UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES

A Participatory Design Approach to Developing Upper Limb Prostheses for Children and Young People

by

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PhD Thesis

April 2014

Word Count: 76,739

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF HEALTH SCIENCES

Health Sciences

Doctor of Philosophy

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By Tara Stacey Sims

Upper limb difference can have both a physical and psychological effect on a child, impacting on functional abilities and activity participation. Fortunately upper limb loss amongst children is a rare condition. This, however, has resulted in a 'postcode lottery' in the provision of services and a lack of clinical guidance. Research that has been conducted into children's satisfaction with devices is scarce and has relied on parent proxy reports and quantitative measures. The views of children and young people have, therefore, not been satisfactorily explained. The views of parents and professionals are also vital to the improvement of services and devices, but are not well represented in previous research.

In order to 'give voice' to the users of paediatric upper limb prostheses and involve them in the development of new devices, a participatory design approach (the BRIDGE methodology), using focus groups and interviews, was taken.

The data was subjected to a number of thematic analyses, revealing the following:

- Children have an ambivalent relationship with prostheses and are dissatisfied with the devices available to them;
- Adjusting to having a child with limb loss is a difficult and complex process for parents and prostheses have a part to play in this process;
- Decisions regarding the prescription of prostheses are influenced by factors related to the client (child and parents), the devices available, and the institution/profession within which the prescriber works.

The findings supported previous assertions that prostheses for children need to be lighter, more comfortable, more useful and more attractive. Additionally, they should be safe, quick and easy to use, and natural (in both appearance and movement).

The findings have implications for clinical practice, device development and research with children. Approaches to assessment and treatment should move away from a medicalised view of using a prosthesis to 'treat' a 'deficiency' and should focus on the needs of the family unit. Device development needs to focus on task-specificity, modularity, comfort and weight. Finally, this study has demonstrated that children and young people can and should be involved as equal partners in the development of daily living equipment.

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Academic Thesis: Declaration of Authorship

I, TARA SIMS, declare that this thesis and the work presented in it are my own and have been generated by me as the result of my own original research.

A Participatory Design Approach to Developing Upper Limb Prostheses for Children and Young People

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;

2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;

3. Where I have consulted the published work of others, this is always clearly attributed;

4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;

5. I have acknowledged all main sources of help;

6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

7. Either none of this work has been published before submission, or parts of this work have been published as: [please list references below]:

Signed:
....

Date:...

ACKNOWLEDGMENTS

Many thanks to my supervisors, Dr Maggie Donovan-Hall and Dr Cheryl Metcalf, who provided fantastic support and guidance throughout and read numerous drafts of my chapters. I am also hugely grateful to the other members of the Child Prosthetics Research Team at the University of Southampton, particularly Dr Andy Cranny (who designed and produced the prototype devices) and Dr Paul Chappell and Thomas Redman, who assisted with the second round of focus groups. Thank you also to the members of the Advisory Board for the study who aided with the development of ideas to enable the study to progress. Thanks to the University of Southampton for awarding me a PhD Fellowship, providing me with the financial means to complete this project.

Thank you also to my partner, Thomas Gebhart, who supported me throughout this long journey, providing love, reassurance and encouragement when I needed it most.

Finally, a huge thank you to the children, young people, parents and professionals, who shared their time, views and feelings to enable this project to take place. Thanks also to Reach Charity Ltd and ISPO (The International Society of Prosthetics and Orthotics) for their assistance with recruitment.

Definitions and Abbreviations of Terms used by the Child Prosthetic Research Team

Acquired amputation: The surgical removal of a limb(s) due to complications associated with disease or trauma.

Bilateral amputee: A person who is missing or has had amputated both arms or both legs.

Body image: The awareness and perception of one's own body in relation to both appearance and function.

Body-powered prosthesis (upper extremity): An arm prosthesis powered by movement in the upper extremity portion of the body, specifically the muscles of the shoulder(s), neck and back. The motion of these movements is then captured by a harness system that generates tension in a cable, allowing a *terminal device* (hook or prosthetic hand) to open and close.

Cosmesis: Used to describe the outer, aesthetic covering of a prosthesis.

Donning and doffing: Putting on and taking off a prosthesis, respectively.

Functional prosthesis: Designed with the primary goal of aiding an individual's anatomical function, such as providing support or stability or assisting with manual tasks.

Limb difference: The congenital absence or malformation of limbs or the absence of any part of an extremity (arm or leg) due to surgical or traumatic amputation.

Myoelectrics: A technology used mainly in upper limb prosthetics to control the prosthesis via muscle contraction using electrical signals from the muscles.

Prosthesis: An artificial limb, usually an arm or a leg, which provides a replacement for the amputated or missing limb. "Prostheses" is the plural.

Prosthetics: The profession of providing those with limb difference functional and/or cosmetic restoration of missing or underdeveloped limbs.

Prosthetist: A person involved in the science and art of prosthetics; one who designs and fits artificial limbs.

Range of motion: The amount of movement a limb has in a specific direction.

Shoulder Disarticulation: The loss of the entire arm from the shoulder joint. The shoulder girdle may also be missing.

Split hooks: *Terminal devices* for upper extremity amputees consisting of two hook-shaped fingers that are operated (opened and closed) through the action of a harness and cable system.

Terminal devices: Devices attached to the wrist unit of an upper extremity prosthesis that provide some aspect of normal hand function, such as grasp, release, etc.

Transverse Humeral Deficiency: The absence of the arm at any level from below the shoulder to just above the elbow.

Transverse Radial Deficiency: The absence of the arm at any level from below the elbow to above the wrist.

Unilateral: An amputation that affects only one side of the body (opposite of *bilateral*).

Introduction

This document is submitted in consideration of the award of PhD and will present findings from a participatory-design based study of upper limb prostheses for children and young people.

Thesis overview

This thesis will begin with a reflection on personal and professional development and the original motivations for engaging in this study. Chapter one will present an introduction to the research area and background to the research. This will include a discussion of the current situation with regard to provision of upper limb prostheses for children in the UK, incorporating statistical information on children with limb difference, exploration of current practice and description of devices that are currently available. Chapter one will also explore the existing literature on children's use of, and views on, upper limb prostheses and involving users in the development of health technologies and upper limb prostheses specifically. Chapter two will present the methodology for the study, exploring the researcher's philosophical stance and how this has influenced, and been applied to, the BRIDGE approach to participatory design. Chapter two will also outline the methods used to carry out the study, including description of the research design, the recruitment process, methods of data collection and analysis, and ethical considerations. The third chapter presents findings from each of the study's stages. The final chapter presents a discussion of these findings and includes implications of the findings and recommendations derived from these, before moving on to reflect on the strengths and limitations of the study and possible future research in the area.

Reflective account of personal and professional development and motivations for the study

This section describes influences from my clinical and academic experience which have motivated me to carry out this research. Details of supervisory meetings, training undertaken and conferences attended whilst studying at the University of Southampton will also be included in this section.

Introduction

I first became interested in childhood and disability studies when still at secondary school due to personal circumstances within my family. It was this interest that motivated me to select Developmental Psychology for a bachelor's degree at Sussex University. Following my degree I decided to pursue a career within children's disability and began working at Whizz-Kidz, a charity providing mobility equipment for children with disabilities. As an administrator on the Equipment Provisions team I quickly became aware of the 'postcode lottery' that existed within NHS wheelchair services and the inequity of service and funding between regions and centres. The term 'postcode lottery' is commonly used in political and media contexts to refer to seemingly random national variations in the provision and quality of public services, including those provided by the NHS (Butler 2000). The 'postcode lottery' within the NHS is reported to be a significant issue across many health conditions, where the theory of an equitable 'national' service greatly differs from the reality of services received (Butler 2000).

I also learned from spending time with the Mobility Therapists at Whizz-Kidz that having a career in which I could have an impact on the independence and quality of life of disabled children was something that appealed to me. I, therefore, made the decision to train as an occupational therapist (OT). During my pre-registration MSc in OT at Brighton University my desire to work as a children's OT developed and I completed an elective placement at Chailey Heritage Clinical Services, a highly regarded school for children with disabilities. Whilst at Chailey, I worked with the children at their weekly cycling group, amongst other things, and this inspired me to carry out a qualitative study on children's experiences of cycling for my MSc research project. Following my OT training I completed a two year rotational position to give me a thorough grounding in the everyday practice of OT before gaining a position as a children's OT in a social care team, where I have worked since 2009, retaining a part-time position, working one day a week, throughout my PhD studies.

As a children's OT, I work with children who have permanent and substantial disabilities including physical disabilities, learning disabilities and behavioural and psychological difficulties. In my clinical work, I have encountered children and young people with upper limb difference only a limited number of times, but my goals for intervention remain the same across the children I work with: to improve their independence and well-being and reduce the stresses on the family system as a whole. Working within a social care setting, I work for a local council and my everyday practice is, therefore, influenced by a legal and political framework. Regularly within my work, I am required to balance my role as an advocate for my service user with the often seemingly rigid criteria set by central government and the local authority for access to the provision of equipment, adaptations and therapy. I have also become aware through networking with other colleagues, professional networks, training and conferences, that provision between local authorities vary considerably.

Working on the ‘front line’ as a health professional, I am able to make differences to the lives of individual children and their families but am largely disempowered when it comes to evoking change within the bigger picture of health and social care provision. This frustration of working within a system I viewed as unfair motivated me to pursue a career in research alongside continuing my clinical work. This led to my decision to seek out a PhD studentship, which involved working with children with disabilities in a research study which could have the potential to bring about change and improvement in the lives of these children. This is where the journey of my PhD studentship at the University of Southampton began.

The PhD studentship advertised by the University was about exploring the views of children on upper limb prostheses in order to improve the provision of prosthetic devices for this service user group. This topic appealed to me immensely as it was clearly concerned with involving children as active research participants and listening to their views. The evident emphasis on a practical outcome of the research (specifically, improving provision of prosthetics) was also something that interested me. Finally, being situated in a clinical area in which OTs work (upper limb prosthetics) and concerning the service user group with which I work (children with disabilities), I felt it was the ideal studentship for me.

Throughout my PhD I have received regular supervision with both my lead supervisor (Dr Maggie Donovan-Hall) and co-supervisor (Dr Cheryl Metcalf) and on a less frequent basis with Dr Andy Cranny (Electronic and Computer Science [ECS]), the fourth member of the research team for this study. Dr Cranny’s role in the project was to create prototype prostheses based on the findings of the qualitative research.

Additionally, during the planning stages of the research, regular meetings were held with all members of the cross-faculty Child Prosthetics Research Team, which as well as the researcher and supervisors involved in this study, includes colleagues from ECS (Faculty of Physical Sciences and Engineering) who are working on complementary studies. External consultants working locally in the field of prosthetics were also invited to some of these meetings to act in an advisory capacity for this study. Having a multidisciplinary research team which combines both researchers and clinicians enabled the study's progress to be shaped by the views of psychologists, OTs, engineers and prosthetists, helping to ensure that the research maintained a practical and clinical focus. One of the main developments influenced by this skill mix, combined with my identified affinity with a transformative research paradigm (which requires the consultation of all main stake holders) was the identification of parents and professionals as users of upper limb prostheses for children, and the subsequent decision to involve them as study participants.

In addition to attending the University's Health Sciences Research Training Programme, external training courses specific to the learning needs of the researcher in relation to this study were attended. These courses included Focus Group Facilitation (University of Surrey), Group Work with Children (Brighton and Hove City Council) and Conducting Research with Children and Young People (WISERD Institute, University of Cardiff). These training courses were identified in order to develop my group-work skills with children to include groups which have a research, rather than therapeutic, focus.

Within the University setting, findings have been presented at the Postgraduate Research Forum, the Rehabilitation and Health Technologies Research Group meeting and the Neurorehabilitation Research Group meeting. Externally, I have given oral presentations at an International Society of Prosthetics and Orthotics (ISPO) conference on the Psychosocial Impact of Disability and Limb Loss (Sydney, Australia), Trent International Prosthetics Symposium (TIPS) (Loughborough, UK), the College of Occupational Therapy (COT) Annual Conference (Glasgow, UK), the BACPAR[1], ISPO and BAPO[2] Collaborative Conference (Sheffield, UK) and the ISPO World Congress (Hyderabad, India). I have had an abstract accepted for presentation at the World Federation of

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[1] British Association of Chartered Physiotherapists in Amputee Rehabilitation

[2] The British Association of Prosthetists and Orthotists

Occupational Therapists (WFOT) Congress in June 2014 (Yokohama, Japan), for which I have received the International Travel Award from the COT. I have also been invited to present at the OT Show in November 2014 (Birmingham, UK). Additionally, I have given poster presentations at the COT Children, Young People and Families Conference (UWE, Bristol, UK); TIPS (Loughborough, UK) and the University of Southampton's Faculty of Health Sciences Postgraduate Research Conference, for which I received the Best Poster prize. PowerPoint presentation slides and posters from these conferences can be found in Appendix A.

1. Chapter One: Background to the Research

The following chapter will present an introduction and background to the research area and is divided into three main sections. The first of these discusses the current situation in upper limb prosthetics for children/young people in the UK, including statistical information on children with limb difference, exploration of current practice and available devices, and the impact of upper limb difference on children and young people. In section two the existing literature on children's use of, and satisfaction with, upper limb prostheses will be reviewed. In the third section, research exploring involving users in the development of health technologies and upper limb prostheses, specifically, will be discussed.

1.1 The current situation in upper limb prosthetics for children/young people

As mentioned in the introduction, my clinical experience with children and young people with limb difference is limited to a small number of service users. Before embarking on my research journey it was necessary to educate myself on the impact of these disabilities on children and the services and treatment they currently receive in the UK. The first section of this chapter will, therefore, describe available statistics on upper limb difference in childhood and use of prosthetic services. It will then go on to discuss the different prosthetic devices that may be prescribed to children and young people, and at what age children generally receive these devices, as well as considering alternative and augmentative treatments. Finally, the potential impact of limb difference on children and young people will be considered, addressing functional, participatory, psychosocial and physical impacts to provide an holistic account.

1.1.1 Incidence of upper limb difference in the UK

Limb difference in children can be the result of congenital factors or acquired amputation (Smith 2006). A congenital limb deficiency is present at birth and can involve either the upper or lower limb or, in rare instances, multiple limbs (Smith 2006). Acquired amputations can be the result of cancer, trauma or severe infections, such as meningococcal septicaemia (Smith 2006).

1.1.1.1 Congenital

Broomfield (2009) reports that the number of babies born with congenital upper limb difference has remained constant for many years, and that the cause of limb difference usually remains unknown, although occasionally genetic factors or restricted blood supply to the developing limb can be the cause. Congenital upper limb difference can range from the partial loss of a finger, to the complete loss of both arms (Broomfield 2009). The most common congenital limb difference, excluding missing digits, is left-sided trans-radial difference, which describes a difference across the forearm of the left upper limb (Cuccurullo 2004). Some congenital limb deficiencies develop across the growing limb, where the residuum resembles an amputated residual limb, in which the limb has developed normally to a particular level beyond which no skeletal elements are present. This is referred to as *transverse* limb difference (IS0 8548-1, 1989). Others, however, may be due to the complete absence or shortening of an arm bone, where the rest of the limb beyond the absent or shortened bone develops normally. This is referred to as *longitudinal* limb difference (IS0 8548-1, 1989).

Broomfield (2009) suggests that approximately 60 children are born with congenital limb difference annually in the UK. There are however no published statistics on this. Fraser (1998) attempted to calculate an estimate for the overall number of people living in the UK who have upper limb congenital difference, through examining data provided in studies from the UK and North America conducted by McDonnell et al (1988), Kyberd et al (1997) and the UK Amputee Medical Rehabilitation Society (AMRS) (1997). The figures suggested in these studies range from 1:4,670 (AMRS 1997) to 1:13,500 (Kyberd et al 1997) for people with upper limb congenital difference for whom prosthetic provision could be considered. Fraser (1998) calculated an approximate estimate of the expected number of people with congenital upper limb difference in the UK, using the total population figure for the UK for 1995 of 58,606,000 and comparing it with the figures gained from the McDonnell et al (1988), Kyberd et al (1997) and AMRS (1997) studies. From this calculation Fraser (1998) suggested that between 1,270 and 9,236 people with congenital upper limb absences in the UK are not registered with a prosthetic clinic. As this calculation is derived from figures collected at least 15 years ago it can be assumed that this figure has now risen given the relative increase in population. Furthermore, there is a substantial range in the estimate (of approx. 8,000) meaning that this, unfortunately, tells us very little about the number of people with congenital upper limb difference in the UK.

1.1.1.2 Acquired

The upper limb accounts for between 3% to 15% of all amputations across adults and children (Jain & Robinson 2008). This wide range implies that the incidence of upper limb amputation is estimated, potentially affecting funding allocation and research priorities in this area (McDonnell et al 1988). Furthermore, this figure applies across all ages, giving us little indication of the actual percentage for children and young people. The major reasons for amputation in the upper limb, again not accounting for age differences, are trauma (43%), congenital absence (18%), and cancer (14%) (Jain & Robinson 2008).

There are no published statistics detailing the demographics of paediatric amputations in the United Kingdom. Roche & Selvarajah (2011) performed a review of children and adolescents who had undergone a traumatic amputation and were referred to a regional limb-fitting centre in the UK between 1930 and 2010. The study compared the data with similar cohorts from other regional limb fitting centres in the UK. They found that 19% of all amputations were in the upper limb (Roche & Selvarajah 2011). The figures were found to correspond to those from a United Kingdom national statistical database of amputees which showed that on average four traumatic paediatric amputees were referred to each regional limb centre every ten years (Roche & Selvarajah 2011).

1.1.1.3 Statistics on referrals to prosthetic services

In 2006-2007, 4957 new referrals were made to UK prosthetics service centres, of which there are 43 nationwide (Limbless Statistics 2009). Of these, 163 were less than 16 years old. Of these 163, 87 were referred to prosthetics services due to congenital absence and 76 following traumatic limb loss. Upper limb difference accounted for approximately 4% of all referrals across adults and children (approximately 198). However, upper limb referrals were more common in younger people. Approximately 60% of all referrals with a congenital absence were aged less than 16 years of age. Fraser (1998) suggests, however, that 64.5% of people with upper limb congenital absences who are aged 16 years and above are not registered with a prosthetic clinic as they are not using prostheses. This is perhaps due to a propensity to learn adaptive behaviours in the congenital population or potential limitations of the devices.

There is no information reported on Limbless Statistics (2009) regarding the numbers of under 18 year olds who are active patients of UK limb services, as the reported statistics only relate to new referrals. Although the percentage of new referrals relating to children with an upper limb difference is small (3%), these service users will require the support of limb services for a longer time frame than adult users (Limbless statistics 2009). Child users are likely to become lifelong users of prosthetic services, and they will have unique and changing needs as they grow and develop. Furthermore, the College of Occupational Therapists (COT) (2006), which is the presiding body for OT in the UK, reports that the number of upper limb amputees and limb deficient children, when examining ‘active’ files at limb fitting centres, is approximately 20% of service users. They report that this is due to the aetiology, as upper limb service users are generally quite young and otherwise fit and healthy compared with lower limb service users, who may represent a more elderly population with vascular problems (COT 2006).

Due to the way the statistics have been gathered and presented, they do not, therefore, facilitate the calculation of the number of children and young people across the UK who are accessing limb clinics due to upper limb difference, whether congenital or acquired. Furthermore, the Limbless Statistics database has not been updated since 2006-2007 as a result of funding being withdrawn, so these are the most recent statistics that are available. The database is now overseen voluntarily by Loughborough University (UK) impacting on the time and funds that are able to be invested in its maintenance.

The scant and vague reporting of statistics on children with limb difference may have implications for the allocation of research priorities and funding of services, as accurate planning of these requires accurate estimations of the population affected (McDonnell et al 1988). Conditions of lower incidence may be less likely to be invested in not only due to the fact that a small percentage of the population is affected but also because of the poor reporting of statistics: the lower the percentage of the population considered to be affected, the less the amount likely to be invested. Furthermore, the incidence of less common conditions tends to be *estimated*, which is the case in paediatric upper limb difference, due to poorly collated and presented figures. This may lead to policy makers and funding allocators being less likely to place importance on them when developing policies and distributing funding (McDonnell et al 1988).

1.1.2 Current prosthetic practice and treatment options

1.1.2.1 Types of prosthesis

In current practice, there are three main types of prosthesis that may be prescribed for children – passive prostheses, body-powered prostheses and myoelectric prostheses (Broomfield 2009).

A passive prosthesis (see figure 1) is designed to look as natural and aesthetically pleasing as possible (Broomfield 2009) and is shaped and coloured to match the unaffected arm (Watve et al 2011). A passive prosthesis is usually the first prosthesis a child will be prescribed with (COT, 2006). Passive prostheses are lightweight and do not usually contain moving parts (Broomfield 2009). Despite the drawback of a lack of movement, a passive prosthesis can still be useful. The child can support objects with the prosthetic hand (Broomfield 2009) and they may also perform a passive assistive role to the unaffected arm, such as steadying a piece of paper when writing (Watve et al 2011).

Passive prostheses are usually manufactured from foam or using one of three materials: flexible latex, rigid PVC (polyvinyl chloride), or silicone (Miguelez et al 2010). These types of prostheses require less maintenance but can become marked or damaged easily.

Figure 1: PVC Passive Upper Limb for a small child (Chabloz-Orthopedie 2012).

A body-powered prosthesis (see figure 2), such as a voluntary opening/closing split hook or hand, contains moving parts and is, therefore more practical for use in activities of daily living (ADLs) than a passive prosthesis (Broomfield 2009). A body-powered prosthesis utilises a harness and cabling to control a terminal device (or hand) and an elbow unit (Miguelez et al 2009). The harness system is controlled by gross body movements (such as scapular abduction) (Miguelez et al 2009). It is simple in design, making it highly durable and suitable for use in tasks that involve water, dust, and other conditions that could damage an electric prosthesis (Miguelez et al 2009). Some users of body-powered prostheses report that the cable tension simulates proprioception, enabling enhanced spatial awareness and allowing the wearer improved feedback on the position of the prosthesis (Miguelez et al 2009). Miguelez et al (2009) reported that maintenance costs for body-powered prostheses are relatively low. Broomfield (2009), however, suggests that body-powered prostheses require more maintenance than passive prostheses, due to the cabling system required to work them. Another drawback identified by Broomfield (2009) is that they are heavier. This may be particularly significant for children as the small body mass of a child may result in any weight increase having a bigger impact than it would on an adult user. This may cause physical strain to be put on the child's body and have an adverse effect on the comfort of the user (Fisk 2002). Another negative aspect, which users have identified, is that the harness can be uncomfortable and restrictive (Miguelez et al 2009). Although new materials aid in reducing discomfort, the harness must fit tightly to capture the movement of the shoulders and to suspend the prosthesis, which can restrict proximal joint range of motion (Miguelez et al 2009). The harness and cable system also limits the possible grip force of the terminal device (Miguelez et al 2009). A further consideration is that a body-powered prosthesis is less lifelike than a passive prosthesis (Miguelez et al 2010), which may have implications for users for whom the main purpose of their prosthesis is for cosmetic or psychosocial reasons.

Figure 2: Body-Powered Prosthesis (Lam 2010).

Myoelectric prostheses (see figure 3) offer the advantage of combining looks and functionality as they can have cosmeses, which have the appearance of a real hand, but are more useful than passive prostheses when it comes to performing ADLs (Egermann et al 2009). A myoelectric prosthesis uses electromyographic signals from voluntarily contracted muscles within a person's residual limb. These signals are detected by sensors on the surface of the skin and control the movements of the prosthesis (Watve et al 2011). Proportional control allows the patient to control to some extent the speed and force of the hand, wrist and elbow movements by varying the strength of the muscular contraction (Muzumdar 2004). For example, the larger the myoelectric signal, the greater the grip force or speed of opening and closing (Muzumdar 2004). A myoelectric prosthesis uses battery-powered electric motors to operate resulting in significantly increased grip force (Muzumdar 2004). However, because of the battery system and the electrical motors, myoelectric prostheses tend to be heavier than other prosthetic options (Muzumdar 2004). Furthermore, when repairs are required, they are often lengthy, complex and expensive because of the sophistication of the device (Muzumdar 2004). Additionally, an electrically powered prosthesis is susceptible to damage when exposed to moisture (Muzumdar 2004).

Figure 3: Myoelectric Prosthesis and Cosmesis (Chabloz-Orthopedie 2012).

According to the COT (2006), there are two myoelectric prostheses available for children: the RSL Steeper ‘Scamp’ hand (figure 4) and the Otto Bock Electrohand 2000 (figure 5). The Scamp hand is available in two sizes to suit children between the ages of 6 months and 6 years old and is designed to operate from a single switch or myoelectric control system (COT 2006). The Electrohand 2000 is available in four sizes, the smallest being suitable for a child between the ages of 1.5 and 3 years and is operated using a myoelectric control system (COT 2006).

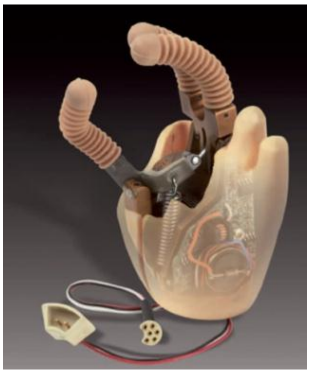

Figure 4: RSL Steeper Scamp Hand without cosmesis (RSL Steeper 2012).

Figure 5: Ottobock Electrohand 2000 without cosmesis (Ottobock 2012).

In addition to commercially available prostheses for children and young people, there may also be a need for custom-made task specific devices (Broomfield 2009). It is probable that the provision of these will vary nationally as custom-made devices are likely to require specific skills, which may vary depending on the staffing of the centre and the experience level within team members, as well as the funding and equipment available for manufacturing bespoke devices. Furthermore, clinical decisions regarding which type of prosthesis is most suitable for a child are likely to be guided not only by the child’s age and proposed use for the device, but also by the cost of the device and the funds available within the associated NHS trust. This may lead to treatment regimens varying in different parts of the country (Broomfield 2009). A review of NHS prosthetic services for military amputees (“A Better Deal for Military Amputees” by Dr Andrew Murrison 2011) observed that there is a ‘postcode lottery’ across NHS prosthetic services, which limits service user choice with regard to their prosthetic treatment (see Introduction, pp. 1-2 for explanation of the term ‘postcode lottery’). Murrison (2011) stated that this ‘postcode lottery’ is a result of the discrepancies in funding levels across individual Primary Care Trusts (PCTs) and is perpetuated by a lack of national guidelines for prosthetic provision. Although this review was aimed at exploring services for military amputees, perhaps due to this being politically relevant, the findings are not limited to military amputees using the services but can be implied across all user groups.

Furthermore, children may be particularly susceptible to these funding and service inequalities as a result of their requirement to have new prosthetic devices more regularly than adult users, due to growth and development. There are no figures addressing the exact frequency of replacing upper limbs for children. A study of lower limb prosthesis users found that children generally require a new prosthesis annually until the age of five and every two years into adolescence (Lambert 1972). Despite the age of the Lambert (1972) study and its specificity to lower limb prostheses, the principle finding, that prostheses for children require regular replacement, is still likely to be relevant. Upper limb prostheses for children have not changed vastly in recent years and children are not prescribed devices that adjust with their growth and development.

As discussed, different types of prostheses offer different levels of functional and cosmetic benefit to their users. It is probable that considerations such as aesthetics and functionality will be important factors contributing to a child’s acceptance of a prosthesis. The importance of function versus aesthetics is, however, likely to change for the young person as they grow and develop (Broomfield 2009). Furthermore, OT literature advises that a child is likely to go through different stages of prosthesis use, just as they will go through different developmental stages (Celikyol 1984). It is suggested that children of primary school age, having previously been accepting of prostheses, may opt not to use them as they may become a hindrance during this very physically active developmental stage (Celikyol 1984). During adolescence, however, both aesthetics and functionality may become more important to the young person as appearance becomes a more valued attribute and leisure or work activities become more demanding bimanually, requiring fine prehension (Celikyol 1984). It would be useful however to explore these issues and changing use patterns again as these factors may have altered over the last 30 years due to the huge technological advances that have occurred, impacting on children’s exposure to media and different technologies.

Not only is the desired purpose of prostheses likely to change for children as they move from childhood to adolescence, but Smith (2006) suggests that adolescents are likely to be more involved in choosing whether or not to wear a prosthesis than children are. He argues that parents are likely to make decisions on behalf of smaller children, but as children grow and become teenagers, parents may involve them more in the decision-making process (Smith 2006).

1.1.2.2 Age of fitment

The timing of fitting children with upper limb prostheses is hotly debated and varies between prosthetists and limb services (Staheli 2006). Literature from the USA, states that some prosthetists fit at about 6 months of age (Staheli 2006) as at this age many children begin to demonstrate functional reaching, attempting to move their hand toward objects of interest (Carroll & Edelstein 2006). Developmental signs, such as this, guide the time of fitting (Shaperman et al 2003). Other developmental signs clinicians consider include independent sitting ability, exploration by the unaffected hand and trying to hold things against the chest or in the elbow joint (Shaperman et al 2003).

Developmentally, children usually accomplish independent sitting at around 6 months, using their arms to support their body (Shaperman et al 2003). Once a child achieves independent sitting balance without relying on their arms for support, they may begin to use their hands for manipulative tasks, which may be one reason for fitting a child with a prosthesis at this developmental stage (Shaperman et al 2003). In addition to developmental signs, US Limb fitting clinics in Shaperman et al's (2003) study reported that the child's chronological age also influenced the decision to fit a prosthesis.

The COT (2006) reports that the aim of wearing a prosthesis so early is to give the child the best possible chance of becoming a skilled user as he/she develops and to help the parents to adjust, encouraging the development of a positive attitude toward the prosthesis and their child's limb difference. The COT (2006) also suggests that wearing a prosthesis from a very young age allows the child to get used to its weight and using two limbs of the same length in a bimanual way. It is reported that most children receive a passive prosthesis before their first birthday and receive a body-powered prosthesis at around 18 months of age (Shaperman et al 2003). This, however, is likely to vary depending on the limb centre that is local to the family, in terms of the size of the centre and the expertise available. Age of fitment, therefore, may also be subject to a ‘postcode lottery’ across NHS prosthetics services.

Research focusing on the relationship between age at initial fit and prosthesis use has reported that late fitting adversely impacts subsequent acceptance of the prosthesis (e.g. Scotland & Galway 1983; Brooks & Shaperman 1965). Scotland & Galway (1983) and Brooks & Shaperman (1965) concluded that children who are fitted with prostheses after the age of two years are more likely to subsequently reject them. Furthermore, Biddiss & Chau (2007a) found that people who had prosthetic fittings within two years for congenital limb difference and within six months for acquired amputations were 16 times more likely to continue using their prostheses. The older a child is when fitted with their first prosthesis, the more proficient they will have become at performing activities without a prosthesis which may mean that they are less motivated to learn the new skills that are required for integrating a prosthesis into daily activities (COT 2006).

A systematic review of studies examining age of fitment (Meurs et al 2006) found that evidence for a relationship between the early fitting of a first prosthesis in children and subsequent non-use rates or functional outcomes is minimal. Meurs et al (2006) purport that this demonstrates that clinical decisions regarding the age to fit a child with a prosthesis are guided by clinical experience rather than by evidence-based practice.

1.1.2.3 The multidisciplinary team

Rehabilitation for people with upper limb difference is multidisciplinary (Hanspal 2003). The clinical team at the limb clinic should include, amongst others, a Consultant in Rehabilitation Medicine (CRM), a prosthetist, an OT and a counsellor (Hanspal 2003).

A) Consultant in rehabilitation medicine (CRM):

The main roles of the CRM are to provide clinical leadership to the multidisciplinary specialist rehabilitation team and to address the service user’s medical needs. This may involve making recommendations for an ongoing programme of rehabilitation, prescribing treatment as appropriate and preventing any additional complications that may result from an underlying medical condition (UK Limb Loss Information Centre 2012).

B) Prosthetist:

The prosthetist specialises in designing, fitting and manufacturing prosthetic limbs (UK Limb Loss Information centre 2012). They work very closely with the service user to assess for and provide prostheses, using their specialist skills to design and select the best possible prosthesis for service users of all ages (NHS Careers 2012a). They also advise service users on how to use the prosthesis, aiming to enable the service users to participate in work and leisure activities (NHS Careers 2012a).

C) OT:

The Amputee and Prosthetic Rehabilitation Standards and Guidelines (2nd Edition) (British Society of Rehabilitation Medicine, BSRM 2003) advises that the involvement of a specialist OT at an early stage is an essential part of a child's treatment. OT practitioners use a holistic approach that emphasises the importance of the service user's roles, daily activities, personal experiences and values in developing rehabilitation plans (Dillingham et al 2002). Interventions carried out by an OT may include training in prosthetic use, but OTs can also train service users in how to carry out activities using one-hand (Hanspal 2003) or with their feet. Therapy for limb difference should not be synonymous with prosthetic treatment as some service users may opt not to use a prosthesis at all (Edelstein 2006), but may require OT input for adapting activities in the areas of self-care, work and leisure (Dillingham et al 2002). OTs can also provide an important link in increasing the understanding of the child's wider social circle, such as school staff (Hanspal 2003).

D) Counsellor:

The Amputee and Prosthetic Rehabilitation Standards and Guidelines (2nd Edition) (BSRM, 2003) recommends that limb centres should have a counselling psychologist or Nurse Counsellor on their staff or, at least, have access to the counselling service provided in their NHS trust. This is so that support can be provided to the parents and family during a potentially highly stressful period.

The aim of counselling is to provide service users and their families with the opportunity to talk confidentially about their feelings and experiences (UK Limb Loss information Centre 2012). Counsellors' specialist training enables them to help service users to solve psychosocial issues they may be struggling with through enabling service users to understand more about themselves in order to make positive decisions for the future (Hanspal 2003).

The ‘postcode lottery’ referred to earlier (as identified by Murrison 2011) may result in limb centres being forced to make difficult decisions between the equipment and devices they can purchase and having a full staff team. A lack of national guidelines relating to the staffing requirements for limb centres further complicates this issue. In addition to this, NHS prosthetic services are often provided by commercial prosthetic manufacturing companies working under contracts with the NHS (National Careers Service 2012), impacting on the devices available at the centre. In practice, this may result in limb centres not having a counsellor or OT on their staff team, due to their being deemed as the ‘less essential’ team members. Having visited several limb centres across the country and networked with other professionals at conferences, it is apparent that many centres do not have an OT or counsellor on their staff or even have access to these professionals at other services. Moreover, the UK Limb Loss Information Centre (2012) does not list Counsellors as ‘core’ members of the amputee rehabilitation team. This may be further compounded by the very specialist skill sets required to be an OT or counsellor in a limb centre and the limited number of professionals who have the relevant skills or experience to undertake these roles. This can result in service users not getting specialist psychological interventions they require or not having access to prostheses that they would be able to access if they lived in another part of the country.

1.1.3 Impact of UL difference on children and young people

Upper limb difference can have both a physical and psychological effect on a child (Smith 2006). The impact of the impairment is likely to vary greatly due to several factors, including the type and level of limb difference; whether the dominant hand was affected; whether the difference was congenital or acquired; the young person’s age and stage of development; and the reaction and acceptance of their parents (Smith 2006).

1.1.3.1 Impact of limb difference on function and activities of daily living

"Hands play a unique and important role in a person's life; they serve prehensile, proprioceptive and communication purposes" (Lake 1997; p.3). The loss of one or both hands can, therefore, cause a potentially devastating loss of function and difficulties performing daily tasks (Ibbotson 2002). Upper limb difference can impact on a child's development at all stages (Ibbotson 2002). During the first few months of life, children may struggle with the lack of symmetry when learning to play with objects in midline and their sitting balance, crawling and walking abilities may be affected (Ibbotson 2002). Many ADLs require bilateral hand use (Krumlinde-Sundholm & Eliasson 2003). Unilateral upper limb difference may render some activities extremely difficult to perform (Krumlinde-Sundholm & Eliasson 2003). Consequently, when a child gets to pre-school age, they may struggle to develop the bimanual skills alongside their peers (Ibbotson 2002).

Research on the functional impact of limb difference on children is limited as the majority of research on the functional abilities of children with limb difference centres around the functional abilities of prosthesis wearers and how to measure these appropriately. There is some research carried out in Australia that focused on the functional and occupational impact of limb difference on adult amputees (Jones & Davidson 1995; Davidson 2001). Davidson’s (2001) study found that adults with limb difference were dissatisfied with their performance of ADLs that ordinarily required bimanual manipulation (such as, using cutlery and tying shoelaces). Jones & Davidson (1995) found that adults with limb difference found self-care tasks difficult, particularly females who have a more elaborate self-grooming regime.

This research helps to draw attention to the difficulties of fine motor ADLs for adults with limb difference. The participants of the aforementioned studies were, however, adults who had suffered traumatic limb difference and, whilst similar difficulties may be encountered by children with limb difference, the impact may be lessened by children’s propensity to adapt to and compensate for the difference, particularly if it is of congenital aetiology (Kuyper et al 2001). Indeed, it has been found that prosthesis use does not influence functional ability in children and that non-wearers of upper limb prostheses can perform just as well as, or even better than, their prosthesis-wearing peers (James et al 2006).

1.1.3.2 Impact of limb difference on leisure, recreation and participation

The World Health Organisation's (2001) International Classification of Functioning, Disability, and Health (ICF) describes participation as "involvement in life situations", including participation in leisure and recreation activities. For children and young people, regular participation in recreation and leisure activities, as well as school and work activities, is an important aspect of health, well-being and development (Law 2002). Children and young people with disabilities have been found to be more restricted in activity participation than their peers (Brown & Gordon 1987). Furthermore, children with limb difference (and other physical disabilities) use health services frequently, which can impact on their ability to participate in school and extra-curricular activities (Weir & Mackenzie 2010).

Jones & Davidson (1995) conducted a study of the leisure activities of adults with limb difference. They found that 70% of participants reported a change in leisure activities as a result of their amputation. Amputees reported that even if they participated in the same leisure activities as previously, they carried them out more slowly and awkwardly and found them more frustrating than before. Activities that participants had ceased to take part in, due to them now being more difficult and less enjoyable, included sewing and playing musical instruments. Out of the 16 participants, 14 stated that their limb difference had caused them to stop playing sports as they required bilateral arm function for balancing and catching.

Several other studies noted that participation in sports and recreation is a major concern for people with limb difference and that these activities are important for their rehabilitation (e.g. Nissen & Newman 1992). Participation in sports is important physically as it can result in improved strength, balance and muscle co-ordination (Webster et al 2001). It can also have positive psychological effects on mood, confidence and self-esteem (Anderson 1998). Furthermore, for a child with limb difference, involvement in sport and recreational activities is especially important as it provides opportunities for development of motor coordination and socialisation with peers (Anderson 1998) and has a positive impact on long-term mental and physical health (Simeonsson et al 2001).

1.1.3.3 Psychosocial impact of limb difference

1.1.3.3.1 Quality of Life

Quality of Life (QoL) is an important concept in the psychological functioning of children with chronic disorders (Michielson et al 2011). QoL can refer to aspects of a person's well-being (physical, psychological, social), as well as aspects of the environment (Michielson et al 2011). Psychological well-being, self-esteem, body image and happiness are constructs related to QoL (Michielson et al 2011). Evidence from the literature suggests that adolescents with disabilities are at greater risk for psychosocial difficulties than adolescents who are not disabled (Michielson et al 2011). Michielson et al (2011) examined the health-related QoL of children and adolescents (aged 8-18 years) with lower limb difference living in the Netherlands. Michielson et al (2011) found that the QoL for the participants did not differ from the norm. The adolescents with lower limb difference (aged 12 and over) did, however, report significantly less diversity and lower quality of social activities than their peers.

1.1.3.3.2 Self-esteem and body image

Children with chronic physical disorders have been found to have an increased risk of self-esteem issues (Wallander et al 1988). Self-esteem is an aspect of self-concept that refers to the judgements we make about our own value and the emotions associated with these judgements (Berk 2008). It is important at all life stages (Rosenberg 1979), but may be more prevalent during adolescence as appearance and attractiveness become more highly valued attributes (Leahy & Shirk 1985) and young people begin to make social comparisons (Stipek & MacIver 1989).

Body image is closely linked to self-esteem as it involves the conception of and attitude toward one's physical appearance, which intrinsically involves judging one's own worth (Berk 2008). Horgan & MacLachlan (2004) defined body image as "the combination of an individual's psychological experiences, feelings and attitudes that relate to the form, function, appearance and desirability of one's own body..." (p. 839). Winchell (1996) suggested that, as well as an individual's internal psychological response to their body, body image is also impacted by social factors and life experiences and can, therefore, change with age and changes in societal responses. Furthermore, the media portrayal of an ideal body can heighten body image concerns for people with limb difference or other physical disabilities. This is particularly apparent amongst those with upper, as opposed to lower, limb difference, due to the higher visibility of arms and less options for disguising or camouflaging the disability than with lower limbs (Winchell 1996).

Winchell (1996) argued that another influence on the impact of limb difference on body image is whether the difference is congenital or acquired. A child with congenital limb difference, Winchell (1996) purported, does not have a body image adjustment to make until adolescence. Furthermore, the adjustment required is less extreme than that required of a child who has lost a limb later in childhood, after awareness of that limb has been incorporated into their body schema. Desmond & MacLachlan (2002) supported this idea with their argument, which resulted from their research with adults with limb difference, that the adaptation of body image to a congenital limb difference evolves within the normal process of personality development.

An individual's developmental stage is also a crucial factor in the impact of limb difference on body image as, at some developmental stages, an individual may be more susceptible to issues associated with body image than at other times in their life (Desmond & MacLachlan 2002). During adolescence, for example, a young person may become more aware of their sexuality and physical appearance, leading to body image difficulties in a previously well-adjusted child (Desmond & MacLachlan 2002).This is supported by Erikson's (1968) theory of identity development which purports that in adolescence, the establishment of personal values with regard to body image, sexuality and career are dominant psychosocial issues. This may contribute toward explaining the identification of aesthetics and peer acceptance as high priorities in prosthesis use for adolescent users of prostheses (Jain 1996).

