects that may be present.

Threats to validity

Saunders et al. (2007) describe six threats to the validity of research, the first of which being ‘history’. This is concerned with the timing and past events associated with participants. If a significant event has just occurred before the research is conducted it can have a dramatic and often misleading effect on the results collected, unless the research is to ascertain information about the significant event. The research can be carefully planned and completely valid, however if conducted at the wrong time can invalidate results and render the research ineffectual. The second threat to validity is ‘testing’ which relates to the participants feeling that they may be disadvantaged in some way by the results as the research is setting out to test them(Saunders et al., 2007)(Saunders et al., 2007)(Saunders et al., 2007)(Saunders et al., 2007). ‘Instrumentation’ is the third threat to validity. This involves changes being made within an organisation for example in between testing of groups. This will mean the results for the first group and second group may be completely different and not able to be compared. The fourth threat to validity is ‘mortality’ which refers to participants choosing to drop out of the study. If case studies are being produced on a finite number of people, one or two people dropping out can cause large problems and threaten the validity of the study. ‘Maturation’ is the fifth threat to validity which involves problems arising for longitudinal studies as changes may have been made within organisations or events happen that affect the participants and change the variable being studied quite significantly. The final threat to validity is ‘ambiguity about causal direction’. Saunders et al. (2007) describe this as being a particularly difficult issue. It may not be possible to ascertain whether a negative result from a study may be causing negative attitudes amongst participants or the negative attitude is causing the negative results.

3.3 The importance of Research Design

Robson (2002) describes research design as turning the research question into a research project. Figure 3.3 depicts the research onion of which the three inner most layers are associated with the process of research design. The research design is described by Saunders et al. (2007) as being a general plan of how the research questions will be answered and therefore contain clear objectives, derived from the research questions, specify the sources from which data will be collected and consider constraints such as time and budget (Saunders et al., 2007). A large part of the research design will be choosing a research strategy which will be dictated by the nature of the research questions and whether an inductive or deductive approach is necessary.

Robson (2002) outlines a number of steps to be taken when choosing a research strategy.

- A choice must be made between a fixed (quantitative) or flexible (qualitative) design strategy with the ability to pre specify the data collection being the basis for the decision.
- Is the study an evaluation? A fixed design is usually indicated if the focus is on outcomes and a flexible design if the focus is on processes.
- If action research is to be conducted a flexible design is usually indicated.
- When a fixed strategy is employed the choice must be made between experimental and non-experimental strategies. An experimental strategy involves the researcher purposefully introducing some form of change into the situation being studied in order to induce a change in the behaviour of participants. A non-experimental strategy has the same overall approach as an experimental strategy however the researcher does not attempt to change the experience of the participants.
- When a flexible strategy is employed the three common studies relevant to real world research are case studies, ethnographic studies and grounded theory studies. These are not however the only studies that could be used and should not be thought of as such.

3.4 Ethics in Research

The ethics of research is described by Gray (2009) as concerning the ‘appropriateness of the researcher’s behaviour in relation to the subjects of the research or those who are affected by it.’ Research conducted in the real world will be open to ethical issues from the outset due to the personal nature of such research. Ethical concerns can prove to be far more complex than simply using common sense. Korac-Kakabadse et al. (2002) suggest that ethical actions lie in a 'grey zone' where right and wrong may not be clear cut therefore making acting ethically very challenging. Research must be conducted in a responsible and morally defensible manner, therefore the moral principles guiding the research must be set out during the planning stages. Blumberg et al. (2005) describe ethics as being sets of moral principles used to guide moral choices of behaviour and relationships with others. These principles are however not easily constructed and simply applied due to many different considerations. Research ethics therefore relates to how the research topic is formulated and clarified, designed and access to participants is gained, data is collected, processed and stored and data is analysed and written up in a moral and responsible way.

The Economic and Social Research Council (ESRC) (2004) in the UK has set out a list of issues that involve a normally larger element of ethical risk:

- Research involving vulnerable groups i.e. children and young people, those with learning disabilities or individuals in an unequal or dependent relationship.
- Research involving sensitive topics i.e. sexual or illegal activities or people's experience of abuse or violence.
- Research where subjects can only be accessed via a gatekeeper i.e. some ethnic or cultural groups.
- Research involving an element of deception such as covert observation used without the participant's full or informed consent.
- Research involving access to confidential records or information.
- Research that would lead to stress, anxiety or humiliation amongst target groups.
- Research involving intrusive strategies that people would not normally meet in their everyday lives i.e. administration of drugs or extreme exercise.

Gray (2009) states that ethical principles fall into four main areas:

- Avoid harming participants.

- Ensure informed consent of participants.
- Respect the privacy of participants.
- Avoid the use of deception.

The avoidance of harm is seen as the cornerstone of ethical issues involved in research. The way in which consent is obtained, confidentiality is preserved, data are collected and results are analysed and presented can all cause harm to participants (Saunders et al., 2007). The concept of harm encompasses not only physical harm, but emotional and mental harm (Gray, 2009). Sudman (1998) describes harmful research as being that which causes a participant to be belittled, embarrassed, ridiculed or generally subject to mental distress. Gray (2009) adds that research is considered harmful if it causes negative emotional reactions or produces anxiety or stress to participants. Data collection techniques such as questionnaires and interviews have the potential to be intrusive and provoke anxiety and stress (Saunders et al., 2007). Informed consent involves explaining to potential participants every particular of the research and ensuring that they have understood what is to be asked of them and that they are comfortable with the situation. It must be made explicit that participation is of a voluntary nature and they have the right to withdraw partially or completely at any stage of the process. Participant's privacy is extremely important and should be considered at every stage of the research. The data being collected must be stored correctly to avoid others gaining access unlawfully. The Data Protection Act 1998 imposes restrictions when personal data (including both facts and opinions) of a living individual who can be identified either from the data or from other information is being held. These restrictions are placed on how the data is obtained, recorded, stored and the analysis conducted on it (Gray, 2009). Deception involves researchers misrepresenting their research to participants. This can be as simple as not telling participants that a focus group they have agreed to could take over an hour to complete. Many researchers are guilty of deception, in that they are not completely open with participants about the work being conducted in order to elicit the most natural response. Deception must be avoided to ensure a negative reputation is not built, which could lead to a reduction in participation.

Ethical issues must be carefully considered during each stage of the research process, as depicted in Figure 3.4 (Saunders et al., 2007). Ethical issues surrounding data collection techniques and studies being conducted are therefore discussed in more detail in the following chapters.

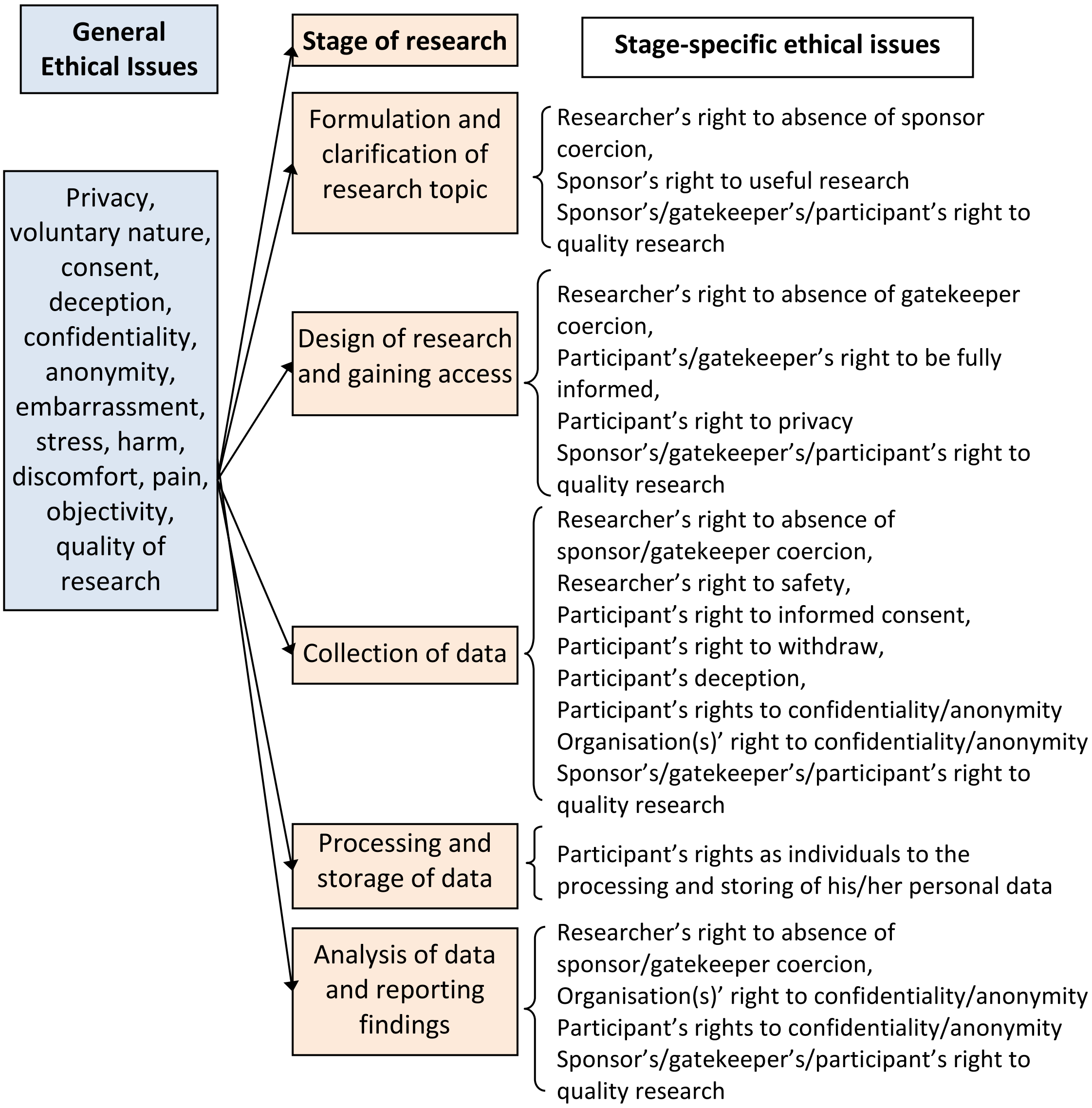


Figure 3.4: Ethical issues associated with each stage of a research project (Saunders, Lewis & Thornhill 2007)

3.5 Conclusion

There are a number of important factors to consider when designing research, some of which may not be within the control of the researcher. When looking at the research questions for this work it is clear that an inductive approach will be used with much of the work being conducted using a survey strategy. There are certain ethical considerations inherent with this work which will be dealt with in future chapters. Figure 3.5 illustrates the decision process with regard to the research design.

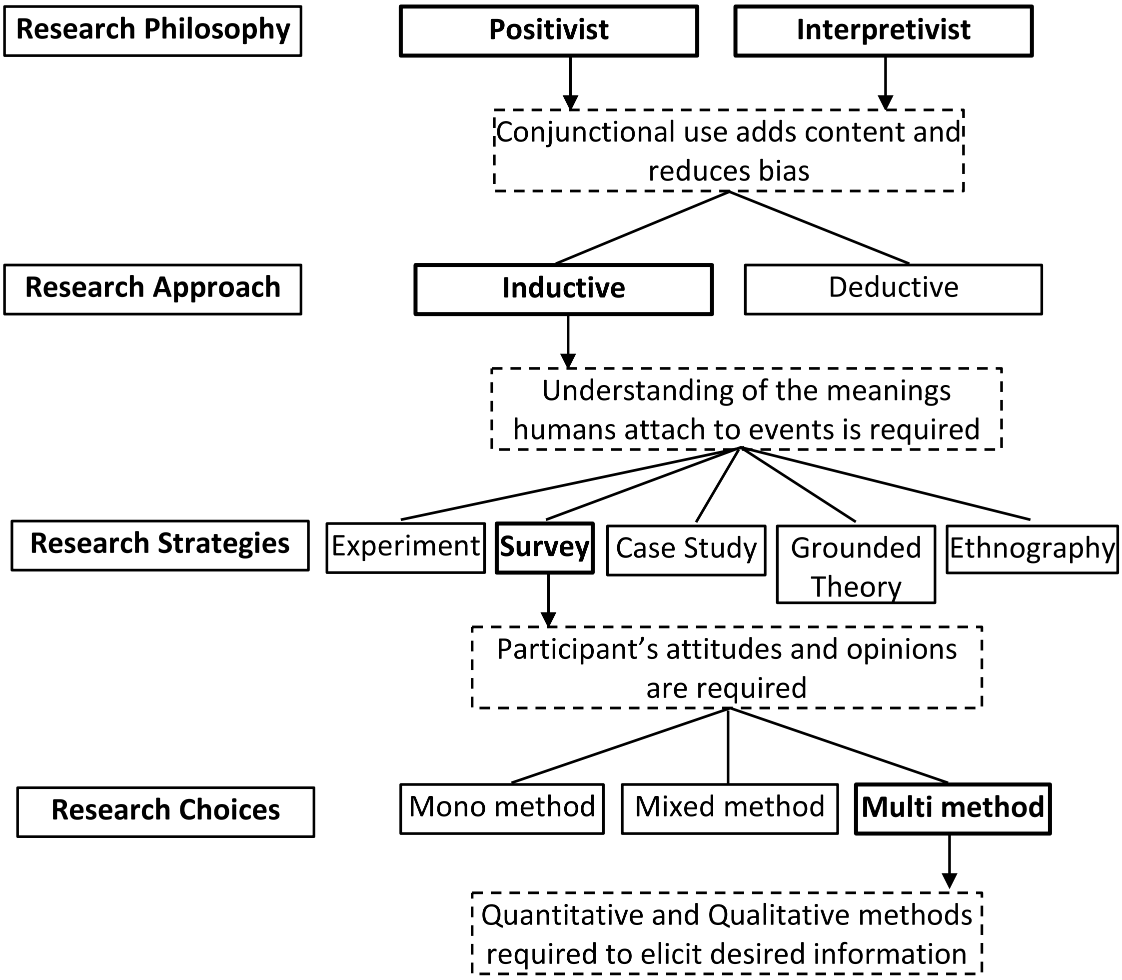


Figure 3.5: Decision process for the research design

Chapter 4: Study 1 – A Countrywide study of NHS Disablement Services Centres

4.1 Summary

The overall purpose of this study was to investigate the current NHS prosthetic service provision in order to ascertain the problems, if any, encountered by service providers. The scope of this study was to explore the service currently being provided by different NHS Disablement Services Centres in order to develop an understanding of how the service is functioning and the problems that may hinder the effective treatment of patients. Interviews with staff at NHS DSCs across the country were conducted to explore the current service provision and any perceived problems with the service. Interview data were used to gain an insight into whether the service provided to amputees across the country is uniform and identify the problems staff at the centres face when trying to deliver a high level of service. These data would also be used to direct further studies involving patients of the service, intending to ascertain the opinions of amputees on the service they are provided.

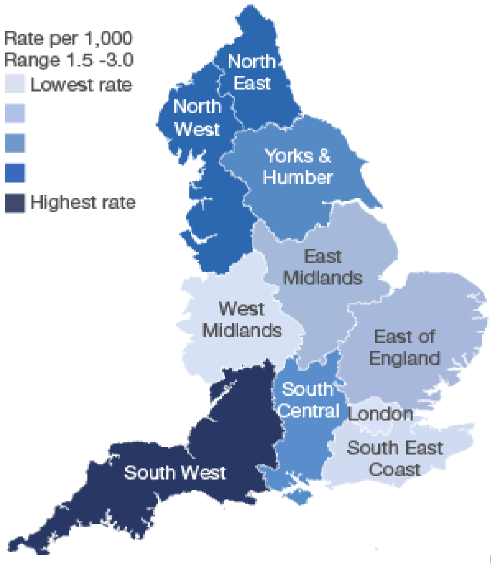


Figure 4.1: Illustration of the rate of major amputations on patients with Type 2 diabetes, 2004-2009 (Jeffreys, 2010)

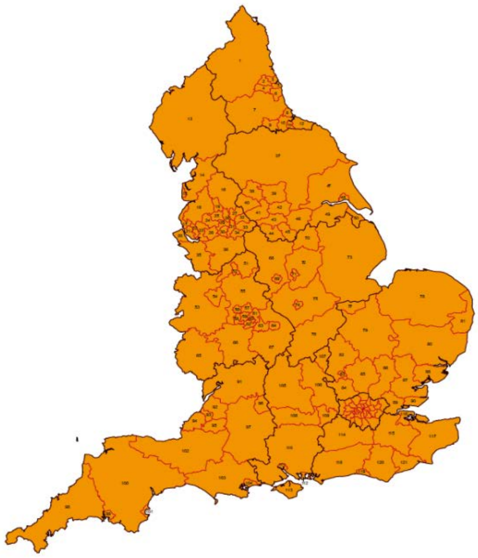


Figure 4.2: Illustration of the PCT boundaries as of October 2006

4.2 Aims and Objectives

The aim of this study was to investigate the current NHS service provision of prosthetic limbs through a series of study specific objectives.

Research question 1: How do Disablement Services Centres currently function and what are the constraints (if any) on service provision?

Objectives - To ascertain through appropriate data collection methods:

4.1: The members of the prosthetic team and their role in patient rehabilitation

4.2: The process an amputee goes through during their first year following amputation

4.3: The perceived problems facing members of the prosthetic team when trying to deliver a quality service

Research question 2: Is service provision uniform in centres across the country?

Objectives - To ascertain through appropriate data collection methods:

4.4: Whether there are significant differences in service provision between DSCs across England

4.5: The particular services (e.g. physiotherapy and counselling) which differ the most between centres

Research question 3: If differences in service provision are present, why are they occurring?

Objectives - To ascertain through appropriate data collection methods:

4.6: The reasons for the differences in service provision, as perceived by the staff at the DSCs

4.3 Rationale

The main purpose of this study was to ascertain the current NHS prosthetic service provision and the discrepancies in service provision between DSCs. In order to gain a full overview of the service, the service providers themselves were the focus of the study. An overview of the service provided by the NHS could be found on the internet (NHS Choices, 2012)(NHS Choices, 2012)(NHS Choices, 2012)(NHS Choices, 2012)(NHS Choices, 2012), however in order to ascertain the exact process patients were taken through at each centre, further information from these centres was necessary. Due to the detailed nature of the information required from individual DSCs, the staff at these centres were considered to be the most knowledgeable and therefore the most reliable sources of information. The prosthetists being interviewed were employed by the company holding the contract with the centre, not by the NHS therefore could be approached independently of the NHS.

4.4 Methods

4.4.1 What is qualitative research?

Green and Thorogood (2009) state that the most basic way of characterising qualitative research is to describe the aims as seeking answers to questions about ‘what’, ‘how’ or ‘why’ of a phenomenon, rather than simply questions about ‘how many’ or ‘how much’. Flick (2007) describes qualitative research as intended to approach the world ‘out there’ and to understand, describe and sometimes explain social phenomena ‘from the inside’. Green and Thorogood (2009) believe it to be impossible and also unhelpful to characterise qualitative research in a way that is completely separate from quantitative research due to the cross over in methods of data collection and data produced. Pitney and Parker (2009) however differentiate qualitative from quantitative data leaving only three similarities, that they are both systematic, guided by principles and answer specific questions. Producing a common definition of qualitative research is therefore extremely difficult due to the multiplicity of approaches and differences in opinion between researchers. Qualitative methods have increased in popularity and acceptance in the last decade, especially in the medical professions, despite debates about validity, legitimacy and rigor (Pitney and Parker, 2009).

Flick (2007) describes three different approaches which can be used to produce meaningful accounts that offer rich insight into the ways in which people construct the world around them, what they are doing or what is happening to them:

- Analysis of experiences of individuals or groups.
- Analysis of interactions and communications in the making.
- Analysis of documents such as text, images, film or music or similar traces of experiences and interactions.

In order to answer the ‘what’, ‘why’ and ‘how’ of the objectives of this study, qualitative techniques were employed (Green and Thorogood, 2009). The nature of this study meant that a considerable number of questions encompassing various different topics would need to be covered; therefore the appropriate qualitative data collection technique was essential.

4.4.2 Interviews

Kvale and Brinkmann (2009) describe the qualitative research interview as a means of understanding the world from the subject’s point of view and unfolding the meaning of their experiences through conversation that has structure and purpose. Research interviews are professional conversations where knowledge is constructed and interpretations are derived in the interaction between the interviewer and interviewee rather than facts or laws (Kvale and Brinkmann, 2009; Warren, 2002). These conversations are not however between equal partners due to the researcher defining and controlling the situation as well as critically following up on the participants answers (Kvale and Brinkmann, 2009). Figure 4.3 illustrates the different forms of interview available to researchers.

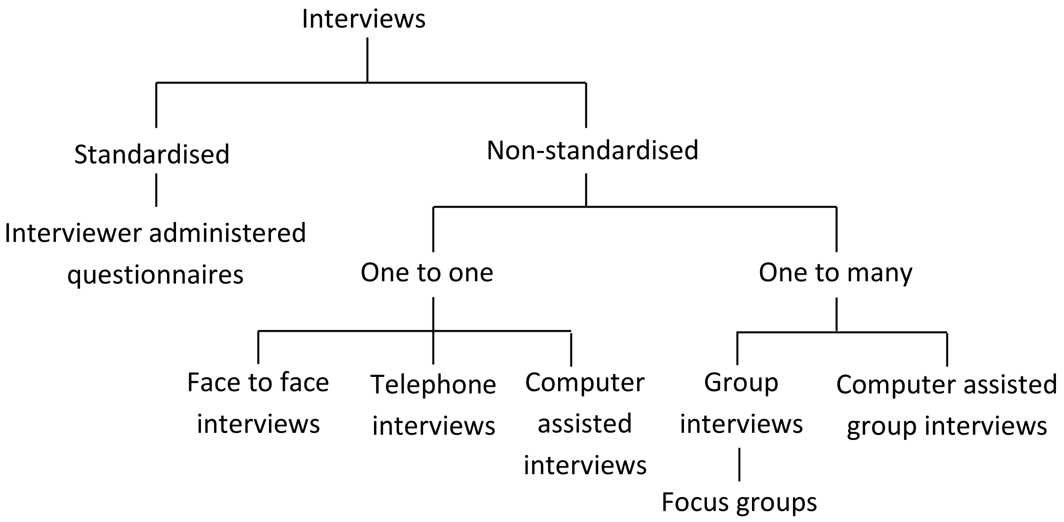


Figure 4.3: Forms of interview (Saunders et al., 2007)

4.4.3.1 In-depth interviews / Unstructured interviews

Qualitative interviews can often be described as unstructured in order to differentiate them from the formalised quantitative (structured) interview. Britten (1995) describes the term ‘unstructured’ as being misleading due to no interview being completely without structure as there would be no guarantee that the data gathered would be appropriate to the research being conducted. DiCicco-Bloom and Crabtree (2006) agree that no interview can be truly unstructured however they state that some interviews can be “relatively unstructured and are more or less equivalent to guided conversations”. Unstructured interviews are also known as in-depth interviews and have been described by Britten (1995) as being less structured than semi structured interviews and that they “may only cover one or two issues but in much greater detail”.

Britten (1995) and DiCicco-Bloom and Crabtree (2006) differ in their description of an in-depth interview. Britten states that the initial question asked is focused on the specific research question with further questions being based on the interviewee’s responses in order to gain clarification and probe for details. In contrast DiCicco-Bloom and Crabtree (2006) state that the basic research question may be used as the first interview question however between five and ten more specific questions are developed. This is said to enable the interviewer to “delve more deeply into different aspects of the research issue”. These differences in opinion do not have a great impact upon the possible use of this method as both structures may be valid in specific situations. Britten's (1995) structure may be more suited to a very experienced researcher who has the knowledge and tools to think of appropriate questions very quickly. The structure described by DiCicco-Bloom and Crabtree (2006) may be more suited to less experienced researchers and also projects relating to health care due to the interviewer wishing to reconstruct perceptions of events and experience related to health and healthcare delivery. Healthcare research requires the basic research question to be sufficiently focused in order to ensure that a relatively homogeneous group of individuals will have shared experiences. Following this, an interview structure which allows for interviewee expression but also steers the conversation to elicit the desired information is desirable for healthcare research.

Ghauri and Gronhaug (2002) state that the advantage of in-depth interviews is the ability to "gain a more accurate and clear picture of the respondent's position or behaviour". This is achieved due to the open ended structure of the interview and the ability of the interviewee to answer with their own ideas rather than being constrained by alternatives put forward by the interviewer. Sensitive or complicated issues can be dealt with in this manner due to the interviewer having the opportunity to ask for further elaboration on comments made. There are however disadvantages to in-depth interviews. They can be very long and sometimes require multiple sessions with the same respondent. Also the data can be very difficult to analyse and the personal background of the analyst may greatly influence the interpretation which causes problems of objectivity. The interviews also demand a skilled interviewer who is able to ask appropriate questions when probing for further information (Ghauri and Gronhaug, 2002).

The advantages of these interviews greatly outweigh the disadvantages as the information which can be drawn from the data gathered can be of great use and importance in understanding the area being studied.

4.4.3.2 Semi structured interviews

Semi structured interviews differ from unstructured interviews in that they are generally not used in conjunction with observational data and are often the sole data source for a research project. These interviews are usually conducted at a predetermined time in a designated place, outside of everyday life. The structure is also very different, in that the interview is conducted using a basic set of open ended questions which directs the conversation to the research topic. This allows for the interviewee to go into more detail about certain topics of interest and for the interviewer to ask further questions in order to elicit information relating to interesting statements the interviewee may make (Britten, 1995). Semi structured in-depth interviews are said to be the most widely used interviewing format for qualitative research projects and can last between 30 minutes and several hours (DiCicco-Bloom and Crabtree, 2006).

4.4.3.3 Telephone Interviews

Using telephone interviews as a substitute for face to face interviews must be considered carefully when designing a qualitative study. Discussed below are the criteria for making such a decision as well as the advantages and disadvantages of telephone interviewing.

Shuy (2002) produced a list of criteria that researchers and others had set out for deciding between telephone and face to face interviews:

- The type of interview to be carried out e.g. research, medical, journalistic
- The type of information sought e.g. personal, sensitive
- The attitudinal variability, safety and workload of the interviewers
- The need for consistency and/or uniformity among multiple interviewers
- The social variability of individual participants e.g. gender, race, age
- The need for contextual naturalness of response and setting
- The need to let participants generate responses with little or no influence from the questions
- The complexity of the issues and questions
- The economic, time and location constraints of the project

There are a number of potential advantages of using telephone interviews during qualitative data collection, relating to access, speed and lower cost. It is not always practical to include participants who are based large distances away due to time and cost constraints, however telephone interviews allow contact with these participants to be made (Saunders et al., 2007). In most cases, interviewing by telephone is less expensive than face to face interviewing and research has shown that situational variables are easier to control in telephone interviews (Shuy, 2002). Another advantage is that despite the time expended during face to face interviews being roughly equal to that expended during telephone interviews, additional time is required for making arrangements and travel to interview sites for in person interviews. This means that the completion time of the interviewing phase will be shorter for a study using telephone interviews.

There are however a number of issues related to this method, which need to be considered before its use. Saunders et al. (2007) stress the importance of establishing personal contact when conducting in-depth interviews as a position of trust should be established in order that participants feel comfortable talking openly, especially when asked sensitive questions. For these reasons telephone interviews may lead to issues of reduced reliability due to participants being less willing to engage in an exploratory discussion, or refusal to take part. Research has shown that face to face interviews have better response rates than telephone interviews (Shuy, 2002). There are also practical issues to be considered such as recording the data and the ability to control the pace of the interview. Saunders et al. (2007) state that taking notes while conducting a telephone interview is extremely difficult and therefore recommend that audio recording be used. Telephone interviews also remove the opportunity to witness non-verbal behaviour of the participants, which Saunders, et al. (2007) believe “may adversely affect your interpretation of how far to pursue a particular line of questioning.” Participants may also be less willing to spend as much time on the telephone as they would during a face to face interview, therefore restricting the amount of data collected. More complex questions can also be more difficult to develop over the phone in comparison with face to face interviews. Also face to face interviews have been found to be clearly superior to telephone interviews when interviewing older, hearing impaired and minority participants (Shuy, 2002).

Saunders et al. (2007) state that interviewing by telephone is “likely to be appropriate only in particular circumstances”. Telephone interviews may be appropriate for a follow up interview to clarify the meaning of data already collected in a face to face interview as a level of trust has already been established. Also if telephone interviews are necessary due to distance restrictions then prior contact must be made in order to establish personal credibility and also explain that the requirements of the interview are reasonable and guided by ethical principles.

4.4.3.4 Computer Assisted Interviews

Computer assisted interviews have become increasingly widespread during recent years (Kvale and Brinkmann, 2009). Morgan and Symon (2004) use ‘electronic interviews’ as a definition for interviews held both in real time using the internet and those that are conducted through email correspondence. There are significant differences in electronic interviews dependent upon whether the interview is conducted in real time i.e. synchronous or offline i.e. asynchronous (Saunders et al., 2007).

Advantages of electronic interviews

There are significant advantages to using electronic interviews over face to face interviews, which will be discussed below.

- **Wide geographical access –** electronic interviews are a practical solution for conducting interviews with individuals or groups that are geographically dispersed (Saunders et al., 2007). Interviews are not restricted to one country and can even be conducted between continents.
- **Cost and Time savings -** Costs are significantly reduced using computer assisted interviews as savings can be made in a number of areas. Compromises regarding participants are usually made when conducting face to face interviews due to participants being dispersed geographically. In order to maximise participation rates, travel costs and time input for participants need to be minimised which can ultimately increase time and travel costs for the researcher, creating further

problems (Mann and Stewart, 2000). Electronic interviews eliminate the cost and time barriers presented by travel therefore allowing participants from all over the country (or the world) to be included in the research. Electronic interviews are also self-transcribing which negates the need for recording equipment and transcription of interviews, therefore saving the researcher time and money (Kvale and Brinkmann, 2009).

- **Eliminating transcription bias –** Mann and Stewart (2000) state that many qualitative researchers agree that if the whole text of an interview is available that the analysis will be more effective and reliable. Seidman (1991) states that the participants' words are the embodiment of their thoughts and therefore "to substitute the researcher's paraphrasing or summaries of what the participants say for their actual words is to substitute the researcher's consciousness for that of the participant". Accurate transcription of interviews can be a very time consuming and exhausting process for researchers and can also be problematic due to accents or lack of clarity leading to transcription mistakes (Mann and Stewart, 2000). Researchers can preselect sections of an interview to transcribe in an attempt to save time however Seidman (1991) warns against this time saving technique as researchers could impose a frame of reference too early. There is also the tendency for researchers to be reluctant to revisit the sections of the tape they did not transcribe at a later date.
- **Ease of data handling –** Software has been produced which can help analyse qualitative data such as NVivo 9 (QSR International Pty Ltd, 2010). Due to the textual data from the electronic interviews already being computerised, it's movement to analysis software or other computer functions can be done effortlessly. Mann and Stewart (2000) state that electronic interviews "more than any other type of communication, can capitalise on the speed and flexibility computers can offer".
- **Participant friendly –** electronic interviews are held in an environment chosen by the participant which helps them to feel more comfortable as it is not intrusive. Participants are able to think about and take time over their responses before they respond which is not always possible in a face to face or telephone interview situation (Mann and Stewart, 2000). This offers them a safe

environment to communicate their experiences freely without the pressure of a recording device or time constraint of a phone call. Saunders et al. (2007) state that some researchers believe it possible to build up considerable rapport with participants during an online interview. It has also been suggested that because the participant can choose to remain anonymous during these interviews they feel more inclined to be open and honest in their responses especially regarding sensitive issues.

Challenges of electronic interviews

Electronic interviews are not completely straightforward and have a number of drawbacks and challenges to be overcome which will be discussed below.

- It is not always possible to be sure the person answering the questions is the person required for the research. Hacking of personal accounts can occur, which means the person being contacted may not be the intended participant. It is also possible for anyone to create an email address and claim to be someone they are not, therefore unless the email addresses are gained from a reliable source there can be issues with reliability.
- Email correspondence can take weeks to conduct due to participants having no real need to reply instantly. Emails can be forgotten about and participants may simply lose interest.
- Typing skills of participants can be an issue as their ability to respond to questions in real time can be impaired. If a participant takes fifteen minutes to respond to one question they are unlikely to want to complete an interview containing ten questions.
- People with no access to the internet are completely excluded from research using this method of data collection which may skew results. If the research being conducted is with the elderly, computer assisted interviews are not recommended.
- The information provided by participants cannot always be trusted as participants are easily able to provide false answers to questions (Gray, 2009).

4.4.3.5 Group Interviews

Group interviews involve a group of participants being asked questions and then given the opportunity to discuss their answers. The structure of these interviews can range from highly structured to unstructured, however they tend to be relatively unstructured and free flowing (Zikmund, 2000). Group interactions can lead to highly productive discussions, however it is not possible to build up a personal rapport with each participant therefore certain participants may attempt to dominate the interview leaving others feeling inhibited (Saunders et al., 2007). This can result in some participants agreeing with views expressed by more dominant members of the group when in reality they disagree. Stokes and Bergin (2006) describe the consequence of this being that any reported consensus may in fact be a view nobody wholly supports and no one disagrees with. Dillman (2007) also reports that test taking behaviour can be invoked through group interviews using a questionnaire. Respondents were observed to be checking through questions on completion and even changing answers (Dillman, 2007). There are however a number of advantages to using group interviews. Due to the number of participants present a breadth of points of view can emerge allowing for discussion and evaluation of these views. Explanation and exploration of concepts is possible with a dynamic group due to their ability to respond to, generate and evaluate ideas. The number of participants able to be interviewed can increase considerably from one to one interviews which allows for the possibility of the sample being more representative (Saunders et al., 2007). Costs can also be reduced, allowing for more focus groups to be conducted which in turn increases the number of participants and the possibility of generalising (Gray, 2009).

Group interviews can be conducted in a variety of different ways, including multiple interviewers, joint interviews and focus groups. When multiple interviewers are present it is possible for them to assume different roles such as note taker and chairperson. This allows each interviewer to gain their own observations and thoughts which can be compared and discussed to ensure no data has been overlooked. Joint interviews involve two participants being interviewed by one interviewer simultaneously about the same topic. The advantage of this scenario is that participants can discuss their views or thoughts of an event and data omitted by one participant can be provided by the other. This can however cause one participant to dominate the interview and participants are easily able to divert each other's attention (Gray, 2009). Focus groups have increased in popularity over the last two decades (Flick, 2007). They are a low cost data collection method with a high level of enthusiasm and cooperation required of participants (Gray, 2009). Carson et al. (2001) describe focus groups as being a group interview that clearly focuses upon a particular issue, product, service or topic and encompasses the need for interactive discussion amongst participants. Interactions are therefore encouraged but also more carefully controlled by the interviewer to keep focus on the topic being discussed (Saunders et al., 2007). Groups should be comprised according to the research question and intended comparisons. The number of groups to be held will also depend on how the groups are to be compared. The research interest and purpose of the study should dictate the setting up of homogeneity and heterogeneity within groups. Focus groups can be compared in two ways: between groups and within groups. In order to facilitate good comparison using either method, well planned selection and composition of the groups and their members is essential (Flick, 2007).

4.4.4 Appropriate interview structure for Study 1

Each of the interview techniques were evaluated in order for the appropriate method to collect meaningful data be employed:

- Email interviews are usually conducted with a small or moderate length questionnaire and should have few places in which the questions move in a new direction. This technique was considered inappropriate for the collection of the data required due to the limiting nature of email interviews and the inability to probe for more in-depth answers. Some participants may find it hard to articulate their answers, which could lead to incomplete or unclear data. There is also the problem of not being certain of the identity of the respondent, as the email recipient may forward the email on to a colleague who has more time than themselves and this information may not be disclosed when the questionnaire is returned (Kuper and Kuper, 2005). In order to gain valid and reliable data it was imperative that prosthetists were interviewed therefore the uncertainty inherent with email interviews rendered them impractical.

- Telephone interviews resolve some of these problems, in that the interviewer has a degree of control over who is interviewed and can ask further questions if required. More complex and detailed questions can be asked, however Saunders et al. (Saunders et al., 2007) recommend that interviews should be kept to a maximum of half an hour to avoid respondent fatigue. The data required from these interviews was such that half an hour would have been extremely limiting. A number of telephone interviews of half an hour could have been required in order to gain all of the data required. Telephone interviews are also easily forgotten and therefore due to a prosthetist's busy work schedule, the telephone call could be missed or not taken due to other commitments.
- Personal interviews allow for lengthy and in-depth interviews and give the interviewer the opportunity to have control over the interview and assess whether the questions being asked are being understood (Kuper and Kuper, 2005). The interview situation also ensures a response, which the other methods do not. A time is booked and the interview organised therefore the prosthetists would be less likely to organise clinical activities at the designated time. Due to the nature of this study, it was not possible to determine exactly how long the interview would take as each centre could be different. The opportunity to speak to different members of staff would not be available with email and telephone interviews. Visiting the DSC could also provide a good insight into the facilities provided for patients and the opportunity to look around the workshop and other areas. Personal interviews were therefore deemed to be the most appropriate data collection technique.

4.4.5 Analysing qualitative data

The analysis of qualitative data can take a number of forms, depending on the nature of the research and the type of data gathered. A number of these analysis methods are discussed below. According to Braun and Clarke (2006) qualitative analytic methods can be roughly divided into two groups. The first group contains methods tied to or stemming from a particular theoretical or epistemological position. The second contains methods that are essentially independent of theory and epistemology and can be applied across a range of theoretical and epistemological approaches. Each of the methods discussed can be said to be in the first of these groups apart from thematic analysis, which as Braun and Clarke (2006) state is firmly in the second group.

4.4.5.1 Conversation Analysis

Conversation analysis is the systematic analysis of talk-in-interactions, which is the conversation produced in everyday situations of human interaction. These interactions are 'naturally occurring' and are situated as far as possible away from being prearranged or set up in laboratories (Auerbach and Silverstein, 2003). Hutchby and Wooffitt (1998) state that this system is used to discover how participants understand and respond to one another in their turns at talk, with a central focus being on how sequences of actions are generated. This type of analysis has been described by Braun and Clarke (2006) as having relatively limited variability in how the method is applied within the framework.

4.4.5.2 Discourse Analysis

Discourse analysis can be used in order to gain information about the discursive construction of social reality. Willig (2003) states that this type of analysis should be used to analyse naturally occurring text and talk, such as naturally occurring conversations in a formal or informal 'real world' setting. The focus of this type of analysis is on how participants use discursive resources and with what effects. There are two versions of discourse analysis 'discursive psychology' and 'Foucauldian discourse analysis'. These two versions address different sorts of research questions and identify with different theoretical traditions. Willig (2003) describes the questions asked by each version in a project:-

Discursive psychology – "How do participants use language in order to manage stake in social interactions?"

Foucauldian discourse analysis – "What characterises the discursive worlds people inhabit and what are their implications for a possible way of being." (Willig, 2003)(Willig, 2003)(Willig, 2003)(Willig, 2003)

Discourse analysis directly shapes the research question due to the epistemological assumptions, intrinsic to this method, dictating what can and cannot be asked.

4.4.5.3 Narrative Analysis

Narrative analysis is concerned with interpreting narrative accounts using particular narrative elements. The interview structure to gain narrative accounts is designed to provide an opportunity for the participant to give a detailed narrative account of an experience of interest. Each narrative is examined for the structure and tone, what issues are the main themes, underlying beliefs and values and what images and metaphors are used. Murray (2003) states that when conducting a narrative analysis it is important to be aware of what theoretical assumptions are guiding the analysis while at the same time being open to new ideas and challenges.

4.4.5.4 Grounded Theory

Grounded theory as described by Willig (Willig, 2008) involves the progressive identification and integration of categories of meaning from data. Grounded theory is both the process of category identification and integration and its product. It was designed to identify and explain contextualised social processes and to allow categories to emerge from the data during analysis. This method is used to investigate how people negotiate and manage social situations and how their actions contribute to the unfolding of social processes. Willig (2008) states that research questions for Grounded Theory research can be about processes, experiences, structures or even cognitions.

4.4.5.5 Thematic Analysis

Thematic analysis identifies, analyses and reports patterns within data and as stated by Braun and Clarke (2006), should be seen as a foundational method for qualitative analysis. Due to the theoretical freedom of the method, it provides a flexible and useful research tool. The analysis can potentially provide a rich and detailed as well as complex account of the data. Braun and Clarke (2006) state that it provides an accessible and theoretically flexible approach to analysing qualitative data.

4.4.6 Appropriate qualitative data analysis technique for Study 1

Using the information collated on qualitative analysis techniques, thematic analysis was found to be the most flexible method. This is due to thematic analysis being independent of theory unlike most other methods (Scherer, 2002). Conversation analysis would not be appropriate due to this method being mainly used for naturally occurring conversation and to investigate how sequences of actions are generated. Similarly, discourse analysis would not be suitable due to naturally occurring conversation being necessary and the fact that this method is focused on how participants use discursive resources and with what effects. Narrative Analysis would also be inappropriate as the interviews were conducted to gain information about DSCs not about personal experience working at the centres. This type of analysis may be of use when analysing the results from the second, patient based study. Due to Grounded Theory being used mainly to analyse how people negotiate and manage social situations and how their actions contribute to the unfolding of social processes, it is not applicable to the data to be collected. Thematic analysis was the only technique found that provided the flexibility needed for analysis of the data collected.

4.5 Design

4.5.1 Designing an Interview

The main asset of research interviewing is the open structure, however this can also be one of the biggest problems. There are no standard procedures or rules for research interviews however there are standard choices to be made. These choices include approach and technique utilised at different stages of the interview investigation (Kvale and Brinkmann, 2009).

4.5.1.1 The Seven Stages of Interviewing

Kvale and Brinkmann (2009) describe an interview enquiry as having seven distinct stages which may be followed in order to retain the initial vision and engagement throughout the research. These stages are described below.

1. Thematising – This stage involves the formulation of the purpose of the research and the conception of the theme to be investigated. The questions *why* and *what* must first be answered before the question *how* can be asked.
2. Designing – This stage involves planning the design of the study with intended knowledge to be gained and ethical issues in mind.
3. Interviewing – This stage involves conducting the interviews using a reflective approach to the knowledge sought ensuring personal influence is kept to a minimum.
4. Transcribing – This stage involves transcribing the recording of the interview into written text in order to prepare it for analysis.
5. Analysing – This stage involves deciding upon the correct analysis techniques for the information gained and using these techniques to produce conclusions from the data.
6. Verifying – This stage involves ascertaining the validity, reliability and the ability to generalise the results.
7. Reporting – This stage involves communicating the findings of the research in such a way that lives up to scientific criteria.

Rubin and Rubin (2005) have a different approach known as ‘responsive interviewing’ which they describe as “an approach that allows a variety of styles yet incorporates what is standard in the field”. This is a much more flexible approach than that laid out by Kvale and Brinkmann (2009). Responsive interviewing is a dynamic and iterative process whereby researchers modify and adapt the questions and approaches used in response to new circumstances which arise during the interview process.

The following sections will concentrate on the second of the seven stages: Designing. Designing the interview is the key to obtaining convincing results and should be carefully thought out (Rubin and Rubin, 2005). Rubin and Rubin (2005) describe the design stage as involving choosing the topic to be covered, the interviewees and deciding the questions with which to begin the interview and how to ask them. The topic to be covered in this thesis has already been chosen;

therefore these sections will concentrate on choosing participants and deciding upon the questions to be used.

4.5.1.2 Main Questions, follow up questions and probes

Rubin and Rubin (2005) describe three different types of questions to be used in qualitative interviews: main questions, follow up questions and probes.

Main Questions: these are the “scaffolding” of the interview and ensure that the research problem will be examined in great detail and each area of the broad topic explored (Rubin and Rubin, 2005). The initial research question in most projects is simply too broad for participants to answer, therefore the role of the main question is to translate the research topic into a form that is relatable. This is extremely important as it means that participants are able to discuss the topic freely without misunderstanding becoming a barrier. These questions are used to encourage the participant to talk about their experiences and feelings freely (Rubin and Rubin, 2005).

Main questions are usually prepared before the interview and must be carefully thought through in order to cover all of the research topics but also avoid restricting or predetermining the participant’s responses (Rubin and Rubin, 2005). A limited number of main questions should be drafted in order to keep the interview moving but also elicit detailed responses from participants (Rubin and Rubin, 2005).

Follow up Questions: Follow up questions are specific to the comments made by the participant and are vital to obtaining depth and detail in specific areas of interest (Rubin and Rubin, 2005). In order to ask appropriate follow up questions Rubin and Rubin (2005) state that the interviewer “listens hard to hear the meaning of what the conversational partner has said”. It would be impossible to follow up on all interesting points due to time constraints however follow up questions are normally asked on subjects that seem important to the participant and are relevant to the research question (Rubin and Rubin, 2005). Follow up questions can be prepared using information from previous interviews and recognition of certain matters raised by more than one participant (Rubin and Rubin, 2005).

Probes: Probes are techniques used to provide clarification on certain topics and also to keep a discussion moving forward (Rubin and Rubin, 2005). Probes usually ask the participant to keep talking on a subject mentioned to give some clarification on what has been said or fill in missing information and therefore elicit further information without a change in focus (Rubin and Rubin, 2005). Other probes are used to obtain examples or evidence for particular points made by participants. Probes encourage the participant to talk freely and in detail about the subject rather than keeping the answers short and concise (Rubin and Rubin, 2005).

4.5.1.3 Reliability and validity

Reliability and bias

Reliability in relation to qualitative research is concerned with whether alternative researchers would reveal similar information (Easterby-Smith et al., 2008). Another concern is the issue of bias, of which there are a number of types to consider. Interviewer bias as stated by Saunders et al. (2007) is when the comments, tone or non-verbal behaviour of the interviewer creates bias in the way the interviewees respond to questions being asked. This is possible due to interviewers attempting to impose their own beliefs and frame of reference through the questions being asked. Interviewers may also do this subconsciously by giving more time to people they believe to be of higher social ‘rank’ (Gray, 2009). Oppenheim (2000) suggests a number of ways in which bias occurs:

- Altering factual questions
- Careless prompting
- Departures from the interviewing instructions
- Asking questions out of sequence
- Biased probes
- Poor maintenance of rapport with the respondent
- Biased recording of verbatim answers
- Rephrasing of attitude questions

In order to reduce the risk of interviewer bias it is necessary to standardise the interview schedule and the behaviour of the interviewer. Grey (2009) suggests that a protocol can be drawn up which requires the interviewer to read the questions exactly as they are written, to repeat a question if asked, to accept a respondent's refusal to answer a question without irritation and to probe in a non-directive manner (Gray, 2009).

Interviewee or response bias may be caused by perceptions about the interviewer or in relation to the perceived interviewer bias (Saunders et al., 2007). If the credibility of the interviewer is in doubt the value of the information gained may be limited, raising doubts on its reliability and validity (Saunders et al., 2007). This type of bias may however have no link to perception of the interviewer. Participants may be reluctant to speak about certain subjects as openly as required for the proposed interview. They may therefore avoid certain subjects as they know this would lead to probing questions they do not wish to answer. This can result in participants withholding information in order to cast his or herself in a socially desirable light or reduces the appearance of negative feelings towards an organisation or event (Saunders et al., 2007).

Robson (2002) suggests that bias may result due to certain individuals not wishing to take part in research. Time constraints and negative feelings towards research can influence individuals into not taking part which can bias the sample of people from whom data is collected.

Validity and generalisability

Validity concerning interviews refers to the extent to which the researcher gains access to a participant's knowledge and experience and is able to deduce what was meant by the participant from the language used in the interview (Saunders et al., 2007). Carefully conducted interviews can achieve a high level of validity if the questions have been clarified, meanings of responses probed and topics discussed from a variety of angles (Saunders et al., 2007). Arksey and Knight (1999) suggest that validity can be strengthened by:

- Giving participants the scope to express themselves by using interview techniques that build up trust and rapport
- Prompting participants to expand on their initial responses

- Ensuring the interview is sufficiently long to address all subjects properly
- Constructing interview structures that contain questions drawn from the literature and pilot work

Saunders et al. (2007) state that qualitative research using semi-structured or in-depth interviews will not be able to be used to make statistical generalisations about the entire population where it is based on a small and unrepresentative number of cases. It may be possible to generalise from interviews when the project is on a small scale. Arksey and Knight (1999) offer two practical principles which can make generalising from interview findings more plausible:

- Try to select a sample that allows for a subject to be viewed from all relevant perspectives
- Keep increasing the sample size, or sub samples that represent different perspectives, until no new viewpoints emerge from the data. A sample size of eight is often sufficient, however a survey should be used to verify the data.

4.5.2 Interview structure for Study 1

The seven stages of interviewing (Kvale and Brinkmann, 2009) and responsive interviewing (Rubin and Rubin, 2005) were combined in order to use each of them to their best advantage without constraining the study by using only one. The seven stages of interviewing were used as a guideline for progress which was referred back to in order to ensure completeness of each stage. Responsive interviewing was used as the main approach, incorporating the flexibility it offered to create a dynamic and well-rounded interview inquiry.

Main questions were designed using the information gained from the pilot centre visit and focus group. Each subject covered had a main question and a small number of follow up questions were prepared in the event that they would be needed. The use of follow up questions and probes would be at the discretion of the interviewer as each of the main questions may elicit diverse amounts of information from different interviewees. A list of the main questions can be found in Appendix 4A.

In order to ensure the reliability of the work, an interview schedule was laid out and adhered to. The researcher conducted every interview and avoided prompting or leading questions. Each of the suggestions made by Arksey and Knight (1999) on strengthening validity of work were followed. Generalisation of the population as a whole was desired from the work therefore interviews were conducted until data saturation had occurred.

4.5.3 Interview Strategy

A convenience sample of three centres was taken, including the pilot centre, in order to ascertain whether the interview structure in use was eliciting the desired information from the members of staff at the Disablement Services Centres. These centres were chosen not only to ensure the data being collected was valid and of use with regards fulfilling the objectives of the study, but also to gain and analyse the data quickly to allow time for alterations if necessary. Figure 4.4 indicates the research strategy employed in gaining a relevant and complete data set.

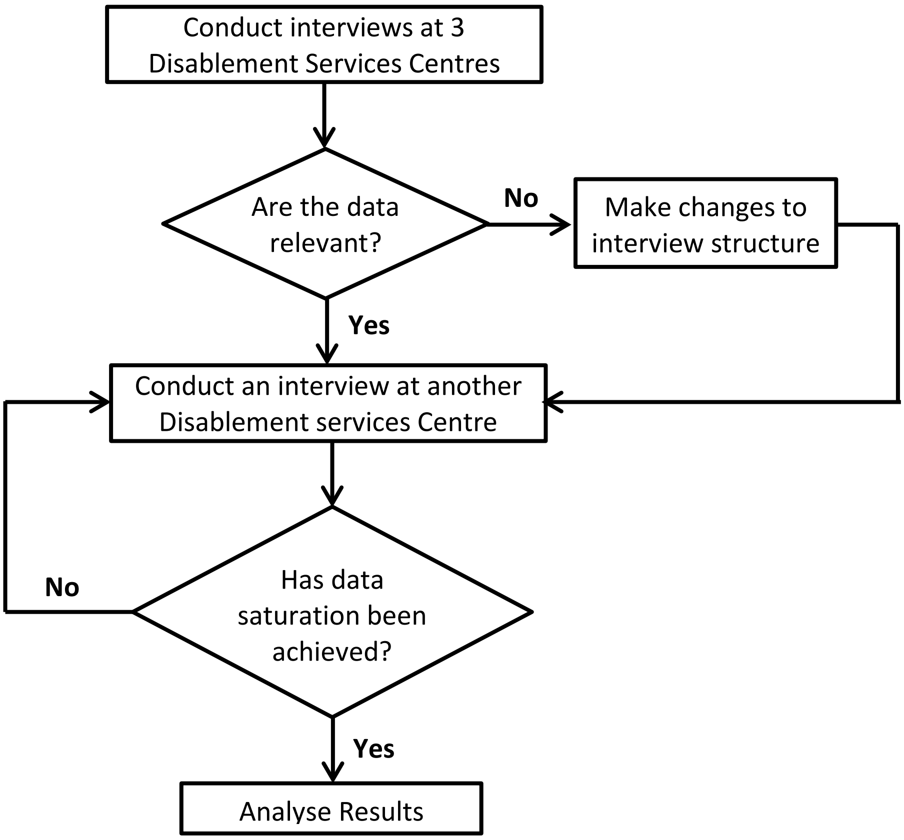


Figure 4.4: Flow diagram illustrating the interview strategy for Study 1

The initial three interviews were conducted and preliminary analysis of the data indicated that the data being collected was of great relevance and with further visits could be used to answer the research questions. A further 9 centres were visited in order to obtain data saturation. The data from the twelfth centre provided no new information therefore analysis of the results could be conducted.

4.6 Ethical Considerations

4.6.1 Theory of ethical considerations

Kvale and Brinkmann (2009) describe the ethical issues at each of the seven research stages. These ethical considerations must be made when entering into research in order to protect the participants and researcher from harm.

- Thematising – The purpose of the study should not only seek to add to scientific knowledge but also look to improve the human situation under investigation.
- Designing – Considerations during this phase are obtaining participants informed consent, securing confidentiality and also considering the possible consequences for participants.
- Interview Situation – Stress during the interview and changes in personal understanding are possible personal consequences of the interview and must therefore be considered.
- Transcription – Confidentiality of participants must be protected and consideration must be given to whether the transcription is true to the oral statements of the participant.
- Analysis – The questions in this stage are whether the participants should have a say in the way their statements are interpreted and how penetratingly the interviews can be analysed.
- Verification – The ethical responsibility of the researcher is to report knowledge that is as verified and secured as possible. This involves the issue of how critically an interviewee may be questioned.

- Reporting – Confidentiality is a major consideration when reporting private interviews in public as well as the consequences for the participants and groups they belong to on publishing of the report.

During the interview stage there are a number of ethical issues to take into consideration. The central ethical issue surrounding interviews is that participants should not be harmed in any way, therefore if a participant appears to be anxious or upset during an interview it should be terminated immediately (Gray, 2009). Over-zealous questioning should be avoided as well as pressing participants for a response due to the possibility of causing distress (Sekaran, 2007). Participants must also be informed that they have the right to decline to respond to any questions asked and that they may terminate the interview before completion if they wish to (Gray, 2009; Gillham, 2000). Sekaran (2007) states that questions which may be construed as demeaning for participants must be avoided. Zikmund (2000) suggests that it would be unethical to attempt to prolong an interview when it is evident that the participant has other commitments. Informed consent is essential for all interview situations.

4.6.2 Ethical considerations for this study

The nature of this study was such that questions being asked were of a non-personal or sensitive nature. Information about the NHS service provision was sought, with no intention to collect data on personal performance, therefore the possibility of causing harm or distress was minimal.

In order to ascertain whether ethical clearance from the NHS was needed a number of sources were consulted. Firstly the National Research Ethics Service (2012) website was investigated to find guidance on whether the pilot study and Study 1 would require NHS ethical clearance. Defining Research (National Patient Safety Agency, 2009) revealed that the proposed studies fell under the ‘Service Evaluation’ bracket and therefore did not need a Research Ethics Committee (REC) review (Please see Appendix 4B for the Defining Research document). This was because the study had been designed and conducted solely to define or judge current care and the service was to be assessed with no reference to a standard. The study did not fall under the ‘Research’ category in any of the outlined headings.

The Centre Manager of the Healthcare Innovation and Technology Evaluation Centre for Derby Hospitals NHS Foundation Trust was also consulted as to whether NHS ethical clearance was necessary. She confirmed that due to the nature of the work no NHS ethical clearance would be required.

In order to comply with ethical procedures in place at Loughborough University for research involving human participants, an ethical checklist was completed. The checklist revealed that no further ethical clearance measures would need to be undertaken in order to conduct the study.

4.7 Piloting

A strategy was outlined in order to create an interview structure which would provide useful data. The initial interview structure was very basic and included questions which were only thought to be relevant. Two actions were taken in order to improve this interview structure, the first being a visit to a pilot centre. The pilot centre was chosen due to its geographical location as the centre was local and therefore a visit could be easily arranged. The second action was to visit the pilot centre’s user group at one of their monthly meetings. This was organised in the hope that the patients would be able to provide a different view on the service provided and therefore help create more relevant questions. Figure 4.5 shows the development strategy for the interview structure.

4.7.1 Visit to the pilot centre

Once an initial interview structure was designed a visit was made to the pilot centre to interview the prosthetist. It was explained that the questions were only preliminary and therefore any extra relevant information would be appreciated. The first few questions were asked in the prosthetist’s office, however the prosthetist felt it would be of great value to look around the centre at the casting and fitting rooms and also the workshop. There was a considerable amount of information previously unknown and therefore relevant to improving the interview structure.

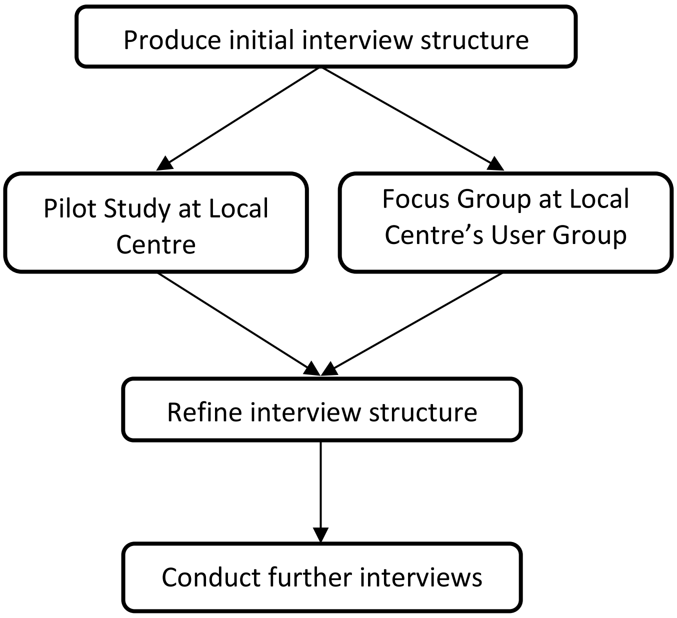


Figure 4.5: Flow diagram illustrating the interview development strategy for Study 1

4.7.2 Pilot study findings

4.7.2.1 General Information

The NHS Primary Care Trusts are responsible for commissioning NHS prosthetic services in the UK. The majority of NHS centres have a contract with one of the four companies described in Section 2.1.5 to provide prosthetic services which last between 2 and 5 years. When the contract is up for renewal the centre puts together a requirements report and each of the four companies is allowed to put forward a proposal. The NHS centre manager then reviews each proposal and awards the contract to the company that will provide the best value for money. The company awarded the contract is then paid a lump sum by the primary care trust to provide services for one year. The money paid to the companies is used to employ prosthetists and technicians and provide some basic components such as stump socks. Components costing over £20 (such as feet and knees) are bought using a separate budget known as the componentry budget. This budget is allocated to centres once a year by the Trust and should be used to provide all patients with sufficient components for their needs. Prosthetists are able to prescribe components from each of the four companies at their discretion.

4.7.2.2 The Prosthetic Service Team

The prosthetic team at the pilot centre comprised of two prosthetists, one of whom was part time, and two technicians (employed by Company 1), a consultant, an amputation nurse, a physiotherapist and an occupational therapist (OT) (all employed by the NHS). In this centre the prosthetist prescribed the limbs and only consulted the consultant when a complex patient was in need of treatment. Physiotherapy was held twice a week at the centre, with a new patient receiving physiotherapy before the prosthetist saw them in order to promote healing. The amputation nurse saw all new amputees on the ward before they were referred to the DSC and the occupational therapist visited patients in their homes to help them adjust to their home environment.

4.7.2.3 Patients

The reported number of amputees registered to the service at the pilot centre was 300 with a reported average age of 68, with most of these patients having either diabetes or vascular conditions. No children were treated at the pilot centre as it was not large enough to have separate facilities deemed appropriate for children. Due to the size of the centre, patients were able to see the prosthetist quickly if they had a problem.

4.7.2.4 Prostheses

Prostheses were manufactured in a workshop at the pilot centre by two technicians, who were able to do repairs within a day if necessary. Primary (new) amputees usually received their limb two weeks after their casting appointment however it was possible for the workshop to produce a limb in a week or less. There were different types of prostheses and sockets which were chosen depending upon the patient. Patients at the pilot centre were required to fulfil certain criteria, the most important of which being activity level, to be prescribed a spare leg. Shower legs and water activity limbs were prescribed but only for those patients that qualified for them. The prosthetist at the pilot centre had to refuse people technology they asked for because it was too expensive.

4.7.2.5 Prosthetic process

At the pilot centre primary amputees were seen by the amputee nurse on the ward preferably before, but certainly after amputation. The physiotherapist also saw patients on the ward and once transferred home, patients went to the DSC for physio twice a week. An Occupational Therapist can be seen on the ward if deemed necessary but were usually sent to patients homes to help them adjust to their home environment. Once patients were fully healed they were seen by the prosthetist and either cast for a prosthesis, told they must have more physio or that they were likely not to be able to cope with a prosthesis. Due to many amputees having vascular problems and the energy requirements involved in using a prosthesis, some patients do not have the physical ability to be a limb wearer and prescribing a prosthesis may be unsafe or detrimental to their rehabilitation. If deemed healthy enough to be a limb wearer, a patient was then cast using plaster and a prosthesis was produced in conjunction with a physio appointment either the following week or the week after. The prosthetist was required to make any adjustments to alignment needed at the fitting appointment and once fitted the patient was sent to physio to learn to use their new limb.

4.7.2.6 Changes to the interview structure

The information collected from the pilot study visit highlighted the need for certain questions to be added to the interview structure.

All centres should be asked:

- Which company held their contract
- Questions relating to the members of the prosthetic team and their roles
- Questions about physiotherapy, its frequency and whereabouts
- The number of patients and their mean age
- Information regarding treatment of children
- Emergency appointments and how quickly patients could be seen
- Where the prostheses were manufactured and the delivery time

- Questions concerning spare limbs and their prescription
- Whether centres found it unavoidable to refuse patients technology due to cost
- The process for new (primary) amputees
- The method used for casting

4.7.3 Focus group with amputees

Basch (1987) defines focus groups as a qualitative research technique used to obtain data about feelings and opinions of small groups of participants about a given problem, experience, service, or other phenomenon. Creating an accommodating environment can help participants to share their opinions and perceptions in a variety of ways (World Health Organisation, 2001) and allow them to generate their own questions and discuss their own priorities (Barbour and Kitzinger, 1999). Gallagher and Maclachlan (2001) state that focus groups are particularly appropriate when trying to ascertain how people consider their experience of amputation and wearing a prosthesis as well as determining their feelings, thoughts, ideas, attitudes and experiences. In order to create an appropriate interview structure, the thoughts and experiences of amputees and their carers were necessary. The main focus of this thesis is on the patient experience and ways in which this can be improved. A questionnaire using insights from a prosthetist only would not be appropriate as the needs of the patient would not be properly represented. Patients of the service may provide some data that the prosthetist is unaware of or would not consider to be relevant.

A visit was scheduled for one of the user group's monthly meetings to conduct a focus group to help inform the interview design. Six amputees and two carers were present for the discussion, each of whom was involved in giving ideas and opinions.

4.7.4 Focus Group findings

4.7.4.1 Counselling

No formal counselling was available to amputees or carers at the DSC. This was felt to be a significant gap in the rehabilitation service by all of the amputees and the carers. The carers both said they were able to cope due to the support they had from members of the user group and felt that counselling for them and their close family would have been very beneficial to aid coping with the lifestyle changes inherent to caring for someone post amputation. One amputee explained that before her amputation she was afraid of amputees due to an experience as a child and did not cope well with becoming one herself. She felt she would have benefitted from having counselling to help her with her fear and learn to deal with her own amputation.

4.7.4.2 Assessing Aims and Goals

Each of the amputees said that they had not had their aims reassessed since their initial appointment with the prosthetist following amputation. At this appointment they were asked what they would like to achieve and because they had only recently had their amputations, most of them replied that their goal was to walk again. They now considered themselves established amputees and felt that they had further aims which had not been discussed. They felt that this was a failing of the system as they wished to know if there was any prosthesis that would be better for them and help them achieve their new aims but felt rude or embarrassed to mention this to the prosthetist themselves.

4.7.4.3 Aesthetics and socks

The oldest of the amputees at the discussion group was 76, had a below knee amputation and was in a wheelchair. She had severe arthritis in her hands which made it very difficult for her to put her prosthesis on and take it off. She was distressed by her prosthesis as the covering had started to move and form lumps as well as holes, some of which were large enough for the pylon (metal rod connecting the socket and foot component) to be clearly visible through them. When she mentioned how bad it was to the prosthetist, she was told it looked alright and not to worry about it. The same amputee also said that she had not been given any new socks for two years and had asked for some more, only to be told that her current sock she was wearing looked fine, even though this was the only one she had left which wasn’t worn out. She felt very uncomfortable asking and felt this was unfair, as the socks were an essential item and should have been offered to her due to the amount of time she had been using the same set. Another amputee stated that he was becoming very uncomfortable because he had to wear five socks in order to keep his prosthesis on but the prosthetist had told him this was acceptable. Another amputee said that she had worn seven socks before the prosthetist re-cast her for a new socket.

4.7.4.4 Information

The only above knee amputee in the group spoke of the lack of information she was given about the Disablement Services Centre and what was going to happen during the casting process. She was unaware before she arrived that she would have to stand up for the duration of the casting, which she would have liked to have known beforehand. She was also very apprehensive about what was going to happen to her at the casting appointment due to the lack of information. Following these comments the other amputees agreed that they were all unaware of the casting process and the pathway they were likely to take following amputation. They all agreed that more information would have eased their minds and made the experience less daunting. The carers also stated they would have liked more information as they were the support for the amputee and were unable to lessen their worry as they had their own concerns due to the uncertainty going into these appointments.

4.7.4.5 Changes to the interview structure

The members of the focus group had provided information that had not been collected during the pilot centre visit, therefore contact with patients was considered essential during further studies. This information was clearly of great importance to the patients themselves however it had not been mentioned at all by the prosthetist at the centre they attend. Further questions were added to the interview structure in order to incorporate the views of the patient as much as possible.

All centres should be asked:

- Whether the centre has a counselling service
- Whether there are procedures in place to facilitate on-going assessment of aims and goals
- Questions about aesthetic limbs and socks

- The level of information given to amputees

The changes to the interview structure were collated and used during the design process in order to create an interview that covered aspects of the service provision that both prosthetists and patients deemed important.

4.8 Sampling

4.8.1 Random Sampling

Fink (2002) states that “a good sample is a miniature of the population – just like it only smaller”. In order to select a representative sample, random assignment of the participants should take place (Gray, 2009). Random sampling is the process of selecting a sample from a population where each member of the population is of equal likelihood to be selected (Saunders et al., 2007). Taking a random sample, however, does not eliminate the possibility that the sample is not representative of the population (Black, 1993). The likelihood of this can be reduced through multiple studies of the same population using different random samples (Robson, 2002). If multiple studies are not possible, random sampling is preferable over purposive (researcher selected) sampling in order to reduce the risk of a non-representative sample (Gray, 2009). There are five random sampling methods recognised in the literature.

4.8.1.1 Simple random sampling

This sampling technique relies on having access to a complete list of the population as a completely random sample is taken. Random number generators can be used to select the sample, which allows selection of the sample without bias (Gray, 2009).

4.8.1.2 Stratified random sampling

This technique involves dividing the population into two or more relevant ‘strata’ based on one or a number of characteristics. Using this technique means that the sample can be more representative as each strata is proportionally represented by the sample. Easily distinguishable strata are necessary in order to use this sampling technique (Saunders et al., 2007).

4.8.1.3 Systematic sampling

This sampling technique is conducted by selecting the sample at regular intervals using a sampling fraction calculated from the sample size and population. This technique works well with small or large samples and when the population covers a large geographical area, systematic sampling is likely to provide well dispersed cases (Saunders et al., 2007).

4.8.1.4 Cluster sampling

This technique involves dividing the population into clusters based on any naturally occurring grouping. Samples are then taken from these clusters instead of the whole population. This technique can provide less representative samples than stratified random sampling (Gray, 2009).

4.8.1.5 Multi-stage sampling

This technique is a development of cluster sampling and involves taking a series of cluster samples, which each involve some form of random sampling. This technique is often used when the population in geographically dispersed and face to face interviews are required.

4.8.2 Sample Size

This is an area that has been debated many times in the literature, with Kvale and Brinkmann (2009) concluding that interviews should be conducted with “as many subjects as necessary to find out what you need to know”. Saunders et al. (2007) state that sample size is an ambiguous issue with no rules for guidance. It is difficult to obtain the correct number of participants in a qualitative study as the tendency is to either have too many or too few participants (Kvale and Brinkmann, 2009). If the sample size is too small it is difficult to generalise, too large and time constraints can inhibit in-depth analyses of all of the interviews (Kvale and Brinkmann, 2009). Saunders et al. (2007) and Kvale and Brinkmann (2009) agree that sample size is dependent on research questions and objectives. Patton (2002) states that sample size depends on “what you want to know, the purpose of the enquiry, what’s at stake, what will be useful, what will have credibility and what can be done with available time and resources”. This shows that there are many considerations to take into account when deciding upon a suitable sample size. The solution in many text books is to conduct interviews until data saturation is reached which means that data should be collected until the interviews are providing little or no new insights (Saunders et al., 2007). When planning an interview study this information is not overly helpful as time and monetary constraints require an estimate of the number of interviews to be conducted. There are differing views on the number of interviews to plan for. Kvale and Brinkmann (2009) state that the number of interviews is commonly 15 +/- 10. This is due to analysis of current interview studies revealing that many would have benefitted from conducting fewer interviews and taking more time preparing and analysing them (Kvale and Brinkmann, 2009). Guest et al. (2006) suggest that for a fairly homogeneous population, 12 in-depth interviews should be sufficient. Guest et al. (2006) state it must be noted that 12 interviews may not be adequate for a heterogeneous population or focus of the research question is very broad. Creswell (2007) suggests that when conducting a general qualitative enquiry, between 25 and 30 interviews would be a logical estimate.

4.8.3 Sampling technique used for Study 1

A list of all 44 centres was available for sampling purposes. Due to all of the centres being known, simple random sampling was used to ensure that every centre had an equal likelihood of being selected. This technique was chosen to ensure reliability and validity of the results. Stratified sampling could have been used as a number of different choices of strata were available. The centres could have been divided into strata using three different characteristics: the companies that provided their service, the size of the centres and urban and rural centres. The centres were not divided into strata by the companies that provided their service as there was no guarantee that centres governed by the same company would have the same processes and procedures. In 2010, when the research was being conducted, each company held contracts with centres of varying sizes, therefore NHS funding was different at each centre leading to differences in service provision. Also, the lack of NHS guidelines meant that centres were not guaranteed to be run in a similar way despite having the same company providing their service. Dividing the centres by size was also considered, however, the lack of consistency in NHS funding of the centres meant that centres with similar numbers of patients could have different numbers of clinical staff, different procedures and also provide different levels of technology to patients. This would have led to strata that were not consistent and therefore not reliable for analysis. The final possibility was splitting the centres based on their urban or rural location; however, this was not possible due to many centres having such large catchment areas that they treated patients from both rural and urban areas. One such example is the Norwich centre which provides prosthetic services for the whole of the county of Norfolk, which includes Breckland, considered to be mostly rural and Norwich which is entirely urban.

Each centre was allocated a random number and a random number generator on a calculator was used to select the sample. The sample size was not decided upon when selecting the sample, as it was not possible to establish at what stage data saturation would occur. A list of 15 centres, selected at random, was produced with each centre being contacted in order. The pilot centre was included in this list; therefore a follow on interview was required to obtain data for the additional items on the questionnaire. Visits were scheduled at the first ten centres following which an initial analysis of the results was conducted to ascertain whether data saturation had occurred. Visits to two more centres were required to obtain data saturation.

4.9 Equipment

Interviews were recorded using a portable Dictaphone to allow conversation during movement, such as a tour around the Disablement Services Centre, to be easily recorded. Each participant was asked for their consent before the interview took place and note taking equipment was available in the event that consent was not given.

4.10 Interview Procedure

Contact was made via email with centres that were randomly selected in order to ascertain their willingness to take part. Once contact was made with the prosthetist at each centre, information about the research was sent and consent to visit the centre was obtained. A visit was booked and confirmation that the visit was still taking place was obtained the day before. Prosthetists were interviewed and the interview structure was strictly adhered to. Other members of the prosthetic team were interviewed if the opportunity arose. Recordings of every interview were made with the consent of the interviewee being obtained first.

4.11 Data Analysis

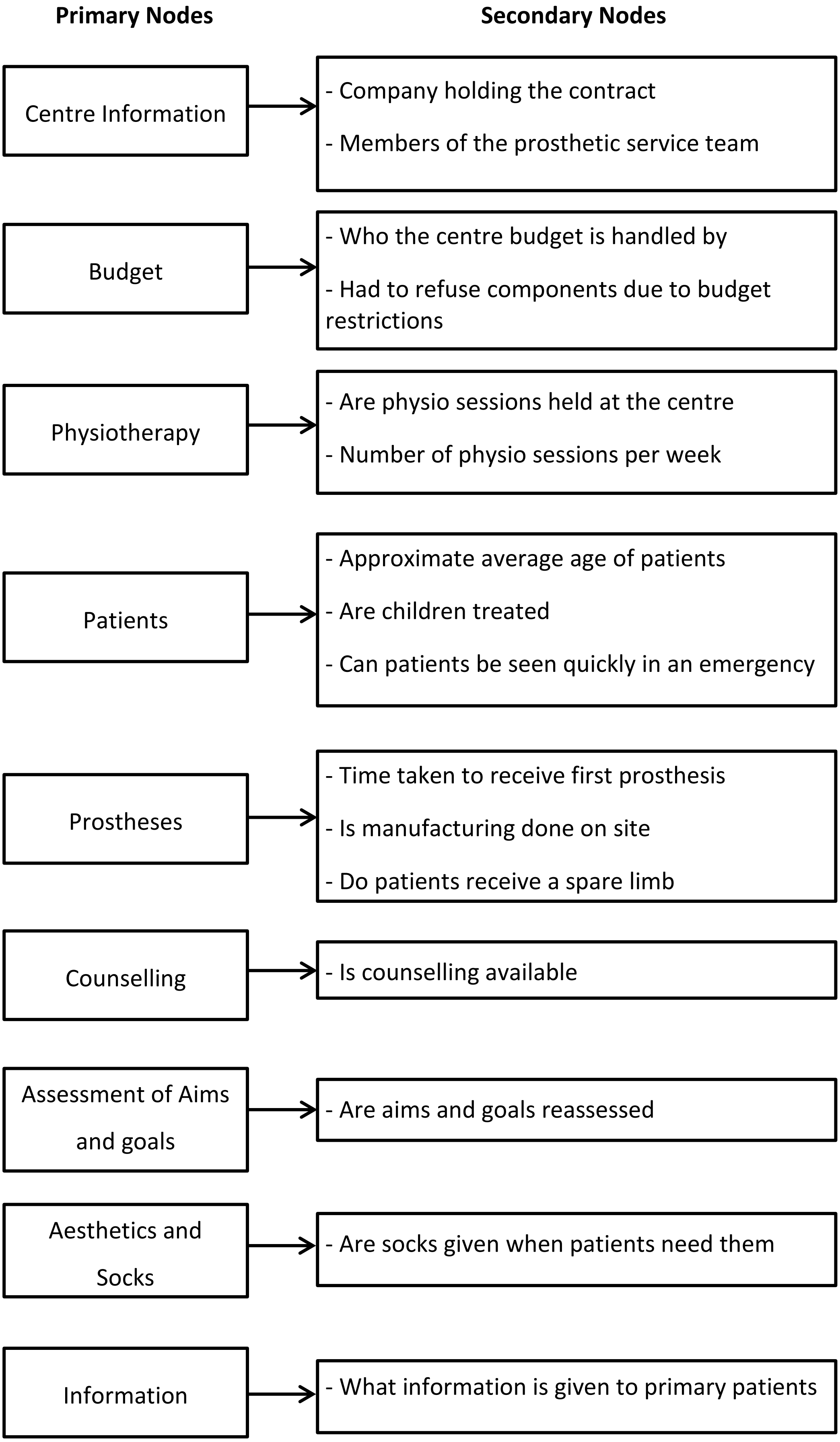
Centres cannot be named for confidentiality reasons therefore each centre was assigned a letter, A to L, in the order that the visits took place. Quantitative analysis was conducted on the data collected from the closed questions in order to produce frequencies of the variables being measured. This was done in order to allow the researcher to compare the results from all 12 centres. The results of these analyses are represented in tables and in graphical form to illustrate the comparisons made.

In order to analyse the open ended questions, interviews were fully transcribed and thematically analysed using an inductive approach. The transcripts were loaded into NVivo 9 (QSR International Pty Ltd, 2010) and primary codes were assigned to each of the subjects around which questions were asked. Following this secondary codes were assigned to the specific details given by the prosthetist or member of the prosthetic team. A separate set of nodes were created for the companies which hold the contract with each of the centres to allow for comparison of the services they provide. The nodes used for interview analysis can be seen in Figure 4.6. In total 16 prosthetists (with representatives from all four private companies), four Centre Managers, two physiotherapists and one occupational therapist were interviewed at the 12 centres.