Another contributing factor toward the impact of limb difference on body image and identity difficulties in adolescence may be associated with the functional impact of the disability. If the limb difference has a detrimental effect on the young person's skills, they may believe they are no longer able to participate in activities they had previously perceived themselves to excel in (Fisher & Hanspal 1998). Specifically, some adolescents may have spent many years acquiring a specialist skill, such as playing a musical instrument or participating in a sport (Fisher & Hanspal 1998). They may experience a particular challenge to their body image if the change to the form and function of their body impacts on their level of accomplishment in their skill, threatening their identification with the role of ‘musician’ or ‘sportsperson’, for example (Fisher & Hanspal 1998).

Furthermore, for people with upper limb difference, it is difficult to disguise the amputation with clothing, particularly as hand use has strong cultural implications in Western society (Watve et al 2011). It is, for example, very common to shake hands with someone when meeting them in a formal setting – this would result in physical differences being immediately apparent for someone with upper limb difference (Watve et al 2011). Conversely, lower limb difference can more easily be camouflaged by clothing (Winchell 1996), allowing the person to be more in control of when and how they choose to reveal their limb difference to others.

1.1.3.3.3 Social relationships

Varni et al (1992) demonstrated the existence of greater behavioural and emotional problems and lower social competence in children with limb deficiencies than in children without disabilities. Behavioural and emotional problems that were clinically significant were reported for 23% of the children in their study and 14% of the children were found to have clinically significant social difficulties (Varni et al 1992). This compares to a rate of 10% in the general population for both behavioural and emotional problems and social competence, which is marginally lower (Varni et al 1992). This corresponds with Odom’s (2002) findings that children with disabilities are more likely to be socially rejected than their non-disabled peers. Children who face rejection from their peers are likely to lack effective communication and social skills (Odom 2002). Having friendships in childhood is, however, essential to cognitive, language, social and emotional development (Buysse et al 2002). This can hinder a child in developing the capacity to understand the perspectives of others and impact on their emotional well-being (Buysse et al 2002), creating an unhappy cycle, which may be difficult to break.

1.1.3.4 Physical impact of limb difference

Following acquired unilateral upper limb difference, function may be transferred from one arm to the other. This can lead to an increased workload for the remaining arm and the use of compensatory movement strategies, which do not follow normal patterns of movement, to complete bimanual tasks

(Peterson 2011). This can result in overuse symptoms later in life. Overuse syndrome is usually diagnosed as a result of persistent or recurrent musculoskeletal pain without an obvious traumatic cause (Gambrell 2008). In a study by Jones & Davidson (1995), 50% of upper limb amputees were found to have developed overuse problems in the unaffected limb and the closer the amputation was to the trunk, the more likely and severe the problems were found to be.

Another physical complication for acquired unilateral upper limb amputees is changes in statics of the spine. These changes are likely to occur as a result of asymmetrical posture of the spine and muscular asymmetries (Greitemann et al 1996). In a study conducted by Greitemann et al (1996) the postural symmetry of upper limb amputees was examined. It was found that upper limb amputations caused a shift of the trunk to the side of the amputation (in order to compensate for the weight imbalance), spinal scoliosis and elevation of the shoulder on the side of the limb difference (Greitemann et al 1996).

Although the above studies discussed the physical impact of acquired limb difference, congenital upper limb difference can also have an effect on physical development. Broomfield (2009) advises that because the affected arm weighs less than the normally developed limb, weight is placed on the developing spine asymmetrically. He argues that this can lead to postural problems as the child grows and may cause back pain in later life. In addition, Powers et al (1983) found an increased incidence of scoliosis in people with congenital upper limb deficiencies when compared to people without limb difference.

1.1.4 Section summary

The preceding section of the background chapter has described available statistics on upper limb difference in childhood and use of prosthetic services; the different prosthetic devices that may be prescribed to children and young people; at what age children generally receive prosthetic devices; and the multidisciplinary team of a limb centre. Areas which may lead to disparity between regional services have been alluded to. The potential impact of limb difference on children and young people was then considered: potential functional, participatory, psychosocial and physical impacts were discussed. The following sections of the background chapter will consider existing relevant research and what this contributes to the knowledge base of upper limb prosthetics for children, including presenting the systematic search strategy employed for identifying the relevant studies.

1.2 Paediatric prosthesis users' use of, and satisfaction with, prostheses

Non-use rates of upper limb prostheses amongst children vary widely throughout the literature but they have, in some studies, been reported to be as high as 50% (Shida-Tokeshi et al 2005). This implies that the impact of limb difference on the physical, psychosocial, functional and recreational wellbeing of children is not being addressed fully.

Furthermore, the impact on the NHS of equipment rejection should also be noted. Of the NHS's current contribution toward climate change, 60% comes from procurement, including medical devices and equipment, such as prosthetics (The Climate Connection 2009). The Climate Connection (2009) advises that health trusts should minimise waste when buying devices and equipment through making decisions based on the whole lifecycle costs of the device/equipment. High non-use rates of upper limb prostheses amongst children and young people may, therefore, have an impact on the NHS's contribution to climate change, as well as having financial implications.

The following section will examine children's use of prostheses, and the satisfaction of users with devices, in order to contribute to an understanding of why non-use of prostheses is so high amongst children and young people. Key terms will be defined and systematic search strategies explained prior to a review of the existing literature.

1.2.1 Defining the key terms – "use" and "satisfaction"

1.2.1.1 Defining prosthesis "use"

One difficulty in examining children's use of upper limb prostheses is the inconsistency in definitions of the term "prosthetic use". Definitions of "prosthetic use" in the literature include both the activities that a person finds a prosthesis helpful in and the amount of time a person uses a prosthesis for (Hubbard-Winkler 2009). Furthermore, the amount of time a person uses a prosthesis for is measured in some studies on a continuous scale and in others using a categorical scale (such as, whether the prosthesis is worn, "all the time", "occasionally" etc.) (Hubbard-Winkler 2009). Even when looking separately at either continuous or categorical measurement studies, measurement is not standardised and may relate to different types of prostheses, which often goes unstated (Hubbard-Winkler 2009). This discrepancy in descriptions has resulted in a vast range (7%-88%) of reported use (Hubbard-Winkler 2009). This makes it difficult to develop an understanding of how, when and why prostheses are used by children and young people. Coupled with the vagueness of the published statistics on children accessing limb clinics in the UK, this may result in an underestimation of the importance of prostheses for children and young people with limb difference. To better understand use patterns of prostheses, research should consider that participants may have more than one prosthesis, each used for a different purpose.

Heard et al (1994) demonstrated that a full-time wearer is not necessarily a full-time user. It is possible to wear a prosthesis without using it as a tool. Children do not necessarily wear their prostheses to complete ADLs as they will only do so if the activities are performed more easily or quickly (Heard et al 1994). However, for many bimanual tasks, such as riding a bicycle or using scissors, it is necessary to use both hands, and, consequently, the prosthesis (Heard et al 1994). Therefore, the use of a device may be better measured through consideration of the activities it is useful for, and the value the individual places on completing these activities independently, as opposed to wearing time.

1.2.1.2 Defining “satisfaction” with prostheses

Prosthetic “satisfaction” is another factor relating to upper limb prosthetic research in which there is inconsistency in operational definitions, leading to a range of reported results (Hubbard-Winkler 2009). “Satisfaction” within studies of prostheses has been used to refer to satisfaction with the ability to perform specific activities, overall satisfaction with the prosthesis and satisfaction with the individual characteristics of the prosthesis (Hubbard-Winkler 2009). The Oxford English Dictionary (2010) defines “satisfaction” as “fulfilment of one’s wishes, expectations, or needs”. Satisfaction is therefore, a subjective concept and can only be measured against individuals’ expectations, needs or desires: something that may meet the expectations of one person may lead to dissatisfaction in another.

The studies discussed in the following sections use different operational definitions for these terms. In the current study, children's use of prostheses will not be quantified in any way, but rather considered in relation to how useful or meaningful prostheses are to the participants. Satisfaction is understood in terms of The Oxford English Dictionary's (2010) definition and, therefore, to encompass satisfaction with both the device itself and the benefits or drawbacks it may present to participants.

1.2.2 Review of literature on children's use of and satisfaction with prostheses

A review of recent literature was undertaken to explore the existing research that examines children's use of and satisfaction with upper limb prostheses. Practicing from an OT perspective, issues concerning disability and assistive devices are regarded as being multifaceted and holistic. That is to say they encompass physical, social, psychological and health-related factors. A range of databases were, therefore, included in the search to access research related to all the aforementioned factors. The databases searched were the Allied and Complementary Medicine Database (AMED), the Cumulative Index of Nursing and Allied Health Literature (CINAHL), MedLine, PsychArticles and PsychInfo.

The search terms used were prosthesis (and alternatives), upper limb (and alternatives) and child (and alternatives). A Boolean search was performed using search devices such as 'wildcards' when appropriate to the database. In addition to these searches, reference lists in relevant articles were hand searched for other relevant research and forward citation searching was performed using Web of Knowledge. Publication dates were restricted to 2000 onwards to ensure findings are relevant to current practice and to English language only to avoid mistakes being made in the translation of documents.

The CINAHL, MedLine, PsychArticles and PsychInfo databases were searched using EBSCO. This search yielded 303 results (after automatic removal of duplicates). Following scrutiny of the abstracts of these articles, 32 research studies relevant to children's upper limb prosthetics were identified. Performing the same search on AMED (Ovid) yielded 16 results. Seven of these were duplicates of articles obtained via the EBSCO search and six were not relevant to children's upper limb prosthetics, resulting in three articles relevant to paediatric upper limb prosthetics. Further scrutiny of the articles obtained via the two searches resulted in the identification of eight articles relevant to the current literature review. Citation searching provided a further two relevant studies. See figure 6 for explanation of how the results were narrowed down to the relevant articles. See Appendix B for details of search terms used.

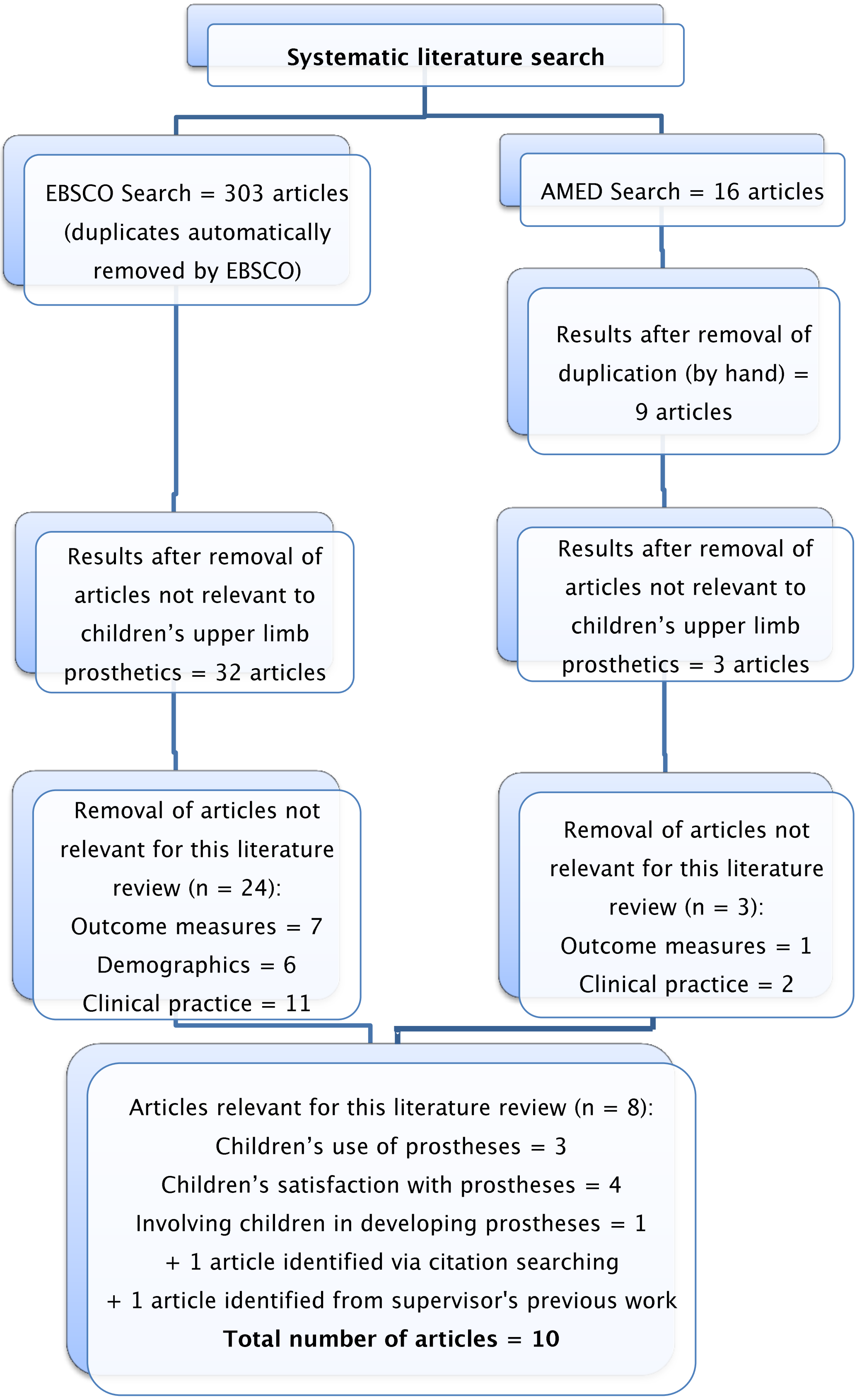

Figure 6: Results and selection process of literature search.

1.2.2.1 Children's use of prostheses

Three relevant articles were found in relation to children's use of prostheses from the EBSCO and AMED searches and one additional article was identified through citation searching. Two of the studies were conducted in the USA and two in Europe. They will be discussed in the following section.

Crandall & Tomhave (2002) used questionnaires to explore prosthesis use in 34 paediatric unilateral below elbow amputees (aged from 6 to 21 years old), attending the Shriners Hospital in Minneapolis, USA. They found that 44% of participants used a passive device, 41% used a body-powered prosthesis and 41% used multiple devices. The authors concluded that children may choose to use different devices depending on the intended use, and that they should, therefore, be offered a range of prosthetic options to enable them to carry out daily activities to their optimum potential.

Buffart et al (2007) carried out a study, in the Netherlands, of 20 children (aged 4-12 years old) with congenital upper limb difference. The study combined observational assessments of functional activities with parent-report questionnaires focusing on daily activities. They found that children were able to use their prostheses in 68% of activities but chose to use them in only 30%. Furthermore, whilst the prosthesis was rated by only 37.5% to be useful for general use, when specific activities were considered (such as using scissors or riding a bicycle) the usefulness of the prosthesis rose to 75%. They concluded from this that children may wish to use prostheses for specific activities, rather than for general daily activities, and that prosthesis prescription should take this into consideration.

James et al (2006) examined prosthesis use in 489 children and adolescents (aged 2-20 years old) attending the Shriners Hospital in California, USA. They used five standardised tests to explore a range of factors related to prosthesis use. Some of the tests were administered to the children and others to their parents. They found that prosthesis use did not influence functional ability and that non-wearers of upper limb prostheses performed just as well, or even better than their prosthesis-wearing peers. These findings may suggest that although prostheses may not improve function, they may serve other purposes for children and young people, such as promoting social acceptance and for use as a tool for specific activities/sports (James et al 2006). Young people may, therefore, benefit from being able to choose their prosthesis based on the needs of the activity they require it for, calling in to question the prescription of general use functional prostheses for young people.

Egermann et al (2009) carried out a retrospective study, in Germany, of myoelectric prosthesis use with 41 children aged less than six years. The families of prosthesis users completed a questionnaire exploring the child's use of their prosthesis in everyday activities, such as playing indoors and outdoors and at Kindergarten. The authors considered prosthesis use of more than two hours a day as a 'successful' use of the prosthesis and found that 76% of the participants were using their prosthesis 'successfully'. They found that the children preferred to use their prosthesis for indoor as opposed to outdoor play, which may be related to the feedback from the participants that the technical reliability of the prosthesis was unsatisfactory and that it was prone to breaking down. The authors concluded that the poor durability of the myoelectric prosthesis reduces its compatibility with certain child-centred occupations, such as outdoor play. They suggest, therefore, that children should be provided with a range of prosthetic options so that they can change their prosthesis throughout the course of a day in order to select the most appropriate device for the task or environment.

The studies discussed may all be using different operational definitions of "prosthesis use" and not all the studies clearly state what definition they are using. It is also worth noting that the countries in which the research was conducted (USA, Germany and the Netherlands) have different healthcare systems, which all differ from the NHS in the UK, and have different degrees of government and private funding. The different funding methods may have implications for the devices that are issued and the way services are delivered. This can pose difficulties when combining or collating their findings to draw conclusions. Furthermore, the studies largely depend on collection of data in the form of a questionnaire completed by the children's families. The results collected, in terms of prosthetic use will, therefore, inevitably have an adult influence due to using adult proxies to gain the children's perspectives. Despite these methodological drawbacks, these studies all engender the same conclusions: that, as opposed to general purpose prostheses, children should be provided with a range of task-specific prosthetic options so that they can select the most appropriate device for the desired use.

1.2.2.2 Children's satisfaction with prostheses

Four studies relating to children's satisfaction with prostheses were identified through a systematic search of the literature. An additional study which is of significance to the present research was identified from prior work completed by the supervisor (Donovan-Hall 2010). Studies relating to children's satisfaction with prostheses will be discussed in the following section with consideration given to the different methodologies employed – parent proxy reports, quantitative studies and qualitative studies.

1.2.2.2.1 Parent proxy studies

Wagner et al (2007) carried out research with 168 children with unilateral congenital transverse forearm total deficiency (UCTFTD), who had attended prosthetic rehabilitation clinics in the USA and Canada, and who did not wear a prosthesis. Due to the perceptions of the researchers that the children would be limited in their answers by their age, they asked parents to answer (on behalf of their children) "What are the reasons for not wearing a prosthesis?" Their findings indicated that dissatisfaction with the prosthesis was related to choosing not to wear a prosthesis. The two most common reasons given were the prosthesis does not help function (53%) and the prosthesis is uncomfortable (49%).

Biddiss & Chau (2007b) explored users' satisfaction with their prosthesis using mixed methods. They used an online questionnaire, with both open and closed questions, to collect information on demographics, experience of limb difference, ADLs, prosthesis use and prosthesis satisfaction. The questionnaire was completed by 242 participants over the age of 12 and with all levels of limb difference from across the USA, Canada and the Netherlands. Parents were requested to complete the questionnaire on behalf of any children under the age of 12 as it was deemed too complex for children below this age. The researchers found that those who rejected their prosthesis were dissatisfied in the areas of appearance, comfort, function, ease of control, reliability and cost.

A strength of these studies is that they included open-ended questions allowing participants to express their views without being restricted to predetermined categories. However, in both studies, parents were asked to answer on behalf of child participants. Furthermore, in the Biddiss & Chau

(2007b) study, any questionnaires which had been completed by children under the age of 12 were subsequently excluded from the results. This is interesting given that, in completing the questionnaire, the children were challenging the notion that the methods were too complex for them.

Using parent proxy reports to explore the views of children raises questions about the truthfulness of the results obtained. The ability of adults to know what children think and feel, and therefore act as their proxies in research is an outmoded concept (O'Kane 2008). Research comparing the views of adults and children on matters pertinent to the young people has found consistent differences between the two group accounts, suggesting that adults experience the same situation differently and are not capable of assuming the child's perspective (Lightfoot & Sloper 2002). With relation to paediatric prosthetics, Sheffler et al (2009) compared self-report with parent proxy report of function and QoL amongst children with limb difference. They found that parents underestimated their children's physical function and overestimated their comfort. Parents also reported lower social functioning than the children. Research aimed at improving provision of prosthetics for children must, therefore, directly address the child's experiences and viewpoint. Furthermore, from an ethical perspective, Article 12 of the United Nations Convention on the Rights of the Child (1990) states that children have the right to share their opinion on anything that affects them and that what their views must be listened to carefully. The Children Act (1989, 2004) also stresses the importance of seeking children's views about services.

1.2.2.2.2 Quantitative studies

Pylatiuk et al (2007) conducted an internet survey of 54 German users of myoelectric prostheses, which included 11 child participants (aged 14 or under). The survey was either completed by the child or their parent(s). The survey asked the participants to rate their prosthesis on noise, weight and cosmetic appearance using a Likert scale. They found that all of the child participants rated the weight of their prosthesis as either a little or much too high. The survey also presented participants with a list of activities they may wish to perform with their prosthesis and found that 83% of children wanted to be able to use their prosthesis for personal hygiene, using cutlery and dressing/undressing.

An internet survey benefits from the potential to capture a large sample of participants from a wide demographic range, and allows participants to complete the survey in their own time. However, due to the complete anonymity of the data collection method, there is no way of knowing whether the young people participating completed the survey themselves, whether their parents supported them to complete the survey or if the parents completed the survey on their behalf.

Routhier et al (2001) used a quantitative approach to examine satisfaction of 18 Canadian children who used an upper limb myoelectric prosthesis in order to identify which factors influence the use or non-use of an upper limb myoelectric prosthesis. They used the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) (Demers et al 1996) to assess the degree to which the children were satisfied with their prostheses. The QUEST (Demers et al 1996) explores the importance that participants attribute to different aspects of their prosthesis and rates their degree of satisfaction with each of these attributes using a 5-point Likert scale. The most important variables identified by the children were: weight, comfort, effectiveness, appearance, simplicity of use and training. More than half of the participants reported that they were not satisfied with the heat, weight, comfort and freedom of movement provided by their prosthesis. They also reported issues with lack of wrist rotation and loss of tactile sensation.

Whilst these studies did directly involve children and young people as participants, as opposed to using parents as proxies, using quantitative surveys to examine the satisfaction of participants may have resulted in the participants being restricted in their answers. The choices given were predetermined by (adult) researchers, which may have an effect on the priorities and perceptions identified by participants (Crow 2000). Qualitative methods, however, appreciate individual perspectives of participants as they are able to influence the agenda of, for example, the research interview (Crow 2000). Furthermore, the reality of how disability and technology affect the individual may be subjective in nature. Using qualitative methods ensures that the factors and areas that are important to the participant are highlighted to the researcher and allow participants to speak in their own voice, rather than being confined to categories imposed on them by others (Mack et al 2005).

1.2.2.2.3 Qualitative studies

The Our Bodies Our Views project (Donovan-Hall 2010) encompassed several studies exploring children's views of prostheses, which involved a three phase mixed-methods programme of research. This included using a questionnaire with both closed and open questions to examine children's views about upper and lower limb prostheses. The questionnaire contained information about the participants' limb difference/loss; how satisfied they were with their prosthesis (if they wore one); what aspects of the prosthesis were important to them and reasons for not wearing a prosthesis. The appearance and function of the prosthesis were found to be very important to 70% of the participants and nearly 90% of participants indicated that being involved in choosing the prosthesis was important to them. Open questions about reasons for not wearing a prosthesis revealed the following contributing factors: the comfort of the prosthesis (including if it is itchy/irritating, hot/sweaty, too heavy or causes pain); managing better without a prosthesis and issues relating to appearance (such as, it gets dirty and draws attention from others).

Donovan-Hall (2010) also used interviews to explore the views of children and young people (aged 11 to 18 years) on prostheses. The participants included 11 males and 10 females who had upper or lower limb absence. The main issues found to be of importance were appearance, comfort and weight. For a number of participants the appearance of the prosthesis influenced their satisfaction with the prosthesis and the majority wanted their prosthesis to be lifelike in appearance so that it would be less noticeable to others. Comfort also influenced satisfaction with the prosthesis with participants reporting that the prosthesis could often be hot and sweaty to wear. Issues related to the function of the prosthesis seemed to mainly refer to the durability of prostheses and the desire to have prostheses that would last for a long period of time. Participants described how the cosmesis could become stained quite quickly or parts of the prosthesis could become loose and break.

This project illustrates the importance of communicating with children to discover their views on the aspects of prostheses that are important to them; developing a deeper understanding of the factors influencing prosthesis use and satisfaction for children and young people. In order for the value of this research to be fully recognised through its application to practice, further research exploring children's views on priorities for device development is needed so that the device-specific issues relating to satisfaction and use can be addressed and be included in future prosthetic design.

1.2.3 Section summary

The previous section discussed research relating to children's use of, and satisfaction with, prostheses, as identified through a systematic search of the literature. Although the studies presented varied in the appropriateness of methodologies employed, general conclusions can be derived from them. Firstly, the prostheses that are currently being prescribed are not as useful as they may potentially be for children and young people and, secondly, children and young people are not satisfied with these devices. It is proposed that, in order to address these two main assumptions, research which includes child service users in the development of new devices is required.

1.3 Involving users in the development of UL prostheses

Having demonstrated in the previous section that there is evident dissatisfaction with prostheses amongst children (albeit with minimal research directly addressing children's views), the following section will examine the existing literature that aims to address this dissatisfaction through involving users in the development of new devices. The section will begin by providing an introduction to the involvement of users in the development of health technologies generally. The involvement of end users, lay users and professional users in the development of upper limb prostheses specifically will then be discussed.

1.3.1 Involving users in the development of health technologies

Within healthcare research there has been increasing emphasis on the importance of involving users of services, including when designing technology intended for use in healthcare settings (Allsop et al 2010). Users of health technologies can be defined as people who use the device for their own treatment or therapy or that of others (Cifter & Dong 2008). Users of health technologies have traditionally been regarded as healthcare professionals ("professional users") and patients ("end users") (World Health Organisation 2003). An "end-user" of a device is the "person who is the ultimate beneficiary of the use of the device" (Shah & Robinson 2008, p.6). A "professional user" is a person who has specific knowledge about the use of the device gained through specialist training (Cifter & Dong 2008). Users of health technologies can, however, also include carers ("lay users"), suggesting that users of health technologies are a heterogeneous group, with different levels of expertise who use the devices in different ways and with different goals (Shah & Robinson 2008). "Lay users" have no formal training in the area in which the device is used, but have a particular role to play in the use of the device (Cifter & Dong 2008). In the area of child prosthetics, the three main user groups are the children ("end users"), their parents or carers ("lay users") and the clinicians who work with them ("professional users"). There are also likely to be additional "lay users", such as school staff, friends and other relatives.

Users of health technologies are the primary stakeholders of the devices (Shah & Robinson 2006). Involving them in health technology development and taking account of their needs is, therefore, important (Shah & Robinson 2006). Understanding the needs of users may determine the success or failure of the device being developed (Shaw 1998) and the quality of the end product (Keiser & Smith 1994). User involvement can lead to improved function, ease of use, safety and quality of devices (Shah & Robinson 2006). Comprehensive consideration of the needs of all the user groups ("end", "lay" and "professional") is essential if better devices are to be developed (Shah & Robinson 2006). In order to maximise the use and effectiveness of the device, development that takes into consideration the context in which the device will be used, including social and cultural context, is required (Bridgelal Ram et al 2007). Consulting all main user groups provides a more holistic account of the device's use: professional users will focus on the function of the device in relation to their clinical setting, whereas end users will provide the perspective of the device's function within their daily life (Weir 2006).

User involvement should begin at the early stages of device development so that users' views can be incorporated at an early stage in the design process (Saiedian & Dale 2000). Research has found that involving users at early stages results in successful and long-lasting medical devices (Shah & Robinson 2008). Neglecting to consult users early on in the design process can lead to the device not meeting the needs of users and, subsequently being rejected (Shah & Robinson 2008).

Whilst users should be involved early on in the design process, it is suggested that professional, end and lay users can be involved at all stages from the development of ideas through to the marketing, sale and evaluation of the product (Shah et al 2009). Focus groups and interviews are regarded as useful for involving users in the design process and for evaluating concepts (Nielsen 1997). Focus groups can be applied at various stages of the product development process, which particularly suits the iterative nature of the design process (McDonagh-Philp & Bruseberg 2000). An iterative approach is recommended for producing devices that are both clinically effective and culturally contextualised (Bridgelal Ram et al 2007). Focus groups are not only useful for specifying user needs at the outset but also at later stages in the process when evaluating prototypes (McDonagh-Philp & Bruseberg 2000). They can provide detailed insights into peoples' beliefs and experiences, enabling designers to develop empathy with users, encouraging the generation of new ideas (McDonagh-Philp & Bruseberg 2000). Combining focus groups with in-depth individual interviews provides the additional benefit of being able to better explore the nuances of the experiences of individuals (Matzler & Hinterhuber 1998). Inclusive design emphasises the importance of involving people with a range of abilities, both physical and cognitive, in the design of everyday objects with the aim of designing products that are usable to all people (Allsop et al 2010).

Exploring product design from this perspective involves going beyond considering the usability of the device to include its perceived usefulness and social acceptability (Keates and Clarkson 2003). Although inclusive design is concerned with the design of everyday objects for use by all, as opposed to specialist health technologies, its holistic way of viewing devices could be useful when applied to health technologies as the relationship people have with healthcare technology is more complex than merely how usable the device is in its medically intended context (Kirk 2008).

1.3.2 Involving children in technology design and healthcare research

Increasing recognition of children’s rights in research has led to a considerable increase in their involvement in healthcare research. Children are increasingly being asked for their opinions on the services and treatment they receive (Sinclair and Franklin 2000). Sinclair and Franklin (2000) argue, however, that although increased amounts of data on the views of children is being gathered, there is limited information about how this data is being used to bring about change in healthcare. Furthermore, children are regularly not provided with feedback on the outcomes of research they have been involved in, which can result in a feeling that their participation was merely an act of tokenism and that their views have not been truly listened to (Sinclair and Franklin 2000).

Nesset and Large (2004) conducted a literature review of research involving children in the design of information technology. They discussed projects by Druin et al (1999, 2002) that involved children in the design of storytelling software and digital library software for children. These studies incorporated the use of brainstorming, low tech prototyping and participant observation to understand the needs of users. Nesset and Large (2004) argue that the involvement of children in the design of these products resulted in software that was flexible and creative and truly met the children's needs. They suggest that likes and dislikes were revealed which were contrary to the researchers' preconceived ideas about the children and would have remained unknown without their involvement.

Nesset and Large (2004) also describe a study conducted by Large et al (2002) into developing web portals for children. This study employed a focus group approach to critique web portals currently available to children. Children were encouraged to express their views in order to develop a list of design criteria for children's web portals. They found that a focus group approach was suitable for research of this kind.

Research involving children in the design of healthcare technologies is, however, rather scant. Clarke et al (2001) explored children's use of assistive and augmentative communication devices, such as speech synthesisers and symbol/picture books. The researchers found that although the children considered the devices to be useful they also thought they were boring and "uncool". This emphasises the need to consider social and psychological aspects of technology use and not just the usability or usefulness of the device. Other examples of research involving children in the design of healthcare technology include Light et al (2007) and Rigby et al (1996). Both these studies involved incorporating the views and preferences of children into the design of assistive equipment, but there is a lack of information about the methods used and the success of these methods. Cooke (2004) involved children in the design of a hospital building using play sessions, interviews and focus groups to elicit their views. Cooke (2004) found using these methods it was possible to gain insight into how children felt about being in hospital and how these beliefs and fears shaped their behaviour. These findings were then taken into account when designing a new hospital building with simple additions, such as porthole windows in doors at a suitable height for children in order to reduce their fears about what was behind closed doors.

Weightman et al (2010) involved children in the development of devices for home therapy for the upper limb for children with cerebral palsy. Weightman et al (2010) used a range of methods to involve children, including the traditional approaches of questionnaires and interviews to explore their views, and peer tutoring methods to test the usability of the device. Whilst they found interviews and questionnaires to be useful for gathering the participants' views, the researchers did feel that these methods were commensurate with a traditional and marginalising power relationship, with the adults being in the position of power when asking the questions. They suggested that providing other opportunities for children to express their views could address this by giving children some choice and control over how they participate.

This section has discussed some studies which have highlighted potential benefits of involving children in the design of information technology and healthcare resources: involving children in the design process can lead to innovations that might not have been thought of without the children's input (Nesset and Large 2004). There is, however, still some reluctance from professional designers to accept children as equal contributors (Scaife and Rogers 1999) and issues of power dynamics and perceived hierarchies may still be apparent. Nesset & Large (2004) suggested that this reluctance results from a historical view of professional designers that children cannot be viewed as equals in a team setting, leading to a disinclination to accept that they can contribute meaningfully to the design process. The current study will, therefore, involve children in designing prosthetic devices, recognising that their views and ideas have equal merit to those of adults.

The frameworks and methods used vary considerably between the studies discussed, suggesting that the question of how to involve children in design may be more pertinent than the question of whether there is value in doing so. The methodology chapter will, therefore, discuss different approaches to designing with and for children and provide justification for the approach used in the current study.

1.3.3 Involving end users in the development of prostheses

One of the first studies to incorporate user needs into prosthesis design was conducted in India (Sethi 1982). Clinicians working with amputees observed that they rejected their western-style lower limb prostheses, electing to use crutches instead (Sethi 1982). It was concluded from this that the prostheses being prescribed were not suitable for the environment in which the amputees lived and worked, or their cultural and religious practices (Sethi 1982). The high cost of these prostheses coupled with their lack of durability when being worn for manual work in hot and dusty environments meant many users elected not to wear them (Sethi 1982). Five thousand amputees were, therefore, engaged in the design of a new lower limb prosthesis (The Jaipur Limb) that took account of the cultural and environmental needs of the users. Adopting a needs-led, as opposed to technology-driven, approach to device development led to the production of a cheap and easy to make prosthesis that better meets the needs of its users. The Jaipur limb is extremely durable and will last for three or four years, even without wearing any footwear over it (Sethi 1982). Furthermore, it is still being manufactured today at an extremely low cost of £25 to both manufacture and fit (Jaipur Limb Rotary Project 2012).

Although this research clearly demonstrated 30 years ago that involving users in the development of new devices results in prostheses that better meet the needs of their users and the economy, a technology-driven approach is still widely adopted throughout the industry. The significant developments that have occurred in upper limb prosthetics in recent years have been brought about through significant scientific and technological developments (Hong-liu et al 2010), as opposed to in response to the needs and wants of users. However, the 2006 State-of-the-Science (SOS) Meeting in Prosthetics and Orthotics identified that product development should be a priority research area with emphasis on the involvement of end-users in an iterative product development process (Resnik 2011).

More recent research to that of Sethi (1982) has been conducted with a UK population (Kyberd et al 1998). The researchers conducted a survey of adult users of prosthetic services at the Oxford Disablement Services Centre. The survey explored users' use of prostheses and desires for improvements in devices. They found that appearance, function and weight were important areas for improvement to the participants in the study.

The current research attempts to take account of the lessons of the Sethi (1982) study and challenge the technology-driven norm through involving a multidisciplinary cross-faculty team, enabling inter-professional collaboration between health professionals and engineers. This facilitates the adoption of a needs-led, as opposed to technology-driven, approach, as in the design of the lower limb in the Sethi (1982) study.

1.3.4 Involving paediatric end users in the development of UL prostheses

The input of the users of devices is essential in order to fully realise a needs-led approach to the design of prostheses. Regarding prostheses for children, this requires consulting with children and young people on elements of devices that are important to them and involving them in developing new devices.

The only existing research involving children in prosthesis development is research exploring the development priorities of prosthesis users of all ages, which combines the findings from adult and child populations (e.g. Atkins et al 1996; Biddiss et al 2007). This is not a satisfactory methodological approach. If one holds the assumption that children are not simply small adults then this is not an appropriate way to explore children’s priorities for development. It does not recognise children’s needs and views as unique to those of adults. Philosophical and methodological approaches to involving children in prosthesis development will be explored in more detail in the Methodology and Methods chapter (pp. 51-112).

The literature search described in the previous chapter yielded only one result in this subject area. A further research study was identified through the reference lists of articles retrieved through the literature search. Although this article predates the time constraint imposed on the literature search (2000 onwards), due to the paucity of data in this subject area, it will be included in this section. Atkins et al (1996) explored the research priorities of 1,575 people with limb difference of all ages in the USA. They used surveys covering areas including prosthesis cost and maintenance, use patterns, functional abilities, and preferences for areas of improvement to explore users' perceptions of their prosthetic devices and their priorities for improvement of prostheses. Parents of children with upper limb prostheses reported maintenance issues, such as cables needing repair on body-powered prostheses, cosmeses requiring replacement on both body-powered and myoelectric prostheses and batteries needing to be replaced on myoelectric prostheses as issues with current devices. Areas identified for improvement of prostheses largely focused on the prostheses' movement, such as increased wrist rotation, finger movement and thumb movement. Activities participants selected (from a list of 34) that they would like to be able to perform with their prosthesis included opening a door, using cutlery, tying shoelaces, drinking from a cup and typing. The authors concluded that the data suggests that having the ability to hold both large and small objects is important and that improved hand function is a high priority for prosthesis users. The reported results are, however, limited to the quantitative element of the survey and limited to the options provided by the researchers. Furthermore, children's responses were elicited by way of parent proxy reporting.

Biddiss et al (2007) involved service users of all ages from across the USA, Canada and the Netherlands in improving prosthesis design by identifying the priorities of the service users. They also used a survey to examine goals for prosthesis use, satisfaction with prosthesis and design priorities for 242 participants of all ages and levels of upper limb difference. Respondents were asked to list their five highest design priorities in order of importance from a list, but were also given the opportunity to respond with items not on the list. Additional design priorities that were identified by participants that were not on the list included: independently moving fingers (by users of myoelectric prostheses) and elbow and/or shoulder control (by participants with higher level limb absence). Reduced weight was identified as the leading design priority for users of electric devices. Parents of paediatric users of electric devices also reported that wear temperature, noise reduction, ease of donning/doffing, sensory feedback, cosmesis durability, resistance to moisture/dirt, cost, life-like function and appearance, and wrist control were priority areas. Participants who had body-powered hooks also desired reductions in weight in addition to increased harness/strap comfort, lifelike appearance and temperature/perspiration control. Parents of paediatric users of passive prostheses selected fine motor control as a high priority as well as reduced size, ability to clean, resistance to moisture/dust, lifelike appearance and sensory feedback. Across all types of prosthesis, the desire for improvements in function, comfort and appearance were paramount. Design priorities did, however, vary substantially between adults and children and, although this goes some way toward clarifying the distinct design priorities of paediatric and adult populations, the views of children were largely expressed by way of a parent acting as proxy.

Two particular shortcomings in explaining the views of children in the Atkins et al (1996) and Biddiss et al (2007) studies are that participants were required to respond to researcher-determined items and that in many instances parent proxy reports were used to represent children's views. These issues may result in the responses given by participants being influenced by an adult perspective, as being presented with a list of items may influence the responses given (Schwarz 1999) and responses may actually represent parental perspectives rather than the views of the users themselves. To address these shortcomings, the current study will provide children with the opportunity to express their views in isolation of their parents. Additionally the use of qualitative methods will prevent the participants from being presented with a limited number of researcher-determined items.

1.3.5 Involving parents in the development of UL prostheses

Over several decades, many authors have emphasised the impact of involving the parents, and providing them with guidance and information, on the child's acceptance of a prosthesis. As long ago as 1968, Nichols et al emphasised the dominance of parental attitudes on a child's acceptance of a prosthesis, yet there is a paucity of research that involves parents in the development of prostheses for children. More recently, Setoguchi (1991) suggested that the parents are more likely to have a positive attitude toward the prosthesis if they are involved in the decision-making. Krebs et al (1991) emphasised the importance of providing accurate information to enable the parents to be fully involved in the decision-making. Setoguchi (1991) argued that if the parents have a positive attitude toward the prosthesis they will also be more likely to educate the child's wider social circle about prosthesis use. This will strengthen the child's social support network, which has a positive impact on psychosocial health (Varni & Setoguchi 1993).

Postema et al (1999) used a questionnaire design to examine parent's views on, and expectations of, upper limb prostheses. They found that several factors concerning the parents influenced the child's non-use of the prosthesis. Specifically, parental disappointment with the prosthesis' functional capabilities, appearance and weight increased the likelihood that the child would reject the prosthesis. Furthermore, additional factors, such as the parents not feeling adequately involved in decision-making and perceiving that social and emotional factors were not addressed had an impact on the child's acceptance of the prosthesis. These findings infer that parental encouragement may positively impact on a child's use of prostheses. This supports the notion that parents should be involved in the development of prostheses for children and young people, so that prostheses which parents are satisfied with, and feel positive about, can be developed.

1.3.6 Involving professionals in the development of UL prostheses

Professionals can provide expert opinion on prosthetic options, which complements the end and lay users' "expert patient opinions" (Rycroft-Malone 2001, p.239). In the area of prosthetics there are often individual differences and wishes, which make the expertise of both the professionals and the end user paramount in coming to a decision about prosthesis prescription (Rycroft-Malone 2001). Another factor to consider when including professionals in the development of prostheses is that if professionals find it difficult to prescribe or fit the prosthesis or to train service users in using it, the end users of the prosthesis are likely to experience greater problems (Resnik 2011). It can be argued, therefore, that the views of both prosthetists and OTs are particularly relevant to product development when considering the roles of these two professions. Included in the key responsibilities of prosthetists is completing an holistic assessment in order to select and fit the service user with the most appropriate prosthesis. OTs complement these skills by providing specialist input in the areas of activity analysis and environmental assessment. Both professions are, therefore, essential in assessing prostheses and helping the service user to use the prosthesis in their everyday life (NHS Careers 2012a/b). This may be particularly relevant with regard to myoelectric prostheses, as prosthetic use training by an OT has been found to have a direct impact on the successful use of the prosthesis (James et al 2006).

In addition to considering the key professional roles of prosthetists and OTs and the importance of these, the differences in professional viewpoints and backgrounds should also be taken into account. Both professions complete training that is composed of a mix of theoretical study and clinical placement and focussed on the holistic assessment and treatment of people with disabilities (NHS Careers 2012a/b). During training, OTs are required to gain experience in a range of clinical settings, such as physical rehabilitation and mental health services (NHS Careers 2012b). Prosthetists, however, specialise in learning about the impact of disease on human bodily functions and applying engineering skills and ideas to problem-solve service users' issues (NHS Careers 2012a). The views of both prosthetists and OTs are, therefore, likely to be important considerations in product development. Prosthetists may be able to provide specialist insights into the physical science and design-related elements of prosthetic devices and OTs may share views with regard to environmental and functional implications.

Peerdeman et al (2011) involved professionals in the development of myoelectric forearm prostheses by carrying out a workshop for professionals to assess their views on the functional and non-functional needs of the ideal upper limb prosthesis. This study included 19 professionals, which comprised OTs, physiotherapists, rehabilitation physicians and prosthetists. They all participated in a workshop, which focussed on what is required from a prosthesis when completing different ADLs. The workshop enabled the researchers to identify that the professionals viewed having a range of grasps as more important than wrist movement for completing ADLs. This study, however, involved the clinicians representing the "end users" of the device and, therefore, acting as their proxies, as opposed to exploring the elements of the device that are important to the professionals themselves.

1.3.7 Section summary

Users of paediatric upper limb prostheses include children (end users), parents (lay users) and clinicians (professional users). Several authors have stressed the need to consult with all users of medical devices during the development of new products in order to improve quality, safety and ease of use and to minimise subsequent non-use (e.g. Bridgelal Ram et al 2007; Shah & Robinson 2008). There are, however, a limited number of research studies employing user-centred design principles in the development of prostheses for children. Those that have been carried out have not used the most appropriate methods of enquiry in that they have used proxy report, quantitative measures or data collection that combines the views of adult and child participants. These techniques all present some level of compromise to the methodological quality of the existing research. Qualitative research, which directly addresses the views of all users and recognises children as equal partners in the design process, is needed in order to develop a holistic understanding of the experiences of all users. This will enable development of devices that takes account of the needs of users in both the home environment and the clinical setting (Weir 2006).

1.4 Chapter summary

This chapter has described the current situation in upper limb prosthetics for children/young people, highlighting the UK ‘postcode lottery’ of services, which may result from both diffuse funding across PCTs and a lack of clinical guidelines.

Attempts were made to present statistics on upper limb difference and use of prosthetics services in childhood but this was limited by the paucity of available statistics. A brief description of the devices currently available followed. The potential impact of limb difference on children and young people was then considered. This chapter highlighted the conclusions from previous research, although methodologically unsatisfactory, that prostheses that are currently being prescribed may not be meeting the needs of children and young people, and that they are not satisfied with these devices. It is proposed that, in order to address these two main assumptions, research which includes service users in the development of new devices is required. The need to involve users (end, lay and professional) in the development of new products, in order to address these shortcomings, was then highlighted. Existing research studies employing user-centred design principles in the development of technologies, including prostheses were discussed and were found to be lacking in both number and methodological quality. Research directly addressing the views of all users is, therefore, required to address these limitations, and has led to the following research question and shaped the aims and objectives of the current study.

1.5 Research question, aim and objectives

1.5.1 Research question

What are the views of users of children's upper limb prostheses on currently available devices and how can these views be used to inform the design of new upper limb prosthetic devices for children and young people?

1.5.2 Aim and objectives

To respond to the gaps in the existing research an iterative study was designed to address the following aim and objectives.

Aim

To develop an understanding of users' perceptions of their current situation, and draw upon the unique expertise of all users, to contribute toward the design of new upper limb prosthetic devices for children and young people.

Objectives

1. To identify and explain children's perspectives of currently available prostheses and examine their priorities for developing devices through:
    a. Conversational and creative methods that enable them to express their views
    b. Using prototypes to expose them to technological possibilities and gaining their feedback on these
2. To identify and explain parents' perspectives of currently available prostheses and examine their priorities for developing devices through:
    a. Conversational methods than enable them to express their views
    b. Using prototypes to expose them to technological possibilities and gaining their feedback on these
3. To identify and explain professionals' perspectives of currently available prostheses and examine their priorities for developing prostheses through:

   a. Developing an understanding of the views of both prosthetists and therapists
   b. Using prototypes to expose them to technological possibilities and gaining their feedback on these

4. To practically apply the findings from the study through:
   a. Informing the design of prototype devices that can be presented to industry for further development
   b. Identifying key extrinsic factors that impact on the use of prostheses that can contribute to the development of guidelines for the profession

2. Chapter two: Methodology and Methods

The purpose of this chapter is to present the research methodology of this study which coheres with the research questions, aims and objectives presented in chapter one. The researcher's paradigmatic stance will be discussed before presenting the reasoning behind the use, and practical application, of the BRIDGE methodology (Iversen & Brodersen 2007) to developing upper limb prostheses that address user perspectives. An explanation of how the BRIDGE methodology (Iversen & Brodersen 2007) will be applied with a transformative paradigmatic stance will then be provided. This chapter will also provide an explanation for the use of the specific data collection techniques employed, focus groups and interviews, and the analytical approach to the data.

2.1 Introduction to research paradigms

Bryman (2004) describes a research paradigm as a collection of beliefs which influence what should be studied, the methods used to carry out the research and how the results should be analysed and interpreted. Traditionally, research paradigms have fallen into two groups, described by Tashakkori & Teddlie (2009) as positivism and constructivism. Consideration about the nature of scientific methods and beliefs about knowledge in relation to these paradigms has contributed greatly to the debate around qualitative versus quantitative methodologies.

2.1.1 Positivism

According to Tashakkori & Teddlie (2009) the positivist or traditional view of scientific research is associated with quantitative methods and encompasses the following major assumptions:

- There is a single, understandable truth that can explain cause and effect relationships and is generalisable;
- Human agency is purely incidental to, and not interdependent on, the objective natural world;
- Scientific knowledge is determined by the character of the physical world;

- Scientific exploration comprises a rigid set of methods and procedures.

Within this view, the researcher is viewed as an objective observer, gathering information that can then be analysed and expressed in generalisations that can be applied across a society of study (Guba & Lincoln 1994). Further to this, positivism purports that for a theory to be defensible it requires data to have been gathered in experimental conditions which eliminate the influence of any extraneous variables (Guba & Lincoln 1994).

It has been argued, however, that a positivist view is not appropriate for research involving people (Woolgar 1996). It is suggested that an objective realist view of natural artefacts is misleading as it neglects to acknowledge social relationships, values and beliefs that are present within communities and which have an influence on the character of the physical world (Woolgar 1996). Furthermore, Woolgar (1996) argues that definitions of ‘science’ are continually changing in relation to philosophical perspectives and historical and sociological development. It is, therefore, impossible to consider the methods and procedures of scientific study as unitary in nature. Lastly, the positivist stance of researcher as objective observer discounts the impact of social processes, values, beliefs and expectations on the generation of knowledge (Woolgar 1996).

Qualitative research is a research methodology that applies these critiques of traditional positivist science and in itself is informed by a range of complex philosophical beliefs about science. It follows, thus, that many different approaches and routes have been taken within qualitative traditions for investigating social and humanistic phenomena.

2.1.2 Constructivism

Constructivism is a commonly adopted philosophy by qualitative researchers that takes a stance of outright rejection of positivism, believing instead that researchers themselves construct versions of the world through their own activities and political and social histories, rather than objectively reiterating observed ‘truths’ (Henwood 1996).

Researchers working within the constructivist paradigm, attempt to understand the complex world of lived experience from the point of view of those who live it in response to the assumption that knowledge is socially constructed by people active in the research process and is influenced by the researcher’s own values (Schwandt 2000). Constructivism purports that reality is a product of individuals and can change over time (Tashakkori & Teddlie 2009). Further to this, constructivist researchers reject the notion that there is an objective reality that can be known, attempting to understand the multiple social constructions of meaning and knowledge relevant to the participants of study. More personal and interactive modes of data collection are therefore appropriate in constructivist research, such as interviews and observations. The methodological implication of a view that there are multiple realities is that research hypotheses cannot be established before the study begins; rather, questions will evolve and change as the study progresses.

Critics of constructivism argue that there are inherent problems in using subjective knowledge to generate anything that is meaningful in a wider context and can be built on. It is also argued that radical constructivist approaches are so far removed from traditional empirical research that it is extremely rare to be able to explicate any generalisable and useful knowledge about human behaviour (Hamel et al 1993; Yin 1994). Furthermore, adopting a pure positivist or pure constructivist research paradigm can raise challenges when conducting research with children due to the neglect in both paradigms of the consideration of the impact of power differentials (Lightfoot & Sloper 2002). Critical theories, such as the transformative paradigm, however, purport that research should be governed by societal injustice and emphasise the importance of adopting methodologies that allow marginalised groups to have their voices heard (Tashakkori & Teddlie 2009). The transformative paradigm promotes the exploration of the views of all involved parties (Mertens 2007) and is, therefore, an appropriate lens for research that involves exploring the views of all users, such as the current study. Furthermore it is an appropriate framework for research involving children with disabilities as they are a group that has traditionally been marginalised in research.

2.2 The transformative paradigm

The transformative paradigm arose during the 1980s and 1990s partly due to dissatisfaction with research conducted within the dominant research paradigms of positivism and constructivism that was perceived to be irrelevant to, or a misrepresentation of, the lives of minority groups (Mertens 2010a). Greater concern about the rights and welfare of research participants resulted in greater involvement of the participants themselves in the research process, which is a central principle of the transformative paradigm (Mertens 2010a). Transformative researchers felt that the constructivist approach to research did not sufficiently address issues of social justice as relevant to marginalised groups in society or facilitate positive change in the lives of the participants or the institutional contexts in which they lived and worked (Creswell 2003). Denzin & Lincoln (2005) supported this view, arguing that research should be aimed at improving social justice and Sweetman et al (2010) furthered this by emphasising the need to look at issues of power within research and the impact of power on how marginalised societal groups are represented in society. Transformative scholars, therefore, took steps to identify themselves with a specific paradigm position, outlining key differences between the transformative paradigm and positivist or constructivist approaches, described by Mertens et al (1994) as follows:

- It places central importance on the lives and experiences of the diverse groups that, traditionally, have been marginalised (such as, disabled people);
- It exercises awareness of how and why asymmetric power relations exist as a result of oppression, whether historical or current;
- It links social research to social action.

Inequality is evident throughout our daily lives – visible in, for example, work settings and the media (Mertens 2010b). The bases for these inequalities are sometimes visible in the response of society to groups of people whose characteristics have historically been used as a basis for discrimination, such as age and disability. The transformative paradigm is applicable to research with people who experience discrimination and oppression on whatever basis, including those mentioned previously. It enables researchers to gain a fuller understanding of the genuine lived experiences of marginalised participants and to work to have a positive impact on those experiences (Munger & Mertens 2011). The transformative paradigm is based on the recognition of human rights as they are articulated by the United Nations (Mertens, 2010b). Relevant to the participants in the current study are the Universal Declaration of Human Rights (UN 1948), the Convention on the Rights of the Child (UN 1990) and the Convention on the Rights of Persons with Disabilities (2006).

The transformative paradigm places priority on the pursuit of social justice and the furtherance of human rights when considering the four philosophical assumptions of ontology, epistemology, axiology and methodology (Mertens 2010b). Formulating a plan for change as a result of the research findings is critical to the transformative paradigm, as it enables researchers to be ‘transformative’, as opposed to simply reporting findings and moving on (Mertens 2003). This is in contrast to the positivist paradigm, which doesn’t require the researcher to have a plan for how the research findings will be applied (Brown & Hedges 2009). The four main philosophical assumptions of the transformative paradigm – axiological, ontological, epistemological and methodological – will be discussed in further detail in this section, prior to considering the BRIDGE methodology of Participatory Design (see section 2.4.4, pp.68-72) and the application of a transformative lens to such research (section 2.4.5, pp.72-74).

2.2.1 Axiological assumptions of the transformative paradigm

Axiological philosophical assumptions are concerned with the role of values and ethics in research (Creswell 2003). The transformative paradigm’s axiological assumption has a critical influence on beliefs associated with the other philosophical assumptions (Munger & Mertens 2011). This is because in order to address the values that guide research in a transformative manner, researchers need to consider the ethical principles that impact the research and how these ethical principles relate to social justice and power differentials (Mertens 2007). This requires the researcher to take into account the knowledge and strengths of the participants in order to build rapport and respect between the researcher and the participants (Munger & Mertens 2011). Transformative researchers must also attempt to represent the participants accurately so as not to perpetuate the cultural beliefs that may exist about any societal groups to which they belong (Mertens 2007). It is essential, therefore, to explore the history of cultural beliefs about the community and consider their own standpoint on these beliefs (Munger & Mertens 2011). The implicit goal of the transformative paradigm is to empower those who represent a marginalised group in society to have their viewpoints accurately expressed in order to promote a social justice agenda (Mertens 2007). The social-cultural model of disability and a post-structural sociocultural view of childhood are theoretical approaches that are commensurate with an axiological transformative stance and merit further discussion here in the context of exploring historical and cultural beliefs about disability and childhood.

2.2.1.1 The social-cultural model of disability

Historically, disabled people have been involved in research as subjects of, rather than participants in, research studies (Barnes & Sheldon 2007). This was influenced by a widely held belief in the medical model of disability, which locates the disability within an individual's impairment and emphasises an expert-service user relationship in which the expert seeks to cure or at least alleviate the symptoms experienced by the service user (Oliver 1992).

Both disabled and non-disabled campaigners and researchers have, however, criticised medical model approaches to researching disability (Shakespeare & Watson 2001). The transformative research paradigm (Mertens 2007) is underpinned by a social-cultural, rather than an individual medical model of disability. The social-cultural model of disability challenges the medical perspective by allowing people with disabilities to take control over their own lives by focusing on social, rather than physiological factors, in understanding disability (Mertens 2010a). It recognises that disability and impairment are two distinct concepts (UPIAS 1976). The social-cultural model of disability is, therefore, based on understanding the physical, cultural and social barriers that lead to the exclusion or disempowerment of people with impairments (Barnes 2003). Thus, in focusing upon the manner in which disability is socially constructed, the social model gives precedence to the importance of empowerment and inclusion (Mertens 2008). The social-cultural model of disability challenges the traditional medical model by enabling people with disabilities to take control over their own lives by shifting the emphasis onto social factors in understanding disability (Mertens 2008).

The social-cultural model recognises that people with disabilities form a cultural group that historically has been discriminated against in society (Mertens 2008). It recognises the 'problem' of disability as the inadequate adjustments by society to meet the needs of people with impairments (Mertens 2008). This view corresponds closely with the transformative paradigm as both recognise that people with disabilities, as a sociocultural group, experience discrimination and oppression in society and that this oppression should be challenged through conducting empowering and transformative research (Mertens 2008).

2.2.1.2 Theories of childhood

Traditionally, psychological theories of child development (e.g. Piaget's theory of cognitive development 1972) have viewed children as 'becomings' – 'adults in the making' who lack the skills and abilities of the adult that they will become (James & Prout 1997). According to Uprichard (2008) there are two main issues with viewing children as 'becomings', specifically that this view is solely focused on children's future development and that it raises issues about the perceived competency of children. Viewing children as 'becomings' places importance on that which the child will become as opposed to that which the child is presently (Uprichard 2008). The child is seen as an incomplete adult rather than a complete human being (Uprichard 2008). To base our understanding of childhood principally on the child's future status as adult is problematic because it forces us to neglect to consider the realities of everyday experiences of children (Uprichard, 2008).

The second concern is that serious issues relating to competency are raised, specifically that children should be viewed as incompetent and adults as competent (Uprichard 2008). Children are seen as progressing from deficiency to mastery of skills, warranting them vulnerable and in need of protection (Young 1990). This perspective implies that competency is something that is acquired as one becomes an adult and that competency is a characteristic that can only be possessed by adults (Uprichard 2008). This lack of understanding that children have the competence to contribute to decision-making can result in a lack of recognition of children's rights to be heard (Lansdown 2009). This leads to adults underestimating children's capacities or failing to consider their views (Lansdown 2009). The construction of the 'becoming' child is deeply engrained in Western notions of childhood (James & Prout 1997) that deny children opportunities for participation in decision-making because of social and economic dependency and a perception that they need to be protected. This is in contrast to the high value that is placed on civil and political liberties and autonomy (Lansdown 2009). This reduces the opportunities children have for developing their capacity for emerging autonomy, which serves to justify their exclusion from decision making, perpetuating the cycle (Lansdown 2009).

Wyness et al (2004) argue that measuring the status of a child as incompetent against a view of adults as competent, results in an inclination for research approaches *not* to be adapted to make them more suitable for children. Although this applies to all children, for disabled children and young people this issue is compounded by the discrimination and oppression they may be faced with on the grounds not only of being children, but also of being disabled (Martin & Franklin 2009).

Vygotsky (1978) acknowledged the work of Piaget but voiced the need for a more sociocultural frame for understanding children's development, regarding development as taking place through participation in social practice and being influenced by contextual factors. A sociocultural approach to child development involves viewing children as social actors without assuming their views are less competent, based in reason or important than adults (James & Prout 1997). The work of Vygotsky (1978) emphasises the sociocultural dependant everyday practice of children as the basis for child development as opposed to Piaget's (1972) cognitive theory. Vygotsky's (1978) view of child development provides a theoretical framework that focuses on children's everyday practice (and not their cognitive abilities) as the object of study, when studying children and childhood.

Children are viewed as actively constructing their own childhood, and having views and experiences about being a child (Uprichard 2008). This shift of emphasis presents children as agents of their own social worlds and is evident in children's rights legislation. Since the late 1990s the UK government has included within policy developments a commitment to increasing the involvement of children in decision-making processes about their own care and the services they use (Martin & Franklin 2009). Examples of policies that advocate the participation of disabled children and young people include the Children Act (1989, 2004), the UN Convention on the Rights of the Child (UN 1990), the Human Rights Act (1998) and the Convention on the Rights of Persons with Disabilities (UN 2006). Furthermore, a central theme of the National Service Framework for Children, Young People and Maternity Services in England (Department of Health 2004) stresses the importance of consulting and involving children. There can, however, be a danger in stringently adopting a rights-based approach to childhood as there may be a propensity to neglect consideration of the child's future development (Uprichard 2008).

Lee (2002) suggests that childhood should be considered in terms of a fluctuating coexistence of ‘being’ an active participant and ‘becoming’ one’s future self. This construct can, thus, be applied to participants of all ages as individuals, regardless of age, may be more or less competent at doing certain things throughout their lives. This approach addresses the previously supposed duality that makes children ‘different’ to adults (Strandell 2005). It enables competency to be considered as specific to a situation and social and cultural experiences, rather than as determined by a person’s age (James & Prout 1997). From this perspective, both children and adults can be both competent and incompetent depending on what they are confronted with. There is, however, a higher duty of care when conducting research with children than when working with adults (Lansdown 2009).

Thus, a sociocultural view of childhood recognises the fluctuating and culturally developing nature of competency whilst also recognising the child’s legal right to be protected and nurtured. Therefore, a right-based sociocultural approach to childhood reflects a child’s rights both to express their views and to be protected from harm (Uprichard 2008). It is, therefore, necessary to balance the right to participation with the right to protection, recognising that it can be harmful to impose expectations on children in research (Lansdown 2009). Being over-protective, on the other hand, denies children the right to be heard which may inhibit their opportunities to develop their skills in participating in decision-making (Lansdown 2009).

2.2.2 Ontological assumptions of the transformative paradigm

Ontological assumptions are concerned with the researcher’s beliefs on the nature of reality (Cresswell 2003). The ontological assumption associated with positivism is that there is one reality that we can know within a certain level of probability (Mertens 1999). The constructivist paradigm purports that there are multiple socially constructed realities (Mertens 1999). The transformative ontological assumption critiques the constructivist view of multiple realities by suggesting that it is inaccurate to assume an absolute relativism, such that no one perspective is any ‘truer’ than any other perspective (Mertens 1999). Transformative scholars believe that there are diversities of viewpoints with regard to reality and that political, cultural, and economic value systems need to be explored in order to understand the basis for these differences (Mertens

2010b). Furthermore, researchers working within a transformative framework must consider how the research can reveal different versions of reality (Mertens 2007). This ontological assumption leads to considerations of power that influence who will be more or less likely to be included in decisions about the accepted definition of what is ‘real’ (Mertens 2007).

2.2.3 Epistemological assumptions of the transformative paradigm

Epistemology is the study of knowledge and the relationship between the knower and what is known (Cresswell 2003). The issue of objectivity is salient to epistemology, along with implications for the nature of the relationship between the researcher and participants (Mertens 1999). In the positivist paradigm, objectivity is considered to be paramount and is thought to be achieved by observing from a somewhat distant and detached standpoint (Mertens 1999). In the constructivist paradigm, interaction between the researcher and participants is felt to be essential as they strive together to make the participants’ values explicit and create the knowledge that will be the results of the study (Mertens 1999). In the transformative paradigm, objectivity is valued in the sense of providing a balanced and complete view of the issue at study to prevent a lack of understanding of key viewpoints (Mertens 2010b). In order to achieve a complete and balanced view, an interactive link needs to be established between the researcher and the full range of stakeholders to whom the issue of study is relevant (Munger & Mertens 2011). This is essential due to the fact that, historically, researchers have encouraged more powerful members of society (such as parents and professionals) to represent the views of less powerful groups (such as children and disabled people) (Munger & Mertens 2011). This can result in research that does not address the concerns and viewpoints of marginalised groups (Munger & Mertens 2011).

Transformative scholars assume that knowledge is influenced by perceptions of power and social relationships within society; and that an important purpose of gathering knowledge is to have a positive impact on society (Banks 1993). Researchers need to understand appropriate strategies for entering cultural groups in order to establish relationships that have the potential to contribute to change (Mertens 2007). Strategies for developing this understanding include reading about the community, seeking appropriate training and establishing research teams that include important community gatekeepers, which can enhance the researcher's perceived credibility within the communities (Munger & Mertens 2011).

2.2.4 Methodological assumptions of the transformative paradigm

Methodological assumptions constitute the philosophical basis for making decisions about appropriate methods for research (Mertens 2010c). In methodological terms, the positivist paradigm is characterised as using primarily quantitative methods (Mertens 1999). The constructivist paradigm is characterised as using primarily qualitative methods (Mertens, 1999). The transformative paradigm can involve purely qualitative or mixed methods, but not purely quantitative methods as inclusion of a qualitative dimension is critical in order to establish dialogue between the researcher and the participants (Mertens 2010c). Methodological decisions are made with a conscious awareness of social and historical context, particularly in relation to discrimination and oppression (Mertens 2010c). Data collection methods should accommodate cultural complexity, power issues and issues of discrimination and should facilitate interaction between the researcher and the participants (Mertens 2010c). Research methodologies should be sensitive to communities that may be marginalised (Mertens 2007).

Reframing methodological decisions in this way requires the researcher to build rapport and trust with participants in order to obtain valid data (Mertens 2005). This must include recognising the need to modify data collection methods to accommodate the views of various groups and to link the data collected to social action (Mertens 1999).

Methodologies employed by transformative researchers are wide-ranging and continually developing (Mertens 2010a). Empirical transformativist scholars generally use mainly quantitative methods, employing additional care and rigor in following existing methods commonly associated with positivism to avoid prejudiced or biased results (Harding 1993). Other transformative researchers may make use of qualitative methods within a transformative framework (Reinharz 1992). Others still may posit themselves within a participatory action research tradition, viewing it as essential to involve the people who are the research participants in planning the research and collecting, analysing and disseminating the data (Mertens 2010a).

2.2.5 Section summary

The previous section has presented the rationale for positing the current study within a transformative perspective. As the current research study involves participants in developing and designing medical technologies, methodologies concerned with design for/with users are appropriate to the current study and will now be discussed in further detail.

2.3 Designing for and with users

It is now widely accepted that involving users and, indeed, children in design has both ethical and methodological advantages: “the real issue would seem to be [...] how to more effectively engage them in the design process’’ (Nesset & Large 2004, p. 160). The following section will, therefore, discuss several approaches to user involvement in design and the appropriateness of adopting or adapting them for use with children.

2.3.1 User-centred design

This is a research method that is traditionally used for products that have already been developed and are on the market: users are involved as evaluating products for designers to ensure user needs are met (Nesset & Large 2004). Users have little or no control in the process because they only become involved after the technology has been designed (Nesset & Large 2004). A major drawback of user-centred design is that users’ involvement is limited as they are not able to initiate changes themselves only highlight shortcomings to designers post-production (Nesset & Large 2004). Despite this, it was instrumental in introducing the idea of user involvement in design and this principle is what underpins contemporary participatory design methods (Nesset & Large 2004).

2.3.2 Contextual inquiry

Contextual inquiry is intended to be used to enable designers to develop an understanding of the nuances of the work people do and the motivations behind the work (Nesset & Large 2004). Traditionally, ‘work’ was used to refer to the jobs that people performed in industry. As, however, designing with people expanded to include more everyday objects, the definition of work was broadened to encompass a more sociological understanding of the carrying out of tasks, involving the expenditure of mental and physical effort, necessary to our everyday lives (Bodker & Iversen 2002). Developing an understanding of people's work practices enables designers to use their understanding of people's work to influence their decision making (Nesset & Large 2004). Contextual inquiry involves observational study of users performing typical activities in their usual environment (Nesset & Large 2004). Contextual inquiry is, therefore, inconsistent with a philosophical belief that users should be involved as active participants in the research process, as interaction between researchers and users is minimal, and is, therefore, not suitable for the current study.

2.3.3 Participatory design

Participatory design, in its simplest form, can be described as actively involving the stakeholders (usually the intended users of the device) in the design process (Nesset & Large 2004). Participatory Design arises from a belief that workers are the best people to advise on how their work and work life can be improved and that their views on technology hold equal importance to the technical expertise of designers (Carmel et al 1993). It grew, therefore, out of a convergence of a humanistic, emancipatory approach to improving working conditions and a functionalist paradigm perspective aimed at improving the efficiency of the design process (Asaro 2000). Participatory Design facilitates the development of products that take account of the current needs of their users (Bowen 2010a). It ensures that users of technologies are involved in their design; such is their democratic right to be included in the design of things that impact their daily life (Bowen 2010b). Furthermore including them in design will result in 'better' products being developed (Bowen 2010b). It can be seen, therefore, that Participatory Design is embedded in both a political, transformative genus, whilst having scientific and technical features (Ehn 1993).

There are two main themes to Participatory Design. The first is Mutual Reciprocal Learning in which users and designers teach each other about work practices and technical options. In the second, Design by Doing, hands-on design occurs through interactive experimentation and modelling (Carmel et al 1993). Nesset and Large (2004) advise that Participatory Design is suitable for designing with children because its flexible structure enables their enthusiasm and creativity to flourish. However, reluctance of designers to accept children as equal design partners can lead to children's views being paid 'lip service' but not taken seriously or implemented (Nesset & Large 2004). Involving children as testers of prototypes (Druin 2002) is one such example of this.

Within this approach, it is intended that how children interact with prototypes will affect future iterations of the technology (Druin 2002). However, there is no guarantee that the testers’ suggestions will be implemented (Nesset & Large 2004).

2.3.3.1 Critical theory and participatory design

Critical theories, such as the transformative paradigm, aim at emancipating and empowering participants and encouraging their agency through raising awareness of implicit coercion and prejudice (Ehn 1993). Considering Participatory Design from a Critical Theorist standpoint gives rise to the following implications (as outlined by Bowen 2010a):

- Contextual factors impact on the understanding of different stakeholders;
- Uncritical acceptance of these contextual factors compounds ‘oppression’ as there is no challenge to the status quo;
- Challenging understanding through offering alternative views of society can propagate change.

Applied to product development, critical theory implies that users may have low aspirations for products (due to implicit socialisation to accept what is currently available) and could even be seen to suggest that users lack the awareness or ability to aspire to higher ideals (Bowen 2010b). If the researcher is placed in the position of enabler, inspiring users to consider aspects of a product that they had previously deemed unimportant, the researcher could be inadvertently placed in a position of intellectual superiority, contradicting a central aim of the transformative paradigm of eliminating power differentials (Bowen 2010b). Participatory Design methods must, therefore, endeavour to explicitly include the voice of the user. Methods that directly explore user views, as opposed to instigating discussion from a point of departure, such as a prototype, may be a way to minimise the implied reverential status of the researcher.

2.4 Designing with children

The field of Human Computer Interaction (HCI) is considerably further ahead than healthcare in involving users in product design (Glushko 2013). This field provides a rich source of methods that may be used in involving children in the design of healthcare technology. It is, however, important to be aware that children's relationships with computers may be different to their relationships with healthcare technologies which may have implications for the methods used. Healthcare technology is oftentimes something that children *have* to use rather than *choose* to use and they may, therefore, have negative feelings about the necessity and social perceptions of using equipment (Allsop et al 2010), as demonstrated in the study by Clarke et al (2001) that was discussed in chapter one (see section 1.3.2, pp. 39-42).

Child computer interaction (CCI) is a subfield of HCI relating specifically to children's relationships with technology (Markopoulos et al 2008). The development of the CCI discipline has widely accepted, at least in information technology design settings, that children should be involved in the process of designing new technology for children (Iversen & Brodersen 2007). However, this field largely bases its methods and approaches for involving children on a Piagetian understanding of children and learning as children being cognitively immature versions of adults (Iversen & Brodersen 2007). Information is either gathered from parents and teachers with children being marginal to the process, or design with children is treated as a special research domain within the field of design and attributed its own specific methodologies, such as Informant Design (Scaife et al 1997) and Cooperative Inquiry (Druin, 1999, 2002).

2.4.1 Informant design

Scaife et al (1997) observed some shortcomings with the techniques of User-centred Design and Participatory Design when working with children. They argued that User-centred Design is flawed because it is purely reactive, allowing users to respond to technology developed, but not initiate or influence design (Scaife et al 1997). Their reason for suggesting Participatory Design is not an appropriate approach with children is the argument that children, as opposed to adults, do not have the expertise or knowledge to participate in a collaborative design process (Scaife et al 1997). Informant Design (Scaife at al 1997) was developed as a technique for designing educational equipment. It begins with children and teachers (separately) providing information about the strengths and weaknesses of their current equipment, either through observation or discussion-based methods (Scaife et al 1997). This information is then used by designers to identify current problems which are used to inform functionality specifications. Prototypes are then developed and teachers and children provide feedback on them for further development (Scaife et al 1997). It is evident from Scaife et al's (1997) reasoning behind their rejection of Participatory Design methods that Informant Design is founded on traditional stage-based understandings of children's cognitive development, such as Piaget's (1972) theory of cognitive development. It is, therefore, inappropriate for use in the current study due to a lack of recognition of children's competency and agency to participate in decisions affecting them.

2.4.2 Cooperative inquiry

Cooperative Inquiry (Druin 1999) is a method of participatory design that is solely applied to children and emerged as a result of a growing multidisciplinary interest in children as users and producers of technology (Iversen & Brodersen 2007). It emphasises a multidisciplinary partnership with children, observational research that studies the current context of technology use and iterative prototyping (Druin 1999). Children are paired with designers in 'intergenerational design teams', with the aim that children and designers are viewed as equals in the design process (Druin 1999). Cooperative Inquiry begins by using methods adapted from contextual inquiry, as children are observed in their own environment interacting with existing technologies at the outset of the design process (Druin 1999). Following this, all members of the design team participate in an idea generation stage, creating low tech prototypes out of paper (Druin 1999). The design process then moves on to 'technology immersion', which involves the children being exposed to large amounts of technology in order to identify additional roles and patterns that may not have been identified in the contextual observation (Druin 1999). Druin's (1999) Cooperative Inquiry is based on a Piagetian understanding of children as having difficulty in verbalising their thoughts and opinions. Druin (1999), therefore, employs observation instead of discussion-based methods to inform of the child’s current situation, as she argues this provides a concrete experience from which to begin designs (Druin 2002).

A strength of this approach is that it recognises that children have different interests and occupations to adults. These differences are, however, used to legitimise a dedicated method for technology design with children, which is primarily founded on a Piagetian model of cognitive development. This purports that cognitive development occurs in discrete stages throughout childhood in which cognitive skills are acquired and accommodated until the ultimate goal of adult cognitive maturity is attained (Piaget 1972). Furthermore, children working with researchers to create low tech prototypes, as is done in Cooperative Inquiry, could limit and prescribe what children are able to create as opposed to being entirely open to their views, as qualitative discussion-based methods are able to be (Allsop et al 2010). Conducting research following such a framework would represent a contradiction to the proposed transformative paradigm: adopting a viewpoint which identifies children as cognitively immature would serve to compound historical views about childhood and would not facilitate their agency in the design process.

Davis (1998) suggests that the main objective for researchers developing health technologies for and with children should be to identify methods that enable children to express their views and opinions as fully as possible and in an active way. Although methods have developed, such as Cooperative Inquiry, that utilise creative and ‘child friendly’ tools of data collection with an aim to increasing child participation in research, as previously alluded to they imply that children are not capable of meaningful conversations in the same way that adults are (Kirk 2007). This suggests that children are not viewed as independent social actors and are not regarded to be socially competent (Kirk 2007). Furthermore, novel methods for research with children lack sufficient scrutiny and critical reflection (Allsop et al 2010) when compared to more established methods, such as interviews and focus groups.

2.4.3 Children’s roles in the design process

Druin (2002) identified four roles that children can play in the design process. The role of user is that which forms the basis of User-centred Design theory. In this role, children are observed using technology and from this designers identify further developments and innovations. The second role is tester, where children test prototypes of a product before the design cycle is completed in order to influence future iterations of the prototypes prior to market release. Druin (2002) suggests that when children participate as testers the focus is on how well the prototype meets the intended design goals rather than the users' views about the usefulness of the device. The third role, that of informant, stems from Scaife et al's (1997) Informant Design theory. The informant role is positive because it engenders feelings of empowerment in the children because their views are sought. The children's input is, however, largely focussed on the outset of the process with designers choosing the ideas they wish to take forward.

The final role is described by Druin (2002) as Design Partner and forms the basis of Cooperative inquiry. The intention of this approach is that children are viewed as equal design partners and the impact they have on the technology can outweigh the impact the technology has on them. Problems can, however, arise in Cooperative Inquiry as some professionals may find it difficult to work with children as peers and, in response to this, Druin (2002) suggests children should contribute to the design process in ways that are 'appropriate' to both them and the process. This gives rise to a supposition that children, even in Cooperative Inquiry, may not actually be treated as equal partners as the decision about what is 'appropriate' is likely to be made by the researcher/designers, bringing to the fore issues of power dynamics.

2.4.4 Sociocultural approach to participatory design with children

As discussed earlier a post-structuralist view of childhood rejects the notion of cognitive incompleteness and enables children to participate in product design as competent and resourceful partners with a distinct social view, enabling their decisions to be given equal credence in the design process (Iversen & Brodersen 2007). One such methodology that views children as equal stakeholders in the design process is the BRIDGE method (Iversen & Brodersen 2007). This approach argues that, providing consideration is given to context, collaboration and appropriately culturally sensitive tools, children do not need to participate in Participatory Design in a fundamentally different way to adults (Iversen & Brodersen 2007). The BRIDGE method purports that rather than focussing on cognitive differences implied by arbitrary age categories leading to children being considered as cognitively incomplete, the language, materials and environment used should enable equal contribution to the design from children and adults. A fundamental driving belief behind this is that designing a new technology requires active participation of members of the community of users (Iversen & Brodersen 2007). Specifically, the BRIDGE method views children as experts in their everyday lives with their expertise being viewed as equal to any adult stakeholders. Applying sociocultural developmental theory to design implies that at the outset of the design project, the end users are those that possess the knowledge of their current situation. They are, therefore, able to contribute specialist domain-specific knowledge from their own world that to some extent is unknown to the designers. Children's everyday lives and experiences must, therefore, be used as a starting point for the design process (Iversen & Brodersen 2007).

Furthermore, starting with the children's viewpoint is commensurate with a transformative ontological stance that emphasises the importance of giving power to the realities of marginalised groups. The triadic relationship in children's healthcare decisions almost always involves the patient (the child or young person), their parent or guardian and the clinician (Taub 2003). Traditionally, only the parents and clinicians have been involved in healthcare decisions generally, on the assumption that parents or guardians are the most appropriate decision makers, when guided by the clinician, who holds the necessary medical expertise (Taub 2003). Studies on children's encounters in out-patient clinics have found that even older children were routinely excluded from discussions and given limited autonomy (Carter 2002). It appears that the practice of speaking with children, listening to them and involving them in the decision-making process is not widespread among health professionals (Coyne 2011). For the past 20 years, however, involving children in their healthcare has been a growing effort, as a result of the growing body of evidence demonstrating children's ability to make choices about their health and care (Alderson 1993). In essence, it can be seen that historically clinicians have held the greatest position of power in the triad by virtue of their professional expertise, with children and young people being the least valued in the decision-making process as a result of assumptions held about their level of competency. With awareness of this traditional triad, this research attempts to redress this imbalance of power through first consulting with children on their views before exploring the views of parents and clinicians.

The BRIDGE method does not, however, view design as a symmetrical relationship between the user and the researcher. The researcher is viewed as being responsible for providing the correct techniques and tools for involving children and for understanding the children's viewpoints (as opposed to it being the children's responsibility to make their viewpoint understood) (Iversen & Brodersen 2007). It is also the researchers/designers responsibility to come up with technological innovations that demonstrate an understanding of these views and challenge the status quo of their existing practices, as they possess the knowledge of the technical options and feasibilities that is vital to the design process (Iversen & Brodersen 2007). In support of this approach to co-constructing knowledge is Rubin et al's (1994) reflection on the benefits of having a multidisciplinary design team. Rubin et al (1994) argue that a multidisciplinary team approach ensures that children's novel ideas can be gleaned but that technical feasibility can be maintained, preventing the children from feeling disappointed or that their ideas have not been valued (Nesset & Large 2004). Rubin et al (1994) conclude, thus, that design cannot be the sphere of one professional as effective design requires a range of skills, knowledge and experience including that of the intended user.

To date, The BRIDGE method (Iversen & Brodersen 2007) has only been described in relation to the involvement of children in the design process. However, as previously discussed various users are involved in the use of children's health technologies, and should be involved as stakeholders in the process of designing children's technology. The BRIDGE method is, however, intended to be used to include various stakeholders in the design process (Iversen & Brodersen 2007). The current research explores the views of the three main stakeholders in children's upper limb prosthetics (see section 1.3.1, pp. 37-39). Consideration of different types of users is required in the process of device development as different users will vary in their level of training, knowledge and experience (Lewis 2001). Furthermore, their environment, culture, social norms, perceptions and beliefs may also be different (Lewis 2001). In this regard, and consistent with the transformative epistemological stance, recognition of the diversity of backgrounds, motivations and skills of the different types of users is essential (Shah & Robinson 2008).

This also demonstrates an application of a transformative ontological stance that different versions of reality should be revealed through the research. It is important to encourage participants to convey their own personal realities as this may demonstrate a diversity of cultural viewpoints (Munger & Mertens 2011). In the current research this will be achieved through offering participants a choice of methods (one-to-one interview or focus group) so that they can choose the method they feel most comfortable with, potentially encouraging openness and honesty. Furthermore, allowing children to express their views independently of their parents and employing an inductive approach to the data (which will be discussed further in section 2.6.6, pp.97-112) allows participants to express their own views with as minimal an influence as possible from the researcher or their parents. It should be noted, however, that although the influence of parents can be minimised by their lack of presence, as important role models in children's lives, the participants' views may be influenced by those of their parents (Anderson & Cavallaro 2002). They are not, therefore, expressing their views in a vacuum. Furthermore, regardless of the attempts made by the researcher to remain impartial, individual views and biases are likely to have, at least, a subconscious impact on the data collection process (Patton 1990).

The overarching aims of the current research are to contribute toward the development of new prosthetic devices for children and young people and the development of guidelines for professionals by exploring the views of all key stakeholders. It is proposed that these outcomes will improve the experiences of children and young people in using prosthetic devices and associated services, contributing toward improved social justice for the participants who, it is argued, belong to a sociocultural group which has, historically, been subject to oppression and discrimination within society (Mertens 2008). Framing the research in this way clearly demonstrates a link between the research and outcomes which is inherent in both transformative research and the BRIDGE method.

Figure 7 demonstrates how the BRIDGE method was applied to multiple stakeholders using a transformative lens in the current study.

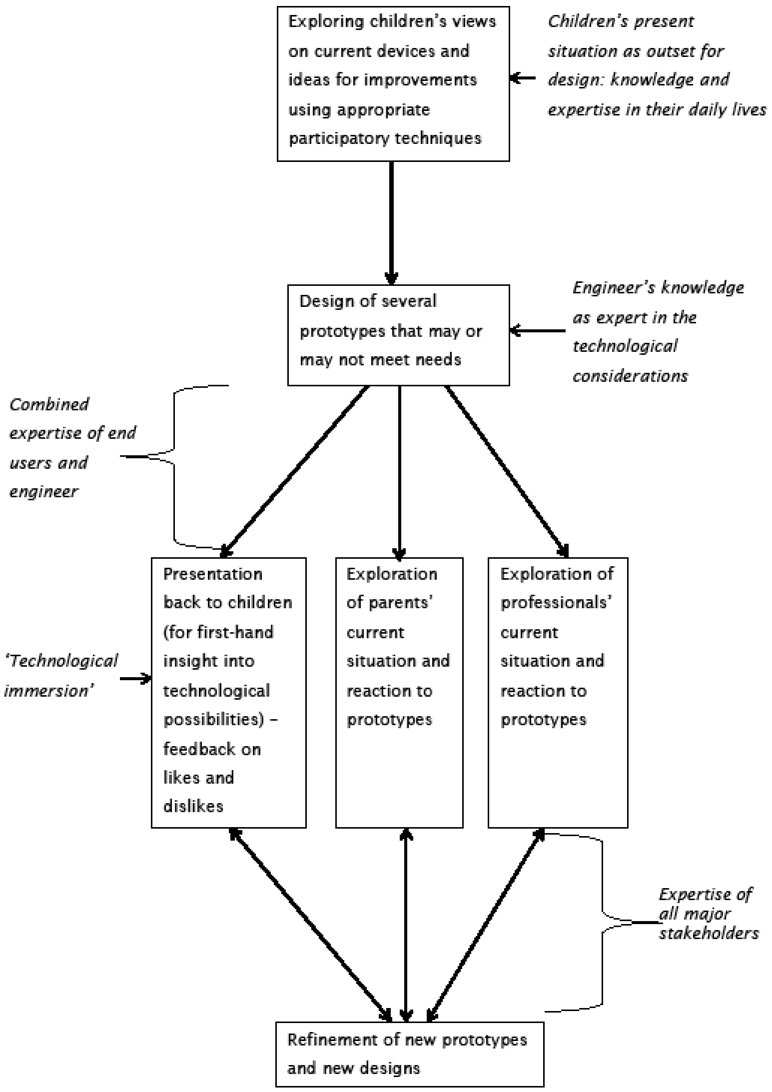

Figure 7: BRIDGE methodology applied to the data collection procedure.