The data were analysed to identify:

- The members of the prosthetic team and their roles in patient rehabilitation.
- The current issues surrounding the prosthetic service as perceived by members of the prosthetic team.
- The differences in service, if any, between centres.
- The process a patient goes through during the first year following amputation.

- The level of information about their treatment given to amputees and how this differs between centres.



Primary Nodes	Secondary Nodes
Centre Information	- Company holding the contract - Members of the prosthetic service team
Budget	- Who the centre budget is handled by - Had to refuse components due to budget restrictions
Physiotherapy	- Are physio sessions held at the centre - Number of physio sessions per week
Patients	- Approximate average age of patients - Are children treated - Can patients be seen quickly in an emergency
Prostheses	- Time taken to receive first prosthesis - Is manufacturing done on site - Do patients receive a spare limb
Counselling	- Is counselling available
Assessment of Aims and goals	- Are aims and goals reassessed
Aesthetics and Socks	- Are socks given when patients need them
Information	- What information is given to primary patients

Figure 4.6: Nodes used for interview analysis

4.12 Results

4.12.1 Prosthetic Service Team

The members of the multidisciplinary (MDT) providing prosthetic care were different or had different roles at each Disablement Services Centre (DSC). Each member of the MDT had a particular area of expertise in order to help patients through rehabilitation. These included:

- Consultant in rehabilitation medicine – Vast knowledge base on rehabilitation of amputees used to assess patient suitability for limb wearing where needed.
- Prosthetist – member of staff that fitted patients with a prosthesis and was responsible for updating the prosthesis when necessary
- Physiotherapist – member of staff that gave patients exercises to strengthen their bodies to enable walking with a prosthesis. The physiotherapist also conducted walking training with patients once their first prosthesis was fitted.
- Occupational therapist – member of staff that helped patients learn how to conduct everyday tasks, such as washing and dressing, with their new disability. Patients may also receive a visit from an occupational therapist at home to ascertain whether any aids or adaptions would be required.
- Amputee nurse – first member of staff to see the patient on the ward before their amputation. Knowledge of wound care, healing and general health.
- Counsellor – member of staff trained to help patients with emotional problems they have with their new disability.

Following amputation patients were assessed by a team from the DSC to ascertain their ability to use a prosthesis. This team comprised of different members of the MDT at different centres.

Table 4.1 describes the different roles of each of the members of the MDT and which role the member of staff fulfils at each DSC.

Table 4.1: Roles fulfilled by members of the MDT at different centres

■ - Centre at which role is employed

Member of MDT	Different roles in existence	Centre at which role is employed											
		A	B	C	D	E	F	G	H	I	J	K	L
Rehabilitation Consultant	Prescribes all prostheses							■	■				■
	Member of assessment team			■		■				■			
	Only consulted in complex cases	■	■		■							■	
	Not available to patients						■						
		A	B	C	D	E	F	G	H	I	J	K	L
Prosthetist	Prescribes and fits prostheses	■	■		■		■					■	
	Fits prostheses			■		■		■	■	■	■		■
		A	B	C	D	E	F	G	H	I	J	K	L
Physiotherapist	Member of assessment team and conducts physiotherapy	■	■	■	■	■			■	■	■	■	
	Conducts physiotherapy						■	■					■
		A	B	C	D	E	F	G	H	I	J	K	L
Occupational Therapist	Member of assessment team and conducts occupational therapy		■			■	■		■			■	
	Conducts occupational therapy	■		■	■			■		■	■		■
		A	B	C	D	E	F	G	H	I	J	K	L
Nurse	Member of assessment team			■				■	■	■			■
	Looks after patient's physical health	■	■		■	■	■				■	■	
		A	B	C	D	E	F	G	H	I	J	K	L
Counsellor	Member of assessment team						■						
	Looks after patient's mental health					■		■		■	■	■	■
	Not available to patients	■	■	■	■				■				

The full time equivalent for the prosthetists at each centre was ascertained and used to calculate the approximate number of patients per prosthetist, shown in Table 4.2. These numbers are only approximate as the prosthetists were unable to provide an exact number of patients that attend the centre. The mean number of patients per prosthetist was calculated as being 318. Centres D, I and K all have much higher numbers of patients per prosthetist than the calculated mean value ($\bar{x} = 318$).

Table 4.2: Number of patients and prosthetists at each centre

Centre	**A**	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
Patients	*300*	*650*	*1700*	800	3000	1300	820	600	2000	1951	2700	2500
Prosthetist	*1.4*	*2.6*	*5.6*	2	11.6	4	3	1.8	4.2	8.6	6.5	7.3
Number of patients per Prosthetist	214	250	304	400	259	325	273	333	476	227	415	342

4.12.2 Rehabilitation process for primary amputees

The rehabilitation process primary patients follow is created by the MDT and is therefore different at every centre. Prosthetists at each centre were asked to describe the process primary amputees follow and the transcribed conversation was coded into stages that were common or not common to all twelve centres. Figure 4.7 illustrates the stages every amputee goes through during rehabilitation and was created by using the stages that were coded as being common to every centre. Although the stages were common to each centre, the members of the MDT involved at each stage were not. Each centre had their own set of additional stages involving different members of the MDT. As examples, the rehabilitation processes for Centres A, C and B are illustrated in Figures 4.8, 4.9 and 4.10 which demonstrate the vast differences between centres.

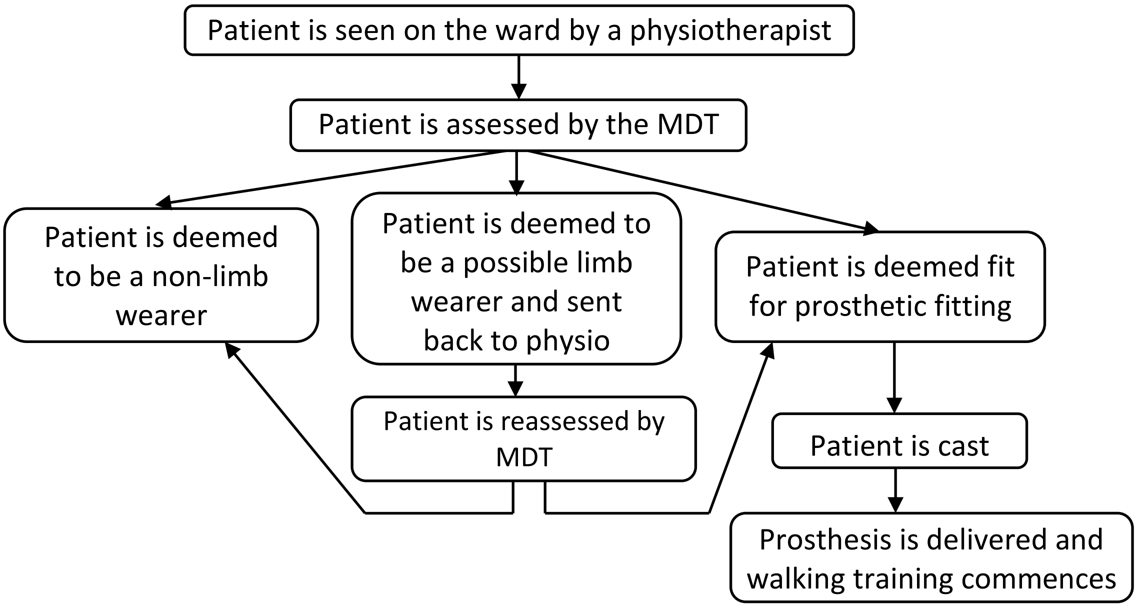


Figure 4.7: Stages of primary patient rehabilitation common to all 12 centres

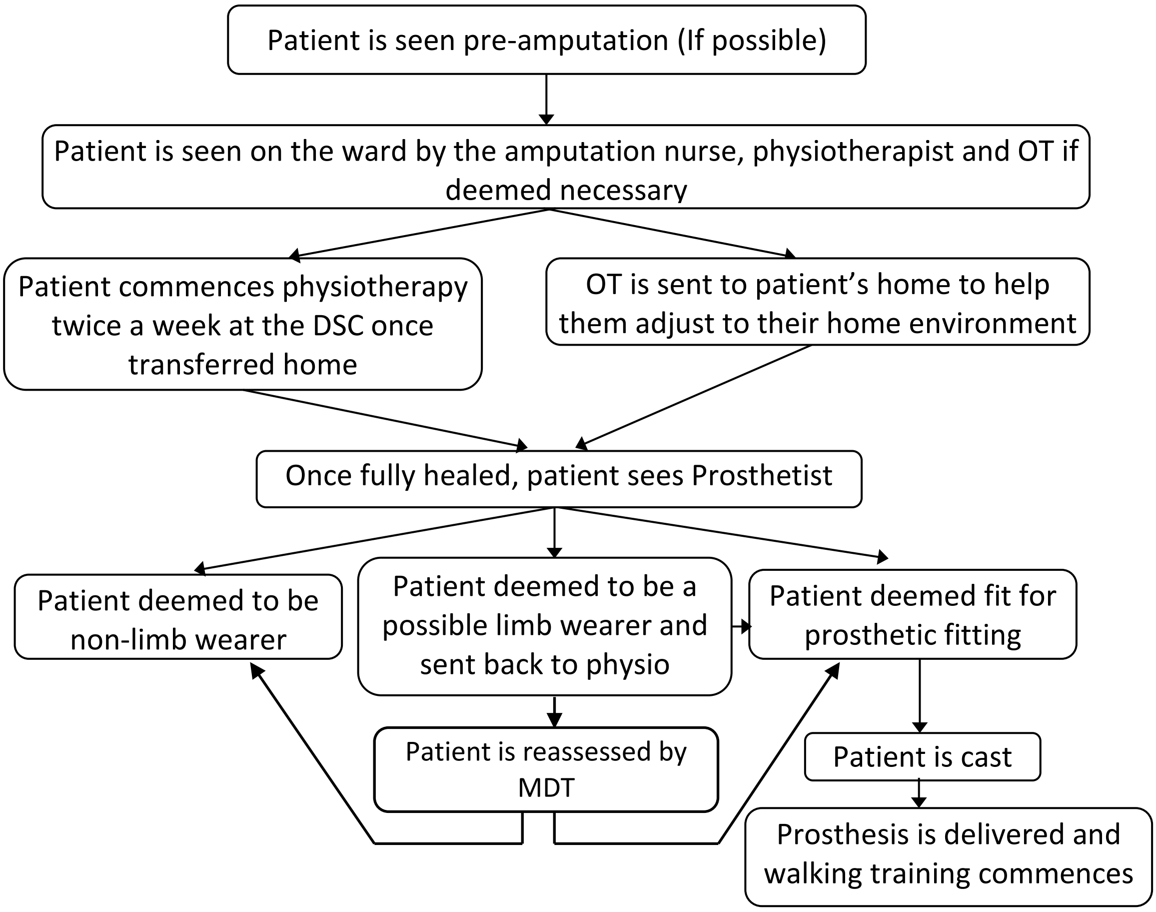


Figure 4.8: Stages of primary patient rehabilitation at Centre A

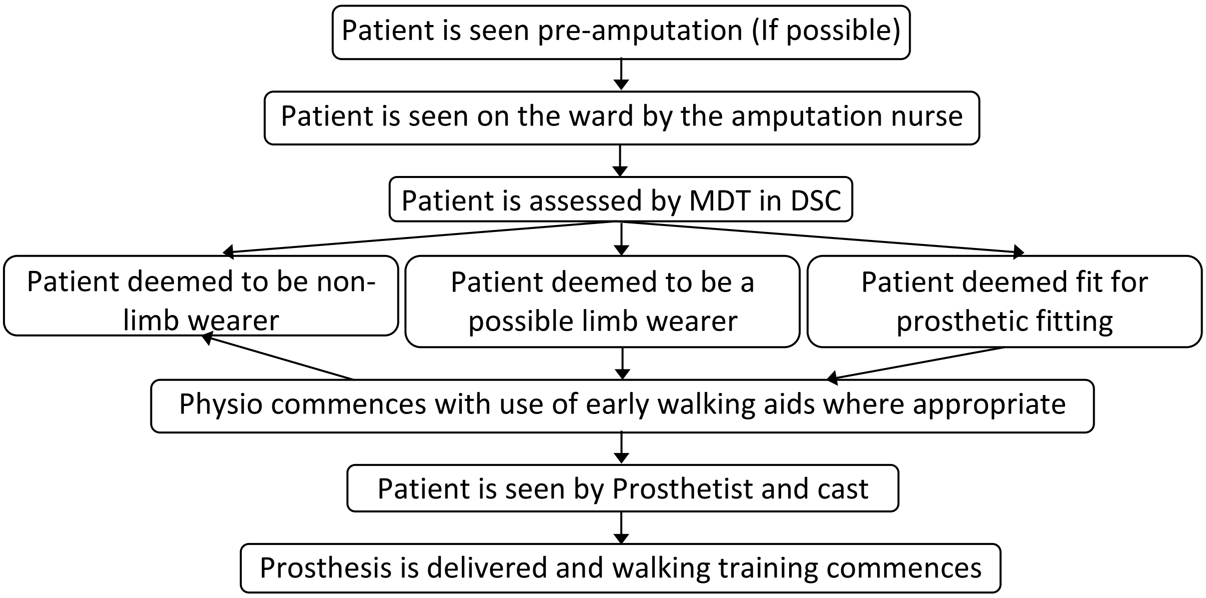


Figure 4.9: Stages of primary patient rehabilitation at Centre C

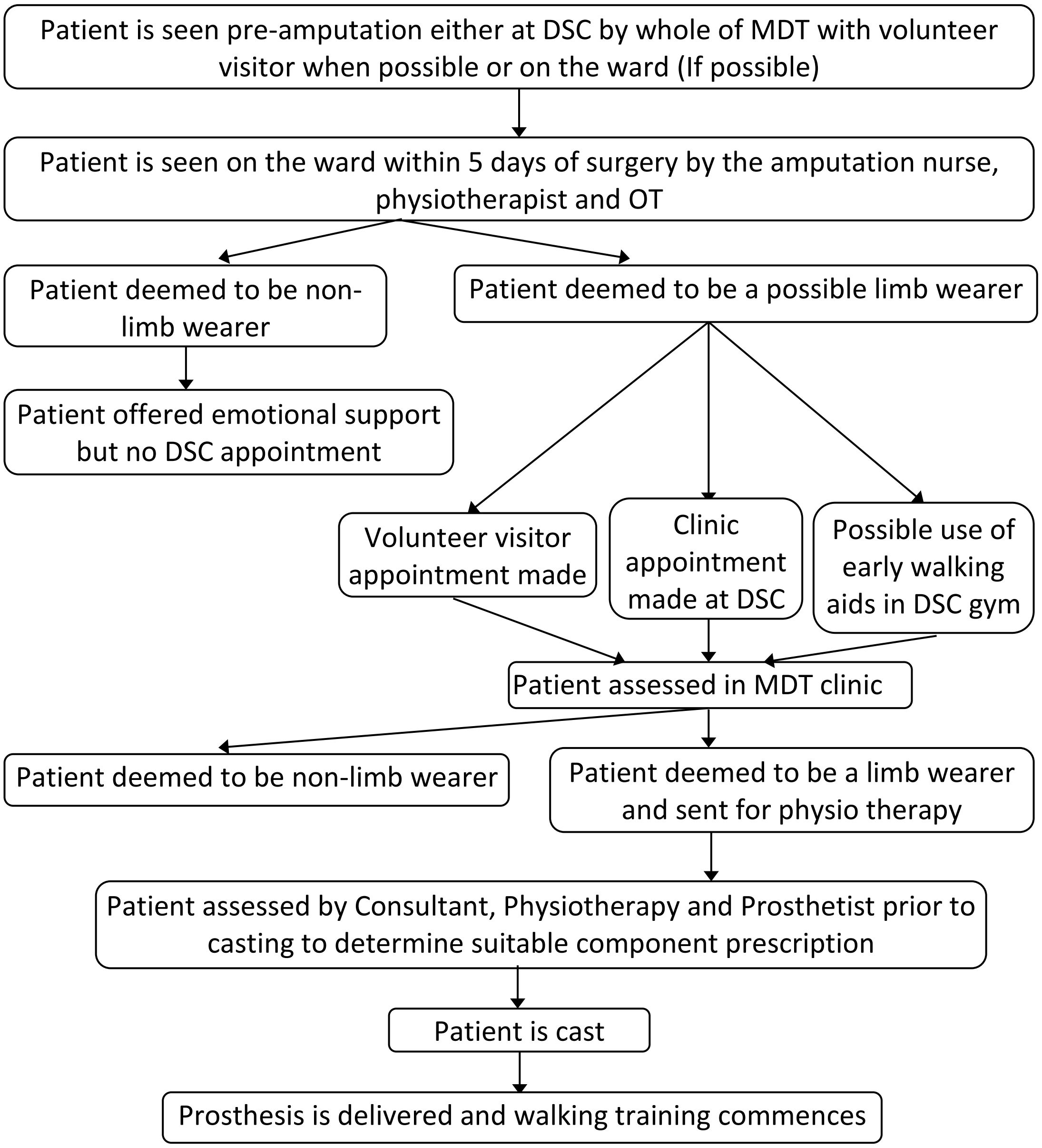


Figure 4.10: Stages of primary patient rehabilitation at Centre B

4.12.3 Differences between centres

Each centre was asked to provide an approximate mean age for the patients that attend for prosthetic care. Table 4.3 shows the reported mean age for each centre. The prosthetist from Centre I explained that the mean age was high for the centre due its location. The catchment area covered by the centre was associated with retirement, therefore the population as a whole had a higher mean age. The Centre Manager at Centre J stated that the mean age for the centre was lower than the majority of other centres as it was a specialist centre which dealt with patients with very complex injuries or amputations. These patients were usually trauma victims and were therefore much younger than the average dysvascular patients. Centres F and I had the highest reported mean age, therefore a larger majority of their patients may also have comorbidities such as arthritis or other age related ailments which can hinder rehabilitation and prosthetic fitting. As stated by the Centre Manager from Centre C, the more comorbidities patients have, the more complex their case therefore fitting them with a prosthesis is more difficult and costly.

Table 4.3: Reported mean age for each centre

Reported Mean Age (Years)	**Centre**											
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
53										■		
60		■		■								
65			■				■	■				■
68	■				■						■	
70						■			■			

4.12.3.1 Provision of limbs

The budget provided to each centre for purchasing components is different at every centre. The budget must be used to cover the ‘clinical needs’ of every patient in the service. There are a wide range of components available to amputees, however the high end technology components, such as the Otto Bock C-Leg or Echelon Foot are very expensive and therefore, in most cases, cannot be provided by the NHS. The prosthetists from each centre were asked whether their budget allowed them to prescribe the components they would like to for every patient, to which all but one (from Centre J) said no. Centre J was an exception as the centre did not have a central componentry budget that covered every patient. Each patient’s prosthesis was funded by their PCT therefore the prosthetists were able to prescribe the components they felt would benefit the patient the most. Every centre was able to apply to their patients PCTs for funding, however, as stated by every prosthetist, this would only be attempted for exceptional cases.

Prior to budget cuts, every patient that required a prosthesis was provided with a spare limb in the event that their first limb failed. Prosthetists from almost every centre stated that this policy had changed dramatically in recent months so patients only receive a spare limb if they fulfil strict criteria. There were two reasons provided for this change, the first being that componentry budgets were being cut and not routinely providing a spare limb was a simple way to save costs with the least amount of inconvenience to the patient. The second reason given was that the prostheses were now in modular form, therefore if one component broke down it could be easily replaced; therefore patients would not be left without a limb for an extended period of time. The majority of prosthetists stated that before the policy changed, the spare limbs provided were usually kept in a cupboard and never used by the vast majority of patients. Table 4.4 illustrates the spare limb policies in place at each of the centres. This shows that only three centres have not chosen to adopt the new spare limb policy that the majority of other centres have put in place. The Centre Manager at Centre G stated that the budget still allowed for spare limbs to be provided and therefore they would continue to do so. The prosthetists at Centres J and L all stated that the number of spare limbs they prescribed was decreasing due to the modular design of the prostheses. New patients were only being prescribed a spare limb if there was a perceived need, such as an active young person or manual worker, who were more likely to break their limb and require a replacement instantly.

Table 4.4: Spare limb policies at each centre

Spare Limb Policy	**Centre**											
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
Patients only receive a spare limb if they fit certain criteria	■	■	■	■	■	■		■	■		■	
Cutting down on the number of spare limbs given										■		■
Almost every patient receives a spare limb							■					

Prosthetists from all centres and all Centre Managers stated that prescription of water activity limbs or shower legs was rare, as patients were required to fulfil strict criteria based on activity levels and general health, in order to receive one.

4.12.3.2 Provision of socks

Every centre apart from Centre H stated that new socks could be provided to patients whenever they were required, which was in conflict with the focus group findings. The prosthetist at Centre H stated that due to budget constraints only five new socks could be given to each patient per year.

4.12.3.3 Services provided

Physiotherapy

The physiotherapists interviewed stated that physiotherapy was an integral part of the rehabilitation process which every patient must go through, regardless of whether they received a limb or not. Every patient was visited by a physiotherapist on the ward only days after their amputation. The physiotherapists explained that some centres were based at the hospitals where the amputations took place, therefore patients would be seen by the same physiotherapist on the ward and at the DSC. The prosthetists at Centre D explained that they were unable to conduct physiotherapy sessions at the DSC and therefore patients were sent out into the community for their physiotherapy sessions. Physiotherapy could be conducted at every other centre visited. Table 4.5 shows the number of physiotherapy sessions per week available at each centre.

Table 4.5: Number of physiotherapy sessions available per week at each centre

Number of physiotherapy sessions available per week at the centre	Centre											
	A	B	C	D	E	F	G	H	I	J	K	L
Intensive daily sessions for up to 10 weeks										■		
All day every day			■			■						
Four									■			
Two or three	■	■						■			■	
Patients usually sent into community					■		■					
None: Patients sent into community				■								

The prosthetists at Centres E and G explained that, due to their centre covering such a large catchment area, their patients were usually sent into the community for their physiotherapy. This was to reduce travelling time for patients as some patients could live over an hour away from the centre. The Centre Manager at Centre J explained that their service was different to the majority of other centres, in that they still had an inpatient service for amputees whereby the patients would be transferred straight from the ward to the DSC. Patients would then receive up to ten weeks of intensive physiotherapy. There was on-going research by Centre J being conducted on whether this method of rehabilitation had any effect on long term outcomes of patients, however, the results of this were not yet available. The occupational therapist at Centre F stated that many of the centres used to have an inpatient facility and that she felt this worked far better for both the patients and members of staff.

Counselling

Counselling was available at seven of the twelve centres. Table 4.6 shows which centres were able to provide counselling for patients.

Table 4.6: Availability of counselling at each centre

Is counselling available at the Centre	**Centre**											
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
Yes				■	■	■	■		■	■	■	
No	■	■	■					■				■

The staff at the centres that were able to provide counselling stated that it was an important part of the rehabilitation process for their patients and the service was invaluable for some patients. One prosthetist stated that in a previous centre he had worked at, the introduction of counselling had reduced the number of repeat prosthetic appointments certain patients were having, therefore freeing up his time for other patients. There were however differing views between members of staff at the centres that were not able to provide counselling. Prosthetists at Centres B, H and L all stated that they felt counselling was an important part of rehabilitation that they would very much like to be able to provide. The Centre Manager at Centre H stated that there had been a pilot scheme for 10 patients to receive counselling at the centre in order to ascertain whether the service should be introduced. The feedback was all positive; however the Centre Manager stated that she was having great difficulty finding the funding for a permanent counselling programme. In contrast, the Centre Manager at Centre C stated that she did not feel counselling was necessary as the members of staff at the centre were a good enough support system for patients. The prosthetist at Centre A stated that counselling was not something she would consider necessary to introduce to the service.

Written information

The written information provided to patients by Centres B, D, E, and G can be seen in Appendix 4C. The other centres were unable to provide the researcher with their information resources; however the resource type itself was ascertained and included leaflets, information booklets and information packs. Leaflets were classed as one A4 sheet containing information relating to one particular subject area, for example the Disablement Services Centre. An example of this is the information provided by Centre E. An information booklet was defined by having more than two pages and information covering a range of different subject areas. An information pack was identified as a group of three or more leaflets or booklets containing a wide range of information. Centre J did not provide any leaflets to patients due to the inpatient setting. The Centre Manager at the centre stated that patients were able to ask questions whenever they wished and were not sent home while healing was still taking place. The amount of information provided to patients was very different between centres. As can be seen in Appendix 4C, Centres B, D and E provided a substantial amount of information covering a wide range of topics, whereas Centre E provided a simple leaflet with very little information. It was ascertained from various prosthetists that the information provided to patients was produced by the individual centres as there were no standard NHS leaflets. It was also stated that there were no guidelines for the amount or content of the information, therefore centres provided patients with whatever information they had the resources to produce. Table 4.7 shows the form in which written information was provided to patients at each centre visited.

Table 4.7: Form of written information provided to patients at each centre

Form of written information provided to patients	**Centre**											
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
None										■		
Leaflets	■	■			■	■						■
Information Booklet								■			■	
Information Pack			■	■			■		■			

Emergency appointments

Every prosthetist, apart from those at Centre I, stated that they were able to see patients within 24 hours in an emergency. Emergencies were classed as components or sockets breaking or the patients having a fall. The prosthetists at Centre I stated that they found it very difficult to fit patients in and would therefore aim to book emergency appointments within 48 hours. The reason for this was stated as being a lack of clinical staff as one prosthetist had left and was replaced by a manager that had no clinical qualifications.

Treatment of Children

Children could be treated at all but one centre, however only three of the 12 centres had specific children's clinics. The Centre Manager at Centre C stated that a children's only clinic was held once a month to try to break down some of the barriers and stigma surrounding being an amputee as most of the children were traumatised by their amputation. Children could be seen at other times during the month if necessary, however they would be seated in a waiting area with amputees of all ages. Centre E was stated as being a specialist clinic for children, by the prosthetist, as children's clinics were held once a week. Children were treated completely separately from adult amputees. The Centre Manager at Centre L stated that children had a separate waiting area to adult amputees. Prosthetists from Centres B, D and F stated that they rarely treated children as they preferred to send them to other centres which had specific children's clinics such as Centres C, E and L. The prosthetist at Centre A stated that children were not treated at the centre due to the clinical staff having a lack of experience in treating children. Table 4.8 shows whether each centre treated children.

Table 4.8: The policy at each centre on the treatment of children

Are children treated?	**Centre**											
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
No	■											
Very few		■		■		■						
Yes							■	■	■	■	■	
Specific children's clinics			■		■							■

4.12.4 Service differences between companies

There were four companies identified as providing prosthetic services to NHS Disablement Services Centres. Each centre has a contract with one of these companies lasting between two and five years. The contract requires the companies to employ prosthetists and technicians to provide the prosthetic service and some basic components, such as stump socks and socket liners. Table 4.9 shows the company that held the contract at each of the centres at the time of the visit.

Table 4.9: Company that held the contract at each centre at the time of interviewing

Company that held the contract	**Centre**											
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
1	■	■	■					■				■
2				■			■				■	
3					■							
4						■			■	■		

4.12.4.1 Time taken to deliver the first prosthesis to a primary patient

The majority of the prosthetists stated that the length of time taken for a primary amputee to receive their first prosthesis was written into the contract with the company. Centre I however had the longest waiting time which was explained by the shortage of clinical staff. Table 4.10 shows the wait time for a primary amputee to receive their first prosthesis at each centre in relation to the companies that held the contract.

Table 4.10: Wait time for a primary amputee to receive their first prosthesis

Company	**Different roles in existence**	**Centre at which role is employed**											
		A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
1	1 Week		■	■					■				■
	2 Weeks	■											
		A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
2	1 Week				■								
	2 Weeks											■	
	3 Weeks							■					
		A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
3	1 Week					■							
		A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**I**	**J**	**K**	**L**
4	1 Week						■				■		
	Up to 4 weeks									■			

Company 2 had the greatest variation in delivery times due to times ranging from 1 to 3 weeks. Centre I appeared to be an anomaly with regards Company 4 as the other two Company 4 centres had wait times of 1 week.

4.12.4.2 Assessment of Aims and Goals

The prosthetists at every centre stated that they reassessed patient's aims and goals periodically following physiotherapy discharge, however there were significant differences between companies. Company 1 had specific paperwork in place to keep track of the aims and goals discussed by the prosthetist and patient and prosthetists at Company 2 centres stated that forms were being introduced for this purpose. There was no mention of any formal record of patient's aims and goals at centres covered by Companies 3 and 4, with the exception of Centre F, therefore implying they had no paperwork in place for this purpose. The prosthetist at Centre F stated that paperwork to reassess aims and goals had recently been introduced and helped both patients and prosthetists keep track of progress. The prosthetist at Centre D stated that no formal records of aims and goals were kept therefore reassessment of initial aims and goals were difficult further into the rehabilitation process.

Every centre, with the exception of Centres G and E stated that their reassessment of patients continued for twelve months, after which the onus was back with the patient to make appointments whenever they had a problem. The prosthetist at Centre E stated that reassessment took place for the first eighteen months and the Centre Manager at Centre G stated that patients were recalled regularly during and after their first year.

4.12.5 DSC staff concerns

The members of staff at each of the centres were asked whether they had any concerns with the current service provision or ways in which they would like to see the service improved. A number of common themes emerged from analysing the results.

4.12.5.1 Budget restrictions

Every prosthetist and Centre Manager interviewed, with the exception of those members of staff at Centre J, mentioned the budget restrictions they faced in some capacity. There were a number of common issues related to budget restrictions which were analysed individually.

Restrictions on providing high end technology

The commonest concern mentioned by prosthetists was that they had to refuse technology to patients due to budget restrictions. Their concerns were that the components being refused could improve the patient's quality of life, which was of high importance. The prosthetist at Centre A stated that they were required to weigh up whether the advantages and outcomes of the patients were improved as much as the expenditure was increased, which was extremely difficult. The Centre Manager at Centre H stated that they would very much like to provide all patients with the level of technology that would benefit them most; however under the current budget restrictions it was simply not possible. The differences between centres and the components they were able to provide was also of concern to prosthetists. It was stated by the Centre Manager from Centre C that patients should be able to attend any DSC across the country and be given the same clear guidelines on the technology the NHS would and would not be able to provide as every other centre.

Increase in Obesity

The majority of prosthetists voiced their concerns with the increase of obese patients as the components for these patients cost considerably more than the standard components also with a decreased range to select from. Due to the restricted budgets in place at centres, the prosthetists stated that prescribing components for obese patients was becoming more difficult due to their increased cost and limiting range.

4.12.5.2 Prescription of Components

The Centre Manager at Centre C stated that there were no clinical guidelines for the prescription of components, therefore patients were being prescribed different components for the same level of amputation, depending on the centre they attended and even the prosthetist they saw within the same centre. The same concern was expressed by a number of prosthetists, that there were no clinical guidelines for which components to prescribe for certain levels of amputation and there was very little literature to offer the clinicians guidance. The suggestion was the production of pathways of appropriate components for different levels of amputation using evidence based research.

4.13 Discussion

4.13.1 Prosthetic Service Team – Objective 4.1

There was extensive evidence of differences in the number of patients per prosthetist across the twelve centres. Figure 4.11 highlights that some centres had far more patients per prosthetist than others.

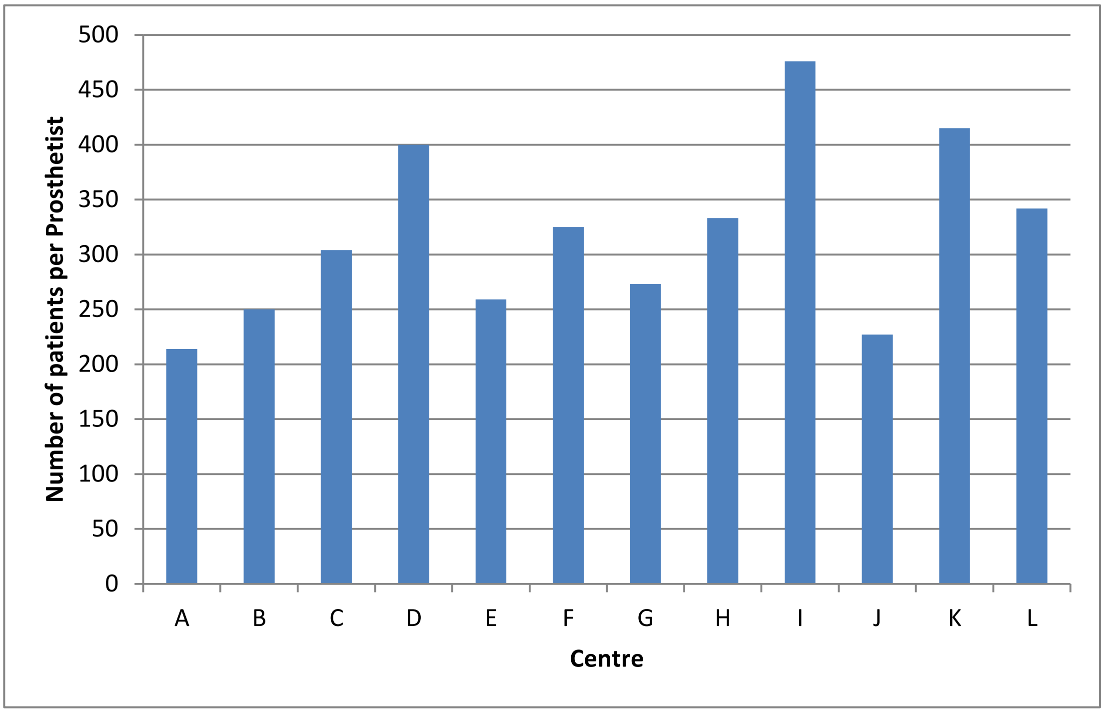


Figure 4.11: Number of patients per prosthetist at each of the 12 centres

Centre I had the highest number of patients per prosthetist which explains why it was difficult for patients to be seen within 24 hours in an emergency and why it took up to a month for primary amputees to receive their first prosthesis. The prosthetist at Centre I stated that they were understaffed which was causing problems with fitting patients in for routine appointments and emergencies. Centres D, I and K all had over 400 patients per prosthetist, which could be leading to prosthetists having less time to spend with patients and therefore providing a lower level of service than the other centres. In order to take this information further, it would be necessary to ask patients whether they were able to be seen quickly in an emergency, how long they must wait for a follow up appointment and whether they are happy with that timescale. Patients should be asked about waiting times as centres may not be able to keep their waiting times to those quoted or the waiting times the centres consider optimum may not be satisfactory to the patients.

4.13.2 Rehabilitation process for primary amputees – Objective 4.2

The information gathered from the visits revealed that there was no NHS process that all centres must follow in the rehabilitation of primary amputees. Although the processes of each centre could be condensed into common stages, as seen in Figure 4.7, there were still distinct differences between the members of the MDT that were seen by the patient at each of these stages. This shows that a patient being treated at one centre will follow a completely different pathway to patients in other centres across the country. In order to create consistency in the service, an evidence based NHS pathway of care would need to be produced for every centre to follow. This would involve gaining the opinions of patients from each centre and ascertaining the important stages of each pathway from clinical staff to produce a pathway of best practice that could be implemented in each NHS centre.

4.13.3 Differences between centres – Objectives 4.4 and 4.5

The differences in mean age of patients treated at centres across the UK could have profound effects on their budget requirements. The older the patients being treated, the more complex fitting of a prosthesis can become due to comorbidities. Budgets of certain cetres could be stretched due to a higher percentage of patients requiring more spectialist care.

One of the barriers voiced by a number of prosthetists to prescribing higher end technology for one patient was the concern of overspending and reducing the funds available for other patients. The system in place at Centre J appears to be more beneficial for patients and less stressful for the staff at the centre due to the flexibility in components available for prescription. There would be a number of difficulties implementing this system across the country, due to the restricted budget of the PCTs (the same will be true of the new CCGs) and the extra administration involved in applying for funding for each individual. The prosthetists were clearly aware of the advantages of certain components that they were unable to prescribe to patients, therefore further research was required into whether patients themselves were also aware of these advantages and if so, how this affects their perception of the service.

The general consensus among prosthetists from all centres was that spare limbs were obsolete and therefore provision of spare limbs was the most logical service to cut to save money with as little inconvenience to patients as possible. The differences in budgets between centres was highlighted by only one centre having the funds to provide these limbs. Patients' opinions on receiving a spare limb, however, could be significant, as the centres could be removing a service that patients feel very strongly about, without realising.

The provision, or rather lack of provision, of shower or water activity limbs was an indication that centres were unable to provide patients limbs that may improve their quality of life without proving that the limb was clinically necessary. Clinical necessity and improving quality of life are very different concepts therefore patients should be asked about their opinion of the restrictions on prescription of such limbs.

Although every centre, apart from Centre H, stated that socks were provided as and when patients required them, the information gained from the focus group in Section 4.7.4.3 highlighted that there may be differences between the stated provision of socks and other components and the actual provision. The opinions of patients from different centres on the provision of socks and other components were required in order to ascertain where the differences between stated and actual provision lay.

There were considerable differences in physiotherapy sessions, their length and frequency between centres. Centres A, B and K were limited to two or three physiotherapy sessions each week which could delay rehabilitation of patients that could cope with more intensive physiotherapy. Centres C and F had physiotherapy sessions every day which gave patients much more choice in their appointment time and the ability to go to the centre for more intense physiotherapy if the DSC staff felt this would be appropriate. The same could be said for Centres H and I which had sessions 4 days a week. If patients were unable to get transport to the DSC they would have to rely on hospital transport to get them to their physiotherapy appointment. This could be a source of restriction for patients due to hospital transport always being extremely busy and requiring at least 48 hours' notice. Centres that provide physiotherapy more than three times a week could take some of the pressure off the hospital transport as there would be no excessively busy days. Patients with access to physiotherapy twice or three times per week may find it more difficult to access hospital transport due to the concentration of patients attending fewer appointments.

A number of centres stated that their patients could go for physiotherapy in the community due to the distance they would have to travel to attend the DSC. The frequency of these sessions was not ascertained, however for patients this may be far more convenient as they would not have to travel such a large distance and may be able to attend the sessions without the need for hospital transport.

Centre D was the only centre in the study which did not offer physiotherapy sessions in house. Due to the centre having such a large catchment area most patients had their physiotherapy in the community. The lack of physiotherapy facilities in the building could be seen as a hindrance due to the prosthetist being unable to visit the patient in physiotherapy if there were any problems with their prosthesis, which is possible in other centres.

Centre J had intensive courses of physiotherapy for each patient, every day for up to ten weeks. Intensive physiotherapy may provide considerably faster rehabilitation enabling the patient to return to work or their recreational activities much more quickly, which in turn could help the patient adapt to the amputation more easily. Ascertaining patients' opinions on the frequency of physiotherapy would allow for comparison of the different physiotherapy systems in place at different centres.

Prosthetists and other members of staff at centres that were able to offer counselling were clearly aware of the positive impact the service could have on patients. This was also true for the members of staff at the centres that were unable to provide counselling. There were only two members of staff interviewed that were not in favour of introducing a counselling service at their centre. The information gathered from members of staff and also patients at the user group discussion (Section 4.7.4) indicated that amputation is a traumatic event and some patients may cope far better than others, possibly due to differences in their home lives and personal support systems. Looking after the mental health of the patient should be as important as dealing with the physical impairments as the quality of life of a patient is not only based on the comfort and ability to ambulate, but also their mood and ability to cope and adapt to the changes that have occurred. Even if a patient has a prosthesis which fits perfectly, if they are too depressed to use it then the prosthesis itself is of no functional use. The differences in opinion of patients that received counselling and those that did not were required in order to ascertain the impact counselling had on the mental health and quality of life of patients.

There appeared to be little consistency across all centres with regards the amount and detail of information given to patients. There were differences even within the companies holding the contracts. It was therefore concluded that there were no nationally agreed requirements for the information given to patients and that most centres produced their own written information with Company 4 being the only company to have specified the information to be given.

Patients should be receiving the same level of information and service regardless of their location, therefore consistency of information provision should be introduced. Patients require a certain level of information to feel at ease with their situation and reduce the amount of anxiety experienced by them and their family members, as found during the focus group in Section 4.7.4. Research revealing how the amount of information had helped or hindered patients and the differences of patient experience between centres would allow for evidence based reasoning for improvement of information provision across the country.

Centre I had by far the highest prosthetist to patient ratio which reflects the statement made by the prosthetist that they were understaffed. Being understaffed meant that the centre was struggling to cope with the number of patients they had and therefore the service was suffering. Further research was required into waiting times for emergency and standard appointments to ascertain what effect understaffing had on patients.

Advantages of separate children's clinics and waiting areas were that children were able to socialise with other children that had the same or similar amputations and parents were able to talk with one another which could prove to be helpful for parents of children with acquired amputations. Further research would be required to ascertain the advantages of separate waiting areas for children.

The research has shown a large number of differences between centres across the UK, therefore there are inconsistencies in service present. These inconsistencies appear to relate to budget constraints, however the age and comorbidities of patients treated could also be a factor. There did not appear to be any patterns between centres emerging with regards the services provided. Each centre appears to be disconnected from the service as a whole making equality in service provision across the UK a difficult concept to introduce.

4.13.4 Service differences between companies – Objective 4.4

There were four companies offering prosthetic services to the NHS, however the interviews with prosthetists and other members of staff had revealed that there were differences in the service provided by each of the four companies.

A number of prosthetists mentioned that they were contracted to provide patients with their first limb within a certain time frame, however this time frame is either not being adhered to at some centres or some centres were not bound by a contractually arranged time. Companies should be providing the same level of service at each of their centres to minimise inconsistencies and work towards an equality in service provision across all NHS centres.

Centre I had the longest time frame of up to four weeks which could be detrimental to the mental health of the patient as they would be unable to begin their prosthetic rehabilitation until they received their prosthesis. The longer a patient has to wait the more frustrated they could become, therefore hindering their rehabilitation (Sullivan et al., 2003). Further research would be required to ascertain what kind of affect having to wait extended periods for their first prosthesis was having on patients.

The differences between centres in assessment of aims and goals could be attributed to the company that held their contract. The lack of reassessment of aims and goals may have an adverse effect on the patient’s experience as there may be many months in between appointments and aims and goals may be forgotten and simply passed over. In order to ascertain how the lack or presence of aims and goals may have affected patients, patients’ opinions on this matter should be sought.

The differences in approach to patient care after the twelve month review were likely to be due to a lack of guidelines and therefore centres created their own pathway of care. Calling patients in routinely may be seen as wasting the prosthetists time if the patient had no problems with their prosthesis, therefore the majority of centres chose to wait for the patient to contact them if they were experiencing any problems. Centre G may have chosen to re-call patients more routinely due to patients not always knowing how to recognise a problem with their prosthesis or gait, therefore problems could escalate so much that a large amount of intervention may be required. If a problem is caught early enough it can possibly save the patient from pain and a longer recovery and also the prosthetist’s time due to only minor adjustments being needed. Calling a patient in routinely helps to keep up the contact with the patient and therefore makes it easier to recognise any problems in their early stages and also helps the prosthetist to keep track of their progress so that limb abandonment is less likely. This, however, does take up a lot of the prosthetist’s time and some appointments may be seen as unnecessary due to the patient having no issues to report. Leaving the patient to contact the centre when they have a problem cuts out the ‘unnecessary’ appointments, leaving the diaries of the prosthetists more free for follow up appointments and emergencies which in turn means that patients are likely to be seen more quickly. This does however mean that when patients see their prosthetist there is always an issue, which may have been easily rectified had they been seen earlier. It also means that the patient is always asking for something or complaining when they see their prosthetist which may make the relationship between patient and prosthetist more difficult and the patient less likely to want to ask for changes or help. This is dependent upon the attitude of individual patients and therefore this pathway of care may be more suitable for some patients than others.

4.13.5 DSC staff concerns – Objectives 4.3 and 4.6

As most prosthetists mentioned, the clinical needs of each patient were being met with regards prosthesis prescription, however the restrictions on budget were causing concerns and affecting patients in a number of capacities. The budget appeared to be the biggest problem facing the DSCs, however it was not something they had control over, nor the means to improve upon. With the prices of components increasing, the challenge of meeting every patient's clinical needs will only become more difficult.

Although every centre (with the exception of Centre J) was in agreement that their componentry budget did not allow them to prescribe the components they would like to for their patients, the components available at each of the centres varied greatly. Some centres were able to offer high end technology such as the newest knees or feet, whereas other centres simply did not have the budget to prescribe them at all. This inconsistency in provision of components was alluded to in a number of reports over the past 3 years (BBC, 2011; Salisbury Journal, 2011; BBC, 2010b). This implies that patients were aware of the inconsistencies as well as prosthetists. The prosthetists base their clinical decisions on the lifestyle and activity level of the patient, however, the systems in place do not promote prosthetists offering new technology; therefore media coverage could highlight componentry that patients were previously unaware of. Unless a patient asks for a certain component or complains that their limb is not fulfilling their expectations, the prosthetist would not mention any technology which may improve their quality of life. Due to the process for applying for extra funding from an individual's PCT only being available to patients with exceptional needs, there was no way for patients to improve their prescription beyond their clinical need. In order to create equality of service, the NHS should produce a document detailing the components that would and would not be available to their patients at every centre. In order to ascertain the impact the limited provision of components had on patients, patients' opinions on this matter should be sought.

The increasing prevalence of obesity (National Centre for Social Research, 2009) was causing concern for many prosthetists due to the increased costs associated with obese patients. The increase in obese patients inherently causes an increase in expenditure on components therefore prosthetists would find covering every patient's clinical needs even more of a challenge.

The lack of clinical guidelines could be another reason for the inequality in service provision between centres. With no clinical guidelines to follow for each amputation level, prosthetists and consultants could choose any component they wished, within the budget restrictions. Clinical guidelines would provide equality in component provision as patients of the same age, with the same level of amputation and physical ability would be given the same components despite the DSC they attended. The clinical guidelines should be produced using evidence based research to ensure the best outcomes possible for each patient.

4.14 Critique of Study

This study was conducted over a period of 2 months in 2010. It is realised that contracts between NHS centres and companies will be renewed and may change in the time following the study and completion of this thesis. It is also realised that staff members will also change and numbers of members of staff may increase or decrease at any time. It is therefore necessary to state that the information gathered in this study is only accurate for the time of collection. The information is however not necessarily incorrect and can therefore still be used as comparative material for further studies.

A further limitation was that the centres chosen at random for inclusion in the study were all in England, leaving Wales, Scotland and Northern Ireland unrepresented. This sampling strategy was chosen to ensure the results would be as valid and reliable as possible. The tendering of contracts to prosthetic companies was abolished by Scottish centres in 2005 therefore the centres are completely run by NHS staff (The Douglas Bader Foundation, 2012). This difference could have a considerable effect on the functioning of the centre and therefore the patient experience. A study involving the five centres in Scotland could be conducted in order to gain data for comparison with centres in England, Wales and Northern Ireland that still have contracts with prosthetic companies. Further investigation into the service provision across the Wales and Northern Ireland would be necessary in order to generalise findings to all 38 centres that have prosthetic company contracts.

4.15 Conclusions

Disablement Services Centres, at the time of visiting, all functioned in unique ways with very little consistency in service provision. The restrictions on service provision were almost completely caused by the budget within which each centre was required to work. The exact budget allocation information for the centres could not be acquired therefore calculations to ascertain the budget per capita by centre could not be conducted. Inconsistency in the pathways patients followed at different centres was also considered to be introducing differences in service.

Services between centres differed in a number of key areas:

- The pathway primary patients followed
- Limb and componentry provision
- Frequency of physiotherapy
- Provision of counselling
- Information provision
- Emergency appointments
- Treatment of children
- Timelines for primary patients
- Assessment of aims and goals

These differences between centres could have profound effects on the rehabilitation of patients therefore further research was extremely important in order to ascertain if patients were being affected and if so, how.

Chapter 5: Study 2 – What do patients think?

5.1 Summary

The overall aim of this thesis was to evaluate the service provided to prosthetic patients by the NHS, with respect to patient experience and provide suggestions for improving service delivery. Study 1 provided understanding of the NHS service provision from the perspective of the Disablement Services Centres' members of staff. In order for patients to evaluate the service, the results from Study 1 were used to produce a questionnaire for NHS prosthetic patients.

There are approximately 5000 new referrals to prosthetic centres every year (National Amputee Statistical Database, 2009). There are however a number of patients who will not be given a prosthesis. As made clear from Study 1, prosthetists feel that some patients are simply not well enough to cope with the energy expenditure related to prosthesis use. Those patients that are deemed suitable for fitting with a prosthesis follow a rehabilitation pathway set out by the DSC they attend. As discovered from Study 1 this rehabilitation pathway is not standardised and therefore patients with the same level of amputation will be rehabilitated differently at different DSCs. The results from Study 1, however, cannot predict how these differences affect the service that is provided to patients, nor give details on what is perceived as good or bad service.

5.2 Aims and Objectives

The purpose of this study was to gain insight into the views of patients on the service they were being provided through a series of study specific objectives.

Research question 4: Are the needs and expectations of amputees being met by the current NHS service provision?

Objectives - To ascertain through appropriate data collection methods:

5.1: The level of information given to patients at different times during rehabilitation

5.2: Whether patients felt this information was sufficient

5.3: The level of importance patients placed on discussing their aims and goals and the provision of spare limbs and water activity/shower limbs

5.4: Whether physiotherapy sessions were at suitable times for patients

5.5: Whether patients were satisfied with the components they received

5.6: The level of importance patients placed on counselling and volunteer visitors

Research Question 5: What are the main issues patients currently have with the service provision?

Objectives - To ascertain through appropriate data collection methods:

5.7: How patients viewed the overall service they were provided, identifying areas of concern

The views of patients are imperative in any patient centred study, therefore the views of amputees on the main issues brought to light through Study 1 were sought.

5.3 Literature review

The results from Study 1 allowed for a more informed literature search, covering topics relevant to work in Study 2. Figure 5.1 is a pictorial representation of Sackett et al.'s (2000) definition of how to improve patient outcomes using evidence based practice. If one of the three factors is weak or missing, the rehabilitation outcomes of patients are compromised. Without knowledge of the patient's values, outcomes for patients can simply not be improved. In order to integrate patient's values, their opinions of the service provision and the topics which are of importance to them must be ascertained.

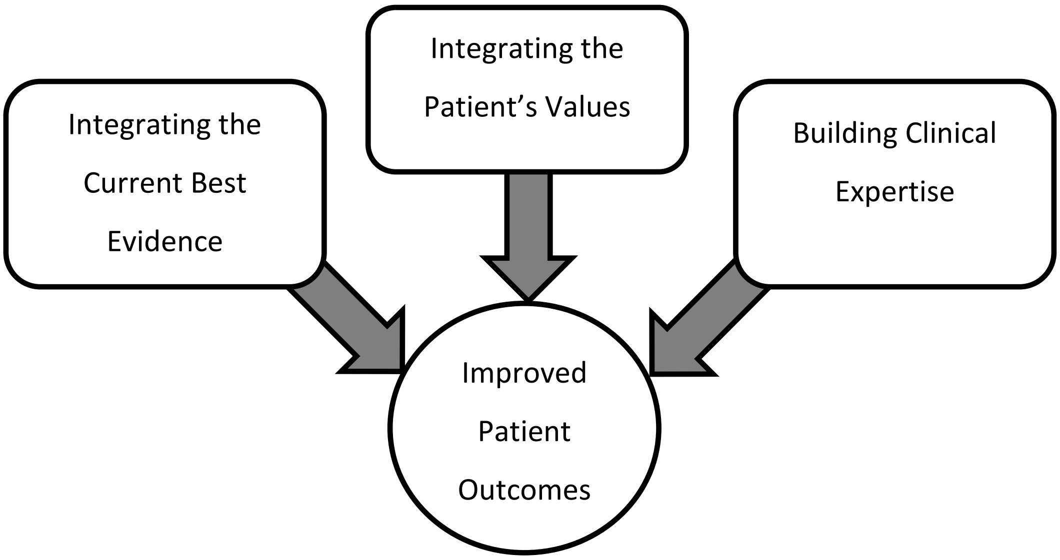


Figure 5.1: The three core factors of evidence based practice that help improve patient outcomes (Sackett et al. 2000)

5.3.1 Reasons for amputation

Pezzin, Dillingham and MacKenzie (2000) describe traumatic amputation as being a source of “permanent impairment and functional limitation among adolescents and young working-age adults”. The amputation results in a loss of functioning which can impair employment and quality of life (2000). Perkins et al. (2012) found that trauma amputees were susceptible to high rates of chronic pain, physical inactivity, psychological problems and cardiovascular abnormalities. These impairments and consequences resulting from amputation are highly frustrating for patients that were previously highly active.

The age group with the most amputations due to dysvascularity and diabetes in the National Statistcs (National Amputee Statistical Database, 2009) were 75 and over and 64-75 respectively. In complete contrast the age group with the most trauma related amputations was 16-54. These figures show that trauma patients are likely to be much younger than diabetic or dysvascular patients. Horgan and MacLachlan (2004) found that studies related to the effects of age on amputees either found no relationship or higher levels of distress in younger individuals. The more recent work of Phelps et al. (2008) found that younger participants in their study consistently reported “significantly higher levels of depressive and post-traumatic stress disorder symptoms.” This work is reflected in a number of studies that found younger individuals have greater difficulty in adjusting to amputation (Desmond and MacLachlan, 2006; Livneh et al., 1999; Fisher and Hanspal, 1998).

Hammarlund et al. (2011) state that dysvascular amputees are usually limited physically due to disease-related symptoms and are therefore less active prosthetic users, whereas Perkins et al. (2012) state that trauma amputees are usually previously active individuals. Davies and Datta (2003) state that the chances of prosthetic mobility decrease with increasing age. These results are reflected in other studies which found that age was one of the most relevant predictors of prosthetic outcome (Geertzen et al., 2001; Traballesp et al., 1998; Leung et al., 1996). Geertzen et al. (2001) found that the negative predictors for successful rehabilitation were co-morbidity, advanced age and the level of amputation.

The main goal of rehabilitation is to help patients regain as much physical mobility as possible and Wetterhahn et al. (2002) found that there was a positive relationship between body image and regular participation in physical activity. Murray and Fox (2002) found that patients that were dissatisfied with their prosthesis had higher levels of body image disturbance. Body image has also been found to be highly correlated between self-esteem, anxiety, depression and life satisfaction, therefore the image an amputee has of themselves can affect these factors in a positive and negative manner (Breakey, 1997). The more negatively an amputee feels about their body, the less satisfied they are with their life therefore if physical activity is restricted for younger amputees due to a painful socket or long waits for repairs the consequences for individuals can be very large. Ide (2004) states that rehabilitation can be simply defined as ‘reintegration’ therefore anything that impedes this reintegration should be addressed. A link has been found between body image and sexualit activity, as loss of a limb can adversely affect body image and therefore sexual functioning and satisfaction (Ide, 2004; Geertzen et al., 2009). Ide (2004) states that physical and psychological aspects equally affect sexual performance, therefore performance of the amputee themselves has a strong influence on their sex life. Satisfaction with sex life is therefore important in reflecting the patient’s reintegration, which can be negatively affected by a negative body image. Body image can be influenced by physical activity and counselling therefore if patients are not able to be physically active or receive counselling they are more likely to have a negative body image and consequently poor sexual satisfaction.

Datta et al. (1999) conducted a 10 year follow up study of lower limb amputees and found that younger amputees required more repairs on their prosthesis than those of older patients. Due to trauma amputees principally being younger and more active, the need for their prostheses to be repaired will be increased and therefore their dependence on their service provider will increase. Patients that are heavily reliant on a service which does not fulfil their needs may be more inclined to take part in research in order to voice their concerns and opinions.

5.3.2 Information

There is very little literature on the importance of information provision for amputees, however Mortimer et al. (2002) state that minimum standards for information relating to phantom limb pain should be introduced. With so few papers surrounding this subject and the findings that content, mode of delivery and co-ordination of information surrounding phantom limb pain needed improvement, it can be surmised that information relating to other aspects of amputee rehabilitation will be in need of similar attention. Nielsen (1991) found that 44% of the amputees that took part in their study reported not receiving enough information and desiring more information before amputation.

A report by the Audit Commission (2002) states that “the quality of user and management information is generally poor”. Auditors conducting the Quality Health Surveys in 1999 states that “users do not know how to register complaints or provide useful feedback on the services provided” (The Audit Commission, 2002). Figure 5.2 shows results from the Quality Health Survey 1999 and clearly indicates that, at that time, patients were concerned about the lack of information they received (The Audit Commission, 2002).

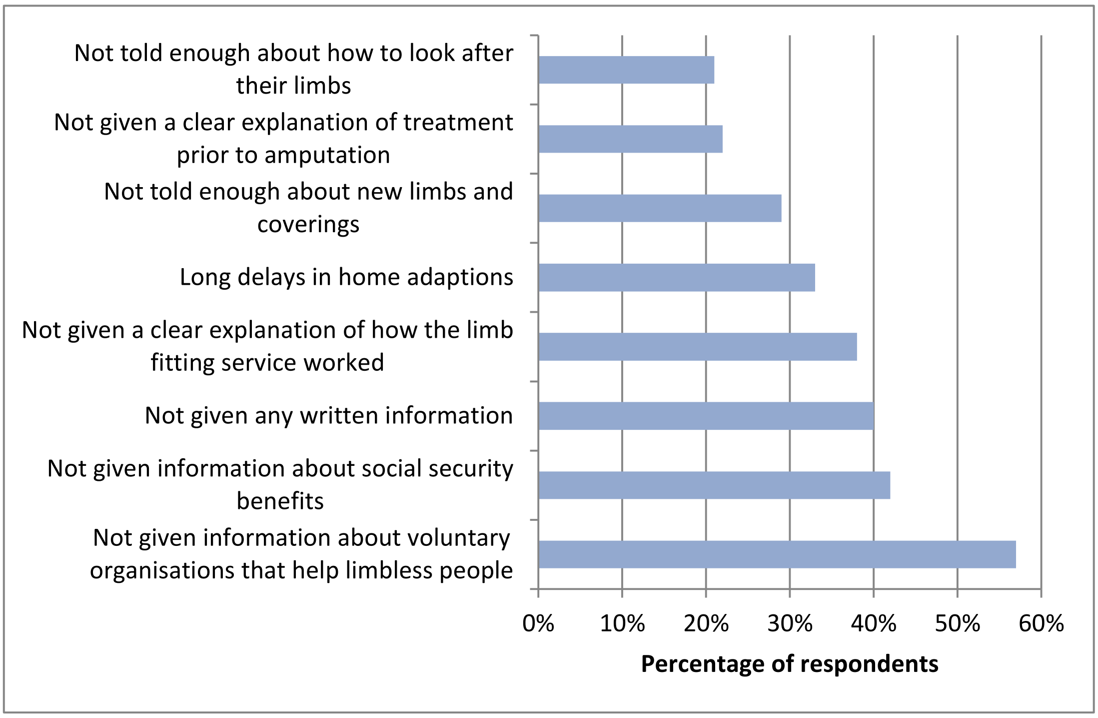


Figure 5.2: User satisfaction with the prosthetic service (The Audit Commission, 2002) (N = 2300)

Due to the lack of literature on information for amputees, literature on information for patients with other medical conditions was sought in order for comparisons to be made.

There are a large number of papers detailing the importance of patient information for various medical conditions (Smith et al., 2009; Hoffmann and McKenna, 2006; Pieper et al., 2006; Wachters-Kaufmann et al., 2005; Stewart et al., 2004; Hoffmann et al., 2004; McGregor et al., 2004; Kendall et al., 2004; Morris, 2001; Fitzmaurice and Adams, 2000). Comparisons can be made between some other medical conditions and amputation due to their life changing and life-long effects. Of these, stroke patients have commonalities with amputees as the majority of stroke patients are over 70 years of age, their lives are changed instantly following the stroke and the resulting disabilities often involve physical impairments (Lee et al., 2011). Although amputation does not cause cognitive impairments, these similarities mean that, due to a lack of literature on amputee information, comparisons will be made.

The importance of educating stroke patients and their carers is universally accepted (Smith et al., 2008; Rodgers et al., 2001) and timely, adequate, accurate and situation specific information is recommended as a key component of care provision (Smith et al., 2009; Wachters-Kaufmann et al., 2005). Improved knowledge about stroke (Forster et al., 2001; Evans and Held, 1984), de-creased anxiety levels (Evans and Held, 1984; Clark et al., 2003), improved family functioning (Clark et al., 2003; Evans et al., 1991), greater patient satisfaction (Rodgers et al., 1999; Clark and Smith, 1998) and improved functional status and social recovery (Clark et al., 2003) are all advantages documented to be brought about by appropriate information provision. Hoffman et al. (2004) state that in order to educate patients and carers the information provided must be what they want as a stroke affects each patient differently therefore the important information for each patient will differ. Despite this, the information provided by professional care providers is often insufficient meaning that the informational needs of patients and carers are not met (Wachters-Kaufmann et al., 2005; Hoffmann et al., 2004). Smith et al. (2009) state that patients' understanding of stroke, the consequences and the support available is very poor. The area most lacking is information concerning the emotional consequences of stroke (Wachters-Kaufmann et al., 2005). Smith et al. (2009) state that inadequate provision of information has important consequences for compliance with secondary prevention and the longer term psyhcho-social outcome for patients and carers. The work by Maclean et al. (2000) reflects this as they found that patients were less motivated to work at their rehabilitation due to anxieties that stemmed from a lack of information. Wachters-Kaufmann et al. (2005) state that it is extremely important to provide carers with information due to the emotional problems associated with stroke and their own anxieties and insecurities. Stroke patients and their carers want care providers to deliver information that is tailored to their needs (Wachters-Kaufmann et al., 2005). Patients and carers prefer the acting physician to give them the information they need (Clark, 2000), and the literature shows that they would like written information to support verbal information that is provided (Wachters-Kaufmann et al., 2005; Hare et al., 2006; Wiles et al., 2002). There are however reported issues with written information for stroke patients as a recent UK survey reported that 45% of the respondents were unable to understand the information given to them in hospital (Healthcare Commission, 2005). Hoffman et al. (2004) state that the inconclusive evidence surrounding written information may be due to the lack of tailored information as each stroke patient is different. They also found that patients want information tailored to their personal situation as this improved the likelihood of information being read and remembered (Hoffmann et al., 2004). The likenesses between the information provision for stroke and amputation patients appear to be many. The lessons learned from stroke patients should be applied to amputees as the benefits of appropriate information can greatly affect patients' quality of life.

These findings are also reflected in literature pertaining to other medical conditions. McGregor et al. (2004) found that providing patients with a class and booklet about their hip replacement preoperatively, improved patient satisfaction and also reduced the cost of the procedure as the length of stay in hospital and therapy input were reduced. Similarly, Pegg et al. (2005) found that when traumatic brain injury patients were given personalised information they exerted greater effort in physiotherapy, were more satisfied with rehabilitation treatment and made greater improvements in functional independence. Work conducted by Stewart et al. (2004) found that patients, especially women, recovering from an acute ischemic coronary event reported receiving much less information than they wanted from their health professionals.

The literature shows that patients with a wide range of medical conditions are not receiving the information they desire from health professionals. The advantages of information provision are well documented and have been found to save services money due to better patient compliance and understanding (McGregor et al., 2004). Although these medical conditions cannot be directly linked to amputation, there are similarities due to the life-long disabilities resulting from the condition and the immediate change in lifestyle that must ensue.

5.3.3 Aims and Goals

Gallagher (2004) states that it is important that the values and requirements of users are considered during rehabilitation. Scherer (2002) found that 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. This implies that medical professionals are using the medical model of disability and consumers the social model. In the medical model described by Bickenbach et al. (1999) disability is defined as a deviation from biomedical norms of structure and function and the disadvantages that disabled people experience are seen as the direct and inevitable consequence of their impairments and disabilities. Scambler (2008) describes the social model as seeing the problems experienced by people with disabilities being the direct product of physical, social and attitudinal environments. It is important that professionals do not concentrate on the medical model and understand the needs of their patient and what they consider to be a successful outcome as well as having an ability to provide patients with technology that will meet their individual needs (Gallagher, 2004).

Siegert and Taylor (2004) describe goals and goal setting as being a fundamental component of any sound rehabilitation programme. There is also an assumption that goal setting is an essential part of rehabilitation for each individual patient as Barnes and Ward (2000) state that “the essence of rehabilitation is goalsetting”. In order for patients to progress through a rehabilitation programme Barnes and Ward (2000) state that agreed goals and outcomes are essential. Although many studies have shown how effective goal setting can be, McLellan (1997) suggests that goals are of little use if they are imprecise, therefore detailed goals must be set combining the efforts of the rehabilitation team and the patient and their family. McLellan (1997) also states that in order for patients to navigate rehabilitation successfully measurement of outcomes is vital. Siegert and Taylor (2004) state that there is a lot of evidence to suggest that goal setting should be a collaborative process with the patient, rehabilitation staff and patient’s family in order to create a set of shared goals that are achievable. There is strong consensus among writers that the SMART acronym should be used as a guideline for goal setting (2004). McLellan (1997) suggests the acronym stand for Specific, Measurable, Activity related, Realistic and Time-specified with regards creating the ideal goal.

Amputation is well documented as being associated with depression, anxiety, grief and social isolation (Desmond and MacLachlan, 2002) therefore it is concerning that patients should then have to deal with concerns with regards their rehabilitation and the lack of goal setting. Hurnet et al. (2006) state that “goals affect performance by focusing attention, directing effort, increasing motivation and enabling the development of strategies to achieve one’s objectives”. Barnes and Ward (2000) state that goalsetting is a “dynamic process that can be changed and adjusted according to process” which clearly indicates that goals should be updated on a regular basis as the patient makes progress through their rehabilitation.

A study conducted by Playford et al. (2000) into professionals’ perceptions of goal setting in rehabilitation showed that goals tended to be formulated and retained by the rehabilitation team rather than the patient and formal goal setting was rarely conducted by or with the patients themselves. The study also showed that external factors such as staff turnover and understaffing had a large impact on the success of any goal setting programme (Playford et al., 2000). Barnes and Ward (2000) showed that patients and their families can have very different viewpoints on what is realistic and important to the rehabilitation specialists, where goal setting is concerned. This can cause conflict between patients and their rehabilitation specialists which may cause further anxiety for patients and their carers.

A study by Rushton and Miller (2002) showed that Goal Attainment Scaling (GAS) was a promising outcome measure for use with patients with lower limb amputations. Goal Attainment Scaling is an individualised health outcome measure for assessing outcomes in mental health treatment (Rushton and Miller, 2002). Rushton and Miller (2002) found that the psychometric properties of GAS could be appropriate for assessing clinically important change in the rehabilitation of lower limb amputees (Rushton and Miller, 2002). Further research in this area should be conducted in order to ascertain whether GAS should be introduced to all DSCs as an improved outcome measure.

5.3.4 Spare Limbs

A report by The Audit Commission (2002) states that "The increasing use of modular limbs and investment in a speedy and efficient repair service means that, for most users, a spare limb is not necessary". The same report by The Audit Commission (2002) found that around 90% of the users given spare limbs "seldom needed to use their second limb, if at all". The report also stated that once targets for repair of limbs were met the service would be "better placed to provide second limbs that enhance users' health, quality of life and social participation – for example, by providing more people with limbs for sports, including swimming". This statement highlights that sports limbs enhance the quality of life of the patients that receive them and therefore every effort should be made to provide them to as many patients as possible.

5.3.5 Physiotherapy

Esquenazi and DiGiacomo (2001) suggest that a day rehabilitation programme, involving physiotherapy for 3 hours a day, 5 days a week or 6 hours a day, 2 to 3 days a week is a good system to foster community reintegration for new amputees. Sullivan et al. (2003) found that patients became frustrated with rehabilitation due to the slowness of the process. Privratsky (2008) found that the majority of prosthetists in their study thought working with a physiotherapist in the same building would not only improve the quality of service but also improve the skills of both clinicians.

Privratsky (2008) states that it is generally accepted and understood that patients benefit most from a cooperative effort by all professionals involved in their care. This is echoed by Boulton et al. (2000) who state that a complete management programme is most effectively delivered by a well-coordinated multidisciplinary team based at the rehabilitation centre.

5.3.6 Counselling

Bhuvaneswar et al. (2007) conducted a review of the many studies on the psychological effects of amputation. Callaghan and Condie (2003) found that there is a “stronger relationship between mental health and quality of life than between physical health and quality of life.”

Price and Fisher (2002) state that the benefits of counselling indicate that the opportunity to access the service should be available to all interested patients.

Desmond and MacLachlan (2002) state that development of realistic rehabilitation expectations should be included in this counselling intervention prior to surgery. It has been proven that emotional disclosure of stressful life experiences can have both physical and psychological benefits and reduce the number of visits to clinicians (Pennebaker, 1997). Medhat et al. (1990) state that acceptance of the amputation is extremely important and can influence the activity of the patient.

5.3.7 Patient Volunteer Visitors

The advantages of patient volunteer visitors have been well documented with Froggatt and Mawby (1981) stating that an experienced amputee can play an important role in offering advice of a practical and emotional nature to new patients. More recent work conducted by Briggs (2006) which found that meeting and talking with other amputees is important, reiterates the earlier findings of Froggatt and Mawby (1981). This is also reflected in the work of Novotny (1996) who states that peer support “expands the resources available for coping with limb loss while educating amputees, family members and others”. Jacobsen (1998) states that meeting with other amputees allows new amputees to gain information on the rehabilitation process, charities for support and coping strategies. Although the staff at Disablement Services Centres treat amputee patients constantly, Butcher (2009) states that peer support provides a perspective that a patient’s healthcare team cannot provide.

5.3.8 Service

Marquis et al. (1983) state that patient satisfaction plays an important role in retaining relationships between patients and healthcare providers. In their study of issues of importance for amputees, Legro et al. (1999) reported that patients listed having a good prosthetist as being important to having a good life. Legro et al. (1999)

also reported that the most important function of the prosthesis was to enable walking and the most important characteristic of the prosthesis was fit.

Nunnally (1967) states that difficulties lie in clarifying whether the connection between satisfaction and other variables, such as socket fit, are due to "differences in expectations and readiness to express negative views or actual differences in the quality of healthcare provided".

Gallagher and Maclachlan (2001) found that patients in their study described the fit of their prosthesis as something they are rarely satisfied with and the main source of stump pain was an ill-fitting prosthesis. Figure 5.3 shows the results from a quality health survey conducted in 1999 for the reasons why patients could not wear their prosthetic limb (The Audit Commission, 2002).

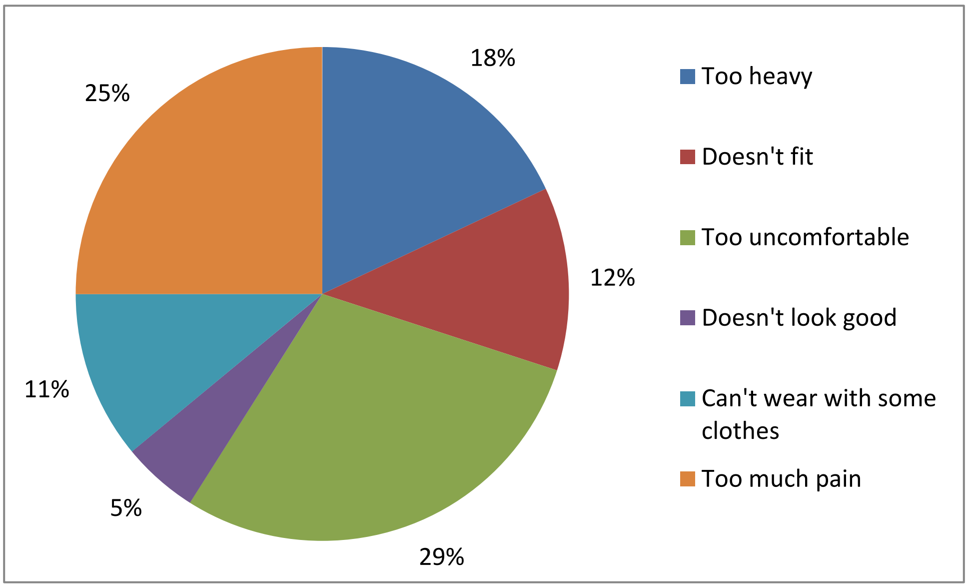


Figure 5.3: Reasons for not wearing prosthetic limb (The Audit Commission, 2002)

5.4 Rationale

The main purpose of this study was to ascertain patient opinions on the service they were provided by NHS Disablement Services Centres. In order to gain this information, patients were the sole focus of the study. The information gained in Study 1 had provided the necessary insight into prosthetic rehabilitation to allow questions of relevance for patients to be designed. The results from Study 1 revealed that the policies in place at the centres may not always be followed by clinicians therefore patient experiences may be very different to the description of the service provided by the members of staff. The data collection method used was required to elicit accurate accounts of experiences, of a variety of different services, from patients.

5.5 Methods

Due to the number of referrals to prosthetic centres each year (National Amputee Statistical Database, 2009) the population for enquiries into the NHS prosthetic provision is relatively large. It would be impossible to sample every amputee registered at every centre in the UK due to the time and budget constraints of this research as well as the practical and ethical issues associated with gaining information on every patient. It became apparent that an approach using interviews would limit the sample size due to the length of time interviews take to conduct, therefore limiting the ability to generalise the results. Another issue was that the objectives of this study dictated that a large number of questions must be answered, therefore making an interview very time consuming. It was deemed unfeasible to use such a large interview structure as participants may well become fatigued, reducing the reliability of the answers given. An alternative method of data collection that allowed for a large number of questions on a variety of subjects was therefore sought.

5.5.1 What is Quantitative Research?

Quantitative research is described by Saunders et al. (2007) as being any data collection technique or data analysis procedure that generates or uses numerical data. Quantitative research tends to be focussed on finding ‘facts’ with the researcher having very little relationship with the subjects of the research (Gray, 2009). The distance kept between researcher and participant can be emotional, so that researchers maintain detachment from the issues being investigated, physical, using data gathering techniques which do not require direct contact with participants, or both (Gray, 2009). Quantitative studies seek to verify theory as they usually begin deductively with a theory which is then tested through the research process (Gray, 2009). Questionnaires are the data collection method most commonly associated with quantitative research.

5.5.2 Questionnaires

Questionnaires are one of the most widely used techniques for gathering primary data(Gray, 2009). Gray (2009) defines questionnaires as “research tools through which people are asked to respond to the same set of questions in a predetermined order.” Using this definition, questionnaires encompass both structured and telephone interviews as well as those which are answered without an interviewer being present. Due to the uniformity of the questions being asked, questionnaires are an efficient way of collecting responses from a large population.

5.5.3 Questionnaire techniques

5.5.3.1 When to use questionnaires

The use of a questionnaire should always be carefully considered with reference to other data collection methods such as semi structured interviews in order to ascertain the appropriate method for a particular project (Saunders et al., 2007). Questionnaires are not usually suitable for exploratory research or research requiring large numbers of open ended questions. Robson (2002) describes questionnaires as working best with standardised questions, the interpretation of which can be confidently assumed to be the same by all respondents.

Questionnaires have inherent advantages when used for quantitative investigation.

- Costs are low in both time and monetary terms. Questionnaires can potentially be sent out to thousands of respondents with very little cost incurred.
- Data can be collected very quickly and from a large number of people.
- Respondents are able to complete the questionnaire at a time that is convenient for them.
- Data analysis of closed questions can be done quickly and with relative ease.
- Anonymity of respondents can be guaranteed.
- Interview bias is not an issue (for self-administered questionnaires) (Gray, 2009; Gillham, 2000).

Questionnaires do however have their disadvantages which must be taken into consideration before the decision is made to use this form of data collection. Unless participants find the questionnaire engaging or rewarding they are unlikely to complete it which can lead to very low response rates. This can be worsened by the length of the questionnaire. Gillham (2000) advised that return rates can be adversely affected by lengthy questionnaires and should therefore be limited to four to six pages. Researchers are not in a position to know when respondents have given inaccurate or misleading answers and there is no opportunity to ask questions or ascertain the meaning of ambiguous answers (Gray, 2009).

5.5.3.2 Types of questionnaire

Figure 5.4 shows the different types of questionnaire as described by Saunders et al. (2007). The design of a questionnaire depends on how it is to be administered and the amount of contact there is between investigator and respondent (Saunders et al., 2007). Self-administered questionnaires are completed with no contact from the investigator and can therefore be administered by a number of different means. Interviewer administered questionnaires are usually conducted over the telephone or in person depending upon the research project.