2.4.5 How the current study applies the BRIDGE method of participatory design through a transformative lens

Table 1 describes the philosophical assumptions of axiology, ontology, epistemology and methodology and the interpretation of these within the transformative paradigm and BRIDGE method, providing examples of their application in the current study. The following section will discuss the specific techniques of data collection in the current study, demonstrating how techniques used have been influenced by the application of BRIDGE principles to design with children and a transformative philosophical stance. Techniques used for developing upper limb prostheses with user participation will be explained, including justification of the use of focus groups and interviews as data collection methods; the need for an iterative design; and how data was analysed within the BRIDGE framework.

Philosophical Assumption	**Transformative paradigm**	**Application in the BRIDGE method**	**Exemplified in current study**
Axiology	1. Disability as a sociocultural notion 2. Competency viewed as fluctuating and not age-related 3. Children traditionally marginalised as a result of assumptions held about age and disability	1. Children assumed as equal stakeholders in design process 2. Adapted adult methods (as opposed to different methods) for participation 3. Children recognised as experts in their social worlds	1. Children allowed same participatory rights as adults 2. Age appropriate information provided and data collection methods used 3. Participants given a choice between focus group and interview
Ontology	Different versions of reality impacted on by notions of power	1. Supports exploration of multiple stakeholder views to contextualise development 2. Design begins with direct exploration of children's current situation – challenging potential age-related power differentials	1. Children's views sought first 2. Views of other key stakeholders (parents and professionals) also investigated
Epistemology	1. To provide a balanced and	1. Participation encouraged	1. Understanding of cultural norms

	complete view of the phenomenon of study 2. Interaction between researcher and participants 3. Rapport with participants should be strived for.	throughout the design process 2. Methods used should be adapted to be relevant to different cultural norms of stakeholder groups but same methods should be used to afford equal credence to the views of all groups	within groups developed through clinical work, attendance at conferences and training 2. Additional creative materials available for use in focus groups with children
Methodology	1. Qualitative element 2. Iterative, cyclical process	1. Start with the views of the children 2. 'Technological immersion' to stimulate ideas about what works and what doesn't	1. Child participants only (not parents or professionals) at outset of study 2. Prototypes introduced in later stage 3. Views sought using qualitative methodology

Table 1: Philosophical assumptions of the transformative paradigm and BRIDGE method and application to current study.

2.4.6 Section summary

The previous section has explored various methodologies and theoretical approaches for involving users in the design of devices and presented an argument for the appropriateness of using the BRIDGE methodology with a transformative philosophical approach. The following section will discuss the specific data collection and analysis methods used and examine pertinent ethical issues.

2.5 Methods

2.5.1 Justification of data collection methods

Prior to commencing data collection and throughout the iterative design process the researcher sought to continually develop understanding of the participant groups, which demonstrates an application of a transformative epistemological stance. This was achieved though the researcher's professional experiences as a children's OT (working closely with children with disabilities and their families), attending training on engaging children in group work, reading widely in the subject area, attending relevant conferences and liaising with Reach Charity Ltd (a registered charity for children with upper limb difference). An understanding of the culture of professionals working in the area of paediatric prosthetics was also developed through consulting with professionals on the project's Advisory Board, networking at professional conferences and visiting local limb clinics to learn about the role of prosthetists and OTs specialising in prosthetics. Guba & Lincoln (1985) purport that this can improve credibility of study findings as it can help researchers to build trust, become familiar with the culture and become aware of their own biases, enabling researchers to build awareness of contextual factors and different perspectives of participants within the social scene. This, argues Mertens (2010a), enables researchers to identify their own biases and be cognisant of the potential influence of these biases on the analysis. The current study used a combination of focus groups and interviews within an iterative design process and these will now be discussed in further detail.

2.5.1.1 Focus groups

A focus group is a form of group discussion that enables the researcher to select participants with rich experiences to share perspectives, ideas, insights and opinions on the topic that is the subject of study (Powell & Single 1996). In focus groups, people are encouraged to talk to one another and comment on the experiences and viewpoints of other group members (Kitzinger 1995). The method can be used to examine not only people's knowledge and experiences but also *how* they think and *why* they think that way (Kitzinger 1995). This enables the researcher to draw upon participants' opinions, values and experiences, which are more likely to be revealed through the social interaction created in a focus group.

Focus groups are a particularly useful methodology with children as this method minimises the demands that may be placed on them by quantitative methods, such as the limitations of literacy and reading ability (Kennedy et al 2001). Furthermore, Kennedy et al (2001) suggest that children are likely to feel more comfortable in the company of same-age peers as talking with people who have had similar experiences can be a supportive and empowering process (Kitzinger 1995).

Focus group methods within an iterative design complement the transformative paradigm’s ethos of empowering research participants because the participants become an active part of the research process. This occurs through the development of ideas within the focus group and through influencing the material discussed in further focus groups (Goss & Leinbach 1996). As discussed previously in chapter one (see section 1.3.1, pp. 37-39) focus groups are particularly suited to an iterative design process (McDonagh-Philp & Bruseberg 2000), leading to the production of effective and culturally relevant devices (Bridgelal Ram et al 2007). Furthermore, focus groups acknowledge the participants as experts in their experiences, aiming to discover children's views of their world (Levine & Zimmerman 1996).

In their seminal work, Morgan & Kreuger (1993) advise that focus groups are particularly useful when there may be potential power differences between the participants and researchers, making them an appropriate tool for exploring the views of children. Furthermore, in Kitzinger’s (1995) influential article, it is argued that the interaction between participants brings attention to their particular worldview, with emphasis on the language they use to explain their values and beliefs about a situation or issue pertinent to them. This is highly relevant to research with children and young people as it allows the language that is used in the research to remain more relevant to their social worlds, minimising the influence of an adult perspective. In addition, focus groups free children and researchers from the limitations placed by literacy/reading levels that are prevalent in quantitative self-report methods (Gill et al 2008). Furthermore, participation in focus groups can benefit child and youth participants: the opportunity to be involved in decision making processes (Race et al 1994), to be valued as experts, and to have input into the research process (Goss & Leinbach 1996) can be empowering. This is particularly evident if participants are actively involved in something which they feel has the potential to engender change (Gibbs 1997).

In order to maximise the appropriateness of focus groups for use with children and young people, it may be necessary to modify approaches and techniques used. The current study uses several techniques to make the focus groups more suitable for children. These include the collaborative setting of ground rules, the use of ice-breaker games and activities to help provide a relaxed environment (Lightfoot & Sloper 2002) and provision of drinks and snacks to improve participants' comfort and put them at ease (Mansell et al 2004). These are also methods of aiding the development of rapport between researcher and participant, which can improve 'honesty' amongst participants, adding to the credibility of results. Participants were also provided with art materials so that they could make their own name stickers enabling them some ownership over the process (McNaughton & Smith 2005); and providing them with an opportunity to express themselves in ways other than verbally if they wished to (Turner et al 1995). These techniques were identified as appropriate for use with children through completion of, and reflection on, a pilot focus group, details of which can be found in Appendix C.

One drawback of focus groups is the practicality of accessibility to participants being limited to location. The current research, therefore, also used semi-structured interviews. Qualitative interviews with children can also provide a rich and reliable account (Gill et al 2008). Furthermore, the semi-structured interview format provides children with some guidance on what to talk about, which children generally find useful in an interview situation (Gill et al 2008).

2.5.1.2 Interviews

Individual interviews are the most widely-used data collection strategy in qualitative research (Nunkoosing 2005). Individual interviews can enable researchers to collect detailed accounts of participants' views and experiences of a particular phenomenon (Streubert-Speziale & Carpenter 2003). One important rationale for conducting qualitative interviews with children and young people is to allow them to express their views and interpretations in their own voice, minimising the impact of adult interpretation (Eder & Fingerson 2002).

A drawback of individual interviews is that participants may choose to withhold certain information or embellish other details to portray a desired self-image or provide the interviewer with the answers they think they would like to hear (Fielding 1994). This is particularly pertinent when conducting interviews with children as children may find it difficult to admit that they don't know the answer to a question, instead providing a response that doesn't represent their experience or view of the situation (Kellet & Ding 2004).

Semi-structured interviews and focus groups share many common features and both are useful in enabling an in-depth understanding of participants' views and experiences (Gill et al 2008). Due to the nature of the group discussion, however, focus groups enable researchers to gather information on collective views, and explore the meanings and motivations behind those views (Gill et al 2008). Interviews and focus groups are, therefore, appropriate as complementary methods to ensure as wide a range of viewpoints as possible.

2.5.1.3 Combining focus groups and interviews

There is an increasing recognition of the merit of combining quantitative and qualitative methods in research (mixed methods designs), but less attention is paid to the implications and potential benefits of combining qualitative data collection methods (Morse 1999). It is important to be clear about the reasons for combining qualitative methods and to ensure that the combining of qualitative methods is appropriate within the philosophical lens of the research (Barbour 1998). Combining focus groups and individual interviews can be beneficial to researchers as complementary views of an experience may be uncovered (Lambert & Loiselle 2008). Three main reasons researchers choose to combine interviews and focus groups are 1) for pragmatic reasons, 2) to compare and contrast participants' perspectives and, 3) to obtain data completeness and/or confirmation (Lambert & Loiselle 2008). The current research combines focus groups and interviews for both pragmatic and confirmatory reasons and also to enable participants to have a choice in which data collection method they participated in. Due to the constraints of proximity on participation in a focus group, participants were offered a choice of an individual interview if they were unable or unwilling to attend the focus group. Combining the methods in this way, may lead to higher recruitment levels and fewer subsequent withdrawals, as individuals can choose the method that is most convenient for them (Lambert & Loiselle 2008). Combining focus groups and interviews in the present study was also felt to be beneficial in terms of data confirmation, as the two methods may reveal different elements of the account of children's views and experiences of prostheses (complementary views), which can contribute to a deeper and more comprehensive understanding (Lambert & Loiselle 2008). For example, participants may be more comfortable expressing personal experiences in an individual interview, whereas general opinions may be more easily generated through a focus group as a result of the impact of group interaction on idea generation and problem-solving.

Additionally, providing participants with a choice of data collection methods recognises an ethical assumption that research methods should be adaptive and responsive to meet the needs of individual children, rather than expecting children to fit in with what adult researchers presume to be the ideal methods of participation (Martin & Franklin 2009). Providing participants with a choice between a one-one interview and a focus group also enables the participants to have some input into the process. This is one way of redressing potential power imbalances between an adult researcher/designer and child participants and enables children to feel their ability to contribute to transforming their reality is acknowledged, contributing toward feelings of self-confidence (Caraveo et al 2009).

Other factors that can enhance equality of power include: protected idea sharing, respect of privacy and ownership of ideas (McNaughton & Smith 2005). Furthermore, participants should be provided with a safe environment in which to share their ideas and influence changes to their situation (McNaughton & Smith 2005). This can be further enhanced by the focus group facilitator refraining from expressing challenge to, or critique of, the children's views (McNaughton & Smith 2005). A technique applied in the current study which aimed to ensure the research adhered to these principles was the collective setting of ground rules (between participants and researcher) at the start of the focus group, which included "respect other people's opinions", "no right or wrong answers" and "things shared within the group are not to be discussed with others outside of the focus group", for example.

Using focus groups and interviews for data collection methods also lends credibility to the research findings as Shenton (2004) advises techniques for ensuring credibility in qualitative research include using data collection and analysis methods that have been used successfully in comparable research studies and triangulation of data. Triangulation involves the use of different methods in order to compensate for weaknesses in the individual methods and to make the most of their particular strengths (Guba & Lincoln 1985). Taylor-

Powell & Renner (2003) propose that if the data from the different methods point to the same conclusions you can have more confidence in the credibility of the data. The results section demonstrates how, in the present study, combining focus groups and interviews resulted in identification of the same initial codes.

Furthermore, individual interviews and focus groups are now well-established methods for researching children's views, having been used widely with child participants for 15 years (Gibson 2012). They are even used successfully in the study of sensitive topics, such as mental health (e.g. Roose & John 2003) and sexual behaviour (e.g. Barker & Rich 1992). Shah & Robinson's (2006) systematic review also found focus groups and individual interviews to be commonly used and appropriate techniques for studies concerning user involvement in healthcare technology development. It is, therefore, argued that the data collection methods used in the present study adhere to this principle of using well-established and appropriate methods.

2.5.1.4 Iterative approach

For research exploring user views to contribute toward the design or development of a new product, an iterative approach is recommended that progresses from a stage of broad exploration of users' views to more device-specific discussion later in the process (McDonagh-Philp & Bruseberg 2000). Exploring users' views in the first stage of the process should enable the development of an understanding of user-related product requirements at an early stage, which can be used to directly inform the next iteration (McDonagh-Philp & Bruseberg 2000). The initial focus groups or interviews should, therefore, be conducted with a low degree of structure to explore user needs at an open level (McDonagh-Philp & Bruseberg 2000). This can then inform further focus groups and interviews in which the product developer's understanding of the user's needs can be presented back to the user through the sharing of initial prototypes and design ideas to gain their feedback. This enables there to be a continual flow of data between the research and the design process (McDonagh-Philp & Bruseberg 2000). The current study employs an iterative design. This iterative process is commensurate with a transformative lens which recommends the development of an ongoing relationship with participants, where the results of one cycle of enquiry feed into decisions about the next cycle of enquiry (Mertens 2010b). This cyclical approach also complements a Participatory Design research process.

2.5.2 Ethical considerations

The current research attempts to empower children with limb difference to share their individual views and experiences in their own words. This will enable them to contribute toward developing prosthetic devices that better reflect their wishes and requirements. This reflects a transformative axiological stance.

In the current research, these techniques were applied through making sure that the children and young people were aware that they could refuse to participate or stop taking part at any time (without the need for explanation), enhanced by the use of participant information sheets that were designed specifically for children. Furthermore, a safe environment was used for the data collection (either the child's own home or hired meeting room space), which was free from the associations of hospital, which may have the potential to cause distress. Safeguarding procedures were ensured through the researcher maintaining up-to-date training in the area and having direct clinical experience of working with children in a social care setting for whom child protection procedures are in place.

Demonstrating a respect for children's competency to express their views was addressed through allowing children to make a choice about whether they wanted their parents to be present during data collection and through using their views to guide the future iterations of the study (through the development of prototypes).

2.5.2.1 Ethical approval

Ethical approval for the various stages of this study was granted by the University of Southampton's Faculty of Health Sciences Ethics Committee in June 2011 (FoHS-ETHICS-2011-056), November 2011 (FoHS-ETHICS-2011-075) and May 2012 (Ethics ID 1224). Prior to granting ethical approval, the Ethics Committee required a current CRB check for the researcher (as working with a vulnerable group), evidence of agreement of collaboration from Reach Charity Ltd and a risk assessment outlining lone working procedures. Due to some of the study's participants (the children and young people) being regarded by the Ethics Committee as a vulnerable group, certain ethical considerations are particularly relevant and will be discussed in the following section.

2.5.2.2 Age-appropriateness

Consideration was given to the language, and design, of all materials relating to the study (such as Informed Assent Forms and Participant Information Sheets) and during the focus groups and interviews, in order to make sure that it was age-appropriate. This is important for ensuring participants are able to make an informed decision with regard to consent: if jargonistic or over-complicated language is used, participants may not fully understand what is involved in participating in the research and what, therefore, they are consenting to (Royal College of Nurses, RCN, 2011). Consent is discussed in further detail in section 2.5.2.5 (pp.83-84). Using age-appropriate language also helps to ensure that the data collected is rich and reliable through using language that is meaningful to the participants (Barnes et al 1999).

2.5.2.3 Child protection

The Child Protection code of conduct, as described by Save the Children (2004), was adhered to at all times. The researcher maintained up-to-date training in Safeguarding Children procedures. The duty to protect the welfare of participants was paramount at all times and would have overridden the duty of confidentiality if concerns had arisen that a participant, or another person, was at risk of harm.

2.5.2.4 Risks to participants

Although participants were required to discuss their personal experiences, it was not of a highly emotive nature and, therefore, “the risks of harm [...] in the research are not greater, considering probability and magnitude, than those ordinarily encountered in daily life” (National Commission, 1979; p.4). In order to further minimise the risk of harm to participants, they were clearly informed of their rights to refuse to participate; to take time when deciding whether to participate; to withdraw at any time and to refuse to answer some or all of the questions asked of them. The participants may even have benefitted from taking part through being enabled to make the most of their abilities and having a voice in matters that are important to them (Alderson & Morrow 2004).

2.5.2.5 Consent/assent

The Royal College of Paediatrics and Child Health (2000) defines consent as positive agreement to participate in a research study after having been informed of all elements of the research that are relevant to the decision to participate. The National Institute of Health Research (NIHR) (2009) states that informed consent must be documented on a written, signed and dated form. Guidance relating to children's consent to participate in research varies between sources. The Medical Research Council (MRC) (2004) and the National Children's Bureau (NCB) (2003) suggest that where children have sufficient comprehension and cognitive skills to understand what is proposed, it is their consent and not that of their parents that is required by law. According to the Gillick competence assessment, young people under the age of 16 years can give their consent to take part in a research study if they satisfy these criteria (Alderson and Morrow 2004). The Department of Health (DOH) (2001), however, state that research participants under the age of 16 must have consent provided by an adult. Furthermore, deciding whether children are competent to consent on their own behalf can be a difficult judgement to make, particularly when the researcher has not had the opportunity to build a rapport with the participant prior to the research (Alderson & Morrow 2004). Therefore, in the present research, consent of parents/guardians was required and assent was sought from the participants themselves.

Informed assent is the participant's positive agreement to participate in the study (Broome 1999) and not merely an absence of dissent. Informed assent is recommended in research with children and young people as ensuring they have a choice recognises their developing capacity to make decisions, but requiring it as an addition to parental consent enables children to remain protected from harm in research. This is particularly relevant as understanding that research participation is voluntary can be difficult for children, as they are socialised to obey adults and look up to them as experts (European Council Working Group 2008). Furthermore, the process of gaining informed assent may enhance the relationship between researcher and participant, giving the young people ownership of the task and encouraging continued engagement (Lang et al 2012).

Consent and assent were viewed as an ongoing process throughout this research project, as recommended by The MRC (2004). Specifically, participants were made fully aware that they could withdraw from the research at any point and their data would be destroyed. In future data collection sessions, consent and assent were re-sought from participants and their parents and not assumed to remain in place.

A thorough approach to consent/assent also helps to rectify power differentials as it demonstrates respect for children's privacy by recognising that their right to refuse to participate is equivalent to an adult's rights (McNaughton & Smith 2005). By viewing consent/assent as a continual process, young people are enabled to maintain ownership of their ideas as they can withdraw their data at any stage in the research process (McNaughton & Smith 2005). Children and adolescents cannot, however, legally provide informed consent (Johnson & Christensen 2008). Their ability to only assent or withdraw from research may compromise their sense of autonomy (Mertens 2005). In the current study, assent was sought from all participants and information relating to the study was provided in child-appropriate language, enabling children to make an informed decision.

2.5.2.6 Anonymity and confidentiality

The Data Protection Act (1998) states that there should be procedures in place, which are regularly monitored, for the safe storage of research data, to include both paper and electronic material and that procedures should include the disposal of material when it is no longer required. This research adheres to data protection requirements and respects participants' confidentiality in the following ways:

- From transcription stage, all participant data was identifiable only by a participant pseudonym and kept on a password-protected computer;
- Any facts or locations mentioned in the discussions which may serve to identify participants were also changed or omitted at the transcription stage;
- Any personal information about the participants was kept in a locked drawer.

2.5.2.7 Rewarding participants

Some researchers offer financial or material rewards to participants who take part in their research and may argue that it is important that all people should be paid for their time and effort (Wiles et al 2007). These may, however, be seen as incentives to participate and, in the extreme, could comprise a form of coercion, bringing into question the voluntariness of the participation (Wiles et al 2007). That is to say that, financial or material rewards might encourage potentially vulnerable people to participate without fully considering what is entailed and the implications for them.

Payment to parents for their child's research participation could potentially influence parental decisions in favour of participation and, for this reason, it may not be appropriate for parents to receive money as incentive for their child's research participation (Grady 2005). Enabling a child to participate in research can, however, be inconvenient and costly for parents (Grady 2005). It may, therefore, be appropriate, to compensate parents for time and/or expenses incurred. Furthermore, rewarding child participants directly with financial or material gifts instead of providing the reward to their parents can pose its own difficulties, as children appreciate money and gifts differently depending on their age (Grady 2005). A demonstration of appreciation of children's participation in the research is, however, necessary in order to demonstrate respect for their contribution (Kennedy et al 2001).

Based on the arguments discussed, the decision was taken to provide a reimbursement payment to parents and a certificate of thanks to participants for taking part in the study. Reimbursement payments compensate parents for expenses incurred directly through participating in the research, such as travel and meal expenses. For this reason, reimbursement payments should not distort parents' or children's decision making and are deemed ethically acceptable within the bounds of informed consent/assent (Wendler et al 2002).

2.6 Study design

The following section will provide specific details of how the methodology outlined in figure 7 (p.72) was applied to the current study. Figure 8 outlines the different stages of data collection in the study.

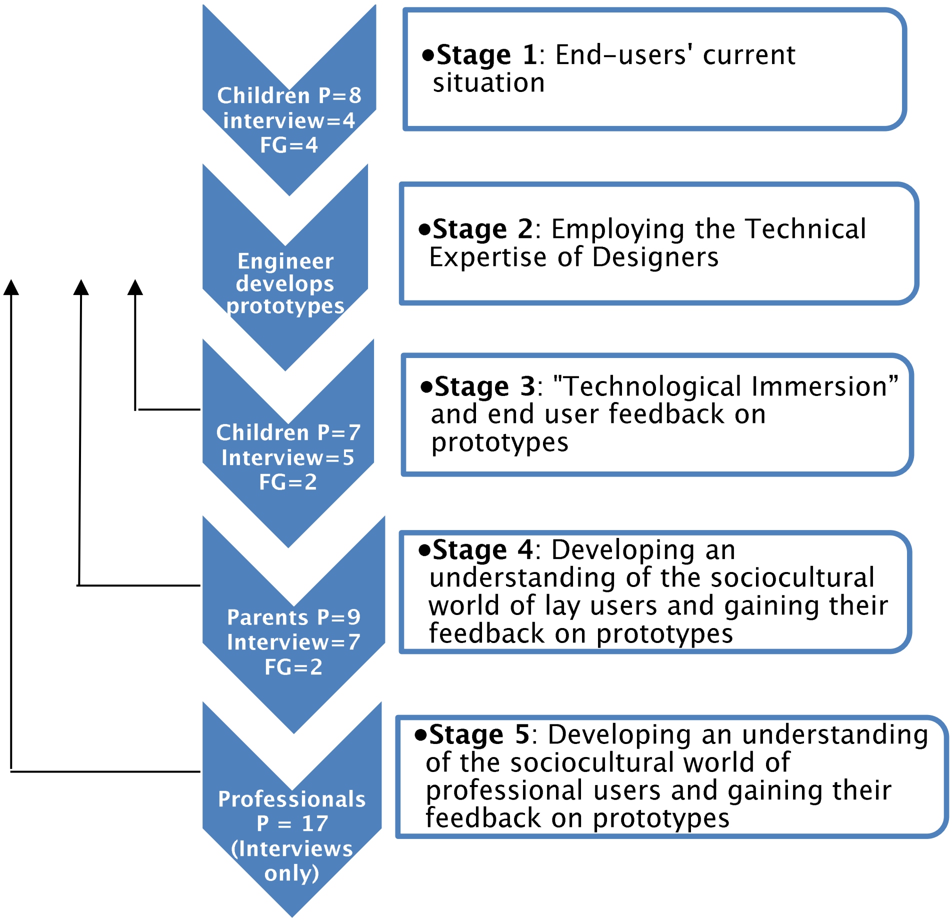

Figure 8: Stages of data collection as related to the BRIDGE methodology.

2.6.1 Stage 1: End user's current situation

As previously discussed the first stage of the study involved exploring children's views on their current situation and their ideas for improving prosthetic devices. This represents a recognition of the children as experts in their own lives and provides domain-specific knowledge at the outset of the design process.

2.6.1.1 Participants

Eight participants took part in the first stage of the study: four took part in a focus group and four participated in a one-to-one interview. Participants were aged between eight and fifteen years old with a mean age of eleven.

2.6.1.2 Sampling

Purposive sampling is the most common sampling technique used in qualitative research (Marshall 1996). Purposive sampling enables the researcher to actively select the most appropriate participants to answer the research question (Marshall 1996). The sample being studied is, therefore, not representative of the general population but rather a choice, in which participants are selected based on characteristics that are of particular interest to the researcher (Marshall 1996). This enables the researcher to glean a greater depth of information from a small number of carefully selected participants (Tashakkori & Teddlie 2009). The participants of this stage of the study were, therefore, selected based on their identification with the group children/young people with upper limb difference. On the participant reply slip, information was collected relating to the participants' age and gender, their level and type of limb difference and their experience as a user of prostheses. The aim of this was to ensure participants with a range of experiences and demographics were included in the study. For details relating to gender, aetiology of limb difference, level and side of limb difference and experience of prosthesis use, see below tables.

Male	**Female**
4	4

Table 2: Gender of participants.

Congenital	**Acquired**
7	1

Table 3: Aetiology of limb difference.

Right arm below elbow	**Left arm below elbow**
5	3

Table 4: Level/side of limb difference.

Currently uses a prosthesis daily	**Currently uses a prosthesis occasionally**	**Previously used a prosthesis**
2	4	2

Table 5: Experience of using prostheses.

2.6.1.3 Recruitment

Participants were recruited through Reach Charity Ltd. Reach Charity Ltd sent participant information packs to their members and three months later followed up with an email reminder about the study. The packs contained: an introductory letter, two participant information sheets (one for children aged 7-11 years and one for parents and children aged 12-16 years) and a reply slip which included some basic screening information about the respondents. See Appendix D for copies of these and the consent/assent forms used.

It was felt that recruiting through Reach Charity Ltd was the most appropriate strategy as it would enable access to participants throughout the UK, which may not have been possible if recruiting through regional prosthetics clinics due to the ethics procedures required when recruiting through the NHS. Furthermore, Reach Charity Ltd is a highly valued and trusted resource by families of children with limb difference, so their endorsement of this research may have encouraged potential participants to view it positively and, therefore, be willing to take part.

2.6.1.4 Inclusion/exclusion criteria

The age range selected for the study sample was between seven and 16 years (inclusive). Children under the age of seven were excluded as the pilot focus group demonstrated that the researcher lacked sufficient skills to meaningfully engage children below this age in the data collection process. Children over the age of 16 were excluded because at this age they will be able to access adult prosthetic hands, so different and potentially more advanced prosthetics will be available to them.

All participants were required to have either congenital or acquired upper limb difference and to have had some experience of using an upper limb prosthesis. This was to ensure the participants would have sufficient depth of knowledge about prosthetics to obtain rich data in a qualitative enquiry with a small sample size.

Due to the researcher's limited experience in qualitative research, the decision was taken to exclude children who have a communication or learning disability that would make it difficult for them to participate in a traditionally conducted focus group or interview. It was felt that the level of skill required to adapt methods to make suitable for children with additional communication needs would be outside of the researcher's skill base at this early stage in the study, particularly as there was no training for this available at the University or funding for external training. Children who were not fluent in English were also excluded for this reason.

Inclusion Criteria	Exclusion Criteria
• Congenital or acquired upper limb difference • Experience of using a prosthesis	• Under 7 years old or over 16 years old • Communication or learning disability • Not fluent English speaker

Table 6: Inclusion and exclusion criteria for stage one of the study.

2.6.1.5 Data collection procedure

The following section outlines the procedure followed in stage one of the study: focus group and interviews with children and young people.

Focus group procedure

On arrival at the focus group, participants and parents were greeted and introduced to the facilitators and offered a drink. They were then asked if they would like to make a name sticker for themselves as this worked well to relax and engage participants in the pilot focus group. Participant information sheets were then read, although participants had been previously been sent this information, so that any questions the participants and parents had could be answered by the researcher. Consent forms were then signed by the parents and assent forms were signed by the participants.

Once all participants had arrived and signed their consent forms, an ice-breaker activity was carried out to help the children relax and to encourage them to interact with one-another. The ice-breaker activity required participants to say their name aloud at the beginning as it was felt this may have improved the success of the activity in the pilot focus group. See Appendix E for activity analysis of the icebreaker activity. Following the ice-breaker activity, all the parents left the room, with the agreement of the participants. Ground rules were then set within the group (to help manage group dynamics, as identified in the pilot focus group) and the participants were reminded about the confidentiality of the information they would share.

They were also made aware that they could have drinks and snacks and use the art materials placed in the middle of the group at any time. The digital Dictaphone was placed in the middle of the group (to aid recording clarity, as identified in the pilot focus group) and switched on and the discussion began. The discussion followed the topics specified in the focus group schedule whilst allowing the flow of the discussion to be guided by the participants. See Appendix F for focus group schedule.

The focus group was carried out in a meeting room at a central London location. There were good transport links to the venue for all participants and access to the venue was via secure door entry system so it was felt to be a safe place for a focus group for children and young people. A neutral location was chosen (as opposed to a hospital setting, for example) to prevent the participants from feeling threatened or intimidated, enabling them to feel as safe and secure as possible, which is supported by a transformative approach to research (MacNaughton & Smith 2005) and encourages sharing of information. The meeting room was free from external interruptions and distractions, facilitating the flow of conversation (HSE 1998). Participants sat around a table in a semi-circle configuration, enabling them to see and hear each other easily (HSE 1998).

The materials required for conducting the focus group were digital Dictaphones; participant information sheets and consent forms; stickers; pens; snacks and drinks; art materials (paper, coloured pencils, felt pens) and certificates of thanks for the participants.

The focus group was facilitated by a moderator and a co-facilitator (from the supervisory team). This was to ensure the discussion ran as smoothly as possible, as the moderator guided the overall focus group process and discussions and the co-facilitator was available to ensure all recording equipment was working correctly and to respond to any participants' needs related to comfort. Having two facilitators also allows for verification of interpretation in the analysis stage, improving rigour (Krueger & Casey 2001).

Interviews procedure

Prior to the start of the interview, participant information sheets were read, although participants had been previously been sent this information, so that any questions the participants and parents had could be answered by the researcher. Consent forms were then signed by the parents and assent forms were signed by the participants. Participants were then asked whether they would like their parent to stay in the room or leave the room. All except one participant chose for their parents to leave the room. Children were offered this choice due to an awareness of the importance of talking with children in private, as, in the presence of parents, children may conceal some of their feelings to prevent upsetting their parents (Aldgate & Bradley 1999). The views expressed by children interviewed when their parents are present may, therefore, be different to those gained when the children are alone (Garth et al 2009). Consideration also needs to be given to why a parent may wish to be present during research interviews with children: they may want to control the child's responses to ensure that the family is presented positively (Mauthner 1997) or they may perceive a need to protect their child from distress (Gardner & Randall 2012). In the current study, although in one interview a parent remained in the room, he sat in the corner of the room working at his computer and did not participate in the interview at all. It can be assumed, therefore, that the impact of his presence on his son's responses was minimal.

Interviews were conducted in the participants' homes. All interviews were carried out in either the kitchen or the living room, with the participants' parents remaining at the property but in a different room (apart from in one case where the parent remained in the same room).

The materials required for conducting the individual interviews were a digital Dictaphone; participant information sheets and consent forms; pens; art materials (paper, coloured pencils, felt pens) and certificates of thanks for the participants.

2.6.2 Stage 2: Employing the technical expertise of designers

Following completion of stage one, data was analysed and presented to an engineer to enable the development of an understanding of the current situation for children with upper limb difference. This resulted in the engineer creating several prototypes, some of which directly addressed the views expressed by the participants and others which served to challenge the perceived status quo. See chapter three (section 3.4.2, pp. 183-193) for information on these prototypes.

2.6.3 Stage 3: 'Technological immersion' and end user feedback on prototypes

In the third stage of the study the prototypes developed were presented back to the original participants to gain their views on what worked and what did not and to stimulate further idea generation.

2.6.3.1 Participants

Seven participants agreed to participate in a follow up interview or focus group: two took part in a focus group and five elected to participate in a one-to-one interview. One participant declined to take part in a follow-up interview as she was completing exams at school and did not feel able to commit any further time to the study. The fact that she felt able to decline at this stage and was not coerced into further participation by her parents or the researcher demonstrates that consent was viewed as an ongoing process. This indicates the child participants were afforded the same rights to participate (or, indeed, decline) as adult participants were, which is in line with a transformative axiological stance.

2.6.3.2 Data collection procedure

The following section outlines the procedure followed in stage three of the study: focus group and interviews with children and young people.

Focus group procedure

On arrival at the focus group, participant information sheets were read and discussed again and any questions the participants and parents had about this stage of the study were answered by the researcher. Consent forms were then signed by the parents and assent forms were signed by the participants. Parents left the room at this stage to participate in a focus group in an adjacent meeting room

An ice-breaker activity was not used in this focus group as there were only two participants and both had met at the previous focus group. The ground rules from the previous focus group were revisited and agreed and the participants were reminded about the confidentiality of the information they would share. As previously, participants were made aware that they could have drinks and snacks and use the art materials placed in the middle of the group at any time and the digital Dictaphone was switched on. The first half of the focus group focused on showing the participants the prototypes and gaining their thoughts and feedback on them. The second half of the focus group involved a discussion of the themes deduced from stage one of the study for more in-depth exploration and to verify the researcher had interpreted the participants' views correctly. This constitutes a form of 'member checking', which this is a particularly powerful technique for improving a study's credibility (Tashakkori & Teddlie 2009). Member checking can involve verification of the researcher's developing ideas and can include asking participants to provide reasons for particular patterns identified by the researcher (Guba & Lincoln 1985).

The focus group was carried out in the same location as the stage one focus group. This helped with encouraging the participants to feel comfortable and relaxed and to build trust and rapport with the research team (HSE 1998).For information about the materials used, please refer to the information about the stage one focus group.

The focus group was facilitated by a moderator and a co-facilitator from the design/engineering team. This was to enable the design team to fully explain the technical aspects of the prototypes and answer any questions the participants had about them. It also enabled the researcher to learn more about the prototypes to ensure sufficient knowledge when conducting one-one interviews.

Interviews procedure

Prior to the start of the interview, participant information sheets were read and discussed and any questions the participants and parents had were answered by the researcher. Consent forms were then signed by the parents and assent forms were signed by the participants. Procedure, setting and materials were the same as in stage one but the content of the interviews differed. The interviews conducted in this stage followed the format of the focus group. The order was however, varied with some participants seeing the prototypes first and others discussing the stage one themes first, to reduce the possibility of the effects of question order bias on the views presented (Turner 2010).

2.6.4 Stage 4: Developing an understanding of the sociocultural world of lay users and gaining their feedback on prototypes

The fourth stage of the study involved developing an understanding of the sociocultural worlds of parents of children with upper limb difference and incorporating their perspectives into the design process. As referred to earlier in the chapter (section 2.4.4, pp.68-72), consulting the parents after speaking to the children but before speaking to the professionals reversed the traditional hierarchy found in the triad of healthcare decision-making for children.

2.6.4.1 Participants

Nine parents took part in the study: two took part in a focus group and seven participated in one-one interviews.

2.6.4.2 Sampling

All participants in stage four of the study were parents of stage one participants. Purposive snowball sampling was, therefore, used as the participants were selected through their identification with a previous participant. This was a convenient and quick method for ensuring sufficient participant numbers from this user group.

2.6.4.3 Recruitment

As with the children, all parents were recruited via Reach Charity Ltd. The only inclusion or exclusion criteria applied were that participants had to be parents of a child with upper limb difference and, if both parents wanted to participate, they had to be willing to be interviewed separately or take part in separate focus groups. This decision was taken in response to advice from the Faculty of Health Sciences Ethics Committee that having both parents participating in the same focus group could result in participants not feeling able to be honest with the researcher or the research potentially leading to disagreements between parents if their views did not correspond. Only one set of parents both wanted to participate and they chose to take part in separate interviews. See Appendix G for copies of participant information sheets and consent forms.

2.6.4.4 Data collection procedure

The following section outlines the procedure followed in stage four of the study: focus group and interviews with parents.

Focus group procedure

On arrival at the focus group, and once all consent/assent procedures had been completed for the children (participating in stage three of the study), participants were provided with participant information sheets to read and any questions the participants had were answered by the researcher. Consent forms were then signed by the parents.

Ground rules were set within the group and participants were reminded about the confidentiality of the information they would share and were made aware of refreshments provided. The discussion was carried out in a meeting room adjacent to the room where the participants' children were also participating in a focus group and it was recorded using a digital Dictaphone.

The focus group was facilitated by a project supervisor, who is highly experienced in qualitative research, and consisted of three key sections. The first part of the focus group explored participants' views and experiences of being the parent of a child with limb difference. The second part of the focus group discussed key themes identified by the children in relation to their dissatisfaction with prostheses. Lastly, participants were shown the prototypes and asked to share their views and ideas related to these.

Interviews procedure

Prior to the start of the interview, participant information sheets were read, participant questions were answered by the researcher and consent forms were completed. The interviews then followed the same format as the focus group. Three of the interviews were completed over two separate sessions due to the length of them.

2.6.5 Stage 5 – Developing an understanding of the sociocultural world of professional users and gaining their feedback on prototypes

The fifth stage of the study involved developing an understanding of the views of the third main user group, professionals, on upper limb prosthetic provision for children.

2.6.5.1 Participants

As discussed in chapter one (see section 1.3.6, pp. 46-47), it was felt that the views of both prosthetists and OTs were of particular relevance to the research question. Differences in the cultural and social experiences of the two professions, as related to their education, professional paradigms and key roles in the work place, warranted involvement of both within the study. Eight prosthetists and nine OTs participated in the study. Professionals from seven different limb clinics in England participated in the study. The prosthetists who participated in the study had been working in paediatric prosthetics for between two years (least experienced) and 40 years (most experienced), with a mean of 18 years' experience. The OTs who participated had been working in paediatric prosthetics for between four years (least experienced) and 30 years (most experienced), with a mean of 12 years' experience. Participants were required to have a minimum of one year experience in the field of upper limb prosthetics as this is the experience level considered by employers to be adequate for specialisation (in, for example, paediatrics). See table 7 for the inclusion and exclusion criteria applied to this stage of the study.

Inclusion Criteria	**Exclusion Criteria**
• Working as a prosthetist or therapist in the field of paediatric upper limb prosthetics • Employed in an NHS prosthetics service	• Less than one year experience in upper limb prosthetics

Table 7: Inclusion and exclusion criteria for stage four of the study.

2.6.5.2 Sampling

Purposive sampling was used to ensure a range of experience levels and an equal mix of professional backgrounds. This was to influence the richness of data collected in terms of diversity of encounters and diversity of the NHS environment as a workplace.

2.6.5.3 Recruitment

Professionals were recruited at conferences and through professional networking groups. This recruitment method was used for two purposes. Firstly as a way of developing trust and credibility within the cultural group (in order to improve the 'truthfulness' of the knowledge shared by participants) and also from a pragmatic position: recruitment in this way ensured participants from a range of NHS sites were able to participate without the requirements of gaining ethical and R&D approval at each of the separate trusts. See Appendix H for copies of participant packs and consent forms.

2.6.5.4 Data collection procedure

Focus groups were not used with the professionals for ethical reasons: it was felt that participating in a focus group with colleagues may put participants in a potentially harmful situation if they were to disclose something in a focus group which left them in an unfavourable light with colleagues. Even if focus groups were devised so that participants came from different NHS trusts, the professional world of paediatric upper limb prosthetics is small and close-knit, which may have resulted in participants being reluctant to answer honestly and openly.

Interviews procedure

Participants were offered to attend an interview at the University, their own home, their work place or another venue (such as a public meeting room or library). All participants chose to have the interview conducted at their place of work. Prior to the start of the interview, participant information sheets were read, participant questions were answered by the researcher and consent forms were completed. The interviews then followed a three-stage format. To begin with, participants were asked to share their own views and experiences of paediatric prosthetics. They were then asked to share their views in relation to the themes identified from the stage one research with the children. Lastly, participants were asked to comment on the prototypes developed.

2.6.6 Data analysis

Data was analysed following the same multi stage process as the data collection/product development procedure (as described in figures 7 and 8, p.72 and p.86). Figure 9 shows the order in which data was analysed.

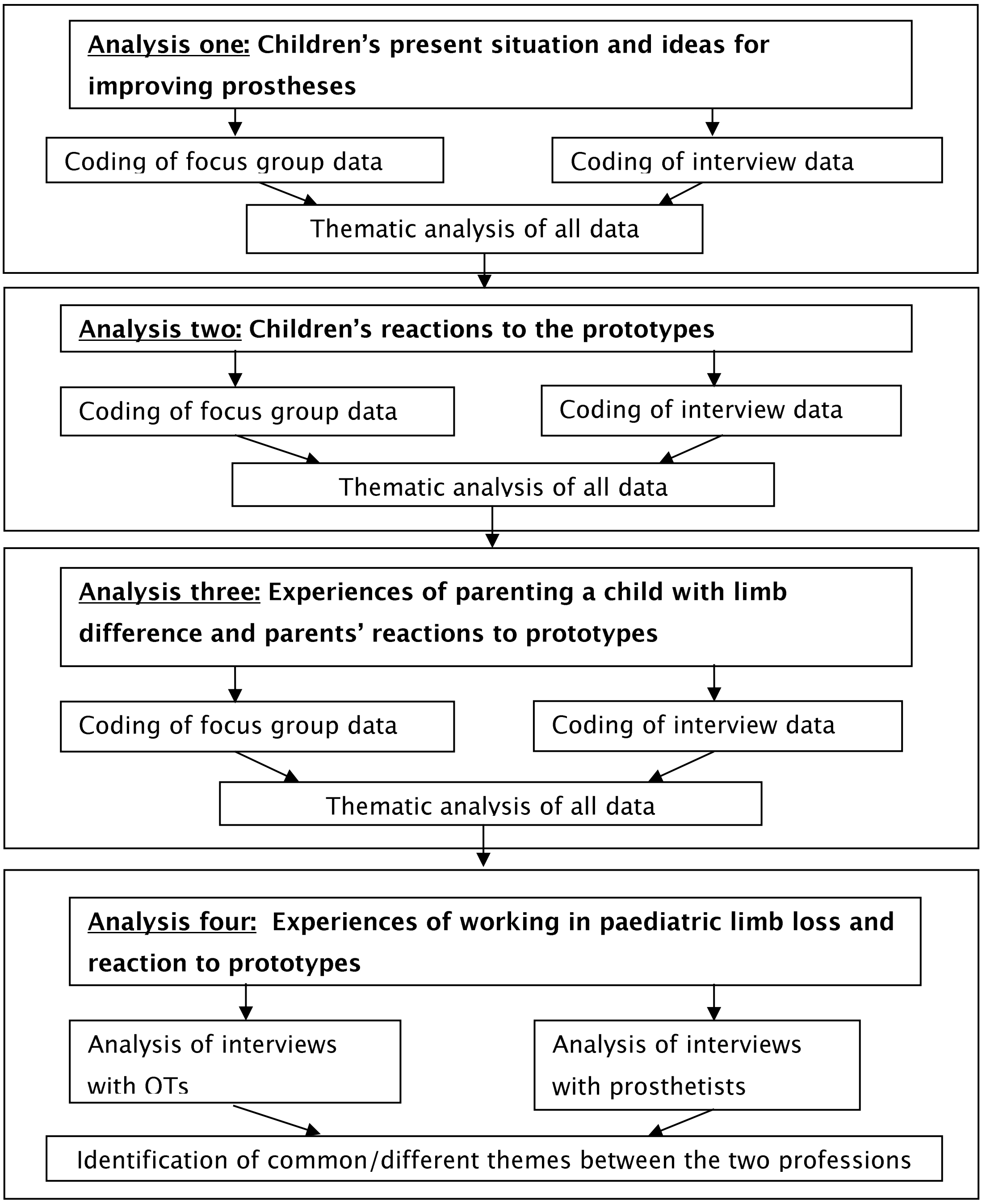

Figure 9: Overall data analysis process.