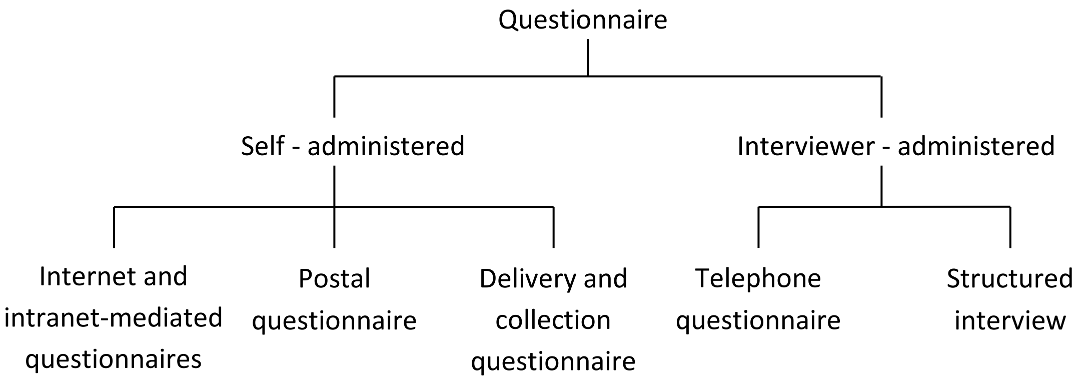


Figure 5.4: The different types of Questionnaire (Saunders et al., 2007)

Choosing the right questionnaire depends on a variety of factors which are related to the research question(s) and objectives of a project. Saunders et al. (2007)

describe six factors which should be carefully considered when choosing the type of questionnaire to be used.

- Characteristics of the respondents from whom the data is to be collected
- The importance of reaching a particular person as respondent
- The importance of respondents' answers not being contaminated or distorted
- The size of the sample required for analysis, which should take into account the likely response rate
- The type of question needing to be asked to collect relevant data
- The number of questions needing to be asked to collect enough data

The attributes of the population to be sampled should be carefully considered so as not to skew the results. Internet mediated questionnaires are useful for reaching a wider audience however those who cannot use or afford the internet are immediately excluded. Postal and delivery and collection questionnaires can remove this problem, however this requires names and addresses to be known which is not always possible. Internet mediated questionnaires can be placed on forums, websites and the links emailed out to people which helps to include much larger numbers of the population needing to be sampled. Delivery and collection questionnaires also run the risk of lower response rates due to participants feeling their confidentiality could be compromised due to the investigator knowing which questionnaire was retrieved from their house. Telephone and structured interviews also have the same problems that postal questionnaires do in that the telephone number of the participant must be known in order to conduct or arrange an interview. This is simply not possible in some circumstances and therefore internet mediated questionnaires are the only option.

It can be difficult to ascertain whether the correct person has responded to the questionnaire when using postal or delivery and collection questionnaires which reduces reliability of responses (Saunders et al., 2007). The same could be said for internet mediated questionnaires as it is impossible to know who is answering the questionnaire if it is placed on a website or forum. Witmer et al. (1999) states that the reliability of internet mediated questionnaires used in conjunction with email offer a greater control because most patients read and respond to their own emails. Interviewer administered interviews removes this issue completely and therefore increases the reliability of results as well as offering the option of recording non-respondents to ascertain the impact of bias caused by refusals (Saunders et al., 2007).

Distortion and contamination of answers greatly reduces data reliability therefore steps should be taken to minimise the possibility of this happening. Respondents may deliberately guess an answer due to insufficient knowledge on the subject which is known as 'uninformed response'. This is increasingly likely when an incentive is offered for the completion of the questionnaire (Saunders et al., 2007). Dillman (2007) found that respondents to self-administered questionnaires are less likely to give answers that they perceive to be more socially desirable or believe to be what the investigator needs. Respondents may however discuss their answers with others which, in turn, contaminates their response. Respondents to telephone questionnaires and interviews are more likely to respond in a manner they think they should in order to please the interviewer due to the personal contact involved. This can be minimised by correct wording of questions and good interviewing technique (Saunders et al., 2007).

Response rate is something that must be considered when choosing a questionnaire. Interviewer administered questionnaires usually have a higher response rate than self-administered questionnaires. Internet mediated questionnaires have the lowest response rate with 11% being typical (Saunders et al., 2007). Postal questionnaires have variable response rates with 30% being reasonable. Interviewer administered questionnaires have a high response rate usually in the region of 50-70% (Saunders et al., 2007). The sample size and way in which respondents are selected have implications for the confidence in the data and the extent to which the results can be generalised.

Oppenheim (2000) suggests that longer questionnaires are best to be conducted as a structured interview. Interviews also allow for the inclusion of more complicated questions than other forms of questionnaire (Oppenheim, 2000). Telephone interviews are advised to be no longer than half an hour which can limit the number of questions the interviewer can ask. Making sure the respondent is engaged and does not become bored or lose interest is very important, therefore the length of the questionnaire should be carefully considered (Saunders et al., 2007). Complicated questions should only be used in interviewer administered questionnaires due to the difficulty with ambiguity of responses. Self-administered questionnaires should use mainly closed questions with complicated questions kept to a minimum (Saunders et al., 2007).

The resources available for data collection will have a large influence over the data collection method. Time, financial situation, availability of interviewers and ease of automating data entry are all factors to be considered. Self-administered questionnaires typically take between 2-8 weeks from distribution to collection. Interviewer administered questionnaires take longer to complete for the same sample size and will depend greatly on the number of interviewers and the number of interviews to be conducted (Saunders et al., 2007). Costs involved in internet mediated questionnaires are minimal due to many new automated expert systems reducing costs and saving investigators time. Costs involved in a postal questionnaire should be calculated and the advantages weighed up against the cost implications. Printing, outward and return postage, clerical support and data entry are all costs incurred for a postal questionnaire. Telephone interviews can also be expensive due to the cost of the call, employing an interviewer, clerical support and data entry. Structured interviews incur the added cost of travel which can be the deciding factor in whether to use this data collection method or not (Saunders et al., 2007).

A questionnaire was a more appropriate format for this study as participants could answer at a time convenient for them and the whole process would take no more than 15 minutes to complete. The type of questions needing answers could be manipulated into multiple choice questions with very little need for open ended questions. Bosmans et al. (2009) state that the use of a questionnaire with particular items for a specific target group were deemed an acceptable method for producing improvement suggestions for daily practice in healthcare. The questionnaire was designed to include questions that covered each of the objectives with a mixture of attitude, multiple choice and open ended questions.

5.5.4 Reliability and Validity

5.5.4.1 Assessing validity

The internal validity of a questionnaire is the ability of the questionnaire to measure what it is intended to and therefore what is found from the data is representative of the reality of what is being measured (Saunders et al., 2007). Cooper and Schindler (2005) state that content validity, criterion related validity and construct validity are referred to when discussing the validity of a questionnaire. Content validity is concerned with how well the questionnaire covers the research questions. This can be assessed through piloting and discussion with others in the field in order to ascertain whether the questions are all relevant and necessary for answering the research question (Saunders et al., 2007). Criterion related validity is concerned with the ability of the questions being asked to make accurate predictions (Saunders et al., 2007). Questions, for example, can be used to predict the buying behaviour of customers and therefore the accuracy of the predictions can be tested using the predictions from the questionnaire and the data on buying behaviour of customers. Construct validity refers to the extent to which the questions measure the presence of the constructs they are intended to measure. Constructs are usually aptitude, personality tests or attitude scales (Saunders et al., 2007).

5.5.4.2 Threats to Validity

Gray (2009) suggests that the validity of a questionnaire can be affected by poor wording and sequencing of questions and confusing structure or design. It is also imperative that the questions cover the research issues in terms of content and detail, therefore avoidance of unnecessary questions is very important. The addition of irrelevant questions increases the length of the questionnaire which could reduce the number of respondents. External validity is then threatened if the response rate becomes too low as this will limit the generalisability of the findings (Gray, 2009).

5.5.4.3 Testing for reliability

The reliability of a questionnaire is concerned with how robust the questionnaire is and whether it will produce consistent findings at different times under different conditions, i.e. with different samples, assuming that what is being measured has not changed (Black, 1993). In order to assess reliability the data collected can be compared with data from a variety of sources if this is possible. Mitchell (1996) has outlined three other common approaches to assessing reliability which are test re-test, internal consistency and alternative form. Correlation of data collected using the same questionnaire under as near equivalent conditions as possible is the method for obtaining test re-test estimates of reliability (Mitchell, 1996). Respondents are asked to complete the same questionnaire twice, which can be difficult as respondents may be reluctant to answer the same questions again (Mitchell, 1996). Respondents are likely to answer differently the longer the time period between the first and second questionnaires. Saunders et al. (2007) therefore suggest that this method be used in conjunction with other assessment methods. Internal consistency involves correlating the responses to each question with other questions in the questionnaire. This allows measurement of the consistency of responses across those questions which have been correlated (Saunders et al., 2007). Alternative form, as outlined by Mitchell (1996) is the comparison of responses to alternative forms of the same question or group of questions. These are often known as 'check' questions and their use can introduce an added issue of respondents noticing their presence and referring back to their previous answer. It is also difficult to ensure check questions are substantially equivalent to the original therefore should only be used sparingly (Saunders et al., 2007).

5.6 Design

5.6.1 Questionnaire development

An evaluation of a number of questionnaire models designed for use with prosthetic patients was carried out in order to ascertain which one, if any, could be used for this research. A study conducted by Geertzen et al. (2002) into consumer satisfaction in prosthetics and orthotics facilities used a modified SERVQUAL questionnaire which was created by Parasuraman et al. (1988) in order to assess customer perceptions of service quality. The five domains present in SERVQUAL are Tangibles, Reliability, Responsiveness, Assurance and Empathy (Parasuraman et al., 1988) within which questions were asked twice to gauge the importance of the issue and the patient's experience with that issue (Geertzen et al., 2002). The model used a five point Likert type scale for data collection, with the inclusion of a sixth option of 'cannot be answered due to lack of experience' so that participants that had no experience of the service being evaluated could opt out of answering the question rather than giving an inaccurate answer (Geertzen et al., 2002). Bosmans et al. (2009) state that the service of the facility attended is not the only factor in consumer satisfaction. Consumer satisfaction is also dependent on "the use and the functioning of the device and on the satisfaction with the cosmetics of the device". Due to this, Bosmans et al. (2009) recommend the use of a more extensive questionnaire as SERVQUAL "lacks assessment of these issues".

Work conducted by Van Der Linde et al. (2007) used a variation of the QUOTE (Quality Of care Through the patient's Eyes) instrument, created in The Netherlands. The important concept imbedded in the QUOTE model, was the central position given to patients in its development (1998). The QUOTE model has been adapted to produce a number of QUOTE questionnaires for different categories of frequent users of healthcare, such as the elderly and HIV patients (Hekkink et al., 2003; Sixma et al., 2000; Van Campen et al., 1998; Van Campen et al., 1997). Focus groups, of patients from the relevant healthcare background, were used to create each of these questionnaires to allow patients to provide the subjects of importance requiring investigation. The work conducted by Van Der Linde et al. (2007) used a 24 item QUOTE questionnaire, split into four categories: service demand, formulation of the prosthetic prescription, training, information and aftercare and claim and insurance aspects. The model used the same technique as SERVQUAL to assess importance and experience by asking patients to answer the same set of questions twice (1998). Wording of individual items was kept as simple as possible to reduce the possibility of participant perceived ambiguity and confusion (Van der

Linde et al., 2007). The factors being addressed in the QUOTE instrument were not all relevant to the research questions in this study and therefore model as a whole could not be used.

Legro et al. (1998) designed the Prosthesis Evaluation Questionnaire (PEQ) which allowed the participant to rate the qualities of their prosthesis, their ability to perform various activities and the psychological and social effects of amputation. This model has been used in a number of studies and has a high degree of content validity (Boone and Coleman, 2006). The questionnaire itself comprises of 82 questions, divided into 9 scales. Seventy six of the 82 questions required the use of a visual analogue scale, with the other six questions being open ended (Ferriero et al., 2005). A study conducted by Ferriero et al. (2005) found that the response format for the PEQ was poor, creating scaling problems and also increasing the completion time. The questions and response format within this model were deemed unsuitable for use within this study as participants would be answering online and not in person with a clinician.

Gallagher and MacLachlan (2000) developed the Trinity Amputation and Prosthesis Experience Scales (TAPES) in order to evaluate the adjustment of lower limb amputees to amputation and use of a prosthesis. The development of these scales was deemed important as general disability measures are not sensitive to “the particular peculiarities” of amputation (Gallagher and MacLachlan, 2000). The scales consist of three main sections: psychosocial adjustment to limb loss, activity restriction due to limb loss and prosthesis satisfaction. Each statement in Sections 1 and 3 require a response on a five point scale from strongly agree to strongly disagree. Section 2 requires a response on a 3 point scale from limited a lot to not limited at all. This model has been used in a number of investigations and has been deemed valid and reliable through extensive research (Gallagher and Maclachlan, 2001; Gallagher and MacLachlan, 2000; Gallagher and MacLachlan, 2004; Gallagher et al., 2001). Evaluation of this model highlighted that the questions in use did not cover all aspects of the research questions and therefore the model in its entirety could not be used.

Heinemann, Bode and O'Reilly (2003) developed the Orthotics and Prosthetics Users' Survey (OPUS) due to perceived need for a set of valid and reliable measures to assess relevant aspects of prosthetic and orthotic patients' perspectives of function, quality of life and satisfaction. These measures could be used to help establish clinical pathways and standards of care, serve as the foundation for research-based quality improvement initiatives and support the regular appraisal of various clinical practices (Heinemann et al., 2003). The OPUS also used Likert type scales for participants to report their answers, with a range of different categories including physical ability (Heinemann et al., 2006). As with the other models, OPUS did not cover all of the necessary subjects to answer the research questions of this study, therefore only principles from the model could be used.

Due to the lack of an appropriate model, elements of each of the models discussed were taken forward for use in the development of a new questionnaire that would cover all factors in the research questions.

In order to create a valid and reliable questionnaire the reasoning set out by Fitzpatrick (1991) on how to design questionnaires was followed with the integration of the elements taken from the four different models. The work conducted by Fitzpatrick (1991) has been utilised by many researchers in order to produce a valid and reliable questionnaire (Coulter et al., 2009; Antoniotti et al., 2009; Boyer et al., 2009; Sofaer and Firminger, 2005).

5.6.2 Questionnaire design

Fitzpatrick (1991) outlines a number of considerations when designing a questionnaire, all of which will be discussed in this section:

- Episode specific or more general termed questions – Fitzpatrick (1991) states that "the argument for episode specific questionnaire items is that they should reflect more accurately individuals' actual experiences". Due to the nature of the objectives, episode and factor specific questions were deemed appropriate.
- Questions asking directly about satisfaction or those that infer satisfaction from the choice of answer – Fitzpatrick (1991) states that neither approach has been reported to have advantages over the other therefore the questions were be

worded in the most logical and transparent manner in order to avoid participant confusion.

- Focus of questions - Fitzpatrick (1991) states that comparisons are more easily made between satisfaction with different elements of care if the questions are clearly focussed, therefore each element of care was given a section of its own with questions specific to that element of care only.
- The form of answers offered to participants - Fitzpatrick (1991) describes a number of response formats including the simple ‘yes’ or ‘no’. The advantages of the simplicity of this format, however are said to be outweighed by participants often providing a positive answer in response to questions about healthcare. Nunnally (1967) suggests that increasing the number of responses available to participant increases the reliability and precision of the question, however increasing the responses above seven has a minimal effect and five response categories are most common. Using this information questions were designed using ‘yes’ or ‘no’ responses and more complex response formats.
- Inclusion of ‘background’ variables - Fitzpatrick (1991) states that variables such as age, sex and education may all “exert as strong an influence on levels of satisfaction as any direct effect of health services”. Age is the only variable consistently related to satisfaction as older respondents appear to express more positive satisfaction (Fitzpatrick, 1991).

5.6.2.1 Likert type attitude items

Although the Likert scale is now rarely used, the question format Likert created is now one of the most frequently used in survey research (Babbie, 2010). Likert type attitude items are considered advantageous due to the range of choices available with respect to the number of responses as well as the unambiguous nature of the response format (Babbie, 2010). The research objectives require information from participants based on their attitudes, opinions and beliefs therefore Likert type attitude items were deemed the most appropriate for some elements of care. Preece et al. (2011) present guidelines for the use of Likert type attitude items, which were followed with the following design decisions being made:

- A five point scale – allows for more accurate data than a three point scale. A seven point scale was not deemed necessary due to its over complex structure and the proposed length of the questionnaire.
- Responses arranged from Strongly Agree to Strongly Disagree – this reduces confusion as the responses are set out in a logical manner.
- Each set of Likert type attitude items to use the same response format – this reduces error as once participants have used the response format once they are likely to answer the next question using the assumption that the responses are set out as they were previously.

Kahneman and Kruegar (2006) state that there is no guarantee, when investigating wellbeing, that participants will use the scales provided for response comparably. In order to minimise this, words which have clear and common meanings to all participants were used when creating the questions. Negatively worded questions have been suggested in the literature (Weijters and Baumgartner, 2012) as being beneficial guarding against acquiescent behaviours or respondents' tendencies to generally agree with statements more than disagree. Weijters and Baumgartner (2001) state that agreement response bias is a distorting influence when measuring attitudes, which can be corrected for by the use of reversed items. Tourangeau, Rips and Rasinski (2000) recommend the use of a balance of items with opposite wording as this can help guard against participants developing a 'response set' whereby they provide more general feelings about the subject and pay less attention to the content of the specific statements. Reversed items may also act as cognitive 'speed bumps' (Podsakoff et al., 2003) and disrupt participants from mindless repetition of responses. There has been a debate about the use of negatively worded items for many years, however Barnette (2000) states that in the past twenty years most of the research on this practice has revealed problems with factor structures, internal consistency and other statistics. Schriesheim et al. (1991) state that the internal consistency reliability was significantly reduced by the use of polar-opposite items. Confirmatory factor analysis was completed by Benson (1987) on three forms of the same questionnaire (all positively worded, a mixture of positive and negatively worded and all negatively worded questions) which produced results that suggest response patterns are different for each format and therefore score interpretation could potentially become biased. De Vellis (2003) argues strongly against the use of negatively worded items for these reasons. Barnette (2000) states that validity and reliability of scores on surveys using a balance of negative and positively worded items is reduced and therefore an alternative to this would be to use a bidirectional response format to protect against agreement or response set bias. A bidirectional response format would involve reversing the responses from Strongly Agree - Strongly Disagree, to Strongly Disagree – Strongly Agree. Barnette (2000) states that this does not result in a loss of internal consistency, however it was previously decided to use the same response format in order to reduce participant confusion. The latest research conducted by Weijters and Baumgartner (Weijters and Baumgartner, 2012) analyses the previous research on negatively worded items and advocates the continued use of such items.

Due to the lack of recent research opposing the use of negatively worded items and the conclusive work presented by Weijters and Baumgartner (Weijters and Baumgartner, 2012), negatively worded items were included in the initial questionnaire structure and Cronbach's alpha was calculated to determine internal Consistency (Pallant, 2010). Cronbach's alpha is the most commonly used method for calculating internal consistency, however there are a variety of other methods that can be used (Saunders et al., 2007)

Another issue to consider was whether or not to use a forced rating scale or include a 'Don't know' option. Friedman and Amoo (1999) state that using forced choice rating scales will bias results as they eliminate the participants that have no opinion or are undecided as these participants will probably select from the middle of the scale. This action will bias results by shifting the median and the mean towards the middle of the scale and implying that every participant has an opinion, which may not be true (Friedman and Amoo, 1999). Tull and Hawkins (1993) also state that when it is believed by the researcher that potential participants could truly have no opinion regarding the subject under investigation, less accurate responses will be provided if the 'don't know' option is removed. If a researcher is confident that the majority of potential participants will have an opinion and wish to eliminate the option to not disclose their opinion, Friedman and Amoo (1999) state that removal of the 'Don't know' option is then reasonable. The potential participants for this study all have very different experiences and opinions and therefore it is not certain whether they will all have an opinion on every subject being investigated. Patients who had traumatic amputations for example may not have been given any information at all until they reached rehabilitation due to their incapacity at the time. Forcing them to answer questions on their attitudes towards information would therefore provide inaccurate results.

5.6.2.2 Question design

In order to answer the study objectives completely, each objective was given a separate section within the questionnaire and appropriate questions were created using the information gained in Study 1. It was felt that open-ended questions were appropriate for a very small number of questions as more in-depth information was required, therefore they were included with the intention of analysing the results thematically. Questions were kept as simple as possible to avoid ambiguity and participant confusion.

5.6.2.3 Satisfaction and experience

The role of consumer satisfaction is increasing in importance with respect to quality of care reforms and health care delivery across Europe and the United States of America (Bleich et al., 2009). The views of patients are an important tool in evaluation and improvement of current services (Ahmad et al., 2012). A study conducted by Alazri and Neal (2003) into how satisfaction with service provision effects outcomes in patients with Type 2 diabetes, found that recovery from illness was more swift in patients satisfied with the service provision, as compliance with the medical regimes given was increased and medical resources provided were used appropriately. Although not all amputees have Type 2 diabetes, satisfaction with service provision clearly has an impact on patient's compliance with interventions which will translate to many other services including prosthetic rehabilitation.

Patient satisfaction therefore plays a very important role in the recovery of patients and should be evaluated in order to aid improvements to the service.

Ahmad et al. (2012) define patient satisfaction as a set of “attitudes and perceptions of patients towards health services” and therefore can be measured by the degree to which individuals regard their health care as beneficial and effective. There is on-going debate in the literature as to what influences patient satisfaction with Williams (1994) stating that patients may have a “complex set of important and relevant beliefs which cannot be embodied in terms of expressions of satisfaction”. Bleich (2009) state that there are two challenges for consumer satisfaction studies the first of which being the lack of a universally accepted measure and definition (Crow, 2002; Hudak and Wright, 2000; Sitzia and Wood, 1997; Carr-Hill, 1992). The second challenge is the dual focus found in this area of research, as some researchers focus on patient satisfaction with the quality and type of health care services provided (Nguyen Thi et al., 2002; Jackson et al., 2001; Kane et al., 1997; Linder-Pelz, 1982) while others focus on patient’s satisfaction with the health system on a more general level (Starfield, 1991; Blendon et al., 1990). Avis et al. (1995; 1997) found that within the UK satisfaction could not be explained entirely in terms of meeting expectations. Satisfaction in healthcare is therefore thought to be determined by a number of factors which can be divided into two groups: the characteristics of the patient and the features of the health care delivery services.

The work conducted by Crow et al. (2002) describes the different factors in each group:

- Patient Characteristics
    - Experience
    - Expectations
    - Health Status – e.g. physical health, disability, low quality of life, psychological distress
    - Socio-economic and demographic characteristics – e.g. gender, age, race, education

- Health Service Factors
    - In-hospital satisfaction – e.g. nursing strain and exhaustion
    - Outpatient care – e.g. professional standards, interpersonal relationships
    - Primary care – e.g. long wait times, patient – doctor communication, restricted access to services, longer consultations
    - Patient – practitioner relationship – e.g. physician interpersonal skills, information provision and advice

Bleich, Özaltin and Murray (2009) found that experience had a large influence on patient satisfaction however, factors external to the healthcare system such as expectations, health status and type of care had more influence on satisfaction. There are clear discrepancies in the literature about the influences on satisfaction, however these factors should all be considered when creating a satisfaction survey. The research questions dictate that there should be a mixture of questions relating to the patient experience and the patient satisfaction with their service provision. Experience and satisfaction are two separate issues and should be evaluated as such.

A study conducted by Smith et al. (1995) found that within three disablement services centres, satisfaction with counselling, comfort of the limb and number of alterations before the limb was deemed acceptable were all low. These results were reflected in a study conducted by Kark and Simmons (2011) which found that attitudes towards the prosthesis and the self-perceived functional ability of patients were important in improving patient satisfaction. Van der Linde et al. (2007) found that satisfaction with the prosthetic service was reduced when there was a discrepancy between the expectations of patients and their experience. Satisfaction with prosthetic services is complex, therefore a number of questions covering a wide range of subjects are required in order to answer the study objectives and ascertain satisfaction as accurately as possible.

5.6.3 PACPROSE

Using the principles from the five models discussed in Section 5.6.1 and questionnaire design, a new questionnaire for the evaluation of patient opinions of the prosthetic service was created: PAtient Centred PROsthetic Service Evaluation (PACPROSE). The advantages and disadvantages of each model were evaluated and the principles that could be taken forward for use in development of a new questionnaire were ascertained, as shown in Table 5.1.

Table 5.1: Advantages, Disadvantages and Principles taken from five patient satisfaction evaluation models

Model	Advantages	Disadvantages	Principles taken forward
SERVQUAL	Deemed valid and reliable Used extensively in health research	Found by Bosmans et al. (2009) not to be extensive enough. Required participants to answer questions twice.	Use of opt out answer
QUOTE	Deemed valid and reliable Used extensively in health research	Used four point scale. Required participants to answer questions twice.	Simplified wording of questions
PEQ	Deemed valid and reliable	Poor response format Completion time too long	Use of open ended questions
TAPES	Deemed valid and reliable Used in clinical settings	Did not cover all research questions Completion time too long	Use of Likert type response format
OPUS	Deemed valid and reliable	Did not cover all research questions	Use of separate sections for different factors

PACPROSE contained ten discrete sections each with a mixture of question styles, with a total of 58 questions (full questionnaire can be found in Appendix 5A):

1. Participant Details (Age, year of limb loss, level of amputation etc.)
2. Information Provision
3. Aims and Goals
4. Spare Limbs
5. Physiotherapy
6. Components and Technology
7. Appointments

8. Counselling
9. Patient Volunteer Visitors
10. Service Provision

Careful attention was paid to the wording of questions to avoid ambiguity and the layout of the questionnaire was kept as simple as possible to ease participant's progress. A mixture of Likert type items, 'Yes' or 'No' questions and open ended questions were included in order to gain the appropriate information from participants to answer the research objectives as fully as possible.

5.7 Ethical Considerations

When conducting quantitative research the ethical principles outlined in Section 3.4 should always be carefully considered and adhered to. There is however further consideration required when the internet is used to facilitate data collection (Gray, 2009). Confidentiality and anonymity are the main ethical issues when communicating via the internet (Saunders et al., 2007). It is easy to break confidentiality when using the internet as emails can be forwarded and answers to questionnaires copied and pasted for others to see. This must be avoided at all times as a promise has been made to participants that their answers will remain confidential, therefore breech of this promise may cause distress or harm to the participant. Communications must also be monitored to ensure that the demands upon participants are not too great and that they do not feel the questions are too intrusive (Saunders et al., 2007).

5.7.1 Ethical Clearance

Completion of the Loughborough University Ethical Checklist revealed no requirement for full University ethical approval.

5.8 Piloting

It is essential to pilot a questionnaire due to the fact that once it is sent out to participants it cannot be changed. Piloting the questionnaire enables researchers to refine any questions which are considered ambiguous, inaccurate or difficult to complete (Gray, 2009). It also allows for assessment of the validity of the questionnaire and likely reliability of the data that will be obtained (Saunders et al., 2007). A preliminary analysis on the data gathered can also be conducted in order to ensure that the questions being asked are answering the research question(s) (Saunders et al., 2007). Gillam (2002) suggests that an initial list of questions be shown to two people who are not part of the target group so that they may identify ambiguous questions. This allows for the face validity of the questionnaire to be assessed, i.e. whether it appears to make sense (Saunders et al., 2007). Saunders et al. (2007) suggests that questions should initially be shown to an expert or group of experts for comments on their representativeness and suitability. The population to be used for the pilot test is suggested to be as similar as possible to the final population being sampled (Saunders et al., 2007). Saunders et al. (2007) state that there are a number of factors which will affect how many people are involved in the pilot testing and how many times the questionnaire is tested:

- The research question(s) being answered
- The objectives of the study
- The size of the research project
- The time and money resources available
- How well the questionnaire has been designed

The questionnaire should be piloted on a sufficient number of people to include any major variations in the population that are felt likely to affect responses. Fink (2003) suggests that 10 participants is a minimum number for piloting a student questionnaire. Dillman (2007) suggests that for large surveys 100-200 participants is usual. All completed pilot questionnaires should be checked to evaluate whether respondents have had problems with answering any questions and also whether they have followed all the instructions correctly (Fink, 2003).

5.8.1 Appropriate piloting technique for Study 2

The questionnaire was created in an online survey tool named Survey Monkey (2012) in order to facilitate ease of distribution and analysis. Survey Monkey allowed easy distribution as a direct link to the questionnaire could be sent to participants or placed on a website or Facebook group. Analysis was also made simpler by this software as the results could be downloaded directly into analysis software. Due to the use of an online tool pre-piloting was essential to ascertain whether there could be usability issues and if so correct for them as much as possible. Gray (2009) suggests the use of colour, navigational routes if questions must be skipped, on screen instructions and the ability of participants to know how to input their answers are all issues that should be considered. Gray (2009) also suggests other factors relating to the questionnaire itself to be considered when piloting:

- Instructions given to participants
- Formality or informality of the questions in terms of presentation and tone
- Length of questionnaire – is the response rate likely to be affected if it is too long
- Quality of individual questions – are they understood and answered in the way that was intended
- Appropriateness of response formats used

Gillham (2000) advised the use of one or two pre pilot subjects that are not part of the target group. Following this advice, the link to the questionnaire was sent via email to two experts in questionnaire design at Loughborough Design School to assess the factors Gray (2009) suggested. A summary of the observations made by the experts can be seen below:

- The instructions were clear and concise without need for alteration.
- The tone and presentation of questions were appropriate however the presentation was not. The question numbers became very confusing due to the need for participants to skip questions if they answered in a particular way. Numbering required alteration.
- The questionnaire was of a suitable length however could be shortened if possible.
- Individual questions were easily understood and appropriately worded.
- The response formats were easily understood.

- The usability of the online tool was sufficient. The only issue was with following questions when it was required that some were skipped. Alteration of numbering would resolve the issue.

The questionnaire was altered in accordance with the suggestions made by the members of staff and the improved questionnaire was then sent via email to three amputees that had shown an interest in the study (Gillham, 2000). Each of the three pilot participants responded that the structure and wording of the questionnaire were suitable and that the usability of the online tool was acceptable.

In order to ascertain the internal consistency of each scale like item Pallant (2010) suggests the use of Cronbach's alpha coefficient. This is described by Field (2009) as being whether the items within the scale all "reflect the construct" it is measuring. The construct is defined as being the overall theme each of the questions relates to, for example, the information given to patients. De Vellis (2003) reports that the Cronbach alpha coefficient of any scale should ideally be above 0.7, therefore anything with a value lower than this should be reconsidered. The Cronbach's alpha coefficient was calculated using SPSS (2011) statistics software for each Likert type item using the pilot results as shown in Tables 9. Full results can be found in Appendix 5C.

Table 5.2: Cronbach's alpha for the combination of Likert type items in each section

Subject of Likert type item	Cronbach's Alpha
Information given to patients	.933
Aims and goals (if patients had them)	.905
Aims and goals (if patients didn't have them)	.885
Counselling (if patients received it)	.893
Counselling (if patients didn't receive it)	.711
Service	.900

As shown in Table 5.2 the Cronbach's alpha coefficients for each scale were above the suggested 0.7 and therefore had a high degree of internal consistency.

5.9 Sampling

There are two forms of sampling: Probability and Non-probability sampling. Probability sampling involves the probability of each participant being selected being a known quantity (Saunders et al., 2007). Probability sampling is not appropriate for the work in this chapter as it is not possible to gain the details of every amputee registered to each DSC in the UK. Non-probability sampling is therefore the only option for this inquiry.

5.9.1 Sampling techniques

There are a number of non-random sampling techniques widely used in the research arena. The following techniques will be discussed to ascertain their merit for use in this work; Quota sampling, Purposive sampling, Snowball sampling, Self-selection sampling and Convenience sampling.

5.9.1.1 Quota Sampling

Quota sampling is typically used for interview surveys as it is entirely non-random. This type of sampling allows for the variability in the population by splitting the population into strata and non- randomly selecting participants until each of the strata is represented fully (Saunders et al., 2007; Gray, 2009). The population is first divided into specific groups and the quota for each group is calculated based on relevant and available data (Saunders et al., 2007). This type of sampling can be quickly undertaken and does not require a sampling frame however it is usually used for large populations.

5.9.1.2 Purposive Sampling

Purposive sampling allows the researcher to select participants that they feel will best enable them to answer their research question, based on one or more specific characteristics (Saunders et al., 2007; Gray, 2009). Gray (2009) states that this technique “may, indeed, succeed in achieving a true cross-section of the population”. This sampling strategy is usually used for very small samples and therefore cannot be considered statistically representative of the total population (Saunders et al., 2007). There are five different subtypes of purposive sampling each of which will be discussed below.

- **Extreme case** or **deviant sampling** focuses on special or unusual cases in order to collect data that will allow the researcher to most effectively answer their research question and fulfil their objectives (Saunders et al., 2007). Patton (2002) describes extreme cases as being relevant in the understanding or explanation of typical cases and therefore are very useful for some research projects.
- **Heterogeneous** or **maximum variation sampling** allows the researcher to collect data that describes and explains the observed key themes (Saunders et al., 2007). Patton (2002) states that although a small sample may contain completely different cases, this is a strength of this type of sampling as any patterns that do emerge are likely to be of great interest and represent the desired key themes. Uniqueness can also be documented from the findings of this type of sample (Saunders et al., 2007). Patton (2002) advised that the diverse characteristics required of the participants are identified before the sample is selected in order to ensure maximum variation in the sample.
- **Homogeneous sampling** concentrates on one particular sub group in which all of the participants have similar attributes. This allows for in-depth study of this particular group.
- **Critical case sampling** involves critical cases being selected as they are deemed important or seen as being able to make a point dramatically (Saunders et al., 2007). Data collection is focussed on understanding what is happening in the critical cases in order to produce logical generalisations (Saunders et al., 2007).
- **Type case sampling** is used to produce a descriptive profile using a representative case and is therefore not intended to be definitive (Saunders et al., 2007).

5.9.1.3 Snowball Sampling

Snowball sampling is typically used when identifying members of the desired population is particularly difficult. Initial contact with participants is usually the main problem, however once this contact is made these participants are asked to identify other potential respondents. Each participant is asked to identify further members of the population and therefore the sample ‘snowballs’. The disadvantage of this technique is that the problems with bias tend to be substantial due to respondents, in most cases, identifying potential respondents that are very similar to themselves which results in a homogeneous sample.

5.9.1.4 Self-Selection Sampling

This technique involves allowing potential participants to voice their desire to participate in the research. It is therefore necessary to publicise the need for respondents through appropriate media e.g. posters, or by asking them to take part (Saunders et al., 2007).

5.9.1.5 Convenience Sampling

Convenience sampling involves selecting a sample based only on the fact that they are conveniently available (Gray, 2009). This technique is prone to bias and influences beyond the control of the researcher due to the cases only appearing because they were easy to obtain (Saunders et al., 2007). Gray (2009) states that this technique “may be a useful indication of trends but must be treated with extreme caution”.

5.9.2 Demographics Specification

It was important that participants in this study were able to evaluate their own experiences within the NHS therefore inclusion criteria were needed.

- The person answering the questionnaire must have an amputation of one or more limbs, persons with congenital absence were also included – parents of children with amputations were not included.
    - This was to ensure that all participants were answering using their personal experience of the service provision as the objectives of this study dictated that patients themselves be sampled.
- The amputation(s) were conducted within the NHS and the first prosthesis was provided by the NHS
    - This was to ensure that the experiences being recounted related only to the NHS as the purpose of this thesis was to investigate NHS service provision.
- No ex-service personnel due to speciality treatment

- Ex-service personnel were likely to have received care from Defence Medical Rehabilitation Centre Headley Court and therefore their experience would have been completely different to those within the NHS. Headley Court is a specialist rehabilitation centre for wounded service personnel where patients receive intensive rehabilitation.

These specifications were detailed in any communication with potential participants including the instructions of the online questionnaire.

5.9.3 Recruitment

A study by Carr-Hill (1992) found that most user surveys carried out within the NHS trusts found "generally high patient satisfaction with their treatment", however although these data provide the trusts with reassurance the report also stated that these surveys can "give a false picture for several reasons".

1. Users could be reluctant to criticise services on which they depend for their mobility.
2. Their responses may be influenced by their perception of their condition, an example of this is patients whom have had to wait extended periods of time for treatment will be grateful to finally receive the treatment and not want to complain that this treatment took so long.
3. A large proportion of patients will have few expectations on which to base an evaluation on the service they receive.
4. The survey tools in use may not be sufficiently sensitive to recognise dissatisfaction.
5. Non-respondents may be less satisfied than respondents (Carr-Hill, 1992).

Conducting the research independently of the NHS would remove the reluctance of patients to criticise the service as patients would feel more comfortable conveying their true feelings due to their service provider not being involved in the data collection. Also, the lack of NHS involvement could encourage patients that would not normally take part in questionnaires, to contribute their opinions as they are able to freely express their feelings without fear of consequences. Heinemann et al. (2003) found that while they were developing Orthotics and Prosthetics Users'

Survey (OPUS), participants as a whole reported high levels of satisfaction with the service they received. The explanation given for this was that, even though participants completed OPUS with a research assistant and not a member of clinical staff, they may have been concerned about confidentiality of their answers and therefore minimised their dissatisfaction (Heinemann et al., 2003). The report by The Audit Commission (2002) found that surveys conducted independently of the NHS can provide results showing less satisfaction with the services being provided by DSCs.

In light of the research stating that NHS involvement can have a detrimental effect on the reliability of results (The Audit Commission, 2002; Heinemann et al., 2003; Carr-Hill, 1992), the study was conducted independently of the NHS.

Once this decision was made it was found that the most effective way of reaching amputees was through the internet as figures produced by the Office for National Statistics in (2011) showed that 77% of households in the UK had access to the internet. This would bias the results towards those people that had access to the internet, however due to the difficulties inherent in postal questionnaires (as discussed in Section 5.5.3.2), an internet based questionnaire was the most logical option. Statistics for 2012 show that 34.6% of all adults defined as disabled by the Disability Discrimination Act had never used the internet (Office for National Statistics, 2011). Due to this Act covering a whole range of disabilities, not just amputees, the internet would be an unavoidable selective filter of potential participants. Another advantage was that participants would not be restricted on time as they could complete the questionnaire at their convenience in their own home or in a location providing internet access. Wright (2005) states that the use of the internet as a tool for survey distribution can aid communication with people who may be reluctant to meet face to face. It has already been seen through the work of Heinemann et al. (2003) that face to face, participants are less likely to provide honest answers due to their concerns with confidentiality. An online survey allows participants to take part with confidence that their identity cannot be used unless they are willing to provide that information.(Heinemann et al., 2003)

Self-selection sampling was the only sampling method available for this study due to the lack of contact details for amputees (Gray, 2009). Due to the nature of self-selection sampling, there was no guarantee that anyone would participate in the study therefore the sample size was fixed at 100 but a time limit was placed on the questionnaire being live. Further forms of distribution were considered to obviate publication of the questionnaire not yielding as many data sets as hoped.

A number of formats were used to publicise the study and encourage people to participate. Firstly contact was made with members of staff at the Limbless Association and Limbcare which are both charities aiming to raise awareness and protect the rights of amputees. The Limbless Association is a charity that was founded in 1983 and provides information and support to members of the limb-loss community. They support people of all ages and backgrounds through a variety of existing programmes and services (Limbless Association, 2012). Limbcare is a charity that was founded in 2010 and offers education for all limb impaired individuals in the UK and internationally. They help create independence through counselling, help, support, fitness, sport, dance and music (Limbcare, 2012). Permission was granted for a short explanation of the study to be published on both charities' websites. The Limbless Association also offered to publish information on the study in their quarterly magazine; Step Forward. The article detailed the work being carried out and asked for participants to email if they had any interest in taking part in the research. Facebook groups were also joined and the study information posted to the wall for every member to see. This was repeated a number of times throughout the study to encourage members of the group to participate. There were no messages sent to individual members asking for their participation and the group is accessed by members voluntarily therefore no-one was coerced into taking part.

5.9.4 Distribution

In order to distribute the questionnaire the link to the questionnaire was sent to every individual that had been in contact via email, as a result of the article in Step Forward magazine and placed on the wall of the Limb Power and Limbcare Facebook groups. The individuals that had emailed in answer to the magazine article may not have been representative of the population as a whole, however gaining a truly representative sample would have required access to the contact details of every amputee that attended an NHS DSC across the UK in order for a random sample to be taken. Due to the questionnaire being conducted independently of the NHS for the reasons described in Section 5.9.3, individuals that had shown interest in the research were contacted. A page of information was provided at the beginning of the questionnaire explaining that all answers were completely confidential and no personal answers would be fed back to NHS centres. The participants were made aware that they gave their informed consent to take part in the questionnaire by completing it.

5.10 Analysis

5.10.1 Analysis of Variance (ANOVA)

In order to analyse the Likert type items it was necessary to ascertain the independent and dependent variables to be used for analysis. The independent variables of interest were sex, age, amputation level, centre attended and year of amputation with the dependent variables being the statements used for the Likert type items. The independent variables were also split into two groups in two cases; Age was split into 'Age in 5 year intervals' and 'Age in 10 year intervals' and Year of amputation was split into 'Year in 5 year intervals' and 'Year in 10 year intervals'. This was done in order to ascertain whether small differences in age and year of amputation had an effect on any of the dependent variables. It was also necessary to remove some of the options within the independent variables from the analysis as there were not enough cases in them to conduct analysis. Pallant (2010) states that in order for calculations to be reliable, there should be no less than 10 cases per variable. One such variable was amputation level, where only participants with below knee and above knee amputations could be used in calculations as there were less than 10 participants with the other levels of amputation.

Ordinal data are described by Allen and Seaman (2007) as being 'data in which an ordering or ranking of responses is possible but no measure of distance is possible'. Parametric tests are said to require data with an approximately normal distribution

(Vickers, 2005), which the majority of ordinal data is not. Although Likert data are considered ordinal there have been many studies conducted and papers written confirming that Likert data can be analysed using parametric statistics (Norman, 2010; Carifio and Perla, 2007; Rasmussen, 1989) as long as the assumptions are met. ANOVA is used to analyse how well certain independent variables predict a single dependent variable, for example whether age has any effect on satisfaction with service provision (Cardinal and Aitken, 2006). The most appropriate statistical analysis technique was believed to be one way ANOVAs with each independent variable being tested separately. This was due to sample sizes not being adequate across every independent variable therefore different cases would have to be excluded for each ANOVA conducted with a different independent variable.

Analysis of the Likert type items could be conducted in two ways, analysis of the individual items and analysis of the scale. In order to legitimately analyse the summed scores of the Likert type items in each scale, calculations of Cronbach's alpha to determine internal consistency of each scale were necessary. These calculations had already been conducted and reported in Section 5.8, with the results showing that each scale had good internal consistency and could therefore be used for further calculations. In order to use the results from each scale, the scores for individuals from each Likert type item were summed and the mean found. The mean calculated for each participant was then used for further statistical calculations.

Conducting one way ANOVAs required a large number of assumptions to be met, the first of which being that the data should be normally distributed. In order to assess normality, it was necessary to conduct Kolmogorov-Smirnov tests on each of the scales. This test compares the scores in the sample with a normally distributed set of scores with the same mean and standard deviation (Field, 2009). If the Kolmogorov-Smirnov sig value is below 0.05 then the distribution is significantly different to a normal distribution and therefore ANOVA cannot be conducted (Field, 2009). The Kolmogorov-Smirnov sig values for each scale are shown in Table 5.3.

Table 5.3 shows that only one of the scales could be analysed using ANOVA therefore another form of analysis for the other scales and individual Likert items was required.

Table 5.3: Test for normal distribution on Likert type item scales

Scale	**Kolmogorov-Smirnov Sig.**	**Normal Distribution?**
Information given to patients	0.002	No
Aims and goals (if patients had them)	0.000	No
Aims and goals (if patients didn't have them)	0.028	No
Counselling (if patients received it)	0.002	No
Counselling (if patients didn't receive it)	0.177	Yes
Service	0.002	No

5.10.2 Non Parametric Statistics

Non parametric tests are used when the data are not normally distributed as the tests use a principle of ranking the data and conducting analyses on the ranks rather than the actual data (Field, 2009). As there were a number of different independent variables requiring analysis and some had more than two groups within them (i.e. Year of Amputation in 10 year intervals) it was necessary to use two different analysis techniques. Those independent variables with only two groups (i.e. Sex) were analysed using the Mann-Whitney test (Field, 2009). This test analyses the differences in the ranked positions of scores in different groups, therefore the group with the lowest mean rank is the group with the greatest number of low scores. If the calculated significance value is less than .05 the results are said to be significant (Field, 2009). In order to analyse independent variables with more than two groups within them (i.e. Age in 10 year intervals) the Kruskal-Wallis test was used. This test uses the same principles as the Mann-Whitney test with the difference being that the data are ranked regardless of group, then put back into the groups for analysis (Field, 2009). Analyses using these techniques should be conducted on groups of 10 or more as less than this could introduce reliability issues (Field, 2009).

The questionnaire contained a number of questions requiring a 'Yes' or 'No' answer, therefore a statistical test was required to explore the relationship between these answers and independent variables such as Sex or Amputation Level. The Pearson's chi-square test for independence was used as this test compares the observed frequencies or proportions of cases that occur in each of the categories, with the values that would be expected if there was no association between the two variables being measured (Pallant, 2010). In order to conduct the analysis a minimum of 5 cases per cell was required. The questions were analysed using the Chi-Square test with each of the independent variables being tested separately.

5.10.2.1 Analysis of Likert type items

The Mann-Whitney test was conducted on each of the individual Likert type items from each section for the independent variables Sex and Amputation level. In order to conduct the tests in some cases it was necessary to exclude certain independent variables as there were not enough cases in the sub groups for the tests to be considered reliable (i.e. less than 10 cases per sub group). Following this, the individual Likert type items were combined to produce a scale for each of the dependent variables. This was possible as the Cronbach's Alpha of each scale was above the recommended level and therefore the scale was deemed reliable. Each scale was then subjected to the Mann-Whitney test for Sex and Amputation Level except the scale for participants that had not had counselling as the results had been found to be normal therefore ANOVA was conducted.

Following on from the Mann-Whitney tests, Kruskal-Wallis tests were conducted on each individual Likert type item for the independent variables Age in 5 year intervals, Age in 10 year intervals, Year of amputation in 5 year intervals and Year of amputation in 10 year intervals. It was not possible to test every independent variable for each Likert type item as in some cases there were not enough cases per sub category to produce reliable results. Further tests were conducted on the scales used previously for the Mann-Whitney tests to ascertain whether there were any significant differences between age groups or year groups with regards overall subjects (i.e. service). As previously stated, it was not possible to calculate a sig value for every independent variable due to the small number of cases in each subgroup.

5.10.3 Analysis of open ended questions

Two analysis techniques were required for analysis of the open ended questions within the questionnaire. Certain questions simply required grouping due to the answers given being one or two words only. Groups were created whenever a new topic was mentioned during analysis and each answer was added to the relevant group. Percentages of each group could then be calculated to ascertain which topics had been mentioned most frequently.

Thematic analysis was required for questions that necessitated sentences rather than one or two words. Nodes were created with each answer being added to the relevant node. The number of answers in each node illustrated the frequency that the subject of the node had been mentioned and the three most frequently mentioned subjects could be ascertained.

5.11 Results

The results were downloaded from the online survey tool and a preliminary scan was completed to detect any anomalous entries. There were 105 data files, only 96 of which were usable due to duplicates or the entire questionnaire being blank. The IP address provided by the online survey tool for each data file was checked in order to identify duplicate files. IBM® SPSS® (2011) statistics software was used for statistical analysis and the open ended questions were analysed both descriptively and thematically. SPSS (2011) is a statistics software package that provides tools to allow the quick viewing of data, formulation of hypotheses for additional testing and the completion of procedures to clarify relationships between variables, identify trends and make predictions (IBM, 2012). The data could be directly downloaded into an SPSS file format leading to ease of data analysis. Of the 96 participants 58% were male and 42% female. Age of participants ranged from 24 to 82 with a mean age of 54, mode of 50 and median of 53. Ninety percent of respondents had a lower limb amputation with 57% being a below knee amputation. The most common reason for amputation was trauma, with 51% of participants reporting having a traumatic amputation. Patients from 30 of the 44 DSCs took part in the questionnaire. Full participant details can be found in Appendix 5B.

The National Statistics for 2006-07 (National Amputee Statistical Database, 2009) show that trauma accounted for 7% of amputations in the UK that year. The vast majority of amputations were recorded as being a result of dysvascularity. Fifty percent of the participants from this study were trauma amputees with only 10.5% reporting having an amputation due to diabetes or a vascular condition (Table 5.4). These results are in contrast with the national statistics. There are a number of possible reasons for this inconsistency such as trauma amputees having more difficulty accepting their amputation and therefore wish to express their views of the service more readily (Desmond and MacLachlan, 2006; Livneh et al., 1999; Fisher and Hanspal, 1998).

Table 5.4: Primary reason for amputation

	Frequency	Rounded Percentage
Trauma	48	50.0
Cancer	12	12.5
Infection	11	11.5
Congenital	9	9.4
Vascular Condition	6	6.3
Other	6	6.3
Diabetes	4	4.2

5.11.1 Level of sufficiency of information

To address objectives 1 and 2, participants were asked what level of information they were given at five different stages, pre and post amputation. These five stages were chosen using the information gained from visits to DCSs about the pathways patients follow pre- and post- amputation. Figure 5.5 illustrates the type of information given to participants throughout the five stages of amputation.

Those participants that answered N/A to the two stages prior to amputation were the participants that stated they had a traumatic amputation. Forty eight percent of the remaining participants received no information on the ward prior to their amputation with 41% of the participants receiving no information on the ward post amputation. Full results can be found in Appendix 5C. Figure 5.5 illustrates how few participants received written information which indicates that DSCs either do not have the resources to provide written information or are not aware of the potential benefits to patients. The preferred mode of information delivery is clearly using verbal communication, however, this may not be the most beneficial information delivery system for the patient.

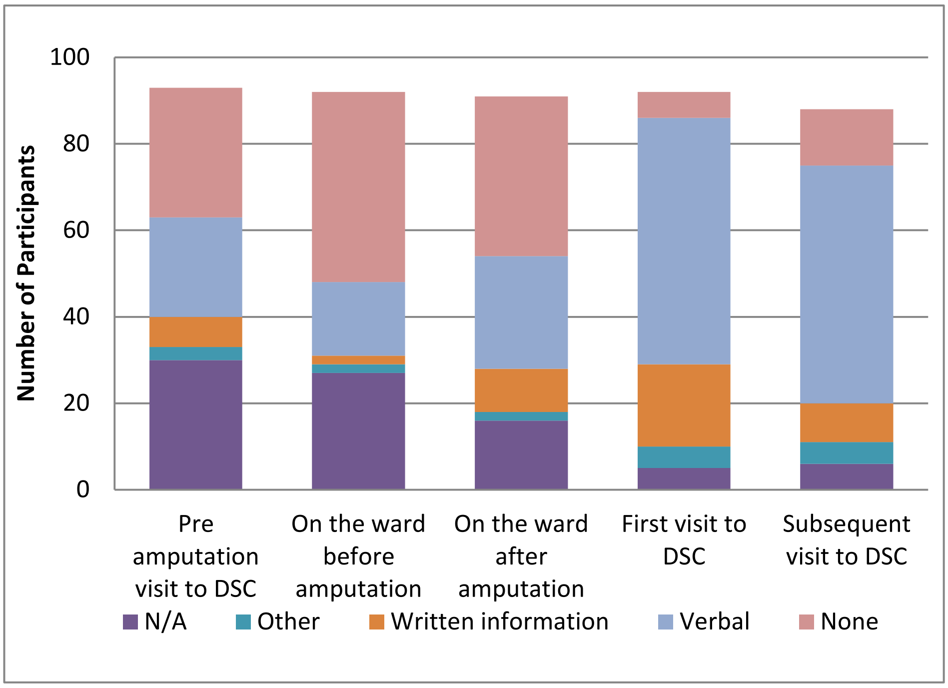


Figure 5.5: Information provision at different stages pre- and post-amputation

The Mann Whitney and Kruskal-Wallis tests conducted revealed no significance between groups tested, therefore there were no significant differences in the opinions of males and females, below knee and above knee amputees or different age groups. This indicates that any information provided may not require specific tailoring for the different sexes, amputation levels (apart from amputation level specific information) or age.

5.11.2 Aims and Goals

The literature indicates that goal setting is an integral part of rehabilitation, however, 38% of the participants had not had their aims and goals discussed (Figure 5.6), which indicates that some centres are not providing patients with a service that could improve their outcomes. These results also highlight the inconsistency of service provision across the UK.

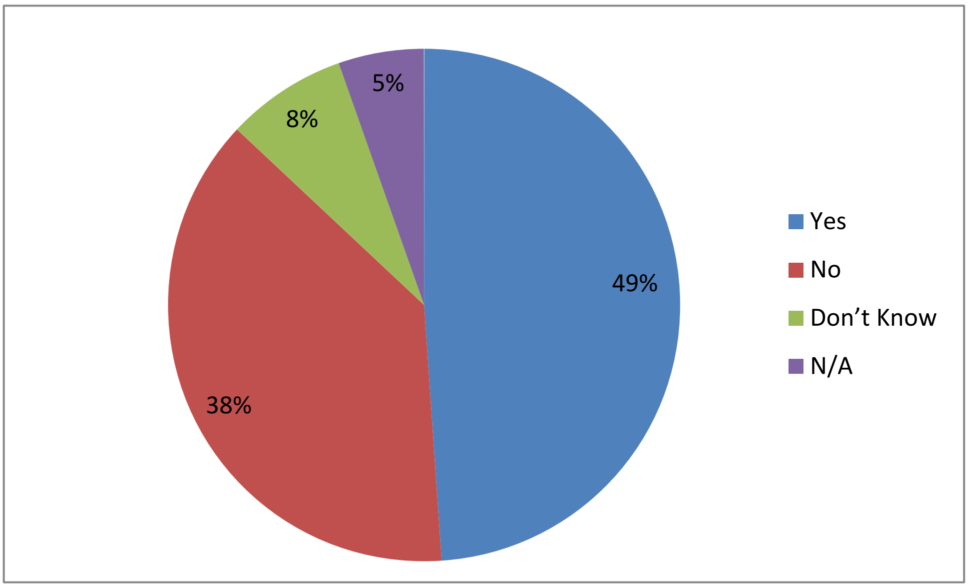


Figure 5.6: Whether patients had their aims and goals discussed

There was no significance found between the discussion of aims and goals and sex, amputation level or age in 10 year intervals when analysed using a Chi-square test. The results can be found in Appendix 5D.

The results of the Mann Whitney and Kruskal-Wallis tests showed no significance between groups tested. This indicates that there were no significant differences in the opinions of males and females, below knee and above knee amputees or different age groups with regards their aims and goals.

5.11.3 Spare Limbs

The changing spare limb policy was of particular interest as most centres visited during the preliminary study were no longer giving spare limbs as standard practice due to their budget decreasing (Wagner et al., 2008). Interestingly 66% (N= 88, where N is the number of participants that answered the question) of the participants received a spare limb which was in contrast with the spare limb policies at 9 of the 12 centres visited in Study 1. Seventy one percent (N=34) of participants that did not receive a spare limb were unhappy with this situation which clearly indicates that patients place high importance on these limbs, even though reports state that very few patients need or use them. This is confirmed by 76% of these participants stating that they believe having a spare limb would have a positive impact on their daily life. There was no significance found between the sexes, amputation levels or age groups with respect to receiving a spare limb when analysed using a Chi-square test. Full results can be found in Appendix 5E.

5.11.4 Water activity and shower limbs

The enhancements to quality of life that water activity or shower limbs can bring, as outlined by The Audit Commission (2002) are reflected in the results from this study through 73% (N=33) of participants stating that the water activity or shower limbs had a positive impact on their life. The importance of these limbs was also reflected in the results gained from participants that were not prescribed a water activity limb, due to 88% (N=15) of participants being unhappy about the lack of provision. There was no significance found between the sexes, amputation levels or age groups with respect to those that received or did not receive a spare limb when analysed using a Chi-square test.

5.11.5 Physiotherapy

Figure 5.7 illustrates where the participants received their physiotherapy and reflects the findings of Study 1 in that not all centres are able to offer physiotherapy in house. There is evidence that there is a breakdown in communication between prosthetists and physiotherapists at some centres due to 31% (N=75) of participants stating that their prosthetist had not come into their physiotherapy session if there had been a problem. This is reflected in 24% of participants stating that their prosthetist was not aware of their progress in physiotherapy. Privratsky (2008) and Boulton et al. (2000) both state that a multidisciplinary team is important for successful rehabilitation, therefore it is important that prosthetists are aware of the progress of their patients' physiotherapy. There was no significance found between physiotherapy and sex or amputation level when analysed using a Chi-square test. The results can be found in Appendix 5G.

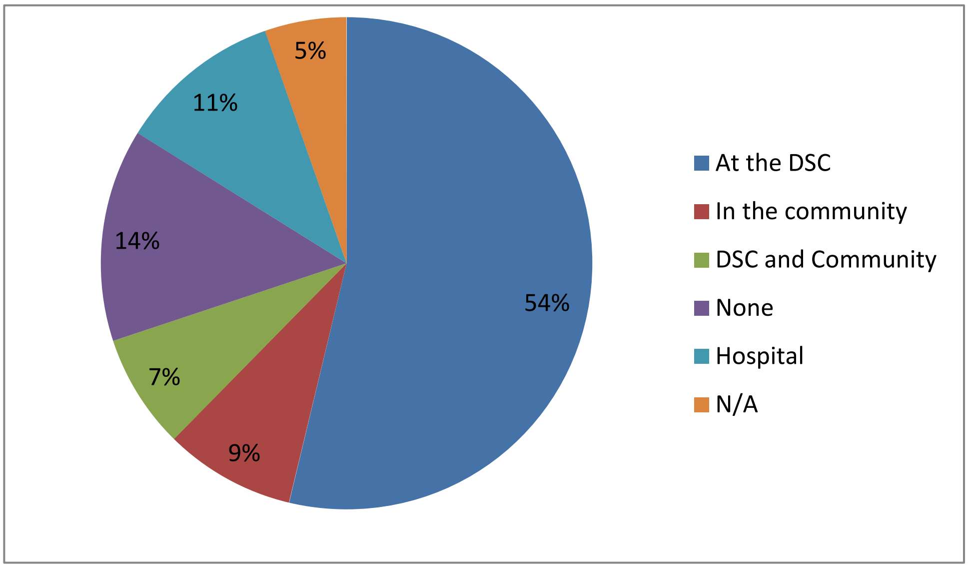


Figure 5.7: Location of participant's physiotherapy sessions

5.11.6 Components and Technology

Figure 5.8 illustrates the sources participants used to gain information on components they felt may benefit them. These results show that the internet was the most utilised source of information therefore participants were likely to access information on the latest technologies via companies websites.

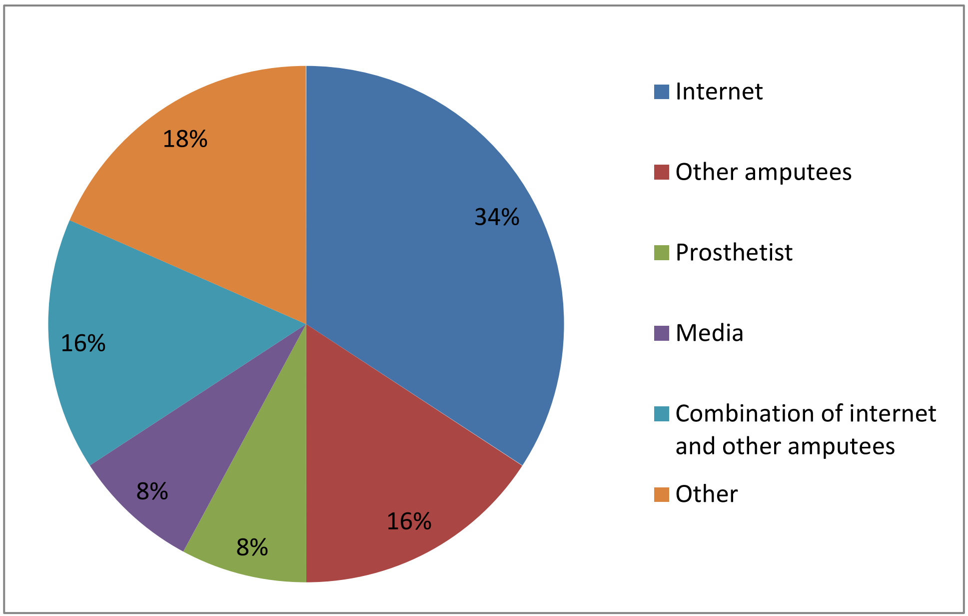


Figure 5.8: Where participants found information on components

The components that participants in this study were refused were expensive components such as knees and feet in 81% (N=26) of cases and due to the limited budgets of each centre they do not have the funds to provide them to patients. Forty seven percent (N=88) of the participants stated that they would contribute money towards getting a component they desired, which clearly indicates the importance of these components to the participants. There was no significance found between provision of components and sex or amputation level when analysed using a Chi-square test. Full results can be found in Appendix 5H.

5.11.7 Appointments

Figure 5.9 illustrates the length of wait for an appointment experienced by the participants which reflects the results of Study 1 in that the time frames vary from less than one week to over four weeks. Twenty seven percent (N=88) of the participants stated that they were not happy with the time frame they stated, which is in contrast with the work of Smith et al. (1995) that reports high levels of satisfaction with booking of appointments. There was no significance found between appointments and sex, amputation level or age in 10 year intervals when analysed using a Chi-square test. The results can be found in Appendix 5H.

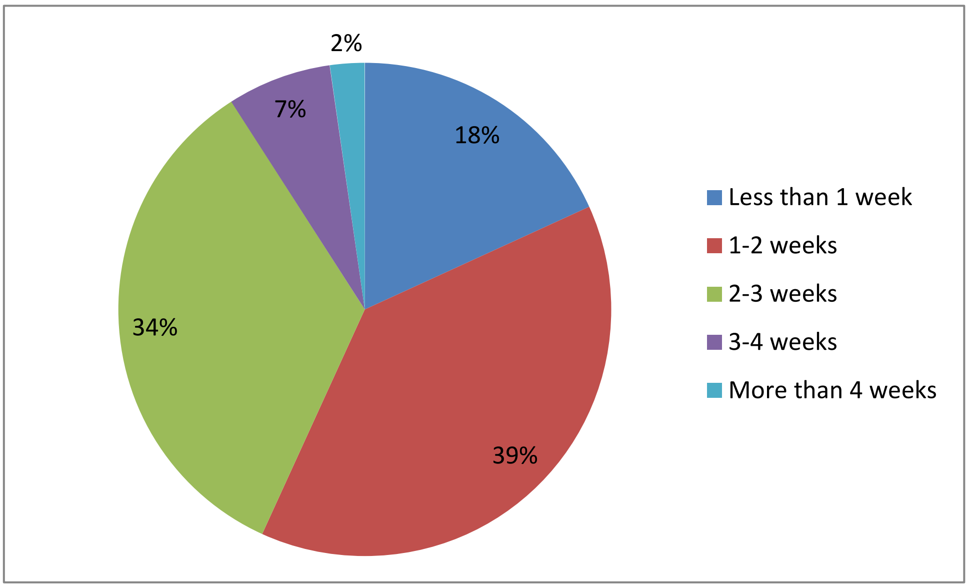


Figure 5.9: Length of wait for an appointment

5.11.8 Counselling

The results provide evidence that counselling is not being discussed with every patient due to 30% (N=87) of participants being unaware of whether counselling was available to them. There was no significance found between provision of counselling and sex or amputation level when analysed using a Chi-square test. The results can be found in Appendix 5J.

Counselling was regarded highly by those participants that had access to it, with 94% (N = 38) stating they felt the service should be available at every DSC. When asked at what stage was counselling most useful, 26% (N = 31) of participants stated that it was most useful a year or more after amputation, which concurs with Price and Fisher’s (2002) studies which indicated that emotional problems become apparent 6-24 months after surgery. The Mann Whitney and Kruskal-Wallis tests conducted revealed no significance between groups tested, therefore there were no significant differences in the opinions of males and females and below knee and above knee amputees on counselling. This indicates that the provision of counselling could not be provided based on sex or amputation level.

Fifty two percent (N=62) of the participants stated that they would use the counselling service if it became available which indicates that their psychological needs are not being met by their current service provision. Thirty-five percent of these participants stated that they would have liked counselling pre-amputation which corresponds to Butler et al. (1992) and Sherman’s (1997) work which indicates that appropriate preparation for surgery alleviates stress and eases rehabilitation. The Likert type scale results for those participants that did not have access to counselling were found to be normally distributed (Section 5.10) therefore T-Tests and ANOVA could be conducted on the independent variables with enough cases in the subgroups. The results showed that there were no differences in opinion on counselling between the sexes or participants with different amputation levels, reflecting the previous finding that counselling could not be provided based on sex or amputation level.

5.11.9 Patient Volunteer Visitors

The results showed that 84% (N=19) of the participants that were visited by a patient volunteer visitor found the experience beneficial and 71% (N=70) of those that were not visited would have liked the service to have been available. This reflects the work conducted by Frogatt and Mawby (1981), Briggs (2006) and Novotny (1996) on the importance of amputee visitors. There was no significance found between participants receiving a volunteer visitor and sex or amputation level when analysed using a Chi-square test. Full results can be found in Appendix 5K.

Those participants that had a visitor were very positive about the experience with 78% (N=18) stating that speaking with the visitor was comforting and put their mind at ease, which is reflected in the work of Novotny (1996). Seventy six percent (N=70) of the participants that did not receive a visitor stated that they would have found the opportunity to ask questions beneficial and 62% (N=69) stated that a visit would have made them less apprehensive. As is suggested by Butcher (2009), this shows that patients benefit greatly from speaking with peers as their clinicians cannot provide them with the same insight that an amputee themselves can. Seventy nine percent of the participants (N=64) stated that they felt the NHS should be funding the volunteer visitor service which indicates that patients feel it is something that should be provided routinely as part of the service provided by the NHS.

5.11.10 Service

It was initially anticipated that there could be a connection between satisfaction with a prosthesis and satisfaction with service provision. This is reflected by 60% (N=78) of participants stating that they were happy with both the service and their limb. These figures are very similar to those of Nicholas et al. (1993) who found that 59% of 94 patients were satisfied or somewhat satisfied with the comfort of their prosthesis. Fifteen percent expressed dissatisfaction with both the service provision and their prosthesis and 13% expressed satisfaction with the service provision but dissatisfaction with their prosthesis. The reasons given by those participants satisfied with the service but dissatisfied with their prosthesis were centred on wanting better quality components or better cosmesis, with only one participant mentioning socket fit and stating that this was due to the level of their amputation. It appears that these patients accept the limitations of the NHS with one participant stating “It is a compromise as it is not cosmetically as good as it could be, but it is as good as it is going to get given the system we operate in.” These patients do not appear to associate their dissatisfaction with their prosthesis with the service they receive. In complete contrast, those participants that stated they were dissatisfied with both the service and the limb had issues with fit in 92% of cases. When asked if their prosthesis fulfilled their expectations, 31% of the 86 participants that answered the question stated that theirs did not. The reasons for this were grouped and showed that in 54% of cases, the prosthesis did not fulfil expectations due to the limiting affect it had on their activity levels. The work of Gallagher and Maclachlan (2001) reflects this as they found that satisfaction with a prosthesis was dependent on the extent to which the capabilities of the limb coincided with the patient’s expectations of what could be achieved. There was, however, no significance found between satisfaction with a prosthesis and sex or amputation level when analysed using a Chi-square test. Full results can be found in Appendix 5L.

Participants were then asked to state the three most stressful times during their rehabilitation and the reasons why these were stressful. These answers were thematically analysed and revealed that there were a large number of different situations patients found stressful.

The three most frequently mentioned stressful situations were:

1. When the socket does not fit
2. Learning to walk
3. When patients do not receive enough information

The three most frequently mentioned reasons why the situations were stressful were:

1. Apprehension due to unknowns
2. Frustration with socket fit due to pain it causes
3. Frustration with not being able to get on with life

These results indicate that socket fit and information are of great importance to participants. There could be physical and mental health consequences caused through poor socket fit and information provision, highlighted by participants mentioning the apprehension and frustration these cause.

There were 23 participants that stated they had complained about the service they received, of which eight stated that nothing had been done to rectify the problem.

This is concerning due to patients being so dependent on their prosthesis for their mobility.

5.12 Discussion

The high number of participants with traumatic amputations compared with the national statistics indicates that there may be differences in attitude to service provision between trauma patients and patients with disease related amputations. As discussed in Section 5.3.1, trauma amputees are likely to be young, previously highly active individuals, therefore if the service they are being provided is not enabling them to return to an active lifestyle they are more likely to wish to complain and hence take part in surveys such as this one. The literature suggests that younger amputees are less likely come to terms with their amputation than older amputees therefore they may be more inclined to participate in surveys due to their own inability to accept their condition which results in a poor view of the service they are being provided. These younger patients are also more likely to have access to the internet and therefore the ability to search for new prosthetic components which they would like to use, but are not available on the NHS, giving them more reason to become frustrated. The literature indicates that if patients are not satisfied with their prosthesis, this can have a negative effect on body image, which has influences on not only anxiety and depression, but sexual functioning, self-esteem and life satisfaction, therefore these patients are more likely to complain.

The reduced mobility of older and dysvascular patients may decrease their personal need for continued prosthetic care and therefore reduce their desire to take part in research such as this study. These patients may also be completely satisfied with their service provision and therefore not feel the need to offer their opinion about their service. These patients are also likely to be over 65 which increases the possibility that they are not able to access the internet. National Statistics (2012) show that at the time the survey was online, 40% of 65-74 year olds had never used the internet and 70.8% of over 75 year olds had never used the internet. This study was purely internet based therefore the majority of over 75 year old dysvascular patients will have been excluded.

Further research is needed in order to ascertain whether traumatic amputees are less satisfied with the service they are being provided and if so, what are the factors influencing this. Further research should be conducted in a number of forms in order to include those missed by the use of an online questionnaire in order to ascertain whether age has an effect on satisfaction with the service.

5.12.1 Information – Objective 5.1 and 5.2

Provision of information was identified as a key issue that required further investigation. Results from this study concurred with Nielsen's (1991) work due to the high percentages of participants not receiving any information on the ward prior to their amputation, indicating that the NHS is not preparing all patients for the life changing operation they are about to undergo. Further evidence of this was found when the individual patient's information was tracked, revealing that over a quarter did not receive any information at all until they had their first visit to the DSC. Results from the report by the Audit Commission (2002) also reflected these results as 22% of the participants in that study did not receive a 'clear explanation of treatment' prior to amputation. Most of the information that was given to the participants was verbal with very little written information, consequently the information is highly transient and patients have nothing to reference at a later date. Results from the same report by the Audit commission (2002) showed that 40% of the respondents (N = 92) did not receive any written information, which is also reflected in the work conducted in this study as the majority of information given to participants was verbal. This shows that between 1999 and 2012 very little has changed with regards the delivery of information to patients.

The literature relating to traumatic amputees reveals that they are prone to psychological problems and high rates of chronic pain (Perkins et al., 2012). The results of this study clearly showed that the information being provided to trauma amputees was mainly verbal and therefore was not providing the patients with any time to process what they were being told. Due to trauma amputees having no time to adjust to the concept of losing a limb, the information provision for them should be far better in order to help them come to terms with their amputation and therefore reduce the psychological impact as much as possible.

The results from this study concur with the literature in that there is very little written information being provided to patients. The impact this has on patients could range from increased anxiety to the development of psychological problems therefore further research is essential to ascertain what information patients would have liked before and after their amputation and whether the provision of such information has a positive impact on their rehabilitation.

5.12.2 Aims and Goals – Objective 5.3

Goals and goal setting are highly regarded as an integral part of rehabilitation (Siegert and Taylor, 2004; Barnes and Ward, 2000; McLellan, 1997; Hurn et al., 2006), which is not reflected in the numbers of patients that had their aims and goals discussed with them. Over a third of the participants stated that they had not had their aims and goals discussed with them which, according to the literature, would indicate that the rehabilitation process is not sound and cannot be expected to succeed. Two thirds of these participants would have liked to discuss their aims and goals, which clearly indicates that in some centres the needs of patients are not being met. Centres not discussing aims and goals with their patients are not using highly regarded tools in order to motivate and push their patients to achieve and could be causing their patients to become anxious as highlighted as almost half of the participants stating that they were concerned by the lack of aims and goals.

The work by Playford et al. (2000) highlighted that aims and goals may not be formulated by or with the patient which goes some way to explaining over half of the participants that stated their aims and goals were not updated regularly. Understaffing was also highlighted by Playford et al. (2000) as being detrimental to the success of goal setting programmes and as found in Study 1, some centres across the country could be understaffed and therefore the prosthetist’s time for each patient has to be utilised for clinical purposes only. If goals are not updated the motivation they inspire in patients can be lost (Barnes and Ward, 2000) and the rehabilitation team have no way of knowing what individuals wish to achieve, for instance, beyond learning to walk again.

It is clear that there is no consistency across the country with regards setting and updating of patient's aims and goals. It is in the interest of the patient that the NHS should produce a national standard for goal setting which must be adhered to by every DSC. The work conducted by Rushton and Miller (2002) on Goal Assessment Scaling should be continued to ascertain whether it could be utilised in creating a new Aims and Goals approach for the DSCs to follow in order to create goals with their patients, assess progress and update the aims regularly. This would not only encourage patients and motivate them to achieve their goals, but also give the MDT good outcome measures and indicators of where further rehabilitation may be required.

5.12.3 Spare Limbs – Objective 5.3

Due to the recent change in policy, as outlined in Section 4.12.3.1, there is no literature pertaining to the advantages of spare limbs for prosthetic patients. Centres may find it difficult to stop prescribing spare limbs for those patients that have been routinely receiving one for years; therefore there is a higher possibility of those patients receiving a spare limb over primary amputees. These practical reasons for not providing a spare limb may be true, however, the results from this work clearly show that, for participants, having a spare limb is important and that it gives them peace of mind. There is the possibility that patients are being constrained in their life choices through fear of damaging their prosthesis and not having a spare limb to utilise. There is clearly a communication breakdown as the clinicians are fully aware that patients rarely use a spare limb and patients seldom benefit from them, however patients are either not aware of this or have not been reassured that a spare limb is not necessary. The concerns patients have about not receiving a spare limb should be discussed openly with clinicians to stop this concern from becoming an issue for patients. Further research is required to ascertain whether having the reasons for not receiving a spare limb being fully explained reduces the importance of the spare limb to the patients.

5.12.4 Water activity and shower limbs – Objective 5.3

If the benefits of such limbs are known, it may be surmised that the NHS simply does not have the funds to provide these limbs to every patient that would like one despite the health and social benefits. These participants are aware of the benefits water activity or shower limbs could have on their lives and would therefore be willing to spend their own money to obtain one. An explanation from a prosthetist during Study 1 revealed that patients are not able to purchase such a limb from the NHS centre and must therefore go to a private clinic in order to obtain one. The breakdown in communication is evident again as one third of the participants that did not receive a limb did not have the reasons for this fully explained to them. It is therefore important for further research to be conducted into how this breakdown in communication between patients and clinicians can be bridged to allow patients to fully understand the reasons for not receiving limbs they would like.

5.12.5 Physiotherapy – Objective 5.4

The evidence of a breakdown in communication between prosthetists and physiotherapists means that if the patient is progressing well in physiotherapy and could be upgraded to a better component, the prosthetist will not be aware of this and it could therefore take much longer for any upgrades to be implemented. This could cause frustration on the part of the patient due to their rehabilitation being delayed simply through a lack of appropriate communication. It may also be surmised that cost savings could be made if prosthetists were present in physiotherapy sessions if issues arose. The prosthetist would be able to identify the problem with the prosthesis and possibly correct it in that session, rather than the patient having to book another appointment with the prosthetist and come back to the centre for adjustments which may only take a few minutes. This would not only free up the prosthetist for treating another patient, but also save the patient time and travel expenses. The lack of knowledge of patient's progress could be due to prosthetists not feeling this information is necessary in order to conduct their work, therefore education of prosthetists may be needed in order for the advantages of such information to be highlighted.

There is also evidence that it is of benefit to the patient and clinicians to have physiotherapy based in the same setting as the prosthetic care. Patients that have physiotherapy in the community rather than at their DSC may not be receiving the same level of care as those patients that have their physiotherapy at the DSC. It is difficult for all patients to attend the DSC for physiotherapy due to the very large catchment areas, therefore the MDT at the centre would be required to take into account the general health, ability to travel, and rehabilitation needs of individual patients to decide the most suitable location for physiotherapy for each patient.

5.12.6 Components and Technology – Objective 5.5

Technical advances are constantly being made in the prosthetics industry with new component information being easily accessible on the internet. Information on new technologies has also been in the media far more frequently in recent years due to the increased media coverage of the Paralympics and also the service personnel injured in current military conflicts. The components participants in this study were refused were high end technology and therefore too expensive for the NHS to provide. The results indicate that the NHS should look into a top up system for prosthetic components. A top up system would allow patients to gain the cost of their original prescription and put it towards a component they want and simply pay the deficit themselves. This could not only improve the quality of life of patients but also increase their satisfaction with the service provision.

Further research is required to ascertain how this lack of components they desire is affecting patients however it is clear from the results that components are something that the majority of patients are willing to invest their own money in. There is growing media coverage of the Paralympics in the UK which can increase the expectations of new amputees due to the athletes being pictured wearing specialist carbon fibre running blades. Due to this, patients may be disappointed with the service they are being provided by the NHS as they are aware of prostheses which are far superior to those that they have been prescribed.

5.12.7 Appointments

Patients generally only visit their prosthetist when they have a problem, therefore if they have a skin complaint or their prosthesis no longer fits, they may have to wait two or more weeks to see their prosthetist to have the problem assessed and if a re-fitting is required this can take even longer. This can seriously inconvenience prosthesis wearers as they may be unable to wear their prosthesis for a number of weeks and therefore not be able to go about their daily lives as they would wish to. This can cause frustration, which in turn can have a negative effect on the mental wellbeing of patients. As previously mentioned, Sullivan et al. (2003) reported that patients in their trial reported frustration with the slowness of rehabilitation, therefore it is important that patients are seen as soon as possible in order to minimise frustration.

5.12.8 Counselling – Objective 5.6

The results highlight the differences in service provision across the UK due to the high percentage of participants not knowing if the service was available to them. A lack of discussion about the service indicates that the emotions associated with amputation may not be properly addressed by clinicians, leaving patients to deal with their amputation in their own way. This could cause the adoption of inappropriate coping mechanisms such as the use of drugs and alcohol (Desmond and MacLachlan, 2002). The results clearly indicate that participants regard counselling highly and could benefit from the introduction of the service months or years after amputation. The literature also concurs with the results of this study with respect to primary patients receiving counselling prior to their amputation to help alleviate anxiety and prepare the patient for the life changing operation. It is therefore in the interest of the NHS to provide counselling for patients as proper expectation management and emotional support could reduce the number of repeat appointments with patients who are dissatisfied with their prosthesis and therefore save clinicians time and the service money. Counselling could also prevent patients developing psychological problems requiring medication or hospital treatment, therefore could save the NHS money in the long term.

5.12.9 Patient Volunteer Visitors – Objective 5.6

Patient volunteer visitors are experienced amputees that volunteer their time to visit primary amputees in hospital or at the DSC to provide support and advice. Participants in this study are clearly aware of the important role a volunteer visitor can play in the rehabilitation of participants due to the very high percentage stating that they would consider taking on this role themselves. It is evident that peer support can help provide the assistance for primary amputees to accept their amputation and help encourage productive rehabilitation. The results show that patient volunteer visitors could alleviate anxiety, provide comfort in a traumatic situation and ease patient's minds, therefore potentially reducing the risk of psychological problems. The majority of participants felt that this service should be provided by the NHS therefore it is important for the NHS to be seen to be acting upon this and providing the support patients need for their mental and physical wellbeing.

5.12.10 Service – Objective 5.7

The results from this study indicate that satisfaction with the service being provided is closely linked with satisfaction with the prosthesis. Following amputation patients will require some form of rehabilitation and assistive technology for the rest of their lives, making the relationship between them and their DSC a very important one. This is a clear indicator that it is important to establish the expectations of a patient when assessing the outcome of their rehabilitation. Further research is required to ascertain whether these patients could be fitted with an appropriate prosthesis or their expectations have not been properly managed, causing their dissatisfaction. It is therefore necessary to conduct further research into the quality of the care being provided by the DSCs and compare these findings with the opinions of patients.

The three most stressful experiences most frequently described by participants indicate that having a socket that fits is an extremely important part of life and can cause great anxiety and stress if it does not fit. This was reflected by the high frequency of participants mentioning frustration due to the socket causing pain. These results reflect the work by Gallagher and Maclachlan (2001) and The Audit Commission (2002) that ill-fitting sockets cause pain and therefore can cause patients to abandon limb wearing or become frustrated that they are unable to continue with their daily activities.

The third most frequently mentioned stressful moment was when participants were not given enough information, resulting in the most frequently mentioned reason for stress being apprehension due to unknowns. The issues relating to information are discussed in section 5.12.1, however these data show that a lack of information can detrimentally affect patients anxiety levels. The appropriate use of information can alleviate anxiety due to unknowns as patients are made aware of what lies ahead of them with regards rehabilitation and what to expect in the future.

Complaints should always be treated with importance and some action taken as patients rely on the prosthetic service for their mobility and an ill-fitting prosthesis or poor experience of rehabilitation can have serious consequences with regards mental and physical health.

5.12.11 Likert type items

The results from the Mann-Whitney and Kruskal-Wallis tests show that sex, amputation level, age and year of amputation have no effect on participant's opinions on any of the issues covered. This indicates that the problems faced by amputees are universal and therefore solutions to these problems would not have to be individualised to males and females or patients of different ages, for example. These results should be treated with caution as the sample sizes in each group were small and therefore the results could be skewed. Further research involving much larger samples should be conducted in order to ascertain whether these factors do or do not have an effect on patients opinions of the issues covered.

5.13 Critique of Study

This study was conducted independently of the NHS as literature and personal interaction with patients suggested that NHS involvement could skew the results in a positive direction. This however has caused the sampling method to be less reliable as participants were not randomly selected. This also limited the number of participants as it was not possible to contact hundreds of amputees across the UK and only those that use Facebook, visit the Limbless Association or Limbcare websites or read ‘Step Forward’ magazine would know about the questionnaire. The use of the online questionnaire also removed a number of patients from the sample as the majority of amputees are 55 and over, which means that a large proportion of them may not have access to the internet or be confident using the survey website. Also, the majority of participants that took part in this study had traumatic amputations, which is at odds with the statistics in NASDAB (1999 and 2009).

Although measures were taken to identify participants with one amputation that had completed the questionnaire more than once, these measures could not detect a participant completing the questionnaire on several different computers. In order to eliminate this possibility the name of each participant would be required, however due to this question being voluntary, this information was not provided by every participant.

Further research would need to combat these issues by conducting a questionnaire within the NHS in order to access patient names and therefore take a random sample in order to fully represent patients with amputations due to other causes and representative ages. This would also ensure that participants only completed the questionnaire once. Future research would also need to be conducted by an independent body that assured patients that their answers would not be passed back to their DSC to ensure that patients would be comfortable taking part and provide accurate answers. Striking this balance would be imperative in order to gain reliable and accurate data.

A further issue with the sampling method was that patients from every DSC in the UK could answer, however visits had only been made to 12 centres in England. This made comparison of the information gained from visits and data gained from patients very difficult. Very few patients from the centres visited in Study 1 took part in the questionnaire therefore the issues found at individual centres could not be investigated in the answers given by patients. Further work should involve visits to each of the 43 centres to ascertain their level of service provision and a sample of patients from each of the centres taken to complete the questionnaire in order to make comparisons.

Small sample sizes caused the statistics calculations to be unreliable as with larger sample sizes could reveal significance between groups that have shown no significance in these results. Much larger sample sizes should be sought to ensure the reliability of the calculations.

Comments from participants brought to light that the questionnaire was mainly aimed at patients that had become amputees very recently such as *“Your survey is hardly appropriate for one who has been an amputee for 68 years”* and *“The questionnaire appears to deal with recent amputations not old amputations or non-amputations”.* It is therefore suggested that for future work patients are split into groups and different forms of the questionnaire are given to these groups. This would allow comparison across the groups for certain questions but will also provide up to date opinions on the service they receive now for those patients that had their amputations many years ago.

A number of questions asked participants if they were ‘happy’ or ‘unhappy’ with a certain service or situation. It is recognised that happiness is subjective and cannot be easily defined. This decision was made to encourage participants to decide whether the service or situation they were in was causing an emotional response. The wording of these questions should be considered and possibly altered if further work is to be conducted using the same questionnaire. Further work into the expectations of patients, whether these are being met and how this affects satisfaction should be considered.

5.14 Conclusions

Data was gathered from 96 participants via an online questionnaire and analysed in order to fulfil the study objectives. It was found that amputees receive very little written information with most information from their health professionals being conveyed verbally. The provision of information was lacking for participants before amputation which could have caused anxiety due to patients being unaware of the rehabilitation pathway following surgery. It is believed that simply providing the correct information at the appropriate time could alleviate anxiety among patients and allow for a smooth entry into rehabilitation. Participants of this study valued spare limbs and water activity and shower limbs very highly, with many participants being unhappy at not receiving them. A potential solution would be for better communication between the prosthetist and patient to allow patients to fully understand why a spare limb may not be necessary and therefore alleviate any anxieties they may be having. The study also highlighted the importance of aims and goals in the rehabilitation of patients and that further research is required into creation of a nationwide protocol for the assessment of aims and goals. Physiotherapy sessions were found to be quite agreeable for participants, however prosthetists were not aware of patients' progress in a significant number of cases. The provision of counselling and patient volunteer visitors were highly regarded by participants, therefore centres should be working to provide support for patients in the form of counselling or patient volunteer visitors due to the perceived benefits of these services. Satisfaction with service provision was found to have a strong connection with satisfaction with the prosthesis; therefore research is needed on the connection between socket fit and provision of service, with particular attention paid to whether expectation management and counselling could be used to improve this.

The recommendations from this study include the need for a more informed process of expectation management as well as on going and timely support at critical points in the patient pathway. These can be provided by improving and standardising the information provided to patients, offering counselling at key points and improving the access to patient volunteer visitors who offer peer support. These interventions, which attract little cost, would significantly improve the patient experience and reduce the demand, and hence cost, placed upon the clinical services.

Research within the NHS would be essential for further studies concerning many of the problems highlighted in this study. Information has been identified as an area requiring further investigation and any suggestions made for the introduction of information provision could be integrated into the current processes across all centres and can provide patient centred support, at low cost.

Chapter 6: Study 3 – The importance of information for amputees

6.1 Summary

Information is a critical element in the process of amputation, as Study 2 has found. Lack of information can cause patients unnecessary stress and therefore hinder rehabilitation. Study 2 has shown that comprehensive information covering all aspects of rehabilitation could ease anxiety and provide patients and their families with the means to digest and come to terms with the rehabilitation process in their own time. In order to ascertain patients' information requirements pre- and post-amputation, a qualitative study was conducted using telephone interviews. The interviews were thematically analysed and conclusions drawn about the information provision required for primary patients in order to minimise anxiety. The detail of this study is reported here.

6.2 Aims and Objectives

The aim of this study was to gain an insight into the information patients feel should be provided to them at different stages of their rehabilitation in order to make recommendations for appropriate patient-centred information. This was to be achieved by fulfilling four study specific objectives.

Objectives - To ascertain through appropriate data collection methods:

6.1 What information do patients feel should be provided to them?

6.2 At which stage of rehabilitation do they feel this information should be provided?

6.3 In what form do patients feel would be the most appropriate to provide this information?

6.4 Whether content and format should be tailored to the patient's age?

Due to there being no guidelines or requirements set out by the NHS for information given to patients, the experiences of patients from across the country are very different. As found in Study 2, lack of information can be very stressful for patients as this can induce a fear of the unknown which can have both physical and psychological side effects.

6.3 Literature review

6.3.1 Rehabilitation

Klute et al (2009) found that amputees felt enhanced collaboration and communication could improve future amputee care. Participants were desperate for more information on the recovery path following amputation and suggested that amputees be given comprehensive information to allow them to understand their treatment, rehabilitation and the range of possible outcomes (Klute et al., 2009). Each participant agreed that they are ultimately responsible for their care which emphasises why detailed information about each phase in the recovery path is so important (Klute et al., 2009). However there is a lack of literature pertaining to the feelings of amputees about the rehabilitation process they experience and the information they are provided about this process (Watanabe et al., 1999).

6.3.2 Psychological impact of amputation

Amputation is unique among disabling surgery as patients experience a loss of physical 'wholeness' (Heafey et al., 2012) which has been likened, by Parkes (1975), to the loss of a spouse. Due to this sense of loss, patients often report feelings of helplessness, sadness, anger, anxiety, guilt and frustration (Sjödahl et al., 2004; Ferguson et al., 2004) as well as concerns about occupational, social, sexual and familial relationships (Liu et al., 2010; Davidson et al., 2002). Regardless of aetiology, amputation of a limb can not only disturb physical function, but psychological and social function also (Sjödahl et al., 2004; Davidson et al., 2002). Literature shows that amputee patients report elevated rates of depression and post-traumatic stress disorder (Phelps et al., 2008), social discomfort related to body image change

(Gallagher and Maclachlan, 2001; Rybarczyk et al., 1995) and negative body esteem (Taleporos and McCabe, 2005).

Desmond and MacLachlan (2002) state that adjustment to life after amputation is likely to be challenging for the majority of people. Depression, anxiety, feelings of hopelessness, fatigue and low self-esteem can all be associated with difficulties in adjustment. These problems can also lead to further issues such as poor social functioning, loss of functional independence and an adoption of drug or alcohol consumption as a coping mechanism (Desmond and MacLachlan, 2002). Fitzgerald (2000) states that one of the most distressing losses caused by amputation is the destruction of the "false sense of security" that people have until a catastrophic event occurs. Patients can therefore feel vulnerable, powerless, violated and alone (Fitzgerald, 2000). Ferguson (2004) states that a full recovery from limb loss requires "deep psychological and social support" which involves help from friends, family and the community.

6.3.2.1 Psychological responses to amputation

There is debate in the literature about psychological responses to amputation as to whether amputees, like other patients with disabling conditions, undergo a 'psychological transition' (Parkes, 1975; Waites and Zigmond, 1999) or whether amputation incurs 'distinct' psychological consequences (Maguire and Parkes, 1998). Table 6.1 illustrates the psychological responses to amputation as detailed by Gallagher (1999) Price (2005) Waites and Zigmond (1999) and Langer (1994). These responses can be used by patients to adjust to the amputation or can lead to the development of other psychiatric symptoms (Waites and Zigmond, 1999; Price Jr, 2005). Research conducted over twenty years ago showed that just under half of the amputee study population were at risk of developing psychiatric illness (Thompson and Haran, 1983) and 85% of another study population were 'significantly mentally scarred' by the operation (Waites and Zigmond, 1999). Horgan and MacLaghlan (2004) found much the same evidence in literature spanning thirty years.

Table 6.1: Psychological responses to amputation (Waites and Zigmond, 1999; Gallagher and MacLachlan, 1999; Price Jr, 2005; Langer, 1994)

Negative psychological responses to amputation		**Positive psychological responses to amputation**
Grief	Sadness	Hope / Optimism
Anger	Psychosis	Relief
Feelings of mutilation	Vulnerability	Euphoria
Body image changes	Regret	Eventual adjustment
Tearfulness / Distress	Denial	
Sexual difficulties	Bitterness	
Uncertainty	Depression	
Mania	Anxiety	

6.3.2.2 Depression

Clinical depression has been shown to be a relatively common reaction to amputation (Rybarczyk et al., 2004) with reported rates varying from 23 to 60% (Desmond and MacLachlan, 2002; Rybarczyk et al., 1995; Langer, 1994; Cansever et al., 2003; De Godoy et al., 2002; Rybarczyk et al., 1992). Diabetes accounts for approximately one third of the amputations that take place in the UK each year (National Amputee Statistical Database, 2009) and research has found that older patients with diabetes are more likely to develop major depression than older people without the disease (CARE, 2003). Singh et al. (2007) found that depression and anxiety symptoms were rapidly resolved during a period of inpatient rehabilitation. Work conducted by the same team then revealed that, although there may be an initial drop in incidence of depression and anxiety symptoms after amputation, there is then an increase between 2-3 years after surgery (Singh et al., 2009). Studies have also shown that the increased level of depression can persist for up to 17 years following amputation (Fisher and Hanspal, 1998; Parkes, 1975). Singh et al. (2009) also found that the reoccurrence depression was associated with comorbidities and having previously shown signs of depression immediately after amputation.

Effect of Age

Briggs (2006) found that the effect of age on levels of mental health problems following amputation is highly debated in the literature, with most literature over 30 years old claiming that advanced age has a detrimental effect on mental health of amputees. Demet et al. (2003) found that younger age at the time of amputation resulted in better emotional responses to health related quality of life measures. Rybarczyc et al. (2004) argue conversely that older patients are more likely to have experienced loss or bereavements which may have led to the formation of ‘templates for adaptive coping’ which help the patients to adapt to the loss of a limb which reduces the likelihood of depression developing. In contrast Singh et al. (2009) found no connection between age and prevalence of depression. The differences in these findings were reported by Briggs (2006) as being due to methodological difficulties in comparing long term outcomes between age groups of amputees.

Mobility

A review of the literature conducted by Horgan and MacLachlan (2004) found that activity restriction and depression in amputees is interrelated, therefore prosthesis use and physical activity are extremely important for the emotional well-being of amputees. Callaghan et al. (2008) found that limitations in physical activity present at one month post-surgery was a predictor of the presence of anxiety and depression at six months post-surgery. Regular prosthesis use is therefore important to allow patients to engage in daily functions and social activities which can influence mood and quality of life (Callaghan et al., 2008; Condie et al., 2006). Studies have shown that ambulation with a prosthesis can be limited to the home in some cases and more so for older amputees (Wan-Nar Wong, 2005a; Andrews, 1996). Inability to use a prosthesis due to stump pain or other physical impairments can lead to frustration, depression and anxiety in patients which in turn can affect satisfaction with social contacts, income adequacy and quality of life (Horgan and MacLachlan, 2004; Condie et al., 2006; Callaghan et al., 2004).

Isolation

Williams et al. (2004) conducted a two year longitudinal study of social support for amputees and found that their participants were less likely to integrate socially than non-disabled groups. They also found that mobility and function were increased in those patients that believed they had greater social support, as the patients spent greater amounts of time engaged in meaningful activities than those with a perceived lack of social support (Williams et al., 2004). Demet (2003) and Seymour

(2002) state that social isolation would affect older amputees more and Williams et al. (2004) found that social isolation was likely to increase with time. Predicting patients vulnerable to social isolation may be possible due to Williams et al. (2004) finding that amputees with non-traumatic amputations and those that are single are more likely to suffer social isolation.

Phantom limb pain

Rybarczyc et al. (2004) found that phantom limb pain was a strong predictor of depression among amputees, with cases of depression with psychotic features being described. Horgan and MacLachlan (2004) found through a review of the literature that there is much debate over the connection between phantom limb pain and depression with some authors arguing that there is no connection at all. The mixed findings in the literature make it difficult to draw any conclusions about the connection between phantom limb pain and psychological distress (Horgan and MacLachlan, 2004).

Time

Rybarczyc et al. (2004) found that overall risk of depression in patients following amputation did not decrease over time in most of the studies they reviewed. Cansever (2003) found no connection between time and depressive symptoms; with De Godoy (2002) finding that overall quality of life did not improve with increased time after amputation. In contrast Price and Fisher (2002) found that emotional problems were most likely to become apparent six to twenty four months after surgery. A study conducted by Oaksford et al. (2005) found that psychological growth and adjustment to the disability occurred in some patients as early as six months post amputation.

6.3.3 Sexual activity

Ide et al. (2002) state that it is surprising that the knowledge of sexual aspects of limb amputees has not widened very much over the last twenty years. Sexual function and sexual concerns present two separate areas for research with the area concerning sexual function having far more literature. Sexual function of physically disabled people has almost exclusively focused on fertility and pregnancy with the area of sexual concerns being left relatively untouched (Ide, 2004; Bodenheimer et al., 2000). The reasons for this are stated by Ide (2004) as being:

- Sexual function of amputees including fertility and pregnancy is rarely impaired.
- Because lost physical function of amputees is compensated by a prosthesis, most medical professionals terminate their care after limb fitting
- The physical performance of amputees is better than that of patients with of other physical disabilities and most amputees live an independent life. Therefore they only tend to require technical advice from medical professionals.

Geertzen et al. (2009) conducted a literature review of all papers on sexual activity and amputees. Eleven papers dating from 1945-2002 were reviewed. The low number of papers found proves the lack of research into this area. Due to the diversity of the papers and lack of consistency in some results, very few conclusions could be confidently drawn. The review did however show that all eleven studies found an impact of amputation on sexual functioning (or concerns about) to some degree (Geertzen et al., 2009). Most of the publications reviewed showed that a variable amount of amputees (13-75%) were not satisfied with their sexual life, despite the amputation having no effect on their interest in sex (Geertzen et al., 2009).

The discussion of sexual issues has been recognised as having value during the rehabilitation process of amputees however it is apparent that rehabilitation professionals do not appear to be sufficiently prepared to deal with such issues (Geertzen et al., 2009; Williamson and Walters, 1996). Williamson and Walters (1996) found that less than 10% of their participants had been given any information on sexual activity by their healthcare providers. Discussion of sexual concerns during the rehabilitation process may not be conducted due to the culture of ‘shame’ surrounding such discussions (Ide et al., 2002). Many people, including some medical professionals, feel that discussion of sexual issues should only be between sexual partners and it is also considered immoral and shameful in some cultures (Ide, 2004). Ide et al. (2002) found that, in a study of 85 amputees, none of them spoke to medical professionals about their sexual concerns. Ide (2004) states that physical and psychological aspects equally affect performance. Performance of a partner has a strong influence on an individual's sexual activity in many cases therefore sex life is important in reflecting the patient's re-integration and consequently its evaluation is important (Ide, 2004; Bodenheimer et al., 2000; Williamson and Walters, 1996). Geertzen et al. (2009) concluded that most authors agreed that there should be more attention and understanding for sexual concerns and that assessment of sexual function should be an integral part of the rehabilitation process. It was suggested that at least one member of the rehabilitation team be trained in such assessment and be able to provide advice for patients (Geertzen et al., 2009). Ide (2004) suggested that discussing quality of life with patients should be considered as well as setting up a relaxed atmosphere so that amputees could discuss their sexual activity.

Following the analysis of a number of previous studies Ide (2004) concluded that careful evaluation of body image may be the first issue to be investigated as the basis for discussing sexual activity. The amputation of a limb would give patients a unique body image compared with people with other physical disabilities, therefore understanding this is an important part of understanding why sexual issues may occur (Ide, 2004; Bodenheimer et al., 2000; Williamson and Walters, 1996). Patients may be embarrassed to show a partner their residual limb or be afraid of rejection by new partners. Ide et al. (2002) found that many patients reported a reduced libido even though amputation does not directly affect sexual function except in rare cases.

6.3.4 Peer support

The literature suggests that peer support has been found to be a salient factor in the successful recovery of primary amputees (Butcher, 2009; Liu et al., 2010; Thompson and Fisher, 2010; Berke, 2004). Amputee support groups, peer visitation and consumer awareness have all been proven as useful resources for primary amputees (Berke, 2004). Peer visitors can provide excellent support for primary amputees as they hold the unique position of truly understanding the emotions related to amputation due to their own experiences (Fitzgerald, 2000). The information and education provided by peers can be invaluable to the mental health of primary patients and cannot easily be achieved through any other means (Thompson and Fisher, 2010). Peer visitors not only provide primary amputees with a positive role model (Fitzgerald, 2000) but also accessible and credible encouragement (Liu et al., 2010). Meeting others with limb loss can help patients to put their own experiences into perspective (Liu et al., 2010) and even empower them to persevere despite other injuries or illnesses (Ferguson et al., 2004). There is opportunity for patients to relieve stress, as they are able to see others with similar injuries or levels of amputation, integrated back into society (Ferguson et al., 2004; Liu et al., 2010). Sharing of experiences and creating friendships have all been found to have positive effects on patient recovery (Ferguson et al., 2004; Liu et al., 2010; Fitzgerald, 2000; Thompson and Fisher, 2010; Berke, 2004).

6.3.5 Support for carers and families

Although carers and families of amputees are considered to have a vital role in their rehabilitation (Boulton et al., 2000; Van Ross and Carlsson, 2006; Larner et al., 2003), there is very little literature on support or information for these individuals. Literature on caring for patients with other chronic illnesses and disabilities was therefore reviewed. Driscoll (2000) found that carers receive very little information from health professionals concerning their patient's health problems and care once discharged from hospital. The work also concluded that carers that received information while their patient was in hospital experienced a decrease in anxiety during the patient's convalescence at home and their patients experienced fewer medical problems post discharge (Driscoll, 2000). Work conducted by Kendall et al. (2004) highlighted the need for information to be given to carers of patients with epilepsy as their needs and anxieties very often go unrecognised. Morris (2001) reported similar findings, that relatives of patients with head injuries were given very little information and therefore found the information booklet being trialled to be 'invaluable' and helped alleviate some of the anxiety of the uncertain situation they were in.

There is increasing evidence that providing care for seriously ill patients is both stressful and damaging to the health of the carer, whether a partner or family member (Neno, 2004; Öhman and Söderberg, 2004; Llewelyn and Payne, 1995;

Anderson, 1987). Persson et al. (1998) found that carers of seriously ill family members felt distressed and restricted with limited or no support leaving them in a state of severe powerlessness. There have also been a number of studies showing that when the spouse or partner is the caregiver, it affects the marital relationship (Snelling, 2006; Söderberg et al., 2003; Paulson et al., 2003; Flor et al., 1987). Studies have also shown that carers feel there is a lack of information regarding the help available to them and specific information to their family member's situation (Öhman and Söderberg, 2004; Wennman-Larsen and Tishelman, 2002). Anderson (1987) states that carers wanted information about services and disabilities and continued support from the primary care team in order to prevent feelings of abandonment. These findings were reflected by Öhman and Söderberg (2004), as they found that carers had a distinct lack of knowledge about the disability their family member had, with the majority of useful information coming from carers in similar situations to themselves. These studies both highlight the need for information and support to be provided by the primary care team in order to reduce stress and psychological impact on carers of disabled relatives (Öhman and Söderberg, 2004; Anderson, 1987). There is clearly a lack of information in this area with respect to carers of amputees and the current literature is in need of updating (Thompson and Haran, 1985).

6.3.6 Information delivery systems

Due to the shortening of hospital stays patients and their families require detailed information about the process of rehabilitation and specific information relating to amputation (Kessels, 2003). The demand for this information is growing as patients and their families wish to have information that will help them participate effectively in their own rehabilitation and make the best health choices possible (Johnson and Sandford, 2005). There are however barriers to the absorption of such information as 40-80% of medical information provided by healthcare practitioners is forgotten immediately (Kessels, 2003). The memory of the patient plays a large part in how much information is accurately recalled, with the mode of information delivery (e.g. written versus verbal) having an equally important role (Kessels, 2003). Older patients or those that are particularly anxious often have very poor memories therefore medical information is not retained. Verbal information has been found to be a poor communication method for medical information (Thomson et al., 2001). Written or visual material has been found to increase the levels of treatment adherence (Kessels, 2003) with structured, tailored and/or interactive information being found to increase patients' understanding (Trevena et al., 2005). A review conducted by Johnson et al. (2005) suggested that both verbal and written health information be used when communicating with patients and/or family and carers as standardised care information could be provided and appeared to improve knowledge, satisfaction and also decrease levels of anxiety. Reviews have also shown that in some cases verbal and written information used in combination can reduce the use of health service resources (Coulter and Ellins, 2007).

The provision of written information is well documented as being valuable to patients; however there are a number of concepts of such information that should be considered. Following a review of the literature on written patient information Arthur (2008) describes four important concepts for consideration:

1. Is the information actually of use to patients?
2. Can they understand and recall the information?
3. Does the information improve compliance?
4. Are patients satisfied with the amount, quality and detail of the written information?

Arthur (2008) suggests that although the provision of written information can be beneficial to patients, the provision of information that has no relevance or is not easily understood could induce an even more frustrating situation for patients, than receiving no information at all. Colledge et al. (2008) however, state that in some circumstances guiding patients to a reliable source of information for them to read and digest then inviting them for a follow up appointment is more appropriate. There is evidence that patients struggle to find reliable healthcare information due to the lack of signposting by UK health professionals (Swain et al., 2007). A number of studies have shown that introducing 'Information Prescriptions' are a useful tool in signposting high quality, evidence based information for patients (Ko et al., 2006;

Ritterband et al., 2005; D'Alessandro et al., 2004). Information prescriptions not only provide printed or alternative format sources, they can be used to include details about support or self-help groups, charities or an Expert Patient Programme (Ko et al., 2006; Ritterband et al., 2005; D'Alessandro et al., 2004).

Scott (2004) found in a review of the literature that pre-operative information for patients staying in intensive care was “unquestionably of value” due to a decrease in patient anxiety. The provision, pre-operatively, of written information and nurse visitation were both found to have benefits for patients and nurses as the patients were able to ask questions and feel less anxious as they were aware of the procedure they were to undergo (Scott, 2004). Kessels (2003) found that visual or written material was essential to reinforce verbal information and visual aids were especially effective in low literacy patients. A more recent trial of patients about to undergo aesthetic surgery found patients that had been given a CD-ROM containing information about the surgery were significantly less anxious and knew more about the purpose and details of the procedure than those who had not (Danino et al., 2005). A study conducted by Molenaar et al. (2007) on the usefulness of an interactive CD-ROM on treatment options in breast cancer found that patients used the aid intensively. Patients were found to spend, on average, 70 minutes searching and reading information (Molenaar et al., 2007). This style of information provision, combined with other communication strategies, helped patients become informed of their treatment options and feel less anxious about the chosen treatment (Molenaar et al., 2007). CD ROMS allow patients to freely access the information they wish to read at a time convenient to themselves and gives patients the opportunity to digest the information on their own terms. DVDs have also been found to be a useful source of information for patients and their families (Ong et al., 2009; Kinnane et al., 2007). Gazmararian et al. (2009) found that diabetes patients required continued education on their condition as well as support group discussions and information in different forms to allow for the best possible absorption of the relevant medical information.

Technology is advancing rapidly; therefore access to healthcare information is no longer limited to leaflets or verbal information from healthcare providers (Colledge et al., 2008). Technologies such as email, websites, interactive digital TV, text messaging, CD ROMs, DVDs and podcasts could all be used in the advancement of healthcare information dissemination (Colledge et al., 2008). Usage of the internet has increased from 55% of households in the UK in 2006 (Office for National Statistics, 2006) to 80% in 2012 (Office for National Statistics, 2012), therefore distribution of healthcare information should be developing with the new technologies. There has been an increase in randomised controlled trials that demonstrate the use of different information delivery formats, including text messaging, video and the internet, that show these formats are more effective in many cases than verbal or written communication (Suggs, 2006; DeWalt et al., 2004). Podcasts have not been included in any randomised controlled trials, however they are similar in nature to other forms of audio recording (Colledge et al., 2008). A project by Powell et al. (2010) found that a number of interventions using the internet and digital technology have been tested on various platforms and clinical and social benefits have been reported, however, due to the different contexts and nature of the research, these findings are difficult to generalise. Although the findings may not be generalisable, the findings are still of importance in understanding patient acceptance of new technologies.

A number of trials have shown success with the use of written information and new technologies in provision of information relating to certain health conditions. The use of pictograms alongside written information were found to improve patient understanding in a number of studies (Houts et al., 2006; Mansoor and Dowse, 2003) with particular success in medical instrument instructions (Brotherstone et al., 2006) and HIV medication information (Wilby et al., 2011).

Personalised information prescriptions helped patients to access reliable information easily in paediatrics (D'Alessandro et al., 2004) and general practice (Coberly et al., 2010). Introducing personalised information about their illness and treatment options improved cancer patients' comprehension of their condition (Ouwens et al., 2009). Introducing multimedia programmes of games relating to their condition for children with asthma improved compliance and therefore clinical outcomes. A study conducted by Huang et al. (2009) found that the use of an interactive multimedia device improved diabetic patients understanding of their condition.

Colledge et al. (2008) state that providing audio recordings of consultations with clinicians may provide a number of benefits to patients. This statement was investigated through two studies involving parents of seriously ill babies (Koh et al., 2007; Koh et al., 2005). The results showed that parents had an enhanced recall of information following the introduction of the audio recordings. Hack and Degner (2010) provided cancer patients with audio recordings of their interactions with clinicians and found that patients were able to recall information more accurately, understood their treatment more clearly, had more confidence that critical aspects of treatment had been discussed and were able to assume a more active role in consultations. Family and friends also benefitted from the audio recordings as the patient was able to initiate conversation about their illness more easily and with more confidence (Hack and Degner, 2010).

The use of text messaging in two studies was found to enhance disease monitoring and management leading to improved outcomes (Fjeldsoe et al., 2009; Krishna et al., 2009). Previous studies involving asthma and diabetes patients had found that introduction of the text messaging service had improved compliance with medicine taking, recognition of symptoms and self-efficacy (Rami et al., 2006; Ostojic et al., 2005). Two studies found smoking quit rates to increase following the introduction of a text messaging service (Vidrine et al., 2006; Rodgers et al., 2005).

The use of DVDs or videos to convey important medical information, was found to improve compliance and knowledge of the medical condition (Colledge et al., 2008). Studies involving breast, prostate and colon cancer patients revealed that an informative DVD improved awareness and knowledge of their illness (Davis et al., 2008; Walker and Podbilewicz-Schuller, 2005; Frosch et al., 2003). Introduction of a video to explain informed consent information for intravenous contrast administration, knee arthroscopy and fracture surgery increased patient knowledge and acceptance and decreased their anxiety about the procedure (Schenker et al., 2011; Cowan et al., 2007; Rossi et al., 2005). A video informing patients about pretest information on HIV testing was found to be as effective as a personal conversation by Calderon et al. (2006). Patients about to undergo cataract surgery had increased knowledge of the procedure following the introduction of an information video (Colin et al., 2010). Chemotherapy patients were found to retain more information about management of side effects and reporting important treatment related symptoms when they had watched an informative DVD prior to treatment (Kinnane et al., 2007). A similar study on pre-operative patients found that patients and their families were more knowledgeable and prepared for the approaching surgery if they had watched the informative DVD (Ong et al., 2009). Nurses also found an increase in knowledge and engagement in post-operative activities of those patients that had watched the informative DVD prior to surgery (Ong et al., 2009).

Webb et al.(2010) and Coulter and Ellins (2007) found that websites and the internet improve knowledge, provide high user satisfaction and beneficial effects on self-efficacy and health behaviour. These findings were reflected in studies relating to asthma and pain management where improved perceived quality of care and decreased pain levels were reported (Bender et al., 2011; Hartmann et al., 2007; Sciamanna et al., 2006).

In a study of patients about to receive cataract surgery Shukla et al. (2011) found that information sheets and videotape presentations were the optimum forms of information when describing the risks, benefits and treatment alternatives. This work is not directly related to amputation, however it provides evidence that verbal information can be inadequate when describing important aspects of surgery to patients. Each of the trials listed and discussed provide evidence to suggest that improved information delivery can have many beneficial effects for patients.

Mortimer et al. (2002) conducted a focus group with 31 amputees to ascertain the information provision for phantom pain and improvements patients could suggest for such provision. They found participants had a range of experiences, some receiving informative and useful information with others receiving little or none at all (Mortimer et al., 2002). The conclusions that were drawn indicated that information about phantom limb pain should be provided pre-amputation or very quickly post-amputation, verbally by a healthcare professional or a volunteer visitor (Mortimer et al., 2002). Although this paper is a decade old, the provision of information for amputees does not appear to have improved as the variation in information provision found by Mortimer et al. is reflected by the data collected in Study 2.

The quality of information and accessibility could be improved dramatically with the development of regional or national patient resource libraries that offer patient education materials in a variety of formats (Colledge et al., 2008). Such a resource bank would allow information prescriptions to be provided in the format that would be most appropriate for each individual patient. The cost implications for creating such a resource would require consideration however, Schillinger et al. (2002) found that increased use of interactive education and higher health literacy increased glycaemic control and decreased retinopathy in diabetic patients. Studies have shown that higher medical costs and use of expensive emergency health services are both related to poor health literacy (Nielsen-Bohlman and Panzer, 2004), therefore improving the information given to patients should decrease the cost of medical care for these patients.

Information should be readily available for patients in the format they desire, with their information needs being discussed at every stage of rehabilitation. Empowerment of patients to ask questions and support in understanding the information provided is essential to their involvement in decision making (Colledge et al., 2008).

6.4 Rationale

As information provision has been shown to have such positive benefits, the main purpose of this study was to ascertain the nature of the information patients would have liked to have been provided with pre- and post-amputation and in what format. In order to gain the information required, patients of NHS Disablement Services Centres were the sole focus of this study. The data collected in Study 2 had provided the necessary insight into the information provided to patients, or lack thereof. Study 2 highlighted that very little information was being provided to patients pre-amputation and information provided at other stages was mainly verbal.

6.5 Methods

The data collection method was required to elicit patients' experiences and opinions on the information that they were given and felt they should have received. Due to the sensitive and personal nature of the topic being discussed, interviews were identified as the only appropriate form of data collection. Interviews allow for in-depth discussion and can be conducted over the telephone or in person, providing a number of options for data collection. It would not be possible to solicit the required information from patients via a questionnaire or email/mail interview as in-depth information is needed requiring probing questions which cannot be used in questionnaires and responses to email/mail interviews can be delayed or participants can easily lose interest. Even though group interviews can provide more representative information due to the increased number of participants and in-depth discussion on certain topics, they were considered inappropriate as they can stifle an individual's ability to convey their thoughts due to one or two dominant participants. Group interviews also do not allow a rapport to be built up between the interviewer and participant which reduces the possibility of participants sharing more personal information (Saunders et al., 2007). Even though the number of patients that could be interviewed would be small in comparison to the amputee population, the information provided by individuals was considered more valuable than information collected from a larger number of participants all treated at the same DSC. Due to budget constraints of this research, group interviews would only have been possible to conduct in one or two areas of the country. This would mean that all participants would be from one particular DSC and all have had the same or similar experiences with information given. Due to the differences in information provided to patients across the country, interviewing patients from only one or two DSCs was inappropriate.

Due to the necessity to involve participants from as many different DSCs as possible, telephone interviews were the most appropriate. Time and budget constraints limited the number of face to face interviews possible. The advantages and disadvantages of telephone interviews, discussed in section 5.5.3, were carefully considered and due to the larger number of participants possible with telephone interviews, it was decided they were the most appropriate data collection method.

6.6 Design

Semi structured interviews were considered the most appropriate in order to gain the rich qualitative data required. Five main questions were designed using the data collected from Study 2, with the research objectives in mind. Pilot interviews were used to create some relevant follow up questions with probing questions being used when required. The five main questions were:

1. What information would you have liked on the ward before your amputation?
2. What information would you have liked on the ward after your amputation?
3. What information would you have liked at your first visit to the DSC?
4. How would it have been best to provide you with that information?
5. Who would you have liked the information to come from?

6.7 Ethical Considerations

Zikmund (2000) suggests that it would be unethical to attempt to prolong an interview when it is evident that the participant has other commitments, either in a face to face or telephone interview. It is also important to arrange telephone interviews at reasonable times of the day that are suitable for the participant, with informed consent being essential (Saunders et al., 2007). Participants taking part in telephone interviews should be sent information about the interview with enough time for them to read it so that they may ask any questions they may have before the interview commences. Participants should be sent a copy of the consent form as well as being asked for verbal consent before the interview begins. When dealing with sensitive or difficult topics, participants may ask for guidance or become upset and distressed. In this situation contact details of organisations such as support networks and telephone helplines should be provided to the participant and an attempt made to ensure the participant is left feeling positive at the end of the interview.

Ethical clearance was necessary for this study as both the participants and researcher required protection from harm. Ethical approval seeks to do this by laying out the intentions of the studies and having them scrutinised by members of an ethical committee. Due to the nature of the questions being asked, the emotional welfare of the participant was the main concern. It was necessary to write the questions so that they were unlikely to cause any distress, however questions relating to counselling were necessary and these may be harder for some participants to answer than others due to different experiences. No information regarding the nature of the counselling sessions was sought, only information relating to if and when counselling was offered. The questions were written to be in no way judgemental of the service that the participants had received and were only used to ascertain the experiences of participants. It was also necessary to plan for the interview having an adverse effect on participants so that in this very unlikely event, the appropriate action could be taken. The appropriate course of action, if the interview appeared to be causing distress, was to stop the interview immediately and if necessary refer the participant back to their local health professional for guidance. In this situation the telephone conversation would not be ended abruptly, an attempt would be made to reassure the participant and talk about a different topic entirely to try to leave them feeling positive when the conversation ended. Each participant was sent an information sheet and asked verbally at the beginning of the interview whether they were willing to take part. The option for the participant to withdraw from the interview or research at any time was also stated at the beginning of each interview and participants were asked whether they were comfortable with the conversation being recorded.

6.8 Piloting

The interview structure was piloted in order to ascertain whether the questions were eliciting the information required for analysis and to practice using probing and follow up questions appropriately. Due to the semi structured nature of the interview, each interview was going to be different however it was necessary to ascertain whether the questions were adequately stimulating the conversation required. Due to the personal relationship built up with members of the user group from Centre A, two members were asked to participate in a pilot of the interview. The participants were told they were pilot participants and that their feedback was very important due to the nature of the interview and importance of the research. Both members of the user group agreed and pilot interviews were carried out using conference call facilities on a landline telephone and a dictaphone to record the conversation. The participants both had no changes to make to the interview structure and conversation flowed freely and easily which indicated that the questions, as well as follow up and probing questions, were appropriate to elicit the desired conversation. The interviews were provisionally analysed and the data addressed all of the study objectives therefore the interview was appropriate for use with the study participants.

6.9 Sampling

Participants that filled in the questionnaire in the previous study were asked to provide their contact details if they would be willing to participate in any further research. A list of all of these participants was created including the year that they had their amputation. The interviews were conducted in January 2012 therefore in order to get the most accurate and relevant information, participants that had undergone amputation in the past 5 years were chosen. There were 22 participants that had agreed to be contacted for further research that underwent amputation between 2006 and 2011. Each of these participants were contacted via email or telephone as the maximum possible number of participants was sought. Participants contacted via email were given 1 week to respond before a follow up email was sent. Twenty two participants replied to the first or second email or agreed to participate following a telephone call asking for their assistance. The estimates by Guest et al. (2006) and Creswell (2007) suggest that participant numbers should be anything from 12 up to 30. Even though Creswell (2007) suggests between 25 and 30 interviews, the data that could be collected from participants that underwent amputations in 2005 or earlier was considered to be less reliable and therefore more detrimental than advantageous to include. Due to the age of most participants being over 55 it was thought that trying to recall memories from over 7 years ago would not be appropriate or helpful to the overall results of the study.

6.10 Analysis

The interviews were digitally recorded allowing for full transcription. The transcripts were analysed using thematic analysis with the aid of NVivo 9 (QSR International Pty Ltd, 2010) in order to gain the necessary insight into the data and fulfil the objectives of the study. Four general categories of themes were created to answer each of the research objectives. Each interview was coded using these general categories; Information, Media, Service given or wanted, Time. Once the first coding pass was complete, more in-depth coding was conducted with the creation of nodes within the general categories. The nodes were then grouped into categories, creating a coding tree with three levels. Following the completion of the coding process the number of participants that mentioned each topic was ascertained as analysis using the number of times a subject was mentioned was not possible. This was due to a number of participants mentioning one subject more than five times which skewed the results and would therefore have produced unreliable conclusions.

6.11 Results

A total of 22 participants took part in the telephone interviews. Carers of two of the participants were present for the interviews and provided information on certain topics. Descriptive details of each participant were taken in order to ascertain whether there were any differences in information desired between ages. Table 6.2 shows the details of the participants that took part in the study. Detailed information on the participants can be found in Appendix 6A.

Table 6.2: Details of participants of the interview study

Male/ Female	13 Male 9 Female
Age	Range: 32-79 Mean: 51
Year of Amputation	2006 – 5, 2007 – 6, 2008 – 4, 2009 – 2, 2010 – 4, 2011 – 1
Reason for Amputation	Trauma – 6 Vascular Condition – 5 Infection – 5 Cancer – 3 Diabetes – 2 Congenital absence – 1
Level of amputation	Below Knee – 13 Above Knee – 5 Bilateral below knee – 1 Through Knee – 1 Through Hip – 1 Above elbow – 1

The participants in this study are more representative of the national population than the participants in Study 2 due to the more even representation of trauma, vascular and infection related amputations. The number of participants with each level of amputation is highly representative of the national population.

6.11.1 Information

Participants were asked what information they received and they would have liked at different stages of rehabilitation. The information participants mentioned was coded into 8 groups, within which nodes were created for specific items.

6.11.1.1 DSC Information

A literature search revealed no literature on the importance of amputees knowing and understanding the roles of their rehabilitation team. Warmuz et al. (2004) stated that most amputees are afraid of the unknown and therefore their fear should be decreased in any way possible. Not knowing who the health professionals are and what they will be doing could have a negative effect on the mental health of amputees, especially when they are already dealing with the distress of losing a limb (Warmuz et al., 2004). Seven topics were mentioned relating to information about the DSC by participants. The topics and the number of participants they were mentioned by can be found in Table 6.3.

Table 6.3: Topics mentioned by participants relating to DSC information

Topics mentioned by participants relating to DSC Information	Number of participants
Who staff were and what they'd be doing	11
Contact information for support	8
Centre specific information	6
Hospital transport	2
Recall for check ups	2
How to get an Orthopaedic consult	1
User group information	1

The half of the participants mentioned the information relating to the DSC that was important was who the staff were and what each individual would be doing with the patient. One participant stated:

"In fact when I was told 'oh the prosthetist is coming to see you this afternoon' when I was there which was several weeks on, I said 'What's a prosthetist, never heard of one.'"

Another participant stated:

*"I actually asked ***** a few weeks later if he could fill a form in for me, for my disability living allowance thinking that he ran the clinic and found out that he was probably the lowest of the low, you know. And he said 'Well I'm not a professional actually you need to ask this one and that one' and I'd never even seen these other people."*

It is evident that tasks such as applying for disability living allowance can become more difficult when the role of each member of staff is not known or not understood.

Over one third of the participants mentioned that contact information for support was important. It appears that the information relating to support groups and amputee forums is not being made available at the DSC and therefore patients have to find this information for themselves:

"I mean I had to find it all out myself on the internet about the support groups and the forums and everything, it would have been a help if I'd known before instead of

just typing in amputees."

Further to this one carer stated:

*"When ***** first came out of hospital he was coming home for weekend stays and while ***** was home for the weekend he didn't have anybody to call on if there were any issues."*

Centre specific information included directions, the contact telephone number, opening hours, times of clinics and how to book an appointment, all of which is essential for new patients. Hospital transport and recall for check-ups affects most patients that attend the DSC therefore information about these should be readily available. One participant stated:

"I was told an ambulance would come and get me and I had to be ready by a certain time and it didn't turn up. And an hour later it wasn't there and I'm panicking thinking, what am I going to do and saying to my husband 'you'll have to take me' I've got to go I've got to have the appointment. I didn't know that they went round the houses picking people up in all the villages before they got to me and that when I got to the hospital, even if I was an hour behind my appointment they'd still give me the time because that's what happens. But you don't know that until it's happened and you get very upset. Because those appointments are so valuable you know you're waiting for them and you're mentally built up and thinking 'when I go for my appointment you know I might do so and so' oh but the ambulance hasn't come."

6.11.1.2 Rehabilitation

The process of rehabilitation can be a daunting prospect for primary amputees, especially those that have had a traumatic amputation, due to the suddenness of the disability (Klute et al., 2009). Participants mentioned 22 subjects related to rehabilitation that they would have liked explained to them, with one participant stating:

"I mean the week after the operation if there'd been somebody come round and spoken to me and said when you leave here this is where you're going and this is

what they do there and this is the timescale it will take to do this and to do that. You know there is nothing like that at all."

Table 6.4 shows each topic that was mentioned by participants relating to rehabilitation with the number of participants they were mentioned by.

Table 6.4: Topics mentioned by participants relating to rehabilitation

Topics mentioned by participants relating to Rehabilitation	Number of participants
What to expect at rehabilitation	14
What happens after amputation	14
What happens at the DSC	13
Stages of rehabilitation	12
Physiotherapy	10
What happens during casting	9
Exercises to help rehabilitation	9
Timeline for recovery	8
Learning to walk	8
What happens when you go home	7
Improving lifestyle – diet and fitness	7
Wound care	6
Social services	3
Expectation management	3
Phantom limb pain	2
Prescription process	2
Occupational therapy	2
Crutches	1
Prescription	1
Wheelchair use	1
Patient Advice and Liaison Service	1
Wheelchairs vs. buggys	1

The anxiety associated with not knowing what to expect was mentioned by over half of the participants, with one carer stating:

"I didn't know what was happening either so I couldn't help calm or reassure her. It was a really stressful time. Some information on what was going to happen would have eased her mind as well as mine."

6.11.1.3 Driving

An amputation can invalidate car insurance therefore patients must inform the DVLA and their insurance company before they start driving again. The two topics mentioned by participants can be found in Table 6.5.

Table 6.5: Topics mentioned by participants relating to Driving

Topics mentioned by participants relating to Driving	**Number of participants**
Car adaptions	4
DVLA	4

Driving can be an important element in returning to social functioning following an amputation. One participant stated:

"One of the biggest fears I had was that I would never be able to drive again and that was information that I had to find out for myself, that I could actually get a vehicle adapted so again information like that would be helpful."

6.11.1.4 Support groups

As found in Study 2, a patient volunteer visitor is a valuable asset in the rehabilitation of patients as they can help ease patient anxiety and provide practical as well as emotional advice. As Butcher (2009) found, information on life after amputation can rarely be provided by clinical staff as personal experience is required. Support groups were mentioned over a third of the participants as being an important part of their rehabilitation. One participant stated:

"I mean my DSC didn't have a user group at the time either so there wasn't really anyone else for me to go to at the time for support or anything like that so I think anything like that would have been ideal, just to know what you could do and that life need not end once you're an amputee."

A carer of one of the participants stated:

*"Wheelchair rugby has been a real godsend I think for *****'s mental health as well as his physical progression.*

One participant stated:

"It would be nice to know what sports centres are out there that are wheelchair accessible and accessible to amputees as well because it took me such a long time to find that there isn't anything local to me, you know like gyms and stuff that are actually wheelchair friendly or cater for amputees."

The topics mentioned by participants related to support groups can be seen in Table 6.6.

Table 6.6: Topics mentioned by participants relating to support groups

Topics mentioned by participants relating to Support groups	**Number of participants**
Charities	8
Local sports facilities that cater for amputees	3
Disabled sports	2

6.11.1.5 Prosthesis information

The vast majority of the participants mentioned that they would have liked more information on prostheses. The reasons for this were to allow them to understand their prescription and be informed of improved components they could progress to using in the future. Participants expressed a wish to be provided with this information so that they were aware of the possibilities following their rehabilitation and could strive to achieve physical fitness that allowed for the prescription of such prostheses. One participant stated:

“One of the things that would be very helpful in my position or as an amputee is what you’re actually entitled to under the NHS because that seems to vary very widely.”

Other important points mentioned by participants were concerning the effects wearing a prosthesis could have on their physical health. Subjects included skin sores, problems with liners, tattooing of the stump, problems caused by prosthesis use with other limbs or joints and what to do if you fall. All topics mentioned by participants relating to prosthesis information can be seen in Table 6.7.

Table 6.7: Topics mentioned by participants relating to prosthesis information

Topics mentioned by participants relating to Prosthesis information	**Number of participants**
Which components are available on the NHS	13
General information on prostheses	12
Skin sores	5
What a prosthesis is	5
What to do if you have a fall	5
Keep going back if the prosthesis is not right	5
What to do if there is a problem with your prosthesis	4
Cannot start rehabilitation until stump is fully healed	2
Problems with remaining leg that can be caused by prosthesis use	1
How to choose shoes	1
How many stump socks to wear before going back to the DSC	1
Tattooing of the stump	1
Problems caused by liners	1
Explanation of why components are not available	1
Customisation of socket available	1
Levels of amputation	1
Construction of a prosthesis	1

A very interesting topic mentioned was information relating to choosing shoes. Shoes must be chosen very carefully by primary amputees as the heel height and pitch of the shoe must be precise in order to accommodate the prosthetic foot. Equally as important is to advise primary amputees that in order to change their shoes they would have to buy a pair of shoes with the identical physical characteristics of their old pair of shoes (such as heel height and pitch) or their prosthesis would be misaligned and would cause gait problems and possibly damage to the remaining leg. This means that for most amputees, wearing slippers is not possible.

6.11.1.6 Benefits

Benefits and financial help provided by the government were not mentioned by many participants, however one of the trauma amputees that took part in the Study stated:

"It's a bit of a lack of information with regards what benefits you might be entitled to afterwards. Obviously going from an able bodied person to a disabled person, we had to dig around for that to find out if I was entitled to anything with regards living allowance and things like that but that was a bit of a search around for that and I think they could have been a bit more helpful with that information."

Participants mentioned three topics relating to benefits or other help, all of which can be seen in Table 6.8.

Table 6.8: Topics mentioned by participants relating to benefits

Topics mentioned by participants relating to Government help	Number of participants
Disability living allowance	4
Mobility driving scheme	1
Radar keys	1

6.11.1.7 Life after amputation

Every participant mentioned that they would have liked information on what life is like after amputation which clearly indicates how important such information is for primary amputees. Each participant stated that talking to an established amputee would be the best way of gaining the information they needed. The topics mentioned by participants relating to life after amputation can be seen in Table 6.9.

Table 6.9: Topics mentioned by participants relating to life after amputation

Topics mentioned by participants relating to life after amputation	Number of participants
What life is like as an amputee	22
Seeing someone succeed	7
How amputation can affect sexual activity	1

6.11.1.8 Support for mental health

Mental health can be a difficult subject to speak about due to the social taboo surrounding the subject. One participant felt able to share her experiences:

"In August, just after the amputation I tried to commit suicide. Because of circumstances to do with the amputation etc., money etc. and I wasn't the only one who had had mental problems and I think there should be more done on that."

This is clear evidence that amputation can push patients to suicide if their mental health is left unchecked. This participant also mentions others with mental health problems, indicating that other patients attending the same DSC were not receiving support for their mental health difficulties following amputation.

The topics mentioned by participants relating to support for mental health can be seen in Table 6.10.

Table 6.10: Topics mentioned by participants relating to support for mental health

Topics mentioned by participants relating to support for mental health	**Number of participants**
Support for partner	6
Counselling	6
Mental health problems	1
Explaining to children what is happening to their parent	1

There is very little literature covering information provision for carers of amputees, however information for carers of seriously ill patients is widely accepted as being important and necessary for the metal health of the carer (Kendall et al., 2004; Morris, 2001; Driscoll, 2000). The subject mentioned by the most participants was support for partners of patients, or lack thereof, with one carer stating:

"Carers need help too. They feel very isolated as there was no support for him. That's commented on a lot at the amputee club. They have just as many questions and concerns as the amputee does. There is a lot of stress and anxiety and no one to share it with. There is no advice on what to do to help and how to be of use so there is lots of pressure to try to support your partner in the best way you can. You're flying blind. Carers need consideration from the NHS, peer support, discussions with professionals so they know what to expect and how to help. It's very important to have support and help or you can begin to resent your partner."

It is clear from this statement and statements from other participants and their carers that the NHS is overlooking the importance of information and support for carers and families of primary amputees.

6.11.2 Stages of Rehabilitation

There were clear differences between the stages of rehabilitation and the information participants would have liked and the delivery system they felt would have been the most appropriate. The information patients wanted and at which stage can be seen in Table 6.11. The shading used illustrates the differing number of participants that mentioned each subject. Full results can be found in Appendix 6B.

Table 6.11: Matrix of the information participants wanted at different rehabilitation stages

	Pre Amputation Visit to DSC	On Ward Pre Amputation	On Ward Post Amputation	First Visit to DSC	Subsequent Visits to DSC
Driving	0	0	3	1	0
DSC Information	2	2	10	7	3
Government Help	0	0	5	0	1
Information on Life after Amputation	5	5	10	3	1
Prosthesis Information	8	5	13	8	12
Rehabilitation	8	4	16	9	4
Support for mental health	2	0	7	6	1
Support Groups (Charities and Sports)	0	1	5	2	2

6.11.3 Information delivery

Over half of the participants stated that they had not been given enough information that they could refer back to at a later date as the majority of the information provision was verbal. One participant stated:

"Certainly written information as I needed time to think and you know read digest and understand….. take them away, read them and think about them then put them down and pick them up another time."

The sentiment of this statement was repeated during the vast majority of interviews as each of the participants appeared to feel the same about the provision of written information. Despite this, many of the participants still stated that at times they wanted verbal information in the form of explanations or introductions to staff. Table 6.12 illustrates the information delivery system patients felt was most appropriate at the different stages of rehabilitation. Full results can be found in Appendix 6C.

Table 6.12: Matrix of the information delivery system participants wanted at different rehabilitation stages

	Pre Amputation Visit to DSC	On Ward Pre Amputation	On Ward Post Amputation	First Visit to DSC	Subsequent Visits to DSC
CD ROM	0	0	5	1	2
Diagram	0	0	0	0	0
DVD	1	1	6	1	0
Explanation from staff	1	0	1	2	3
Introduction to Staff	1	0	0	0	0
Photo Booklet	0	0	0	1	0
Poster	0	0	0	1	1
Poster with photos of staff	1	0	0	1	0
Verbal	5	1	8	3	3
Visit from Amputee	3	5	11	1	1
Visit to Centre	1	0	1	0	0
Website	0	1	2	0	1
Written Information	7	5	15	12	14

6.11.4 Age

There does not appear to be any large differences between the information desired and the age of participants. Participants of all ages mentioned information on prostheses and rehabilitation most frequently, which shows that, regardless of age, these are the most important topics to patients. With regards information delivery, the participants of 60-69 years appeared to desire more visual information, such as photograph booklets, posters and DVDs more than the younger age groups. A visit from an amputee was also mentioned most frequently by 60-69 year olds. The 40-49 age group mentioned a CD ROM more than any other age group which implies that these patients are aware of their existence and potential benefits. The information delivery systems mentioned by the five different age groups can be seen in Table 6.13 and the information mentioned by the different age groups can be seen in Table 6.14. Full results can be found in Appendix 6D.

Table 6.13: Matrix of the media patients preffered at different ages

	Age = 30-39	Age = 40-49	Age = 50-59	Age = 60-69	Age = 70-79
CD ROM	0	4	2	1	0
Diagram	0	0	0	1	0
DVD	0	3	2	3	0
Explanation from staff	0	1	1	2	0
Introduction to Staff	0	0	1	1	0
Photo Booklet	0	0	0	1	0
Poster	0	0	0	2	0
Poster with photos of staff	0	0	0	2	0
Verbal	3	6	4	4	0
Visit from Amputee	2	4	3	6	0
Visit to Centre	0	1	2	3	0
Website	0	1	2	1	0
Written Information	3	7	4	5	1

Table 6.14: Matrix of the information patients wanted at different ages

	Age = 30-39	Age = 40-49	Age = 50-59	Age = 60-69	Age = 70-79
Driving	0	1	1	2	0
DSC Information	2	5	2	3	0
Government Help	0	2	1	1	0
Information on Life after Amputation	2	5	2	6	0
Prosthesis Information	1	5	4	6	0
Rehabilitation	2	7	4	6	0
Support for mental health	1	1	2	4	0
Support Groups (Charities and Sports)	1	2	2	1	0

6.12 Discussion

6.12.1 Information and mode of delivery – Objective 6.1

6.12.1.1 DSC Information

The staff at the DSC should be making tasks, such as applying for disability allowance, as easy and straight forward as possible to reduce stress for the patient and ease their transition back into society. Information relating to the staff at the centre would be simple to produce and could alleviate anxiety in many new patients. Over half of the participants mentioned written information, such as a leaflet or booklet as being a good information delivery technique. Other suggestions made by less than a quarter of the participants were a DVD, CD ROM, photograph booklet, poster with staff names and roles, a website and verbal introduction to staff themselves.

As previously mentioned, peer support can play a very important role in the successful acceptance of an amputation and successful rehabilitation (Butcher, 2009). The lack of information relating to support groups could leave patients feeling isolated and lead reduced social integration and increased possibility of depression (Williams et al., 2004). Information relating to support when at home and out of hours support should therefore be included in any information package supplied to new patients as they may have questions or concerns which require immediate attention and without this information, a highly stressful situation could arise. An information booklet would be the most appropriate way of delivering this information as patients could take the information home, read it as many times as they desired and store it for future reference.

Disablement Services appointments are very important to patients and as alluded to by the participant in Section 6.11.1.1, they can also be mentally draining, therefore extra stress caused by not knowing the ambulance system is unnecessary and easily avoided. A leaflet containing all the details of hospital transport and phone numbers would allow patients and their carers to read the information at their leisure and always have it to refer back to if needed. The same could be said for self-referrals as many of the centres do not routinely call their patients in on a regular basis to check progress. Details of this should be explained to patients so they are aware of their responsibilities with regards their on-going treatment. Orthopaedic consults may only be necessary for patients that have had a traumatic amputation and have issues with their other leg or arm, however for those patients there should be a clear pathway to get the help they require as their rehabilitation can be hindered by problems with their remaining limb. Specialist information should be available to prosthetists so that they are able to refer patients that require such consultation.

6.12.1.2 Rehabilitation

The results in this study concur with the work of Klute et al. (2009) in that patients stated the need for improved information about the process of rehabilitation and an increased involvement in the process. If patients are made aware of the stages they will progress through they would be able to prepare themselves mentally for the task ahead and not have to deal with anxiety due to unknowns (Robinson et al., 2010; Watanabe et al., 1999). Verbal explanations of the process patients would be taken through, reinforced with written information for them to read and digest at their convenience, would give patients the chance to ask questions about the rehabilitation process as well as having something to refer back to if they could not remember specific details.

Specific elements of rehabilitation, such as the first casting appointment, require full explanation due to their intimate and potentially physically challenging nature. Above knee amputees are required to stand, with the lower proportion of their body covered only by their undergarments, for an extended period of time while the casting takes place. This information is essential to these patients as they may need to prepare themselves, physically and mentally, to stand for that length of time and be in the presence of a clinician they will not know very well, dressed only in their undergarments.

It is appreciated that not all patients will follow exactly the same rehabilitation pathway as timelines may vary, however information provision should not be restricted by this, as patients will all progress through rehabilitation to a certain extent, therefore they are entitled to information on what is likely to happen and steps they can take to improving the success of their rehabilitation. Due to patients being very different in physical and emotional aspects, the suggestion of a website or CD ROM containing the information on rehabilitation was made. These would allow patients to search for the information they required as and when they wished to read it, rather than handing out booklets of information which may be overwhelming at the time.

6.12.1.3 Driving

Driving can be an important element in patients’ lives and can ease their transition back into society following amputation, therefore information on car adaptions and the DVLA are essential to promote a stress free return to driving.

Information about adaptions for cars and how to go about getting a car adapted should be readily available for patients so that they are aware of the options, e.g. hand controls or changing the position of the accelerator, and do not have to spend their time searching for the information themselves. A lack of information relating to the DVLA and insurance for patients that do not use the internet and have no other way of knowing this could cause serious issues as these patients could return to driving with invalid insurance. Leaflets were mentioned by three participants as being the most desirable information delivery option for this topic as they could be handed to the patient on the ward and referred to whenever the patient felt they wished to consider driving again.

6.12.1.4 Support groups

As discussed in section 6.3.4, it is well documented that support from peers can be of great emotional help to primary amputees in coming to terms with their disability (Froggatt and Mawby, 1981; Briggs, 2006; Novotny, 1996; Jacobsen, 1998; Butcher, 2009). User group information should therefore be provided routinely (if a user group exists) so patients are able to interact with their peers and use their support to learn coping strategies and improve rehabilitation (Novotny, 1996; Butcher, 2009). Contact details for charities should also be provided, especially in cases where no user group exists, so that patients feel they have somewhere to turn if they are having problems adapting to their disability or feel they need some support. This information was suggested to be provided in leaflet form by six participants, with contact details and website addresses for various charities and user groups.

As discussed in Section 6.3.2, helping primary amputees to develop a positive body image is of great importance for their mental and physical health. Wetterhahn et al. (2002) found a positive relationship between regular physical activity and body image among lower limb amputees, therefore information for primary amputees on taking part in physical activity should be readily available.

Although only mentioned three times, it was felt that information regarding sports facilities that cater for wheelchair users and amputees was of great importance. The evidence suggesting the connection between improved mental health and physical activity (Wetterhahn et al., 2002) reinforces the need for patients to be as physically active as possible following amputation, not just for their physical health and progression.

Removing the obstacle of having to search for information on accessible sports facilities could encourage patients to go to such facilities and take part in physical activity as some patients may have been unaware that such accessible facilities existed. A list of the local facilities and sports clubs could provide great encouragement to primary amputees as the list of options would be reinforcing evidence that life need not end after amputation and there are plenty of activities that they could become involved in. Written information regarding physical activities available for amputees should be routinely given to primary patients to encourage them to take part in such activities for their mental and physical well-being.

6.12.1.5 Prosthesis information

It is clear from the analysis that patients are not informed of the components that are available on the NHS or may be of benefit to them by their prosthetist. There is currently no literature pertaining to providing amputees with information about prostheses that are available on the NHS; however it can be surmised from this Study and Study 2 that the provision of such information is important to patients.

The ‘postcode lottery’ can induce confusion as patients may discuss their prostheses in online forums for amputees and find that patients with similar levels of amputation have been prescribed higher technology components. This can cause frustration in patients as they may not be progressing as quickly as they would like to and may believe the reason is the technology in their prosthesis (Sullivan et al., 2003).

Each of the topics mentioned by participants could have a serious impact on their health if left without discussion yet they could be easily covered in information leaflets or other forms of communication.

An example of DSCs providing patients with inadequate information was found in a documentary broadcast on Channel 5 called ‘Losing one of my giant legs’ (Baker, 2011). The woman involved had an extremely rare medical condition making her an extraordinary case. The DSC she attended did not provide her with any information on appropriate footwear which led to her purchasing two pairs of expensive shoes, one of which was not appropriate. This lack of information provision resulted in the patient, not only spending large amounts of money on shoes that would be of no use, but also becoming very excited by the prospect of being able to wear the shoes she had bought only to be disappointed. Choosing appropriate footwear is clearly an important process therefore patients should be provided with ample information both verbally and written in order to help them make the correct decisions to save them time and money. Staff at the DSC could direct patients to a website or catalogue with appropriate shoes in order to help them make the right choice from a reputable and reliable source.

6.12.1.6 Benefits

The nature of traumatic amputation means that very few patients are aware the amputation is going to happen and therefore becoming disabled is a shock to them. If the patient had been able bodied before the amputation they may not have been aware of any of the benefit systems or Government schemes available to them, unlike patients with other comorbidities, who may have been through the process before, for other ailments. Losing a limb through trauma is already a distressing experience therefore any information regarding monetary help that could ease patient’s anxieties about being able to go back to work would be of great comfort. This information should be available to all patients, regardless of the reason for their amputation as patients are entitled to know the benefits they are able to claim and not have to search for the information themselves. Leaflets containing the relevant information were suggested by participants of the study, so that patients could take the information away, read it in their own time and digest the information at their own pace.

6.12.1.7 Life after amputation

The introduction of a patient volunteer visitor service for primary amputees would allow primary patients to ask any questions they had on life after amputation, with little need for written information to be provided.

Only one participant mentioned sexual activity, which is possibly due to the subject being so personal. Participants may have been reluctant to discuss the matter, even though a problem existed (Geertzen et al., 2009). Further work is required to ascertain the extent to which an amputation affects sexual activity and the interventions that could be put in place to assist patients in combatting these effects.

6.12.1.8 Support for mental health

As discussed in Section 6.3.2, amputation can have a large psychological impact on patients, with anxiety and depression being common (Phelps et al., 2008). Support and information for patients suffering from such illnesses was mentioned by over half of the participants as being scarce. As with sexual activity, mental health can be considered as a taboo subject, therefore not as many participants mentioned the subject as previously expected (Seah, 2012).

The participant that stated other patients attending her DSC had mental health problems (Section 6.11.1.8) supports the notion that mental health problems in amputees are prevalent and require greater attention (Liu et al., 2010). There is an increasing amount of literature suggesting that mental health of amputee patients is as important, if not more so than their physical rehabilitation (Phelps et al., 2008; Briggs, 2006; Ferguson et al., 2004; Srivastava et al., 2010; Scobbie et al., 2009).

As discussed in Section 6.3.5, carers are put under a lot of emotional strain often resulting in mental health problems (Neno, 2004; Öhman and Söderberg, 2004; Llewelyn and Payne, 1995; Anderson, 1987). The number of participants that mentioned this indicates there is a need for far more information and support for carers to help them come to terms with the inevitable change in lifestyle and provide them with the knowledge to competently care for their relative or spouse. Much of the anxiety due to unknowns could be erased through conversations with

DSC staff and leaflets designed for carers of amputees with details of important information, such as signs of depression, charities and support networks. As caregiving is well documented as having effects on the marital relationship (Snelling, 2006; Söderberg et al., 2003; Paulson et al., 2003; Flor et al., 1987), support for carers is essential to ensure they are able to cope with the lifestyle changes required and can provide their spouse with the care and attention they require without introducing avoidable strain into the relationship.

More research is required into whether improved information provision has an effect on compliance and knowledge and therefore reduces costs to the NHS.

6.12.2 Stages of Rehabilitation – Objective 6.2

The results from this study show that the participants' feelings mirrored a statement made by Fitzgerald (2000) as information regarding life after amputation and meeting an amputee pre-amputation were frequently mentioned by participants. The results show that patients should meet an amputee pre-amputation if possible but certainly on the ward post-amputation. The information needs of the participants changed over time, with information regarding prostheses becoming much more important again on subsequent visits to the DSC as participants wished to know about the components they may be entitled to. Written information appeared to be the most appropriate form of information delivery throughout the rehabilitation process; however the introduction of a CD ROM or DVD were suggested on the ward post amputation. Written information pre amputation would provide patients with the information they desired in a form that allowed them to pick it up when they felt ready to read it and also share the information with family members. The most critical time for information provision was clearly on the ward post-amputation, as participants stated their information needs to be at their greatest. This finding is important for primary amputees as centres are currently not providing enough information at this critical point, which could have detrimental effects on their mental health and also their personal relationships (Liu et al., 2010).

These data have clearly shown that information provision is vital pre- and post-amputation in order to prepare patients for the upcoming surgery and reassure them following surgery that they can still live an active and fulfilling life. Providing information to patients at the correct time is essential in order to allow them to prepare and also accept the process they must follow post-amputation. The provision of such information is even more important on the ward post-amputation for those patients that did not have the opportunity to discuss their amputation before surgery. The timing of the information provision is critical and these results show that the majority of participants were in agreement with the topics they would like information to cover and when the information should be provided.

6.12.3 Information Delivery – Objective 6.3

The fact that verbal information was mentioned by almost every participant shows that patients still need contact from DSC staff to guide and reassure them. Visits from amputees were also frequently mentioned by participants as being highly desirable. As previously discussed, patients themselves are able to provide information to primary amputees about life after amputation that clinicians and members of staff at the DSC simply could not provide.

As discussed in Section 6.3.6, memory is a large barrier to patients absorbing and remembering verbal information, especially if patients are old or anxious, which is the case for the majority of amputation patients (Kessels, 2003). There have been many studies on the advantages written information provides patients (Johnson and Sandford, 2005; Thomson et al., 2001; Trevena et al., 2005; Coulter and Ellins, 2007; Coulter et al., 1999), therefore amputees should be given written information alongside verbal information. The human brain can only stay focused on the written page for approximately 15 minutes (Fritz, 2009); therefore written information relating to amputation should be detailed but concise so patients are not overwhelmed by the information presented to them. As Arthur (2008) describes, the information must be of use and easily understood by patients, covering all of the topics they require. Simply providing leaflets, however, is not sufficient as patients need explanation and reassurance from members of staff with the leaflets simply there to reinforce and remind patients of the information they have already been provided verbally. Written information was the most mentioned information delivery system by participants as participants expressed a need for information that they could refer back to at a later time when they were able to absorb the information properly and felt emotionally able to re-visit the topics already discussed with them.

Written information however, is not the only form of information delivery system that could be put in place to enhance the user experience at DSCs. Due to the continuing advances in technology and widespread use of the internet DSCs could be utilising some of these technologies to provide reliable information to their patients. CD ROMs and DVDs were mentioned by participants as being desirable for the provision of information, which is reflected in the literature as being useful for decreasing patient anxiety and increasing knowledge (Danino et al., 2005; Molenaar et al., 2007; Ong et al., 2009; Kinnane et al., 2007; Walker and Podbilewicz-Schuller, 2005; Frosch et al., 2003; Cowan et al., 2007; Rossi et al., 2005; Calderon et al., 2006; Shukla et al., 2011). Although these interventions attract an initial production cost and continuous costs to produce for each new patient, there is the potential for the benefits and money saved by better compliance and understanding to outweigh the costs to the NHS (Schillinger et al., 2002; Nielsen-Bohlman and Panzer, 2004).

The use of reliable websites in information provision in healthcare has been well documented as being extremely useful for increasing patient satisfaction, compliance and self-efficacy as well as improving a patient’s knowledge of their condition (Coulter and Ellins, 2007; Ko et al., 2006; Webb et al., 2010; Bender et al., 2011; Hartmann et al., 2007; Sciamanna et al., 2006). This could be another intervention used to help amputees find all of the information they require quickly and easily. A website containing all of the information provided to them by the DSC and more from experienced amputees could be of great benefit to patients and would attract less cost than a DVD or CDROM. Centralising all of the information onto one website would enable patients to access the information they desired quickly and easily without having to search through a number of websites to find the topic they were looking for.

Information prescriptions could also be extremely useful for primary amputees, as members of staff at the DSC could provide them with a prescription containing information they felt the patient should be aware of, which the patient could then read at their convenience and ask questions about at the next visit to the DSC. Providing patients with the exact location of the information they desire would reduce anxiety as patients would be able to find the information they wanted quickly and easily and also increase the number of patients that actually accessed the information (Ko et al., 2006; Ritterband et al., 2005; D'Alessandro et al., 2004).

An interesting suggestion made by one participant for the provision of DSC staff job roles was the production of a photograph booklet containing a photograph of each member of staff, their name, job role and a short description of the part they play in rehabilitation. This could be easily altered when staff changed and would incur very little cost to the DSC. The booklet could be taken with the amputee nurse when she visited the primary amputee in hospital and also shown to new patients on their first visit to the DSC. Leaflets could also be easily produced for patients to take home; however these would incur printing costs and would require updating if staff changed. A board at the DSC could also be produced detailing each member of staff which would provide a constant reminder to patients of the staff at the centre and could be easily amended in the event of staff changes.

There are clearly many options for improving the information provision for patients at DSCs across the UK. A website, DVD or CD ROM could be produced and used by every DSC with little need to tailor the information to individual centres as centre specific information could be provided in leaflet form. Information about the centre itself such as contact details and opening times could be required more often than other information such as wound care, therefore would be more beneficial to patients in leaflet form so they could keep it and refer to it whenever required.

Table 6.15 provides a summary of the information participants detailed as required for amputee patients, the time at which the information should be provided and the information delivery system thought to be the most appropriate.

Table 6.15: Topics mentioned by participants relating to DSC information

Stage of rehabilitation	**Type of information**	**Information delivery system**
Pre-amputation visit to the DSC (if possible)	Life after amputation	Volunteer Visitor
	DSC and rehabilitation process	DVD
	Explanation of what prostheses are	Member of clinical staff
On the ward pre-amputation (if possible)	Life after amputation/support	Volunteer Visitor
	DSC and rehabilitation process	Member of clinical staff
	Explanation of what prostheses are	Member of clinical staff
On the ward post amputation (if possible)	Life after amputation/support	Volunteer Visitor
	DSC Information – members of staff and their roles	Member of clinical staff and leaflets
	Rehabilitation – stages, casting, learning to walk	Member of clinical staff and leaflets
	Driving – car adaptions, blue badge, DVLA	Leaflets
	Social Services and Benefits	Leaflets
	Support for mental health – Counselling service	Member of clinical staff and leaflets
	Charities and support groups	Leaflets
	Skin and stump care – warning signs of infection etc.	Leaflets
	Ways to improve health and speed up rehabilitation	Leaflets
First visit to DSC	DSC Information – members of staff and their roles	Member of clinical staff
	Rehabilitation – stages, casting, learning to walk	Member of clinical staff
	Counselling service	Member of clinical staff
	Skin and stump care – blisters and skin irritation	Member of clinical staff and leaflets
	Charities and support groups	Member of clinical staff
	Prostheses – components that are available on NHS and progression to receive better components	Member of clinical staff and leaflets
	Spare limbs – why they're not necessary	Member of clinical staff and leaflets
Subsequent visits to DSC	Best practice for getting used to limb	Member of clinical staff and leaflets
	Stump care – what to do and who to call if irritation occurs	Member of clinical staff and leaflets
	Falling/ emergencies – what to do and who to call	Member of clinical staff and leaflets
	Upgrades to components	Member of clinical staff and leaflets

6.12.4 Age – Objective 6.4

The findings detailed in Section 6.11.4, relating to older patients desiring more visual information, concur with the literature on patient memory as visual aids were found to increase understanding and retention of information in older people (Briggs, 2006; Trevena et al., 2005). This also suggests that older patients may not know how to use a CD ROM and therefore provision of one would be a waste of money and not provide any benefits to the patient. There was however very little difference in the topics mentioned by the different age groups.