To analyse and interpret the data, a separate thematic analysis was conducted for analysis stages one-three (figure 9). For the fourth stage of data analysis, two separate thematic analyses were conducted on data from the two different professions prior to combining and comparing the themes to describe the overall picture presented by the data from professionals. Analysing the data in these discrete stages enabled the development of an understanding of the sociocultural lives and occupations of the three main user groups, enabling reflection on the similarities and differences between them. It also allowed the exploration of the relationships with and responses to different prosthetic devices for the three groups, resulting in an holistic understanding of the requirements of the device for informing future design. The results are presented in the subsequent chapter, but prior to that a step by step description of the data analysis process that was applied in each stage will be given, with examples provided from the stage one analysis.

2.6.6.1 Thematic analysis

Thematic analysis was chosen as it represents a systematic approach to the analysis of qualitative data (Taylor-Powell & Renner 2003). There are numerous and varied approaches to the analysis and interpretation of qualitative data due to the diverse range of epistemological and theoretical perspectives and the various disciplines that engage in qualitative research (Guest and MacQueen 2012). Interpretive Phenomenological Analysis (IPA), for example, is bounded in phenomenological epistemology and aims to understand the everyday experience of reality for an individual in order to gain an understanding of a particular phenomenon (McLeod 2001). Grounded theory, alternatively, aims to generate a theory of a phenomenon that is grounded in the data (McLeod 2001). Both phenomenology and grounded theory are situated in the broad spectrum of constructivist methodologies. They are, therefore, unsuitable in the current study due to their neglect to consider the influence of power differentials on the accepted version of ‘reality’. Thematic analysis, however, is not tied to a specific theoretical or epistemological perspective and can, therefore, be applied across a range of approaches (Braun & Clarke 2006).

Thematic analysis requires the identification of themes and concepts within the data as opposed to quantifying words and phrases (Guest and MacQueen 2012). Guest and MacQueen (2012) argue it may be the most useful method of data analysis for portraying the depth of meaning within written data. It focuses on participants’ own reports of events and experiences (Guest and MacQueen 2012), yet enables themes to be interpreted in relation to the research topic and the wider context (Boyatzis 1998), which makes it appropriate for a study, such as the current one, in which an understanding of the experiences and practices of several stakeholder groups is sought.

The theoretical and epistemological adaptability of thematic analysis enables it to be a flexible analytic tool, which can provide a rich account of a variety of textual data (Braun & Clarke 2006). Thematic analysis can be a method which works well within a transformative approach to research as its flexibility means it can acknowledge individual experience whilst still taking account of the wider social context (Braun & Clarke 2006). Furthermore, it is an appropriate methodology for product or policy development studies (Braun & Clarke 2006) making it suitable for use in the current study. It is also a relevant method for analysing data with children and young people, as it enables results to be presented in a more accessible format, making the findings more understandable and user-friendly for the study's participants. Finally, it enables consideration of both social and psychological factors, providing a more comprehensive account, which sits comfortably with the researcher's holistic approach to healthcare as an OT and also corresponds with the BRIDGE methodology's approach to learning and experience as a sociocultural process . For these reasons thematic analysis was selected as the data analysis method for the current study.

2.6.6.1.1 Key concepts in thematic analysis

Defining a theme

A theme symbolises a pattern within the data and denotes that some important or interesting information in relation to the research topic is contained within that data (Braun & Clarke 2006). There are no hard and fast rules to follow in identifying themes and the researcher needs to employ judgement and flexibility about whether an identified pattern really is a theme through consideration of such factors as the prevalence of the pattern and the importance of how it relates to the overall research question (Braun & Clarke 2006). Thematic analysis involves searching across an entire dataset, such as several interviews or focus groups, to find repeated patterns of meaning (Braun & Clarke 2006).

Identifying a theme

The flexibility of thematic analysis requires the researcher to make decisions regarding the depth of analysis performed and the way themes are identified within the data (Braun & Clarke 2006). The first decision to make is with regard to how the data is approached – whether from an inductive or deductive standpoint (Braun & Clarke 2006). An inductive approach means that the themes identified are strongly linked to the data (Patton 1990) and no attempt is made to fit the data into a previously devised framework (Braun & Clarke 2006). The researcher's own epistemological and theoretical assumptions will influence how the data is analysed, but there is a tendency to be more open to unanticipated insights from participants when employing an inductive, rather than deductive, approach (Braun & Clarke 2006). In a deductive approach to analysis, codes are established before the analysis begins using categories derived from previous research or existing theory (Ayers et al 2007). New data is then analysed within this pre-devised coding framework (Ayers et al 2007). In the current study, an inductive approach was taken to minimise the influence of the researcher's biases on the data which is consistent with a transformative approach to research. Although broad questions/areas for discussion were devised prior to the first focus group/interviews, when analysing the data, the researcher was mindful of preconceptions and their potential influence and attempted to code the data without fitting it into a coding frame.

The second decision the researcher has to make is with regard to the depth of analysis – whether to carry out a semantic or latent analysis of the data. A semantic approach to thematic analysis involves identifying themes within the surface meaning of the data rather than looking beyond what the participant has said to surmise underlying assumptions and ideologies, which is required in a latent approach (Braun & Clarke 2006). This does not mean, however, that the analysis is purely an organised description of the data: there should still be an attempt to theorise the meanings and implications of the themes in relation to previous research, current theory or contextual implications (Braun & Clarke 2006). A semantic approach to data analysis needs to represent analytic claims that, although grounded in, go beyond the surface of the data to explore the meanings of the themes, the assumptions underpinning them and the implications of these (Braun & Clarke 2006). A semantic approach is more appropriate to transformative research involving children as it enables the participants to maintain ownership over their ideas and minimises the influence of adult assumptions on the analysis, maintaining the voice of the participants. Maintaining focus on the implications of the themes also enables clear demonstration of the transformative assumption of conducting research to evoke change. A semantic approach to analysis was, therefore, employed in the current research.

A systematic approach to data analysis

Due to the need to take a systematic approach to qualitative data analysis (Taylor-Powell & Renner 2003), the stages of thematic analysis, as described by Braun & Clarke (2006) were adhered to in the analysis of data in the current study. Thematic analysis is a poorly defined, yet widely used method and Braun & Clarke's (2006) paper provides one of a limited number of guides to applying thematic analysis systematically. Furthermore, it is written with novice researchers in mind. The following section will describe the data analysis that was carried out for each of the five individual thematic analyses in the study using Braun & Clarke's (2006) guide to thematic analysis with relevant examples from the stage one analysis provided. Fully documenting the different stages of the analysis process enables others to see the decisions that were made and how the decisions were reached allowing others to take into account the impact of individual biases on interpretation (Taylor-Powell & Renner 2003). Another reason it is important to make explicit how data has been analysed is so that others can compare or use in conjunction with other research in the subject area (Braun & Clarke 2006) and build on the research to develop future studies (Attride-Stirling 2001). Full documentation acts as an 'audit trail' of the analysis (Shenton 2004), showing how the raw data was eventually transformed by the researcher into the recommendations resulting from the study (Shenton 2004).

Due to the differences in the two data collection methods of focus groups and interviews that were used in stages one – three of the study, the data from these stages were coded separately according to the data collection method used. The data was then brought together during the formulation of thematic maps.

2.6.6.2 Stages of data analysis

2.6.6.2.1 Stage 1: Transcription and Immersion

Analysis is likely to begin during data collection as the researcher becomes aware of developing patterns and topics of interest (Braun & Clarke 2006). The analysis may, therefore, become entwined with the data collection as, when areas of interest are identified, they may influence the progression of the research interview or focus group. Further to this, reflecting on the data collection process and noting down ideas immediately after the data collection method aids with analysis, as Braun & Clarke (2006) advise that the analyst should continually move between considering coded extracts and the entire data set throughout the process. Beginning writing at this early stage can help inform this habit. Following each interview and focus group, the researcher wrote a brief reflection on the data collection process including any interesting points relating to context, family or other environmental factors that may have influenced the data collection. At this stage, the researcher also listened back to the raw data and made a list of interesting points raised by the participants. The researcher's recording of initial impressions of each data collection session and patterns appearing to emerge in the data can aid with data analysis and managing researcher biases (Shenton 2004). Figure 10 (below) shows an example of a reflective note and figure 11 shows an example of notes written about the data immediately following the interview.

James: Reflective Notes

- *Dad stayed in the room during the interview. He was doing work at the computer and wasn't involved in the conversation - but his presence may have impacted on the atmosphere - would James have been more open if his Dad wasn't in the room?*
- *James was quite chatty - he talked about 'being cool' when wearing his prosthesis*
- *James seemed to contradict himself on whether or not he finds his prosthesis useful - he may be confused by the procedure he is currently going through to obtain a myoelectric arm and may not want to say negative things about prostheses for fear it will impact on him getting a myoelectric prosthesis.*

Figure 10: Reflective note.

Gareth: Notes

Good points of current prostheses:

- *Simple ideas*
- *Lots of movement*
- *Designed to help with specific activities*

Bad points of current/previous prostheses:

- *Heavy*
- *Sweaty*
- *Nothing you can do with them that you can't do without them*
- *Uncomfortable/hurt - Not much room inside for residuum*

Current activities/Places prosthesis is used:

- *Golf – has good grip for holding club securely and flexible wrist for swinging*
- *Press-ups – supports the forearm and spreads the weight*
- *Cycling*

Ideas for improving prostheses:

- *Lighter*
- *Smoother on the inside*
- *Stronger fingers*
- *More flexible wrist/movement at wrist*
- *Less restrictive at elbow*
- *Holes for air circulation*
- *Colour to match own skin*

Figure 11: Data notes.

Thorough analysis requires a good understanding of the data, which necessitates listening and re-listening to recordings and/or reading the transcripts multiple times (Taylor-Powell & Renner 2003). These techniques enable the researcher to become immersed in the data and develop an understanding of the depth and scope of important points raised, which is an important element of qualitative analysis (Braun & Clarke 2006).

Transcription can be a very effective way to begin immersing oneself in the data as transcribing requires active listening to every detail of the recorded conversation in order to get an accurate written record (Langdridge & Hagger-

Johnson 2009). For this reason, all the transcription was carried out by the researcher. Braun & Clarke (2006) recommend that transcription should provide a verbatim account of the interview or focus group. Verbatim transcription should be done as accurately as possible, without correcting colloquialisms, mispronunciations and grammatical errors, to enable the data to remain true to the voice of the participant (Langdridge & Hagger-Johnson 2009). It is also important to transcribe both the interviewee's and the interviewer's comments to ensure the contextual relevance is maintained (Langdridge & Hagger-Johnson 2009). Following transcription, the recorded raw data should be listened to again in order to check the transcription against the recording to ensure accuracy (Braun & Clarke 2006).

In order to ensure that data was transcribed in an accurate manner, retaining the participants' voices, the researcher carried out the transcription using a devised transcription template. See Appendix I for this template. Although time-consuming, transcription was found to be a useful method of familiarisation with the data and was considered time well spent. See figure 12 below for a transcribed extract of the focus group data and figure 13 for a transcribed extract from an individual interview. See Appendices J-N for examples of transcripts.

Focus Group Location: London
Date: 19th November 2011
Number of Attendees: 4. 2 female, aged 8 and 14. 2 male, aged 10 and 12.
Name of Transcriber: Tara Sims

F: Were there any things that you did like about it?
Anna: Um, I did find it useful for some things. I think I used my cosmetic one for, um, riding a bike, and, um, I don't really know. I can't remember. It's been quite a long time since I wore them. I did have one that was a hook and it kind of separated like that.
David: Yeah.
Anna: I found that easier.
Becky: I had one…

Figure 12: Example of focus group transcription.

Location of Interview: Participant’s home
Date: 6th December 2011
Interviewee: Male, aged 15.
Name of Transcriber: Tara Sims

I: So, you said before you got these ones it was a couple of years since you’d had a prosthesis?
Gareth: Yeah, just because the only time I think I’d really need one was just wearing it out and about but it just got quite heavy and sweaty so I didn’t really find any point in it.
I: So, did you have one just for wearing out and about for a while?
Gareth: I did, but I still only rarely used it. It just opened and closed.

Figure 13: Example of interview transcription.

Stage 2: Generating initial codes

Once the data has been transcribed and the researcher has begun immersing himself in the data, the process moves on to generating initial codes (Braun & Clarke 2006). Coding is the process of systematically categorising data to begin the process of understanding and describing its meaning (Langdridge & Hagger-Johnson 2009). Categorising the data into codes does not involve assigning numerical codes as in quantitative analysis (Taylor-Powell & Renner 2003), but assigning descriptive labels to extracts of the textual data (Langdridge & Hagger-Johnson 2009). These labels identify prominent characteristics of the data, but are only a basic description of the meaning of the data (Braun & Clarke 2006). Although coding involves organising data into meaningful groups, codes differ from themes in that themes are often broader than codes and themes include interpretive analysis of the patterns identified, relating the patterns to the research question and area of interest (Braun & Clarke 2006).

When coding, the analyst should work systematically through the data and give equal attention across the data set, especially when analysing inductively, so as to minimise bias toward particular aspects of the data (Braun & Clarke 2006). When coding manually, as in the current research, highlighting extracts and writing notes in the margin can be a useful way of identifying potential patterns (Braun & Clarke 2006). See table 8 below for an example of the focus group transcript from stage one with highlighted extracts and initial codes.

Transcript with highlighted phrases	**Initial Code**
Becky: Yeah, um, the battery kept like not working. F2: So why did you stop using them? Becky: Because, um they didn't really last very long. My one, which is in my mum's handbag, the glove has ripped. And like the nails have like flaked off. David: Yeah Becky: That's what happens sometimes. Anna: I stopped using my electric one because I found it was more hassle than it was worth because all it did was that and it was really heavy so it ended up being less convenient than without.	Unreliable Durability Breaks Weight Easier to do things without

Table 8: Example of the focus group transcript with highlighted extracts and initial codes.

When conducting an inductive analysis, all data extracts should be coded and then collated together within each code, rather than identifying a code and seeking out data that fits within that code (Braun & Clarke 2006). See figure 14 for an example of an initial code and collated data extracts representing it (from stage one).

Easier to do things without:

"I didn't have any for a couple of years just because I didn't really need them for anything"

"I didn't really find and point in it"

"... There wasn't much I couldn't do without it that I could do with it."

"... You couldn't hold the club 'cause it was sliding around."

"I used to wear it 'cause I thought it would always help me with things but then after a while I thought it's not really helping me to do anything I couldn't already."

"... There's not really much you can do that you can't do without it."

"You can't do anything with it that you can't do without it."

"I stopped wearing them then because I didn't think that they were like, well I didn't feel like I needed them anymore really."

"I was wearing it and it was just doing nothing."

"... It didn't do nothing."

"... If I wanted to carry shopping or something I had to take it off and it was just stopping me from doing things."

"... It blocks you from using your elbow so you can't use it. So it's there but you can't do much stuff with it."

"... More bother to do things with it I found..."

"... It was kind of blocking how to pick up things and stuff like that – I found it made it harder a bit..."

"... It didn't seem like there was any need for it anymore."

"... It gets in the way and I just don't find, with the way I am now, that there's any point in wearing it."

"... It was still restraining me with things."

"It was more hassle than it was worth because all it did was that and it was really heavy so it ended up being less convenient than without."

"It doesn't actually help you much because you just have to carry it like that."

Figure 14: Example of an initial code and collated data extracts representing it.

Braun & Clarke (2006) provide three key guidelines when coding data. They recommend that, at this stage as many potential patterns as possible should be coded for (to prevent losing data at this early stage that may appear interesting later), that surrounding data should be retained if necessary to prevent loss of context, and that data should be coded into more than one code if appropriate. Braun & Clarke (2006) also stress the importance of retaining views that diverge from the majority account, which is particularly pertinent in transformative research, in which it is vital to give voice to minority and marginalised participants.

Stage 3: Searching for themes:

In this phase, the codes are sorted into potential themes with all the relevant coded data extracts being collated together (Braun & Clarke 2006). This is the beginning of the analysis of the codes to consider how they may combine to form overarching themes (Braun & Clarke 2006). Some initial codes may at this stage be assessed as constituting a main theme, whereas others may form part of a theme or a subtheme or be discarded as they are deemed not to add anything to the understanding of the area of interest (Braun & Clarke 2006).

Following this, the researcher should have a list of potential themes and subthemes and all relevant data extracts should be organised within the themes (Braun & Clarke 2006). Braun & Clarke (2006) recommend that during this stage, it can be useful to create mind maps to help organise and understand the themes. See figure 15 below for the early stage thematic map developed for the first stage of the study.

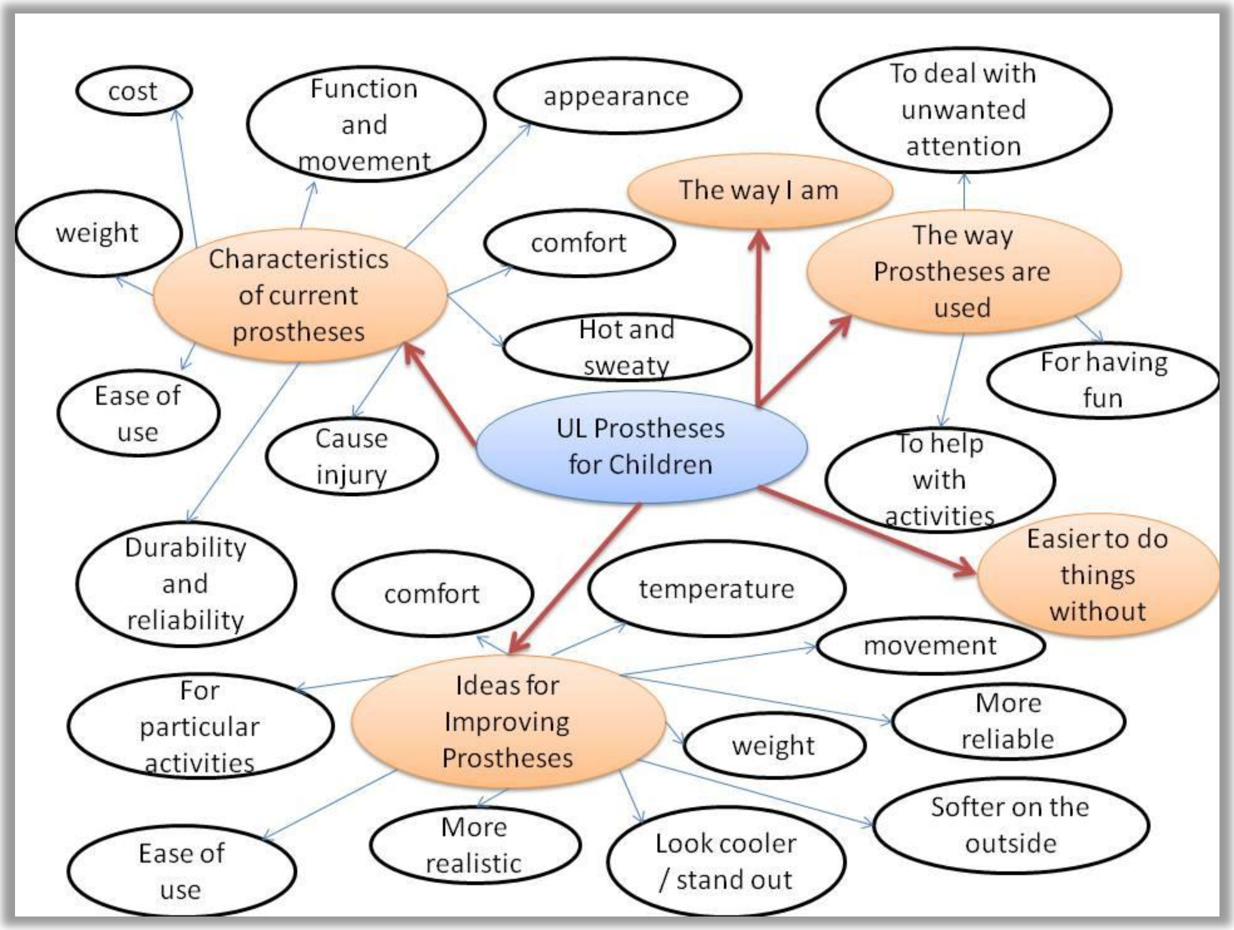

Figure 15: Early stage thematic map (stage one of study).

Stage 4: Reviewing themes

Once a list of proposed themes has been created, the next stage requires the researcher to review and refine the themes (Braun & Clarke 2006). Through review, it may become evident that some of the proposed themes do not have enough data to be considered themes, that some themes should be combined as there is not enough diversity in the pattern they explain, or that some themes need to be broken down further into separate themes (Braun & Clarke 2006). During review of themes, it is necessary to consider whether the data collated within the themes coheres and whether there are recognisable differences between the individual themes (Braun & Clarke 2006). This is carried out through reading all the collated extracts for the themes to assess whether the data coheres into a cohesive pattern (Braun & Clarke 2006). Once satisfied that all data within themes coheres (and that all themes are distinct), it is necessary to consider the importance of the themes in relation to the whole data set and whether the themes appear to accurately represent the meanings the participants were attempting to portray (Braun & Clarke 2006).

Throughout this phase, the initial thematic map is revised and developed (Braun & Clarke 2006).

In the present study, during the stage one analysis, the themes relating to characteristics of current prostheses and ideas for prosthesis development were combined as the subthemes within them cohered very closely and represented the notion that participants are not satisfied with currently available prostheses. Themes and subthemes relating to why children do or don't choose to use prostheses were also reorganised to represent the conflicting notion that prostheses can be both a help and a hindrance. See figure 16 for the stage four thematic map for stage one of the study.

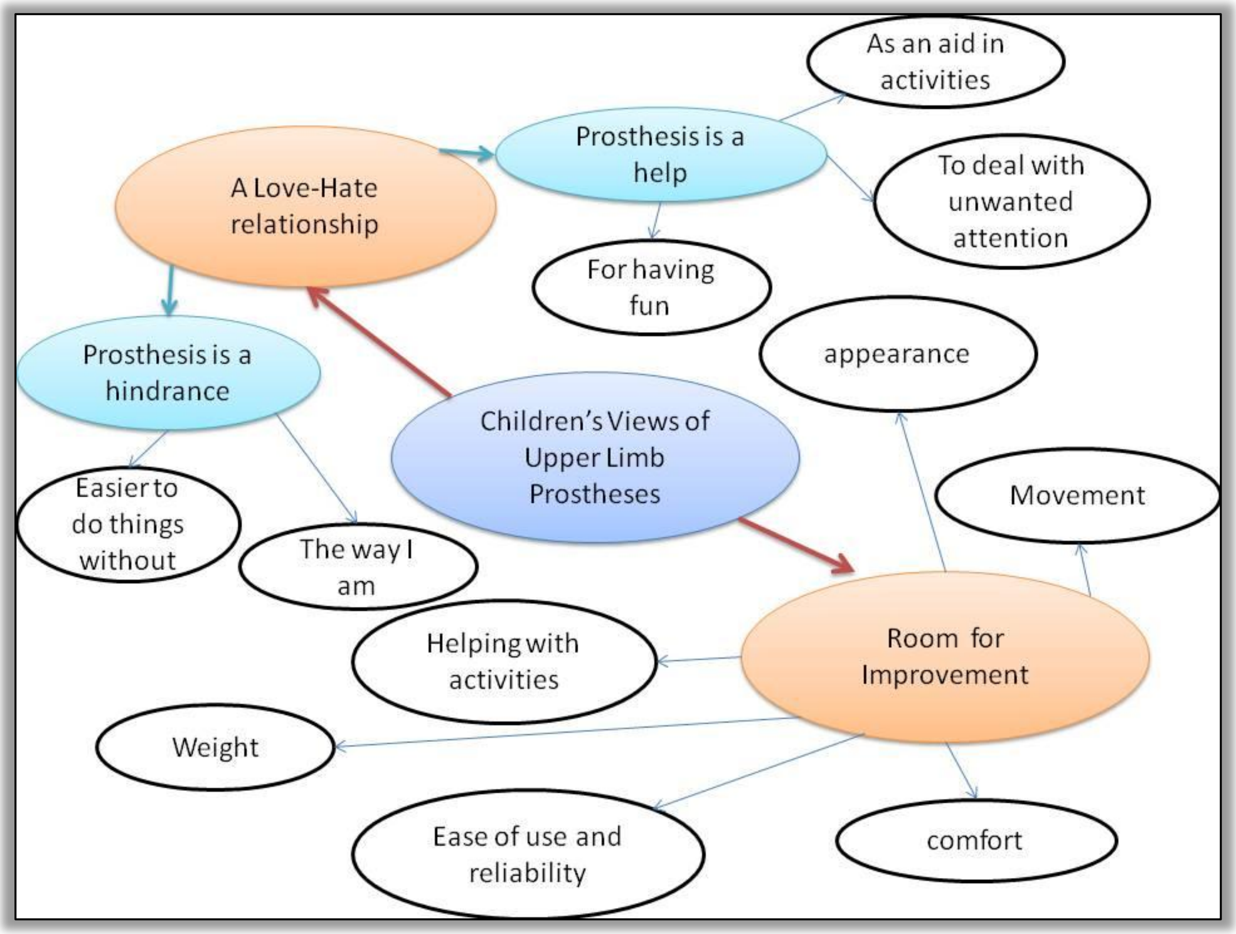

Figure 16: Stage four thematic map (stage one of study).

Stage 5: Defining and naming themes

Once it has be determined that the themes identified are a satisfactory representation of the data, the themes need to be defined and named through identifying the core meaning of the themes and which aspects of the overall picture each theme represents (Braun & Clarke 2006). At this stage the themes should be analysed to identify what aspects of them are particularly informative and for what reasons (Braun & Clarke 2006). It is now that a detailed analysis of each theme is written, considering what the essence of the individual theme is and how it contributes to the overall representation of the findings, in relation to the research question or questions (Braun & Clarke 2006). It might also be necessary at this stage to reconsider a potential theme's status as either a main overarching theme or a subtheme. Subthemes can be useful for providing a more meaningful structure to particularly large and complex themes (Braun & Clarke 2006).

At the end of this phase themes should be clearly defined and given appropriate names that will suitably represent the essence of the theme (Braun & Clarke, 2006). The themes can now be written up for presentation of findings in a concise and coherent manner in order to articulate the meanings identified within the data (Braun & Clarke 2006). The following chapter contains the representation of these findings (referred to by Braun & Clarke (2006) as stage 6 of the thematic analysis process) for stages one and three-five of the study.

2.6.7 Section summary

The previous section outlined the specific data collection and analysis techniques that were used in order to conduct a Participatory Design study for the development of upper limb prosthetics for children using the BRIDGE methodology as guided by a transformative philosophical lens.

2.7 Chapter summary

The Methodology and Methods chapter has presented reasoning and rationale for the use of a transformative philosophical stance and the BRIDGE methodology as an appropriate approach to answering the research question, aim and objectives. Specific data collection and analysis techniques were outlined as well as relevant ethical issues. The following chapter will present the findings for stages one and three-five of the study.

3. Chapter Three: Results

This chapter will present the findings from the focus groups and interviews conducted with children/young people, parents and professionals. The current situation with regard to upper limb prosthetics for each of the distinct user groups will be presented individually. A brief description and justification for the prototypes developed will then be presented. Finally the feedback from all three groups on the prototypes will be presented together, with similarities and differences highlighted. Throughout the chapter, participants will be referred to by pseudonyms to provide anonymity. In addition, any places, or other information that could be used to identify participants, have been removed or changed.

The Discussion chapter will follow (pp.197-251), enabling an in-depth discussion of upper limb prosthetics for children and priorities for development that take account of the views of the relevant members of the social scene. From this recommendations for further developing devices and for changes to clinical practice will be drawn.

3.1 Section one: Children’s current situation

This section presents the findings from stage one of the study: developing an understanding of end users’ (children and young people) current situation. Figure 17 shows which element of the BRIDGE process these findings relate to (bold and underlined). Two overarching themes, ‘a love-hate relationship’ and ‘room for improvement’ were identified. This section presents those themes and the subthemes within them, providing quotes to support and illustrate the themes.

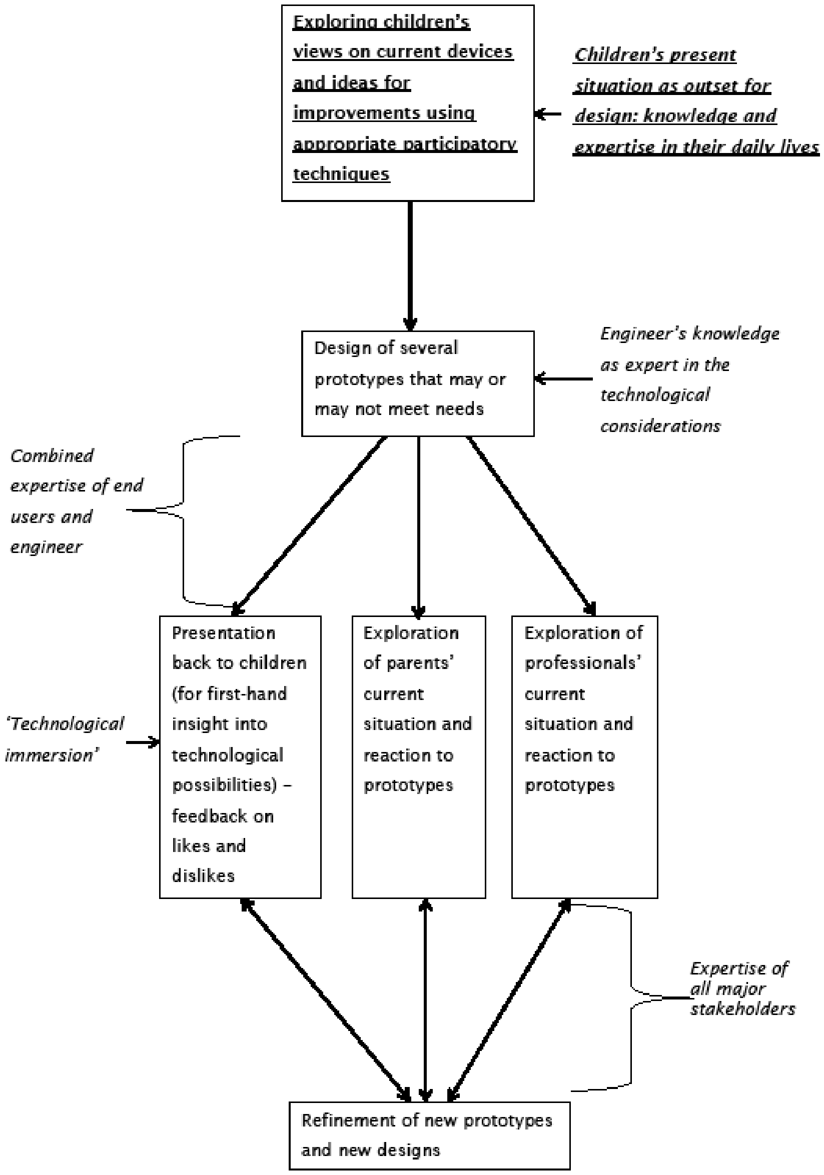

Figure 17: Understanding end users' current situation as part of the BRIDGE process.

3.1.1 Theme one: 'a love-hate relationship'

Throughout the data, participants described both positive and negative views of their prostheses, with some participants displaying a seemingly ambivalent relationship with their prosthesis, recognising that it is helpful in some circumstances yet is "*more hassle than it is worth*" (Anna, 14) at other times. The balance between the prosthesis' perceived usefulness and the view of it as a hindrance clearly impacts on whether or not the participants elect to use their prosthesis. The following section describes the theme in more detail, having divided it into two subthemes – 'Prosthesis as a help' and 'Prosthesis as a hindrance' and exploring within these subthemes the particular ways the participants view the prosthesis as either helping or hindering them. See figure 18 for a breakdown of the theme, subthemes and constituent components.

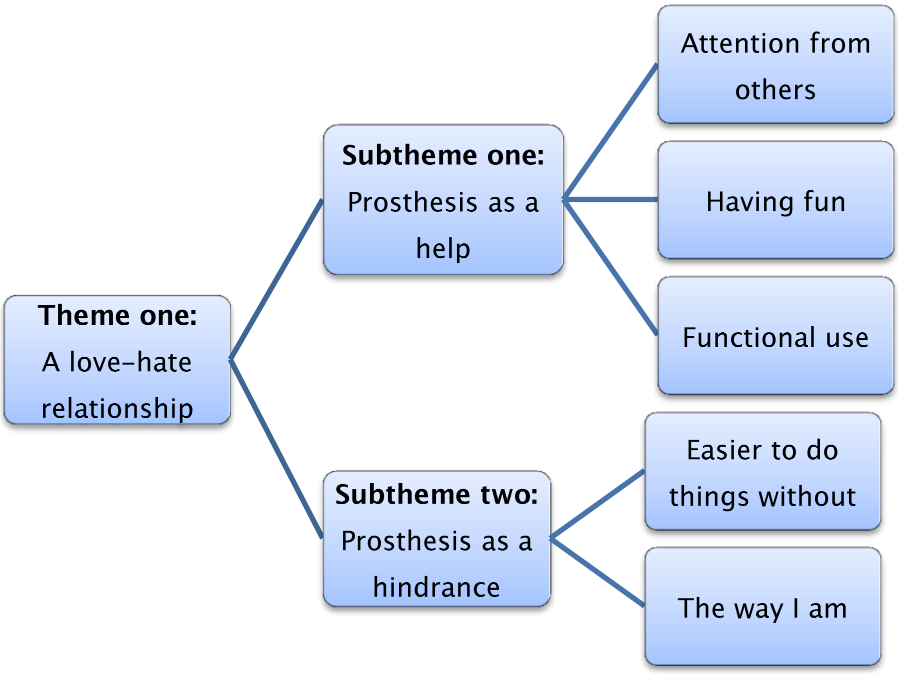

Figure 18: Breakdown of theme one: A love-hate relationship.

3.1.1.1 Subtheme one: 'Prosthesis as a help'

Attention from others

Participants described using their prostheses to deal with unwanted attention. This reinforces the notion of disability being a socially constructed phenomenon as unwanted attention is an extrinsic societal factor as opposed to an impairment-based issue. This is evident in the below quote from Becky, 8, who makes it clear that it isn't people noticing her limb difference that affects her *per se*, but the assumptions they make and the hurtful things they say:

> *"... If they can see and they come up to me and say "Hey, you've got one hand" that might make me feel in a way sad. But, then if they didn't like, if they saw and then didn't make an opinion on it I wouldn't mind that."* (Becky, 8)

The unwanted attention the participants described included staring, asking questions and teasing, such as:

> *"... Say if I've had a bad day at school I normally wear it the next day. I don't know why. Like, people are teasing me or something"* (Becky, 8).

On further discussion with Becky (8) it became apparent that "*a bad day at school*" referred to receiving too much unwanted attention from others and being teased by her peers and called names because of her limb difference. The participants described wearing prostheses to prevent unwanted attention and teasing at school as well as in other settings (such as when out in public), particularly in situations where they will come across people they don't know.

Emma (9) talked about wearing her prosthesis at school to prevent getting unwanted attention from the younger children. She also talked about children "*getting used to* [limb difference]" through gaining awareness of people with limb difference. This, she felt, was helped by people with limb difference being represented in the media, referring specifically to a children's television presenter who has upper limb difference:

> *"... It sometimes helps when I'm in assembly because all the little kids like stare and I find it quite annoying. I think some of the little kids get used to it by watching CBBC but some of them don't. So sometimes they stare."* (Emma, 9).

David (10) felt that it was the amount of people he didn't know that influenced his decision to wear a prosthesis rather than their knowledge of limb difference *per se*:

> *"I usually wear it everywhere except home if there's too many other people around"* (David, 10).

Some participants talked about how their prosthesis had helped them gain self-confidence – *"It was handy because it gave me more confidence" (Laura, 14)* – to the extent that they no longer felt the need to wear it:

> *"There'd be no point in me wearing it now because I'm fine with it, I've got used to everyone looking and my arm so it doesn't bother me anymore so I just stopped wearing it."* (Laura, 14).

Inherent in this desire to deflect unwanted attention was a feeling that others, and the participants themselves at times, viewed them as 'different' as a result of their limb difference, and that this could cause embarrassment and isolation for the participants. Anna (14), for example, remembered a time when she was younger and was required to wear gloves as part of a costume:

> *"... we had this dancing thing, where we had to wear, everyone had to wear, two blue gloves, and so I had one, a cosmetic hand, so that I could wear two blue gloves as well. I was embarrassed that everyone else had two and I only had one."* (Anna, 14).

Furthermore, the participants recognised that all people are individuals and, by definition 'different', but that others don't always seem to recognise this:

> *"... when people say 'Oh look you've got one hand' then I usually just say 'Well, you're different too aren't you'... I think that everybody's really the same because they're different because everyone is different which makes everybody the same..."* (Becky, 8).

Being identified by others as 'different' appears to lead to a desire by the young people to meet others with similar impairments, perhaps owing to a yearning for a sense of belonging and sameness:

> *"... it would be quite, be quite cool if there was someone there with one hand and we could make friends, but then it's not very likely that there is going to be in that particular place."* (Becky, 8).

Conversely, some participants reported choosing not to wear their prosthesis because they found it led to more unwanted attention than when not wearing it. For example,

> *"I think I feel more, not as much embarrassed, but more self-conscious if I do wear one, especially if I have short sleeves. Then I feel more self-conscious when I'm out and about..."* (Anna, 14)

To summarise, the young people may find their prosthesis a help in dealing with unwanted attention from others and associated issues such as teasing, being asked questions and being stared at. Understandably, they look for strategies to prevent or reduce this attention. They may use their prosthesis to deal with this or find that, due to the unrealistic appearance of the prosthesis, it actually draws further attention from others. The participants appear to value 'fitting in' and being like others but they also demonstrate that being an individual is important to them. It is, perhaps, the response of others to their limb difference that makes fitting in important to the participants, despite being in contradiction with an expressed appreciation of individuality.

Having fun

Another positive element of prosthesis use described by the participants in the study is having fun with their prosthesis and using it in games with friends or for practical jokes. For example:

> *"For a joke at home I say to my sisters 'you wanna piece of me? You wanna piece of me?' and I take my arm off and give it to them"* (Becky, 8).
>
> *"...when we played games of tag, I used to use a prosthetic arm to actually tag the person or grab their t-shirt"* (Gareth, 15).

Functional use

Some participants talked about using their prostheses as a general aid for day-to-day tasks, others talked about using them for specific activities and some participants talked about having prostheses that are specifically designed to aid with particular activities that are important to them.

Participants talked about using their prosthesis as a general aid for day-to-day tasks both in school and at home. For example:

> *"I used to use it for holding paper and stuff… It was useful when I was younger for cutting and stuff"* (Lauren, 14).
>
> *"I might wear it if I was cleaning the bathroom 'cause then I wouldn't hurt my little arm when I'm cleaning or something like that"* (Emma, 9).

Specific activities that the participants used their prostheses for generally involved taking part in sports/PE at school:

> *"When I play hockey it helps me hold my hockey stick 'because you have to have your right arm at the bottom and I obviously can't reach"* (Emma, 9).

Some participants, however, reported that using a general purpose prosthesis in sporting activities was more of a hindrance than a help:

> *"When you're doing sports you always feel like you're trailing it along… Just think it'd kind of slow me down a bit. I wore it for football once but*

> *just kinda gave up after a while just 'cause... I just felt like I was trailing it around"* (Gareth, 15).

Participants appeared to find prostheses that were specifically designed for a task more useful for sports:

> *"I find the one that I've got at the moment, which I use for riding a bike, I find it really helpful when I'm riding a bike because that's the only thing I use it for"* (Chris, 12).

As well as having prostheses for use specifically in sports, which included prostheses for cricket, cycling, golf and press-ups, the participants talked about having prostheses to help with playing musical instruments (*"it's a thing that goes on my arm so that I can attach a plectrum to it so that I can play the guitar"* [Anna, 14]) and for typing.

3.1.1.2 Subtheme two: 'Prosthesis as a hindrance'

Easier to do things without

In parallel to previous research (e.g. Wagner et al 2007) several of the participants reported having periods of not wearing a prosthesis because it did not provide any functional benefit. Gareth, 15, for example stated:

> *"I didn't have any for a couple of years just because I didn't really need them for anything"* (Gareth, 15).

It was not until Gareth (15) was prescribed task-specific prostheses for use in activities that were meaningful to him (golf and gym) that he started using them again. Lauren (14) also reported not using prostheses because they didn't help with activities:

> *"I used to wear it because I thought it would always help me with things but then after a while I thought it's not really helping me to do anything I couldn't already… You can't do anything with it that you can't do without it."* (Gareth, 15).