Further research is required including larger numbers of patients to ascertain whether there are significant differences between age groups with regards the topics and delivery method of information. This work suggests that topics requiring information provision are very uniform across age ranges; however the delivery method of that information requires consideration for different age groups.

6.13 Critique of Study

Information provision is different at every centre, therefore trying to compare experiences of participants from different centres is not possible. Some patients that received a lot of information from their DSC may not have realised how important the information that had been given to them was, simply because it was readily available to them.

Each amputee is very different in relation to their experiences and the information they desire, it is therefore very difficult to ascertain exactly what would be appropriate for every amputee. The age and the reason for amputation can also have an effect on the information they consider to be necessary. Young, trauma amputees, for example, may feel the need for information on sexual activity, whereas older, dysvascular patients may feel information on wheelchairs is far more important. Further research involving larger numbers of participants would allow for comparisons of patients of similar ages and reasons for amputation, therefore giving a much clearer indication of what would be appropriate for new patients with similar attributes.

The participants of this study had their amputations between 2006 and 2011, therefore service provision may have changed dramatically in this time. Also participants that had their amputations four years ago could have forgotten the information given to them or the information they would have liked. Further work should be conducted with patients that had their amputation very recently and up to two years ago, as patients require at least one year for their limb to settle down and for them to become an established amputee.

The interviews were conducted over the phone which could have resulted in participants not sharing all the information they had on the subject as they did not feel comfortable doing so. Subjects such as sexual activity, pain and mental health issues were not mentioned as much as anticipated which suggests that participants were not comfortable talking about these subjects. Face to face interviews should be used in future research to provide an appropriate environment for the more sensitive issues to be discussed.

6.14 Conclusions

Twenty two amputees of varying ages and levels of amputation were interviewed via the telephone in order to ascertain their feelings on the information that they would have liked pre- and post- amputation. Thematic analysis of the data showed there was an overall consensus from participants that information provision is currently lacking for primary amputees and something needs to be done to rectify the situation. The information mentioned by each participant was different, however common themes did appear. The main topics participants would have liked information on were the DSC, prostheses, life after amputation and rehabilitation. The form of information delivery mentioned most often was written information with CD ROMs and DVDs being mentioned by the older participants. Visits from volunteer visitors to provide information on life after amputation pre- and post- amputation were suggested as being extremely beneficial. Participants stated that the topics of information required were different for each stage of rehabilitation; however information on rehabilitation and prostheses were suggested to be beneficial before the amputation took place. The age of the participants did not alter the topics of information participants mentioned but did alter the information delivery system desired. The older participants mentioned preferring more interactive and visual information delivery systems.

The recommendation from this work is a nationwide repository of information available to all patients on a website but also on a CD ROM so that the information could be provided to different patients in the format most suited to them. The CD ROMs would be available to all staff at the DSCs therefore when visiting a primary patient on the ward they could print off the relevant information they felt should be provided at that time and could easily print off other information if the patient requested it. This information provision could have a very large impact on the mental health of patients and therefore save the NHS money in terms of clinician time and treatment for mental health problems. This recommendation fulfills the aim of the study and therefore allows further work to be conducted in order to use the data from this Study to create a deliverable that could be evaluated.

Chapter 7: Study 4 – Improved Rehabilitation Pathway

7.1 Summary

The results of Studies 1, 2 and 3 have provided insight into the rehabilitation pathway NHS patients currently follow and have shown that there is little consistency across the country with regards the pathway followed or the information provided to patients. Studies 2 and 3 highlighted the importance of information in alleviating patient anxiety and helping both patients and carers through the difficult process of rehabilitation. In this chapter the information from all three studies was collated and used to produce an evidence based patient pathway for Disablement Services Centres to follow, detailing the information to be given to patients, when it should be provided and by whom.

7.2 Aims and Objectives

The purpose of this stage of the research was to collate the information gathered in Studies 1, 2 and 3 to produce an evidence based patient pathway that could be evaluated through a series of study specific objectives.

Research question 6: Can the experience of amputees be improved without great cost to the NHS?

Through appropriate data collection methods:

7.1: Use data gathered in Studies 1, 2 and 3 to ascertain the important stages of rehabilitation for the patient.

7.2: Ascertain which members of staff should be present at each stage of rehabilitation using data gathered in Studies 1, 2 and 3.

7.3: Collate the information gained to produce an evidence based patient pathway.

7.4: Use Study 3 data to place the relevant information patients require and from whom into the sections of the patient pathway.

7.5: Have the proposed patient pathway critically evaluated by clinicians.

7.6: Produce an updated patient pathway using the critique from the clinicians.

The rehabilitation pathway takes primary amputees from pre-amputation visits to the DSC through to 18 months post amputation, therefore any new proposal should be based on patient and clinician opinion in order to create a pathway that is clinically acceptable but also caters to the needs of the patient.

7.3 Literature review

7.3.1 Clinical Pathways

Clinical pathways are stated by Wade (2012) as using evidence based practice to help ensure that care is organised, timely and focused. Optimisation of patient outcomes and maximisation of clinical efficiency are both recognised outcomes following introduction of clinical pathways (Rotter et al., 2010). Due to the need for multidisciplinary collaboration, clinical pathways introduce timely involvement from all clinical staff and continuous review of care (Wade, 2012). Treating amputee patients requires person-centred partnership working, in which patient involvement is valued. Working alongside the patient aids the creation of meaningful, collaborative goals and supports the value of effective multidisciplinary working (Moroney and Knowles, 2006). Clinical pathways have been found to optimise rehabilitation for patients and care providers (Hallett et al., 2009).

A study conducted by Schaldach (1997) found that the simple introduction of a consultation with rehabilitation services post-amputation reduced the length of stay in hospital and therefore cost to the health service. Introduction of a rehabilitation-focused clinical pathway increased the number of patients able to return home from acute care and also reduced hospital charges significantly for each patient. Patients with below knee amputations that had followed the clinical pathway had significantly shorter hospital stays and lower hospital charges than patients that had no intervention or a rehabilitation consultation (Schaldach, 1997). The work showed that by introducing a clinical pathway patient care became more efficient and of higher quality and costs were significantly reduced. Although this study is dated, many studies involving different ailments in more recent years have produced similar results:

- Stephen et al. (2003) found the introduction of a clinical care pathway reduced stay in hospital and cost after elective colon resection.
- Kariv et al. (2007) found that length of stay in hospital and costs were reduced without increasing complications when a clinical care pathway was introduced postoperatively for ileal pouch-anal anastomosis.
- Smith et al. (2011) found that introducing a care pathway reduced costs by 35% and had no detrimental effect on survival rates of patients.
- In a review of 27 studies, Rotter et al. (2010) found that clinical care pathways were associated with improved documentation and reduced in-hospital complications.

Clinical care pathways have been found to improve patient outcomes and economic profiles for service providers (Ward et al., 2010), therefore their production and introduction into care for amputees should be seriously considered. Due to cost reduction at DSCs becoming a necessary exercise, the introduction of a clinical care pathway could help reduce costs without negatively affecting patients' outcomes. Removal of a spare limb from patients' prescriptions is currently the chosen cost reduction technique at many centres, however as the data gathered in Study 2 suggests, this is having a negative effect on patients' everyday lives. The introduction of a clinical pathway could negate the need to reduce the number of spare limbs prescribed simply by reducing overall costs for DSCs.

7.3.2 Stages of rehabilitation

Esquenazi and Meier (1996) state that limb amputation rehabilitation should be divided into nine discrete periods of rehabilitative evaluation and intervention:

1. Preoperative
2. Amputation surgery
3. Acute Postsurgical
4. Preprosthetic
5. Prosthetic Prescription and fabrication

6. Prosthetic training
7. Community Integration
8. Vocational Rehabilitation
9. Follow Up

Although this literature is dated, it has been cited by many papers from the past five years (Kohler et al., 2009; Bhuvaneswar et al., 2007; Østlie et al., 2011; Schaffalitzky, 2010; Kollewe et al., 2009; Churko et al., 2009; Daley, 2009; Ohnishi et al., 2007). The nine stages of rehabilitation have been well recognised and utilised in literature pertaining to rehabilitation of amputees, therefore their use in this research was considered appropriate. The stages described below are the ideal pathway determined from the literature.

Stage 1 – Preoperative

The preoperative stage of rehabilitation only applies to those patients for whom amputation is the only option left to them following weeks, months or even years of treatment. Trauma victims rarely get the opportunity to visit the DSC before their amputation therefore their pathway of care would be different. The interventions patients should receive in this stage are well documented in the literature.

- Pre-amputation visit to the Disablement Services Centre with a family member (when possible) where patient is shown around the facility and meets with the clinical team responsible for their rehabilitation. Explanation of rehabilitation and the pathway they will follow should also be included with leaflets provided covering the details explained verbally (Berke, 2004; Statewide Rehabilitation Clinical Network, 2012b).
- Physiotherapy should commence with a focus on cardio-vascular endurance, range of movement and strength (Berke, 2004; Hallett et al., 2009; Statewide Rehabilitation Clinical Network, 2012b).
- Home assessment by occupational therapist to ascertain whether the patient's discharge destination is suitable and any changes required should be made (Hallett et al., 2009; Statewide Rehabilitation Clinical Network, 2012b).

- Consultation with appropriate clinical staff regarding pain management and phantom pain, preferably with a family member present (Berke, 2004; Hallett et al., 2009; Statewide Rehabilitation Clinical Network, 2012b).
- Patient and family should meet with a counsellor or psychiatrist trained in the care of amputee patients. Psychological impact of the upcoming surgery should be explored with the patient and family to ease rehabilitation and a psychological assessment should be made in order to put into place any interventions that may be necessary in order to avoid serious psychological episodes (Butler et al., 1992; Berke, 2004; Hallett et al., 2009; Statewide Rehabilitation Clinical Network, 2012b).
- Meeting with an established amputee should be offered for both patients and families in order to provide peer support and share experiences (Ferguson et al., 2004; Liu et al., 2010; Fitzgerald, 2000; Thompson and Fisher, 2010; Berke, 2004).
- The aims and goals of the patient should be discussed with the relevant clinical staff and family in order to solidify reasonable expectations for recovery time and achievements post-surgery (Butler et al., 1992; Berke, 2004; Hallett et al., 2009; Statewide Rehabilitation Clinical Network, 2012b).

Stage 2 –Amputation Surgery

The patient and family should be aware of the level of amputation being performed, ways to minimise complication during surgery and information regarding wound dressings.

Stage 3 – Acute Postsurgical

This stage begins immediately following amputation and continues until the patient is discharged from hospital. Interventions for trauma patients very often begin at this stage due to the unexpectedness of the amputation. In these cases every intervention mentioned for the preoperative stage should be carried out if possible. Home alterations should be conducted while the patient is still in hospital with the aid of the family so that patients do not feel returning home will be an obstacle to their recovery (Hallett et al., 2009). Desmond and MacLachlan (2002) state that rehabilitation following amputation does not just concern the prescription and fitting of a prosthesis, but helping patients to adjust psychologically to their situation as rehabilitation is fundamentally linked with the individual's psychological adjustment to the injury. Prescribing a prosthesis is only really the start of the prosthetic rehabilitation process and professionals in the field may not need an in-depth knowledge of the psychological disorders associated with limb loss but they should be aware of the psychological issues that may influence the rehabilitation of their patients (Desmond and MacLachlan, 2002). The development of realistic rehabilitation goals and expectations can be beneficial in the long term rehabilitation programme. Rybarczyk et al. (2004) found that even though three of the four participants had limited follow up with a psychologist, each case illustrated the importance of a mental health professional in the rehabilitation process. Rybarczyk et al. (2004) state that mental health intervention is important as those at risk for poor adjustment and factors likely to influence adjustment could be identified early, therefore services to facilitate adjustment in the short and long term could be organised.

Interventions mentioned in the literature for this stage of rehabilitation are discussed below.

- On-going emotional support and counselling for the patient and their family. Emotional support post amputation has been found to reduce the time patients stay in hospital (Van Dorsten, 2004) and also provides the clinical staff with the information they require to organise appropriate interventions for patients that are more vulnerable to psychological episodes (Rybarczyk et al., 2004; Van Dorsten, 2004). Patients should be seen by a counsellor or psychiatrist daily while in hospital with families being seen two to four times per month.
- Physiotherapy should be started, focussing on range of motion and muscular strength in both upper and lower limbs (Berke, 2004; Hallett et al., 2009; Statewide Rehabilitation Clinical Network, 2012b).
- Assessment by a rehabilitation specialist should be conducted on the ward alongside discussion of the rehabilitation process and the aims and goals of the patient. Written information regarding rehabilitation and prosthetic limbs

should be provided to the patient if necessary (some patients will be deemed unfit for prosthetic rehabilitation) or information regarding wheelchair options should be provided (Berke, 2004; Hallett et al., 2009; Statewide Rehabilitation Clinical Network, 2012b).

- Written information should be provided regarding any topics the patient has questions about. These leaflets should be discussed with the patient and a further appointment made to discuss any questions the patient has following further reading and absorption of the information (Kessels, 2003; Johnson and Sandford, 2005; Coulter and Ellins, 2007).
- Pain control and phantom limb pain should be continuously reassessed with interventions in place for patients with higher levels of pain (Berke, 2004; Statewide Rehabilitation Clinical Network, 2012b).
- A visit from an established amputee should be offered very soon after amputation to allow the patient to speak with someone with experience of their condition and ask questions clinical team members cannot answer (Butcher, 2009; Liu et al., 2010; Fitzgerald, 2000; Thompson and Fisher, 2010; Berke, 2004).

Stage 4 – Preprosthetic

This stage is variable in length for every patient as fitting of a prosthesis can only occur once the stump is completely healed. Dysvascular patients can take much longer to heal therefore will spend longer in the preprosthetic stage (Berke, 2004). The interventions involved in this stage should be considered on an individual basis as each patient will require a different intervention at different times.

- Increasing range of movement, muscle strength and cardiovascular training through physiotherapy. Use of an early walking aid is possible to introduce patients to the feeling of walking again in preparation for prosthesis use (Berke, 2004; Statewide Rehabilitation Clinical Network, 2012b).
- Continued psychological help for the patient to ensure health coping strategies are in place and reduce the likelihood of a serious psychological episode. Support for the family should also be continued (Rybarczyk et al., 2004; Van Dorsten, 2004).

- Information regarding charities and support groups should be provided to allow patients to contact their peers for support and encouragement (Thompson and Fisher, 2010).
- Information regarding skin care and healthy diet options to promote healing should be provided to give patients the best opportunity to heal as quickly as possible (Berke, 2004; Statewide Rehabilitation Clinical Network, 2012b).

Stage 5 – Prosthetic prescription and fabrication

The prescription and fabrication of a prosthesis is the most important stage in the rehabilitation process to provide patients with their independence and regain their physical function.

- The multidisciplinary team at the DSC should be involved in assessing the patient and helping to prescribe the most appropriate components in order to satisfy the needs, desires and ability of the patient (Berke, 2004; Statewide Rehabilitation Clinical Network, 2012b)
- All interventions should be continued throughout this stage to support patients both physically and mentally (Berke, 2004; Statewide Rehabilitation Clinical Network, 2012b).

Stage 6 – Prosthetic Training

This stage involves physiotherapy to improve functional use and wearing time.

- On-going assessment by the MDT is necessary to keep track of the patient's progress and make sure interventions are in place if necessary (Berke, 2004).
- Emotional support should be available to reduce the impact on patients if setbacks occur and help the patient cope with phantom pain (Rybarczyk et al., 2004).

Stage 7 – Community integration

Psychological support for patients is extremely important due to the many emotions associated with amputation (Horgan and MacLachlan, 2004). Community integration can be particularly difficult for amputees due to fear of the reaction from the public (Rybarczyk et al., 1995; Rybarczyk et al., 1992).

- Support from a counsellor or psychiatrist as well as peer support can ease this transition back into the community (Esquenazi, 2004).
- Integration back into the family can also be challenging due to feelings of being a burden and also intimacy problems (Ide, 2004; Geertzen et al., 2009).
- The MDT should support the patient in taking part in previous or adapted recreational activities to help the patient both physically and emotionally (Horgan and MacLachlan, 2004; Condie et al., 2006; Callaghan et al., 2004). Components to allow recreational activities should be considered and provided to the patient if necessary.

Stage 8 – Vocational Rehabilitation

This stage involves assessment and training for work activities as some patients may be able to return to their previous line of work yet others may require a change in career.

- Assessment by the MDT should allow for special prescription of spare limbs or other necessary components for patients that require them to return to work mentally (Berke, 2004; Statewide Rehabilitation Clinical Network, 2012b).
- Reintegration to work should be gradual with the continued support of the MDT and counsellor (Statewide Rehabilitation Clinical Network, 2012b).

Stage 9 – Follow up

Amputation is a lifelong condition, therefore follow up by the DSC continues until the patient passes away or abandons limb wearing.

- Patients should be seen by one of the members of the MDT every three months in the first 18 months post-amputation and every six months following that for physical assessment (Berke, 2004).
- Emotional support should be available to patients when they require it at any time post-amputation as psychological problems can arise at any time (Price and Fisher, 2002; Rybarczyk et al., 2004).

7.3.3 Introduction of Clinical Commissioning Groups

Fundamental changes to the structure of the NHS, detailed in the White Paper “Equity and Excellence: Liberating the NHS”, were made law through the Health and

Social Care Act 2012 (Department of Health, 2012b). Clinical Commissioning Groups (CCGs) were introduced as a replacement for PCTs, to commission the majority of NHS services and therefore be responsible for designing local health services in England. These changes were introduced to “empower NHS professionals to improve health services for the benefit of patients and communities” (Department of Health, 2012b). The CCGs will become fully operational in April 2013, therefore funding for the majority of services could change considerably. These changes to the NHS could have a positive impact on the proposal of the pathway as the CCGs were created to benefit patients and ensure services are patient centred. The CCGs should therefore be motivated to improve the patient experience and patient satisfaction. The potential to improve patient experience and reduce costs through implementation of the pathway could be very attractive to the CCGs as this would help fulfil the main principle of their introduction.

7.4 Pathway Design – Objectives 7.1, 7.2 and 7.3

Design of the pathway aimed to combine the needs of the patient and the necessary stages required in rehabilitation, to produce a pathway that both satisfied the clinical staff and also improved the patient experience. The data gathered in Studies 1, 2 and 3 were collated and used to inform the design process as well as the use of the relevant literature. Comparison of the pathways in place at each of the 12 centres visited in Study 1 with Esquenazi and Meier’s (1996) nine stages of rehabilitation was conducted in order to ascertain which Centre, if any, was fulfilling all of the criteria stipulated in the nine stages. Centre B was found to have the most comprehensive pathway, therefore this structure was utilised as a base for the proposed pathway. Each stage was analysed and amended using the relevant literature and data from Studies 2 and 3. The data gathered in Study 3 were used to produce an information timeline for use with the pathway that indicated the topic of information and the person most suited to supplying this information at each stage of the pathway.

7.5 Patient Pathway

The designed patient pathway can be seen in Figure 7.2. The stages were numbered to correspond with the information timeline as shown in Section 7.5.1. This pathway was intended to illustrate the minimum standard of care for prosthetic patients.

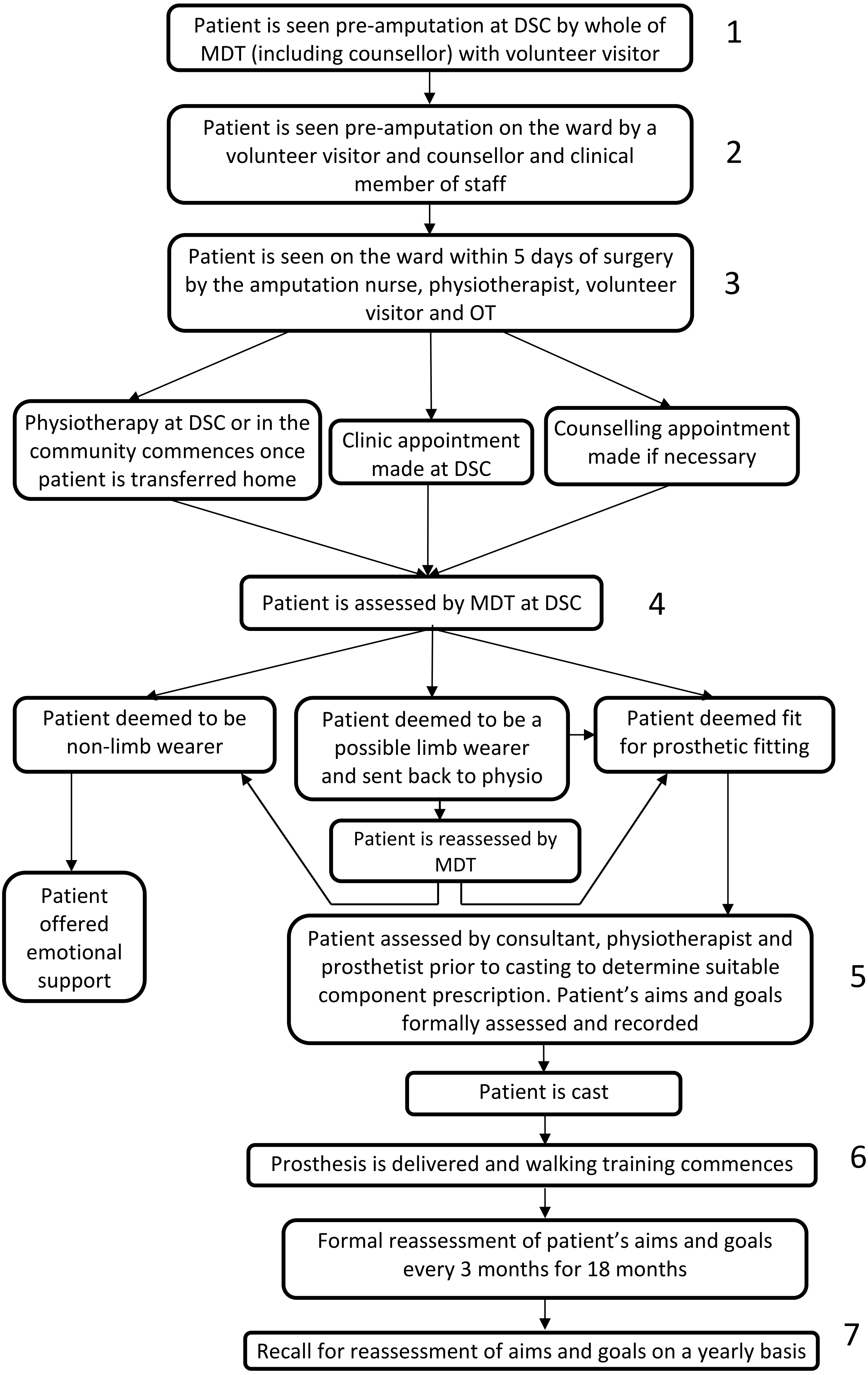


Figure 7.2: Proposed Clinical Pathway

7.5.1 Information Timeline – Objective 7.4

The data collected in Study 3 were used to produce an information timeline for primary patients. The timeline specifies the mode of information delivery and the information to be provided at each stage of the proposed pathway.

Stage 1 – Patient seen pre-amputation at DSC

- Volunteer Visitor – Life after amputation
- DVD that can be taken home – DSC and Rehabilitation Process
- Clinical member of staff – Explanation of what prostheses are

Stage 2 – Patient seen pre-amputation on the ward

- Volunteer Visitor – Life after amputation and support
- Verbal information and leaflets – DSC and Rehabilitation process
- Clinical member of staff – Explanation of what prostheses are

Stage 3 – Patient seen on the ward within 5 days of surgery

- Volunteer Visitor – Life after amputation and support
- Explanation and leaflets – DSC and Rehabilitation process
- Leaflets:
    - DSC Information – members of staff and their roles
    - Rehabilitation – stages, casting, learning to walk
    - Driving – car adaptions, blue badge, DVLA
    - Social Services and Benefits
    - Support for mental health – Counselling service
    - Charities and support groups
    - Skin and stump care – warning signs of infection etc.
    - Ways to improve health and speed up rehabilitation

Stage 4 – Patient assessed by MDT at DSC

- Explanation from staff
    - DSC Information – members of staff and their roles
    - Rehabilitation – stages, casting, learning to walk

  - Support for mental health – Counselling service
  - Skin and stump care – blisters and skin irritation
  - Ways to improve health and speed up rehabilitation

Stage 5 – Patient assessed prior to casting

- Leaflets and explanation from staff
  - How to improve health and speed up rehabilitation
  - Prostheses – components that are available on NHS and progression to receive better components
  - Spare limbs – why they're not necessary

Stage 6 – Prosthesis is delivered

- Leaflets and explanation from staff
  - Best practice for getting used to limb
  - Stump care – what to do and who to call if irritation occurs
  - Falling/ emergencies – what to do and who to call

Stage 7 – Recall for assessment on a yearly basis

- Upgrades to components – discussion with staff

7.6 Clinical Conference Focus Group – Objective 7.5

In order to evaluate the patient pathway, the opinions and critique of clinicians was sought. The manager of research at Company 1 was approached to ascertain whether evaluation of the patient pathway would be possible with their employees. An invitation to conduct a workshop at the annual company conference was received and accepted. The workshop was to be 45 minutes and would be attended by prosthetists, research staff and the Managing Director of the Company.

7.6.1 Rationale

The main purpose of this study was to produce and evaluate the patient pathway for primary amputees to follow pre- and post-amputation. Evaluation by clinicians was required in order to highlight any gaps in the pathway and the difficulties that would be faced in putting this pathway into place. The data collection method used was required to elicit the opinions the clinicians had on the proposed pathway.

7.6.2 Method

The data collection method used was restricted by the 45 minute time period provided by the organisers of the conference. Individual interviews were not appropriate due to the time restriction and immediate discussion of the opinions was desired therefore a questionnaire was also unsuitable. As discussed in section 4.4.3, group interviews can lead to highly productive discussions with little personal rapport required (Saunders et al., 2007). The information being discussed was not of a personal nature therefore no privacy or personal rapport was required and so a group interview was the only appropriate data collection method.

7.6.3 Design

Due to the expected number of participants being 20, a strategy to elicit the desired information was created. In order for the participants to understand the work being presented to them, a presentation of the results from Studies 1, 2 and 3 was necessary. Due to the large group size, a full group discussion would be very difficult to manage and would not give participants the opportunity they needed to evaluate the pathway. Smaller working groups were necessary to allow participants to discuss their opinions in a controlled environment. Specific questions for the participants to answer were required to keep the discussions focussed. A full group discussion of each working group's evaluations was also necessary in order to ascertain whether there was consensus between the working groups and, if not, where the differences lay. A structure was created to facilitate the desired outcomes which can be seen in Figure 7.3.

7.6.4 Clinical conference procedure

Following the presentation participants were split into four groups of five and were provided with an A3 copy of the proposed pathway and sticky notes to write on and stick where they thought the gaps were or problems would arise. Groups were then asked in turn for their opinions on the pathway and the restrictions in place that would hinder its use. These were written on a chart so that the whole group could be asked to comment on the other working groups' opinions. The A3 copies of the pathway were collected from each working group and the flip chart paper was taken for analysis.

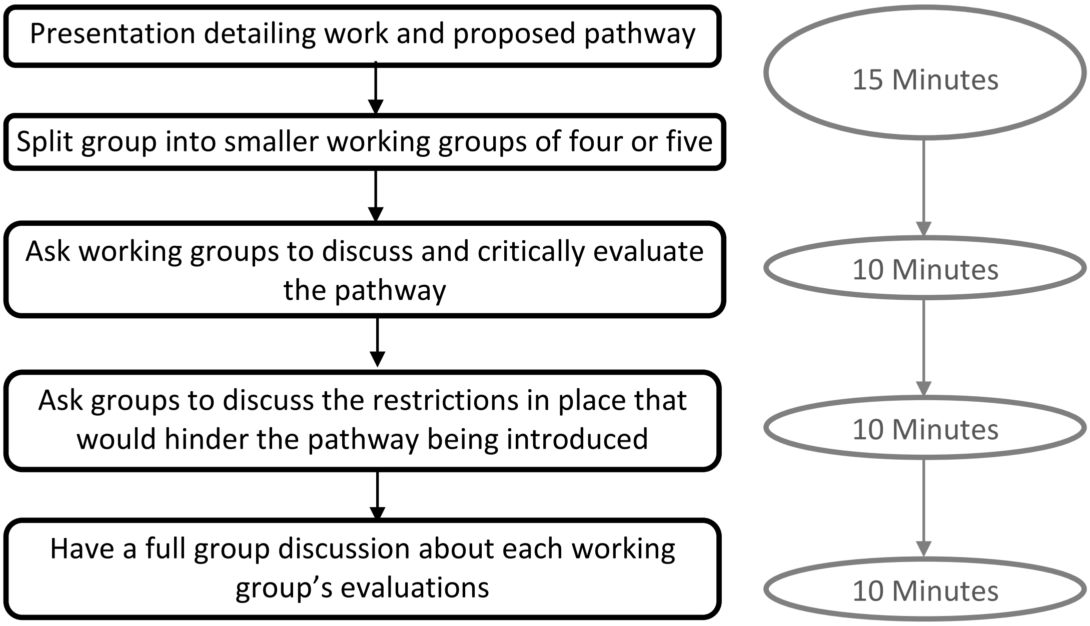


Figure 7.3: Group interview Structure

7.7 Data analysis

Each of the group's comments and suggestions were mapped onto another pathway in order to allow comparison of all four groups. The barriers described by the groups were organised into themes with similarities and differences between the comments being identified.

7.8 Results

Each stage of the pathway was analysed individually to allow specific comments to be given the correct level of importance. The number of groups that mentioned each suggestion or barrier is denoted by a number in brackets at the end of each sentence.

7.8.1 Rehabilitation Stages

1. Patient is seen pre-amputation at DSC by whole of MDT (including counsellor) with volunteer visitor.

Suggestions

- Aims and goals should be discussed at this stage to allow MDT to conduct expectation management so that the patient has realistic expectations of rehabilitation. (4)
- Education of the surgical team to inform them of the rehabilitation process and the requirements of the patients to aid rehabilitation. (3)

Barriers

- Volunteer visitors must be trained and selected carefully so they provide helpful information and match the primary patient as closely as possible. (4)
- Communication between surgical team and DSC is not always in place therefore the MDT may not be aware the patient is coming to the DSC for a pre-amputation visit or may not be aware of the patient that requires a visit to be organised. (3)
- Time constraints (3)
- This is not standardised across centres. (1)
- The prosthetist is often not involved with the patient before their amputation. (1)
- Volunteer visitors must be introduced at an appropriate time for individual patients therefore this will be different for each primary amputee. (1)
- NHS does not have the money to fund counselling. (1)

2. Patient is seen pre-amputation on the ward by a volunteer visitor, counsellor and clinical member of staff.

   Barriers

   - Lack of funding for counsellor. (1)
   - Decision about whether volunteer visitor is appropriate for individual patients is required. (1)

3. Patient is seen on the ward within 5 days of surgery by the amputation nurse, physiotherapist, volunteer visitor, counsellor and occupational therapist.

Suggestion

- Introduce an introductory visit to the DSC prior to discharge to meet the MDT and discuss aims and goals. (1)

Barriers

- Time constraints. (2)
- It is not always appropriate for every patient to be seen by each of these members of staff. (1)

4. Physiotherapy at DSC or in the community commences once patient is transferred home; clinic appointment made at the DSC, counselling appointment made if necessary.

   Barriers

   - Community physiotherapists do not have the time or training expertise to rehabilitate amputees properly. (1)
   - Lack of funding for a counsellor. (1)

5. Patient is assessed by MDT – No comments made.

6. Patient deemed to be a possible limb wearer; patient deemed fit for prosthetic fitting; patient deemed to be a non-limb wearer.

   Suggestions

   - Patients deemed to be a non-limb wearer should have an occupational therapy assessment at home to determine progress and be referred to other services if necessary. (2)
   - Patients deemed to be a non-limb wearer should have the option to attend physiotherapy to improve their range of movement, strength and cardio vascular endurance. (2)

7. Patient assessed by consultant, physiotherapist and prosthetist prior to casting to determine suitable component prescription. Patient’s aims and goals formally assessed and recorded.

Barriers

- The patient is not always made aware of what the MDT has decided. (1)
- Patient is not to decide what they need, that is the job of the professionals. (1)
- Consultants and physiotherapists do not have up to date prosthetic knowledge therefore should not be included in the decision. (1)
- Consultants and physiotherapists do not have the time for such appointments. (1)

8. Patient is cast – No comments made

9. Prosthesis is delivered and walking training commences – No comments made

10. Formal reassessment of patient's aims and goals every 3 months for 18 months.

    Barriers

    - Time constraints. (3)
    - Patients that have a lot of appointments are red flagged for investigation. (1)

11. Recall for assessment of aims and goals on a yearly basis

    Barriers

    - Under financial pressures therefore cannot spare the money for the extra paperwork and administration. (1)
    - Patients have to be realistic and take responsibility. (1)

7.8.2 Information provision

The clinicians also evaluated the suggestions for the provision of information at different points in the rehabilitation process.

Suggestions

- Interpersonal skills training for prosthetists to provide them with the skills they require to support patients and assess their individual needs. (4)

- Introduction of different information delivery systems such as DVDs and images. (2)

Barriers

- Lack of time and funding to create leaflets or other forms of information. (4)
- Centres across the UK not communicating and sharing their information resources. (3)
- Patients are very individual therefore information provision is difficult to standardise. (2)

7.9 Discussion

The general consensus among the prosthetists was that the pathway was very good; however, it would not succeed in practice due to budget constraints, lack of communication between the surgical ward and DSC and time constraints on clinical staff. However, each of the suggestions made could be taken forward and used to improve the proposed pathway. The introduction of aims and goals at a very early stage concurs with the literature (Butler et al., 1992; Berke, 2004; Hallett et al., 2009; Statewide Rehabilitation Clinical Network, 2012b) and could therefore be included in the modification of the clinical pathway. Education of the surgical team would require funds to be devoted to a small training session for the surgeons and cover while the surgeons were in training. Cost benefit analysis would be required to ascertain whether such training would be beneficial to the NHS. The suggestion of a visit to the DSC prior to discharge appeared to be a logical addition to the pathway as the patient would meet the clinical staff responsible for their rehabilitation and have the opportunity to ask any questions that had not previously been answered. The addition of physiotherapy and occupational therapy services for patients that were considered to be non-limb wearers was mentioned by only two of the groups, yet these interventions could drastically improve a patient’s life.

Many of the barriers mentioned by the prosthetists were surrounding time and budget constraints as well as the individuality of the patient. A solution to this could be the introduction of an amputation co-ordinator who would be assigned to the patient as soon as the decision was made to amputate or as soon as they were admitted to hospital following trauma. The concept of an amputation co-ordinator emerged from discussions with a trainee Occupational Therapist who attended the clinical conference. She explained that occupational therapists are trained in metal health and wellbeing as well as physical health, therefore could be used to help identify patients that would be susceptible to mental health problems and advise patients how best to cope with rehabilitation. This was developed further by ascertaining that this training could be utilised to help co-ordinate the rehabilitation and therefore reduce the number of staff involved in initial stages, reducing costs for the NHS and providing a point of contact for the patient. Co-ordinators such as this are already used in neurological rehabilitation, stroke rehabilitation and cardiac rehabilitation (Chevignard et al., 2010; Allen et al., 2004; Brodie et al., 2006). The OT would be required to have specialised in care of amputees and be aware of the mental as well as physical needs of the patients. The co-ordinator would be the point of contact for the patient, therefore reducing the number of unnecessary appointments with GPs, prosthetists and other clinical staff. The co-ordinator would be able to refer the patient to the correct clinical member of staff in the case of skin problems or pain so that the patient received the correct treatment as quickly as possible without the risk of having an appointment with the wrong clinician. Due to the co-ordinator having contact with the patient from the beginning of their journey through rehabilitation, they would be best placed to make decisions regarding the information to be provided to the patient and when the patient should see the members of the MDT and a volunteer visitor. Discussion with the patient about the information they would like and their options for meeting a volunteer and members of the MDT would help the patient to feel in control of their rehabilitation but keep the decision making with the co-ordinator. The patient may not know what information they would like or whether to meet a volunteer, therefore the co-ordinator would have to use their skills to determine the best course of action for that particular patient. The cost benefits to the NHS of introducing an amputation co-ordinator for each patient could be substantial. Having one person overseeing the progress of the patient could allow for early detection and treatment of mental episodes or physical problems. Each centre would require a minimum number of co-ordinators to be trained for the position to ensure one co-ordinator would be available to see a patient at all times, therefore reducing the impact of maternity leave, illness and holidays on the implementation of the pathway. Due to each centre having such different numbers of patients referred each year (Table 2.1) the number of co-ordinators required at each centre would vary. The suggested number of co-ordinators per referrals can be seen in Table 7.1. Each co-ordinator would be required to oversee a maximum of 50 new patients per year. Consultations with the patient would vary in length however a maximum of two hours per session would be advised. The job of amputation co-ordinator would be in addition to the daily job of the occupational therapists, however a weekly allowance of time would be provided to the co-ordinators, depending upon the number of patients under their care, for their co-ordinating duties. An alternative strategy would be to employ one amputation co-ordinator whose only job was to visit patients and co-ordinate clinic visits. If this strategy were undertaken, one co-ordinator may be able to cover two or three centres within one area due to numbers of referrals being so different and the geographical locations of the centres across the UK (Figure 2.6). The number of co-ordinators would be considerably less, however their only job would be co-ordination of amputation patients, therefore they could not be utilised for any other clinical work. Occupational therapists that do not practice for over two years can no longer be registered as an OT, therefore amputation co-ordinators would have to work on a rota system in order to keep their OT licence. In order to ascertain which strategy would be most logical and successful, discussion with clinicians and managers at DSCs would be required. The benefits to the patient would also be considerable due to the patient having the peace of mind that their best interests were being considered by the co-ordinator at all times and interventions for mental or physical problems could be organised by the co-ordinator if necessary. Cost benefit analysis of the introduction of such a service would be required.

Table 7.1: Number of amputation co-ordinators suggested for the number of referrals per year at DSCs.

Number of referrals per year	Number of amputation co-ordinators required
1-49	2
50-99	3
100-149	4
150-199	5
200-249	6
250-299	7

No comments were made about the topics covered in the information timeline, merely that the information delivery formats required modification. As stated in Study 3, the most appropriate information delivery techniques would be DVDs for the initial stages to provide patients and their families with visual information regarding rehabilitation and CD ROMs or a website for further information that could be accessed by the patient when they wished. The introduction of an amputation co-ordinator would mean that the co-ordinator could discuss the information available to the patient and print off sections for them to read whilst on the ward or provide them with the CD ROM to search through if they had a laptop with them in hospital. The co-ordinator could decide how much information the patient should be provided and the appropriate time for its provision. This would reduce the onus on other members of staff to provide written information and would allow the patient to decide what information they would like to receive and when.

7.9.1 Resistance from prosthetists during workshop

The groups involved in the workshop were self-selected as the prosthetists split themselves up into groups relating to the number of years of experience they had. The prosthetists present primarily fell into two groups representing prosthetists with many years of experience and those with under five years of experience. This was ascertained by asking each group how many years of experience they had on average, however the exact number of years of experience each prosthetist had were not ascertained. These two sub-groups presented different perspectives on the work being described. Prosthetists with more experienced were observed to be resistant to the work; examples of comments are detailed below:

- Comment made when discussing improved components for patients: "*The patient is not to decide what they need, that is the job of the professionals*".
- Disagreement from one prosthetist with the suggestions surrounding the members of staff to visit patients on the ward post amputation.
- Mention of the lack of funding for interventions such as counselling with no suggestions for possible solutions.
- Comment made when discussing prosthetic prescription: "*Consultants and physiotherapists do not have up to date prosthetic knowledge therefore should not be included in the decision*".

These comments suggest that the more experienced prosthetists were unreceptive to research findings recommendations. These observations were interesting due to the concept that the managers of these prosthetists may be unaware of the resistance of their employees to patient centred research and possible solutions to benefit the patient and staff. The research findings presented were strongly in favour of the introduction of counselling, however the more experienced prosthetists were observed as being non-receptive of the findings. Such resistance would not be conducive to the introduction of any intervention, as all members of the MDT would need to be positively engaged with the intervention and implement it to the best of their abilities.

The prosthetists with fewer than five years of experience were observed as being more actively engaged with the research findings and appeared to be more amenable to the introduction of an intervention.

If the general trend in resistance to patient centred interventions is represented in the national population of prosthetic care providers, then a range of consequences may occur including:

- Resistance to implementation of proposed interventions, therefore leading to required changes not being implemented or being implemented badly. This would lead to the benefits of the pathway not being realised due to poor implementation. This would not only cost the NHS large sums of money due to non-compliance, but also impact upon the working relationships between the NHS and the companies providing the service to them.

- Benefits of the interventions not reaching the patients due to bad implementation of the intervention. The pathway was produced to improve the patient experience, therefore helping patients and reducing costs for the NHS. If the patients were not receiving the benefits from the implementation then the NHS would not see any cost reduction, therefore making the implementation a waste of time and resources.
- Frustration causing friction between members of staff due to differences in opinion over the intervention. Due to prosthetic care being provided by an MDT, good working relationships are essential to ensure good quality care. If relationships became strained, this could impact upon the care provided and create animosity between members of staff. Patients could become aware of this and complain, causing further problems for staff and increasing costs due to each complaint needing to be dealt with appropriately.
- Continuation of the ‘Postcode lottery’ of service due to resistance in some DSCs and complete compliance in others. The pathway was created to reduce the postcode lottery as much as possible, therefore non-compliance would only exacerbate the current service differences. Non-compliance would therefore completely negate the introduction of the pathway, making its implementation a waste of time and resources.
- Patient dissatisfaction and frustration due to interventions not improving their experience. Improving the patient experience is one of the most important outcomes desired from the implementation of the proposed pathway, therefore reduction of this would nullify the implementation. If the pathway did not improve the patient experience, the NHS would not benefit from the cost reductions associated.

Each of these consequences could be extremely costly to the NHS therefore a strong training programme for managers and employees of the DSCs would be required to ensure each member of staff was aware of what the interventions were and why they were being implemented. The cost of training would therefore have to be offset against the overall cost effectiveness of implementing the pathway. Gaining the support and confidence of the members of staff would be essential to the successful implementation of proposed interventions. Monitoring of progress and problems encountered would also be essential to ensure employees were continuing to implement the interventions with problems being resolved as they arose. Managers of the centres would be responsible for appropriate monitoring of the implementation of the pathway and required to take action if resistance from members of staff was hindering its operation. Appropriate measures of the success of the pathway would be essential to quantify the improvements experienced by the NHS and patients. Patient satisfaction surveys and evaluation of the number of repeat appointments and complaints received would be used to ascertain the success of implementing the pathway.

The Managing Director of Company 1 was present during the focus group and observed that maybe the prosthetists were not being given the appropriate interpersonal training at University to equip them for interaction with traumatised individuals following amputation. There was agreement from the younger prosthetists present that they had been provided no formal training in interpersonal skills and would have liked this to be part of their course at University. There are only two universities in the UK that run the course to become qualified as an orthotist or prosthetist; Salford and Strathclyde. On inspection of the modules for each year of the course at both Universities it was evident that very little time is given to directly training the students in interpersonal skills. Salford had one module in the first year that dealt with 'effective communication skills' however this was coupled with ethical issues, professionalism and codes of conduct. Strathclyde had one module in the second year that was designed to 'enhance the interpersonal and communication skills required to be able to effectively implement prosthetics and orthotics clinical and technical skills in a professional setting', however this was also coupled with ethical issues, professionalism and codes of conduct. In order to improve the way in which prosthetists interact with patients formal training, preferably at University level, should be introduced.

7.10 Modified Patient Pathway – Objective 7.6

Using the suggestions and taking some of the perceived constraints into consideration, the original patient pathway was modified. This clinical pathway was created to represent the needs of patients; therefore certain aspects were retained despite the barriers mentioned by clinicians. The modified pathway can be seen in Figure 7.4. The stages added to the pathway are outlined in red and those that have been altered are outlined in blue.

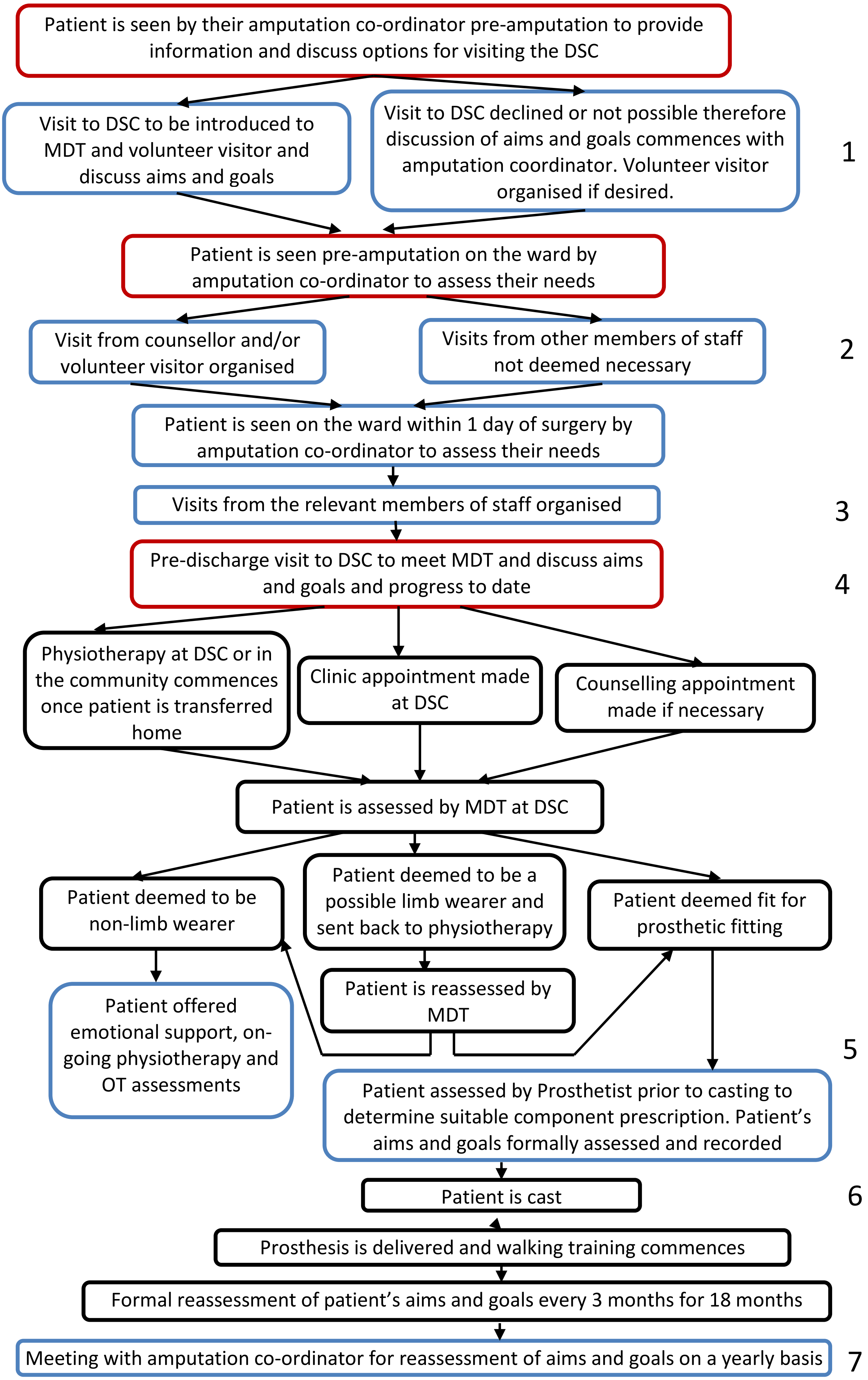


Figure 7.4: Modified Clinical Pathway

7.10.1 Rehabilitation stages

7.10.1.1 Amputation co-ordinator

The introduction of an amputation co-ordinator would allow fewer staff to be involved in the pre- and post-amputation consultations as the patient is only seen by the members of staff perceived to be necessary for their mental and physical health. Communication between the surgical ward and the amputee co-ordinator would require introduction and the surgical team should be made aware of the importance of this member of the clinical team for the mental and physical health of the patient. The co-ordinators would be required to be the amputee's contact if they had a problem and co-ordinate further treatment if deemed necessary. The co-ordinator would also see the patient yearly to assess progress and help the patient decide whether they required any further prosthetic upgrades. This would reduce the time spent with the prosthetist and allow patients to have their needs met either through discussion or further clinical intervention.

7.10.1.2 Aims and Goals

Discussion of aims and goals of the patient were moved to the pre-amputation consultation either at the DSC or with the amputation co-ordinator. This was not only to benefit the patient but also allow staff to begin expectation management to ensure the patient was not expecting too much of themselves and the service. Expectation management should be introduced at this point to attempt to avoid patient disappointment with the service and themselves and to give the patients realistic goals to strive for.

7.10.1.3 Volunteer Visitors

The introduction of volunteer visitors was not removed from the pathway as Studies 2 and 3 revealed the importance of these patients to primary amputees. The cost of training such patients to become a volunteer visitor could reduce costs for the DSC due to the important practical knowledge on wound care and personal rehabilitation that the visitor could provide.

7.10.1.4 Counselling

The presence of a counsellor within the pathway was not removed despite the prosthetists mentioning budget constraints made this service difficult to provide. This was due to counselling being recognised in the literature as being a fundamental part of successful rehabilitation and participants in Studies 2 and 3 stated that the inclusion of this service would have been and still could be helpful to them. The introduction of counselling could also provide long term cost reduction due to the potential for reduced repeat visits to clinicians and reducing the number of patients developing more serious mental illnesses.

7.10.1.5 Pre-discharge visit to DSC

Introduction of a pre-discharge visit to the DSC would allow the patient to become familiar with the DSC and clinicians involved in rehabilitation and have the opportunity to discuss their aims and goals with their prosthetist. This visit would be co-ordinated by the amputation co-ordinator who would be present to take notes for the patient and provide follow up discussion if necessary.

7.10.1.6 Non limb wearers

The addition of physiotherapy and OT services for non-limb wearers was added to the pathway following the suggestion from the prosthetists at the clinical conference. Non limb wearers should be cared for and given rehabilitation to help them achieve the best mobility possible.

7.10.1.7 Formal reassessment of aims and goals

The formal reassessment of patient’s aims and goals every three months for the first 18 months was not removed from the pathway due to the perceived necessity for patient progression. Study 2 has revealed that although aims and goals may be discussed early on in rehabilitation they are not always updated, which could cause frustration for the patient.

7.10.1.8 Comparison with international best practice

The role of an amputation co-ordinator is not currently recognised in international prosthetic rehabilitation, however, the addition of this role would enable the UK to follow the international best practice guidelines, as discussed in Section 2.4, as the co-ordinator could oversee each stage of the rehabilitation and reassess the patient periodically, which is common practice in the developed countries reviewed. The USA already utilises learning assessments, thorough patient education and behavioural health assessments within their prosthetic practice. Each of these interventions could be organised by the amputation co-ordinator, reducing the need for extra staff but also providing patients with the best care possible. The inclusion of discussions and reassessment of aims and goals is in line with the current practice in Australia and the USA as proper discussion of these are stated as being an important and necessary factor in their rehabilitation process. Peer support is also internationally recognised, as it is an integral part of the rehabilitation of patients in the Netherlands and Germany. Patients are seen to benefit from the support and advice from their peers therefore making the introduction of the service highly desirable. Introducing counselling would bring the UK in line with internationally accepted guidelines as its provision would allow for appropriate behavioural health assessments and treatment as well as a fully interdisciplinary assessment process as currently found in the rehabilitation process in the USA. Psychological help is recognised as being an important part of the rehabilitation process in almost every country reviewed in Section 2.4, making the introduction of counselling essential to bring the UK in line with international best practice (Rommers et al., 1997; World Health Organisation, 2004; Chiong and Lim, 2007; Department of Veterans Affairs, 2008; Geertzen et al., 2011; Statewide Rehabilitation Clinical Network, 2012a).

7.10.2 Information provision

With the introduction of the amputation co-ordinator the information timeline could be used by the co-ordinator as a guide to the information that should be provided to the patient at certain times. Discussion of such topics could then commence with the patient to ascertain whether they would like the information in written form. The topics within the timeline remained unchanged following the group interview as no comments were made pertaining to them. The stages within the modified clinical pathway were numbered to coincide with the information timeline.

7.10.3 Cost benefit for the NHS

The benefits to the patient of the introduction of the proposed pathway can be easily speculated; however the cost benefit to the NHS is difficult to estimate. There is literature pertaining to certain interventions reducing costs for the health provider due to reduced clinician visits (Desmond and MacLachlan, 2002), however quantifying the reduction in cost without using some form of calculation would be impossible. The quality-adjusted life year (QALY) is a model used by medical statisticians to quantify value for money of a medical intervention (Gudex, 2002). QALYs involve the use of health state and years lived in that state of health to provide a value that can be used in calculations to develop a cost-effectiveness analysis of any treatment (Gudex, 2002). In order for cost benefit of the proposed pathway to be analysed, QALYs would be required. The use of QALYs in the calculation of cost-effectiveness is conducted by medical statisticians and could therefore not be conducted during this research due to the costs and skills this would involve. Continuation and progression of the research would require these calculations and therefore funding would be essential.

7.11 Critique of Study

The pathway was produced using literature, the pathways from the 12 centres visited in Study 1 and information gathered from patients in Studies 2 and 3. The work carried out to produce this pathway was patient centred, therefore this could have contributed to barriers to adoption of the pathway. A patient centred approach was chosen rather than a user centred approach due to the lack of patient centred studies with regards prosthetic care. Not involving other users in the research could be one reason for some prosthetists appearing not to support the pathway. Including all users such as clinicians, patients and carers in the production of a pathway via a user centred approach is extremely important to help each party feel that their opinions have been taken into account. This would ensure that the clinicians did not feel that they were being advised how to run their practice by patients that have no clinical qualifications and the carers of the patients would feel that their needs were being realised as well as their family members. Further work of any kind should adopt a user centred approach to reduce the occurrence of barriers to adoption of the pathway by any of the stakeholders.

The information gathered in Studies 2 and 3 could not be considered representative of the entire amputee population due to the small sample sizes, therefore the pathway cannot be stated as being a pathway of which all amputee patients would approve. The pathway was also critically evaluated by prosthetists from Company 1 only; therefore differences in opinion between companies were not ascertained. This approach was taken as time and budget restrictions associated with the work reduced the ability of the researcher to contact prosthetists from other companies. The clinical conference attended was the only conference of its kind in the latter stages of the research, therefore contacting prosthetists from other companies was not possible. Had further funding been available, an evaluation by prosthetists from across the country would have been possible at the British Association of Prosthetists and Orthotists conference in March of 2013. The care provided by each of the companies is not uniform, therefore there may be barriers within the companies that were not found due to Company 1 being the only company used for evaluation. The limited number of prosthetists involved in the evaluation means that many other opinions will have been missed, which could have provided important information for improving the proposed pathway. Other members of the MDT such as OTs and physiotherapists were not included in the evaluation even though their opinions and suggestions could be used to refine the pathway even further. This was the case due to an inability to involve large numbers of these clinicians in the evaluation. The implications for this are that the pathway may be missing key stages or important information provision due to prosthetists being the only source of evaluation. Physiotherapists, OTs and other members of the MDT will have very different opinions on the care to be provided to primary patients as they are involved with patients at different stages of rehabilitation and may see certain issues with the current provision that prosthetists are not aware of. Patients and carers were also not included in the evaluation which could prove to be of great value. The opinions of patients and carers would provide a different perspective to the pathway and enable the researcher to tailor the stages to both patient and clinician requirements. In order to take this work forwards, further evaluation by the MDT and patients and their carers would be required.

7.12 Conclusions

A clinical pathway was designed using literature and results from Studies 1, 2 and 3 in this thesis. The pathway was critically analysed by 20 prosthetists at a clinical conference and their suggestions and barriers to the pathway were recorded. These data were analysed to reveal changes that needed to be made to the pathway in order to improve the patient experience and support the prosthetists in their work. There was agreement among the prosthetists that aims and goals should be discussed pre-amputation and due to the individuality of patients, their needs should be assessed before patient volunteer visitors and other members of staff were sent to visit them. There was also agreement that budget restrictions hindered the introduction of a counsellor and that prosthetists should be given interpersonal skills training to aid them in supporting their patients. Using this information an improved pathway was produced which could be used to improve the experience of patients and possibly reduce costs for the DSC.

The recommendation from this work is to conduct a further study within the NHS involving patients to ascertain their view on the proposed pathway to ensure the work remains patient centred. The details of this study are discussed further in Section 9.3.4.

Chapter 8: Overview and Synthesis

8.1 Summary

The purpose of this research has been to ascertain the problems faced by patients with the current NHS prosthetic service and to deliver a potential solution that improves the patient experience and is cost effective for the NHS. Studies 1, 2, 3 and 4 have all provided data essential to answering the research questions of this work. This chapter provides a synthesis of the work carried out with the benefits, drawbacks and threats for both patients and the NHS being discussed.

8.2 Benefits, drawbacks and threats for patients

The overriding theme throughout this research was ensuring work was patient centred. The patient was the focus of each of the studies, with improvement of the patient experience being of upmost importance as improving the patient experience has been found to improve satisfaction and in turn quality of life (Van der Linde et al., 2007; Kark and Simmons, 2011). The work highlighted the importance of implementation of certain changes for patients, however the drawbacks for patients had not been considered.

8.2.1 Benefits

The implementation of the proposed clinical pathway should provide a variety of benefits to primary patients therefore improving their experience of the service and in turn their quality of life. Each potential benefit for patients is discussed in the following sections.

8.2.1.1 Uniformity of service across the UK

As discussed in Section 1.1 there is currently a large amount of media coverage surrounding the ‘postcode lottery’ within the NHS. The introduction of the proposed patient pathway would remove this postcode lottery as all centres would follow the same pathway and therefore provide the same level of service to every patient. The uniformity of service provision would remove the media coverage pertaining to differing levels of service across the country and would therefore give patients more confidence in their DSC. Creating uniformity of service would be a high cost intervention for the NHS due to the necessity to introduce a new patient pathway. The suggested patient pathway would require further research and testing as well as the initial set up costs across all 44 centres making it a very costly intervention.

8.2.1.2 Clear pathway to follow outlined at beginning of amputation process

Introduction of the proposed pathway would provide patients with a clear pathway to follow for their rehabilitation so they could fully understand and accept what would be happening to them at each stage of rehabilitation. Removing the element of 'unknown' from their rehabilitation would decrease patient anxiety and allow them to discuss the pathway with their family and ask any questions they or their family may have.

8.2.1.3 Improved information provision

The importance of information for patients suffering from debilitating conditions is well documented in the literature (Smith et al., 2009; Hoffmann and McKenna, 2006; Pieper et al., 2006; Wachters-Kaufmann et al., 2005; Stewart et al., 2004; Hoffmann et al., 2004; McGregor et al., 2004; Kendall et al., 2004; Morris, 2001; Fitzmaurice and Adams, 2000). The documented advantages of timely and adequate information can be surmised to apply to primary amputees due to the similarities between amputation and other debilitating conditions. The introduction of the proposed clinical pathway would provide patients with an opportunity to gain information when they desired it and in the best format for them. The creation of a nationwide repository of information from which the patient or amputation co-ordinator could obtain the information desired would allow patients to obtain relevant and accurate information that would support and inform their rehabilitation. Provision of such information could decrease anxiety levels, improve the functional status and social recovery, promote greater patient satisfaction and improve the family functioning (Smith et al., 2009; Smith et al., 2008; Clark et al., 2003). Anxiety is a well-documented consequence of lack of information provision which can lead to demotivation to take part in rehabilitation activities and therefore impact heavily on the quality of life of the patient (Wachters-Kaufmann et al., 2005; Maclean et al., 2000; Klute et al., 2009). Removal of this demotivating anxiety could be achieved through the introduction of the proposed pathway, therefore improving patient outcomes and their quality of life. The family of the patient would also benefit from improved information provision as they could access the information repository at any time and therefore improve their knowledge of rehabilitation and other important aspects of amputation such as mental health and skin sores, to alleviate their anxiety and also help them support their family member as much as possible. Support of family members is an important part of rehabilitation therefore improving the support that the family could provide would not only benefit the patient but also the mental health of the family members themselves as feelings of helplessness would be less common (Clark et al., 2003; Klute et al., 2009; De Godoy et al., 2002). Providing patients and their families with an opportunity to access reliable and useful information at any time provides them with the means of understanding the rehabilitation pathway they will follow and also have the feeling that they retain some level of control over their lives. This intervention would require a comparatively small amount of funding due to the intervention being used across all centres. The information would need to be collated and checked by clinicians and patients to ensure its suitability and translated into a number of different languages for accessibility purposes.

8.2.1.4 Discussion of aims and goals

Goal setting is well documented in the literature as being a fundamental component of rehabilitation (Siegert and Taylor, 2004; Barnes and Ward, 2000; McLellan, 1997; Playford et al., 2000; Ward et al., 2010). The proposed clinical pathway would introduce goal setting at the earliest possible point of contact with the patient whether that is pre- or post-amputation. Non trauma patients would have the opportunity to discuss their aims and goals with their amputation co-ordinator to allow the patient to express their needs and desires and allow the amputation co-ordinator to manage the patient's expectations. Trauma patients would have the opportunity to discuss their aims and goals as soon as they were seen by their amputation co-ordinator at the earliest possible time. Discussion of aims and goals can focus the attention of the patient, allow them to develop strategies to achieve their goals and therefore increase their motivation, which in turn improves rehabilitation outcomes and therefore quality of life (Siegert and Taylor, 2004; Barnes and Ward, 2000; Hurn et al., 2006). The continued discussion of aims and goals throughout the rehabilitation process and beyond allows patients to continue to improve their prosthetic prescription, achieve better levels of mobility and therefore live a more active and fulfilled life and potentially return to work and in doing so, contribute to the national economy. These discussions would attract very little cost due to the only associated cost being the prosthetists time. The prosthetists would simply need to discuss patient's aims and goals and keep a record that could be updated.

8.2.1.5 Explanation of spare limb policy

Study 2 revealed that participants were concerned about the lack of provision of spare limbs. The pathway would introduce discussion of the spare limb policy to allow patients to fully understand why they may not receive one and the opportunity for the patient to ask questions and discuss their concerns. This would ultimately improve patient's perceptions of the service they were provided as the understanding brought about through appropriate discussion would reduce anxiety and improve acceptance of the spare limb policy. As with aims and goals, the cost of this discussion would only be the prosthetists time, making the intervention very cost effective.

8.2.1.6 Explanation of components available on the NHS and progression to achieve them

Study 3 revealed that participants would have liked a clear explanation on what components were available to them on the NHS and discussion about improving their prescription. The implementation of the pathway would introduce discussion with the patient about the NHS provision of components, the reason for their initial prescription and the improvements to their prescription they could have and how to achieve them. This would allow patients to understand their prescription and provide them with motivation to improve their prescription through physiotherapy. Explanation about componentry could also remove the resentment patients alluded to in Study 3, as they would be aware of what the NHS could provide and therefore not feel that information was being kept from them in order to reduce costs. Improved components can provide patients with the ability to achieve greater mobility and therefore improve their quality of life, therefore providing them with the motivation to participate in all rehabilitation activities. This intervention would also only attract the cost of the prosthetists time, therefore making it another cost effective intervention.

8.2.1.7 Availability of Counselling

As discussed in Section 6.3.2, the psychological impact of amputation can have severe consequences for the patient's quality of life. Callaghan and Condie (2003) found that there is a "stronger relationship between mental health and quality of life than between physical health and quality of life"; therefore in order for patients to achieve the best possible quality of life, their mental health should be of greater importance than their physical progress during rehabilitation. Many studies indicate that counselling should be available to all patients about to undergo amputation (Desmond and MacLachlan, 2002; Bhuvaneswar et al., 2007; Price and Fisher, 2002). The results of Studies 1, 2 and 3 concur with this statement as prosthetists at almost every centre stated how important counselling was as part of the service and participants in Studies 2 and 3 stated how valuable counselling was or that they would have liked the service. The introduction of counselling would provide patients with the emotional support they required to accept their amputation and progress through rehabilitation more smoothly due to the establishment of healthy coping strategies. The quality of life of patients could be significantly improved therefore benefitting patients and their families. The early introduction of counselling could prevent patients from developing serious mental health conditions and therefore save patients and their families from the traumatic experiences associated with such conditions. Introduction of counselling at every centre would require a considerable amount of funding, however the money saved from the decrease in repeat appointments and production of multiple sockets would help to balance this cost out.

8.2.1.8 Availability of Patient Volunteer Visitors

The importance of peer support for primary amputees is well documented in the literature (Froggatt and Mawby, 1981; Briggs, 2006; Novotny, 1996; Jacobsen, 1998; Butcher, 2009). Patient volunteer visitors would be specially trained and chosen to suit the individual amputee therefore could provide relevant practical and emotional advice to individual patients. This advice could not only benefit the patient but also the family as the volunteer visitor could educate the patient and family about the process of moving home and provide tips to make this transition as smooth as possible. The volunteer visitor also provides the patient with a perspective that no able bodied person could provide, therefore helping the primary patient feel less isolated and alone (Butcher, 2009). The volunteer visitor also provides the patient with physical evidence that life continues following amputation and could supply the incentive for primary patients to work hard during rehabilitation as they are aware of the outcomes they could achieve. The emotional support provided by volunteer visitors could have a significant impact on the wellbeing of the patient and therefore improve their quality of life and in turn their physical progress. The introduction of patient volunteer visitors would be greatly beneficial due to the positive impact they could have on patients and their families lives. Introducing this service would require an initial injection of funding to set up groups of amputees across the country with the correct resources and training to provide appropriate support to primary amputees. This initial outlay would not necessarily have to fall on the NHS, with limbless charities being possible candidate to take on this responsibility.

8.2.1.9 Amputation Co-ordinator

The amputation co-ordinator would provide patients with a point of contact for all of their questions and emotional or physical needs. Due to the co-ordinator providing such service, a rapport could be built between the patient and their co-ordinator therefore allowing the patient to feel more comfortable in talking about personal problems such as mental health or concerns about their sex life. The discussion of such topics is extremely important (as discussed in Section 6.3) in order for the patient to accept their amputation and progress through rehabilitation.

The co-ordinator could be contacted by phone or email therefore giving patients options for communication as they may feel more comfortable emailing a concern than speaking about it over the phone. This would allow patients to contact a clinical member of staff quickly about any concerns and therefore ease their mind without the need to make an appointment. The co-ordinator could advise patients to visit their prosthetist or another clinician if the situation demanded it, or simply provide advice over the telephone or via email therefore saving the patient the time and money associated with attending the DSC. Simple problems could therefore be identified quickly, reducing the risk of them manifesting into something more difficult to treat which could save the patient from pain, emotional distress and further treatment. Introduction of this post could initially be extremely costly to the NHS, as the co-ordinators would require training and extra personnel would be needed to cover the work the co-ordinator would no longer have time to do. The potential cost savings for the NHS would only become apparent after an extended period of time, therefore the initial outlay for this intervention not be recovered immediately.

8.2.1.10 Introduction of pre-amputation visitation for all patients

Introducing a visit by their amputation co-ordinator to every patient pre-amputation would provide patients with the opportunity to ask questions receive information in written and verbal form and request further help from other services such as counselling and patient volunteer visitors. It would also provide an opportunity for the patient to discuss their aims and goals and create realistic expectations for their rehabilitation (Desmond and MacLachlan, 2002). Patients would therefore be more informed about the process they were to go through following amputation, reducing anxiety due to unknowns and allowing them to prepare themselves for surgery. Information provision at this time would also allow patients and their families to read and absorb relevant details about the rehabilitation process and ask their amputation co-ordinator any questions they may have. This would allow the patient’s family to feel more involved in their rehabilitation and be more aware of the possible negative effects amputation could have on the patient’s mental health and therefore more readily able to report any problems to their co-ordinator. Pre-amputation visits could reduce patient and family anxiety and create realistic aims and goals for the patient to work towards post-amputation therefore encouraging patients to become actively involved in rehabilitation. Reducing anxiety of patients and families could reduce long term costs with regards mental health interventions, complaints and prolonged appointments, therefore the introduction of this intervention, which would only attract the cost of the clinicians time, can be seen as very cost effective.

8.2.2 Drawbacks

The implementation of any new pathway would produce drawbacks for both patients and the NHS. There are specific drawbacks for patients that would arise from implementation of the proposed pathway that would require particular attention to ensure their effects did not outweigh the advantages.

8.2.2.1 Heavy reliance on amputation co-ordinator

Despite the perceived benefits of the amputation co-ordinator, patients would be heavily reliant on them for information, advice and co-ordination of further appointments. If the co-ordinator did not fulfil their role properly, the patient and their family would bear the consequences. The co-ordinator could be disorganised and not provide the correct information for the patient, not reply to phone calls or emailed questions and not recognise the warning signs for the development of mental health problems. The patient may not get along with their co-ordinator, therefore introducing reluctance to contact their co-ordinator about questions they may have. The co-ordinator and patient may disagree about the members of staff they should see pre- and post-amputation which could cause frustration and anxiety for the patient. The quality of the service provided by the co-ordinator would depend upon the personality and abilities of the clinical member of staff employed as the co-ordinator. The co-ordinators would require training; however training could not guarantee that every staff member would provide a good level of service to patients.

8.2.2.2 Componentry

The introduction of this pathway would not improve the componentry available at each DSC as the budget constraints for individual DSCs would still be in place. With the availability of information relating to the componentry available at their DSC patients may become angry and frustrated due to other patients at different DSCs being offered seemingly better components. With communication via chat rooms and online forums being increasingly simple, patients would be able to share this information and compare the components available at their respective centres. The components available at each DSC would therefore be widely available and could cause patients to become highly frustrated and complain, which could cause tension between themselves and staff at their DSC.

8.2.3 Threats

Threats to the successful implementation of the pathway brought about by patients of the DSCs are of particular concern as the pathway was designed to improve the patient experience and outcomes. Without the co-operation of patients the pathway would become ineffectual.

8.2.3.1 Ex-service personnel

In January of 2011 the Government requested a review into the prosthetic services offered to veterans be conducted by Dr Andrew Murrison MP (BAPO, 2011). The report was commissioned due to concerns voiced by service charities and some serving personnel that the NHS could not provide the same level of service for veterans as they received at Defence Medical Service at Headley Court (BAPO, 2011). The review was published in July 2011 with 12 recommendations, the key recommendation being:

"Ministers should take appropriate powers to provide for national commissioning of specialist prosthetic and rehabilitation services for amputee veterans through a small number of multidisciplinary centres in England, adequately resourced and determined through a tendering exercise" (Murrison, 2011)

On 21st October 2011 the report was accepted by the Government and up to £15 million was invested to support the recommendations made by Dr Murrison with the creation of a number of national specialist prosthetic rehabilitation centres for amputee veterans across the country (BAPO, 2011). The Health Minister at the time, Dr Dan Poulter, stated that the mental health services for veterans was of upmost importance and £1.8 million would be invested every year over the next three years to improve mental health services for veterans and their families (Department of Health, 2012a). The Department of Health is said to be using the feedback and experience from implementing the specialist services to help improve services for all patients in the future (BAPO, 2011).

The expectation is that the introduction of the pathway proposed here would improve the standard of the NHS service therefore minimising the differences between the NHS and Headley Court. The difficulties would arise due to the differences in componentry available to NHS patients and veterans. The NHS patients may be aware of the components being provided to the veterans attending their centre and become frustrated that they were not being offered the same components. Discussion with the amputee co-ordinator on a yearly basis about aims and goals could become difficult due to patients complaining that they are fit enough for the higher end components yet are not being offered them.

8.2.3.2 Unwillingness of patients to comply

Although the proposed pathway was designed to aid patients through their rehabilitation, some patients may not wish to comply with the stages set out in the pathway. Patients could refuse to see their co-ordinator pre-amputation and not wish to speak with anyone on the ward post-amputation. This unwillingness to comply would create complications for staff and could have a detrimental effect on the rehabilitation of the patient.

8.3 Benefits, drawbacks and threats for the NHS

8.3.1 Benefits

The proposed pathway has many potential benefits for the NHS, each of which would require thorough investigation through the use of QALYs and a longitudinal study. These are discussed below.

8.3.1.1 Uniformity of service

Introduction of the proposed pathway across the UK would provide uniformity of service at every DSC, therefore allowing patients to be easily transferred between centres. The defined pathway for patients would allow easy transition between stages of rehabilitation and allow each clinician to understand their role within the treatment of every patient. Communication between DSCs would also be more straightforward as the care provided at one centre would be the same as that provided at another. This could begin open communication between centres which would allow centres to share their knowledge and expertise in complex cases and therefore improve patient outcomes as well as improving professional development.

8.3.1.2 Reduced costs

There are many areas in which the NHS could potentially reduce costs following the introduction of the proposed pathway as clinical care pathways have been found to improve economic profiles for service providers (Ward et al., 2010).

Counselling

Pennebaker (1997) found that counselling not only had physical and psychological benefits for patients but also reduced the number of visits patients made to clinicians. The cost incurred by the introduction of counselling could therefore be recouped through the reduced number of visits to other clinicians. As stated by a participant in Study 3, without the intervention of a counsellor, amputation can push patients to the point of suicide. A patient that has attempted to commit suicide would require treatment in Accident and Emergency, hospitalisation on a mental health ward and on-going treatment. There is the possibility that the early introduction of counselling could prevent patients from becoming suicidal, therefore the costs to the NHS overall would be significantly reduced.

Reduced use of personnel

The introduction of an amputation co-ordinator could significantly reduce the use of other clinical staff throughout the rehabilitation process. The co-ordinator would be responsible for providing the information the patient required, therefore reducing the amount of time spent with other clinicians. The co-ordinator would also determine which members of staff each patient should see and when, for the benefit of their mental and physical progression, therefore reducing the number of wasted appointments and increasing the relevance of the appointments patients attend. The early provision of information by the amputation co-ordinator provides patients with the relevant knowledge to ask questions during their appointments with prosthetists and other clinicians, reducing the time the clinicians require for explanation of the treatment and the possibility of patients requiring more information in another appointment. The facility to ask the amputation co-ordinator questions about problems that arise could also reduce the number of unnecessary appointments with clinicians as the co-ordinator could provide advice over the phone or via email or make an appointment with the relevant clinician for the patient.

Better outcomes

Ward et al. (2010) found that improving patient outcomes also decreased expenditure of health providers, therefore it is within the interest of the NHS to improve patient outcomes. Improved health literacy and understanding of their medical condition has been proven to improve patient outcomes (Schillinger et al., 2002; Nielsen-Bohlman and Panzer, 2004), therefore expenditure on improving information could be recouped through savings due to improved patient outcomes. The amputation co-ordinator would be in a position to assess the mental health of patients at the very early stages of rehabilitation, therefore those patients susceptible to mental health problems could be identified early and measures put in place to stop the problems from escalating into more serious conditions. This would improve the patient outcomes and reduce costs for the NHS as fewer patients would develop and require treatment for serious mental health conditions. Due to a large proportion of the amputations in the UK being due to diabetes, improving outcomes for these patients could prevent a second amputation. Vamos et al. (2010a) stated that in 9-20% of cases, individuals with diabetes require a second amputation within 12 months and in 28-51% of cases within 5 years . Reducing the number of second amputations required would save surgery, hospital and prosthetic care costs and also save the patient from a decline in quality of life.

Improving patient outcomes could also improve their ability to become involved in physical activity which would improve the general health of the patient and reduce the likelihood of the development of co-morbidities (Callaghan et al., 2008).

8.3.2 Drawbacks

Consideration of the drawbacks for the NHS is essential due to tightening budgets and increasing pressure from the public to improve outcomes (Albury et al., 2011).

8.3.2.1 Initial outlay to initiate the pathway

In order to put the proposed pathway into place at every DSC across the UK a considerable monetary cost would be incurred by the NHS. The staff would require training in the new pathway, administration would require updating and services such as counselling and amputation co-ordinators would need to be introduced. The implementation would also cause considerable disruption to normal services due to the changeover and decisions would need to be made regarding patients that were part way through the rehabilitation process when implementation occurred. An implementation co-ordinator would be required to attend each centre as the changeover occurred to help with administration and to make the transition to the new pathway as straightforward as possible, incurring more costs for the NHS. The cost of implementing the pathway cannot be estimated due to the vast array of services involved and the cost for changing or introducing each service to every DSC being unknown. A QALY based assessment would be required to ascertain whether the initial outlay by the NHS would be cost effective following the quality of life improvements the pathway would bring about in patients.

8.3.2.2 Initial outlay for information database

There would be an initial outlay for the creation of an information database both on the web and in CD ROM form. The information relating to each individual centre would also need to be collated and centre specific leaflets and web pages produced. The information would also require translation into a number of different languages in order to fulfil NHS requirements. The production of a DVD that could be used UK wide would also require investment by the NHS, therefore all of these interventions would require a QALY based assessment to ascertain whether they were cost effective. Due to the centres across the UK having differing amounts of information, the information required for the web page and CD ROM could already be in existence and only require altering to fit the online or CD ROM format. The centre specific information could also be obtained easily from Centres; therefore the initial outlay for the NHS may not be as great as may be expected. Further work would be required to ascertain the information available at every centre and collate the information for use on a web page and CD ROM.

8.3.3 Threats

Threats to the successful implementation of the proposed pathway caused by the NHS are of great concern as if the threats are considered too great, the pathway could not be implemented. These threats are discussed below.

8.3.3.1 Staff resistance

As found in Section 7.9.1, resistance from staff to accept the pathway could be a problem for implementation. In order for the pathway to function successfully every member of staff would be required to accept the changes and work with the pathway co-ordinator during implementation. Resistance from prosthetists and other members of the MDT could hinder implementation and cause tension between members of staff due to differing opinions on the pathway. Staff could also go as far as stating that they would not work with the new pathway and cause great disruption for other staff and patients. Resistance from some staff is inevitable due to differences in opinion however explanation of the advantages for patients and the NHS should be fully explained to all staff to provide evidence that the pathway is evidence based and does improve patient outcomes. Following this, further resistance would need to be investigated by the implementation co-ordinator and discussed with management to ascertain the most appropriate course of action.

8.3.3.2 Changing funding

Funding of the prosthetic service is of great concern when implementation of a new pathway is being considered. At the time of writing a statement by the Health Minister has shown that funding will be changing in the very near future:

"From April 2013 all prosthetics services will be planned and paid for centrally, replacing the patchwork of arrangements that are in place at the moment. This will improve services for veterans and in the longer term for everyone." (Department of Health, 2012a)

These planned funding changes could have considerable effects on the services provided by certain centres which would only become apparent once the changes are put in place. The proposed pathway could prove to be extremely valuable following these changes as once the funding was centralised, the pathway could be used to create uniformity across the service, reducing the 'postcode lottery' as much as possible. The cost benefit for the NHS of the proposed pathway would be essential to ensure that any funding received for implementation would not be retracted.

8.4 Implications for patients, the NHS and for the wider research arena

The work has highlighted a number of implications for patients, the NHS and also the wider research arena. Each of these will be discussed separately.

8.4.1 Patients

The implications for patients of the NHS were found to be:

- Information provision has been proven to be significant in amputation rehabilitation, and this may be true of other services. However patient centred research would be required to identify a lack of information and ascertain the patient requirements within rehabilitation and other services treating chronic or debilitating illnesses.
- Counselling has been found to be a service that amputee patients wanted for themselves and their families. There may be other NHS sectors in which counselling would be of use to patients and their families. However clinical evidence for this is lacking and funding is limited, therefore the introduction of this service in the near future is unlikely.

- A lack of support for families of amputees has been highlighted as affecting the patient as well as the family; therefore the support provided by the NHS across all sectors may be failing to fulfil patient needs.
- Informing the patients of limitations of the service and explaining how this will affect the care given was found to be desirable to amputee patients and essential in patients accepting a compromised service. Patients in a limited number of other services may also benefit from a full explanation of the limitations of the NHS to help them accept a compromised service and reduce complaints due to budget restrictions, where a compromised service is unavoidable. In outlining the service patients could expect, the NHS would bind itself to providing this level of service as patients would become dissatisfied if the level of service they received did not match the service outlined to them.

8.4.2 The NHS

The implications for the NHS at a local level were found to be:

- The introduction of interventions within any sector of the NHS could be hindered by members of staff that are not cooperative and refuse to apply the new interventions to their work. This refusal could seriously impede the improvement of any services due to the interventions not being implemented accurately.
- Careful management of any intervention would be required in order to minimise resistance and help to inform members of staff of the advantages for their patients and themselves. Involving members of staff in discussions with service designers could help them feel empowered and therefore more willing to implement the interventions.
- Implementation of interventions on a local level could reduce costs for hospitals or clinics and therefore allow them to use the money saved to provide a service less constrained by budget restrictions.
- Improving the patient experience could reduce the number of complaints received and repeat appointments with dissatisfied patients, reducing the time spent on such matters by managers and clinicians, therefore saving the service

money. The reduced workload on clinicians could also improve the service further as they may be able to offer longer appointment times to patients.

- There could be other services lacking in patient pathways for certain procedures or rehabilitation therefore introducing differences in service nationwide. These services could be improved and differences minimised through the implementation of appropriate patient pathways.
- Clinical guidelines used by the NHS may require review as clinicians are constrained by providing care to patients based on their physical attributes and abilities rather than the patient's mental and physical health requirements.

The implications for the NHS nationwide were found to be:

- Implementation of nationwide interventions could introduce further differences in service due to members of staff in some areas being less amenable to change than others. Management and evaluation of the implementation would be required to minimise difficulties inherent in implementing an intervention nationwide.
- Despite the NHS principles, patient centred research has been shown to meet resistance from some members of the prosthetic team; therefore this culture of resistance to research involving the patient opinion could run nationally through other services. The NHS must reiterate its guiding principles to members of staff to help reduce resistance to this important research approach.
- Re-designing of certain services could reduce costs in the long term and therefore help to sustain the NHS.

8.4.3 The wider research arena

The implications for the wider research arena were found to be:

- A patient centred research approach is essential for any research being conducted within the NHS in order to comply with the NHS guiding principles. The principles outline the importance of PPI (patient and public involvement), therefore the views of patients, their families and carers should be sought.
- Patient centred research provides an important insight into the needs and beliefs of the patient which can be used within designing any product or service

for a particular user group. Failure to do so can result in patient dissatisfaction due to their requirements not being considered or met.

- When designing services it must be recognised that the first solution may require a number of iterations before a workable solution is found. Further research would be essential to ascertain how the interventions had affected services and patient satisfaction.

8.5 Conclusions

Evaluation of the proposed pathway that drew on all four studies detailed in this work was conducted and important benefits, drawbacks and threats to the implementation were highlighted. The work has shown that implementation of the proposed pathway could have many benefits for both patients and the NHS. Improving outcomes for patients would in turn improve their quality of life which could be accomplished through changes in information provision, pre- and post-amputation counselling and the introduction of patient volunteer visitors. Cost savings for the NHS could not be accurately estimated however the literature suggests that cost savings could be made by improving patient outcomes.

In order to quantify the benefits and drawbacks discussed, further work would be required including statistical calculation of QALYs and a longitudinal study at one test centre where implementation of the pathway would take place. The extent to which the pathway could improve the outcomes and quality of life of patients is not known and cannot be estimated with any confidence without further investigation.

Chapter 9: Thesis Conclusions and Further Work

9.1 Summary

This chapter outlines the main contributions that have emerged from this work and the areas requiring further investigation. Indication of how the research questions were answered and publication of findings are also present in this chapter.

9.2 Contribution to knowledge

9.2.1 Understanding of differences present between NHS Disablement Services Centres

Study 1 set out to answer Research Questions 1, 2 and 3:

1. How do Disablement Services Centres currently function and what are the constraints (if any) on service provision?
2. Is service provision uniform in centres across the country and if not, what are the differences?
3. If differences in service provision are present, why are they occurring?

The findings from this study indicated that Disablement Services Centres functioned in different ways depending on the staff structure at the centre; therefore comparisons of service provision were difficult. The constraints on service provision were largely due to budget restrictions and in some cases a lack of clinical staff. It was found that the service provided at centres varied greatly due to the lack of specific guidelines for amputee care. The rehabilitation pathway followed by amputees was not uniform between centres and services such as counselling were only available at certain centres.

The differences in service provision between centres were presented at a clinical conference, with abstract publication in its proceedings:

Smalley, G. J., Clift, L. 2010 "Continuity of Service within NHS Disablement Service Centres" Proceedings of the BAPO biannual conference, 4-6th March 2010, pp31.

9.2.2 PACPROSE

Study 2 saw the evolution of a new questionnaire for the evaluation of patient opinions of the prosthetic service: PAtient Centred PROsthetic Service Evaluation (PACPROSE). The new questionnaire was created using principles from five published models and the integration of findings from Study 1. The questionnaire was successful in providing relevant data to answer the research objectives of the Study and could be used in a modified form in further studies to ascertain its reliability and validity. There are plans to publish on PACPROSE in the near future.

9.2.3 Patient opinions of the NHS Service provision

Study 2 set out to answer research questions 4 and 5:

4. Are the needs and expectations of amputees being met by the current NHS service provision?
5. What are the main issues patients currently have with the service provision?

The results from PACPROSE showed that patients' needs and expectations were not being met in a number of areas of service provision. The information provided to patients was mainly verbal and therefore highly transitory and very few patients were provided with written information. Despite the lack of their prescription, participants of the study valued spare limbs and water activity limbs very highly; therefore their needs with regard to provision of these limbs were not being met. Patients' needs with regard to discussion of aims and goals were also going unfulfilled as there was no nationwide protocol for their discussion or reassessment therefore some patients were denied the opportunity to discuss these topics at all. The mental health needs of patients were not being fulfilled by the service provision due to the lack of counselling and patient volunteer visitors. Expectations regarding prostheses were not being fulfilled for a number of patients due to the pain and discomfort caused by their prescribed limb. A strong connection between satisfaction with service provision and satisfaction with the prosthesis was found suggesting that improving the patient's prosthesis could improve their satisfaction with the service provision. No differences were found between males and females, level of amputation and age of participants in decades with regards their opinions of the service they received. The main issues found with the current service provision were the lack of counselling and patient volunteer visitors, a lack of discussion of aims and goals and components available on the NHS, removal of the provision of spare limbs and problems with fit and comfort of the prescribed prosthesis.

The importance of the patient perspective on the prosthetic service provision was published as a book chapter.

Smalley, G., Clift, L., 2012, "Improving the Patient Pathway in Prosthetic Rehabilitation" In Advances in Human Aspects of Healthcare, eds. V.G. Duffy, Taylor & Francis Group, USA, pp471-480.

9.2.4 The importance of information provision for amputees

Study 3 set out to answer research questions 4 and 6:

4. Are the needs and expectations of amputees being met by the current NHS service provision?
6. Can the experience of amputees be improved without great cost to the NHS?

Through the use of telephone interviews, the opinions of 22 amputees were obtained relating to the information provision they had received pre- and post-amputation. The results showed that participants felt the information provision was lacking and in need of improvement. Information relating to the rehabilitation pathway itself was one of the most important topics to participants as well as what life would be like following amputation. Many different topics were mentioned by participants which illustrated the considerable gap in the provision of appropriate information by DSCs. Participants also mentioned the importance of patient volunteer visitors as a supporting and encouraging role model to provide advice and encouragement when needed. Participants also stressed the importance of written coupled with verbal information to allow them to reinforce verbal information through reading and digesting the written information at their leisure. Information provision via CD ROM, DVD and websites were also mentioned as possible improvements to the current provision. There were slight differences in the information delivery systems mentioned by participants of different ages, with older patients favouring more visual information. Further work would be required to ascertain the best form of information delivery for patients of different ages. It was found that by altering the information and delivery system provided by DSCs the patient experience could be improved through reduction in anxiety and better support from patient volunteer visitors. Costs to the NHS would not be too substantial due to the information required for dissemination being largely available through various DSCs already with collation of the information being the main task.

9.2.5 An improved rehabilitation pathway

Study 4 set out to answer research question 6:

6. Can the experience of amputees be improved without great costs to the NHS?

Through collation of information gathered throughout Studies 1, 2 and 3 a rehabilitation pathway was designed for implementation in every DSC across the UK. The pathway detailed the stages of rehabilitation every primary patient should go through pre- and post-amputation and the information the patient should receive and in what form at each stage. This pathway was critically evaluated by prosthetists and it was found that there was some resistance from older prosthetists in the focus group to the ideas brought forward in the pathway. Alterations to the proposed pathway were made using suggestions from the focus group and the introduction of an amputation co-ordinator was considered the most appropriate course of action to provide the patient with the best service possible and reduce the workload on other clinicians. The implementation of this pathway and introduction of patient volunteer visitors, counselling, amputation co-ordinators, information provision and other services would require considerable monetary investment by the NHS. The investment in implementing the pathway would benefit patients and should reduce costs for the NHS in a number of departments such as A&E and mental health, balancing out the cost of implementation and indicating a probable net gain.

9.2.6 The potential improvements that could be brought about through the implementation of the proposed pathway

Study 4 set out to answer research question 6:

6. Can the experience of amputees be improved without great costs to the NHS?

Improvements to patient experience and the NHS could be brought about by the implementation of the proposed pathway. Patients would have decreased anxiety throughout the rehabilitation process due to the improvements made in information provision and discussion with volunteer visitors. The introduction of counsellors would help reduce the number of patients developing serious mental health problems and help patients come to terms with their amputation, in turn improving their outcomes. Improving patients' outcomes also improves their quality of life therefore they are more likely to engage in physical and social activities and less likely to require further amputations. Improved patient outcomes also increases the opportunity for patients to return to work and therefore contribute to the state through tax and National Insurance. The NHS would benefit from the proposed pathway as their service would be uniform across the UK therefore sharing of information and clinical knowledge between centres would become more straightforward. The costs to the NHS should also be reduced due to the predicted improvements to patients' mental and physical health. Further research into the cost benefit of the pathway would be required to make any confident predictions.

9.2.7 Implications for patients, the NHS and for the wider research arena

Chapter 8 set out to answer research question 7:

7. What are the implications of the work for the stakeholders, NHS and wider research community?

The implications for patients of the NHS were found to cover a range of interventions including counselling, information provision, support for families and carers and informing patients of the limitations of the service provision they receive. Each of these interventions were considered positive within prosthetic rehabilitation, therefore other sectors of the NHS could benefit from their introduction, depending on the illnesses being treated.

Implications for the NHS were divided into those for the local NHS services and the NHS nationally. The implementation of patient centred pathways and other patient centred interventions in a variety of NHS sectors could reduce costs for the NHS through an increase in efficiency and a reduction in complaints due to improved patient satisfaction. Nationally, it is within the interest of the NHS to implement patient centred solutions due to the guiding principles set out in the NHS constitution. Resistance from members of staff would require training and careful management to minimise the impact it could have on the success of an intervention.

Implications for the wider research arena focussed on the patient centred research approach and its importance in NHS research as well as design of other services.

9.3 Further work

The need exists for further work in a number of different areas identified through Studies 2, 3 and 4 in particular.

9.3.1 Sexual activity

The effect amputation has on the sexual activity of patients requires further investigation to ascertain interventions that could be put in place to assist patients in combatting these effects. The ability to engage in sexual activities has an important effect both mentally and physically on patients with physical disabilities therefore further research is essential to help understand how to help patients that have both mental and physical barriers. This research could be carried out by any academic party with the appropriate field of knowledge. Funding this research could be difficult to obtain due to the nature of the work, therefore if a proposal to the National Institute for Health Research was rejected, other sources of funding would be required.

9.3.2 Work within the NHS

In order to support the findings of Study 2 the PACPROSE interview structure should be used in a study involving patients of every NHS Disablement Services Centre. In order to ensure validity and reliability of the results, a random sampling technique would be required therefore the work would need to be conducted within the NHS. The data collected could then be analysed and used to ascertain patients' opinions on their DSC and compare DSCs across the UK. This comparison would reveal the centres that were considered to provide good or bad service by their patients. Identification of areas of improvement in the lower scoring centres could then begin as well as work to identify the services that provided good patient satisfaction in some centres that could be applied to others to improve their satisfaction scores. This work could become evidence for the requirement of the implementation of the proposed pathway across the UK due to such a wide variety of differences between centres. This work would be the responsibility of the academic sector with funding from the NHS being desirable.

9.3.3 Information

Collation of information from every centre in order to create a nationwide repository of information would be required in order to allow patients and clinical staff to access information they desired at any time. The entire repository should then be discussed with patients with recent amputations to ascertain any information requiring more detail and information gaps that may be present. Involving patients in the establishment of this repository would be essential due to the reason for its creation being to help reduce patient and family anxiety and increase knowledge of amputation and its resulting effects in both patients and their families. This work could be conducted by limbless charities, however due to the information being provided by the NHS it is thought that funding for the production of the information repository should come from the health service and not charities. A number of interested parties, such as clinicians, patients, charities and carers of patients could become involved in designing and producing elements of the information repository with an academic partner being responsible for the collation of the information and production of accessible material.

9.3.4 Proposed Pathway

In order to continue this work and produce a viable, cost effective solution, studies involving different stakeholders would be required. Figure 9.1 illustrates the subsequent studies necessary to produce a pathway that could be successfully utilised by the NHS. The continuation of this work would be the responsibility of the academic sector with funding coming from an application to the National Institute for Health Research. Funding should be sourced from the health service due to the research primarily benefitting the NHS.

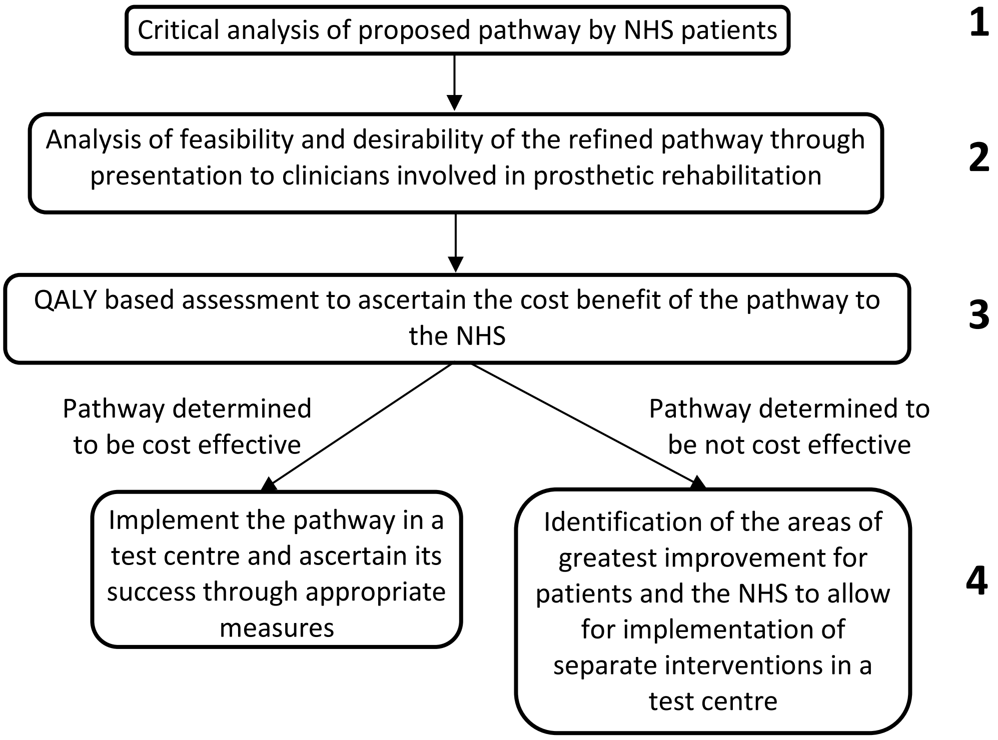


Figure 9.1: Flow diagram illustrating the subsequent studies required in the development of the proposed patient pathway

Inherent in each stage of this work are obstacles requiring careful consideration which are discussed in the following sections.

Study 1: Critical analysis of proposed pathway by NHS patients

This evaluation would require a large number of patients from many different centres across the country to ensure no bias could be introduced through the centre participants attended or the sampling method employed. Participants would therefore need to be selected at random to ensure validity and reliability of the results. In order to achieve this, access to NHS patient records would be required. Accessing patient records and involving NHS patients in the research would require ethical permission from the National Research Ethics Committee (NREC) which has been described by Martin et al. (2008) as "a particularly lengthy and complicated procedure". Wald (2004) has also described the requirement for an NHS ethical review for research, involving no intervention, to be a barrier to conducting research. Permission from the Research and Development (R&D) department of each of the hospitals associated with the DSCs would be necessary following successful ethical permission from NREC. In order to involve patients from every centre across the UK, permission from 44 separate R&D departments would be required. Due to the clinical conference, at which the proposed pathway was evaluated, being at the end of the research, it was not possible to carry out this study due to the time required to gain the necessary ethical and R&D permission.

Study 2: Analysis of feasibility and desirability of the refined pathway through presentation to clinicians involved in prosthetic rehabilitation

As mentioned in Section 7.9.1, resistance from members of staff could create problems with the evaluation of the proposed pathway. Clinicians may be adverse to introducing another member of staff to the team in the form of an amputation co-ordinator due to the perceived disruption involved. Careful consideration of the presentation method used would be required to ensure the clinicians felt this pathway was not being forced upon them and the appropriate evidence was available to reinforce the proposed changes.

Study 3: QALY based assessment to ascertain the cost benefit of the pathway to the NHS

A QALY based assessment could only be carried out by a medical statistician, therefore the cost of the assessment should be ascertained prior to starting Study 1 to allow for appropriate budgeting. Without this study, the NHS would not have enough evidence to support the implementation of the pathway, making this study essential to the continuation of the work.

Study 4 - Pathway determined to be cost effective: Implement the pathway in a test centre and ascertain its success through appropriate measures

In order to test the viability of the pathway for nationwide implementation an appropriate strategy would be required. A minimum of six centres would be required to participate in the longitudinal study involving three centres at which the pathway would be implemented and three to be used as control centres. Each test centre would be chosen based on support from the staff as well as the number of patients typically referred to the centre per year. This would reduce the possibility of resistance form members of staff and ensure evaluation of different sized centres. An attempt would be made to involve a small, medium and large centre as test centres to ascertain whether the pathway would work in centres of all sizes. At least one of the test centres would be required not to routinely provide counselling to patients as the comparison between this centre and a control centre after the introduction of counselling would be of great interest. Each of the test centres would then be matched as closely as possible with regards size, services provided and policies, with another centre to act as a control. Outcome measures would be essential to ascertain the benefits to patients and the NHS. The control centres would be subjected to the same outcome measures used on the test centres however they would not receive any intervention form the research team. The first phase of the research would involve using outcome measures to test the current patients views on their service and views of the clinicians. Patients that were considered to be primary patients i.e. had their amputation less than one year ago would be assessed using The Trinity Amputation and Prosthesis Experience Scales (TAPES). This outcome measure was deemed the most appropriate to test primary patients due to the sections covering psychological and physical progress as well as satisfaction with a prosthesis. All other patients at the centre would be asked to complete a modified version of PACPROSE to ascertain their thoughts on the service they received at amputation and continue to receive years later. Another evaluation method would be required to understand the views of the clinicians employed at the centre. Semi structured interviews could be used due to staff numbers being under 20 in most centres. These interviews would help the researchers understand the current situation and have data to compare with following similar interviews at the end of the research. Expenditure in each department of the centre would be required as well as detailed breakdowns of costs from repeat appointments and components provided to patients. The number of patients referred for psychiatric assessment would also be required as a comparison of the numbers at the end of the study would provide evidence of whether counselling was making a difference to the mental health stability of patients. Information relating to reduction in the budget provided to the centres would also be required to ascertain whether the intervention would help to achieve this. Following this, the control centres would be left to continue as normal for a minimum of two years. The test centres would have the pathway implemented following clinician training. A researcher would be required to be the point of contact for members of the clinical team to contact if any questions were raised and as mentioned in Section 7.9.1, appropriate management and frequent evaluation would be required to ensure the pathway was being implemented correctly. Following the implementation of the pathway for a minimum of two years, each of the centres would be evaluated using the same outcome measures used at the beginning of the research. The data would be used to compare the paired test and control centres to ascertain whether the implementation of the pathway had increased patient satisfaction, improved outcomes and reduced clinician concerns and spending within the centre. Analysis of the data would be required to ascertain whether the intervention had reduced costs and improved outcomes enough to warrant a nationwide implementation.

Study 4 - Pathway determined to be not cost effective: Identification of the areas of greatest improvement for patients and the NHS

The pathway could be evaluated as not cost effective in its entirety, therefore the individual stages of the pathway would need to be assessed and the most effective stages implemented. This would ensure patients and the NHS benefitted as much as possible from the modified intervention.

9.4 Conclusions

The main conclusion that can be drawn from this work is that patient involvement in research pertaining to service provision of any kind should be standard procedure for researchers entering into this domain. Ascertaining patient’s requirements and desires is extremely important in understanding how to improve the service provision as service providers have different agendas and place importance on different aspects of rehabilitation. This research has demonstrated that the involvement of both patients and clinicians in the development and evaluation of new designs can have considerable advantages for both idea development and appraisal of the designs put forward.

The work has identified that there are considerable gaps in the NHS service provision of prosthetic limbs which require further investigation in order to improve the patient experience, which should also reduce costs for the NHS. Improving the information provision was identified as being a simple intervention that would improve the patient experience, help patient's families and reduce costs in the long term for the NHS. The introduction of counselling was identified as an important intervention required for patients across the UK and should be introduced for the mental health of both patients and their families.

The lack of general guidelines for care the of amputees has led to the service provided by Disablement Services Centres across the UK being very inconsistent and lacking uniformity across all services. The introduction of a pathway produced using data collected from studies in this research would remove the inconsistencies in service provision and provide patients with a rehabilitation pathway informed by their peers and clinicians. Cost benefits for the NHS could not be estimated, however further work involving calculations and longitudinal studies would allow for the accurate calculation of the cost effectiveness of the pathway.

Considering the work that has been conducted, vast improvements could be made to the prosthetic care provided to patients within the NHS. These improvements would require monetary investment from the NHS, all of which may not be possible due to budgetary constraints, however, the interventions described hold the potential to deliver financial reward over the longer term in terms of reduction of the burden on the NHS and increased contribution to society by DSC patients. Implementation of simple changes to the service could have great effects on a patient's quality of life; therefore it is hoped that further research will be conducted to ascertain the most appropriate course of action to bring about implementation of these important changes.

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Appendices

Chapter 4 – Study 1

Appendix 4A – Interview questions

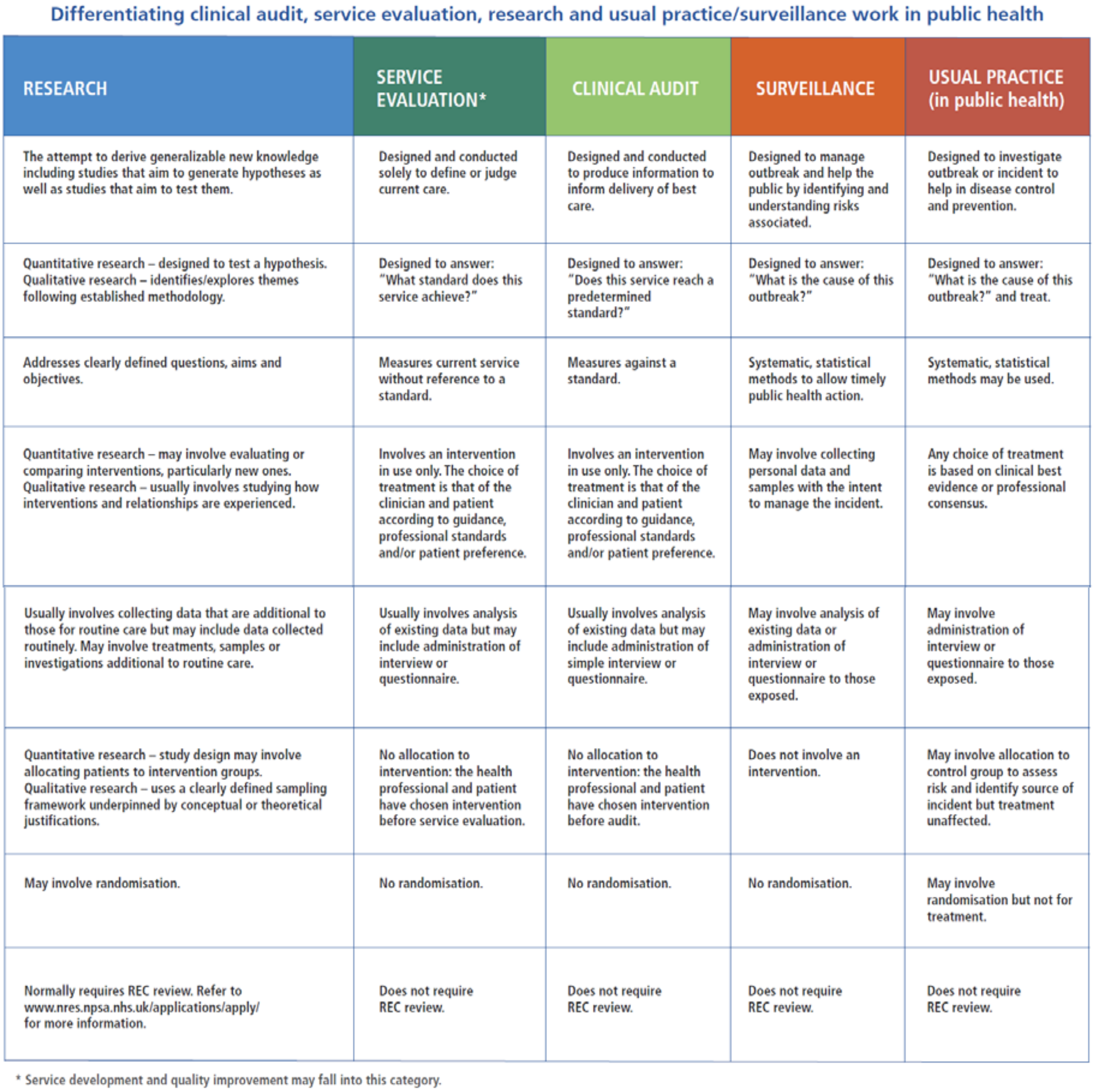
Questions for limb centre Managers

1. Approximately how many patients do you have registered?
2. Which company holds the contract at the centre?
3. How many prosthetists do you have employed at the centre?
4. Who handles the budget?
5. Do you feel the budget you are given is large enough to cater for the needs of all of your patients?
6. Do you offer a counselling service to amputees?
7. Are physiotherapy sessions held in the same building?
8. Are there a set number of hours of physiotherapy allocated to each person?
9. What would you like to do to improve the service offered at your centre and what are the barriers stopping these changes coming about?

Questions for prosthetists

1. What is the average age of your patients?
2. Who are the people on the team and is there communication between departments i.e. OT and physiotherapy?
3. What is the process you go through when you meet a new patient?
4. Are their aims and goals reassessed once they have become comfortable using their prosthesis?
5. What is the most important factor when prescribing a limb?
6. Do you have to refuse people technology due to cost?
7. Do you give out spare limbs very often?
8. Do you offer water activity limbs or shower legs?
9. Are patients able to see you quickly if they have a problem?
10. Is there any information available to new amputees about the process they will go through and what to expect when they see you?
11. Do you use scanning technology or plaster casting to cast sockets?
12. Do you have on site manufacturing? If not where are the prostheses manufactured?
13. On average, how long does it take for a patient to receive their new prosthesis?

Appendix 4B – Defining Research: Ethical Considerations



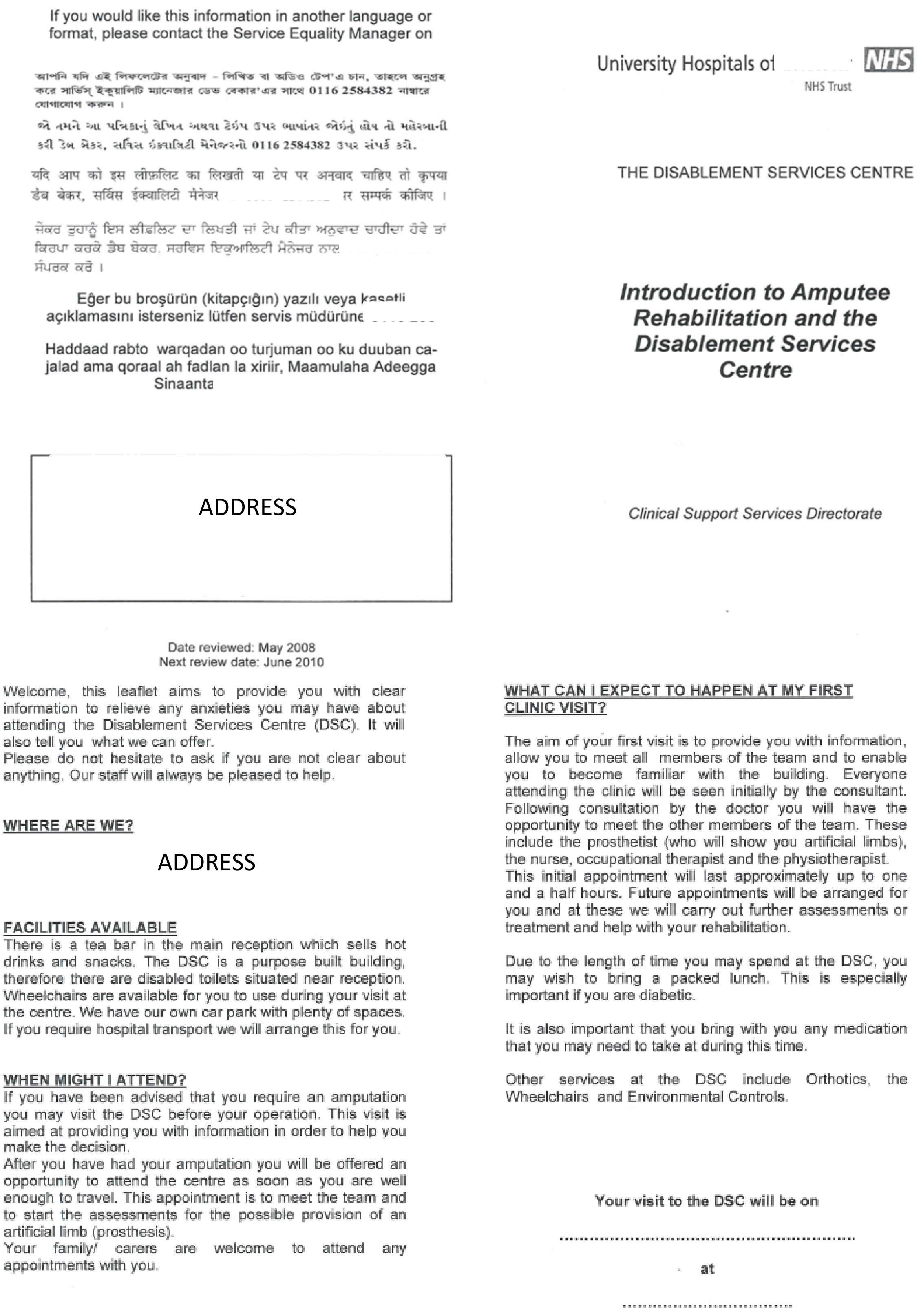
Differentiating clinical audit, service evaluation, research and usual practice/surveillance work in public health

RESEARCH	SERVICE EVALUATION*	CLINICAL AUDIT	SURVEILLANCE	USUAL PRACTICE (in public health)
The attempt to derive generalizable new knowledge including studies that aim to generate hypotheses as well as studies that aim to test them.	Designed and conducted solely to define or judge current care.	Designed and conducted to produce information to inform delivery of best care.	Designed to manage outbreak and help the public by identifying and understanding risks associated.	Designed to investigate outbreak or incident to help in disease control and prevention.
Quantitative research – designed to test a hypothesis. Qualitative research – identifies/explores themes following established methodology.	Designed to answer: "What standard does this service achieve?"	Designed to answer: "Does this service reach a predetermined standard?"	Designed to answer: "What is the cause of this outbreak?"	Designed to answer: "What is the cause of this outbreak?" and treat.
Addresses clearly defined questions, aims and objectives.	Measures current service without reference to a standard.	Measures against a standard.	Systematic, statistical methods to allow timely public health action.	Systematic, statistical methods may be used.
Quantitative research – may involve evaluating or comparing interventions, particularly new ones. Qualitative research – usually involves studying how interventions and relationships are experienced.	Involves an intervention in use only. The choice of treatment is that of the clinician and patient according to guidance, professional standards and/or patient preference.	Involves an intervention in use only. The choice of treatment is that of the clinician and patient according to guidance, professional standards and/or patient preference.	May involve collecting personal data and samples with the intent to manage the incident.	Any choice of treatment is based on clinical best evidence or professional consensus.
Usually involves collecting data that are additional to those for routine care but may include data collected routinely. May involve treatments, samples or investigations additional to routine care.	Usually involves analysis of existing data but may include administration of interview or questionnaire.	Usually involves analysis of existing data but may include administration of simple interview or questionnaire.	May involve analysis of existing data or administration of interview or questionnaire to those exposed.	May involve administration of interview or questionnaire to those exposed.
Quantitative research – study design may involve allocating patients to intervention groups. Qualitative research – uses a clearly defined sampling framework underpinned by conceptual or theoretical justifications.	No allocation to intervention: the health professional and patient have chosen intervention before service evaluation.	No allocation to intervention: the health professional and patient have chosen intervention before audit.	Does not involve an intervention.	May involve allocation to control group to assess risk and identify source of incident but treatment unaffected.
May involve randomisation.	No randomisation.	No randomisation.	No randomisation.	May involve randomisation but not for treatment.
Normally requires REC review. Refer to www.nres.npsa.nhs.uk/applications/apply/ for more information.	Does not require REC review.	Does not require REC review.	Does not require REC review.	Does not require REC review.

* Service development and quality improvement may fall into this category.

Appendix 4C – Information provided to primary patients

Centre B



If you would like this information in another language or format, please contact the Service Equality Manager on

আপনি যদি এই লিফলেটের অনুবাদ – লিখিত বা অডিও টেপ'এ চান, তাহলে অনুগ্রহ করে সার্ভিস্ ইকুয়ালিটি ম্যানেজার ডেভ বেকার'এর সাথে 0116 2584382 নাম্বারে যোগাযোগ করুন ।

જો તમને આ પત્રિકાનું લેખિત અથવા ટેઇપ ઉપર ભાષાંતર જોઇતું હોય તો મહેરબાની કરી ડેબ બેકર, સર્વિસ ઇક્વાલિટી મેનેજરનો 0116 2584382 ઉપર સંપર્ક કરો.

यदि आप को इस लीफ़लिट का लिखती या टेप पर अनवाद चाहिए तो कृपया डेब बेकर, सर्विस ईक्वालिटी मैनेजर र सम्पर्क कीजिए ।

ਜੇਕਰ ਤੁਹਾਨੂੰ ਇਸ ਲੀਫਲਿਟ ਦਾ ਲਿਖਤੀ ਜਾਂ ਟੇਪ ਕੀਤਾ ਅਨੁਵਾਦ ਚਾਹੀਦਾ ਹੋਵੇ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਡੈਬ ਬੇਕਰ, ਸਰਵਿਸ ਇਕੁਆਲਿਟੀ ਮੈਨੇਜਰ ਨਾਲ ਸੰਪਰਕ ਕਰੋ ।

Eğer bu broşürün (kitapçığın) yazılı veya kasetli açıklamasını isterseniz lütfen servis müdürüne

Haddaad rabto warqadan oo turjuman oo ku duuban ca-jalad ama qoraal ah fadlan la xiriir, Maamulaha Adeegga Sinaanta

ADDRESS

Date reviewed: May 2008
Next review date: June 2010

University Hospitals of
NHS Trust

THE DISABLEMENT SERVICES CENTRE

Introduction to Amputee Rehabilitation and the Disablement Services Centre

Clinical Support Services Directorate

Welcome, this leaflet aims to provide you with clear information to relieve any anxieties you may have about attending the Disablement Services Centre (DSC). It will also tell you what we can offer.
Please do not hesitate to ask if you are not clear about anything. Our staff will always be pleased to help.

WHERE ARE WE?

ADDRESS

FACILITIES AVAILABLE

There is a tea bar in the main reception which sells hot drinks and snacks. The DSC is a purpose built building, therefore there are disabled toilets situated near reception. Wheelchairs are available for you to use during your visit at the centre. We have our own car park with plenty of spaces. If you require hospital transport we will arrange this for you.

WHEN MIGHT I ATTEND?

If you have been advised that you require an amputation you may visit the DSC before your operation. This visit is aimed at providing you with information in order to help you make the decision.
After you have had your amputation you will be offered an opportunity to attend the centre as soon as you are well enough to travel. This appointment is to meet the team and to start the assessments for the possible provision of an artificial limb (prosthesis).
Your family/ carers are welcome to attend any appointments with you.

WHAT CAN I EXPECT TO HAPPEN AT MY FIRST CLINIC VISIT?

The aim of your first visit is to provide you with information, allow you to meet all members of the team and to enable you to become familiar with the building. Everyone attending the clinic will be seen initially by the consultant. Following consultation by the doctor you will have the opportunity to meet the other members of the team. These include the prosthetist (who will show you artificial limbs), the nurse, occupational therapist and the physiotherapist. This initial appointment will last approximately up to one and a half hours. Future appointments will be arranged for you and at these we will carry out further assessments or treatment and help with your rehabilitation.

Due to the length of time you may spend at the DSC, you may wish to bring a packed lunch. This is especially important if you are diabetic.

It is also important that you bring with you any medication that you may need to take at during this time.

Other services at the DSC include Orthotics, the Wheelchairs and Environmental Controls.

Your visit to the DSC will be on

....

at

....

University Hospitals of NHS
NHS Trust

The Disablement Services Centre (DSC)

Prosthetic Service Information

Clinical Support Services Directorate
(CSSD)

Introduction

service. The staff are here to help you regain as full and active a life as possible following your amputation.

Hopefully this booklet will reassure you and answer many of the questions you and your family may have. However, if you are still unsure about anything please do not hesitate to speak to any member of staff who will be happy to assist you.

General Information about the DSC

Hours

The DSC is open from Monday to Thursday between 8.30am and 4.30pm and on Fridays between 8.30am and 4.00pm. It is closed on weekends and Bank Holidays.

Where is the DSC?

Transport and parking

The centre can provide transport for you if you are unable to make your own arrangements. This will either be an ambulance or ambulance car depending on how mobile you are.

As the ambulance will be collecting a number of people to bring to the hospital you will need to be ready from 8.00 am. If it is an afternoon appointment you need to be ready for midday. You may find that you have to wait for your transport

and worry that this will make you late for your appointment. Please do not worry about this, as we will be aware of your situation. You might also find that you will have to wait some time after your appointment for the transport to take you home. We will need 48 hours notice to book your ambulance so please keep this in mind when you are phoning up for an appointment.

If you are able to make your own travel arrangements it may be possible to give you an earlier appointment.

If you have an ambulance booked and are either unable to make the appointment or your travelling requirements change, please let us know so that we can cancel the ambulance booking.

The DSC does have car parking although at present we have no designated disabled parking.

Disabled Access

The DSC has been purpose built to make it accessible for people with disabilities. The centre is all on one level with disabled toilets near to reception. A wheelchair will always be available for you during your visit to the centre if you need one.

Children's Area

There is a children's area within reception which has an assortment of toys. Children should not be left unsupervised.

Snack bar

Within the reception area there is a snack bar that sells hot and cold drinks as well as snacks. If there is no one serving at the snack bar please ask at reception and someone will be happy to tend to you.

Mobile phones

Mobile phones must be switched off at all times within the DSC.

Smoking

There is a no smoking policy in place at the DSC.

Interpreter Service

There are interpreters available, however they do need to be booked in advance to attend with you. Please let us know if you require one so this can be arranged. If you are unable to attend your appointment please contact us so that we can cancel the interpreter.

Suggestions/ Comments

If you have any suggestions or comments about your treatment or generally about the building, please either inform a member of staff or use the books on the tables in reception.

You can also contact the Patient Advice and Liaison Service (PALS) if you have any suggestions, queries or concerns. The PALS Office is located near main reception in the main

Medication

When you first attend the DSC you will need to bring with you a list of the tablets you are taking. You should always bring any tablets you may require throughout the day, as your appointment may take longer than you expect and/or you may have to wait for your return ambulance.

Who will be at the DSC?

The prosthetic team consists of:

- Reception staff
- Consultant/Registrar
- Prosthetists
- Physiotherapists
- Occupational Therapist (OT)
- Nurse

On Wednesday mornings members of the Amputee Volunteer Visitors group will also be available to speak to.

The clinics

The multi-disciplinary team clinics take place every Wednesday and Friday morning. The prosthetists hold clinics every day. To attend either of these clinics please telephone the DSC reception to make an appointment.

First visit

On your first visit to the DSC you will meet the members of the prosthetic team. This is for you to discuss your rehabilitation and to start making decisions about the future.
You are welcome to bring family or carers with you.

Future appointments

Initially, in your first year we will give you set appointments as you become used to wearing your prosthesis. After this you can contact us and make an appointment to see any member of the team whenever the need arises.

Fitting rooms

Separate male and female fitting rooms are provided for your privacy.

The Prosthetic Staff

Reception Staff

The receptionist is responsible for arranging your appointments at the DSC. It is important to inform the receptionist when you arrive at the centre and again when you leave. The receptionist will book your next appointment and deal with any queries regarding your hospital transport.

Doctor

The doctor is the consultant or registrar in Rehabilitation Medicine. They will be your doctor whilst you are receiving care from the DSC. This consists of any visits you may make before your amputation and during your early and long term rehabilitation. He/she will:

- Discuss relevant medical issues in relation to your amputation and how it will affect the use of a prosthesis.
- For some he/she will discuss the advantages and disadvantages of having an amputation.
- Review and treat specific conditions related to amputation if applicable.
- With the multi-disciplinary team, decide on the rehabilitation process, type of prosthesis and the components needed.
- Liaise with your GP, other medical or therapy colleagues if needed.

Physiotherapist

The Physiotherapist is responsible for carrying out a thorough holistic assessment of your physical abilities and needs.

From this initial assessment we will be able to identify any problems or issues that need to be addressed to optimise your recovery, following your amputation.

An individual treatment plan will be discussed and agreed, which will work towards set goals, in order for you to reach your full potential.

Further treatment sessions will help you and your Physiotherapist determine together the best and most suitable rehabilitation option for you. This decision will take into account:

- Your physical and mental well-being
- Your wishes
- Your home circumstances
- Your safety
- The progress you make during the sessions

Whichever rehabilitation option is decided upon, we will work with you to achieve your maximum potential.

If in the future if your capabilities or circumstances change we will be happy to review and re-assess you.

Prosthetist

As part of the multi-disciplinary team, the Prosthetist will help with the limb prescription. He/she is then responsible for taking all the necessary measurements and, usually, a plaster cast of your stump.

The cast is then filled, rectified and a socket is made from it. When the limb has been assembled, you will try it on and the Prosthetist will alter it accordingly for length, alignment etc. During this time it is left unfinished, as you will use this leg in physiotherapy. Once your initial physiotherapy input is completed you will be recalled to collect the finished limb and the Prosthetist will do a final check.

The Prosthetist will advise you on the number of stump socks to be worn and how to use the limb correctly.

Adjustments and new limbs will always be required in the future and again the Prosthetist will advise you on this.

Occupational Therapist (OT)

Occupational Therapists (OTs) work with people to give them greater independence by improving their ability to do things that are important to them.

The OT will be involved in the prosthetic rehabilitation of all patients attending the DSC. The OT will assist you to maximise your potential in many aspects of your daily life, with or without an artificial limb.

The OT may carry out your treatment both at the DSC and/or within your own home. If necessary they could visit and review your home environment and/or workplace/school/college and if appropriate re-assess your needs following provision of your artificial limb.

In collaboration with the Prosthetist the OT can assist patients with upper limb loss to identify the most appropriate type of prosthesis and provide training in the use of this.

If required the OT will also be able to assist with the following:

- Meeting with carers and family to provide support and advice
- Provide information regarding benefits and support groups

- Reassessing your wheelchair needs and if necessary re-refer you back to the wheelchair service for further assessment.

Nurse

The nurse at the DSC is experienced in amputee rehabilitation. She will hopefully have already met you whilst you were on the ward recovering from your amputation, and will be involved in your initial assessment when you first attend the DSC.

The nurse supports both patients and relatives as they start the rehabilitation process and will act on your behalf if required. They will liaise with the hospital staff whilst you are in hospital and the community staff when you are discharged home, to ensure that you receive continuous care.

The nurse can offer advice on stopping smoking, diet, diabetes and how to care for your remaining limb. They will also assess and treat any stump wounds you may have whilst you are at the centre.

The nurse can also talk to you about any anxieties or problems you may have either while you are in the centre, or they can visit you in your own home.

Further Information

Diabetes

You should monitor your blood sugars regularly. Following your amputation you may find that your blood sugars become higher as you are less active. However, as you start physiotherapy and your activity increases you will find your blood sugars start to fall to normal again.

If you are diabetic, please ensure you have your breakfast and normal tablets or insulin before coming to the DSC. Please bring your day's medication as well as some food or money to buy yourself a drink or snack, as you may be at the DSC longer than you had intended.

Smoking

Smoking has an effect on your general health and in particular is bad for your circulation. This can lead to vascular disease in both your remaining leg and can cause problems with your stump. You should seriously think of giving up smoking. If you need help to do this, please contact the nurse at the DSC who can give you further advice.

Phantom Sensation

Most people who have an amputation will feel that their leg is still there. The sensations can include itching, tingling, warmth, pressure or sudden 'jerky' movement. This is known as phantom sensation and is quite normal. For some people this feeling can seem so real that they forget they no longer have a leg and will try and stand which can result in a fall.

Phantom Pain

Some people also experience pain in the leg that is not there. This is called phantom pain. This can include burning, cramping, squeezing and stabbing.

There are various things that can be done to try and reduce these symptoms. We can give you tablets that can help with the pain. Other simple methods that may also help include holding and massaging the stump, or wriggling the toes that are no longer there.

There are no definite answers and what works for some people may not work for others. For the majority of people phantom pain decreases over time. However, if you continue to suffer from phantom pain please speak to the doctor.

Counselling

The loss of a limb is a major shock and inevitably means a big change to your lifestyle. People react to it in many different ways and you may have anxieties and worries. Sometimes you will feel sad and unhappy, at other times you will feel angry and frustrated about certain things. Many people who have an amputation describe having these feelings, both in hospital and at home.

It is quite natural to have these feelings and it is important for you to be aware that there are people around for you to talk to if you want to.

Although you may receive support from your family and friends, you may find it useful to talk to someone else. You can approach any member of the prosthetic team to talk about your feelings or to discuss any questions or worries you may have.

A lot of people find it helpful to talk to other amputees who have been in the same situation as you. Within the DSC we have a group of volunteer visitors whose aim is to provide amputees and their families with information and support.

The volunteers can offer you emotional support and practical advice. They are at the DSC every Friday morning so you can talk to them then or, if you wish they will visit you at home or in hospital. If you would like to arrange a meeting, please contact the DSC.

Sexual Relations

You may resume your normal sexual activity when your wounds are fully healed and within the limits of your comfort. If you have any concerns please contact a member of the prosthetic team.

Driving

Once you have recovered from your operation, you may start thinking about returning or learning to drive. It is a legal requirement that you notify the DVLA that you have had an amputation. You will also need to inform your insurance company. It may be that you will be required to drive an automatic car or have special adaptations to your car. For further information please talk to a member of staff or contact the Derby Regional Mobility Centre (see useful contacts).

Returning to work

Returning to work can be a major undertaking. If you are thinking of returning to work and this is causing you worries, please talk to the Occupational Therapist who can help you with this.

Holidays

There are Disablement Service Centres all over the country and if you phone up and speak to them they should see you and assess your problem. If no one is available then contact NHS Direct on **0845 4647** who should be able to help.

If you are abroad you may be able to get emergency care carried out by the National Health Care Scheme in certain countries but there are some countries that may ask you to pay a contributory cost. For more information either visit the Department of Health website:

www.dh.gov.uk/PolicyAndGuidance/healthAdviceForTravellers

or read the leaflet SA30 which is available from your local Social Security Office.

Always carry an E111 form with you and ensure that you have up to date travel insurance.

Frequently Asked Questions

How often do I visit?

You will visit initially when you are medically well enough to attend the centre. Once you have your prosthesis, you will be followed up regularly for approximately a year. At the beginning you will be seen more frequently.

Do I have to attend the appointments made for me?

No, we cannot force you to attend the centre, however it is in your best interest to do so. In the first year when you are still learning about wearing a prosthesis you will find the advice and support staff and other amputees attending the clinics can give you invaluable.

What happens if I have a problem before my next appointment?

You can telephone the centre and make an appointment to see any member of the team, whenever you feel you need to. If you are not sure who you need to see the receptionist will ask you some questions and then direct you to the correct member of staff.

What happens if I have a problem after my year appointment?

You are never discharged from the centre. If you ever have any problems or questions please do not hesitate to ring the centre and we will make an appointment for you.

I live elsewhere in the county, would it not be easier for me to attend my local hospital?

The DSC covers all of Leicestershire and Rutland and all amputees are seen here, as there are no other centres within the county. The staff that work here are specialists in the field of amputee care and rehabilitation, therefore it is in your best interests that you attend the DSC.

Useful contacts

Limbless Association

An association that 'helps limbless individuals of all ages (and their carers) achieve maximum mobility and independence in home, hospital, education, employment and the community.'
Address: Rehabilitation Centre, Roehampton Lane, London, SW15 5PR.
Telephone: 0208 788 1777.
www.limbless-association.org

Leicestershire Amputee Volunteer Visitor Service

A service set up to provide help and support to those people who have had an amputation consisting of a group of people who are amputees themselves.
Telephone: 0116 258 4695

Leicestershire Group for Support for Amputees and their Families (LeGS)

Provides help and support to all amputees, their families, carers and friends.
Telephone: 0116 258 4695

Antenna

Service providing counselling and emotional support for disabled people.
Telephone: 0116 251 5565

British Red Cross Disability Living Centre

Provides impartial information on and displays of equipment for disabled people.
Address: 76 Clarendon Park Road, Leicester, LE2 3AD.
Telephone: 0116 270 0515

British Red Cross Equipment Distribution Service

Provides the loan and hire of equipment for disabled people.
Address: 11 Euston Street, Freeman's Common, Leicester, LE2 7ST.
Telephone: 0116 2544547

Derby Regional Mobility Centre

Provides driving assessments and tuition for disabled people as well as information and advice on vehicles and equipment.
Address: Derby Regional Mobility Centre, Kingsway Hospital, Kingsway, Derby DE22 3LZ.
Telephone: 01332 371929

Fairdeal

Advocacy service for disabled people.
Address: 2nd Floor, Eastgate House, 19-23 Humberstone Road, Leicester.
Telephone: 0116 225 2052
E-mail: fairdeal@btclick.com

Midlands Association for Amputees and Friends (MAAF)

MAAF is a registered charity that was founded in 1986 by a group of people who were amputees, their families and friends.
Telephone: 01773 591 481

Mosaic

Provides advice, advocacy and support for disabled people and their carers.
Address: Richard III Road, Leicester, LE3 5QT.

Telephone: 0116 251 565
E-mail: mosaic@totalise.co.uk

NHS Direct

Confidential phone line providing qualified healthcare advice and information 24 hours a day.
Telephone: 0845 4647
Website: www.nhsdirect.nhs.uk

Dial UK

National organisation for a network of 139 local disability information and advice line services run by and for disabled people.
Address: DIAL UK, St Catherines, Tickhill Road, Doncaster, South Yorkshire DN4 8QN.
Telephone: 01302 310123
Website: www.dialuk/info

Reach

National organisation providing support and advice for children with hand or arm deficiencies, and their parents.
Address: Reach Head Office, PO Box 54, Helston, Cornwall, TR13 8WD.
Telephone: 0845 1306 225
Website: www.reach.org.uk

Disabled Drivers' Association

Advice on returning to driving.
Address: Ashwellthorpe, Norwich, NR16 1EX.
Telephone: 0870 770 3333 .

Centre D

Your visit to the Limb Centre

- **How do I get more socks?**

Call the limb centre as soon as you need some more and we will send you some as soon as possible.

- **What do I do if I cannot make an appointment?**

Call to rearrange at the earliest available opportunity so we can allow someone else to have the appointment.

- **How often do I need to do my exercises?**

Follow your Physiotherapists advice.

- **When do I stop doing the exercises?**

Never!! This is a part of your weekly routine now, and if you stop doing your exercises all together things may slip. If you are walking a lot each day the need becomes less, but if you are not able to do much then it is a lot more important to keep doing them.

- **What do I do if my stump hurts?**

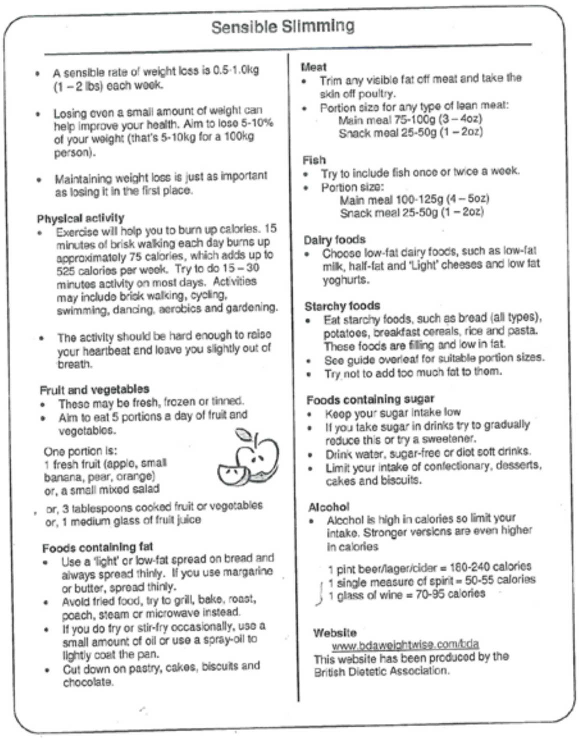
Take the limb off and check the skin for any breakdown. If there is a blister or a sore, leave the limb off until it has heeled.
Then ask yourself:
- Did I have enough socks on?
- Did I have too many socks on?
- Was my leg on "twisted"?
- Or is the leg pushing on that area specifically?

- **How long should I wear my leg when I first get it?**

Follow the guidelines from your Prosthetist and your Physiotherapist. If you overdo it and the stump breaks down we shall have to wait till this has healed before we can continue.

- **What do I do about the phantom limb sensation?**

If you suffer from phantom limb sensation which is uncomfortable, talk to someone within the team about it. Whether you speak to the Doctor, Physiotherapist or Prosthetist, they will all know of different options for what you can do and what is available.



Sensible Slimming

- A sensible rate of weight loss is 0.5-1.0kg (1 – 2 lbs) each week.
- Losing even a small amount of weight can help improve your health. Aim to lose 5-10% of your weight (that's 5-10kg for a 100kg person).
- Maintaining weight loss is just as important as losing it in the first place.

Physical activity
- Exercise will help you to burn up calories. 15 minutes of brisk walking each day burns up approximately 75 calories, which adds up to 525 calories per week. Try to do 15 – 30 minutes activity on most days. Activities may include brisk walking, cycling, swimming, dancing, aerobics and gardening.
- The activity should be hard enough to raise your heartbeat and leave you slightly out of breath.

Fruit and vegetables
- These may be fresh, frozen or tinned.
- Aim to eat 5 portions a day of fruit and vegetables.

One portion is:
1 fresh fruit (apple, small banana, pear, orange)
or, a small mixed salad
or, 3 tablespoons cooked fruit or vegetables
or, 1 medium glass of fruit juice

Foods containing fat
- Use a 'light' or low-fat spread on bread and always spread thinly. If you use margarine or butter, spread thinly.
- Avoid fried food, try to grill, bake, roast, poach, steam or microwave instead.
- If you do fry or stir-fry occasionally, use a small amount of oil or use a spray-oil to lightly coat the pan.
- Cut down on pastry, cakes, biscuits and chocolate.

Meat
- Trim any visible fat off meat and take the skin off poultry.
- Portion size for any type of lean meat:
  Main meal 75-100g (3 – 4oz)
  Snack meal 25-50g (1 – 2oz)

Fish
- Try to include fish once or twice a week.
- Portion size:
  Main meal 100-125g (4 – 5oz)
  Snack meal 25-50g (1 – 2oz)

Dairy foods
- Choose low-fat dairy foods, such as low-fat milk, half-fat and 'Light' cheeses and low fat yoghurts.

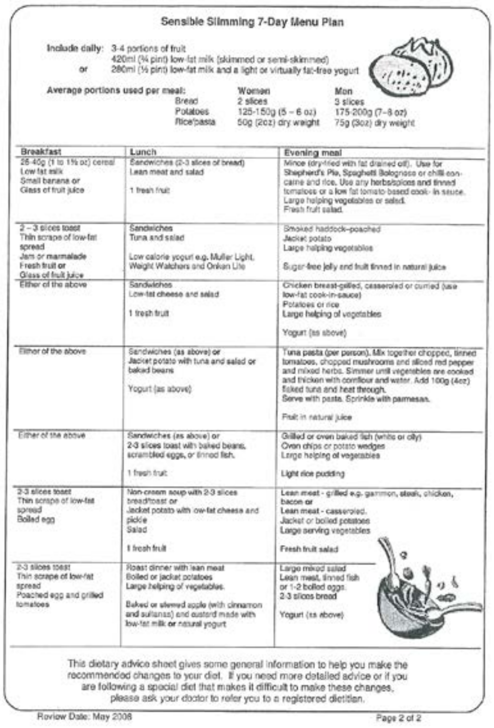
Starchy foods
- Eat starchy foods, such as bread (all types), potatoes, breakfast cereals, rice and pasta. These foods are filling and low in fat.
- See guide overleaf for suitable portion sizes.
- Try not to add too much fat to them.

Foods containing sugar
- Keep your sugar intake low
- If you take sugar in drinks try to gradually reduce this or try a sweetener.
- Drink water, sugar-free or diet soft drinks.
- Limit your intake of confectionary, desserts, cakes and biscuits.

Alcohol
- Alcohol is high in calories so limit your intake. Stronger versions are even higher in calories

1 pint beer/lager/cider = 180-240 calories
1 single measure of spirit = 50-55 calories
1 glass of wine = 70-95 calories

Website
www.bdaweightwise.com/bda
This website has been produced by the British Dietetic Association.



Sensible Slimming 7-Day Menu Plan

Include daily: 3-4 portions of fruit
420ml (¾ pint) low-fat milk (skimmed or semi-skimmed)
or 280ml (½ pint) low-fat milk and a light or virtually fat-free yogurt

Average portions used per meal:

	Women	Men
Bread	2 slices	3 slices
Potatoes	125-150g (5 – 6 oz)	175-200g (7–8 oz)
Rice/pasta	50g (2oz) dry weight	75g (3oz) dry weight

Breakfast	Lunch	Evening meal
25-40g (1 to 1½ oz) cereal Low fat milk Small banana or Glass of fruit juice	Sandwiches (2-3 slices of bread) Lean meat and salad 1 fresh fruit	Mince (dry-fried with fat drained off). Use for Shepherd's Pie, Spaghetti Bolognese or chilli con-carne and rice. Use any herbs/spices and tinned tomatoes or a low fat tomato based cook- in sauce. Large helping vegetables or salad. Fresh fruit salad.
2 – 3 slices toast Thin scrape of low-fat spread Jam or marmalade Fresh fruit or Glass of fruit juice	Sandwiches Tuna and salad Low calorie yogurt e.g. Muller Light, Weight Watchers and Onken Lite	Smoked haddock–poached Jacket potato Large helping vegetables Sugar-free jelly and fruit tinned in natural juice
Either of the above	Sandwiches Low-fat cheese and salad 1 fresh fruit	Chicken breast-grilled, casseroled or curried (use low-fat cook-in-sauce) Potatoes or rice Large helping of vegetables Yogurt (as above)
Either of the above	Sandwiches (as above) or Jacket potato with tuna and salad or baked beans Yogurt (as above)	Tuna pasta (per person). Mix together chopped, tinned tomatoes, chopped mushrooms and sliced red pepper and mixed herbs. Simmer until vegetables are cooked and thicken with cornflour and water. Add 100g (4oz) flaked tuna and heat through. Serve with pasta. Sprinkle with parmesan. Fruit in natural juice
Either of the above	Sandwiches (as above) or 2-3 slices toast with baked beans, scrambled eggs, or tinned fish. 1 fresh fruit	Grilled or oven baked fish (white or oily) Oven chips or potato wedges Large helping of vegetables Light rice pudding
2-3 slices toast Thin scrape of low-fat spread Boiled egg	Non-cream soup with 2-3 slices bread/toast or Jacket potato with low-fat cheese and pickle Salad 1 fresh fruit	Lean meat - grilled e.g. gammon, steak, chicken, bacon or Lean meat - casseroled. Jacket or boiled potatoes Large serving vegetables Fresh fruit salad
2-3 slices toast Thin scrape of low-fat spread Poached egg and grilled tomatoes	Roast dinner with lean meat Boiled or jacket potatoes Large helping of vegetables. Baked or stewed apple (with cinnamon and sultanas) and custard made with low-fat milk or natural yogurt	Large mixed salad Lean meat, tinned fish or 1-2 boiled eggs. 2-3 slices bread Yogurt (as above)

This dietary advice sheet gives some general information to help you make the recommended changes to your diet. If you need more detailed advice or if you are following a special diet that makes it difficult to make these changes, please ask your doctor to refer you to a registered dietitian.

Review Date: May 2008

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FIRST VISIT TO THE LIMB CENTRE

Who you will see:

- You will have a team assessment where we can gather information and where you can ask questions of all members of the clinical team.
- Doctor – medically examines you.
- Prosthetist – Assessment and supply of Juzo (Shrinker sock). Discuss your options. Cast or arrangement of casting for you if appropriate.
- Physiotherapist – Assessment, Trial with early walking aid (in order to see if you are able to cope with a limb). Joint working with the Prosthetist to teach you to use your limb.

If you are diabetic, please bring sandwiches / food for your appointment, as there are no catering facilities at the Limb Centre.

If prosthetic rehabilitation is suitable for you, you will be cast.

- It is a messy procedure in which you might get covered in plaster
- You will be measured and weighed
- You will be given a follow up appointment, for when your limb is made (usually 7 working days) unless there is a problem with supply or manufacture
- You will need to bring a pair of comfortable, sensible shoes. Preferably flat, lace up shoes in good condition.

FOLLOW UP VISIT

- You will get a chance to walk with your leg
- It will be adjusted to help you achieve optimum walking
- The prosthetist and the physiotherapist will teach you how to use it

Usually you will be given your limb on this visit, or it may be given to your physiotherapist.

See advice sheet for further instructions.

Further appointments.

Before you leave the Centre you will be given a 3-month appointment. If you have any questions, please contact the Limb Centre immediately as we will be pleased to help you.

Frequently Asked Questions

- **How long will it take for my stump to shrink?**

Following amputation, your stump is very swollen because it has undergone a severe trauma, regardless of the reason for the amputation. This swelling is part of the bodies repair systems. How long the shrinkage takes varies from one person to another, and sometimes shrinkage continues for years.

- **Why does my artificial limb look bigger than my other limb?**

We have to fit a liner and a plastic socket over the outside of your stump, and this adds layers and therefore makes your already swollen leg appear even bigger. As your stump does come down in size we then can make a smaller liner and socket to fit, which will also be smaller.

- **Why is my leg so heavy?**

A human leg is approximately 1/6th of the full body weight. (e.g. a 12 stone man's leg would weigh ≈ 2 stone.) We keep the artificial limb as light as possible, and they weigh a fraction of the weight of the amputated part. Unfortunately, the artificial limb still feels heavier because it hangs on the body rather than is a part of the body.

- **How do I clean my leg?**

It is important to clean your limb daily as part of your new routine. Different aspects will need different care, and instructions are available for each part of your limb. Unfortunately, many of the prosthetic components cannot get wet as they will corrode, so care is needed to clean the limb in the correct way as appropriate. Most are wipe clean.

Of utmost importance is keeping your socks clean, and changing them at least once a day. In the summer months it may be necessary to change your socks more often.

- **How and when do I contact you?**

Contact the limb centre if you have a problem with the limb or the stump or if the artificial limb becomes noisy or you are aware of a breakage of any part. Catching a repair early is important so we can maintain your prosthesis with as little inconvenience to you the wearer as possible.

List of Contacts

- Prosthetist________________________________
- Physiotherapist____________________________
- Rehab Consultant___________________________
- Nurse_____________________________________
- Occupational Therapist_____________________

Appointments

- Pre Amputation Appointment Date____________________
- Primary Amputation Appointment Date________________
- Appointment Date__________________________________
- Appointment Date__________________________________
- Appointment Date__________________________________
- Appointment Date__________________________________
- Appointment Date__________________________________
- Appointment Date__________________________________

	Initial times	Times at two weeks	Times at four weeks	Times at three months
10 meter Walk:-				
Get up and go:-				

CASTING

SO THAT WE CAN MAKE YOUR LIMB WE NEED TO TAKE A CAST OF YOUR STUMP

Bellow Knee

In order to be cast for a below knee limb you will need to:

- Be able to be exposed to above the knee (mid thigh) level.
- If you have an unusual cast to be taken we may need to expose higher i.e. top of the thigh. But this will be explained to you should this be the casting method of choice.
- Your stump will be wrapped in cling film, followed by a sock, which is drawn on and then a plaster is applied over the top.
- When the plaster is dry it will be removed.
- In certain circumstances the plaster may need to be cut off with a plaster saw, this is noisy but safe.

If you have any queries/questions please ask.

Above Knee

In order to be cast for an above knee limb you will need to:

- Be able to be exposed to at least waist level therefore suitable underwear is required. Please note that your underwear may get wet or covered in plaster during casting therefore a change may be advisable.
- Your stump and possibly your waist will be wrapped in cling film.
- You will then need to stand for the length of the casting (approx 10 minutes).
- Usually a sock will be placed on your stump, then a plastic shaped top will be applied round your stump (to help form a good shape for your leg).
- A plaster will then be applied
- When the plaster is dry it will be removed.

Above Knee (Hand Casting)

Because of the type of cast necessary for your stump there will be no plastic top on the cast, instead the cast will run from waist to bottom of the stump the shape will be produced using hand pressure by the prosthetist, in the groin and buttock area.

If you have any queries/questions please ask.

Hip Disarticulation

In order to be cast for a hip disarticulation limb you will need to:

- Be cast around your waist therefore you will need to be exposed to at least waist level and therefore suitable underwear is required.
- Stand for the length of casting (approximately 20 minutes).
- Cling film will be applied to the whole area (waist included).
- Wear a pair of casting pants which you will be given which will cover the area to be cast.
- Marks will be made on the casting pants.
- Stand whilst plaster will be wrapped round your waist and downwards to the bottom of the stump and equal distance on the other side.
- A plaster rope will then be passed around your waist and crossed diagonally in front of you and the pulled tightly around your middle to produce the correct shape.
- Once the plaster is on you will be asked to balance on a stool, see picture.
- The cast when dry will be cut off with blunt nosed scissors.

Juzo Instructions (Stump Shrinker)

JUZO INSTRUCTIONS (STUMP SHRINKER)

The stump shrinker (Juzo) you have been given is to help reduce and control any swelling present as a result of your amputation, in preparation for the wearing of an artificial limb. You will only be issued with one Juzo.

When to wear your Juzo:

It should only be worn during the day and taken off before you go to bed at night

If it feels uncomfortable the stump shrinker can be worn for short periods of time which can be gradually increased, until you are able to wear it from first thing in the morning to last thing at night.

If pins and needles occur remove the shrinker and replace one hour after they have gone.

Ensure the shrinker is pulled well up (NO Wrinkles)

WASHING INSTRUCTIONS

Machine wash frequently using a delicate / gentle cycle (40 degrees). This keeps the fabric in shape

Rinse well if you wash by hand and do not wring.

DRYING INSTRUCTIONS

Place in a thick towel, roll towel up tightly and firmly to press out excess moisture

Line Dry

DO NOT:

Leave in towel

Leave on radiator

Dry in sun

Dry clean

Fitting

FITTING

In order to make fitting of a leg easier wearing short baggy shorts (for the fitting) will allow easy access for both yourself and the prosthetist.

You will need:

- A PAIR of shoes. (Ideally these should be lace up, low heeled trainer type shoes).

You will be taken to the fitting room which may have other patients present. If you would like to be seen individually please ask.

You will be given socks which are to be worn with your limb.

Below Knee

- You will be shown how to put on and remove your socks/liner and leg.
- You will be taught how to walk.
- Adjustments will be made to the leg to make it more comfortable, and hopefully you will be able to take your leg home with you.

Above knee

- You will be shown how to put on and remove your socks/liner, belt and leg.
- The prosthetist/physiotherapist will check the fit and show you how to check the fit of the leg by placing two fingers on your tailbone and getting you to put weight on your leg.
- Fit will be checked in the groin area by the prosthetist to make sure that there are no areas which may rub.

Hip disarticulation

- You will be shown how to put on your body socks and fit the limb.
- Your prosthetist may need to check the fit in the groin area.

Phantom Limb Sensation

This can be described as many things from a sensation of the actual limb being there, to a painful feeling in the part of the limb that has been amputated.

Many people experience different sorts of sensations which can change as time progresses. It can be normal to have either lots of sensation or none at all, everyone is different and will experience sensations in different ways and at different stages after amputation.

Causes of sensation are varied and stopping them is one of the biggest difficulties faced by both patient and healthcare professional.

Phantom sensation may also get worse when you are first fitted for a limb or use the early walking aid as it can cause pressure on the existing tissues.

After you have had your amputation you can start to gently touch your stump to get it used to gentle pressure, be careful to avoid heavy pressure in the wound area. You can build this up with time and get your stump used to more pressure, as you can tolerate it.

Pins and needles and cramping type sensations are also normal after amputation. Hopefully phantom sensation will tend to fade gradually in time.

There is a difference between phantom sensation and actual stump pain. If you have pain in your existing stump this can usually be dealt with using painkillers, please notify your GP or consultant.

The sensation of the absent limb can cause problems initially as you may be tempted to get up and walk which is obviously dangerous. This is especially important should you be getting up in the night to use the bathroom.

If this is causing you discomfort, then please discuss it with your nursing staff, doctor or physiotherapist.

Make sure that your limb is covered appropriately and you are not exposing your limb to a draft or to extreme heat, which can be uncomfortable.

You can massage the limb at any time and try to do some stretches which your therapist can advise you of.

There are several options to solve problems with pain, these include drugs, TNS machines, acupuncture, exercise and massage. Please ask your Health Care Professional for advice.

SOCKS

You will be given the correct size of sock at the limb centre.

There are many different types of sock but we will split them into a few categories to make it easier to understand.

Thick sock: Furry on inside and smooth on the outside

Thin sock: Smooth on both sides

Nylon: White in colour and has consistency of tights

You will be shown how to put on your socks. It will be explained to you how many socks are appropriate. If you do not understand this please ask.

BUT the number of socks you wear will vary during the day and there may be a difference between morning and afternoon.

- Do not pull the sock too tightly over your stump. This can distort its shape and cause excessive pressure on the end of your stump when wearing the artificial limb.
- Take care not to leave creases in any of the socks you are wearing, this will be uncomfortable and can lead to sore areas on your stump.
- When you first get your artificial limb, you will be supplied with appropriate socks.
- Socks can be re-supplied by personally calling at the centre (ring to check availability) or by telephone request alone, number 01603 623616
- Most people find as they walk greater distances and wear their limb for longer, their limb will shrink in size.
- It will be necessary to adjust the number of socks you wear to accommodate this.
- Temperature can also play a large part in the size of your limb and the number of socks you will need to wear.
- Washing: All socks should be washed with a mild detergent and rinsed thoroughly. Most can be washed in a machine at 40 degrees.
- If you gain or lose weight you may need to change your sock size. This may also be necessary if you do not wear your artificial limb for some time or have further surgery.

HYGIENE

This is a very important part of your DAILY routine

Your limb is the part of your body which allows you to remain mobile. Therefore problems occurring within the skin of this area could well mean that you will not be able to wear your limb for a while.

Cleanliness: Always remember that your limb will spend a greater part of its day enclosed in an airtight or partially airtight socket which does not allow perspiration to evaporate or the skin to breathe. Perspiration is acidic and salty and if it is allowed to dry it will form tiny crystals on the skin and the effect will be similar to sandpaper on your skin. If there is a tear in your skin, bacteria can grow and infections may occur.

Wash your Residual limb (Amputated leg) this should be done with a non perfumed soap then rinsed and dried with a clean towel thoroughly.

At night if your skin is dry a little moisturising cream may be applied i.e. E45. Do not cream your skin prior to putting on your artificial limb.

If you are prone to perspire, you will probably need to wash your limb more than once a day, ensuring that your limb is always dry prior to putting it on again. Moist and damp skin can quickly rub and become sore.

Apply clean socks daily. Everything that comes into contact with your skin i.e. socks and nylons should be washed with a mild detergent and always rinsed well. Silicone socks should be wiped with a damp cloth and left to dry.

The socket should be wiped out with a clean cloth on a daily basis.

It is your responsibility to keep your limb clean as it will avoid problems in the future such as fungal infections.

When you remove your artificial limb always check that there are no sore areas. If you cannot see the end of your limb, use a mirror or get someone else to check for you.

IF you develop a sore place on your limb, clean the area, apply a dry dressing and make an appointment at your Limb Centre. Avoid wearing the Limb until the area has healed up and you have been seen at the Limb Centre, or if immediate treatment necessary contract your Doctor (GP). Do not attempt to try and treat the broken area yourself.

When you are not wearing your artificial limb for any length of time, try and keep it elevated on a stool, board as much as possible when sitting to prevent swelling from occurring. Also continue your exercises taught by your physiotherapist on a regular basis, as they also help to reduce swelling.