Like Gareth, Lauren is also now considering using a prosthesis to help with a specific interest of hers, discus throwing.

Not only did the participants express the view that the prosthesis does not help function, but that it is actually a hindrance in certain activities or due to certain design features. Specifically, Gareth (14) found the grip to be less effective than required when playing golf:

> *"... You couldn't hold the club because it was sliding around."*

Lauren (14) talked about her prosthesis restricting her elbow movement:

> *"... It blocks you from using your elbow so you can't use it. So it's there but you can't do much stuff with it... it was kind of blocking how to pick up things and stuff like that – I found it made it harder a bit..."*

The weight of the prosthesis, combined with limited movement, was also identified as a factor in the prosthesis hindering function in daily tasks:

> *"It was more hassle than it was worth because all it did was that and it was really heavy so it ended up being less convenient than without"* (Lauren, 14).

The way I am

Several participants demonstrated great acceptance of their limb difference, indicating that they are satisfied with who they are and, therefore, do not believe that a prosthesis is helpful to them. For example:

> *"With myself I just think if I can't do that then I just find a way round it because that's what I've done. If there's something I can't do I will try to figure it out because I'm determined like that. I won't let there be anything… there's loads of things I can do with one arm that loads of other people can't do anyway so it doesn't bother me that much"* (Lauren, 14).

This challenges popular opinion about how difficult and unfortunate it must be to have a limb difference and calls into question the clinical assumption that prescribing a prosthesis is always the optimum intervention for young people with limb difference. Consistent with the transformative ontological assumption, this illustrates the importance of encouraging participants to convey their own personal realities, particularly when those realities exemplify human diversity and challenge commonly held assumptions.

3.1.2 Theme two: 'Room for improvement'

The second overarching theme represents the issues with current prostheses that the participants identified and their priorities for improving prostheses. The theme has been divided into subthemes which each representing a different characteristic of prostheses so that areas for improvement of prostheses can be clearly identified to inform the design of new devices. Figure 19 represents how this theme has been divided into subthemes.

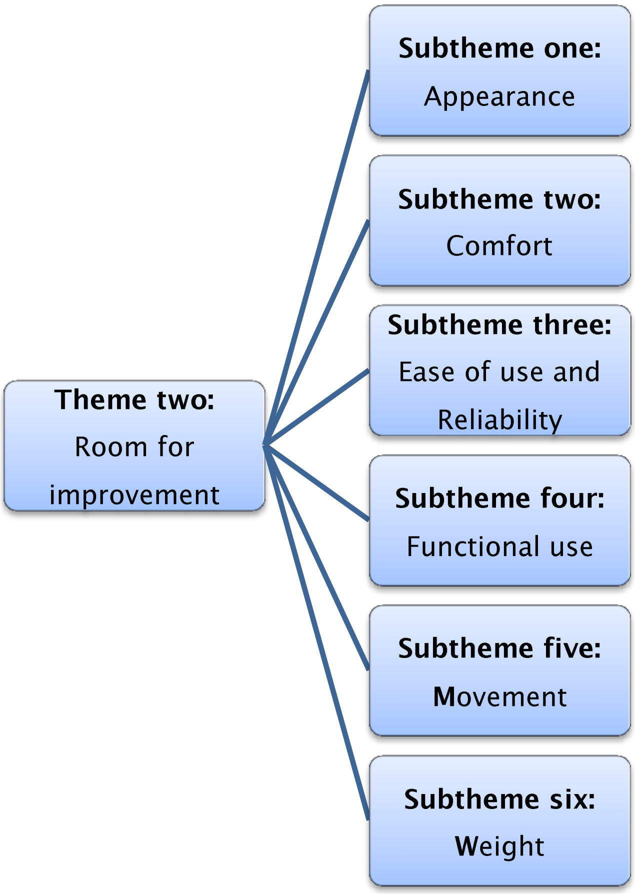

Figure 19: Breakdown of theme two: Room for improvement.

3.1.2.1 Subtheme one: Appearance

Some participants identified that an issue with the appearance of prostheses currently is that they do not look enough like a human hand, making it obvious to others that the person is wearing a prosthesis:

> *"Some of the earlier ones I had they looked really fake"* (Anna, 14).

Issues described by participants relating to improving the realistic look of prostheses include the shape of the prosthesis; matching the colour to the wearer's skin tone; adding veins, freckles and other realistic skin marks and having realistic nails. Participants also described factors that impact negatively on the realistic look of the prosthesis, including the prosthesis being marked with the limb centre's logo and discolouration of the cosmesis through wear and tear.

Some participants, however, felt that current prostheses do look relatively lifelike in appearance but that the movement of the prosthesis is the reason it is noticeable that it is not a real hand:

> *"I think they're doing really well actually 'cause they look like a hand. They don't exactly move like a hand but they're doing quite well."* (James, 8).

The participants in the study felt that the appearance of prostheses could be enhanced, which reflects the young people's use of their prostheses to deal with unwanted attention from strangers. Whilst most participants described a desire for more realistic prostheses, with a better match of skin tone and more realistic features (such as veins), one participant explained how he would prefer his prosthesis to "*look cool*" (James, 8). David (10) explained how the desire to improve the appearance of prostheses was related to the perceptions of others:

> *"That it isn't so obvious that it's fake. [People should think] that you actually have two hands and that you have the ability".*

Others also talked about wanting to *"blend in"* and having a prosthesis that wasn't so obviously *"fake"*. James (8), however, talked about wanting a *"robotic"* arm so that he could look like a hero of his, *"Anakin Skywalker"* and that he could *"look cool"*. Although James' preference for how the prosthesis should look is quite different to the other participants' the motivations driving this, namely self-presentation and perceptions of others, are possibly the same.

3.1.2.2 Subtheme two: Comfort

Comfort was identified as one of the areas participants felt that improvement to prostheses could be made. They specifically talked about how the inside of the sockets they were currently using were uncomfortable and restrictive at the elbow. They felt this could be improved if prostheses were softer on the inside, and less constricted so that the skin on the residuum would not *"go purple"* (Gareth, 15). Emma (9) also identified that the sock she wears in her prosthesis is not comfortable and that a more bespoke 'glove' might be more suitable:

> "*Maybe a glove instead of a sock. Like a little glove with finger holes because that might be a bit easier because when I put my fingers in like that my fingers aren't squished but when I put my hand in the sock it makes my fingers go down and get all squished."* (Emma, 9).

These issues may be evidence of disparity regarding the quality of prostheses young people are offered depending on the geographical area, as opposed to design faults within the devices themselves.

A secondary issue related to comfort identified by participants related to the external material of the prosthesis and may be a factor that it is possible to improve through changes in design. This was related to wearing prostheses for sport but finding that they were uncomfortable if fallen on (such as when goal-keeping). Emma (9) talked about wearing her prosthesis when playing hockey:

> *"it would be ideal for PE to not be as rock hard because I'm always scared that I'm going to bash my face with it 'cause it's quite hard like a rock and I don't really want to lift my arm 'cause it's quite hard and I might go like that and then I'll whack myself and it quite hurts."* (Emma, 9).

Chris (12) and David (10) both identified that when playing football the hard exterior of the prosthesis leads to discomfort:

> *"When you like land on them they could be softer inside because it really hurts if you land on it"* (David, 10).
>
> *"I play football as well, well I don't play in goal, but I know from playing in goal before that it really hurts when you fall"* (Chris, 12).

A third issue identified relating to the comfort of the prosthesis was how warm it causes the residual limb to become, and participants felt that this was an issue that could be improved.

> *"I'd wear it all the time if it does cool down your arm and it doesn't get sweaty I'd wear it all the time"* (James, 8).

Several participants mentioned that excessive sweating was an issue with their current prosthesis. This could lead to the prosthesis feeling very hot and uncomfortable and causing a rash on the residuum, and even cause the prosthesis to fall off. Some participants felt that a way of reducing sweating would be beneficial whilst others suggested that having better air circulation within the prosthesis would be a desirable improvement.

3.1.2.3 Subtheme three: Ease of use and reliability

Participants identified issues related to the reliability of the prosthesis, both in terms of how easy it is to use and in terms of durability. In terms of ease of use, issues identified as potentially problematic by the participants were getting the prosthesis on and off, making sure the prosthesis does not come off when the wearer doesn't intend for it to come off and being able to operate the prosthesis competently and consistently.

Some participants reported that they found their prosthesis easy to get on and off. Others, however, reported difficulties in this area. Some said they had to adopt strategies such as *"wriggling"* or using talcum powder to get the prosthesis on and off. Anna (14) described how she had to ask friends to help her when taking her prosthesis off:

> *"... Sometimes, um, if I was with one of my close friends and if I was wearing it I'd ask them to help me take it off and then it's, sometimes, if it's in the summer or something then it's like a tug of war and I end up staggering back because it's really hard to like pull..."*

This issue with having difficulty getting the prosthesis on and off seems to vary between participants suggesting it may be related to which prostheses are available in their local service and the fitting of the prosthesis, as Chris (12) reported that getting his prosthesis on and off was not something he has difficulty with due to the design of the device:

> *"I don't find the taking off that hard because I've got like a white like a button which I press and I've got like a sock with a metal bit on the end and it's got like... grooves... And you put it in and then it sticks and then when you wanna get it off you press the white button and it comes back and then you've gotta take the sock off."*

Despite the difficulties some participants described with getting the prosthesis on and off due to the tightness of the fit, some participants also described experiences of their prosthesis coming off when they weren't intending for it to. These incidents seemed to generally occur when the participants were wearing their prosthesis for sports or outdoor play, which may suggest that the prostheses children are currently being prescribed are not adequately taking account of the environments they wish to use them in or the occupations they wish to use them for. Chris (12), for example, described an incident when playing cricket:

> *"I play cricket and I have my arm to the bat and it gets really hot sometimes and sometimes when I'm taking a shot it comes off like 'cause it's so sweaty it just comes off."*

The third difficulty participants reported with ease of using the prosthesis was being able to reliably control the movement of the device. Participants reported difficulties with both body-powered and myoelectric prostheses. Participants described not being able to make the prosthesis move due to their residual limb not being in the optimal position:

> *"Sometimes it would be quite awkward 'cause I'd have to move my arm to the right to activate the button but sometimes there wasn't enough movement, like there wasn't enough space inside there. You'd have to hold it in your hand to move it then."* (Becky, 8)

They also talked about times when the prosthesis had opened and closed without them wanting it to and the potentially embarrassing situations this could lead to:

> *"I got my headmaster's hand stuck in it for a while because I didn't know how to work it."* (Lauren, 14)

The prosthesis getting stuck in a closed position was a common occurrence described by the participants and, as Lauren points out, can be as a result of the user not feeling adequately trained or competent in using the prosthesis and may highlight that further consideration should be given to the optimal method for teaching young people how to use prostheses.

A further issue related to being able to rely on the prosthesis is its durability – a prosthesis that becomes damaged easily can also attract attention to the young person wearing it. Areas described by the participants in this study that relate to its durability included the cosmesis becoming damaged and the internal mechanisms breaking down.

With regard to the cosmesis becoming damaged participants reported fingers breaking, nails flaking off and the cosmesis becoming torn. David (10) showed how a screw from the internal mechanism had broken through the cosmesis:

> *"I also find the gloves are really thin because this thing always pokes through... I think they shouldn't make it so sharp because when I feel round the edge of it, it is quite sharp."*

For David, this was quite an issue as he wore a passive prosthesis largely to prevent attention from people he doesn't know and the visible screw attracts attention. Issues with durability, not being able to reliably don and doff the prosthesis and not controlling its movements can lead to situations in which further attention is drawn to the young person wearing it. This contradicts one of the three main reasons for wearing a prosthesis identified by the young people in this study – to minimise the unwanted attention of strangers.

The participants also reported that at times their prostheses have not worked properly due to them not being able to get wet, the batteries being unreliable and the prosthesis just generally *"breaking down".*

3.1.2.4 Subtheme four: Functional use

One of the focuses for the participants when discussing how they would like prostheses to be improved was the activities they would like prostheses to assist them with. Activities were identified across the domains of productivity, leisure and self-care.

In terms of productivity, the participants talked about difficulties with the fine motor activities of writing and typing:

> *"... What would be really, really magic would be if it could write..."* (Emma, 9.)

> *"It would be good if they could make a hand that you'd be able to like touch type, but … it would be too complicated to work out…"* (Anna, 14.)

> *"If I try typing with this hand then I end up just pressing the wrong letter because the key isn't big enough…"* (Becky, 8).

With regard to leisure, the participants discussed how prostheses would be useful as aids in sports and helping with specific hobbies, such as sewing and yoga. One prominent activity for the participants was cycling, due to needing to look over both shoulders when cycling (and this being made difficult by a unilateral limb difference), problems with using brakes one-handed and the need to wear a prosthesis in order to cycle at a standard required by the cycling proficiency test.

Self-care activities were identified as important by the two older female participants in the study (Anna and Lauren, both 14).

> *"Cutting food maybe because I found that quite difficult when I was younger because obviously the plate would slide off"* (Lauren, 14)
>
> *"My biggest problem is tying up my hair and I get so frustrated when I can't do it… And also tying shoelaces and, I can't really think now, but there are loads of stuff, like putting on ear-rings and things like that. Um, if they had more precision in going like that instead of just opening and closing it would be a lot better."* (Anna, 14).

3.1.2.5 Subtheme five: Movement

Another area of improvement that was important amongst the participants was the movement of the prosthesis. This relates to joint movement at the wrist and elbow, grip/finger movement and the control the user has over the movement.

In terms of joint movement, the participants described how more movement at the wrist and more flexibility at the elbow would be helpful:

> *"I think if they kind of used this for the wrist. It bends any way you want quite easily, that'd be quite good as well"* (Gareth, 15).
>
> *"[The elbow should be] more flexible"* (David, 10).
>
> *"Like a flex in the elbow so you can go like that"* (Becky, 8).

Additional finger movement was the most talked about area of prosthetic movement by the participants. Participants felt that they would like fingers to move individually instead of only having one grip as, understandably, they would like the movement to replicate the natural movement of a hand as closely as possible:

> *"… An opposable thumb and a lot more dexterity than just going like that and I think it would be really good if your fingers could move separately"* (Anna, 14)

The final area of movement that the participants felt could be improved was the control the user has over the speed, strength and size of the movement of the prosthesis:

> *"For like the movement, what you do with your hand... say if like you sort of move one of your fingers it could move slightly but then the more you move your finger it moves more down."* (Lauren, 14).

3.1.2.6 Subtheme six: Weight

Weight was also a factor that the participants felt, if improved, would impact on their experience of using prostheses. The participants explained that prostheses are heavy, particularly if they have batteries in them, which can render them useless due to the need to use the unaffected arm to support the prosthesis:

> *"You have to support it with your other hand 'cause it's too heavy"* (David, 12).

Many of the participants voiced the opinion that a more lightweight prosthesis would be better because *"if it was a bit lighter it would make everything a bit easier"* (Gareth, 15), with one participant stating *"If it was really light... then I'd probably get it"* (Anna, 14).

3.1.3 Section summary

As described, two overarching themes relating to upper limb prostheses for children and young people were identified in the data: 'A Love-Hate Relationship' and 'Room for Improvement'. The overall picture that these themes convey is that young people recognise that prostheses do serve particular functions for them and that they are useful in certain circumstances, but that the prostheses that are currently available have many drawbacks that counter the perceived benefits.

3.2 Section two: Parents' current situation

This section presents the findings from stage four of the study: developing an understanding of the sociocultural world of lay users (parents). Figure 20 shows which element of the BRIDGE process these findings relate to (bold and underlined). Two overarching themes, ‘Accepting your child’s ‘difference’’ and ‘What a prosthesis should be’, were identified. This section presents those themes and the subthemes within them.

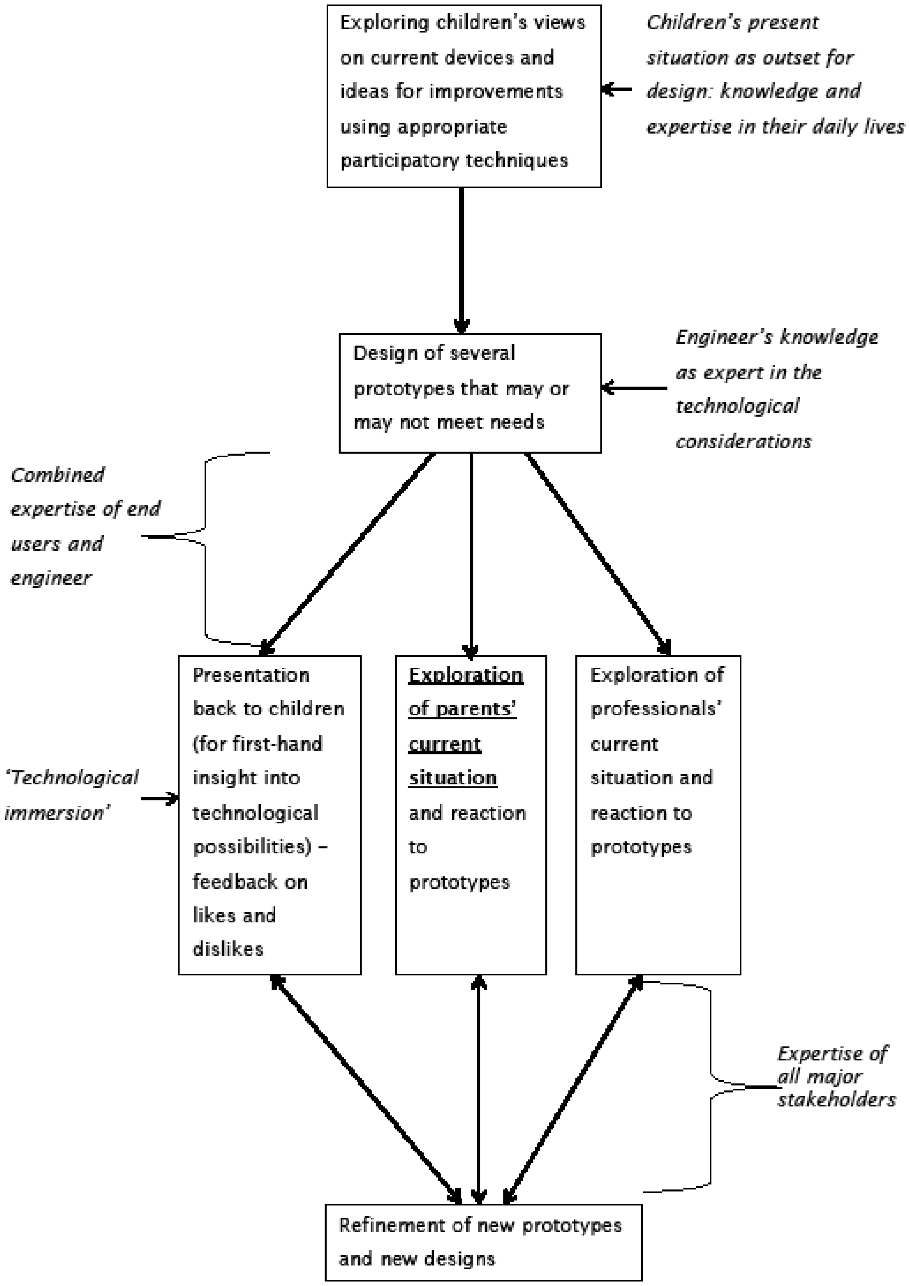

Figure 20: Understanding lay users’ current situation as part of the BRIDGE process.

3.2.1 Theme one: Accepting your child's difference

Many of the parents interviewed described a journey from being acutely aware of their child's difference and wanting them to be the same as other children to no longer even 'noticing' their limb difference or seeing them as any different from their peers or siblings. This experience seemed to prevail regardless of whether or not parents had been aware of their child's limb difference prior to the birth. It was, though, expressed by some that knowing about a limb difference *in utero* can aid parents in preparing for their child's difference and may pave the way for earlier acceptance.

> *"A friend of mine had a baby 2 months before Lauren was born and he hasn't got any fingers. And I can specifically remember asking the radiographer, radiologist whatever, could they check the limbs because obviously my friend's baby had been born so of course it's in your mind when you're pregnant, you worry about everything. And I was told everything was fine, but of course it wasn't fine because Lauren had a limb missing… I think the initial things that need to be looked at before we even get to the prosthesis is if the scan reveals the abnormality I think parents or families need to be start worked with immediately…"* (Mother of Lauren, 14)

Parents described their child's limb difference as a *"shock"* and said they wanted their child *"to look like other children"* (Mother of Lauren, 14) and have *"two hands at the end of their sleeves"* (Mother of Gareth, 15). They described the early months of their child's life as a period of adjustment for them as parents.

Feelings of grief and guilt were evident in the parents participating in the current study. Positive influences on adjustment were viewed to be emotional and practical support, use of prostheses and humour. Figure 21 below shows how this theme is broken down into sub themes.

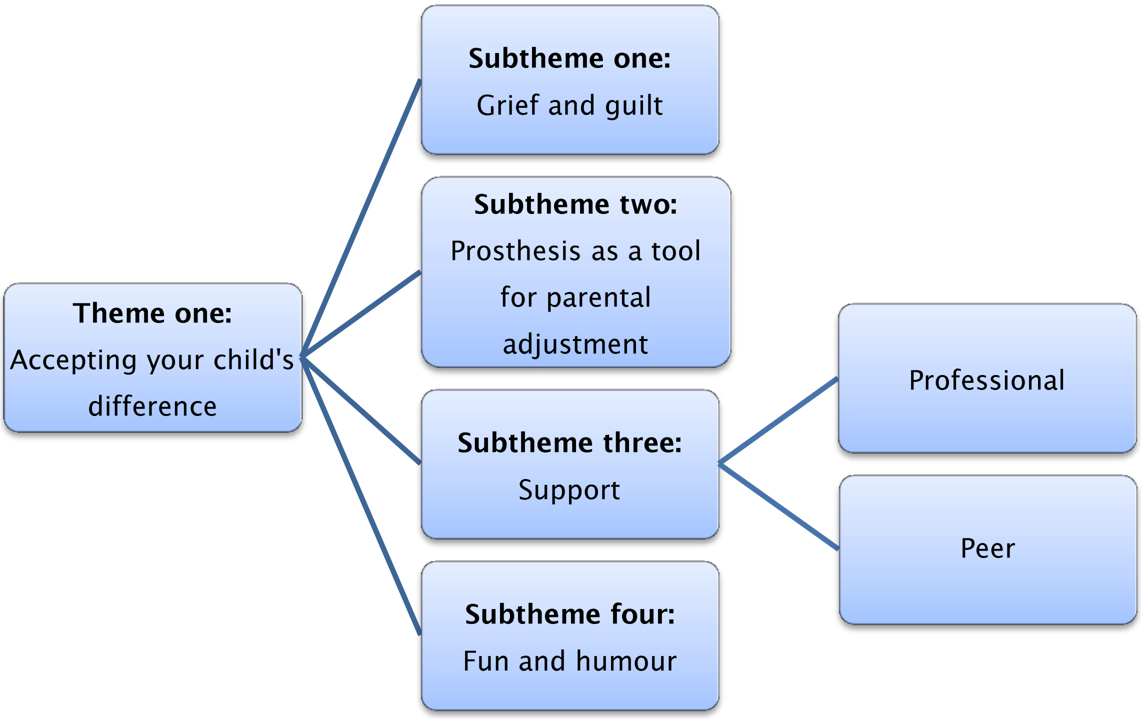

Figure 21: Breakdown of theme one: Accepting your child's difference.

3.2.1.1 Subtheme one: Grief and guilt

Perhaps due to the often unknown aetiology of limb difference in children, parents described feelings of guilt, loss and anxiety, questioning if their actions could have resulted in their child’s disability.

> *“All the time you’re searching and trying to work out what's happened, wondering whether you did anything”* (Mother of Lauren, 14).

These feelings caused huge anxiety amongst new parents, leading parents to conduct independent research into the origins and effects of limb difference. This resulted in them reaching conclusions about their children’s condition and catastrophising about it, believing them to have other disabilities such as learning disabilities.

> *“I’m a registered nurse myself, and people were looking at me going ‘oh, she’s... it’s teratogenic, there’s been a clot, amniotic banding’. I*

> *was like 'excuse me, can we see somebody'... the frustration that I felt that nobody was even trying to find out and it was literally left to my husband and I and then you're looking into things and finding out about syndromes where there's brain damage as well. And then, when Lauren was about five days old, they sent me all this information with extremely deformed children, hydrocephalus, microcephalus, children with limbs missing, thalidomide children... I can remember looking at this and just feeling totally overwhelmed."* (Mother of Lauren, 14).

This understandably resulted in increased grief and anxiety for the parents which led to them wanting to conceal their child's limb difference hindering the process of acceptance of their child's limb difference.

> *"it was all the thing of me trying to, well in a way hide it. You try to hide things and you can't, you know. So I'd have her all wrapped up trying not for her arm to come out. Really, you know, sad, but we had no support."* (Mother of Lauren,14).

Associated with feelings of guilt were anxieties about the child's future abilities, questioning each future developmental milestone:

> *"How's he gonna ride a bike? How's he gonna tie his shoelaces? What's he gonna do about... doing a tie up?... all basic things in life"* (Father of Chris, 12).

Parents described the process of acceptance and coping with guilt as being closely related to a realisation that children with limb difference are capable of reaching the same developmental milestones as their peers and seeing your child achieve these things over time is "*a healer*" (Father of Chris, 12). This developing realisation of their child's capabilities did not however negate their perceived need for their child to have a prosthesis at an early age to help them to adjust to their child's difference.

3.2.1.2 Subtheme two: Prosthesis as a tool for parental adjustment

There was a resounding feeling from the parents interviewed that the first prosthesis their child had received, when only a few weeks or months old, was for the benefit of them rather than the child.

> *" So that one [the first prosthesis] I think was the most important one of them all. Yes that arm was very important because at that stage you*

> *just want your child to have two hands and it did help us a lot."* (Mother of Gareth, 15).

Some parents felt that it was one of the most important prostheses their child had had because it allowed the parents to do the things they considered to be 'normal' for a parent of a small child. To dress them properly, to see them with two hands at the end of their sleeves, for them to be able to wear the same clothes and go to the same places as other children and parents and not to be treated any differently. Some parents reflected on how this seemed trivial to them now and perhaps even felt some guilt about feeling the need to disguise their child's limb difference.

> *"It sounds so trivial because I don't even notice it on him anymore that he's missing a lower arm."* (Mother of Gareth, 15.)

Some parents identified that this need to have a prosthesis to feel 'normal' and disguise their child's limb difference was directly related to a lack of emotional, practical and psychological support regarding their child's limb difference.

> *"I think if we'd had more support when Lauren was born because, we didn't know obviously then that Lauren had the limb deficiency, we had no support at all... it was quite inhumane really. I think that that, if I'd had the right support then, I don't think I would have been concerned in baby clinic if people were looking at her"* (Mother of Lauren, 14)

3.2.1.3 Subtheme three: Support

When discussing the importance of support on the positive adjustment of parents to limb difference, participants explored both professional and peer support and the value of both.

3.2.1.3.1 Professional

Parents talked about a lack of support both prior to and directly after birth or diagnosis having a direct impact on difficulties adjusting to their child's limb difference and a desire to conceal it. Parents described scenarios in which their situation was treated with insignificance and even flippancy by professionals.

> *"There was only two babies born in the hospital that night and the paediatrician came round in the morning and said 'Hello, have you got anything that your worried about your baby?' and I said 'well, he's*

> *only got one hand.' 'Oh, yeah I heard there was a baby born like that last night' she said"* (Mother of Gareth, 15).

There was a feeling that this may have resulted from a lack of knowledge or experience from the professionals making them ill at ease to advise and empathise. Several parents reflected on having experiences with professionals who had not worked with a child with congenital limb difference which may have impacted on the quality of support parents were provided with.

Parents talked about being given different and conflicting information from different professionals. They reported feeling that they had to be proactive in asking for the help/testing they felt they needed and in exploring their child's likely needs or possible diagnoses.

> *"We had to push to get tested that there was nothing else wrong because as young parents and your child's born and you're thinking ok I can see there that there's something wrong but you're thinking that there might be a lot more that's wrong that I can't see. We had to really push to get checks done."* (Mother of Gareth, 15).

This, however, was reported to be extremely difficult and a challenge for parents, even for those with professional experience themselves (such as Lauren's mother who is a nurse). Lauren's mother described the high emotional intensity of the situation as making her feel as though she were in *"la-la land"* and unable to rationally reason things. Parents used highly charged and emotive language when recalling their child's birth, such as *"frustration", "overwhelming"* and *"battle"* and explained how a time which should be full of happy memories is bereft of them as a result of a lack of support.

> *"And I still get really annoyed that that happened to us and we were in that situation because when I look back at Lauren's birth I've got no good memories. There's nothing nice really to remember because of all that, which is wrong really. And that's what you're left with."* (Mother of Lauren, 14).

In more than one instance, the lack of support and appropriate treatment at birth resulted in parents pursuing complaints and even legal action against the NHS.

Parents' reflections on the support they had received from the limb centre included both positive and negative experiences. A prevalent word used to describe the limb service was *"trying"*: families identified that it was very important to them that they felt the staff at the limb centre were willing to try different things and explore different options. There was a feeling that trying is important regardless of whether it is successful as it is reassuring for a parent to know that they have done all they can and have been supported in this.

> *"But she had a go and at least we were able to go to the limb centre and have a go and then she could make her own mind up that it wasn't very successful. So even when things don't work the fact that we can try is better than just saying 'no it won't work'."* (Mother of Anna,14).

Other positive supportive factors exhibited by limb centres were flexibility with appointment times, support in preparing for the next developmental stage, building relationships and having adequate funding. Families felt that limb centres being flexible with appointment times had supported them in maintaining employment and ensuring their child has good school attendance. This level of flexibility is, however, something that appears to differ between services with some families reflecting that because of inconvenient appointment times they were only able to visit the limb clinic in the school holidays and this impacted on frequency of visits.

> *"I'm working full-time so it's very difficult for me to get to appointments. They only have morning appointments Monday to Friday so it's quite restrictive."* (Mother of Anna, 14).

Parents praised staff at the limb centre for helping them to prepare for the next developmental stage and recognised the supportive value of this. They also referred to the staff reassuring their children about future challenges and solutions. This was in relation to staff building good relationships with parents and children, enabling them to feel confident in asking questions or telling staff when they faced difficulties.

> *"I do think they do a brilliant job really. And a good job of building relationships 'cause Emma really likes going. She really enjoys going and the guy who does her arm, who measures her and does all her arms has known her since she was a baby so it's the same person so that is good."* (Mother of Emma,8).

Lastly, some families reflected on how well-funded the services they had attended were, which opened up opportunities to families regarding equipment and therapy available to them. Having a full staff team who work closely together was reported to be a positive experience by parents although, as evidenced by the use of the word "lucky" in the following quote, not something that is assumed to exist in all services.

> *"She's been lucky because the prosthetic technician and the OT really work closely together so I think she's been lucky because she's had really good experiences."* (Mother of Emma, 9).

However, not all reflections on the support of services were positive. Several parents identified that they had not received any psychological support or counselling and identified this as having been detrimental to their coping and acceptance in the early months and years of their child's life.

> *"They did offer counselling but it never materialised which is a shame because I think I would have benefited from that. But, you know, there wasn't a counsellor, so what could they do? They did have access to a counsellor but there was a long waiting list so it never happened. It was the same at my GP surgery, they put me on a waiting list and I never heard anything again."* (Mother of Anna,14).

One parent identified that the child's first prosthesis was an inferior substitute for counselling as it allowed the parent to hide their child's limb difference rather than work through their emotional difficulties and accept it. There was a strong feeling that at least to be offered a counselling service and to know it was available if needed was very important during the process of acceptance and adjustment to limb difference. Other negative experiences at the limb clinic included feeling that the parents and children weren't listened to by professionals. There was an intrinsic message throughout the interviews and focus group that treatment choices should be made by the children themselves and they should be recognised as the experts. The reality expressed by some, however, was that professionals regarded themselves as the experts and attempted to fit the child to the technology available rather than listening to the child and attempting to address their needs and wants.

> *"...our prosthetist has always been very keen on Anna having cosmetic limbs... I sometimes felt he was suggesting Anna might want to have a*

> *hand for cosmetic reasons. ..on several visits he's said 'have you ever considered a cosmetic arm? You really ought to think about it because it would balance you up visually'... he seemed to have his own agenda rather than listening to Anna and noticing that she's confident and doesn't have problems at school. He seemed to have his own agenda that he wanted to put forward... He had his own ideas. He'd been there a long time, he's very senior, really committed and enthusiastic but he had his own ideas that he was quite keen on. But I don't think he was letting her needs lead him, I think it was the other way round."* (Mother of Anna, 14).

Finally, in contrast to the well-funded services described by some, other parents identified the difficulty with getting what they believed their child needed as a result of funding restrictions and bureaucratic processes that appear to be service-driven and not client-centred. Parents described being made to *"jump through hoops"* (Mother of James, 8) to receive a prosthetic device for their child and identified experiences with staff shortages in the services they attended.

> *"So we went to our limb centre but they had no occupational therapist at the time because she was on maternity leave and they had no cover."* (Mother of Anna, 14).

> *"They were down a prosthetist or something so we resolved it ourselves again."* (Mother of Anna, 14).

3.2.1.3.2 Peer

As well as support from statutory services, many participants described the importance of peer support, both in terms of providing emotional support and in sharing practical information to help in preparing for the future. As all of the participants were recruited via Reach Charity Ltd it is perhaps unsurprising that they all expressed how helpful this has been to them in terms of remaining positive and accepting their child's limb difference. Parents talked about seeing children with the same limb deficiency as their child and feeling reassured by a feeling that there are others like them.

> *" Reach was very important. It's a 1 in a 100,000 chance I believe and it's amazing when you go to Reach and you see, you know the first*

> *magazine you pick up and there's children in there with the same arm as your child. That gives you so much reassurance that, you know they're so identical, they're so identical, and more often than not it's the left arm. I'm not saying there's loads out there but to see someone with exactly the same, it's a huge help as a parent."* (Mother of Gareth, 15)

Furthermore, participants in the current study also talked about seeing older children achieving tremendous feats despite their disability and this being a huge positive influence on both them and their children.

> *"There's another young lady who goes there with a similar limb to Lauren, she's about 18, and she's a bronze medallist in the javelin. So I think meeting her has really shown Lauren what she can achieve."* (Mother of Lauren, 14).

They also talked about Reach Charity Ltd being an excellent source of information (which was sometimes felt to be lacking in statutory services). Parents described peer support as being a process that is most important early on in the journey but as they become more experienced as a parent of a child with limb difference they transition from supported to supporter. This was viewed as a positive experience in itself as it enabled parents to reflect on how far they have come. This was also expressed in the participants of the Kerr and McIntosh (1998) study who found that providing support to other parents engendered a feeling of 'closure'.

Some parents did however feel that accessing Reach Charity Ltd was not always a positive experience as within that setting they were required to be *"relentlessly positive"* (mother of Anna, 14) and were not always able to share their true feelings which could be emotionally exhausting. This highlights the need to consider that peer support is not always a positive experience and may not be appropriate for everybody.

3.2.1.4 Subtheme four: Fun and humour

Finally, parents reflected on their own familial relationships and the use of humour within these as a way to help them cope with and accept their child's difference. This was often at the expense of other people who may ask unwanted questions and get a far-fetched response from parent or child as a way to deflect attention and lighten the situation.

> *"…you just get fed up with kids asking questions and I say 'yeah he got attacked by a crocodile and it bit off his arm'. And you just look at their faces and they're horrified."* (Father of Chris, 12).

Humour also took the form of practical jokes using the prosthesis. Having fun with, and making jokes about, the prosthesis or residuum was viewed as a positive experience by parents. It was felt that play, fun and humour are natural responses of children and that using the prosthesis or residuum in this way allows the child's difference to be turned into something positive and 'special' about them. In addition, it was felt that fun and play are ways to motivate children to use their prostheses and to maintain their interest.

3.2.2 Theme two: What a prosthesis should be

The second major theme identified from the interviews and focus groups with parents related to their views on the attributes a prosthesis should possess. Within this, five subthemes were identified: that a prosthesis should be helpful to children, helpful to parents, reliable, usable and available to all (see figure 22).

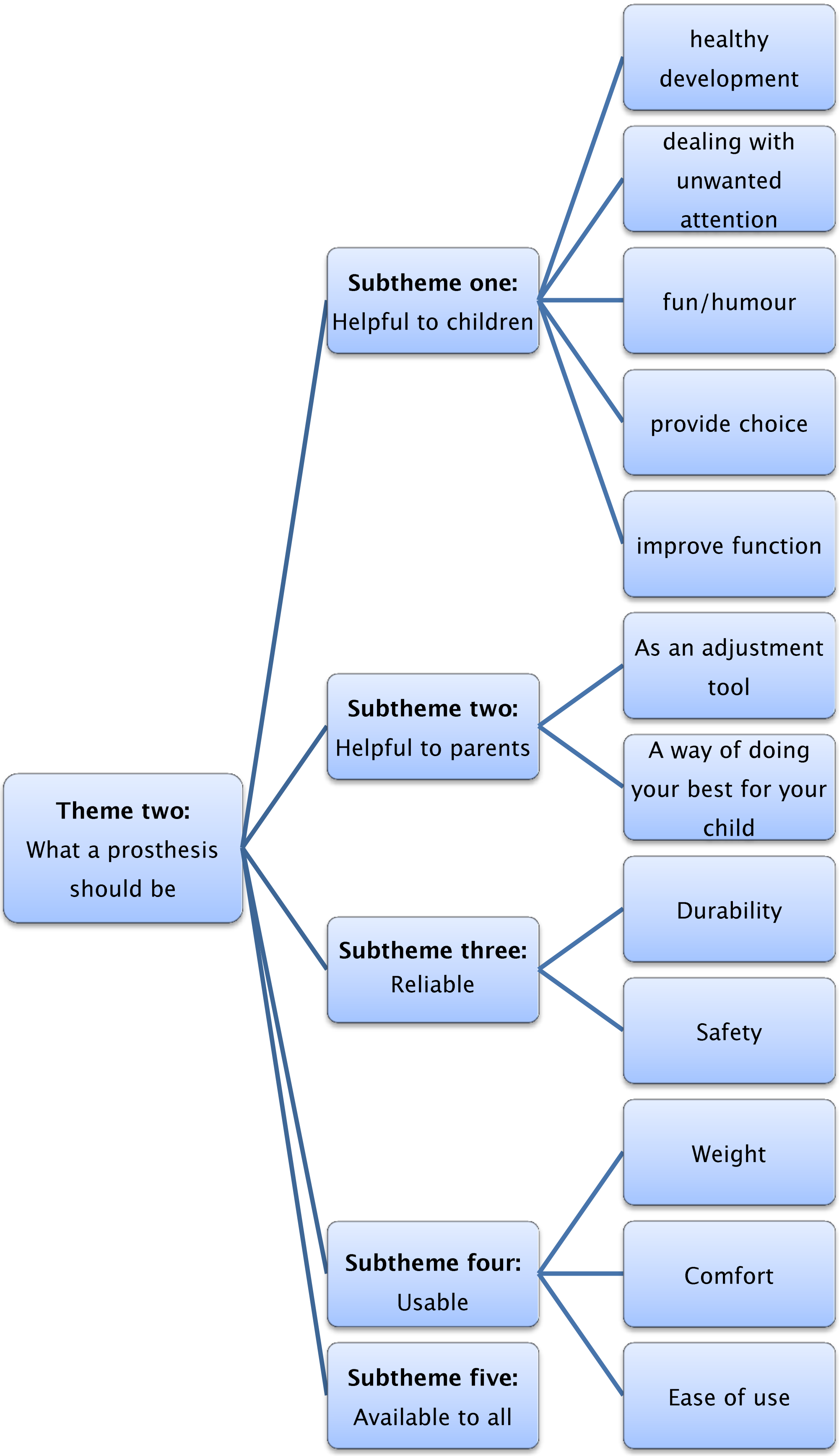

Figure 22: Breakdown of theme two: What a prosthesis should be.

3.2.2.1 Subtheme one: Helpful to children

With regard to how a prosthesis should help children, parents described a prosthesis being important for healthy development, for dealing with unwanted attention, for fun/humour, to improve function and to enable children to have choices.

3.2.2.1.1 Healthy development

In terms of a child's healthy development, parents identified that a difficulty caused by unilateral limb difference is asymmetrical posture and they felt this was a difficulty a prosthetic device could assist with, particularly when cycling due to the need to have contact with both handle bars.

> *"We were worried more about his shoulders because he's very twisted when he rides a bike because he's got his wee arm, so he's quite twisted. And he started wearing it [the prosthesis] and he looked much better and I'm sure it's better for him..."* (Mother of Gareth, 15).

Parents also identified a need for a prosthesis to give a child symmetry when learning to crawl. Parental awareness of the importance of postural symmetry may be as a result of guidance from health professionals.

Some parents, however, felt that prostheses could be detrimental to a child's healthy development because of having additional weight to carry: parents talked about children sitting with a dropped shoulder on the side of the prosthesis and walking *"lopsided"* (Mother of Lauren, 14) – there was concern that this could lead to back problems in the future.

3.2.2.1.2 To deal with unwanted attention

One of the most talked about ways that a prosthesis can be helpful to a child was to deal with unwanted attention. Unwanted attention was generally described by parents as other children, usually younger children who were not known to the child, staring and asking questions.

> *"When she used to go into assembly with the little ones, the little ones always used to stare so she always used to take it in on set days for assembly just so that there isn't any attention really".* (Mother of Emma, 9).

This is similar to the unwanted attention described by the children and young people (see section 3.1.1.1: “Attention from others”, pp. 115-118). Sometimes the unwanted attention went further than staring and asking questions, with other children treating them differently when playing games, for example:

> *“A couple of times they’ve been pretending he’s a monster and they’ve walked up to him and tapped him and he’ll turn around and they’ll go ‘aaarrggghh’ and like run away.”* (Mother of James, 8).

Parents talked about how children can deal with this by deflecting the attention away from their arm by attracting attention in other ways.

> *“He makes silly noises, and he’s a perfectly intelligent child, says stupid stuff. Yeah, basically to deflect attention he’ll do anything.”* (Mother of James, 8).