TAKING YOUR ARTIFICIAL LIMB HOME

On taking your limb home from the Limb Centre:

- You should be able to put it on and take it off
- If you are not sure on how to do this WAIT until you see your Physiotherapist
- You can wear it to sit in but the foot needs to be in contact with the floor or footplate at all times

If you have not been issued with a walking aid from the Limb Centre please do not "have a go" at home with any aids you may have there.

Your Physiotherapist should have made you a follow up appointment. If not please contact them directly. They will instruct you on learning to walk and in the use/care of your Limb.

Your stump is likely to become sore if you try to use your prosthesis all of the time straight away.

By the time you take your prosthesis home you will probably be using it for periods of time in Physiotherapy. However, when you get home this does not mean you can wear your prosthesis all of the time, you need to build up the length of time you can wear it.

Try using it for half an hour in the morning and the afternoon and half an hour in the evening on the first day. If you are tired or sore drop the evening session.

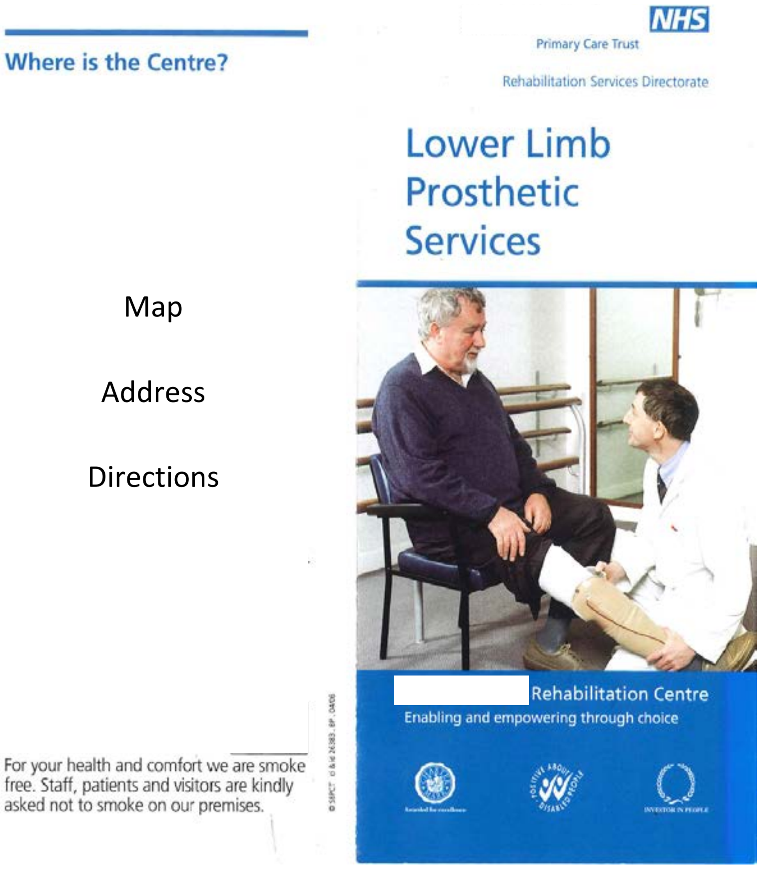
Next day, increase each session by half an hour, i.e. an hour morning, afternoon and evening. Continue building up the time that you use the prosthesis, gradually adding half an hour to each session per day. If you are tired or sore, drop the session.

Whilst you are using the prosthesis, do what you would normally do at that time, do not march up and down for half an hour just because you have the prosthesis on.

Until you are using the prosthesis all day, put the compression sock on whilst you are not using the prosthesis.

If your stump becomes sore or the skin becomes marked stop wearing your prosthesis and ring the Limb Centre on 01603 216956.

Centre E



Where is the Centre?

Map

Address

Directions

For your health and comfort we are smoke free. Staff, patients and visitors are kindly asked not to smoke on our premises.

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NHS
Primary Care Trust

Rehabilitation Services Directorate

Lower Limb Prosthetic Services

[redacted] Rehabilitation Centre
Enabling and empowering through choice

What is a prosthesis?

A prosthesis is a replacement for part of your body, for example an artificial leg or arm, an artificial eye or an artificial heart valve.

What is a prosthetist?

This is a person who is specialised in fitting and caring for someone who needs a prothesis.

What to expect on your first visit

On your first visit you may be introduced to the following members of the clinical team:

- consultant in Rehabilitation Medicine
- prosthetists
- physiotherapists
- occupational therapists
- counsellors
- nurses
- advice and information officers.

What will happen on my first visit to see a prosthetist?

The prosthetist may want to examine you and take some measurements and perhaps a plaster mould of your residual limb (stump). Please bring a pair of well-fitting shoes with you on this visit.

Once the prosthetist has taken the measurements and mould you will be given an appointment to come for a fitting of your prosthesis.

The prosthetist may refer you to other members of the clinical team.

All patients have regular appointments at the centre during the first year of wearing a prosthesis. After the first year you can make your own appointments when you need them.

A prosthesis can be maintained and repaired all over the country.
You can get addresses and contact numbers of other centres from the Information Service on Disability.

Centre G

Welcome to the Mobility Centre

On your first visit, you will be seen by all members of the Rehabilitation Team to ensure that we undertake a detailed assessment with you. This appointment usually lasts about an hour.

The team includes an Occupational Therapist or Physiotherapist, a Prosthetist and a Counsellor. All have a role to play in helping you following your amputation/ birth of a child with a congenital limb deficiency.

Therapists

A therapist will assess your physical capabilities and may start walking training with a temporary prosthesis (artificial limb).

After delivery of your own prosthesis, she will arrange further walking training for you.

Individual Prosthetist

If your residual limb (stump) has healed, an appointment will be made for the following week to take a cast or measurements in preparation for making a limb.

Amputee Counsellor

A Counsellor is available to all new amputees to help overcome any particular challenges - emotional or psychological - that either you or your family may encounter following amputation.

You are welcome to bring a partner/family member with you to discuss and plan your future rehabilitation.

As well as the team, you will also see and meet other amputees attending the Centre who are at different stages of rehabilitation.

Following your initial visit to the Exeter Mobility Centre, you will be given an individual plan for your rehabilitation and a timescale for the provision of your prosthesis.

You will be reviewed 6 weeks, 3 months and 12 months after receiving your prosthesis. However, if you need to see/ speak to any member of staff, please do not hesitate to contact the Centre to book another appointment.

Please ask if there is anything you do not understand at any time during your visits - we are here to help you.

Facilities available at the Exeter Mobility Centre

- Disabled car parking - free to blue badge holders.
- The Trust operates a Pay and Display Car Park for all those attending the Centre without a blue badge.
- Disabled toilets.
- WRVS refreshment bar
- Resource Room

How to find us

Map

Prosthetic Service Feedback

Feedback on all aspects of the service is welcome. If you would like to make suggestions, you can do this by writing to:

Address

Looking after your residual limb

It is important to keep your residual limb clean and check carefully for any signs of rubbing from your prosthesis. This is especially important if you have impaired sensation in your limb.

We advise that you:

- Wash your residual limb every day with warm water and a mild soap.
- Always ensure your skin is dry before putting on your prosthesis.
- Use clean stump socks every day. The sock should fit firmly (not tightly) with no wrinkles.
- If your skin is very dry, you can use a little moisturising cream.
- Examine your skin daily for signs of rubbing. If you find any blistering or skin breaks, contact reception on , if necessary, stop wearing your prosthesis.
- If your residual limb perspires excessively, you can use a non-perfumed anti-perspirant for sensitive skin. Do ask your prosthetist for further advice.

Looking after your remaining leg

- Wash your foot daily, dry thoroughly and inspect for sore areas.
- Wear socks made of natural fibres such as wool or cotton, and avoid any tight elastic tops or garters as these may constrict your circulation.
- Ensure your shoes are not too tight and they do not rub your skin. Soft leather is best and lace-ups give more support.
- Cut toe nails with great care. If you are diabetic or have poor circulation, this is best done by a chiropodist.
- Avoid excessive heat such as a hot water bottle or sitting in front of the fire.
- Avoid tight bed clothes pressing on your toes as this can make them sore.
- Please ask your prosthetist if you require any further advice.

Stump socks

Most prosthetic users need to wear a stump sock to protect their residual limb and make the socket of the prosthesis as comfortable as possible. The sock provides some cushioning and also allows air to circulate whilst absorbing perspiration.

Type of sock available

We stock a range of stump socks and your prosthetist will advise you on the most suitable type for you.

The range includes wool, cotton terry, thin cotton, stretchy nylon and flat nylon. On average, a single amputee requires up to 10 socks a year, although we do not impose restrictions on the number of socks issued. You may need to be seen for a review if the use seems excessive as the socket may need attention.

You should wear a clean sock every day in order to give your skin the best protection. When washing your socks, follow the washing instructions for your particular type of sock. Some socks are machine washable. If not, or if there are no instructions with the sock, then hand wash them using warm water and a gentle detergent. Rinse thoroughly with water. Roll in a dry towel to remove excess water and do not wring out, as this will distort their shape. Pull into shape whilst damp and dry on a flat surface away from direct heat. Do not tumble dry as this can cause shrinkage.

Further supplies

If your socks are becoming worn or misshapen, please contact the Exeter Mobility Centre for further supplies which can be posted to you or collected.

What is the Prosthetic User Group

The Prosthetic User Group is a proactive link between users, carers, parents of children who use the service and the providers of the Prosthetic Service.

Membership of the Prosthetic User Group brings together user representatives from across who have varying amputation levels along with parents of children who use the service.

The group allows members to express their views and opinions with members of staff on all aspects of the prosthetic service.

It consists of 10 user representatives and 3 staff representatives. We have three officers: the Chairperson and Vice Chairperson, who are amputees, and the Secretary who is a member of staff. The group has an annual AGM at which the committee vote to fill these posts.

Objectives of the User Group

- To provide a broadly representative body for all prosthetic users acccessing the prosthetic service provided by the Mobility Centre.
- To provide a forum for the discussion and evaluation of potential developments and changes which may affect the Centre and service.
- To exchange general information and ideas between the Centre and its representative prosthetic patients.
- To review and help develop quality standards and practice within the prosthetic service.
- To agree on the material for display on the Prosthetic User Group notice boards located in the waiting area and each fitting room.

We value you opinion

Committee members are keen to hear from patients who would like to put forward ideas or suggestions about improving the prosthetic service - although they cannot get involved in any aspects of clinical or medical care.

If you have any problems in these areas, please talk to your prosthetist.

How to contact a member of the Prosthetic User Group

If you attend the , you can find the names and contact number of the committee members in the waiting area and in both the male and female fitting rooms. Alternatively, you can ask reception staff for details.

How to become a member of the Prosthetic User Group

Users, carers or parents: if you are interested in joining the group, please contact a current member. Your details will be passed on to the Chairperson who will contact you personally when a vacancy arises.

Enquiry Form

If you would like to contact us with a question or comment, please cut out and use this form.

Name ....

Address ....

....

....

Postcode ....

Telephone ....

E-mail ....

Comments or query ....

....

....

....

....

....

Please return this form to:

Chairperson
Prosthetic User Group

Amputee Resource Room

Whilst you are attending the please feel free to browse in our Amputee Resource Room which holds plenty of useful information and leaflets. This room is located by the waiting area.

Also available are the latest magazines, information and contact numbers for the Limbless Association and Reach (assocation for children with hands/arm deficiency).

Smoke-free at the RD&E

From September 2006 the RD&E hospitals became totally smoke-free sites. This means that no smoking is allowed in and around any of the RD&E buildings, in parked cars, in our courtyard gardens or anywhere on the hospital sites. This applies to patients, visitors and staff. We are very keen to help people in their efforts to stop smoking, so please see your GP before coming into hospital or talk to your nurse about this.

For information on how to give up smoking, phone the **Smoking Advice Service on 0845 1111142**. The benefits begin the minute you stop smoking.

Needing help?

When someone loses a limb or has a child with limb deficiency, the emphasis is often on the medical care and limb fitting procedures. It can be a tense and emotional time for those involved. Sometimes there does not seem to be enough time or space to talk about the difficulties and feelings involved. The support counsellor is available to assist in these areas.

What is counselling?

Counselling allows you an opportunity to share your thoughts, feelings and experiences without fear of rejection/criticism. This can lead to a clearer understanding of how to manage the changes that have occurred since amputation/limb deficiency and help you feel more in control.

Who will I see?

The Support Counsellor at the is:

has an HND in Counselling and is a member of the British Association of Counselling and Psychotherapy (BACP).

Why do people see the support counsellor?

There are many reasons why people choose to seek the support of a counsellor.

Amputee Support Counsellor

The Counsellor provides a listening ear and an opportunity to talk to someone in confidence about your thoughts and concerns in relation to your operation and future.

Therapists

Physiotherapists and Occupational Therapists will help you to learn to use your prosthesis, as well as giving you exercises to strengthen your muscles and prevent joint stiffness.

The Occupational Therapist is also here to help you look at ways of managing at home and carrying out activities of daily living, e.g. dressing/toileting.

This meeting may be useful to discuss concerns regarding any help/aids needed following hospitalisation and surgery.

Please feel free to bring any family members/significant others that you may like to attend this meeting.

How do I arrange a visit?

Ask your surgeon/GP to contact the Centre with a covering letter stating:

1. the reason for your amputation;
2. any medical history.

Upon receiving this information, an appointment will be made and sent to you as soon as possible. If the date/time is not convenient, please contact the Centre to make another appointment.

What is a pre-amputation consultation?

It is an opportunity to provide you with as much information as possible so you can make an informed decision about your future.

At this consultation, we will discuss with you:

- What is involved in wearing and using an artificial limb (prosthesis).
- Your concerns, doubts and fears with the upcoming surgery and aftercare.
- Give you an opportunity to view and handle a prosthesis (arm/ leg as appropriate).
- Meet the people involved in your prosthetic rehabilitation and a tour of the Centre if appropriate.

If you wish to meet an established amputee, a further visit can be arranged at a later date for you to meet and discuss any further concerns/issues if time allows.

Who will you see?

Lead Prosthetic Therapist

Our Lead Prosthetic Therapist will take a medical history (along with your referral information) from you and discuss our role of providing a prosthesis. This includes talking you through the relevant stages, i.e. what to expect after surgery and what is involved in making and wearing a prosthesis (as appropriate for you). The therapist is also available to answer any questions you may have about the process following amputation to limb fitting/wearing.

You may want help:

- with the shock of losing a limb;
- with the shock of having a child born with a limb deficiency;
- with the feelings of loss;
- in coping with physical pain;
- in decision making;
- in building self-confidence;
- in coming to terms with feelings;
- in coping with changes;
- with family relationships.

How do I get in touch with the Counsellor?

You can ask any member of the Prosthetic Team at the Centre to give your name to the Support Counsellor or you can contact

Confidentiality

All discussions which take place between yourself and the Counsellor are confidential and will not be shared with members of your family or staff at the Centre without your complete agreement.

If you are in agreement, she will tell Prosthetic staff and your GP that you are seeing her, but not about any of the issues you discuss together.

The only exceptions to confidentiality are:

- if you are at risk of harm from yourself or from others;
- if there is a risk of harm to another;
- when legally required to do so.

What will happen at the first appointment?

You will see the Counsellor in private at the
At the first appointment you will have the opportunity to talk about the things that led you to ask for the appointment. The Counsellor will explain more fully what counselling is and how she works.

How many times will I come?

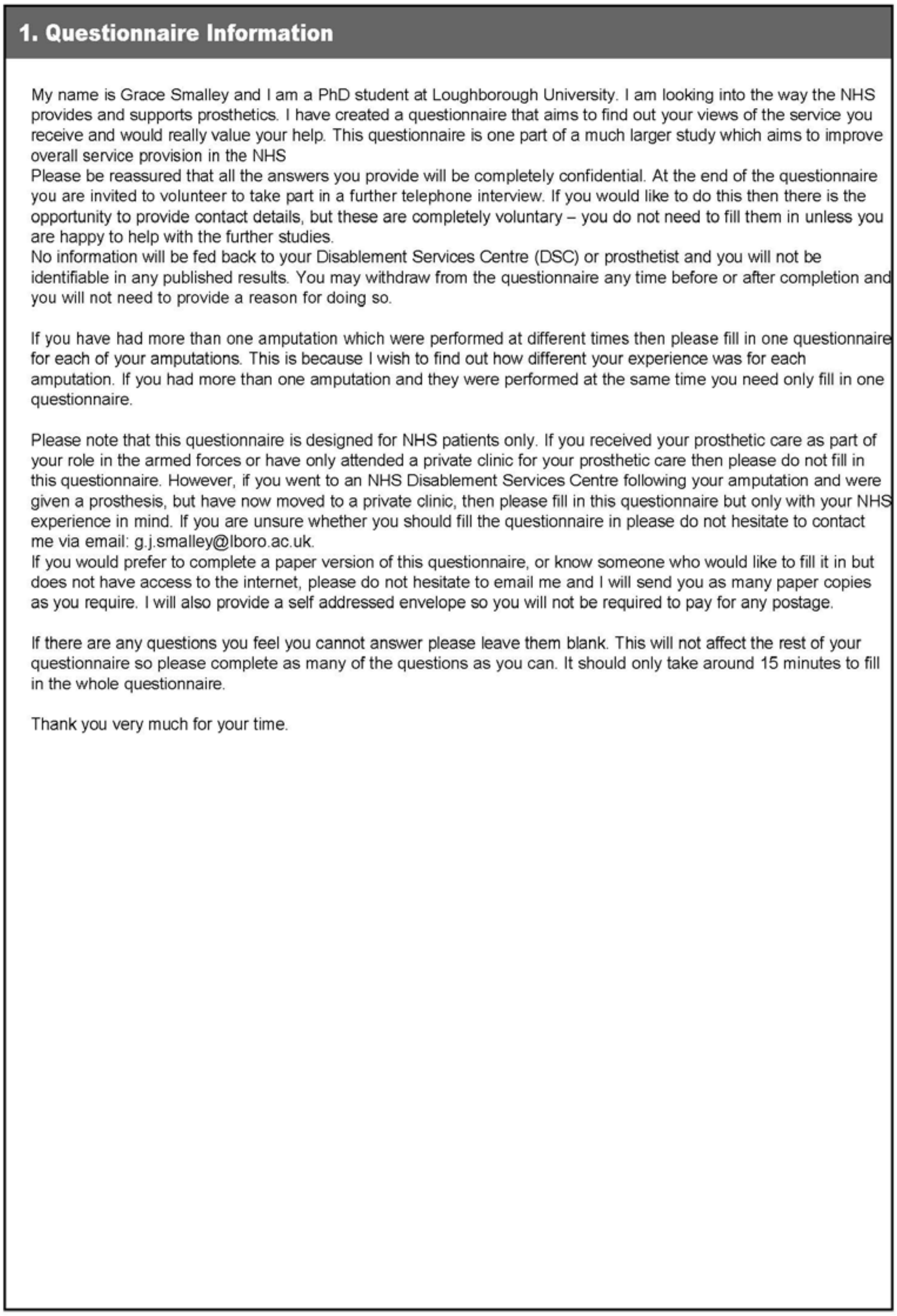
You may want to come once or twice only, or to come for a number of sessions. Whatever you decide, the Support Counsellor will listen carefully to you and work with you to lessen and ease your concerns and feelings.

Will I be able to talk to someone I do not know?

Sometimes it is easier to talk to someone who does not know you and who is trained to help with personal and emotional matters. If you, or a member of your family, are unsure if you want counselling, the Counsellor will be happy to discuss it with you.

Chapter 5 – Study 2

Appendix 5A – Questionnaire



1. Questionnaire Information

My name is Grace Smalley and I am a PhD student at Loughborough University. I am looking into the way the NHS provides and supports prosthetics. I have created a questionnaire that aims to find out your views of the service you receive and would really value your help. This questionnaire is one part of a much larger study which aims to improve overall service provision in the NHS

Please be reassured that all the answers you provide will be completely confidential. At the end of the questionnaire you are invited to volunteer to take part in a further telephone interview. If you would like to do this then there is the opportunity to provide contact details, but these are completely voluntary – you do not need to fill them in unless you are happy to help with the further studies.

No information will be fed back to your Disablement Services Centre (DSC) or prosthetist and you will not be identifiable in any published results. You may withdraw from the questionnaire any time before or after completion and you will not need to provide a reason for doing so.

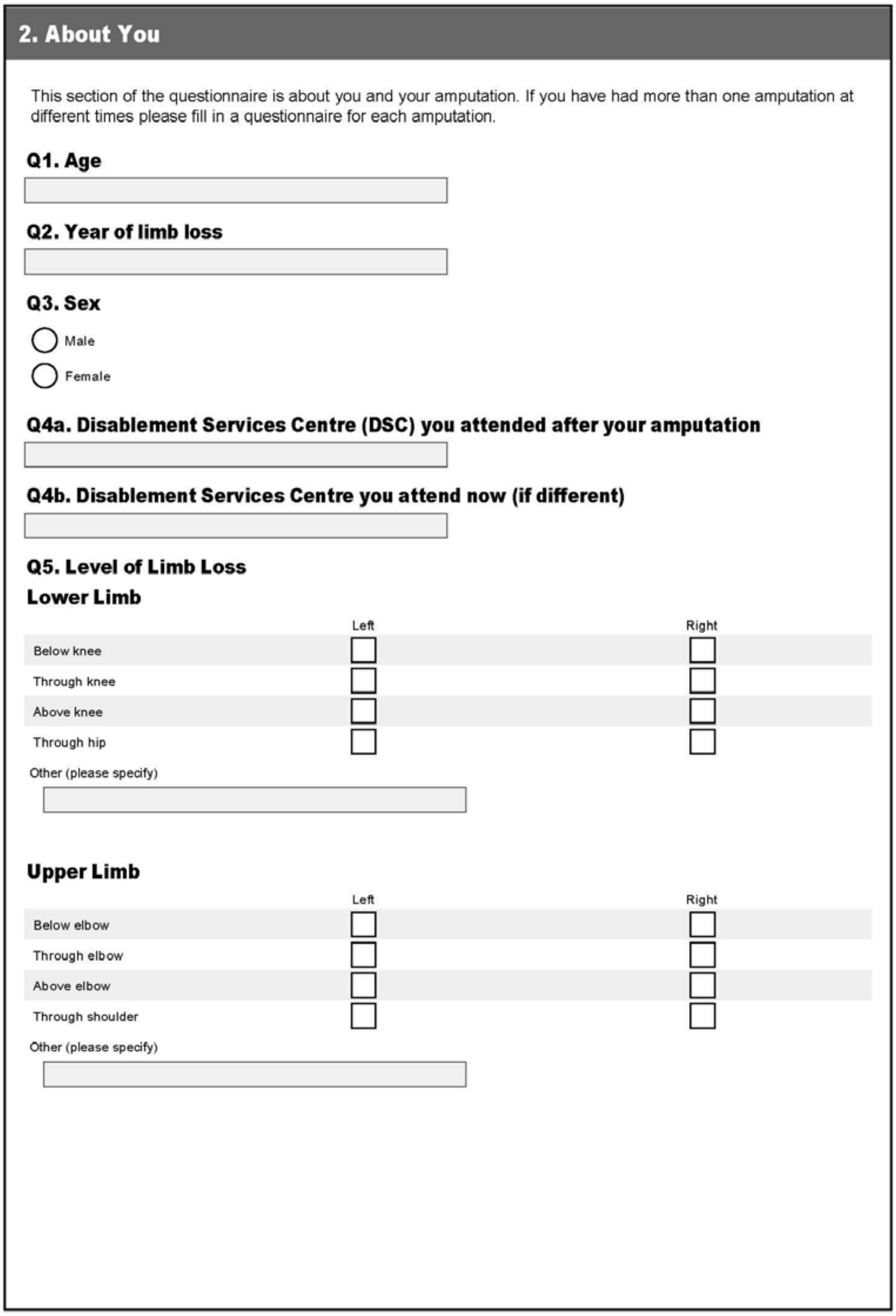
If you have had more than one amputation which were performed at different times then please fill in one questionnaire for each of your amputations. This is because I wish to find out how different your experience was for each amputation. If you had more than one amputation and they were performed at the same time you need only fill in one questionnaire.

Please note that this questionnaire is designed for NHS patients only. If you received your prosthetic care as part of your role in the armed forces or have only attended a private clinic for your prosthetic care then please do not fill in this questionnaire. However, if you went to an NHS Disablement Services Centre following your amputation and were given a prosthesis, but have now moved to a private clinic, then please fill in this questionnaire but only with your NHS experience in mind. If you are unsure whether you should fill the questionnaire in please do not hesitate to contact me via email: g.j.smalley@lboro.ac.uk.

If you would prefer to complete a paper version of this questionnaire, or know someone who would like to fill it in but does not have access to the internet, please do not hesitate to email me and I will send you as many paper copies as you require. I will also provide a self addressed envelope so you will not be required to pay for any postage.

If there are any questions you feel you cannot answer please leave them blank. This will not affect the rest of your questionnaire so please complete as many of the questions as you can. It should only take around 15 minutes to fill in the whole questionnaire.

Thank you very much for your time.



2. About You

This section of the questionnaire is about you and your amputation. If you have had more than one amputation at different times please fill in a questionnaire for each amputation.

Q1. Age

Q2. Year of limb loss

Q3. Sex

○ Male
○ Female

Q4a. Disablement Services Centre (DSC) you attended after your amputation

Q4b. Disablement Services Centre you attend now (if different)

Q5. Level of Limb Loss

Lower Limb

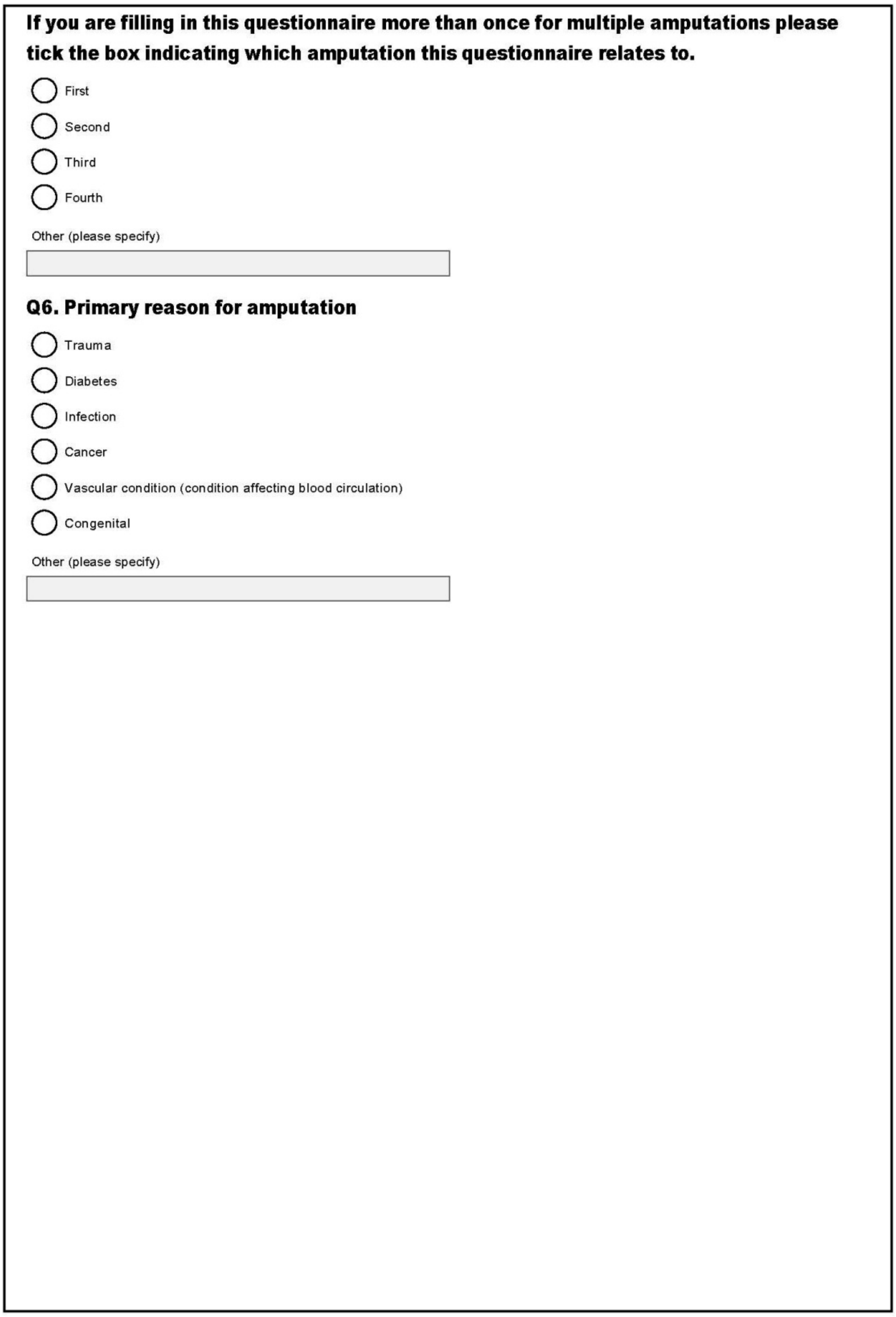
	Left	Right
Below knee	☐	☐
Through knee	☐	☐
Above knee	☐	☐
Through hip	☐	☐

Other (please specify)

Upper Limb

	Left	Right
Below elbow	☐	☐
Through elbow	☐	☐
Above elbow	☐	☐
Through shoulder	☐	☐

Other (please specify)



If you are filling in this questionnaire more than once for multiple amputations please tick the box indicating which amputation this questionnaire relates to.

○ First

○ Second

○ Third

○ Fourth

Other (please specify)

Q6. Primary reason for amputation

○ Trauma

○ Diabetes

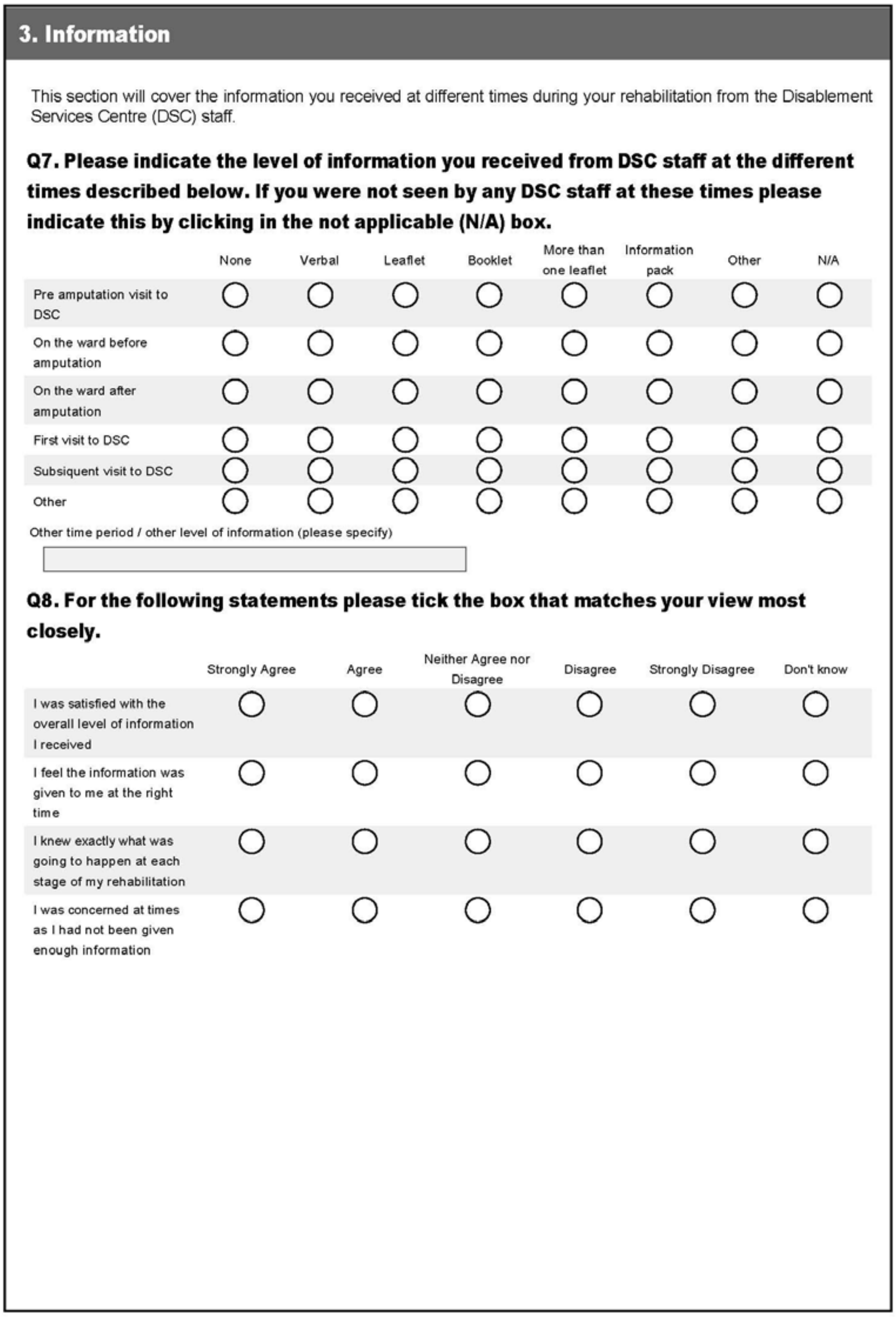
○ Infection

○ Cancer

○ Vascular condition (condition affecting blood circulation)

○ Congenital

Other (please specify)



3. Information

This section will cover the information you received at different times during your rehabilitation from the Disablement Services Centre (DSC) staff.

Q7. Please indicate the level of information you received from DSC staff at the different times described below. If you were not seen by any DSC staff at these times please indicate this by clicking in the not applicable (N/A) box.

	None	Verbal	Leaflet	Booklet	More than one leaflet	Information pack	Other	N/A
Pre amputation visit to DSC	○	○	○	○	○	○	○	○
On the ward before amputation	○	○	○	○	○	○	○	○
On the ward after amputation	○	○	○	○	○	○	○	○
First visit to DSC	○	○	○	○	○	○	○	○
Subsiquent visit to DSC	○	○	○	○	○	○	○	○
Other	○	○	○	○	○	○	○	○

Other time period / other level of information (please specify)

Q8. For the following statements please tick the box that matches your view most closely.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Don't know
I was satisfied with the overall level of information I received	○	○	○	○	○	○
I feel the information was given to me at the right time	○	○	○	○	○	○
I knew exactly what was going to happen at each stage of my rehabilitation	○	○	○	○	○	○
I was concerned at times as I had not been given enough information	○	○	○	○	○	○

4. Aims and Goals

This section is about your aims and goals. Aims are key stages in your rehabilitation and Goals are the steps you take to achieve your aims.

Q9. Were your aims and goals discussed with you at the start of your rehabilitation?

○ Yes (please go to Q10)
○ No (please go to Q12)
○ Don't know (please go to Q14 on the next page)
○ N/A (please go to Q14 on the next page)

Q10. (Once complete please go to Q11)

	Yes	No	Don't know
Were your aims and goals discussed to your satisfaction?	○	○	○
Are your aims and goals discussed and updated regularly?	○	○	○

Q11. (Once complete please go to Q14 on the next page)

For the following statements please tick the box that matches your view most closely.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Don't know
Having aims and goals helped keep me on track with my rehabilitation	○	○	○	○	○	○
Having something to work towards was very useful/helpful	○	○	○	○	○	○

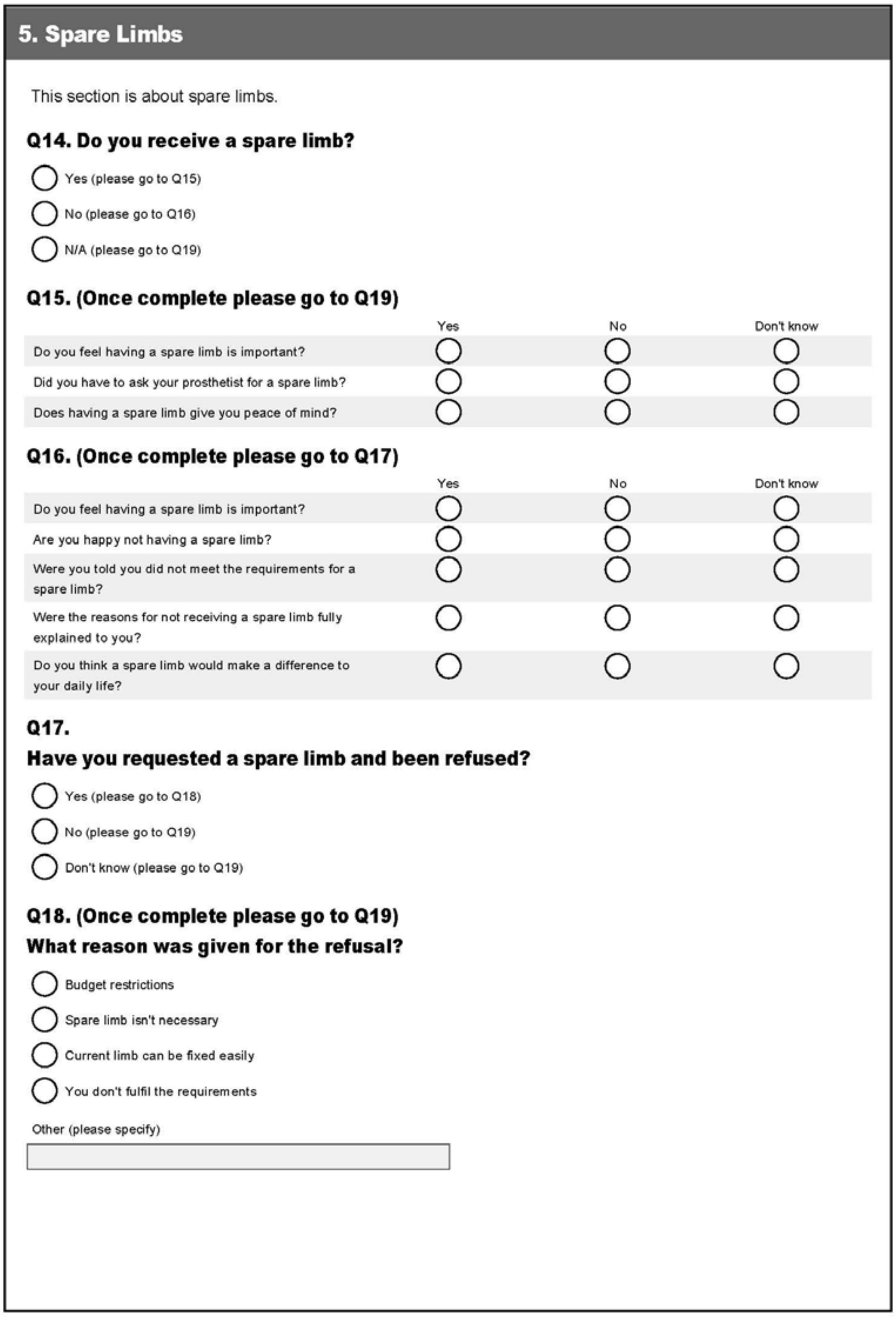
Q12. (Once complete please go to Q13)

	Yes	No	Don't know
Would you have liked to discuss your aims and goals?	○	○	○
Were you concerned by the lack of discussion of your aims and goals?	○	○	○

Q13. (Once complete please go to Q14 on the next page)

For the following statements please tick the box that matches your view most closely.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Don't know
I do not think I needed aims and goals to help with my rehabilitation	○	○	○	○	○	○
I was happy not having set aims and goals to work towards	○	○	○	○	○	○
I do not feel aims and goals need to be discussed with my prosthetist/physiotherapist	○	○	○	○	○	○
I feel aims and goals would have had a positive affect on my rehabilitation	○	○	○	○	○	○



5. Spare Limbs

This section is about spare limbs.

Q14. Do you receive a spare limb?

○ Yes (please go to Q15)
○ No (please go to Q16)
○ N/A (please go to Q19)

Q15. (Once complete please go to Q19)

	Yes	No	Don't know
Do you feel having a spare limb is important?	○	○	○
Did you have to ask your prosthetist for a spare limb?	○	○	○
Does having a spare limb give you peace of mind?	○	○	○

Q16. (Once complete please go to Q17)

	Yes	No	Don't know
Do you feel having a spare limb is important?	○	○	○
Are you happy not having a spare limb?	○	○	○
Were you told you did not meet the requirements for a spare limb?	○	○	○
Were the reasons for not receiving a spare limb fully explained to you?	○	○	○
Do you think a spare limb would make a difference to your daily life?	○	○	○

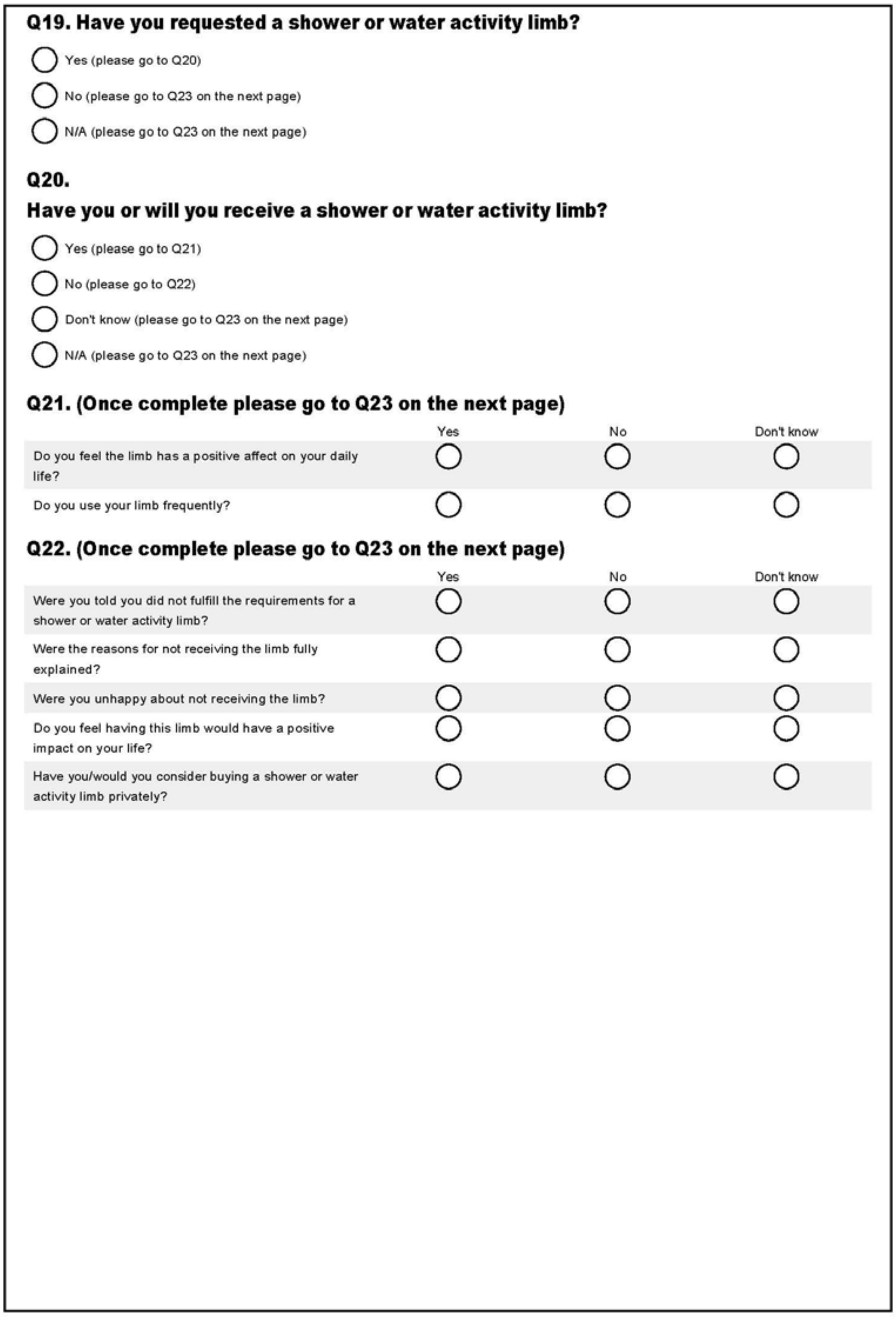
Q17.
Have you requested a spare limb and been refused?

○ Yes (please go to Q18)
○ No (please go to Q19)
○ Don't know (please go to Q19)

Q18. (Once complete please go to Q19)
What reason was given for the refusal?

○ Budget restrictions
○ Spare limb isn't necessary
○ Current limb can be fixed easily
○ You don't fulfil the requirements

Other (please specify)



Q19. Have you requested a shower or water activity limb?

○ Yes (please go to Q20)

○ No (please go to Q23 on the next page)

○ N/A (please go to Q23 on the next page)

Q20.

Have you or will you receive a shower or water activity limb?

○ Yes (please go to Q21)

○ No (please go to Q22)

○ Don't know (please go to Q23 on the next page)

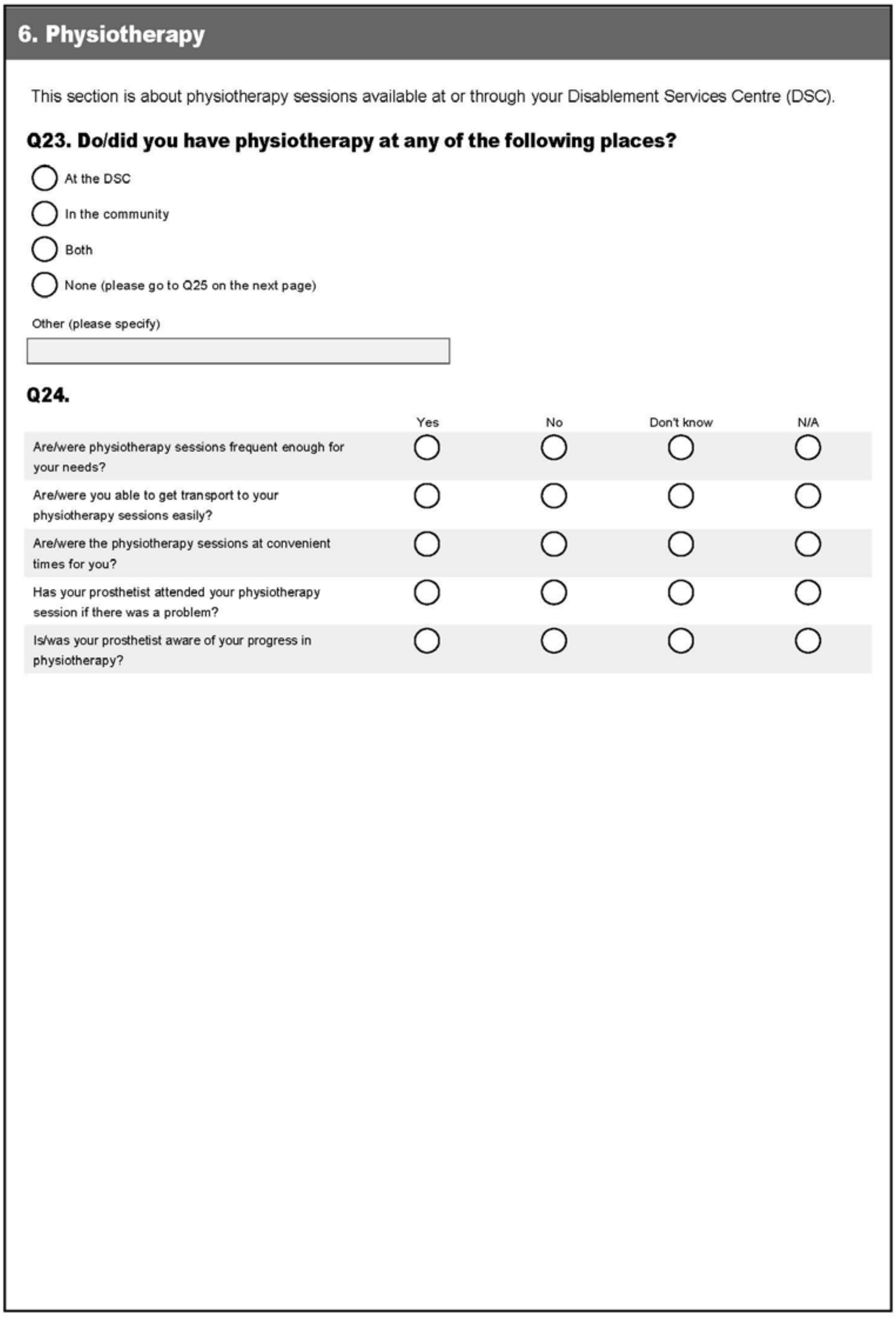
○ N/A (please go to Q23 on the next page)

Q21. (Once complete please go to Q23 on the next page)

	Yes	No	Don't know
Do you feel the limb has a positive affect on your daily life?	○	○	○
Do you use your limb frequently?	○	○	○

Q22. (Once complete please go to Q23 on the next page)

	Yes	No	Don't know
Were you told you did not fulfill the requirements for a shower or water activity limb?	○	○	○
Were the reasons for not receiving the limb fully explained?	○	○	○
Were you unhappy about not receiving the limb?	○	○	○
Do you feel having this limb would have a positive impact on your life?	○	○	○
Have you/would you consider buying a shower or water activity limb privately?	○	○	○



6. Physiotherapy

This section is about physiotherapy sessions available at or through your Disablement Services Centre (DSC).

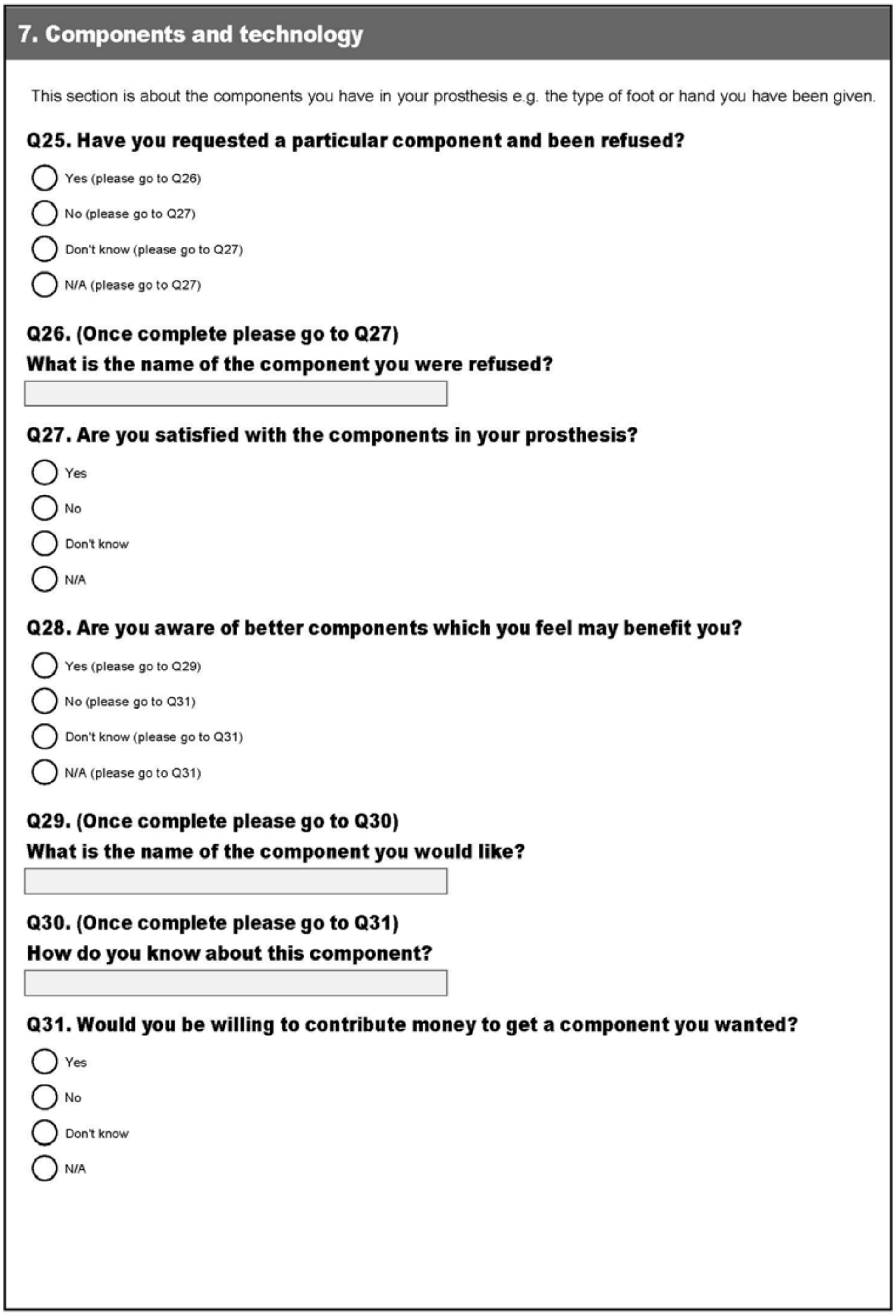
Q23. Do/did you have physiotherapy at any of the following places?

○ At the DSC
○ In the community
○ Both
○ None (please go to Q25 on the next page)

Other (please specify)

Q24.

	Yes	No	Don't know	N/A
Are/were physiotherapy sessions frequent enough for your needs?	○	○	○	○
Are/were you able to get transport to your physiotherapy sessions easily?	○	○	○	○
Are/were the physiotherapy sessions at convenient times for you?	○	○	○	○
Has your prosthetist attended your physiotherapy session if there was a problem?	○	○	○	○
Is/was your prosthetist aware of your progress in physiotherapy?	○	○	○	○



7. Components and technology

This section is about the components you have in your prosthesis e.g. the type of foot or hand you have been given.

Q25. Have you requested a particular component and been refused?

○ Yes (please go to Q26)
○ No (please go to Q27)
○ Don't know (please go to Q27)
○ N/A (please go to Q27)

Q26. (Once complete please go to Q27)
What is the name of the component you were refused?

Q27. Are you satisfied with the components in your prosthesis?

○ Yes
○ No
○ Don't know
○ N/A

Q28. Are you aware of better components which you feel may benefit you?

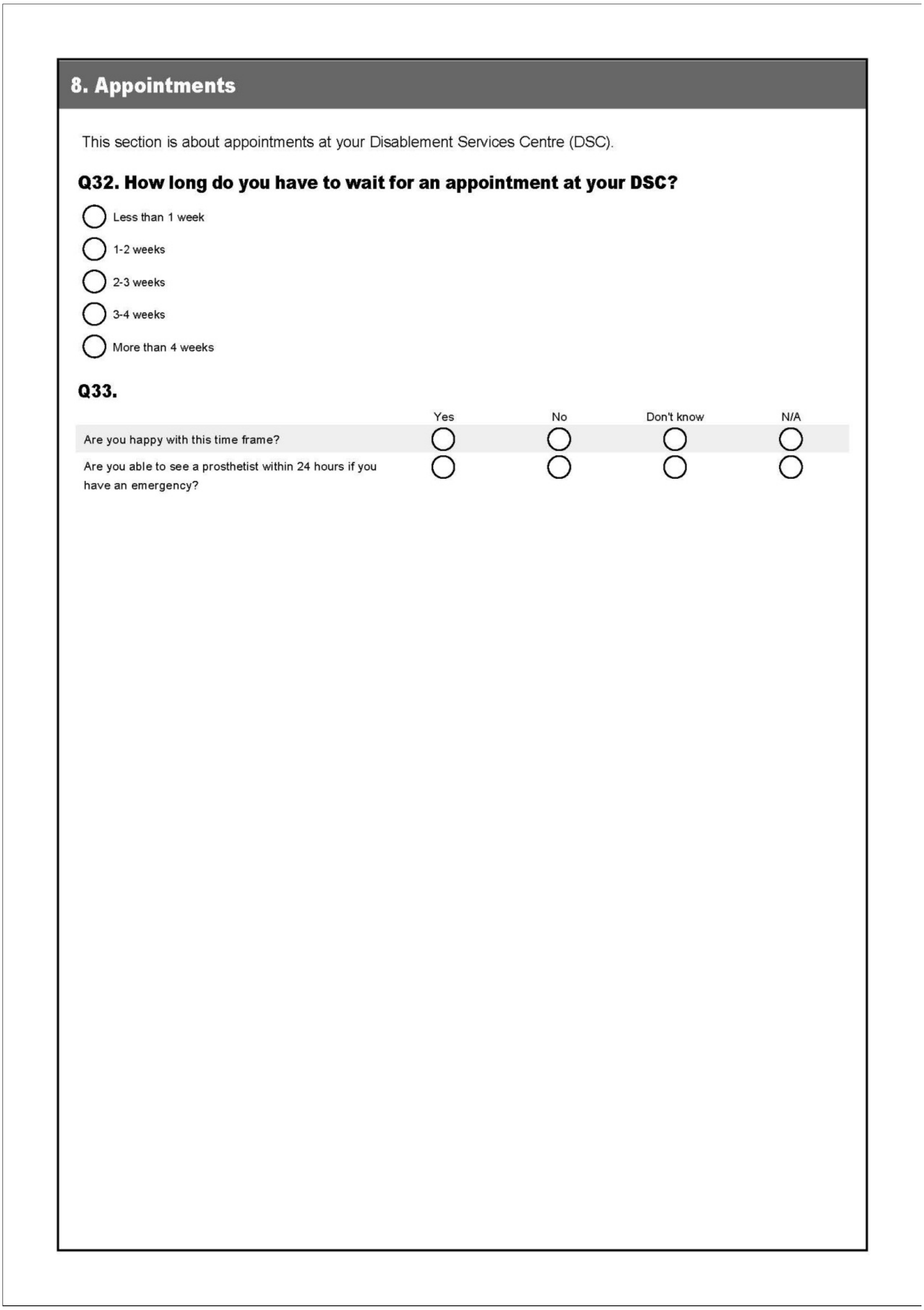
○ Yes (please go to Q29)
○ No (please go to Q31)
○ Don't know (please go to Q31)
○ N/A (please go to Q31)

Q29. (Once complete please go to Q30)
What is the name of the component you would like?

Q30. (Once complete please go to Q31)
How do you know about this component?

Q31. Would you be willing to contribute money to get a component you wanted?

○ Yes
○ No
○ Don't know
○ N/A



8. Appointments

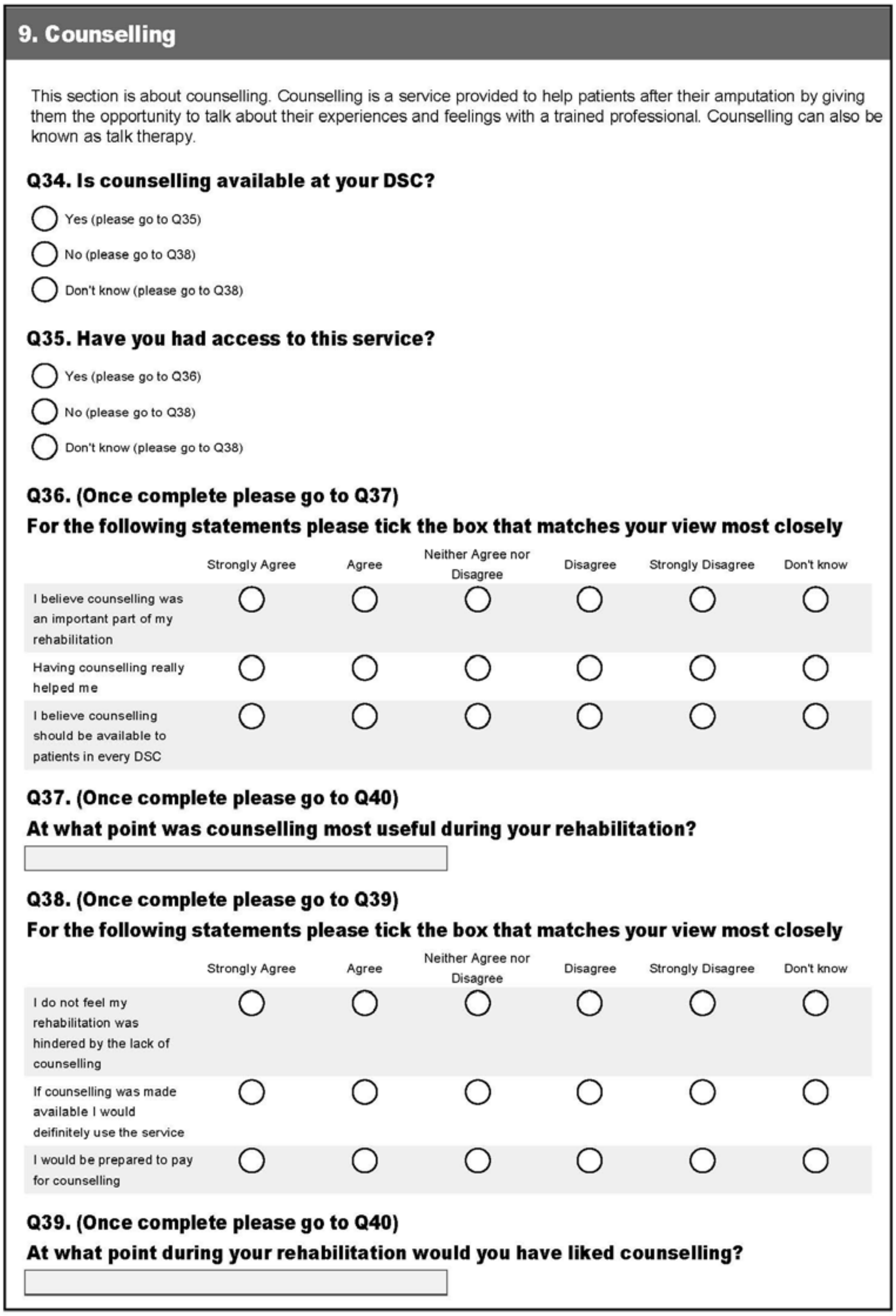
This section is about appointments at your Disablement Services Centre (DSC).

Q32. How long do you have to wait for an appointment at your DSC?

○ Less than 1 week
○ 1-2 weeks
○ 2-3 weeks
○ 3-4 weeks
○ More than 4 weeks

Q33.

	Yes	No	Don't know	N/A
Are you happy with this time frame?	○	○	○	○
Are you able to see a prosthetist within 24 hours if you have an emergency?	○	○	○	○



9. Counselling

This section is about counselling. Counselling is a service provided to help patients after their amputation by giving them the opportunity to talk about their experiences and feelings with a trained professional. Counselling can also be known as talk therapy.

Q34. Is counselling available at your DSC?

○ Yes (please go to Q35)
○ No (please go to Q38)
○ Don't know (please go to Q38)

Q35. Have you had access to this service?

○ Yes (please go to Q36)
○ No (please go to Q38)
○ Don't know (please go to Q38)

Q36. (Once complete please go to Q37)

For the following statements please tick the box that matches your view most closely

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Don't know
I believe counselling was an important part of my rehabilitation	○	○	○	○	○	○
Having counselling really helped me	○	○	○	○	○	○
I believe counselling should be available to patients in every DSC	○	○	○	○	○	○

Q37. (Once complete please go to Q40)

At what point was counselling most useful during your rehabilitation?

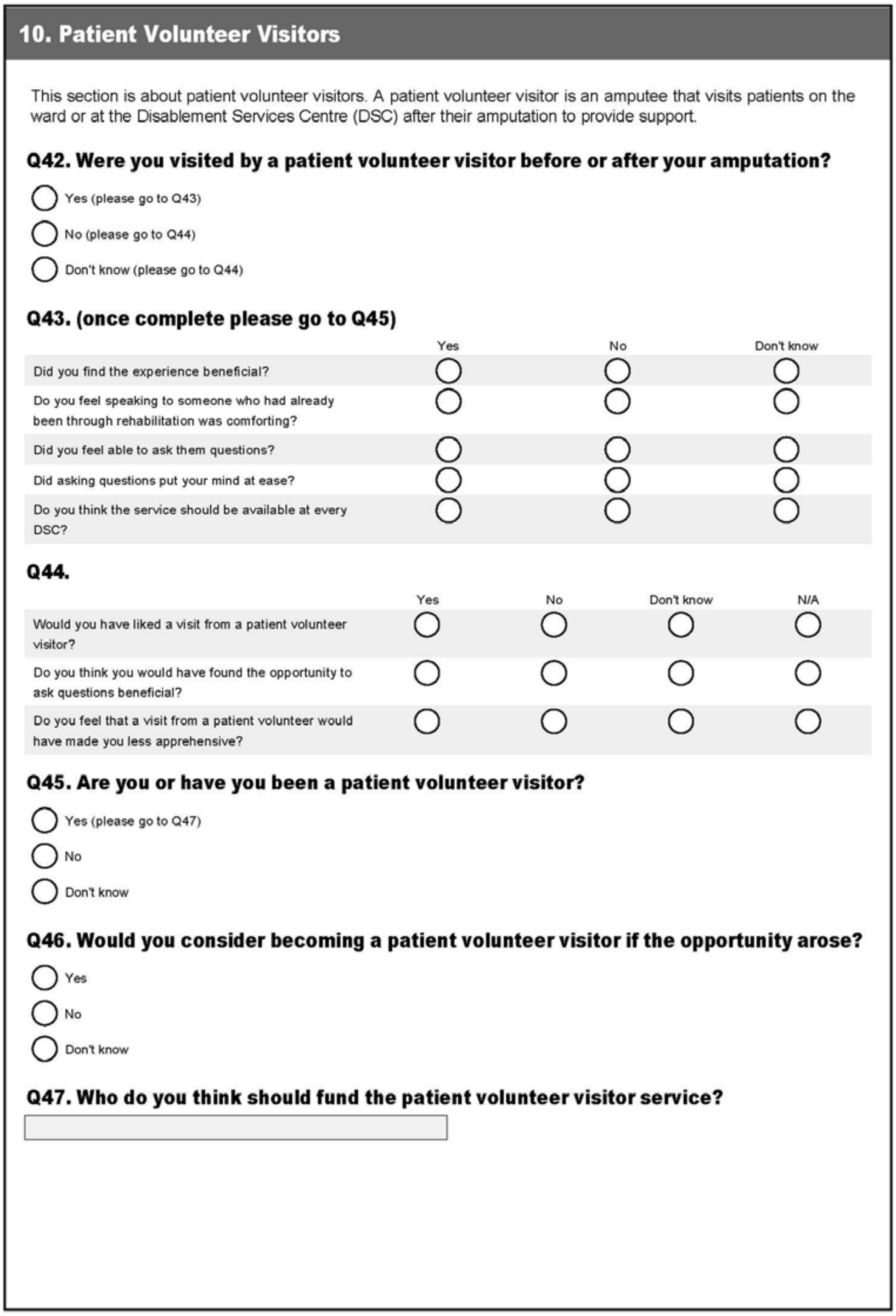
Q38. (Once complete please go to Q39)

For the following statements please tick the box that matches your view most closely

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Don't know
I do not feel my rehabilitation was hindered by the lack of counselling	○	○	○	○	○	○
If counselling was made available I would deifinitely use the service	○	○	○	○	○	○
I would be prepared to pay for counselling	○	○	○	○	○	○

Q39. (Once complete please go to Q40)

At what point during your rehabilitation would you have liked counselling?



10. Patient Volunteer Visitors

This section is about patient volunteer visitors. A patient volunteer visitor is an amputee that visits patients on the ward or at the Disablement Services Centre (DSC) after their amputation to provide support.

Q42. Were you visited by a patient volunteer visitor before or after your amputation?

○ Yes (please go to Q43)

○ No (please go to Q44)

○ Don't know (please go to Q44)

Q43. (once complete please go to Q45)

	Yes	No	Don't know
Did you find the experience beneficial?	○	○	○
Do you feel speaking to someone who had already been through rehabilitation was comforting?	○	○	○
Did you feel able to ask them questions?	○	○	○
Did asking questions put your mind at ease?	○	○	○
Do you think the service should be available at every DSC?	○	○	○

Q44.

	Yes	No	Don't know	N/A
Would you have liked a visit from a patient volunteer visitor?	○	○	○	○
Do you think you would have found the opportunity to ask questions beneficial?	○	○	○	○
Do you feel that a visit from a patient volunteer would have made you less apprehensive?	○	○	○	○

Q45. Are you or have you been a patient volunteer visitor?

○ Yes (please go to Q47)

○ No

○ Don't know

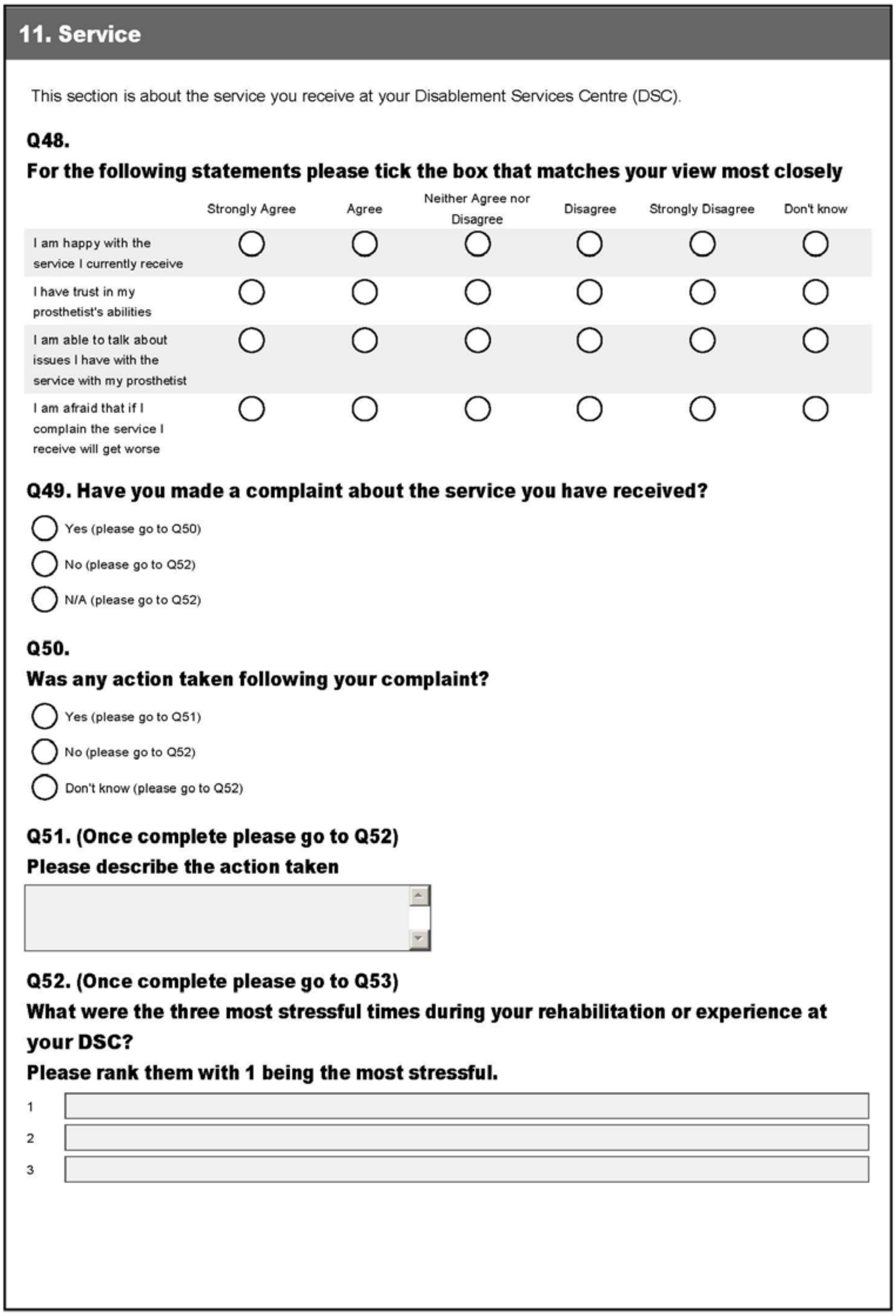
Q46. Would you consider becoming a patient volunteer visitor if the opportunity arose?

○ Yes

○ No

○ Don't know

Q47. Who do you think should fund the patient volunteer visitor service?



11. Service

This section is about the service you receive at your Disablement Services Centre (DSC).

Q48.

For the following statements please tick the box that matches your view most closely

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Don't know
I am happy with the service I currently receive	○	○	○	○	○	○
I have trust in my prosthetist's abilities	○	○	○	○	○	○
I am able to talk about issues I have with the service with my prosthetist	○	○	○	○	○	○
I am afraid that if I complain the service I receive will get worse	○	○	○	○	○	○

Q49. Have you made a complaint about the service you have received?

○ Yes (please go to Q50)
○ No (please go to Q52)
○ N/A (please go to Q52)

Q50.

Was any action taken following your complaint?

○ Yes (please go to Q51)
○ No (please go to Q52)
○ Don't know (please go to Q52)

Q51. (Once complete please go to Q52)

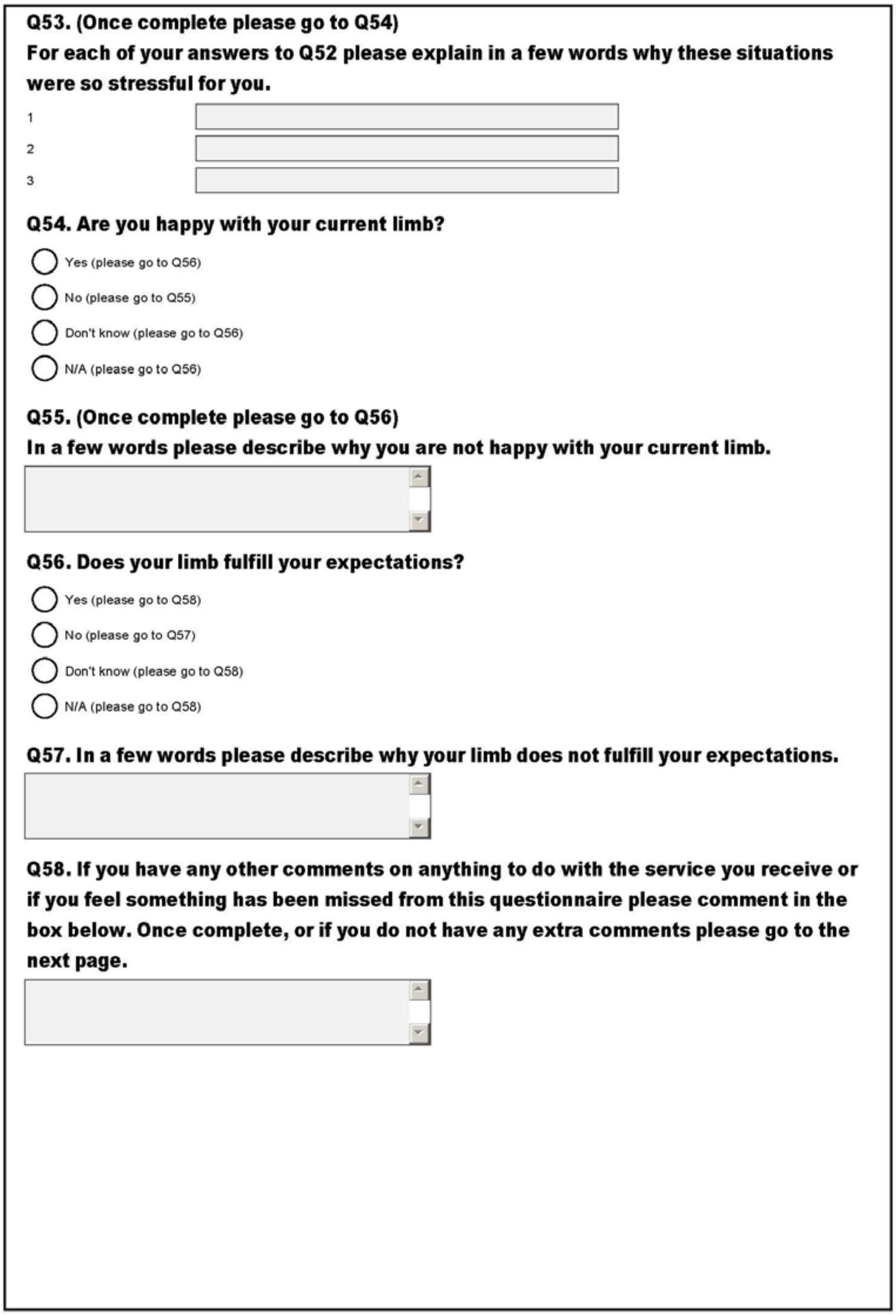
Please describe the action taken

Q52. (Once complete please go to Q53)

What were the three most stressful times during your rehabilitation or experience at your DSC?

Please rank them with 1 being the most stressful.

1
2
3



Q53. (Once complete please go to Q54)
For each of your answers to Q52 please explain in a few words why these situations were so stressful for you.

1
2
3

Q54. Are you happy with your current limb?