This wasn’t viewed by parents as a positive way of dealing with the unwanted attention. It was felt that using a prosthesis can be a more appropriate way of dealing with this, either by preventing the attention occurring in the first place (through use of a cosmesis) or by turning the attention into a positive by celebrating their difference and making it ‘cool’. Parents, for example, talked about using a prosthesis to ‘blend in’, perhaps so that you can just *“get on with what you’re doing”* (Mother of Anna, 14) or because you don’t want to be the one who is different at school:

> *“I could always tell when there were things worrying her because she used to put her prosthetic arm on then. So you could always tell when she was getting too much attention and things and she just wanted to, you know, blend in a bit.”* (Mother of Emma, 9).

This desire to either conceal or celebrate difference was reflected as being affected not only by changing moods and emotions and the social experiences of the young people in school and other settings, but also by cultural norms. Parents reflected that in cultures and situations where hand use is an expected part of social-cultural etiquette, questions from strangers and subsequent concealment and avoidance can be more apparent.

> *“It tends to be more in Germany that people ask because you shake hands, and then you shake hands with the right hand and he doesn’t have the right hand and then people ask. And he never liked to be*

> *asked and sometimes I even answer the questions."* (Mother of David, 10).

Parents also expressed a view that cultural changes can be positive: references were made to a children's television presenter who has upper limb difference and the recent Paralympic Games that were held in London in 2012. Parents remarked how this brought limb difference into the consciousness of more people and in a positive way, encouraging children with limb difference to feel proud about their difference.

> *"And maybe things like the Olympics really do make you think you should be really proud when there's an extra challenge and you overcome it. And she'll talk about her drama and say things like there should be more disabled people on the telly every day. So I think she's kind of got into the mind-set that everybody's different and that should be celebrated. So I think that's quite a positive thing."* (Mother of Emma, 9).

It was also felt that having a prosthesis that children would consider 'really cool' and desirable to have would be beneficial as it would facilitate children being positive about difference and feeling proud of their individuality.

> *"She's seen things like a titanium arm that a chap who lost his arm in a motorcycle accident has. And that's not in any way trying to fool anyone and she looked at that and said 'that is so cool'... she admires that devil-may-care attitude..."* (Mother of Becky, 8).

Parents reflected that this admiration of a lack of care or concern was not something children would always want to put in to practice. The ability or inclination to be care- or worry-free would depend very much on the child's personality, how introverted they are and even how they are feeling emotionally on a particular day.

> *"...having some kind of physical disability can draw attention, whether that's wanted or unwanted... [A prosthesis] could be a useful social tool in the sense of 'I'm so cool...' but I think that would depend on the personality of the person concerned."* (Mother of Becky, 8.)

3.2.2.1.3 Fun/humour

Another way in which it was suggested prostheses could be helpful to children was as an object of fun, play and humour, which could also be a way of turning their difference into a positive. This may reflect parents' observations of their children using their prostheses in games or for practical jokes, as children identified this as important (see section 3.1.1.1: "Having fun", p.118). Parents talked about finding their child's prosthesis in the toy box as it was regarded by the child as another toy. They also reflected on times when the prosthesis had been used in games with peers or to play practical jokes on others.

> *"He enjoys taking it to school because other children, it actually becomes part of the game. So he likes it for that."* (Mother of James, 8).

> *"They were using it for tricks, him and his uncles. What they would do is they would tuck it in the pocket of somebody walking along and it'd be like they just had a hand coming out - he loves all that about it."* (Mother of James, 8).

Fun and humour were viewed as important aspects of prosthesis use for children not only because they are a way of viewing difference as something positive, but also because they are a natural part of children's everyday lives.

> *"I think sometimes people are a bit surprised that you joke with it. They're like 'is he alright with that?' But of course he is because it's just fun. Children aren't interested in anything that's not fun."* (Mother of James, 8).

3.2.2.1.4 Provide choice

In order to meet the perceived need of being able to use a prosthesis to blend in or stand out on different days, parents identified that prostheses should provide children with choice. This may refer to having multiple prostheses to suit the person's mood or activities on a particular day or it could mean having a 'just in case' prosthesis for when they feel like the attention from others is too much to deal with.

> *" She likes to have one and I wouldn't ever refuse to take her to get one because I don't think that's my place, but she doesn't really use one at the moment... she likes having a just in case one which I think is fine."* (Mother of Becky, 8).

Another aspect of prostheses providing choice, as perceived by the parents, was that it is the duty of parents to ensure that children have access to prostheses when they are younger and (in the eyes of some of the participants) unable to make informed choices. This was so that when they are regarded as being old enough to decide for themselves they will be capable of using a prosthesis should they want to and will be fully aware of what their options are and what is available to them.

> *"We used to encourage him to wear it so that when he got to a certain age he could then make up his own mind as to whether he was going to carry on using it or not and we thought well if you never wore it you'll never wake up one day and decide I'm gonna wear an arm."* (Mother of Gareth, 15).

3.2.2.1.5 Improve function

The last way in which prostheses should be helpful to children, as described by the parents participating, was that they should improve function. In terms of everyday activities, parents felt that, although their children managed (usually by finding an alternative way of doing them) activities do take longer and are more hard work for children with unilateral limb difference. Parents felt prostheses could help if they were able to speed up a task and allow it to be performed with more ease.

> *"I'm sure there's a way he would adapt [to exams]. But however he adapts he will still be penalised from the point of view of timing as it will take longer without a doubt."* (Father of Chris, 12).

It was suggested by participants that prostheses have the potential to help by making tasks quicker and easier. However their experiences with prostheses to date appeared to suggest that they can actually make activities more difficult and time-consuming to perform, which echoes the children and young people's views of prostheses as a hindrance (see section 3.1.1.2, pp. 119-120).

> *"She uses her arm as a tool literally for picking things up, holding things and of course she couldn't do this with the prosthesis on so it hindered her more than it helped, definitely, I think so because she*

> *used to get quite flustered because she couldn't use her elbow then to carry things."* (Mother of Lauren, 14).

The majority of discussions relating to prostheses being used as a functional tool were concerned with children finding prostheses helpful or necessary for specific activities, largely relating to hobbies and technology use. These activities included sports that require bimanual hand use (hockey, cycling, golf, cricket and discus throwing), playing musical instruments, typing, and fine motor craft and school activities, such as cutting (paper and food) and drawing around objects. There was a strong feeling amongst the participants that for children to want to use a prosthesis it has to serve a specific and meaningful purpose for that child and to improve their function.

> *"Unless its functional he wouldn't wear it... if there's a purpose for it, you know, he'd wear it... he's more like from the point of view, 'well if it doesn't do anything why would I want to bother?'"* (Father of Chris, 12).

Subtheme one has described the many and varied ways in which prostheses should be useful to children, as expressed by parents participating in the current study. They should be viewed both as cosmetic and functional devices and aid, or at least not be detrimental to, healthy growth and development. They should provide children with opportunities for fun and humour and, in order to meet all these identified needs, they are required to present children and families with ongoing choice.

3.2.2.2 Subtheme two: Helpful to parents

Prostheses were not only seen as aids for helping children with limb difference but it was also identified that it is important that they are helpful to parents. This is in-line with a recognition of parents as 'lay users' of devices, having a central role to play in the use of the prosthesis (Cifter & Dong 2008). In terms of prostheses being helpful to parents, participants felt that a prosthesis was important as an adjustment tool for parents when coming to terms with their child's limb difference (as discussed in relation to theme one) and as a way of helping parents to feel they are doing the best they can for their child.

3.2.2.2.1 Prostheses as an adjustment tool

Prostheses as an adjustment tool for parents refers to children having passive prostheses very early in life to help parents to come to terms with their child's limb difference and prevent unwanted questions and attention from strangers during this time of adjustment. It is discussed in more detail in theme one (Accepting Your Child's Limb Difference) but it was felt important to mention it again in relation to attributes a prosthesis should possess, as parents expressed that this function of a prosthesis was extremely important to them.

> *"I think it's important for parents to be offered that first prosthetic arm definitely. And then once they've come to terms with it, it becomes a lot less important I think."* (Mother of Gareth, 15)

3.2.2.2.2 A way of doing your best for your child

The second way in which prostheses can be helpful to parents is to allow parents to feel they are doing their best for their child. Parents spoke about wanting to atone for their child's disability and one way of doing this is to ensure they are receiving the best treatment that is available to them, which in the views of parents of children with limb difference may equate to the best prosthetic device.

> *"We only went with them [myoelectric prostheses] because we thought they were the best, you want to get the best for your children."* (Mother of Gareth, 15).

Becoming an expert on prostheses can enable parents to become more *"demanding and discerning"* (Mother of Becky, 8) with healthcare professionals regarding what's available, and was viewed as a positive way of focussing energies related to being a parent of a child with a disability.

> *"So then I made that my focus so I turned my energies into what I could do there"* (Mother of Anna, 14).

Another way of doing this may be through supporting other parents whose children are younger or with more recently acquired limb difference, as discussed in relation to theme one (subtheme three: support).

3.2.2.3 Subtheme three: Reliable

The third subtheme relating to attributes a prosthesis should possess concerns the need for the device to be reliable. Aspects of reliability that parents recognised as important were the durability and safety of the prosthesis.

3.2.2.3.1 Durability

Issues concerning the durability of the prosthesis were cosmeses tearing and staining, batteries not lasting long enough, finger wires breaking and internal mechanisms of myoelectric prostheses breaking down. These are similar to the durability issues described by children and young people (see section 3.1.2.3, pp. 124–126). The issue of cosmeses tearing and staining was a big concern for the participants as parents found the cosmesis impossible to clean and found the task of removing a damaged cosmesis and replacing it with a new cosmesis very difficult, as evidenced by the below quotes:

> *"It became dirty very quickly and washing it wasn't easy, it became ingrained. You could not clean the marks off – once it became dirty it stayed dirty unfortunately... They say use soapy water but it never works."* (Father of Lauren, 14).

> *"Changing the gloves, that was a nuisance. Yeah because they got awful dirty and they never cleaned and you just had to replace them once they got dirty."* (Mother of Gareth, 15).

The other major concern that participants had with regard to durability was that internal mechanisms of myoelectric limbs would break down. One parent described a situation in which her child had waited a long time to receive his myoelectric prosthesis, it had broken down twice shortly after being received and the child was still without his prosthesis two months later.

> *"We took it back again and this time they said there was actually a fault. So they mended it and then we went back again to collect it. And then it was much better and he could open it, shut it, open it, shut it, it worked for two days then stopped... so actually it took us months to sort out and then it only worked for two days. And then it just stopped completely, open. It froze, never to move again... so we sent it back and they said they were gonna fix it but that was two months ago"* (Mother of James, 8).

Prostheses breaking down and children being without them for some time when repairs are being carried out can cause additional problems: the child's motivation to use the prosthesis may be detrimentally affected and the child's needs may change due to growth and development. In terms of motivation, if a prosthesis breaks down a child may become frustrated and begin to think that the device not working is due to their inability to use it properly rather than the device itself:

> *"... It's ok as long as he doesn't think it's him that's actually rubbish at doing something, he doesn't cope well with that."* (Mother of James, 8).

The other issue is that, in addition to the physical growth of their bodily structures, children's interests may change relatively quickly. Delays caused by prostheses breaking may compound the lengthy process some parents described having to go through to get the device their child wanted. This may mean that their original interest may have waned or developed into something different once the prosthesis is returned to them.

> *"I think the danger of it taking so long to get it from when he first expressed an interest in it is he might have changed his views by the time he gets it. Children change and develop even more than adults change. And if he does change his mind it won't really be surprising."* (Mother of James, 8).

This may have implications when considering the high 'rejection' rates of prostheses amongst children and young people. If a child has waited several months to receive the prosthetic device, they may no longer want to use it: this does not necessarily imply a 'rejection' of the device, rather that the child's needs and wants have changed since the device was initially deemed suitable. This suggests caution should be exercised when using and interpreting the term 'prosthesis rejection'.

3.2.2.3.2 Safety

In terms of safety, parents expressed a concern that children with unilateral limb difference have to be particularly careful not to injure their sound limb as that can have a huge impact on their function.

> *"It's difficult because one time he got his arm trapped at school his good arm, and it was in a sling for two days and he couldn't do anything. So when someone's got a disability you're extra careful with what they have." (Mother of James, 8).*

Parents felt that prostheses could have the potential to serve a protective function, reducing the necessity for children to carry out particular risky activities using their residual limb. In contrast, however, it was also felt that using a prosthesis could present a risk to a child if there were concerns about the security of the grip and if the prosthesis was not used in the correct way (such as, a weapon).

3.2.2.4 Subtheme four: Usable

Parents expressed that in order for a prosthesis to be usable for a child it ought to be lightweight, comfortable and easy to use.

3.2.2.4.1 Weight

The weight of prostheses was perceived to be an issue because parents identified that mechanical and myoelectric prostheses are too heavy. They suggested that this can be a factor in deterring a child from wearing their prosthesis not only as the extra weight can be uncomfortable and tiring when wearing it but also because the child is less likely to be inclined to take their prosthesis with them for use in a particular activity if it will be heavy for them to carry in their bag. This view was supported by the children and young people, many of whom cited weight as a significant factor in their decision to no longer use a prosthesis (see section 3.1.2.6, p. 128). Parents felt that lighter prostheses would be more useful and have better adherence rates.

> *"But lighter, if anything was to be improved, I may well have encouraged him to wear it more if there was a lighter electronic or Myoelectronic arm available"* (Mother of Gareth, 15).

In addition to heavy prostheses being uncomfortable, burdensome and off-putting, parents felt they may also be detrimental to their child's health and development.

> *"She had shoulder pain and back pain because the weight of it was so heavy and it was tied round her so she couldn't then undo it if she was stuck."* (Mother of Lauren, 14).

The weight of prostheses causing pain and discomfort to other parts of the body is clearly in conflict with a desired need to aid with posture to assist healthy development and prevent scoliosis. Prosthesis weight is also directly related to comfort which was another factor identified by parents in terms of the usability of a device.

3.2.2.4.2 Comfort

Parents talked about having difficulty finding a device that wasn't uncomfortable for their child. The main issues, besides weight, were related to heat and sweating. Parents felt this was as a result of both the tightness of fit required and the materials used not being appropriate for close contact with skin. Heat and sweating could result in children needing to remove their prosthesis more frequently. This would make the task of wearing it more onerous and therefore off-putting for the children. Furthermore, if a child did not, or was not able to, take off their prosthesis when it was hot and sweaty this could lead to skin rashes.

> *"But he also sweated a lot, I think it was to do with the material of the lining and he couldn't wear it for too long because his wee arm used to get all spotty and red and could get quite raw so he could only wear it for a few hours at a time because his skin got quite sore to it. So they [the nursery staff] used to take it off and just let his arm breathe maybe for an hour or so."* (Mother of Gareth, 15).

Parents felt that considering using different materials that may reduce sweat production could be an improvement for prostheses for children.

> *"If it was... made of different sort of stuff that wouldn't be quite as sweaty I just think it would be, you know, really useful."* (Mother of James, 8).

Parents did not discuss issues of accidental self-injury (arising due to the hard external surfaces of devices), which was identified as important by the children and young people (see section 3.1.2.2, pp. 122-124).

3.2.2.4.3 Ease of use

The last important factor in terms of usability identified by parents was that it should be easy for a child to operate a prosthesis. This ease of operation was related to the simplicity of the device, obtaining the correct training and the need for prostheses to replicate natural movement as much as possible. Difficulties with device complexity tended to refer to learning to operate a myoelectric prosthesis.

> *"He did get terribly frustrated with it early on... he could shut it but he struggled to open it."* (Mother of James, 8).

Parents talked about how the movement required to operate a (body-powered or myoelectric) prosthesis is very different to how a hand functions naturally and so has to be practiced in order to become less of a conscious and effortful movement.

> *"I think you have to think quite a lot. I don't think it's natural like when you pick something up with your other hand. I think you have to think about what you're doing and it's quite a slow controlled movement. So I think it is hard to use"* (Mother of Emma, 9).

Parents felt that this could be managed or minimised with appropriate training with an OT incorporating activities that are motivating and meaningful to the child. Some parents had experienced this service at their limb centre, whereas others hadn't, again highlighting a discrepancy in service provision nationally. The quotes below provide an example of both an unsatisfactory and a positive experience of prosthetic training.

> *"Then he had to do all these exercises. Like picking up things from there to there and he didn't really see the point why... it was not really for him"* (Father of Chris, 12).

> *"They gave us lots of explanations of how to use it, things to do with it and how to build up the use of it. Lots of information delivered at James' level for him"* (Mother of James,8).

Another suggestion made by parents was that prostheses are not easy or instinctive for children and young people to use because they are designed from the point of view of technological options rather than based on what they need to achieve and for whom. This supports the supposition that the technological developments of recent years have resulted in prostheses being designed from a technology-driven, and not needs-led, perspective.

> *"They're not intuitive in the way that they work: they're mechanical and they work the way they work because the person who has designed them has started from the perspective of the technology that's available and fitting it into a prosthetic rather than looking at it fresh"* (Mother of Anna, 14).

3.2.2.5 Subtheme five: Available to all

The last subtheme relating to the attributes a prosthesis should have describes the inequality in what is available to different people depending on which NHS service they attend. This refers to the ‘postcode lottery’ within prosthetics services, as highlighted by Murrison (2011), resulting from discrepancies in funding levels across PCTs and a lack of national guidelines for prosthetic provision. The alternative to NHS provision is for parents to fund things privately, resulting in more affluent families being able to access prostheses that are potentially of a higher standard than those available to people through NHS services. An additional factor contributing to inequality of prosthesis prescription was found to be related to the knowledge base of parents and an ability to ask the right questions to obtain what they perceive to be the ‘best’ solution for their child.

Families reported incidences of asking staff at limb centres for particular products (that peers had or that they had seen in the media) and being made aware that these products were not available on the NHS or, at least at their particular limb clinic. There was a general feeling that what is available for private purchase is of a higher standard than what can be obtained on the NHS. There was, however, a suggestion that if you know what to ask for and you ask in the right way you can obtain the prosthesis you want.

> *“We had to ask for it. It wasn’t offered – that’s plainly not their first offer... we’ve got more demanding and discerning as we’ve known more what to ask for”* (Mother of Becky, 8).

This enforces the notion that those most powerful or vocal can obtain a better service than those who are less able to express themselves or less willing to disagree with professionals. Parents also reported privately purchasing items of daily living equipment without being given any professional guidance.

There was also an inherent assumption that some services are better than others:

> *“That was a really good clinic because it was university run and they had lots of funding and they did the Myos, whereas at the NHS hospital it was just the cosmetic ones that they were fitting then.”* (Mother of Gareth, 15).

The best services were, however, deemed to be private services:

> *"It's one of those areas where you have to go private to get what you really want."* Mother of James, 8).

One parent referred to prosthetic provision for children as a *"poor relation"* (Mother of Lauren, 14) in the healthcare system as she perceived funding in this area to be limited when compared to other services. This may reflect the underfunding of low incidence conditions, such as paediatric limb difference, resulting from the poor reporting of statistics in these conditions (McDonnell et al, 1988).

3.2.3 Section summary

Two overarching themes relating to parental experiences of upper limb prostheses for children and young people were identified in the data: 'Accepting your child's 'difference'' and 'What a prosthesis should be'. These themes provide an insight into the impact of having a child with limb difference on parents and factors promoting or inhibiting acceptance and that parents have specific perceptions about particular attributes prostheses should possess. These attributes can be seen to be being met to varying degrees and with varying levels of satisfaction.

3.3 Section three: Professionals' current situation

This section presents the findings from stage five of the study: developing an understanding of the sociocultural world of professional users. Figure 23 shows which element of the BRIDGE process these findings relate to (bold and underlined).

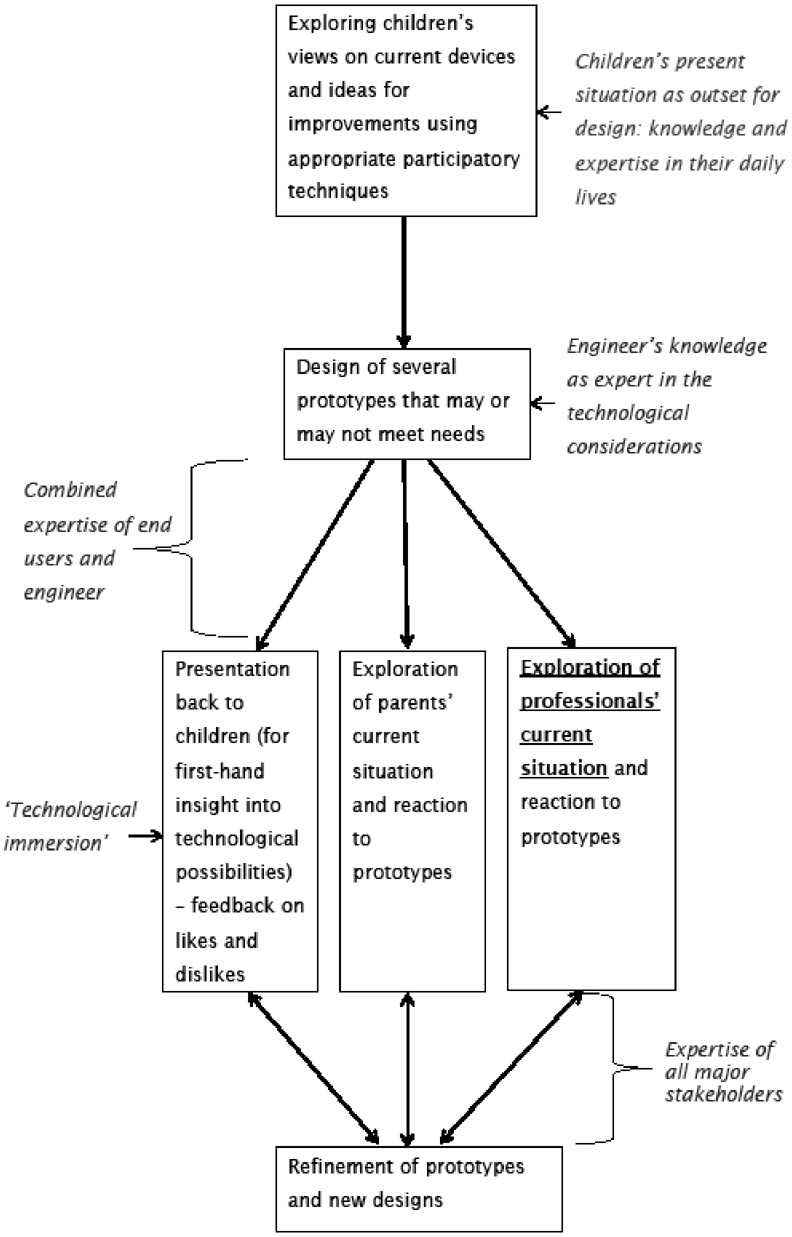

Figure 23: Understanding professional users' current situation as part of the BRIDGE process.

Initial coding resulted in very similar codes being generated from the data from the two professions with a few notable exceptions and subtle differences within how the two professions related to particular topics. The themes will, therefore, be put forward as representing both the prosthetists and OTs. Where, however, something interesting or important was identified regarding differences between the two professions, this will be highlighted within the discussion of the themes.

The data from the two professions highlighted that there are three major factors that are taken into account, and impact on the prescription of upper limb prostheses for children. These are factors relating to the client (child and parents); device-specific factors and institutional and professional factors. These factors will be presented as the three major themes framing the findings.

3.3.1 Theme one: Client factors (parent and child)

As one may expect within a healthcare setting, one of the major things that influenced professionals' use of prosthetic treatment for children with upper limb difference was the children themselves and their parents. Knowledge of clients is fundamental to making appropriate clinical decisions for both professions. OT values interventions that take account of a client's needs, goals, lifestyles and values (Chapparo and Ranka 1997) and professional Standards for Practice for prosthetists stress the need for "inclusion of the service user and their family or carers in treatment planning" (The British Association of Prosthetists and Orthotists, BAPO 2013, p.4).

Furthermore, since the 1960s parents have been regarded as clients, as well as the children themselves, within treatment for childhood disability (McGibbon Lammi and Law 2003). The premise is that any work conducted with families who have a child with special needs should aim to enhance the quality of life for the child and all members of the family (McGibbon Lammi and Law 2003). The ways in which clients influence prescription were seen to separate into two broad categories: the purpose of the device for the client and attributes of the client. Figure 24 shows how the theme is broken down into subthemes and the elements within those subthemes.

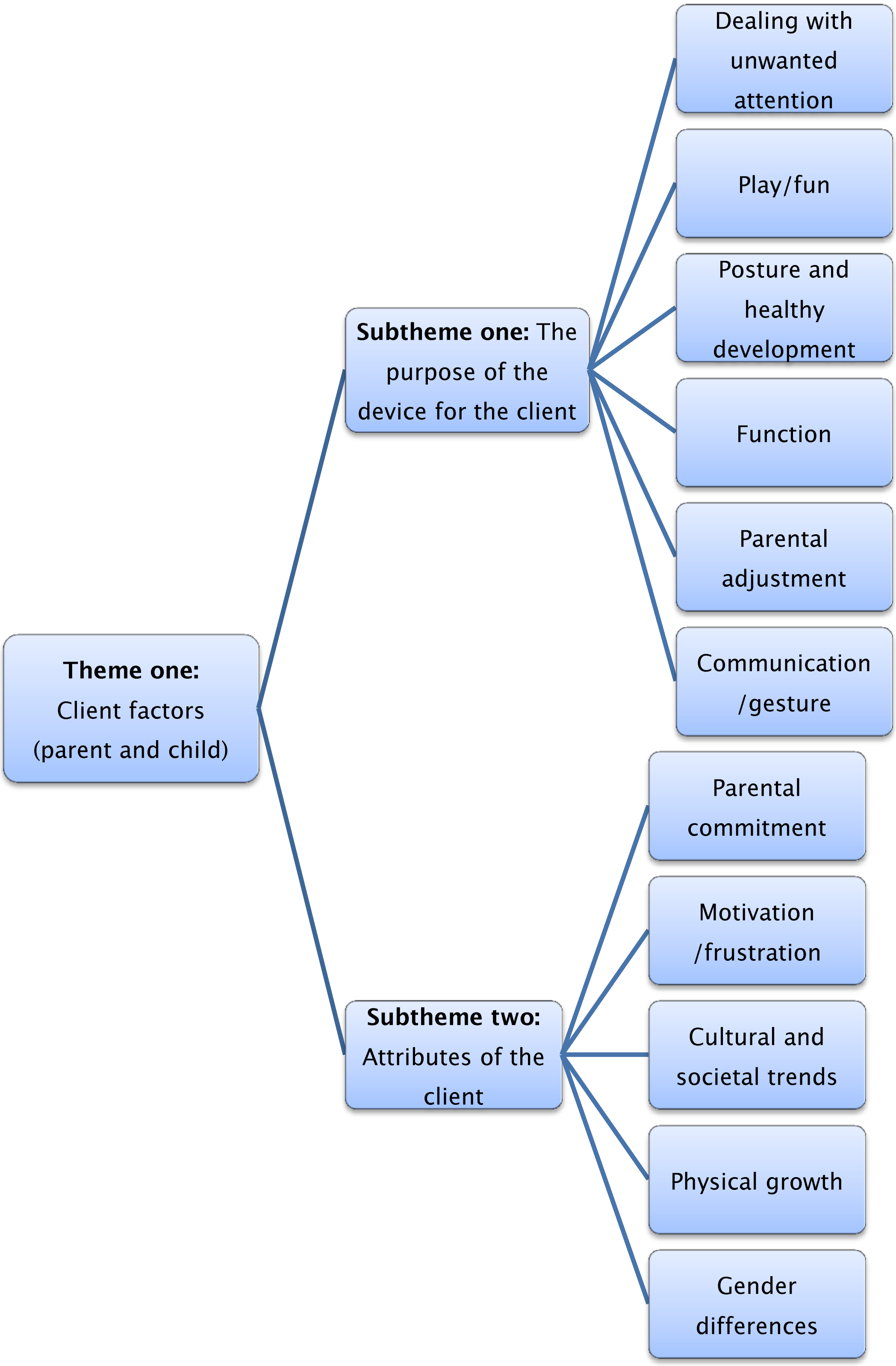

Figure 24: Breakdown of theme one: Client factors.

3.3.1.1 Subtheme one: The purpose of the device for the client

Professionals identified that prostheses may be used by children for a range of purposes, specifically for dealing with unwanted attention, for play/fun, for posture and healthy development, for function, for parents to adjust to the child’s limb difference and for communication/gesture. These uses are largely the same as those identified by the children and parents, suggesting that the professionals who participated in the study have a good understanding of the reasons children and parents would require a prosthesis. For example, all three user groups identified dealing with unwanted attention as a purpose of prostheses:

> *“… all the little kids like stare and I find it quite annoying.”* (Emma, 9)
>
> *“The cosmetic glove he doesn’t really need, it’s just more for the outside world.”* (Mother of James, 8)
>
> *“… they would have a cosmetic one because they get a bit conscious around their peers.”* (P7)

3.3.1.1.1 For dealing with unwanted attention

Similar to the children and parents, professionals expressed a view that prostheses can be used for situations in which strangers will be encountered. It was suggested that a prosthesis can prevent people from asking questions and may give young people confidence. It is interesting to note that, through considering use patterns observed in clinical practice, professionals observed that this is more prevalent during times of transition, such as changing schools or jobs. For example:

> “*They come in at different times like when they’re changing school… when they get to about sixteen they might come back and say I want a dress arm for job interviews or going out with girls or boys or whatever. So for meeting people who don’t know they have limb deficiency.”* (P1).

These clear changes in frequency of use as related to age and transition were described by many of the participants, challenging the use of the term ‘rejection’ to describe a non-wearer of prostheses as it seems evident that use and non-use can be a regularly changing pattern throughout a child or young person’s development. It is widely recognised as a child grows and develops, function, cosmesis, interests, and skill levels change (Patton 2004). Therefore, it seems to follow that a child's need or want for a prosthesis will also change throughout childhood. This, however, does not seem to have permeated in to literature or guidance, in which the terms 'rejection' and 'abandonment' are still widely used.

3.3.1.1.2 For play/fun

Some very brief references were made by professionals to prostheses being viewed as an object of play or fun. These were, however, only fleeting comments made by a couple of participants *("For play as well, for catching a ball."* [OT5]; *"if you can make it like a toy for them in the beginning it can be a strength for them."* [P4]). This suggests that the recognition of prostheses as important for play, fun and practical jokes, as identified by children and young people is, perhaps not considered as important by the professionals. This, however, is understandable considering that play is a child-centric occupation and adults have difficulties in assuming a child's viewpoint. The use of adults as proxy informants on children's lives often produces misleading accounts, and asking children directly often leads to very different responses (Lightfoot & Sloper 2002).

Although play and fun were not necessarily considered to be one of the more important uses for prostheses, they were regarded as important to training in prosthesis use, which will be discussed within theme three: Institutional and professional factors. Furthermore, one participant suggested that prostheses for children could be improved if they were made more fun and playful:

> *"If they were more fun, maybe an element of mix and match so they could change them depending on their mood or what they were wearing, maybe that would enable them to take more ownership over them. Maybe that would help."* (OT 5).

3.3.1.1.3 For posture and healthy development

Professionals talked about prostheses being used to promote natural movement patterns and avoid compensatory movements. Compensatory movements, in conjunction with asymmetrical body shape and weight were seen to be risk factors in developing future pain, muscle contractures and even eventually spinal deformities. Professionals are therefore at times recommending prostheses as a way to encourage healthy development and prevent future health concerns, particularly in the activities of writing and bicycle use. For example:

> *"[Wearing a prosthesis] prevents twisting of the trunk for example if they've got a short residual limb because that can contribute to scoliosis in the future. So a prosthetic just gives them a bit more symmetry in the trunk and in the shoulders. And we also encourage them to wear one if they're cycling because going at fairly high speeds the vibration when they twist the trunk can cause long term issues and we try to prevent any future back pain."* (OT 4).
>
> *"If they don't wear an artificial hand [when writing] then they have to lean right forward putting an extra strain on their shoulder and neck. So it's beneficial functionally and anatomically because it stops you making compensatory movements."* (OT 6).

3.3.1.1.4 For function

All of the professionals, both prosthetists and OTs, described prostheses as being useful for specific activities. Participants described children as managing just as well or better without a prosthesis with regard to general function but reported prostheses being useful as a 'tool' or device for particular tasks, which reflects the views shared by children/young people and parents.

> *"If the arm is not useful to them they don't really use it but if there is a reason to need something like an activity like playing the drums then they want it and its motivating and a positive step."* (P4).

Some of the activities the professionals reported they have found, or would find, prostheses useful for included cycling, rowing, gardening, cutting paper, eating with cutlery, design and technology, playing a musical instrument and using computers.

The children and parents who participated, however, did not seem to reflect that this is the service they are receiving from their limb centre. Considering the professionals' evident insight into the needs and wants of their clients, it seems plausible that this apparent discrepancy may be as a result of the limitations professionals face due to a lack of commercially available devices and the issues surrounding inconsistencies between services. These issues will be discussed later within theme three: institutional and professional factors (section 3.3.3, pp. 172–180).

3.3.1.1.5 For parental adjustment

As explained by the parents, the child's first passive prosthesis can be for the benefit of the parents as opposed to the child. This view was echoed by the professionals who described *"treating the family"* (P 1), not just the child. They talked about the first prosthesis being important for parents to adjust to their child's disability:

> *"When the child is very young the prosthesis can be for the benefit of the parents. Restoration of body-image can help the parents come to terms with* [their child's limb difference]." (P 8).

Professionals explained that some parents had not taken their child out of the home for several months after birth in order to avoid questions and comments. Professionals reflected that providing a passive prosthesis at an early age can minimise the amount of attention received from people in the community enabling families to continue with everyday lives and carry out basic tasks, such as going to the supermarket with their child.

3.3.1.1.6 For gesture/communication:

One additional use for prostheses that was identified by one OT was for use in gesture and communication:

> *"The ability to gesture naturally is a massive missing link… here I am waving my arms about as I am talking to you. So I think we miss that out, for children and adults."* (OT 1).

Considering the relevance of hand use to gesture and communication may be an important, and generally overlooked, function of prostheses.

The first subtheme has described professionals' perceived uses of prostheses for children and young people (and their families). These findings have on the whole complemented the views expressed by the children and parents and appear to corroborate previous research findings. They also highlight, however, that professionals may face a situation in which they are not always able to provide the solution they consider most beneficial as a result of limitations placed on them by both the service and the devices. In addition to the purpose or desired function of a prosthesis for children and families, professionals described how a client's attributes can influence their prescription decisions.

3.3.1.2 Subtheme two: Attributes of the client

Attributes of both children and parents (as influenced by the social and cultural environment) were described by participants as impacting on both the client's decision to use a prosthesis and the professional's decision about what it is appropriate to prescribe. These attributes include parental commitment to a potentially burdensome treatment regime, the child's motivation and frustration, cultural and societal trends, (capacity for) physical growth and gender differences.

3.3.1.2.1 Parental commitment

Professionals talked about the difficulties they have with parents not managing to attend regular appointments and reviews. They recognised that this is likely to result from fairly extensive obligations being placed on parents. These obligations may include being required to encourage their child to use their prosthesis on a day-to-day basis and having to attend numerous reviews and fittings. For example, if using a myoelectric prosthesis, a further substantial commitment to bringing their child to frequent training sessions. This was viewed as being a particular challenge for working parents:

> *"If both parents are working when are they meant to come in for all these reviews and fittings? They also have to commit to a certain number of training sessions, depending on how much training the OT thought they'd need* [and...] *to be very involved and do lots of training with them at home."* (P 6).

In addition to parents having to juggle work and family commitments to attend appointments, professionals were also aware that appointments can result in children missing school, which may deter professionals from issuing myoelectric or custom-made devices:

> *"They don't want to have to be taken out of school too often so to a certain extent you want something that is off the shelf."* (P 1).

Furthermore, in addition to planned appointments which parents are made aware of in advance, professionals reported that prostheses breaking down can lead to additional appointments and an added burden for children and parents:

> *"... the gloves can need replacing quite regularly, which they have to come here for: the guys in the workshop have to do it."* (OT 3).

3.3.1.2.2 Motivation/frustration

Alongside the parents' ability and willingness to commit to a potentially time-consuming treatment regime, professionals recognised that the child's own motivations and ability to cope with frustrations need to be considered when selecting an appropriate prosthesis. Professionals identified that simple, task-specific devices are often most successful for children as having a tangible use, which is meaningful for that child, motivates them to persevere in using the prosthesis to be able to participate in a particular activity and achieve a desired outcome.

> *"Often what we do for children is look at devices or tools, for riding a bicycle, playing the guitar, holding drumsticks is quite a common one. And kids then have the motivation because it's offering them a purpose so then they're much more engaged in using them."* (OT 5).

Motivation (or lack of) was also cited by professionals as a reason why a myoelectric or even body-powered device might not be suitable for a particular child.

> *"Some of the ones that are more functional , so the body-powered and myoelectric prostheses, involve an element of training and learning to use, which the kids don't have that intrinsic motivation to do."* (OT 5).

Furthermore, a child's ability to manage (seemingly inevitable) frustrations when learning to use a myoelectric prosthesis, and their ability to maintain motivation in the face of these, was seen as influencing how successful that device will be for that child.

> "[A myoelectric prosthesis] *can be really frustrating for kids because it's quite slow, especially to start with, but it does get better with practice, but if they're struggling with one of their sites it can be really frustrating if it won't open and close and they can get quite angry with it so it can be an issue."* (OT 3).

3.3.1.2.3 Cultural and societal trends

Professionals recognised the wider social environment as influencing trends in prescription and use of prostheses. Professionals described observing changes in societal attitudes to limb difference during their careers that have affected the need for prostheses. They also discussed media influences having both a positive and negative affect.

Some of the participants who have had long careers within upper limb prosthetics were able to report observations that people's desire for prostheses had reduced over the years. They reflected a feeling that this resulted from changes in society's views of limb difference.

> *"I think it's more acceptable not to have a limb now. Maybe in the past you would feel the need for your child to have something but I think society's different now."* (P3).

This suggests a sociocultural view of disability as the nature, meaning and impact of disability are seen to be influenced by social and cultural trends. Professionals reflected that representations of people with limb difference in the media may have influenced this trend in recent years.

> "*The BBC has had a huge impact and people becoming aware that limb deficiency is just another way of being is interesting. I think the fact that you have cooks on TV with a limb missing, the TV presenter, it all raises public awareness. The TV presenter had a huge impact… now it's just become de rigueur."* (OT 8).

As can be seen from the above quote, media is regarded as having the power to raise public awareness of difference and normalise it. Furthermore, it can also provide children with positive role models, demonstrating that children with limb difference can be successful and achieve just as their typically developing peers can.

> *"I think it was really nice for children to see* [a person with limb difference] *in a presenter's role. She's not wearing anything but she's doing her job just like anyone else. So there are some really positive role models out there."* (OT 3).

The London 2012 Paralympic Games in particular was regarded as having a huge positive impact on children with limb difference, enabling difference to be viewed not as a deficit but as a positive to be celebrated. This resulted in a celebration of limb difference and achievement.

> *"I think the Paralympics has had a huge impact… there seems to be much more pride around being different. Talking to new parents there's sort of a cherishness around it which was different… there is so much more positive attitude towards limb difference being ok than there was previously."* (OT 8).

Media representations of people with limb difference were not, however, always viewed as positive. Professionals described how media reporting about young people using advanced myoelectric prostheses can mislead children and families and raise expectations that cannot be met within an NHS setting.

> *"In this new technological world we've got the internet and magazines and things. Everybody will come wanting something really high-tech, looking more realistic and more robust."* (P4).

> *"The media doesn't always portray the NHS in the best light.*" (OT 4).

3.3.1.2.4 Physical growth

Professionals reflected that an important consideration when issuing prostheses to children and young people is that they are still physically growing and changing, unlike adult users. Practitioners reflected that this has implications for ease of use and comfort of devices as both of these factors can be impacted by the fit of the prosthesis:

> *"Children are always growing and changing so it's hard to get optimal comfort for any length of time because they change so much."* (P 5).

Another issue related to physical growth that impacts on the decision-making of professionals was found to be that the devices can have a shorter duration of use due to the children growing out of them quickly and requiring replacements. This can prevent professionals from feeling able to prescribe the higher end devices, such as myoelectric prostheses or silicone cosmeses, due to the need to consider cost-effectiveness and sensible use of resources.

> *"Children go through them quite quickly. You know if they have a growth spurt they'll need a new socket, a new size hand so it's all got to be taken into account. And the way things are at the moment with*

> *money you just can't afford it on the budgets you're working with."* (P1).

3.3.1.2.5 Gender differences

Professionals reflected on gender differences with regard to what is acceptable aesthetically. General trends were observed with regard to functional 'robotic looking' arms being viewed as more acceptable (by parents) for boys and a drive for cosmetic restoration being more apparent for girls.

> *"With little boys cosmesis is less important. They tend to like the body powered ones and they call it the robot arm. Parents seem to be more accepting of that with boys... I would say that parents try and push towards something cosmetic for girls but with boys they're happier to have something that doesn't look like a hand."* (OT 3).

This seems to suggest the presence of traditional gender-stereotyping when parents are seeking prosthetic treatment for their children. It is argued that parents treat sons and daughters differently from birth, dressing infants in gender-specific colours, encouraging play with gender-specific toys, and expecting different behaviour from boys and girls (Thorne 1993, Burn 1996), encouraging boys to engage in physical play and girls in more sedentary, craft-orientated activities (Gleitman, Friedlund & Reisberg 2000). It may, however, reflect that parents are acting as advocates for their children, as in the current study the only participant who favoured a robotic-looking device was a young male.

The second subtheme has described attributes of children and parents that are viewed by professionals as having an impact on prosthesis prescription. These attributes were seen as being changeable and influenced by cultural and societal trends. The first major theme of Client Factors demonstrates that there is interplay of a large variety of factors relating to the goal the prosthesis is intended to achieve, the child's individual attributes, their family situation and the larger cultural and societal impacts. These many factors, however, represent just one of three influences on prosthesis prescription. The second influence that will be discussed is factors related to the devices themselves.