○ Yes (please go to Q56)
○ No (please go to Q55)
○ Don't know (please go to Q56)
○ N/A (please go to Q56)

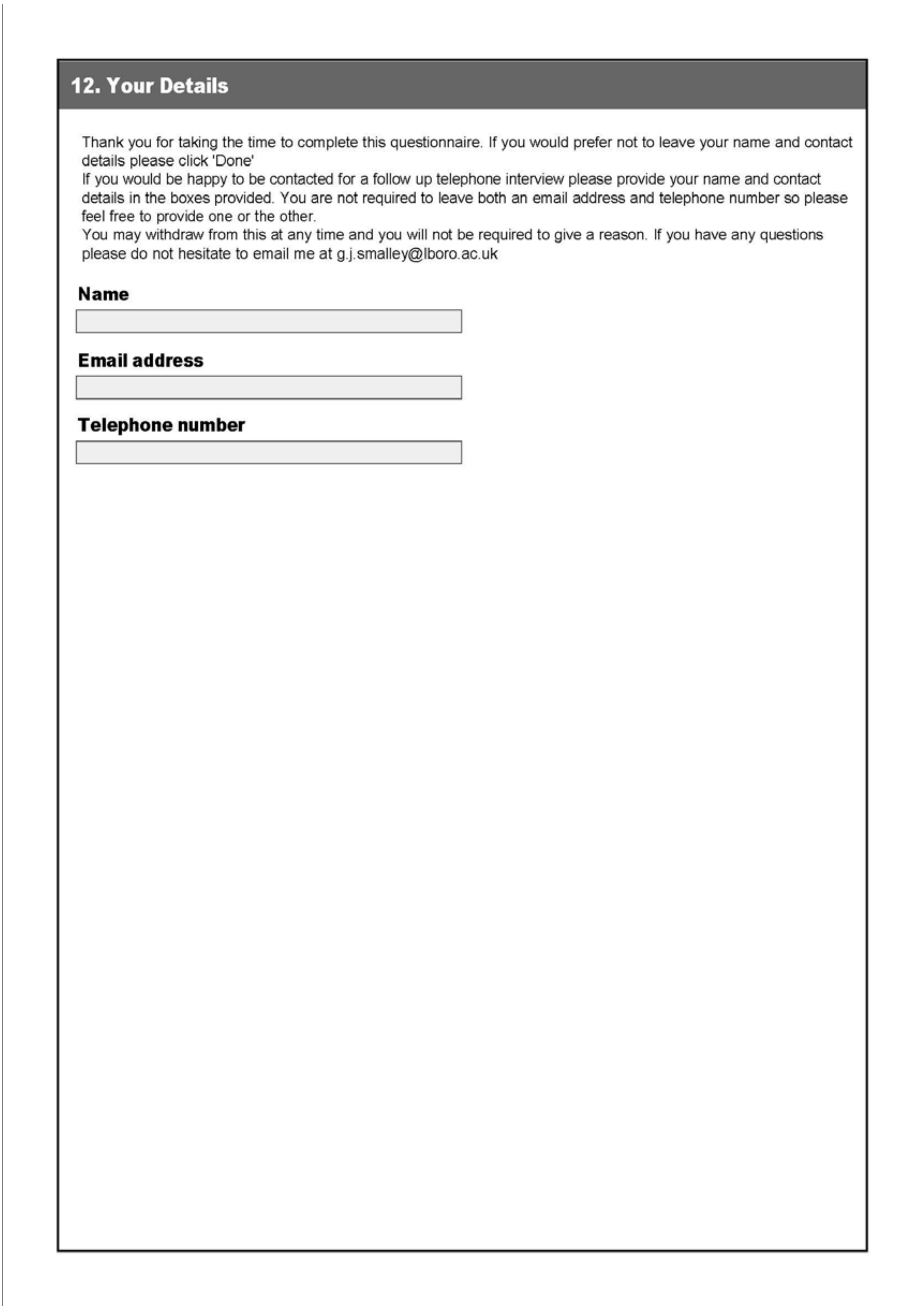
Q55. (Once complete please go to Q56)
In a few words please describe why you are not happy with your current limb.

Q56. Does your limb fulfill your expectations?

○ Yes (please go to Q58)
○ No (please go to Q57)
○ Don't know (please go to Q58)
○ N/A (please go to Q58)

Q57. In a few words please describe why your limb does not fulfill your expectations.

Q58. If you have any other comments on anything to do with the service you receive or if you feel something has been missed from this questionnaire please comment in the box below. Once complete, or if you do not have any extra comments please go to the next page.



12. Your Details

Thank you for taking the time to complete this questionnaire. If you would prefer not to leave your name and contact details please click 'Done'
If you would be happy to be contacted for a follow up telephone interview please provide your name and contact details in the boxes provided. You are not required to leave both an email address and telephone number so please feel free to provide one or the other.
You may withdraw from this at any time and you will not be required to give a reason. If you have any questions please do not hesitate to email me at g.j.smalley@lboro.ac.uk

Name

Email address

Telephone number

Appendix 5B - Detailed participant information for study 2

BK = Below Knee AK = Above knee TK = Through Knee TH= Through Hip
BE = Below Elbow AE = Above Elbow

Age	Year of Amputation	Sex	Level of Amputation
49	1963	Female	TK
50	1962	Male	BK
59	2008	Male	BK
30	2011	Female	BK
52	1977	Male	AK
61	1998	Male	BK
54	1961	Male	AK
53	1998	Female	AK
59	1996	Female	AK
51	1992	Female	BK
54	1970	Female	BK
52	1963	Male	BK
47	1980	Female	AK
54	1970	Female	BK
79	2008	Male	BK
47	1977	Female	BK
60	1968	Female	AK
44	2007	Male	BK
50	1975	Female	TH
35	2008	Female	TK
58	2008	Male	BK
57	1974	Female	AK
73	1999	Male	AK
52	2007	Female	BK
51	1986	Male	BK
49	2006	Male	BK
54	1965	Male	AK
46		Male	AK
40	1986	Female	BK
41	1997	Male	Foot
57	1957	Male	BE
66		Male	AE
45	1993	Female	BK
55	1977	Male	BK
43	1989	Male	BK
39	1995	Male	BK
82	1943	Male	AK
60	2008	Male	AK
51	2005	Male	AK
75	1988	Female	TK
58	2007	Male	BK
38	2011	Male	BK
24	2011	Male	BK
44	2009	Female	BK

Age	Year of Amputation	Sex	Level of Amputation
52	1978	Male	BK
43	1985	Male	AK
62	2000	Male	BK
69	2004	Female	BK
78	2007	Male	BK
56	1969	Female	BK
55	2008	Male	BK
75	1988	Female	TK
54	2003	Male	AK
60	2006	Female	AK
65	2003	Male	AK
44	2010	Female	BK
72	1965	Female	BE
46	2006	Female	AK
78	2007	Male	BK
68	2002	Female	AK
61	2006	Female	BK
47	2002	Male	BK
49	2010	Male	BK
42	1986	Male	TH
52	2010	Female	BK
73	1974	Male	AK
55	1973	Male	AK
62	2007	Female	BK
47	2006	Male	AK
77	1958	Male	BK
53	1999	Male	BK
40	2000	Male	BK
44	1985	Male	BK
61	1975	Female	BK
61	1976	Female	BK
61	2009	Male	BK
44	2010	Male	BK
73	1957	Male	AK
66	2007	Male	TH
45	2010	Male	BK
50	1996	Female	BK
59	1998	Female	AK
50	2005	Female	AK
66	1952	Female	BK

41	2006	Male	AK
65		Female	BK
42	2007	Female	BK
42	1987	Male	BK
42	1997	Female	AK
66	1966	Male	BE
50	1961	Female	Fingers
47	2008	Male	BK
32	2007	Male	AE
42	2008	Male	AK
55	2004	Male	AK

Appendix 5C – Level and sufficiency of information

Results showing the type of information received at different stages of treatment

Answer Options	None	Verbal	Written Information	Other	N/A	Response Count
Pre amputation visit to DSC	30 (32%)	23 (25%)	7 (8%)	3 (3%)	30 (32%)	93
On the ward before amputation	44 (48%)	17 (19%)	2 (2%)	2 (2%)	27 (29%)	92
On the ward after amputation	37 (40%)	26 (29%)	10 (11%)	2 (2%)	16 (18%)	91
First visit to DSC	6 (7%)	57 (62%)	19 (21%)	5 (5%)	5 (5%)	92
Subsequent visit to DSC	13	55	9	5	6	88

Answer Options	Leaflet	Booklet	More than one leaflet	Information pack	Response count
Pre amputation visit to DSC	2 (29%)	0 (0%)	1 (14%)	4 (57%)	7
On the ward before amputation	1 (50%)	0 (0%)	0 (0%)	1 (50%)	2
On the ward after amputation	4 (40%)	1 (10%)	1 (10%)	4 (40%)	10
First visit to DSC	8 (42%)	4 (21%)	2 (11%)	5 (26%)	19
Subsequent visit to DSC	3 (33%)	1 (12%)	2 (22%)	3 (33%)	9

The information given to individual participants was tracked through each of the five stages. Participants that had not given an answer for every stage were excluded (N = 74). This analysis revealed a number of points of interest:

1. Four percent of the participants received no information at all.
2. 27% received no information until their first visit to the DSC.
3. 54% received only verbal information.
4. 34% received some form of written information.
5. 26% received only one set of written information.
6. 7% received two sets of written information and 1% received three sets of written information.

7. 90% of the participants that stated that receiving any information pre-amputation and on the ward post amputation was not applicable, received only verbal information (N = 10).
8. 75% of the participants that stated that receiving any information pre-amputation was not applicable received only verbal information (N = 8).

Cronbach's alpha calculations

Reliability Statistics		
Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.933	.933	3

Item Statistics			
	Mean	Std. Deviation	N
I was satisfied with the overall level of information I received	3.12	1.358	85
I feel the information was given to me at the right time	3.09	1.306	85
I knew exactly what was going to happen at each stage of my rehabilitation	2.95	1.362	85

Inter-Item Correlation Matrix			
	I was satisfied with the overall level of information I received	I feel the information was given to me at the right time	I knew exactly what was going to happen at each stage of my rehabilitation
I was satisfied with the overall level of information I received	1.000	.833	.859
I feel information was given to me at the right time	.833	1.000	.779
I knew exactly what was going to happen at each stage of my rehabilitation	.859	.779	1.000

Item-Total Statistics				
	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
I was satisfied with the overall level of information I received	6.05	6.331	.897	.875
I feel the information was given to me at the right time	6.07	6.876	.836	.924
I knew exactly what was going to happen at each stage of my rehabilitation	6.21	6.502	.856	.909

Mann Whitney test: Sex – Individual items

Ranks				
	Sex	N	Mean Rank	Sum of Ranks
I was satisfied with the overall level of information I received	Male	51	43.31	2209.00
	Female	36	44.97	1619.00
	Total	87		
I feel the information was given to me at the right time	Male	50	40.73	2036.50
	Female	35	46.24	1618.50
	Total	85		
I knew exactly what was going to happen at each stage of my rehabilitation	Male	50	41.45	2072.50
	Female	35	45.21	1582.50
	Total	85		
I was concerned at times as I had not been given enough information	Male	50	42.18	2109.00
	Female	34	42.97	1461.00
	Total	84		

Test Statistics				
	I was satisfied with the overall level of information I received	I feel the information was given to me at the right time	I knew exactly what was going to happen at each stage of my rehabilitation	I was concerned at times as I had not been given enough information
Mann-Whitney U	883.000	761.500	797.500	834.000
Wilcoxon W	2209.000	2036.500	2072.500	2109.000
Z	-.312	-1.039	-.709	-.149
Asymp. Sig. (2-tailed)	.755	.299	.479	.881

All >.05 therefore no significance

Mann Whitney test: Sex – Scaled Items

Test for Reliability

Reliability Statistics	
Cronbach's Alpha	N of Items
.890	4

Test for Normality

Tests of Normality						
	Kolmogorov-Smirnov			**Shapiro-Wilk**		
	Statistic	df	Sig.	Statistic	df	Sig.
Information_Score	.126	85	.002	.938	85	.000

Not normal therefore must conduct Mann Whitney again

Mann Whitney

Ranks				
	Sex	**N**	**Mean Rank**	**Sum of Ranks**
Information_Score	Male	49	41.08	2013.00
	Female	35	44.49	1557.00
	Total	84		

Test Statistics[a]	
	Information_Score
Mann-Whitney U	788.000
Wilcoxon W	2013.000
Z	-.635
Asymp. Sig. (2-tailed)	.526

>.05 therefore no significance

Mann Whitney test: Amputation Level – Individual items

Ranks				
	Amputation Type	N	Mean Rank	Sum of Ranks
I was satisfied with the overall level of information I received	Below Knee	44	37.09	1632.00
	Above Knee	26	32.81	853.00
	Total	70		
I feel the information was given to me at the right time	Below Knee	43	36.29	1560.50
	Above Knee	26	32.87	854.50
	Total	69		
I knew exactly what was going to happen at each stage of my rehabilitation	Below Knee	43	35.77	1538.00
	Above Knee	25	32.32	808.00
	Total	68		
I was concerned at times as I had not been given enough	Below Knee	40	32.75	1310.00
	Above Knee	26	34.65	901.00
	Total	66		

information				

Test Statistics				
	I was satisfied with the overall level of information I received	I feel the information was given to me at the right time	I knew exactly what was going to happen at each stage of my rehabilitation	I was concerned at times as I had not been given enough information
Mann-Whitney U	502.000	503.500	483.000	490.000
Wilcoxon W	853.000	854.500	808.000	1310.000
Z	-.885	-.706	-.710	-.405
Asymp. Sig. (2-tailed)	.376	.480	.477	.685

All >.05 therefore no significance

Mann Whitney test: Amputation Level – Scaled Items

Ranks				
	Amputation Type	N	Mean Rank	Sum of Ranks
Information_Score	Below Knee	43	35.99	1547.50
	Above Knee	25	31.94	798.50
	Total	68		

	Information_Score
Mann-Whitney U	473.500
Wilcoxon W	798.500
Z	-.821
Asymp. Sig. (2-tailed)	.412

>.05 therefore no significance

Kruskal-Wallis test: Age – 10 year intervals – Individual items

Ranks			
	Age in 10 year gaps	N	Mean Rank
I was satisfied with the overall level of information I received	40-49	28	36.86
	50-59	30	37.40
	60-69	16	38.81
	Total	74	
I feel the information was given to me at the right time	40-49	28	35.96
	50-59	29	37.97
	60-69	15	34.67
	Total	72	
I knew exactly what was going to happen at each stage of my rehabilitation	40-49	28	36.54
	50-59	30	37.60
	60-69	15	36.67
	Total	73	

I was concerned at times as I had not been given enough information	40-49	28	34.88
	50-59	28	35.98
	60-69	15	38.13
	Total	71	

Test Statistics

	I was satisfied with the overall level of information I received	I feel the information was given to me at the right time	I knew exactly what was going to happen at each stage of my rehabilitation	I was concerned at times as I had not been given enough information
Chi-Square	.091	.289	.043	.255
df	2	2	2	2
Asymp. Sig.	.956	.866	.979	.880

All >.05 therefore no significance

Kruskal-Wallis test: Age – 10 year intervals – Scaled Items

Ranks

	Age in 10 year gaps	N	Mean Rank
Information_Score	40-49	28	35.68
	50-59	29	37.36
	60-69	15	36.37
	Total	72	

Test Statistics[a,b]

	Information_Score
Chi-Square	.094
df	2
Asymp. Sig.	.954

>.05 therefore no significance

Appendix 5D – Aims and Goals

Results of whether aims and goals were discussed at the start of rehabilitation

	Frequency	Percent
Yes	45	48.9%
No	35	38.1%
Don’t Know	7	7.6%
N/A	5	5.4%
Total	92	100%

The participants that stated that they had their aims and goals discussed were asked:

- Whether their aims and goals had been discussed to their satisfaction:
    - 82% Yes, 16% No, 2 % Don’t know (N = 49).
- Whether their aims and goals were updated regularly:
    - 45% Yes, 55% No (N = 44).

Chi-square tests: Sex

Crosstab				
	Sex	**Yes**	**No**	**Total**
Were aims and goals discussed at the start of rehabilitation?	Male	25	22	47
	Female	18	13	31
	Total	43	25	78
Are aims and goals discussed and updated regularly?	Male	10	15	25
	Female	9	8	17
	Total	19	23	42

Chi-Square Tests		
Continuity correction (due to 2x2 table)	**Were aims and goals discussed at the start of rehabilitation?**	**Are aims and goals discussed and updated regularly?**
Value	0.036	0.261
Asymp. Sig.	0.843	0.609
Phi Coefficient	0.048	0.128

Chi-square tests: Amputation Level

Crosstab				
	Amp. Level	**Yes**	**No**	**Total**
Were aims and goals discussed at the start of rehabilitation?	Below Knee	24	16	40
	Above Knee	15	10	25
	Total	39	26	65
Are aims and goals discussed and updated regularly?	Below Knee	10	11	21
	Above Knee	5	10	15
	Total	15	21	36

Chi-Square Tests		
Continuity correction (due to 2x2 table)	**Were aims and goals discussed at the start of rehabilitation?**	**Are aims and goals discussed and updated regularly?**
Value	0.000	0.264
Asymp. Sig.	1.000	0.607
Phi Coefficient	0.000	-0.143

Chi-square tests: Age – 10 year intervals

Crosstab				
	Age in 10 year gaps	**Yes**	**No**	**Total**
Were aims and goals discussed at the start of rehabilitation?	40-49	12	12	24
	50-59	16	10	26
	60-69	8	7	15
	Total	36	29	65

Chi-Square Tests	
Pearson Chi-Square	**Were aims and goals discussed at the start of rehabilitation?**
Value	0.706
Asymp. Sig.	0.703
Cramer's V	0.104

Cronbach's alpha calculations

Reliability Statistics		
Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.905	.907	2

Item Statistics			
	Mean	Std. Deviation	N
Having aims and goals helped keep me on track with my rehabilitation	4.34	.645	44
Having something to work towards was very useful/helpful	4.36	.718	44

Inter-Item Correlation Matrix		
	Having aims and goals helped keep me on track with my rehabilitation	Having something to work towards was very useful/helpful
Having aims and goals helped keep me on track with my rehabilitation	1.000	.831
Having something to work towards was very useful/helpful	.831	1.000

Item-Total Statistics			
	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation
Having aims and goals helped keep me on track with my rehabilitation	4.36	.516	.831
Having something to work towards was very useful/helpful	4.34	.416	.831

Mann Whitney test: Sex – Individual items

Ranks				
	Sex	N	Mean Rank	Sum of Ranks
Having aims and goals helped keep me on track with my rehabilitation	Male	27	24.17	652.50
	Female	17	19.85	337.50
	Total	44		
Having something to work towards was very useful/helpful	Male	28	24.82	695.00
	Female	17	20.00	340.00
	Total	45		

Test Statistics		
	Having aims and goals helped keep me on track with my rehabilitation	Having something to work towards was very useful/helpful
Mann-Whitney U	184.500	187.000
Wilcoxon W	337.500	340.000
Z	-1.205	-1.326
Asymp. Sig. (2-tailed)	.228	.185

All >.05 therefore no significance

Mann Whitney test: Sex – Scaled items

Test for Reliability

Reliability Statistics	
Cronbach's Alpha	N of Items
.905	2

Test for Normality

Tests of Normality						
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Aims_and_Goals_Had	.226	44	.000	.816	44	.000

Not normal therefore must conduct Mann Whitney again

Mann Whitney

Ranks				
	Sex	N	Mean Rank	Sum of Ranks
Aims_and_Goals_Had	Male	26	23.90	621.50
	Female	17	19.09	324.50
	Total	43		

Test Statistics

	Aims_and_Goals_Had
Mann-Whitney U	171.500
Wilcoxon W	324.500
Z	-1.308
Asymp. Sig. (2-tailed)	.191

>.05 therefore no significance

Mann Whitney test: Amputation Level – Individual items

Ranks

	Amputation Type	N	Mean Rank	Sum of Ranks
Having aims and goals helped keep me on track with my rehabilitation	Below Knee	23	19.48	448.00
	Above Knee	15	19.53	293.00
	Total	38		
Having something to work towards was very useful/helpful	Below Knee	22	20.50	451.00
	Above Knee	17	19.35	329.00
	Total	39		

Test Statistics

	Having aims and goals helped keep me on track with rehabilitation	Having something to work towards was very useful/helpful
Mann-Whitney U	172.000	176.000
Wilcoxon W	448.000	329.000
Z	-.016	-.344
Asymp. Sig.	.987	.731
Exact Sig.	1.000[a]	.769[a]

>.05 therefore no significance

Mann Whitney test: Amputation Level – Scaled Items

Ranks

	Amputation Type	N	Mean Rank	Sum of Ranks
Aims_and_Goals_Had	Below Knee	22	18.93	416.50
	Above Knee	15	19.10	286.50
	Total	37		

Test Statistics

	Aims_and_Goals_Had
Mann-Whitney U	163.500
Wilcoxon W	416.500
Z	-.049
Asymp. Sig. (2-tailed)	.961
Exact Sig. [2*(1-tailed Sig.)]	.963[a]

>.05 therefore no significance

Kruskal Wallis test: Age – 10 year intervals – Individual items

Ranks			
	Age in 10 year gaps	N	Mean Rank
Having aims and goals helped keep me on track with my rehabilitation	40-49	13	21.96
	50-59	14	17.82
	60-69	10	16.80
	Total	37	
Having something to work towards was very useful/helpful	40-49	14	23.21
	50-59	14	17.29
	60-69	10	17.40
	Total	38	

Test Statistics		
	Having aims and goals helped keep me on track with my rehabilitation	Having something to work towards was very useful/helpful
Chi-Square	1.899	3.044
df	2	2
Asymp. Sig.	.387	.218

>.05 therefore no significance

Kruskal Wallis test: Age – 10 year intervals – **Scaled items**

Ranks			
	Age in 10 year gaps	N	Mean Rank
Aims_and_Goals_Had	40-49	13	22.73
	50-59	13	16.42
	60-69	10	15.70
	Total	36	

Test Statistics	
	Aims_and_Goals_Had
Chi-Square	3.725
df	2
Asymp. Sig.	.155

>.05 therefore no significance

The participants that did not have their aims and goals discussed were asked:

- Whether they'd have liked to discuss aims and goals:
  - 67% Yes, 16.5% No, 16.5% Don't know (N = 42).
- Whether they were concerned due to the lack of discussion of their aims and goals:
  - 43% Yes, 43% No, 14% Don't know (N = 44).

Chi-square tests: Sex

Crosstab				
	Amp. Level	**Yes**	**No**	**Total**
Were you concerned by the lack of discussion of your aims and goals?	Male	13	9	22
	Female	6	7	13
	Total	19	16	35

Chi-Square Tests	
Continuity correction (due to 2x2 table)	**Were you concerned by the lack of discussion of your aims and goals?**
Value	0.153
Asymp. Sig.	0.696
Phi Coefficient	-0.125

Chi-square tests: Amputation Level

Crosstab				
	Amp. Level	**Yes**	**No**	**Total**
Were you concerned by the lack of discussion of your aims and goals?	Below Knee	6	8	14
	Above Knee	6	7	13
	Total	12	15	27

Chi-Square Tests	
Continuity correction (due to 2x2 table)	**Were you concerned by the lack of discussion of your aims and goals?**
Value	0.000
Asymp. Sig.	1.000
Phi Coefficient	-0.033

Cronbach’s alpha calculations

Reliability Statistics		
Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.885	.889	4

Item Statistics			
	Mean	Std. Deviation	N
I do not think I needed aims and goals to help with my rehabilitation	2.16	1.151	38
I was happy not having set aims and goals to work towards	2.18	1.111	38
I do not feel aims and goals need to be discussed with my prosthetist/physiotherapist	2.16	1.242	38
I feel aims and goals would have had a positive effect on my rehabilitation	1.89	.981	38

Item-Total Statistics				
	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
I do not think I needed aims and goals to help with my rehabilitation	6.24	8.240	.831	.819
I was happy not having set aims and goals to work towards	6.21	8.765	.768	.845
I do not feel aims and goals need to be discussed with my prosthetist	6.24	8.672	.662	.891
I feel aims and goals would have had a positive effect on my rehabilitation	6.50	9.500	.760	.852

Inter-Item Correlation Matrix				
	I do not think I needed aims and goals to help with my rehabilitation	I was happy not having set aims and goals to work towards	I do not feel aims and goals need to be discussed with my prosthetist	I feel aims and goals would have had a positive effect on my rehabilitation
I do not think I needed aims and goals to help with my rehabilitation	1.000	.843	.606	.709
I was happy not having set aims and goals to work towards	.843	1.000	.546	.638
I do not feel aims and goals need to be discussed with my prosthetist	.606	.546	1.000	.658
I feel aims and goals would have had a positive effect on my rehabilitation	.709	.638	.658	1.000

Mann Whitney test: Sex - Individual items

Ranks				
	Sex	N	Mean Rank	Sum of Ranks
I do not think I needed aims and goals to help with my rehabilitation	Male	25	21.30	532.50
	Female	15	19.17	287.50
	Total	40		
I was happy not having set aims and goals to work towards	Male	22	18.30	402.50
	Female	15	20.03	300.50
	Total	37		
I do not feel aims and goals need to be discussed with my prosthetist/physiotherapist	Male	24	19.67	472.00
	Female	15	20.53	308.00
	Total	39		
I feel aims and goals would have had a positive effect on my rehabilitation	Male	24	19.40	465.50
	Female	15	20.97	314.50
	Total	39		

Test Statistics				
	I do not think I needed aims and goals to help with my rehabilitation	I was happy not having set aims and goals to work towards	I do not feel aims and goals need to be discussed with my prosthetist/physiotherapist	I feel aims and goals would have had a positive effect on my rehabilitation
Mann-Whitney U	167.500	149.500	172.000	165.500
Wilcoxon W	287.500	402.500	472.000	465.500
Z	-.579	-.499	-.241	-.449
Asymp. Sig. (2-tailed)	.562	.618	.809	.653
Exact Sig. [2*(1-tailed Sig.)]	.581[a]	.636[a]	.831[a]	.679[a]

>.05 therefore no significance

Mann Whitney test: Sex -Scaled items

Test for Normality

Tests of Normality						
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Aims_and_goals_didnt	.151	38	.028	.908	38	.004

Not normal therefore must conduct Mann Whitney again

Mann Whitney

Ranks				
	Sex	N	Mean Rank	Sum of Ranks
Aims_and_goals_didnt	Male	22	18.36	404.00
	Female	15	19.93	299.00
	Total	37		

Test Statistics	
	Aims_and_goals_didnt
Mann-Whitney U	151.000
Wilcoxon W	404.000
Z	-.437
Asymp. Sig. (2-tailed)	.662
Exact Sig. [2*(1-tailed Sig.)]	.680[a]

>.05 therefore no significance

Mann Whitney test: Amputation Level – Individual items

Ranks				
	Amputation Type	N	Mean Rank	Sum of Ranks
I do not think I needed aims and goals to help with my rehabilitation	Below Knee	18	16.25	292.50
	Above Knee	12	14.38	172.50
	Total	30		
I was happy not having set aims and goals to work towards	Below Knee	15	15.00	225.00
	Above Knee	12	12.75	153.00
	Total	27		
I do not feel aims and goals need to be discussed with my prosthetist/physiotherapist	Below Knee	16	15.28	244.50
	Above Knee	13	14.65	190.50
	Total	29		
I feel aims and goals would have had a positive effect on my rehabilitation	Below Knee	16	14.28	228.50
	Above Knee	13	15.88	206.50
	Total	29		

Test Statistics				
	I do not think I needed aims and goals to help with my rehabilitation	I was happy not having set aims and goals to work towards	I do not feel aims and goals need to be discussed with my prosthetist/physiotherapist	I feel aims and goals would have had a positive affect on my rehabilitation
Mann-Whitney U	94.500	75.000	99.500	92.500
Wilcoxon W	172.500	153.000	190.500	228.500
Z	-.593	-.763	-.208	-.552
Asymp. Sig.	.553	.445	.835	.581
Exact Sig.	.573[a]	.486[a]	.846[a]	.619[a]

All >.05 therefore no significance

Mann Whitney test: Amputation Level – Scaled Items

Mann Whitney

Ranks				
	Amputation Type	N	Mean Rank	Sum of Ranks
Aims_and_goals_didnt	Below Knee	15	14.73	221.00
	Above Knee	12	13.08	157.00
	Total	27		

Test Statistics

	Aims_and_goals_didnt
Mann-Whitney U	79.000
Wilcoxon W	157.000
Z	-.542
Asymp. Sig. (2-tailed)	.588
Exact Sig. [2*(1-tailed Sig.)]	.614[a]

>.05 therefore no significance

Appendix 5E – Spare Limbs

The participants that received a spare limb were asked:

- Whether receiving a spare limb gave them peace of mind:
    - 87% Yes, 13% No (N = 55)
- If they felt having a spare limb was important
    - 94% Yes, 5% No, 1% Don’t know (N = 63)
- Whether they had to ask their prosthetist for their spare limb:
    - 27% Yes, 73% No (N = 56)

The participants that did not receive a spare limb were asked:

- If they felt having a spare limb was important:
    - 83% Yes, 17% No (N = 35)
- Whether they were happy not to receive a spare limb:
    - 26% Yes, 71% No, 3% Don’t know (N = 34)
- Whether they felt a spare limb would make a difference to their daily life:
    - 76% Yes, 21% No, 3% Don’t know (N = 33)
- Whether the reasons for not receiving a spare limb were fully explained:
    - 13% Yes, 71% No (N = 31)

When asked whether they had requested a spare limb and been refused, 7 participants answered Yes. The reasons for this refusal were as follows:

- Budget restrictions x 2
- Current limb is fixed easily x 2
- A spare limb isn’t necessary x 2
- Providing a spare limb is not standard procedure x 1

Chi-square test: Sex

Crosstab				
	Sex	**Yes**	**No**	**Total**
Is a spare limb received?	Male	33	18	51
	Female	23	10	33
	Total	56	28	84
Was a prosthetist asked for a spare limb?	Male	9	21	30
	Female	5	20	25
	Total	14	41	55

Chi-Square Tests		
Continuity correction (due to 2x2 table)	**Is a spare limb received?**	**Was a prosthetist asked for a spare limb?**
Value	0.288	0.056
Asymp. Sig.	0.591	0.813
Phi Coefficient	-0.114	0.052

Chi-square test: Amputation Level

Crosstab				
	Amp. Level	**Yes**	**No**	**Total**
Is a spare limb received?	Below Knee	28	17	45
	Above Knee	15	9	24
	Total	43	26	69
Was a prosthetist asked for a spare limb?	Below Knee	8	18	26
	Above Knee	5	13	18
	Total	13	31	44

Chi-Square Tests		
Continuity correction (due to 2x2 table)	**Is a spare limb received?**	**Was a prosthetist asked for a spare limb?**
Value	0.000	0.000
Asymp. Sig.	1.000	1.000
Phi Coefficient	0.003	-0.032

Chi-square test: Age – 10 year intervals

Crosstab				
	Age in 10 year gaps	**Yes**	**No**	**Total**
Is a spare limb received?	40-49	16	11	27
	50-59	20	7	27
	60-69	11	5	16
	Total	47	23	70

Chi-Square Tests	
Pearson Chi-Square	**Is a spare limb received?**
Value	1.367
Asymp. Sig.	0.505
Cramer’s V	0.140

Appendix 5F – Water activity and shower limbs

Study 1 revealed that strict criteria were in place for the provision of water activity and shower limbs therefore all participants were asked:

- Whether they had ever requested a water activity or shower limb:
    - 55% Yes, 39% No, 6% Don't know (N = 89)

Participants that had requested a limb were asked:

- Whether they have received or would receive the limb they requested:
    - 72% Yes, 28% No (N = 47)

Chi-square test: Sex

Crosstab				
	Sex	**Yes**	**No**	**Total**
Have you requested a shower or water activity limb?	Male	27	23	50
	Female	21	12	33
	Total	48	35	83
Have you or will you receive a shower or water activity limb?	Male	21	6	27
	Female	12	7	19
	Total	33	13	46

Chi-Square Tests		
Continuity correction (due to 2x2 table)	**Have you requested a shower or water activity limb?**	**Have you or will you receive a shower or water activity limb?**
Value	0.413	0.565
Asymp. Sig.	0.520	0.452
Phi Coefficient	0.095	-0.160

Chi-square test: Amputation Level

Crosstab				
	Amp. Level	**Yes**	**No**	**Total**
Have you requested a shower or water activity limb?	Below Knee	32	12	44
	Above Knee	12	13	25
	Total	44	25	69

Chi-Square Tests	
Continuity correction (due to 2x2 table)	**Have you requested a shower or water activity limb?**
Value	0.045
Asymp. Sig.	0.832
Phi Coefficient	-.127

Chi-square test: Age – 10 Year intervals

Crosstab				
	Age in 10 year gaps	**Yes**	**No**	**Total**
Have you requested a shower or water activity limb?	40-49	16	10	26
	50-59	21	7	28
	60-69	7	9	16
	Total	44	26	70

Chi-Square Tests	
Pearson Chi-Square	**Have you requested a shower or water activity limb?**
Value	4.290
Asymp. Sig.	0.117
Cramer's V	0.248

Participants that received their requested limb were asked:

- Whether the limb had a positive effect on their daily life
    - 73% Yes, 24% No, 3% Don't know (N = 33)
- Whether they used their limb frequently
    - 66% Yes, 31% No, 3% Don't know (N =32)

Participants that did not receive their requested limb were asked:

- Whether the reasons for not receiving the limb were fully explained
    - 40% Yes, 33% No, 27% Don't know (N = 15)
- Whether they were unhappy about not receiving the limb
    - 66% Yes, 17% No, 17% Don't know (N = 17)
- Whether they felt the limb would have a positive impact on their daily life
    - 88% Yes, 13% No (N = 16)
- Whether they would consider buying the limb they requested privately
    - 44% Yes, 38% No, 18% Don't know (N = 16)

Appendix 5G – Physiotherapy

Chi-square test: Sex

Crosstab				
	Sex	**Yes**	**No**	**Total**
Are/were physiotherapy sessions frequent enough for your needs?	Male	33	9	42
	Female	16	7	23
	Total	49	16	65
Has your prosthetist attended your physiotherapy session if there was a problem?	Male	16	16	32
	Female	19	7	26
	Total	35	23	58
Is/was your prosthetist aware of your progress in physiotherapy?	Male	26	10	36
	Female	14	8	22
	Total	40	18	58

Chi-Square Tests			
Continuity correction (due to 2x2 table)	**Are/were physiotherapy sessions frequent enough for your needs?**	**Has your prosthetist attended your physiotherapy session if there was a problem?**	**Is/was your prosthetist aware of your progress in physiotherapy?**
Value	0.255	2.301	0.155
Asymp. Sig.	0.614	0.129	0.694
Phi Coefficient	-0.100	0.235	-0.090

Chi-square test: Amputation Level

Crosstabs				
	Amp. Level	**Yes**	**No**	**Total**
Has your prosthetist attended your physiotherapy session if there was a problem?	Below Knee	19	9	28
	Above Knee	11	9	20
	Total	30	18	48
Is/was your prosthetist aware of your progress in physiotherapy?	Below Knee	22	5	27
	Above Knee	13	8	21
	Total	35	13	48

Chi-Square Tests		
Continuity correction (due to 2x2 table)	**Has your prosthetist attended your physiotherapy session if there was a problem?**	**Is/was your prosthetist aware of your progress in physiotherapy?**
Value	0.366	1.408
Asymp. Sig.	0.545	0.235
Phi Coefficient	-0.131	-0.219

Results for where participants received their physiotherapy

Answer Options	Frequency	Percent
At the DSC	50	64.1%
In the community	8	10.3%
DSC and Community	7	9.0%
None	13	16.7%
Hospital	10	12.8%
N/A	5	6.4%
Total	93	100%

All participants were asked:

- Whether physiotherapy sessions were frequent enough for their needs
    - 65% Yes, 21% No, 9 % Don't know, 5% N/A (N = 77)
- Whether they could transport to physiotherapy sessions easily
    - 62% Yes, 12% No, 1% Don't know, 25% N/A (N = 76)
- Whether physiotherapy sessions were at convenient times
    - 85% Yes, 4% No, 3% Don't know, 8% N/A (N = 75)
- Whether their prosthetist had attended physiotherapy if there was a problem
    - 48% Yes, 31% No, 3% Don't know, 19% N/A (N = 75)
- Whether their prosthetist was aware of their progress in physiotherapy
    - 55% Yes, 24% No, 11% Don't know, 11% N/A (N = 75)

Appendix 5H – Components and technology

The current budget restrictions described by the participants in Study 1, mean that patients are not always prescribed with the most technologically advanced components available, therefore all participants were asked:

- Whether they had requested a particular component and had been refused:
    - 30% Yes, 61% No, 2% Don't know, 7% N/A (N = 88)
- Whether they were satisfied with the components in their prosthesis:
    - 65% Yes, 26% No, 4.5% Don't know, 4.5% N/A (N = 88)
- Whether they would be willing to contribute money to obtain a component they desired:
    - 47% Yes, 30% No, 17% Don't know, 6% (N = 88)
- Whether they were aware of other components that they feel would benefit them:
    - 40% Yes, 37% No, 18% Don't know, 5% N/A (N = 87)

The participants were then asked where they had found the information about components they felt may benefit them.

Results for where participants had found information on components

Answer Options	Frequency	Percent
Internet	13	34.2%
Other amputees	6	15.8%
Prosthetist	3	7.9%
Media	3	7.9%
Combination of internet and other amputees	6	15.8%
Other	7	18.4%
Total	38	100%

The technology or components that participants had been refused were:

- 81% Components such as a knee or foot.
- 11% Socket improvements.
- 8% A cosmetic limb. (N = 26)

Chi-square test: Sex

Crosstab				
	Sex	**Yes**	**No**	**Total**
Have you requested a particular component and been refused?	Male	18	31	49
	Female	8	22	30
	Total	26	53	79
Are you satisfied with the components in your prosthesis?	Male	35	14	49
	Female	21	9	30
	Total	56	23	79
Are you aware of better components which you feel may benefit you?	Male	23	19	42
	Female	12	12	24
	Total	35	31	66

Chi-Square Tests			
Continuity correction (due to 2x2 table)	**Have you requested a particular component and been refused?**	**Are you satisfied with the components in your prosthesis?**	**Are you aware of better components which you feel may benefit you?**
Value	0.459	0.000	0.014
Asymp. Sig.	0.498	1.000	0.907
Phi Coefficient	-0.104	-0.015	-0.046

Chi-square test: Amputation Level

Crosstabs				
	Amp. Level	**Yes**	**No**	**Total**
Have you requested a particular component and been refused?	Below Knee	12	29	41
	Above Knee	10	15	25
	Total	22	44	66
Are you satisfied with the components in your prosthesis?	Below Knee	31	11	42
	Above Knee	16	7	23
	Total	47	18	65
Are you aware of better components which you feel may benefit you?	Below Knee	16	17	33
	Above Knee	12	9	21
	Total	28	26	54

Chi-Square Tests			
Continuity correction (due to 2x2 table)	**Have you requested a particular component and been refused?**	**Are you satisfied with the components in your prosthesis?**	**Are you aware of better components which you feel may benefit you?**
Value	0.394	0.006	0.117
Asymp. Sig.	0.530	0.940	0.733
Phi Coefficient	0.110	-0.045	0.084

Appendix 5I – Appointments

Results for length of wait for an appointment

	Frequency	**Percent**
Less than 1 week	16	18.2
1-2 weeks	34	38.6
2-3 weeks	30	34.1
3-4 weeks	6	6.8
More than 4 weeks	2	2.3
Total	88	100.0

Participants were then asked:

- Whether they were happy with this time frame
  - 67% Yes, 27% No, 5% Don't know, 1% answered N/A. (N = 88)
- Whether they were able to see their prosthetist within 24 hours in an emergency:
  - 69% Yes, 11% No, 17% Don't know and 4% N/A. (N = 83)

Chi-square test: Sex

Crosstab				
	Sex	**Yes**	**No**	**Total**
Are you happy with this time frame?	Male	35	15	50
	Female	23	9	32
	Total	58	24	82

Chi-Square Test	
Continuity correction (due to 2x2 table)	**Are you happy with this time frame?**
Value	0.000
Asymp. Sig.	1.000
Phi Coefficient	0.020

Chi-square test : Amputation Level

Crosstab				
	Amp. Level	**Yes**	**No**	**Total**
Are you happy with this time frame?	Below Knee	30	12	42
	Above Knee	19	7	26
	Total	49	19	68

Chi-Square Tests	
Continuity correction (due to 2x2 table)	**Are you happy with this time frame?**
Value	537.000
Asymp. Sig.	1440.000
Phi Coefficient	-.146

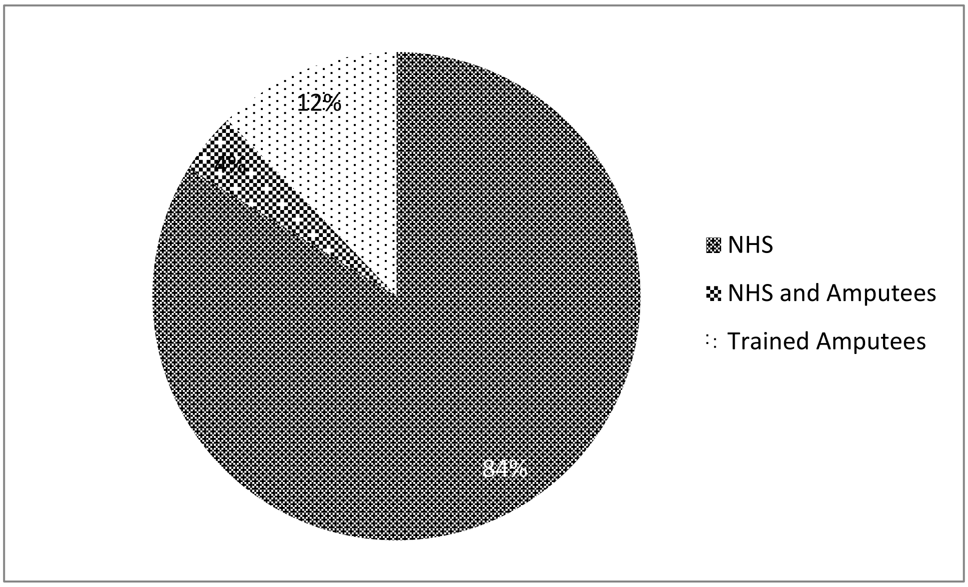
Appendix 5J – Counselling

In the initial study, most DSCs visited stated that they believed counselling to be a very important part of rehabilitation, therefore participants were asked:

- Whether counselling is available at their DSC:
    - 51% Yes, 19% No, 30% Don't know (N = 87)
- Whether they had access to the counselling service:
    - 59% Yes, 41% No (N = 65)
- Whether they felt the counselling service should be free:
    - 97% Yes, 3% Don't know (N = 83)

Results for who participants feel should provide counselling

	Frequency	Percent
NHS	62	83.8
NHS and Amputees	3	4.0
Trained Amputees	9	12.2



Who participants felt should provide counselling

Chi-square test: Sex

Crosstab				
	Sex	**Yes**	**No**	**Total**
Is counselling available at your DSC?	Male	28	7	35
	Female	16	10	26
	Total	44	17	61
Have you had access to this service?	Male	17	24	41
	Female	10	14	24
	Total	27	38	65

Chi-Square Tests		
Continuity correction (due to 2x2 table)	**Is counselling available at your DSC?**	**Have you had access to this service?**
Value	1.694	1.000
Asymp. Sig.	0.193	0.000
Phi Coefficient	-0.204	0.002

Chi-square test: Amputation Level

Crosstab				
	Amp. Level	**Yes**	**No**	**Total**
Is counselling available at your DSC?	Below Knee	23	7	30
	Above Knee	14	8	22
	Total	37	15	52
Have you had access to this service?	Below Knee	13	20	33
	Above Knee	8	11	19
	Total	21	31	52

Chi-Square Tests		
Continuity correction (due to 2x2 table)	**Is counselling available at your DSC?**	**Have you had access to this service?**
Value	0.511	0.000
Asymp. Sig.	0.475	1.000
Phi Coefficient	-0.142	0.27

Participants that had counselling: Cronbach’s alpha calculations

Reliability Statistics		
Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.893	.893	2

Item Statistics			
	Mean	Std. Deviation	N
Having counselling really helped me	3.35	1.427	31
I believe counselling was an important part of my rehabilitation	3.58	1.409	31

Inter-Item Correlation Matrix		
	Having counselling really helped me	I believe counselling was an important part of my rehabilitation
Having counselling really helped me	1.000	.806
I believe counselling was an important part of my rehabilitation	.806	1.000

Item-Total Statistics				
	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation
Having counselling really helped me	3.58	1.985	.806	.650
I believe counselling was an important part of my rehabilitation	3.35	2.037	.806	.650

Mann Whitney test: Sex –Individual items

Ranks				
	Sex	N	Mean Rank	Sum of Ranks
I believe counselling was an important part of my rehabilitation	Male	19	17.58	334.00
	Female	12	13.50	162.00
	Total	31		
Having counselling really helped me	Male	19	16.74	318.00
	Female	13	16.15	210.00
	Total	32		
I believe counselling should be available to patients in every DSC	Male	22	20.09	442.00
	Female	16	18.69	299.00
	Total	38		

Test Statistics[b]			
	I believe counselling was an important part of my rehabilitation	Having counselling really helped me	I believe counselling should be available to patients in every DSC
Mann-Whitney U	84.000	119.000	163.000
Wilcoxon W	162.000	210.000	299.000
Z	-1.262	-.177	-.462
Asymp. Sig. (2-tailed)	.207	.859	.644
Exact Sig.	.236[a]	.880[a]	.715[a]

All >.05 therefore no significance

Mann Whitney test: Sex –Scaled items

Test for Reliability

Reliability Statistics	
Cronbach's Alpha	N of Items
.700	3

Test for Normality

Tests of Normality						
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Counselling_Had	.202	31	.002	.884	31	.003

Not normal therefore must conduct Mann Whitney again

Mann Whitney

Test Statistics[b]	
	Counselling_Had
Mann-Whitney U	95.000
Wilcoxon W	173.000
Z	-.782
Asymp. Sig. (2-tailed)	.434
Exact Sig. [2*(1-tailed Sig.)]	.459[a]

>.05 therefore no significance

Mann Whitney test: Amputation Level –Individual items

Ranks				
	Amputation Type	N	Mean Rank	Sum of Ranks
I believe counselling was an important part of my rehabilitation	Below Knee	14	12.86	180.00
	Above Knee	10	12.00	120.00
	Total	24		
Having counselling really helped me	Below Knee	14	14.00	196.00
	Above Knee	11	11.73	129.00
	Total	25		
I believe counselling should be available to patients in every DSC	Below Knee	16	13.19	211.00
	Above Knee	13	17.23	224.00
	Total	29		

Test Statistics[b]			
	I believe counselling was an important part of my rehabilitation	Having counselling really helped me	I believe counselling should be available to patients in every DSC
Mann-Whitney U	65.000	63.000	75.000
Wilcoxon W	120.000	129.000	211.000
Z	-.306	-.785	-1.567
Asymp. Sig. (2-tailed)	.759	.433	.117
Exact Sig. [2*(1-tailed Sig.)]	.796[a]	.467[a]	.215[a]

>.05 therefore no significance

Mann Whitney test: Amputation Level –Scaled items

Mann Whitney

Ranks				
	Amputation Type	N	Mean Rank	Sum of Ranks
Counselling	Below Knee	14	13.50	189.00
	Above Knee	10	11.10	111.00
	Total	24		

Test Statistics[b]	
	Counselling
Mann-Whitney U	56.000
Wilcoxon W	111.000
Z	-.834
Asymp. Sig. (2-tailed)	.404
Exact Sig. [2*(1-tailed Sig.)]	.437[a]

>.05 therefore no significance

Participants that did not have counselling

Cronbach's alpha calculations

Reliability Statistics		
Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.711	.710	3

Item Statistics			
	Mean	Std. Deviation	N
If counselling was made available I would definitely use the service	3.43	1.253	54
I would be prepared to pay for counselling	2.39	1.188	54
I was not concerned by the lack of counselling	2.57	1.253	54

Inter-Item Correlation Matrix			
	If counselling was made available I would definitely use the service	I would be prepared to pay for counselling	I was not concerned by the lack of counselling
If counselling was made available I would definitely use the service	1.000	.558	.574
I would be prepared to pay for counselling	.558	1.000	.215
I was not concerned by the lack of counselling	.574	.215	1.000

Item-Total Statistics				
	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
If counselling was made available I would definitely use the service	4.96	3.621	.727	.353
I would be prepared to pay for counselling	6.00	4.943	.436	.730
I was not concerned by the lack of counselling	5.81	4.644	.452	.716

Mann Whitney test: Sex –Individual items

Ranks				
	Sex	N	Mean Rank	Sum of Ranks
If counselling was made available I would definitely use the service	Male	36	29.90	1076.50
	Female	23	30.15	693.50
	Total	59		
I would be prepared to pay for counselling	Male	37	29.23	1081.50
	Female	21	29.98	629.50
	Total	58		
I do not feel my rehabilitation was hindered by a lack of counselling	Male	35	28.76	1006.50
	Female	24	31.81	763.50
	Total	59		

Test Statistics			
	If counselling was made available I would deifinitely use the service	I would be prepared to pay for counselling	I do not feel my rehabilitation was hindered by a lack of counselling
Mann-Whitney U	410.500	378.500	376.500
Wilcoxon W	1076.500	1081.500	1006.500
Z	-.056	-.168	-.697
Asymp. Sig. (2-tailed)	.955	.867	.486

>.05 therefore no significance

T- test: Sex –Scaled items

Test for Reliability

Reliability Statistics	
Cronbach's Alpha	N of Items
.711	3

Test for Normality

Tests of Normality						
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Counselling_not	.107	54	.177	.960	54	.072

Considered normal as sig. value is >.05 therefore can conduct ANOVA

T-Test

Group Statistics					
	Sex	N	Mean	Std. Deviation	Std. Error Mean
Counselling_not	Male	33	8.21	3.110	.541
	Female	21	8.67	2.708	.591

t-test for Equality of Means		**Counselling_not_2**	
		Equal variances assumed	Equal variances not assumed
t		-.550	-.567
df		52	46.978
Sig. (2-tailed)		.585	.573
Mean Difference		-.455	-.455
Std. Error Difference		.827	.801
95% Confidence Interval of the Difference	Lower	-2.114	-2.067
	Upper	1.205	1.158

Sig> .05 therefore not significant

Mann Whitney test: Amputation Level –Individual items

Ranks				
	Amputation Type	N	Mean Rank	Sum of Ranks
If counselling was made available I would deifinitely use the service	Below Knee	30	23.83	715.00
	Above Knee	18	25.61	461.00
	Total	48		
I would be prepared to pay for counselling	Below Knee	30	24.93	748.00
	Above Knee	18	23.78	428.00
	Total	48		
I do not feel my rehabilitation was hindered by a lack of counselling	Below Knee	30	24.17	725.00
	Above Knee	18	25.06	451.00
	Total	48		

Test Statistics			
	If counselling was made available I would deifinitely use the service	I would be prepared to pay for counselling	I do not feel my rehabilitation was hindered by a lack of counselling
Mann-Whitney U	250.000	257.000	260.000
Wilcoxon W	715.000	428.000	725.000
Z	-.439	-.289	-.222
Asymp. Sig. (2-tailed)	.660	.773	.824

T- test: Amputation Level –Scaled Items

Group Statistics					
	Amputation Type	N	Mean	Std. Deviation	Std. Error Mean
Counselling_not	Below Knee	28	8.46	2.687	.508
	Above Knee	17	8.76	3.562	.864

t-test for Equality of Means		**Counselling_not_2**	
		Equal variances assumed	Equal variances not assumed
t		-.321	-.300
df		43	27.051
Sig. (2-tailed)		.750	.767
Mean Difference		-.300	-.300
Std. Error Difference		.935	1.002
95% Confidence Interval of the Difference	Lower	-2.187	-2.357
	Upper	1.586	1.756

>.05 therefore no significance

Kruskal Wallis test : Age – 10 year intervals –Individual items

Ranks			
	Age in 10 year gaps	N	Mean Rank
If counselling was made available I would definitely use the service	40-49	16	27.81
	50-59	22	25.05
	60-69	13	25.38
	Total	51	
I would be prepared to pay for counselling	40-49	17	27.91
	50-59	21	24.71
	60-69	12	23.46
	Total	50	
I do not feel my rehabilitation was hindered by a lack of counselling	40-49	18	27.97
	50-59	22	26.00
	60-69	11	22.77
	Total	51	

Test Statistics			
	If counselling was made available I would definitely use the service	I would be prepared to pay for counselling	I do not feel my rehabilitation was hindered by a lack of counselling
Chi-Square	.374	.817	.889
df	2	2	2
Asymp.Sig.	.829	.665	.641

All >.05 therefore no significance

ANOVA: Age – 10 year intervals- Scaled Items

Descriptives								
	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
40-49	16	9.2500	2.95522	.73881	7.6753	10.8247	5.00	14.00
50-59	20	8.6000	3.13553	.70113	7.1325	10.0675	3.00	14.00
60-69	10	7.8000	3.11983	.98658	5.5682	10.0318	4.00	13.00
Total	46	8.6522	3.04935	.44960	7.7466	9.5577	3.00	14.00

ANOVA					
	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	13.035	2	6.517	.691	.506
Within Groups	405.400	43	9.428		
Total	418.435	45			

>.05 therefore no significance

Appendix 5K – Patient Volunteer Visitors

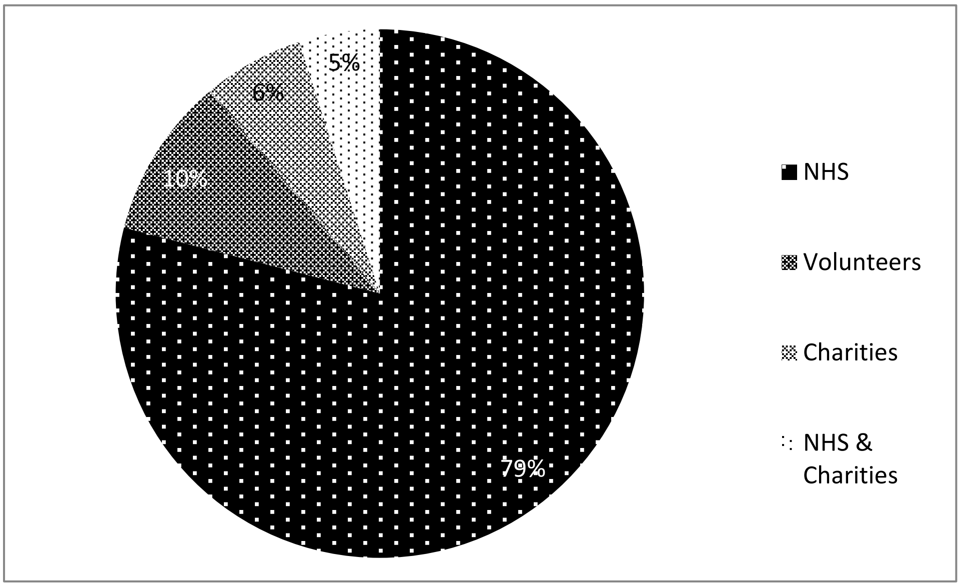
Patient volunteer visitors are active at some, but not all, DSCs, therefore there was value in asking participants whether they felt the service is worthwhile. Participants were therefore asked:

- Whether they had been visited by a volunteer visitor:
  - 20% Yes, 79% No, 1% Don't know (N = 87)
- Whether they would consider becoming a volunteer visitor
  - 93% Yes, 5% No, 2% Don't know (N = 55)

Participants were then asked who they felt should fund the patient volunteer visitor service, the results of which are illustrated in the table and figure below.

Results for who participants feel should fund the PVV service

	Frequency	Percent
NHS	64	79.0%
Volunteers	8	9.9%
Charities	5	6.2%
NHS and Charities	4	4.9%
Total	84	100%



Who patients felt should fund the PVV service

Chi-square test: Sex

Crosstab				
	Sex	**Yes**	**No**	**Total**
Were you visited by a patient volunteer visitor before or after your amputation?	Male	12	40	52
	Female	5	29	34
	Total	17	69	86

Chi-Square Tests	
Continuity correction (due to 2x2 table)	**Were you visited by a patient volunteer visitor before or after your amputation?**
Value	0.457
Asymp. Sig.	0.499
Phi Coefficient	-0.103

Participants that had a visit from a volunteer were asked

- Whether they found the experience beneficial:
    - 84% Yes, 5% No, 11% Don’t know. (N = 19)
- Whether speaking to someone that had been through the experience already was comforting:
    - 78% Yes, 11% No, 11% Don’t know. (N = 18)
- Whether they felt able to ask them questions:
    - 83% Yes, 6% No, 11% Don’t know. (N = 18)
- Whether asking questions put their mind at ease:
    - 78% Yes, 6% No, 17% Don’t know. (N = 18)
- Whether they felt the service should be available at every DSC:
    - 79% Yes, 21% Don’t know. (N = 19)

Participants that did not receive a visit from a volunteer were asked:

- Whether they would have liked a visit from a volunteer:
    - 71% Yes, 13% No, 9% Don’t know, 7% N/A. (N = 70)
- Whether they thought they would have found the opportunity to ask questions beneficial:
    - 76% Yes, 10% No, 9% Don’t know, 6% N/A. (N = 70)
- Whether they thought a visit from a patient volunteer would have made them less apprehensive:
    - 62% Yes, 13% No, 14% Don’t know, 10% N/A. (N = 69)

Appendix 5L – Service

Chi-square test: Sex

Crosstab				
	Sex	**Yes**	**No**	**Total**
Are you happy with your current limb?	Male	36	15	51
	Female	18	9	27
	Total	54	24	78
Does your limb fulfil your expectations?	Male	33	15	48
	Female	16	12	28
	Total	49	27	76

Chi-Square Tests		
Continuity correction (due to 2x2 table)	**Are you happy with your current limb?**	**Does your limb fulfil your expectations?**
Value	0.010	0.595
Asymp. Sig.	0.921	0.440
Phi Coefficient	-0.040	-0.117

Chi-square test: Amputation Level

Crosstab				
	Amp. Level	**Yes**	**No**	**Total**
Are you happy with your current limb?	Below Knee	29	13	42
	Above Knee	15	8	23
	Total	44	21	65
Does your limb fulfil your expectations?	Below Knee	26	15	41
	Above Knee	15	8	23
	Total	41	23	64

Chi-Square Tests		
Continuity correction (due to 2x2 table)	**Are you happy with your current limb?**	**Does your limb fulfil your expectations?**
Value	0.001	0.000
Asymp. Sig.	0.969	1.000
Phi Coefficient	-0.039	0.018

Cronbach’s alpha calculations

Reliability Statistics		
Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.900	.902	4

Item Statistics

	Mean	Std. Deviation	N
I am happy with the service I currently receive	3.65	1.270	82
I have trust in my prosthetist's abilities	4.02	1.154	82
I am able to talk about issues I have with the service with my prosthetist	3.94	1.190	82
I am afraid that if I complain the service I receive will get worse	3.37	1.272	82

Inter-Item Correlation Matrix

	I am happy with the service I currently receive	I have trust in my prosthetist's abilities	I am able to talk about issues I have with the service with my prosthetist	I am not afraid that if I complain the service I receive will get worse
I am happy with the service I currently receive	1.000	.789	.721	.608
I have trust in my prosthetist's abilities	.789	1.000	.765	.599
I am able to talk about issues I have with the service with my prosthetist	.721	.765	1.000	.700
I am afraid that if I complain the service I receive will get worse	.608	.599	.700	1.000

Item-Total Statistics				
	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
I am happy with the service I currently receive	11.33	10.347	.790	.867
I have trust in my prosthetist's abilities	10.95	10.911	.810	.861
I am able to talk about issues I have with the service with my prosthetist	11.04	10.604	.826	.854
I am not afraid that if I complain the service I receive will get worse	11.61	10.957	.694	.903

Mann Whitney test: Sex –Individual items

Ranks				
	Sex	N	Mean Rank	Sum of Ranks
I am happy with the service I currently receive	Male	52	42.37	2203.00
	Female	33	44.00	1452.00
	Total	85		
I have trust in my prosthetist's abilities	Male	52	45.48	2365.00
	Female	32	37.66	1205.00
	Total	84		
I am able to talk about issues I have with the service with my prosthetist	Male	52	45.56	2369.00
	Female	32	37.53	1201.00
	Total	84		
I am afraid that if I complain the service I receive will get worse	Male	52	42.80	2225.50
	Female	31	40.66	1260.50
	Total	83		

Test Statistics[a]				
	I am happy with the service I currently receive	I have trust in my prosthetist's abilities	I am able to talk about issues I have with the service with my prosthetist	I am afraid that if I complain the service I receive will get worse
Mann-Whitney U	825.000	677.000	673.000	764.500
Wilcoxon W	2203.000	1205.000	1201.000	1260.500
Z	-.313	-1.525	-1.555	-.402
Asymp. Sig.	.754	.127	.120	.688

>.05 therefore no significance

Mann Whitney test: Sex –Scaled Items

Test for Reliability

Reliability Statistics	
Cronbach's Alpha	N of Items
.888	4

Test for Normality

Tests of Normality						
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Service	.126	83	.002	.907	83	.000

Not normal therefore must conduct Mann Whitney again

Mann Whitney

Ranks				
	Sex	N	Mean Rank	Sum of Ranks
Service	Male	52	44.14	2295.50
	Female	31	38.40	1190.50
	Total	83		

Test Statistics	
	Service
Mann-Whitney U	694.500
Wilcoxon W	1190.500
Z	-1.055
Asymp. Sig. (2-tailed)	.292

Mann Whitney test: Amputation Level – Individual items

Ranks				
	Amputation Type	N	Mean Rank	Sum of Ranks
I am happy with the service I currently receive	Below Knee	44	36.02	1585.00
	Above Knee	26	34.62	900.00
	Total	70		
I have trust in my prosthetist's abilities	Below Knee	44	36.75	1617.00
	Above Knee	26	33.38	868.00
	Total	70		
I am able to talk about issues I have with the service with my prosthetist	Below Knee	44	36.55	1608.00
	Above Knee	26	33.73	877.00
	Total	70		
I am afraid that if I complain the service I receive will get worse	Below Knee	44	37.11	1633.00
	Above Knee	26	32.77	852.00
	Total	70		

Test Statistics				
	I am happy with the service I currently receive	I have trust in my prosthetist's abilities	I am able to talk about issues I have with the service with my prosthetist	I am afraid that if I complain the service I receive will get worse
Mann-Whitney U	549.000	517.000	526.000	501.000
Wilcoxon W	900.000	868.000	877.000	852.000
Z	-.294	-.713	-.593	-.890
Asymp. Sig.	.769	.476	.553	.374

Mann Whitney test: Amputation Level – Scaled Items

Ranks				
	Amputation Type	N	Mean Rank	Sum of Ranks
Service	Below Knee	44	36.92	1624.50
	Above Knee	26	33.10	860.50
	Total	70		

Test Statistics[a]	
	Service
Mann-Whitney U	509.500
Wilcoxon W	860.500
Z	-.764
Asymp. Sig. (2-tailed)	.445

>.05 therefore no significance

Kruskal Wallis test: Age – 10 year intervals – Individual items

Ranks			
	Age in 10 year gaps	N	Mean Rank
I am happy with the service I currently receive	40-49	27	37.24
	50-59	28	32.38
	60-69	16	40.25
	Total	71	
I have trust in my prosthetist's abilities	40-49	27	38.19
	50-59	27	35.48
	60-69	16	31.00
	Total	70	
I am able to talk about issues I have with the service with my prosthetist	40-49	27	36.63
	50-59	27	35.37
	60-69	16	33.81
	Total	70	
I am afraid that if I complain the service I receive will get worse	40-49	27	33.94
	50-59	27	36.28
	60-69	16	36.81
	Total	70	

Test Statistics[a,b]

	I am happy with the service I currently receive	I have trust in my prosthetist's abilities	I am able to talk about issues I have with the service with my prosthetist	I am afraid that if I complain the service I receive will get worse
Chi-Square	1.833	1.410	.215	.280
df	2	2	2	2
Asymp. Sig.	.400	.494	.898	.869

All >.05 therefore no significance

Kruskal Wallis test: Age – 10 year intervals – scaled items

Ranks

	Age in 10 year gaps	N	Mean Rank
Service	40-49	27	35.78
	50-59	27	35.30
	60-69	16	35.38
	Total	70	

Test Statistics

	Service
Chi-Square	.008
df	2
Asymp. Sig.	.996

>.05 therefore no significance

Chapter 6 – Study 3

Appendix 6A: Detailed participant information for Study 3

BK = Below Knee AK = Above knee TK = Through Knee TH= Through Hip
AE = Above Elbow

Age	Year of Amputation	Sex	Level of Amputation
62	2007	Female	BK
44	2010	Male	BK
60	2008	Male	AK
52	2010	Female	BK
52	2007	Female	BK
44	2007	Male	BK
41	2006	Male	AK
	2011	Male	BK
45	2010	Male	BK
44	2010	Female	BK
66	2007	Male	TH
79	2008	Male	BK
61	2009	Male	BK
32	2007	Male	AE
44	2009	Female	BK
35	2008	Female	TK
49	2006	Male	BK
58	2007	Male	BK
46	2006	Female	AK
61	2006	Female	BK
55	2008	Male	BK

Appendix 6B: Full results for the information wanted at different stages of rehabilitation

	Pre Amputation Visit to DSC	On Ward Pre Amputation	On Ward Post Amputation	First Visit to DSC	Subsequent Visits to DSC
Driving - car adaptions	0	0	3	0	0
DVLA	0	0	2	1	0
Centre specific information	0	0	3	4	0
Centre will recall you for check ups	0	0	0	0	2
Contact information for support	1	1	6	1	1
Hospital Transport	0	0	1	1	0
How to get Orthopaedic consult	0	0	0	1	0
User Group Information	0	0	0	1	0
Who Staff were and What they'd be doing	2	1	7	3	0
Disability living allowance	0	0	4	0	1
Mobility Scheme Driving	0	0	1	0	0
Radar Keys	0	0	1	0	0
How amputation alters sex life	1	0	0	0	0
Seeing someone succeed	0	0	2	1	1
What life is like as an amputee	4	5	10	2	0
Prosthesis Information	0	0	0	0	0
Can't start rehab until stump is fully healed	0	0	2	1	0
Construction of prosthesis	0	0	0	0	1
General info on prostheses	2	1	6	2	2
How many socks to wear before going back to see prosthetist	0	0	0	0	1
How to choose shoes	0	0	0	0	1
Keep going back if leg isn't comfortable	0	0	0	2	3
Problems with good leg caused by amputation	0	0	0	0	1
Problems with liners	0	0	0	0	1

Skin sores	0	0	0	2	3
Tattooing Stump	0	0	0	0	1
Transfers printed onto limb	0	0	0	0	1
What is a Prosthesis	2	0	1	1	0
What prostheses are available on the NHS	2	0	3	3	6
What to do if there is a problem with your prosthesis	0	0	0	0	4
What to do if you have a fall	0	0	0	1	5
Crutches	0	0	0	1	0
Exercises to help rehab	1	0	5	1	0
Expectation management	1	0	2	1	0
Improving lifestyle e.g. diet and fitness improves healing	0	0	4	2	0
Learning to walk	2	0	3	3	0
Occupational Therapy	0	0	1	0	1
Pain during defacation due to pressure on stump	0	0	1	0	0
PALS	0	0	0	1	0
Phantom pain	1	0	1	0	1
Physiotherapy	0	1	6	2	2
Prescription	0	0	0	0	1
Prescription process	0	0	0	0	2
Social Services	0	0	2	0	1
Stages of Rehabilitation	3	0	9	5	0
Timeline for recovery	1	0	4	1	0
What happens after amputation	3	4	8	1	0
What happens at DSC	2	0	5	5	0
What happens during casting	0	0	5	4	0
What happens when you go home	1	0	6	0	1
What to expect at rehabilitation	5	2	9	5	1

Wheelchair use	0	0	0	1	0
Wound care	0	0	6	0	1
Counselling	1	0	2	2	0
Explaining to children about amputation	1	0	0	0	0
Mental health Problems	0	0	1	1	1
Support for partner	2	0	5	3	0
Charities	0	1	5	1	1
Disabled sports	0	0	1	0	1
Local sports facilities - wheelchair and amputee friendly	0	0	1	1	0

Appendix 6C: Full results for the media suggested for information delivery

	CD ROM	Diagram	DVD	Explanation from staff	Introduction to Staff	Photo Booklet	Poster	Poster with photos of staff	Verbal	Visit from Amputee	Visit to Centre	Website	Written Information
Driving - car adaptions	1	0	0	0	0	0	0	0	0	0	0	0	3
DVLA	1	0	0	0	0	0	0	0	0	0	0	0	3
Centre specific information	0	0	2	0	0	0	0	0	0	0	0	0	2
Centre will recall you for check ups	0	0	0	0	0	0	0	0	1	0	0	0	1
Contact information for support	0	0	0	0	0	0	0	0	1	0	0	2	6
Hospital Transport	0	0	0	0	0	0	0	0	0	0	0	0	2
How to get Orthopaedic consult	0	0	0	0	0	0	0	0	0	0	0	0	1
User Group Information	0	0	0	0	0	0	0	0	0	0	0	0	1
Who staff were what they'd be doing	2	0	2	0	1	1	0	1	1	0	0	1	7
Disability living allowance	1	0	1	0	0	0	0	0	0	0	0	1	2
Mobility Scheme Driving	0	0	0	0	0	0	0	0	0	0	0	0	1
Radar Keys	0	0	0	0	0	0	0	0	0	0	0	0	1
How amputation alters sex life	0	0	0	0	0	0	0	0	1	0	0	0	1
Seeing someone succeed	1	0	1	0	0	0	1	0	0	1	0	0	0
What life is like as an amputee	0	0	0	0	0	0	0	0	1	13	1	1	2
Can't start rehab until stump is fully healed	1	0	1	0	0	0	0	0	1	0	0	0	2
Construction of prosthesis	0	0	0	0	0	0	0	0	0	0	0	0	0
Explanation of why components aren't allowed or suitable	0	0	0	0	0	0	0	0	0	0	0	0	0
General info on prostheses	2	0	2	0	0	0	0	0	0	3	0	1	4
How many socks to wear before going back to see prosthetist	0	0	0	0	0	0	0	0	0	0	0	0	1
How to choose shoes	0	0	0	1	0	0	0	0	0	0	0	0	1
Keep going back if leg isn't comfortable	1	0	0	0	0	0	0	0	0	0	0	1	5

Levels of amputation	0	0	0	0	0	0	0	0	0	0	0	0	0
Problems with good leg caused by amputation	0	0	0	0	0	0	0	0	1	0	0	0	1
Problems with liners	0	0	0	0	0	0	0	0	0	0	0	0	1
Skin sores	1	0	0	0	0	0	0	0	0	0	0	0	5
Tattooing Stump	0	0	0	0	0	0	0	0	1	0	0	0	1
Transfers printed onto limb	1	0	0	0	0	0	0	0	0	0	0	0	1
What is a Prosthesis	0	0	1	0	0	0	1	0	0	0	0	0	1
What prostheses are available on the NHS	2	0	1	0	0	0	0	0	1	0	0	0	8
What to do if there is a problem with your prosthesis	1	0	0	0	0	0	0	0	1	0	0	0	4
What to do if you have a fall	1	0	0	0	0	0	0	0	0	0	0	0	5
Crutches	0	0	0	0	0	0	0	0	1	0	0	0	1
Electric Wheelchairs vs Buggys	0	0	0	0	0	0	0	0	0	0	0	0	0
Exercises to help rehab	4	0	1	0	0	0	0	0	1	0	0	1	6
Expectation management	0	0	0	0	0	0	0	0	1	0	0	0	1
Improving lifestyle e.g. diet and fitness improves healing	4	0	2	0	0	0	0	0	1	0	0	1	4
Learning to walk	1	0	1	0	0	0	0	0	1	0	0	0	4
Occupational Therapy	0	0	0	0	0	0	0	0	0	0	0	0	1
PALS	0	0	0	0	0	0	0	0	1	0	0	0	1
Phantom pain	1	0	0	0	0	0	0	0	0	0	0	0	1
Physiotherapy	1	0	1	0	0	0	0	0	0	0	0	0	1
Prescription	2	0	3	0	0	0	0	0	1	0	0	0	9
Prescription process	0	0	0	0	0	0	0	0	0	0	0	0	1
Social Services	0	0	0	2	0	0	0	0	0	0	0	0	0
Stages of Rehabilitation	0	0	0	0	0	0	0	0	0	0	0	0	2
Timeline for recovery	3	0	5	0	0	0	0	0	2	2	0	1	6

What happens after amputation	4	0	2	0	0	0	0	0	1	0	0	1	4
What happens at DSC	4	0	3	0	0	0	0	0	3	1	0	1	9
What happens during casting	3	0	2	0	0	0	0	0	2	1	1	1	6
What happens when you go home	2	0	4	0	0	0	0	0	1	0	0	0	6
What to expect at rehabilitation	1	0	2	0	0	0	0	0	2	0	0	0	5
Wheelchair use	4	0	3	0	0	0	1	0	4	1	1	1	11
Wound care	0	0	0	1	0	0	0	0	1	0	0	0	1
Counselling	2	0	1	0	0	0	0	0	0	0	0	1	5
Explaining to children about amputation	1	0	1	0	0	0	0	0	1	0	0	1	1
Mental health Problems	0	0	0	0	0	0	0	0	0	0	0	0	1
Support for partner	0	0	0	0	0	0	0	0	1	0	0	0	1
Charities	0	0	0	0	0	0	0	0	2	0	0	0	4
Disabled sports	1	0	0	0	0	0	0	0	0	0	0	2	6
Local sports facilities - wheelchair and amputee friendly	0	0	0	0	0	0	0	0	0	0	0	0	1
Driving - car adaptions	0	0	0	0	0	0	0	0	0	0	0	0	2

Appendix 6D: Full results for the information mentioned by participants in 10 year age groups

	Age = 30-39	Age = 40-49	Age = 50-59	Age = 60-69	Age = 70-79
Driving - car adaptions	0	1	0	3	0
DVLA	0	1	1	2	0
Centre specific information	1	1	0	3	1
Centre will recall you for check ups	0	1	0	1	0
Contact information for support	2	2	1	3	0
Hospital Transport	1	0	0	1	0
How to get Orthopaedic consult	0	1	0	0	0
User Group Information	1	0	0	0	0
Who staff were what they'd be doing	2	3	2	3	1
Disability living allowance	0	2	1	1	0
Mobility Scheme Driving	0	0	0	1	0
Radar Keys	0	0	0	1	0
How amputation alters sex life	0	1	0	0	0
Seeing someone succeed	0	1	0	2	0
What life is like as an amputee	2	5	3	6	0
Can't start rehab until stump is fully healed	0	2	0	0	0
Construction of prosthesis	0	0	0	1	0
Explanation of why components aren't allowed or suitable	0	0	0	1	0
General info on prostheses	2	1	4	5	0
How many socks to wear before going back to see prosthetist	0	0	0	1	0
How to choose shoes	0	0	0	1	0
Keep going back if leg isn't comfortable	1	1	2	1	0
Levels of amputation	1	0	0	0	0
Problems with good leg caused by amputation	0	1	0	0	0
Problems with liners	0	1	0	0	0
Skin sores	1	2	0	2	0

Tattooing Stump	0	1	0	0	0
Transfers printed onto limb	0	1	0	0	0
What is a Prosthesis	0	1	0	4	0
What prostheses are available on the NHS	2	4	4	3	0
What to do if there is a problem with your prosthesis	1	1	0	2	0
What to do if you have a fall	1	1	0	3	0
Crutches	0	1	0	0	0
Electric Wheelchairs vs Buggys	0	0	0	1	0
Exercises to help rehab	0	4	3	2	0
Expectation management	1	1	0	1	0
Improving lifestyle e.g. diet and fitness improves healing	0	3	2	2	0
Learning to walk	1	3	1	3	0
Occupational Therapy	0	1	0	1	0
PALS	0	1	0	0	0
Phantom pain	0	1	0	0	0
Physiotherapy	0	1	0	1	0
Prescription	1	5	1	3	0
Prescription process	0	0	0	1	0
Social Services	0	0	1	1	0
Stages of Rehabilitation	0	1	0	2	0
Timeline for recovery	2	5	2	3	0
What happens after amputation	1	2	2	3	0
What happens at DSC	2	5	2	5	0
What happens during casting	1	6	3	3	0
What happens when you go home	1	4	0	4	0
What to expect at rehabilitation	2	2	0	3	0
Wheelchair use	2	5	2	5	0
Wound care	0	1	0	0	0
Counselling	1	3	1	1	0

Explaining to children about amputation	2	2	1	1	0
Mental health Problems	1	0	0	0	0
Support for partner	0	1	0	0	0
Charities	1	0	1	4	0
Disabled sports	2	2	2	2	0
Local sports facilities - wheelchair and amputee friendly	1	1	0	0	0
Driving - car adaptions	1	1	1	0	0