3.3.2 Theme two: Device factors

Professionals described the different attributes of prostheses and how consideration of these in relation to client factors is necessary when choosing an appropriate device for a child. The device attributes described were weight, durability, movement, comfort, ease of use, appearance and compatibility with the environment of intended use. Many of these attributes overlap with those identified by children and parents as needing to be improved when developing devices. Figure 25 shows a breakdown of this theme into the different device attributes.

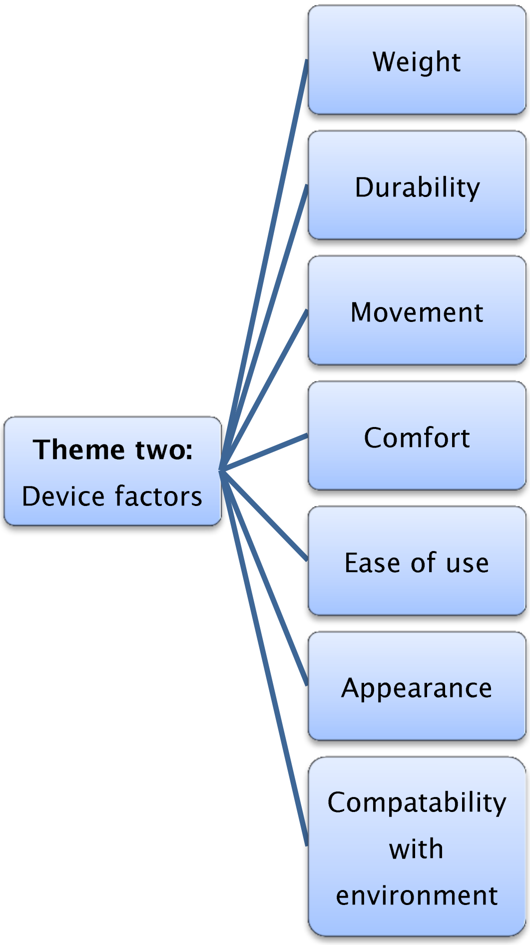

Figure 25: Breakdown of theme two: Device factors.

3.3.2.1 Weight

Correlating with children's and parents' views about prosthesis weight, many of the professionals identified that weight is one of the biggest factors that can prevent a child from using a prosthesis. Participants explained it can lead to a child's arm aching or the child experiencing discomfort and needing to take the prosthesis off to rest. David (10) described having to support his prosthesis with his other hand (see p. 128) and it seems this is not an isolated issue, as professionals also observed this occurring.

> "*If you're having to support the prosthesis with your other hand which you do see some children doing with myos, then it's completely useless.*" (OT 6).

3.3.2.2 Durability

The poor durability of some devices as described by children and parents was corroborated by the professionals who described incidences of myoelectric prostheses breaking down (*"There are problems with the myoelectrics we fit in terms of them breaking or not working properly from the start"* [P 6]) and cosmeses becoming worn (*"The glove sometimes gets stained by things like newspaper print and they can get grubby quite quickly"* [OT 3]). Professionals reported these issues can deter a child from using a device. The reasons for this were seen to be twofold. Firstly, if a device is prone to breaking down this presents an extra treatment burden as it will need to be returned to the limb centre for repair:

> *"It puts people off wearing them because if it's not working then they have to come all the way back in here."* (P 6).

Secondly, a device which may be prone to breaking down is not appealing to a user as they will be reluctant to become dependent on a piece of equipment that may not function reliably for them:

> *"... You have to send it back to someone else to fix. So if you have come to rely on it and it breaks down then you're stuck."* (OT 6).

The impact of the need for repairs on the user was seen to vary between centres, however, as some centres have a workshop on site and are therefore able to carry out same day repairs whereas other have to send the device to another country for repair which, professionals reported, could take three weeks. This difference clearly represents a discrepancy between the levels of service provided in different areas, which will be discussed further within Theme Three: Institutional and Professional Factors (pp. 172-180).

3.3.2.3 Movement

Professionals described movement of prostheses as having the potential to contribute towards both function and cosmesis. The current movement offered by paediatric prostheses was described as being inadequate, particularly in relation to the limited grips and a lack of wrist movement.

> *"I do find when I'm working with a child and I'm trying to get them to pick up something not particularly big they can barely do it with this little grip so it would be nice if there was a bit more flexibility in the grip patterns and more grip patterns."* (OT 7).

> *"If extra function is needed the first bit of extra function I would like to see is wrist manoeuvrability, some sort of wrist flexibility."* (OT 1).

Wrist movement was reported as being both important for function and for creating a more natural aesthetic.

> *"It is incredibly awkward when someone's trying to pick something up and they're in a fixed position and their whole shoulder is up here. I'd love to see some wrist flexion and extension."* (OT 7).

> *"Wrist movement, and flow and being able to rest your hand in your lap and for it to conform would make all the difference."* (OT 8).

The majority of participants felt they would like wrist flexion and extension to be provided in paediatric prostheses as well as more grip options. One prosthetist, however, disagreed that more movement is necessary.

> *"I don't think they need more wrist movement. Only a double amputee would need wrist rotation. They might want different grip patterns but they don't need it… The more complicated it is, the less reliable it is though. I think it's something people imagine they would like but the reality is it's not that much more useful. I'm not a great believer in the need for grips. You just need the prosthetic to hold and support things because you can do everything else with your other hand."* (P 7).

Whilst this view was generally not shared by the other participants, the view that adding movement could result in increased device complexity, and therefore reduced reliability, was echoed by others.

3.3.2.4 Comfort

The issues described by professionals with regard to prosthesis comfort mirrored those expressed by the children and parents. Professionals reported issues with sockets being hot and sweaty and also with strap discomfort with body-powered prostheses. One professional provided an analogy to explain what the discomfort of wearing an upper limb prosthesis is like for wearers.

> *"It's like wearing a pair of really hard walking boots with no socks."* (OT 6).

Some elements of discomfort and heat were considered unavoidable due to the nature of how prostheses are fit (close to the skin) and the continual changing needs of children as a result of growth. It was felt, however, that it may be possible to address harness discomfort by exploring different ways of operating and/or suspending mechanical prostheses.

> *"If there was any way arms could be suspended in a different way... that would be amazing and I think having p-loops and suspension straps and things they just get in the way when you're a kid and they're not very comfortable"* (OT 5).

3.3.2.5 Ease of use

Professionals described how devices that are simple to operate are more successful, particularly with younger children. It was reported that body-powered and myoelectric prostheses can be difficult to use, both physically and cognitively, and that this can discourage a child from using a prosthesis. This cognitive challenge was identified as not being conducive to the way children behave in their everyday lives.

> *"There's a huge amount of high level thinking required to position it in the right place. Children are spontaneous. They just want to do stuff and get on with it."* (OT 8).

This need for a simplistic and naturalistic use of devices was found to challenge the desire for additional movement, with professionals reflecting that it is important to strike the right balance between the two.

> *"I reckon it would be nice to have the option of a few different grips that can be programmed but not too many because if you start adding too many grips it will become more complicated for using..."* (P 2).

3.3.2.6 Appearance

The professionals expressed dissatisfaction with the appearance of prostheses, as did the children and parents, particularly with regard to matching the shape and colour to the child's own skin tone.

> *"Glove colours can be quite restrictive because in different temperatures your hand can change colours so gloves can be quite difficult to get the right colour." (P2)*

> *"The hand sizes, there's only a couple of options, so if you're in between sizes there can be quite a difference between* [the prosthesis] *and your other hand."* (OT 3).

Professionals reflected that this issue was partly due to only having PVC cosmeses available for issue to children due to the difficulties with the cost and durability of custom-made silicone cosmeses. Some professionals, however, identified that it is not necessarily the aesthetics of the device that renders it attractive (or otherwise) in appearance, but that having a device which moves naturally, and which enables the user to move naturally when wearing it, can influence how realistic it appears to be.

> *"Some of the off-the-shelf high spec gloves can look really good but they don't look real because they're not animated."* (OT 8).

Some professionals felt that aiming for realism was an unachievable goal and that, particularly with task specific devices, getting the child involved in designing something that they consider to look attractive can be a successful approach.

> *"We will ask them to bring in some material that they like so we can interface the fabric on to the device. It's about giving the child ownership so they can take pride in what they're wearing. I think appearance is a big thing. If a child doesn't like what it looks like then they won't wear it."* (OT 4).

3.3.2.7 Compatibility with the environment

In addition to the aforementioned device attributes, some participants also identified that it is important to consider not only what a child hopes to achieve with a prosthesis but where they hope to use it. Professionals described children as wanting to use prostheses for play, which could inevitably involve them being less careful with their prostheses and getting them wet: two things which could result in a myoelectric device becoming broken. Some professionals reflected that playing in these ways is a part of childhood development and that if a device cannot be used in the settings for which a child requires it, then the device is not suitable for purpose.

> *"What we said about children and their job is to play. You can't say 'ooh don't do that you're wearing this one'."* (OT 1).

The difficulties in using prostheses for play were discussed more by the OTs than the prosthetists. This is perhaps unsurprising considering that understanding "the need to identify and assess... environmental needs" is part of the Heath and Care Professions Council's (2013) Standards of Proficiency for OTs. What may be surprising, however, is that some OTs described how they educate the children they work with about how delicate their prosthesis is and the need to be careful with it. This may suggest a more medicalised view in which the child is required to adapt themselves to the environment or equipment.

> *"... we make it very clear to the child that they have to look after it. You have to keep it in your bag and put it away."* (OT 4).

Theme two has presented the device-related attributes that professionals consider when issuing prostheses to children. It has highlighted the challenges professionals face as a result of the evident dissatisfaction with many of these attributes. These complement the dissatisfaction parents and children have expressed, with clinicians identifying an additional consideration of, and dissatisfaction with, the device's compatibility with the environments of childhood.

3.3.3 Theme three: Institutional and professional factors

The third area affecting prosthesis prescription for children and young people discussed by the participants related to the setting in which they work, their own professional skills and experience and those of the team they work with. The participants discussed institutional factors that can create additional challenges in upper limb prosthetics for children and shared some creative ways in which these challenges are being, or could be, addressed. The institutional and professional factors discussed represented three broad areas:

involving clients, financial considerations and the (skills and experience of the) multidisciplinary team. Figure 26 shows a breakdown of this theme.

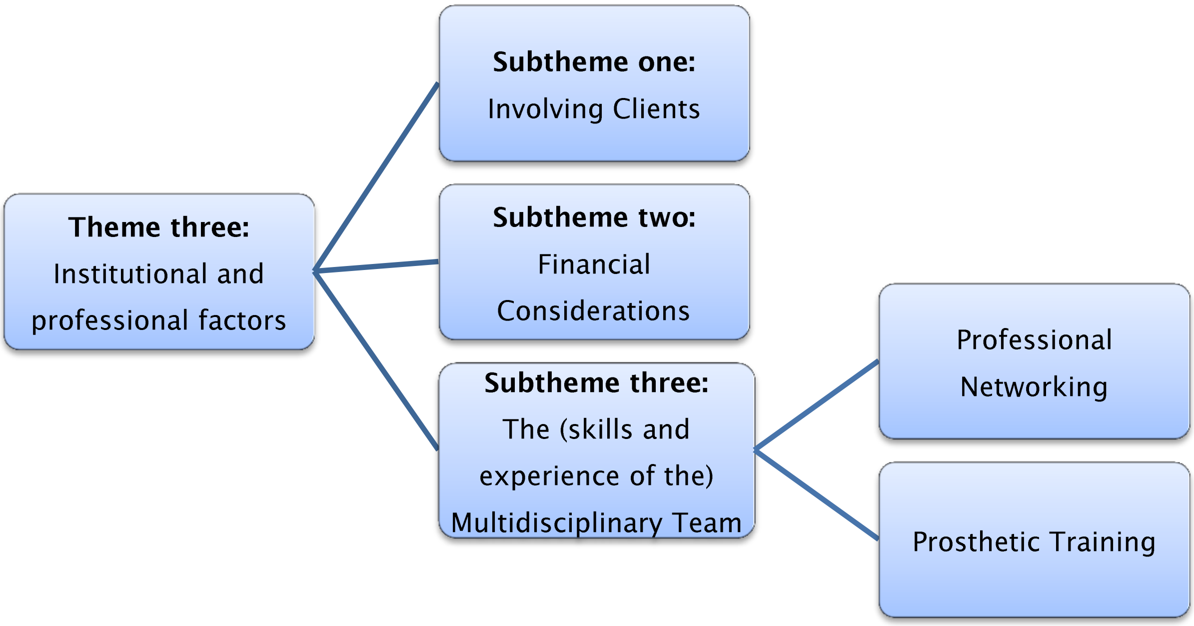

Figure 26: Breakdown of theme three: Institutional and professional factors.

3.3.3.1 Subtheme one: Involving clients

Participants shared the view that it is important to try and involve children and parents as much as possible throughout the process. This appears to be based on the opinion that involving children in choosing a prosthesis enables them to take more ownership of the device and, therefore, be more receptive to it. Some participants talked about 'trying' to offer choice but finding it difficult due to the limitations of the devices available. Centres in which it is possible to offer custom-made devices reflected that this provided an opportunity to involve children in prosthesis design.

> *"We try to customise things... and include colours and designs that the children want, at least in the laminate appliances, we can integrate a favourite character or fabric. Because then they're more involved in the process of choosing, especially if they're new to prostheses, then they're more receptive to it.."* (P 8).

Some centres were also able to use prototyping techniques as a way of involving children in the design of their prosthetic device.

> *"We do a lot of prototype stuff so...[you] can make the prototype and bring them in and that's when the child can have their own design and the parent can have a say too."* (OT 4).

Custom-made devices and prototyping techniques are, however, limited to the centres that have both sufficient funding and onsite technical expertise to be able to carry this out. Some centres do not have this provision and are therefore only able to offer 'off-the-shelf' devices. This limits the opportunities for child and family involvement in these settings. An additional way participants described enabling clients to make choices was by providing literature regarding prostheses. This reflects the provision of information in more than one format which is positive for encouraging informed decision-making.

> *"Here we use a sheet that has disadvantages and advantages of different prostheses so you can show them the arm and explain what it will provide and what it involves so they can make an informed choice."* (OT 2).

However, a lot of this information seemed to be more aimed at parents: it may be beneficial for centres to consider provision of child-tailored information leaflets to improve clinician-child communication and enable children's involvement in decisions.

Subtheme one has presented the view that it is important to try and involve children and parents as much as possible throughout the process of prosthesis prescription. Professionals appear to believe that involving clients leads to feelings of ownership and, subsequently, reduces non-use of devices. The extent to which choice is, or can be, offered varies between services, depending on what devices are available at each particular centre and whether there is the facility to custom-make devices.

3.3.3.2 Subtheme two: Financial considerations

The second subtheme is concerned with the available finances at the different centres. This has implications not only for the devices a centre is able to purchase, but also the staff team that are employed and the use of particular aids to prescription, such as prototyping and trial equipment. The differences observed in the current study ranged from a centre being limited to providing only either a passive limb or a body-powered device, to centres that are able to provide clients with myoelectrics, silicone cosmeses and custom-made devices. These differences are in part due to the funding available to buy particular pieces of equipment.

> *“A certain company does provide a lot of myoelectric limbs, but they’re horrifically expensive, we don’t use [myoelectric prostheses] at all at this centre.”* (P 3).

> *“We have a big budget for silicone but at other centres they have nothing so it’s not fair. It’s a postcode lottery.”* (P 7).

However, funding issues also influence which staff are employed at the centre. Some of the participants described being *“lucky”* to have several OTs employed in their service. Others do not have an OT available to them at all and cited this as a reason that myoelectric provision does not occur due to there being no therapy available to train people to use the devices in everyday activities.

Additional options that well-funded services described having were the use of trial prostheses when deciding whether to provide myoelectric devices and the facility to recycle myoelectric prostheses (due to having the technical expertise available for refurbishment).

> *“We also have some trial arms sitting around here so although the prosthetist still has to measure and cast for it he can just trial it with them.”* (OT 7).

> *“With myoelectrics we can reissue and recycle parts.”* (P 7).

For many centres, trial arms and reissuing equipment are simply not an option currently available to them. Many of the professional participants reflected that if they were able to have trial arms they would feel more confident in knowing if a myoelectric was suitable for particular clients. Furthermore, knowing that there would not be a possibility to recycle or reissue a myoelectric if a client no longer wanted to use it also deterred professionals from prescribing them at times.

> *"If we prescribe a myoelectric limb to someone and they don't use it then we have to chuck it. We can't use that hand for somebody else."* (P6).

These differences between services have clear and potentially significant impacts for children and young people: those living in one geographical area may have many options for meeting their prosthetic needs, whereas those in another area could be limited in their ability to participate fully in daily activities as a result of a lack of devices available to them.

Subtheme two has described the impact of financial issues on prosthesis prescription and the impact this has both on devices available and access to staff. The options available to different services as a result of funding levels appears to vary significantly from some centres only providing either a passive prosthesis or a body-powered device to others that can provide high-cost silicone cosmeses.

3.3.3.3 Subtheme three: The (skills and experience of the) multidisciplinary team

As described in subtheme two, the multidisciplinarity of the team varies between centres as a result of funding issues. Participants reflected that the skills and experience of the professionals have a substantial impact on prosthesis prescription. Some specific factors relating to this were also discussed, specifically professional networking and provision of prosthetic training to clients.

Participants shared the notion that a multidisciplinary team that works well together is highly valued in this setting. Professionals that were talked about as adding particular value to the team were prosthetists experienced in upper limb, OTs (for providing training), nurses (for skin care), technicians, engineers and psychologists. It was felt that not having access to any one particular discipline could result in certain aspects of care not being available to a client. For example, nursing staff were reported to be helpful when a client is experiencing sweating or discomfort with their prosthesis as they can advise on specialist creams to alleviate symptoms. Technicians and engineers were found to be essential for producing custom-made devices, for safety testing these devices and for repairing devices with the minimum upheaval for families. Psychologists were reported as being included when presenting a case for a silicone cosmesis for a young person (for self-esteem and confidence issues). OTs were, several times, reported to be essential in the prescription of myoelectric devices in order to train the client in using the device in everyday occupations.

> *"We don't provide [myoelectric prostheses] currently for children as we haven't got an OT at the moment. OT's are pretty essential if you're going to have successful myoelectric use."* (P 3).

The subject of prosthetic training was talked about at great length by professional participants and will, therefore, be discussed in further detail in section 3.3.3.3.1 (pp.177-180).

In addition to having a multidisciplinary staff team, professional participants expressed the view that the motivation, commitment and ability of the team to work together as equals are important to good client care. Some participants, however, reflected that although this may be the ideal way of working, a hierarchical structure still exists in some centres whereby the consultant, as the person responsible for the finances, makes the decisions about what will ultimately be prescribed.

> *"It's a team decision ideally… well ultimately it's down to the consultant… but yeah we will meet as a team and decide if it's appropriate… ideally it would be a team decision, it doesn't always happen that way but that's what we would like."* (OT 7).

3.3.3.3.1 Prosthetic training

One of the most talked about areas with regard to the multidisciplinary team was the need for OT in relation to the provision of training for myoelectric prostheses. This may be unsurprising considering nine of the participants were OTs and, had counsellors or psychologists participated in the study, the need for psychological support may have been more widely discussed. However, the prosthetists who participated in the study also expressed the view that OTs are essential in the provision of myoelectrics, with centres without an OT being unable to issue myoelectric prostheses.

Training with an OT was seen to be important both before and after issuing a myoelectric prosthesis. Before issuing a myoelectric prosthesis, training with an OT was seen to be important for determining whether the device will actually be suitable for the child and if the child will be able to use it successfully.

> *“Good solid training reduces the amount of rejection. Training... before getting the myo – to make sure that the sites are exactly right for the muscles and also for the person’s understanding - for how to use the muscles for the Myo.”* (OT 1).

Training before issuing the device was also viewed as a way of managing the child’s expectations about what the device is able to do and what it will be useful for. Training was also considered to be important after the myoelectric prosthesis has been issued.

> *“If a child has to think about using it, it’s not going to be natural so for it to be natural a child needs really intensive training.”* (P 3).

Prosthetists may also be able to train clients in myoelectric prosthesis use, as part of their role is to “instruct the service user […] in the use and care of the device” (BAPO 2013, p. 5). However, OTs were identified by participants as the most appropriate professionals to carry out this training due to their specialist skills in analysing an activity and grading it appropriately for a client, incorporating prosthesis use into everyday occupations and engaging and motivating the child by making prosthesis use fun.

> *“You want to look at incorporating it into bimanual activities and applying it to the things they do”* (OT 5).
>
> *“There’s a whole session here with the OT to practice... playing games to keep them interested”* (P 2).
>
> *“And they needed to be motivated, which is difficult with a 3 year old. An OT will make it fun”* (P 3).

However, despite the clear value of training when using myoelectrics, the level of training provided by centres was found to vary from those able to provide several sessions both in clinic and in school to those unable to provide any training at all. The participants explained that they have been working on a training protocol so that all centres can offer an equitable service in terms of myoelectric training. Those without an OT on their staff team will still, however, be unable to provide this. In addition to a protocol enabling a more equitable service, it could also be used as a tool for explaining the process to children and parents prior to issuing the device to ensure they are aware of what is required from them. This may be helpful as participants explained that having a myoelectric prosthesis requires a significant commitment to training that clients do not always adhere to.

> *"We like them to have a commitment to come in and do some training with us… we would want the parents to commit to get the prosthesis..."* (OT 7).

This commitment was felt to be essential for ensuring children are given the best opportunity to succeed with their prosthesis, as issuing a myoelectric which is not suitable for the child was seen as being potentially detrimental.

> *"If you don't give them the training and then they fail I think psychologically you can set them back and then they won't want to try again. But maybe it's not their fault and we didn't support them enough."* (OT 4).

3.3.3.3.2 Professional networking

Professional participants explained a need for them to keep up-to-date with the products that are available and networking with other colleagues was viewed as a valuable way of doing this. Participants explained that to some degree successful prosthesis prescription *"requires the prosthetist to know what products are in existence and to suggest them"* (OT 6).

It was suggested that a way of doing this would be to create a database for professionals so that they can share information and ideas easily, preventing professionals from spending time *"redesigning the same things if someone else has already done it"* (P 8). Participants felt, however, that whilst theoretically this would be a valuable resource, it would be dependent on professionals inputting information into it and being willing to seek advice and assistance from other colleagues, which may pose a challenge to their professional self-esteem. Subtheme three has described the importance of the skills and experience of the multidisciplinary team in achieving successful prosthesis prescription with children. The particular importance of professional networking and prosthetic training in relation to this were presented.

Theme three has presented the issues relating to both professional skills and experience and the workplace environment that impact on professionals' use of prostheses with children. It has highlighted the importance of involving clients in treatment decisions, the difficulties that professionals face as a result of inequity of funding and the value of multidisciplinary teamwork.

3.3.4 Section summary

Professional use of prostheses is affected by three over-arching factors: the client (both their needs and wants and individual attributes), the device, and the professional and institutional environment. This may reflect theories of clinical reasoning, as described by Schell and Schell (2007), suggesting that clinical decisions are impacted by both client-related factors (diagnostic or narrative reasoning) and the practicalities of time, money, equipment, skills, management and the institutional environment (pragmatic reasoning).

Issues related to pragmatic reasoning, such as the availability of equipment and the expertise of the team, can facilitate or hinder professionals in their use of prostheses. Furthermore, the prevalence and impact of these issues varies between centres.

3.4 Section four: Expertise of all major stakeholders

The following section will present findings relating to all three user groups. The section will be divided in to two parts: to begin with those subthemes which are distinct to a particular user group will be presented alongside the implication of this subtheme and what impact this should have on paediatric prosthetics (see tables 9 – 11). Miettinen & Hasu (2002) propose that these distinctions or conflicts are an inevitable product of exploring the motives, world views and expertise of different actors. A neglect to consider these distinctions would, Miettinen & Hasu (2002) argue, suggest that historical and cultural influences on a user's relationship with an artefact have not been considered. Consideration of these influences is essential to conducting research through a transformative lens.

Following this, a brief description of, and justification for, the prototypes developed will be presented, including feedback on each of the prototypes from all three user groups. The section will conclude by drawing together the feedback into the general themes that are apparent throughout. Figure 27 below shows the stages in the BRIDGE process that the succeeding findings relate to (bold and underlined).

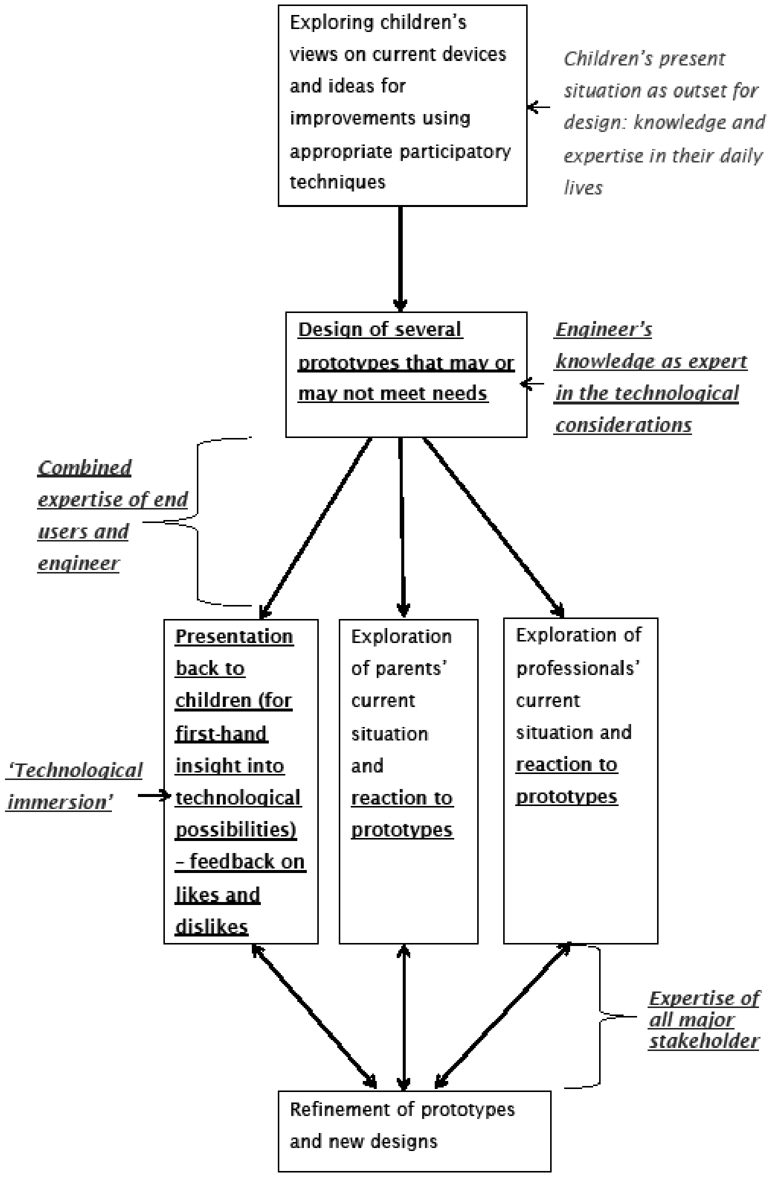

Figure 27: Understanding the expertise of all major stakeholders as part of the BRIDGE process.

3.4.1 Distinct subthemes

The following section presents (in tables 9 – 11) the subthemes which are distinct to each user group. The implications of these distinctions and the potential impact of them are also presented.

Distinct Subtheme	**Implication**	**Impact**
Manage without The way I am	Prosthetic management is not always the best or desired treatment for children.	A move away from prostheses as a necessity – specific tools and activity adaptation may be more acceptable and desirable to clients.

Table 9: Distinct subthemes, implications and impacts from children's data

Distinct Subtheme	**Implication**	**Impact**
Safety	As those ultimately responsible for their child's health and well-being, it is understandable that safety is important to parents.	Any devices developed must be risk assessed: this may create difficulty when custom-making devices.
Grief and guilt	Parents may be experiencing these emotions when attending the limb centre, which could impact on the decisions they make regarding treatment.	Psychosocial support for parents may help them make informed treatment choices.
Doing your best	When choosing prosthetic devices parents feel it is important to them to have 'done their best' for their child.	Professionals should be aware, and accept, that managing client expectations could be made more difficult by this perception of a prosthesis as a way for a parent to do their best for their child.

Table 10: Distinct subthemes, implications and impacts from parents' data.

Distinct Subtheme	**Implication**	**Impact**
Prosthesis for communication	Identification of this subtheme may result from attendance at conferences or academic study May not actually be a required function.	Emphasis to be placed on the functions of prostheses shared by all three user groups (for dealing with unwanted attention, for function, for fun/humour).
Environmental compatibility	May represent that it is the role of professionals (not lay or end users) to match the device to the environment/use.	Prostheses should be suitable for use in child-centred occupations.
Gender differences	Perceived bias regarding which devices are used by boys and girls.	Gender neutral devices would be more open to recycling.
Growth	Due to growth, costly prostheses cannot be prescribed (within NHS budgets).	Modular devices that can be adjusted with growth may help to reduce cost implications.
Parental commitment and children's motivation	Implication that children and parents cannot commit to long training regimes for myoelectric devices.	More flexibility is needed in services – OTs are essential in order to tailor training sessions to children's volitions.
MDT	A multidisciplinary approach is required (but not always present) for providing a satisfactory service.	There should be core staffing requirements that apply to all limb centres so that equitable services can be accessed across the country. The core staff should include OT and psychological therapies.

Table 11: Distinct subthemes, implications and impacts from professionals' data.

3.4.2 Prototypes developed and responses to them

Prototypes were developed based on the findings from the stage one research with children and young people. The prototypes were developed using 3-

dimensional (3D) printing, which is a form of Rapid Prototyping Technology (RPT). RPT provides a means of quickly producing solid, 3D prototypes. 3D printing is a cost effective method of this based on ink-jet technology, where a 3D structure is built up, layer by layer, in 2-dimensional slices. This enables a complete prototype to be created in one printing process.

Six task-specific terminal devices were designed and fabricated by Dr Andy Cranny, Senior Research Fellow and the project's engineer. For the purposes of the current project, the focus was on the terminal devices themselves (as opposed to sockets). An adjustable wrist unit was also designed that would support each of these devices. See figure 28 for photographs of the prototypes.

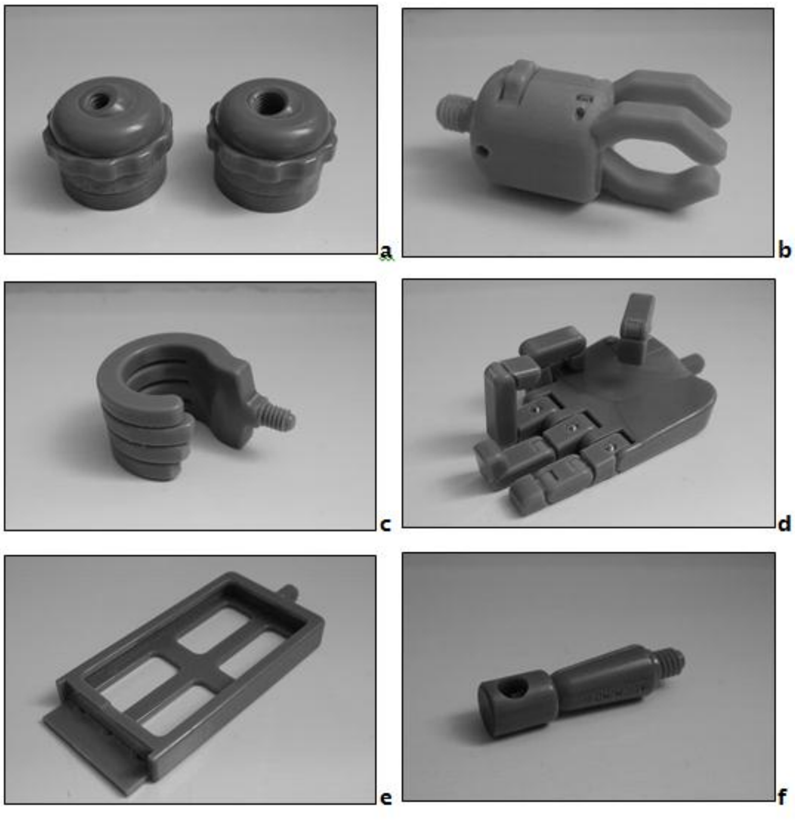

Figure 28: Prototype devices developed from children's input (a=adjustable wrist unit; b=adjustable gripper; c=cycling appliance; d=jointed hand; e=Smartphone holder; f=pen holder).

The following section provides information about the devices developed, with reference made to data from section 3.1 (pp. 113-128) to demonstrate the engineer's use of the child's expertise in the design. Responses to the prototypes are presented following a description of the device. Tables are used to demonstrate which user group(s) expressed the views.

3.4.2.1 **Adjustable wrist unit** (figure 28, photograph a)

Improved wrist rotation was identified as a desired development for a child's prosthetic hand.

> *"I think if…the wrist…bends any way you want quite easily, that'd be quite good as well…because sometimes that restricts quite a bit of movement."* (Gareth, 15).

This was the motivation for the design of an adjustable wrist unit. Furthermore, designing it to work within a modular system provides choice concerning the use of task-specific devices, which corresponds with previous research that has found that children require a range of prosthetic options to enable them to select the appropriate tool for the task and environment (Crandall & Tomhave 2002; Buffart et al 2007; Wagner et al 2007; Egermann et al 2009). Modularity also takes into consideration the impact of growth (see table 11).

The adjustable wrist unit, based on the ball and socket joint, comprises a fully rotatable and lockable wrist unit that supports a range of functional devices (see Figure 28). The device consists of three parts: the wrist mount, the rotation ball and the friction cup. When the friction cup is screwed down over the wrist mount, the rotation ball becomes sandwiched firmly between the wrist mount and the inner surface of the friction cup, locking it securely in place. Unscrewing the friction cup slightly allows the rotation ball to be freely rotated in all axes. A ridged ring around the perimeter of the friction cup makes it easier to grip with the unaffected hand when loosening and tightening. Table 12 identifies both the positive feedback about the device and the drawbacks or areas for improvement identified by participants.

Positives	
More than one user group	• Realistic movement • good angulation/rotation • easy to use
Parents	• secure
OTs	• robust
Areas for Development	
More than one user group	• Difficult to use • not spontaneous
Both Professions	• heavy
Prosthetists	• Cumbersome • May not be durable
OTs	• Unnatural shape • Does not yield/conform

Table 12: Responses to adjustable wrist unit.

The children and young people valued the movement that the wrist device offered. Whilst weight, size and shape were identified as potentially problematic by the professionals these were not attributes that concerned the children and young people.

3.4.2.2 Task-specific terminal devices

A number of task-specific terminal devices were designed to address some of the issues identified by the children that are not available in current commercial devices.

3.4.2.3 **Adjustable gripper** (figure 28, photograph b)

Children acknowledged the need for a gripper-type hand for dexterous tasks, but commented that available devices were uncomfortable and cumbersome.

> *"I've always found those round the shoulder ones too hard to use because…it's really itchy against your skin and it's horrible."* (Chris, 12).

> *"I find [a body-powered prosthesis] is not really practical for anything because you have to put a lot of strength in to open it fully. And sometimes you just can't."* (David, 10).

An adjustable gripper was designed and fabricated to incorporate a moveable digit rotating between two fixed digits. The device is operated with the unaffected hand using the ridged thumb wheel. The device provides a locked and secure grip between the adjustable and fixed digits. An alternative gripper device, operated by a spring mechanism (instead of a wheel) was also designed and fabricated. Table 13 identifies both the positive feedback about the dial-operated adjustable gripper and the drawbacks or areas for improvement identified by participants.

Positives	
More than one user group	• could be useful for particular activities (playing instruments, woodwork) • strong grip
Children	• could be a 'back up' prosthesis for when main one is being repaired
Both Professionals	• easy to use
OTs	• no straps • good control for user
Areas for Development	
More than one user group	• slow • heavy • not cosmetic in appearance • difficult to operate
Children	• tiring to operate
Both Professionals	• requires operation with other hand
Prosthetists	• May not be durable • No direct opposition between thumb and fingers
OTs	• cumbersome • not spontaneous

Table 13: Responses to dial-operated adjustable gripper.

The children and young people identified that this device could be useful as a substitute prosthesis if their primary device was being altered/repaired. This demonstrates that being without a device has an impact on the children and young people. Prosthetists were concerned that the grip it offered may be limited, but children were able to recognise it could have value in certain activities (such as, carrying items and holding instruments).

Table 14 identifies both the positive feedback about the spring-loaded adjustable gripper and the drawbacks or areas for improvement identified by participants.

Positives	
More than one user group	• quick and easy to use
Parents	• could be useful in specific activities (e.g. in the kitchen)
OTs	• more cosmetic than a hook • can conform to different size/shape objects • Can be used without a harness
Areas for Development	
More than one user group	• May not be durable
Both Professionals	• cumbersome • requires use of other hand • not a secure grip
Prosthetists	• fingers and thumb not in direct opposition • heavy
OTs	• not spontaneous/intuitive to use

Table 14: Responses to spring-loaded adjustable gripper.

All user groups agreed that this device would be easier to use than the dial-operated adjustable gripper.

3.4.2.4 **Cycling appliance** (figure 28, photograph c)

A recurring comment from children was that a prosthesis is essential for riding a bicycle. Whilst some participants had success with their cycling prostheses others had not yet found a successful device. This discrepancy is possibly as a result of the variance between centres in their ability to custom-make devices. This motivated the design of a simple cycling appliance, which is a handlebar attachment shaped like a curled hand. The diameter of the inner grip can be redesigned using RPT to match the diameters of a range of handlebars. Table

15 identifies both the positive feedback about the device and the drawbacks or areas for improvement identified by participants.

Positives	
More than one user group	• Useful as lots of children need something to help with this activity • quick and easy to use
Parents	• Brings children up to the right height on the affected side – good for posture
Both Professionals	• Gives good range of movement when used with wrist device
Prosthetists	• lightweight • looks fun
OTs	• Good curved shape • could come in a range of colours to match different bicycles
Areas for Development	
More than one user group	• No quick release mechanism – not safe
Prosthetists	• too big
OTs	• not spontaneous • not cosmetic in appearance

Table 15: Responses to cycling appliance.

All user groups agreed that a device for cycling would be very useful as it is a common activity for children with limb difference to have difficulties with. However, all were concerned about the lack of a quick-release mechanism and the risk this could present. OTs felt the device did not look attractive. The children and young people, however, were not concerned as, due to its task-specificity, they would not be using it for cosmetic reasons.

3.4.2.5 **Jointed hand** (figure 28, photograph d)

A jointed hand was developed based on the comments of children and young people that currently available passive prostheses do not have realistic movement. The hand was designed based on Snyder et al’s (1975) dimensions for an average 8-year old male child, as these were the most recent published dimensions available to the engineer at the time. The hand includes independent movement of all the fingers and thumb. This hand was designed as a conceptual piece to promote discussion among the children during follow-up sessions, demonstrating the introduction of technical expertise which may challenge children's current thoughts about the possibilities for developing prosthetic devices. Through further design it would be possible to automate finger and thumb movement as either a body-powered or myoelectric device. Table 16 identifies both the positive feedback about the device and the drawbacks or areas for improvement identified by participants.

Positives	
More than one user group	• gives natural movement
Both Professionals	• could be used to gesture • tactile • fun and playful
OTs	• May be able to hold objects – combining cosmesis and function
Areas for Development	
More than one user group	• too square – not cosmetic in appearance • may not be durable (because of all the joints) • the movement of the thumb is unnatural
Both Professionals	• joints are too loose
Prosthetists	• not enough opposition between the thumb and fingers

Table 16: Responses to the jointed hand.

All user groups enjoyed the fluid movement that this device offered but were concerned that it should have softer, rounder edges to improve the appearance.

3.4.2.6 **Smartphone holder/technology use** (figure 28, photograph e)

Children identified difficulties in using technology such as keyboards and games consoles.

> *"I play loads of video games that require two hands and I can't play them which is really annoying because most of them are good."* (David, 10).

Although the participants did not directly discuss Smartphone use, this was the motivation for designing a Smartphone holder. In this instance the engineer contributed his own understanding of developing technologies to the children's current situation. The engineer identified that using Smartphones could pose a difficulty for young people with unilateral limb difference as a prosthetic hand would not be tactile enough to operate a touch screen device. However, neither would it be able to hold a device securely or comfortably over long periods of time. A Smartphone holder was designed to support an iPhone4/4S, but using RPT these dimensions could be quickly changed to produce new versions for any mobile phone, tablet or multimedia device. The phone slots into the holder and is secured by closing the hinged lid at the top. Table 17 identifies both the positive feedback about the device and the drawbacks or areas for improvement identified by participants.

Positives	
More than one user group	• Holds the phone securely • cool/gimmick • could benefit adult users (who use their phone a lot)
OTs	• allows other hand to access touchscreen
Areas for Development	
More than one user group	• unnecessary – children will manage without • too much hassle to don and doff • could attract attention
Prosthetists	• needs to come in a range of sizes (for different phones) • fittings are not strong enough • heavy

Table 17: Responses to Smartphone holder.

Some of the children and young people felt they would use a device to hold their Smartphone as they currently felt nervous about dropping it and breaking it. Others, however, felt that they managed to use their phone without a device, having developed their own strategies (such as, placing their phone on a table to type).

3.4.2.7 **Pen holder** (figure 28, photograph f)

This device was designed in response to the children and young people expressing difficulty with holding a writing implement and desiring a prosthesis to aid with writing tasks.

> *"What would be really, really magic would be if [a prosthesis] could write..."* (Emma, 8).

A two-part holder was designed consisting of a tapered tubular body, threaded at each end, and an adjustable clamp. The adjustable clamp has a hole to support a pen or other writing device up to a maximum external diameter of 10mm which, when screwed down onto the body of the holder, clamps the writing implement securely in place. Table 18 identifies both the positive feedback about the device and the drawbacks or areas for improvement identified by participants.

Positives	
More than one user group	• Could benefit bilateral amputees • could have multiple uses
Both Professionals	• easy to use
OTs	• good to have an off-the-shelf solution good for posture - enables child to sit more upright
Areas for Development	
More than one user group	• Requires the use of gross compensatory movements (shoulder and elbow) - could lead to strain • not cosmetic in appearance
Parents	• the activity would be easier without
Both Professionals	• Too far from body - lack of sensory feedback • difficult to tighten • the angle of the aperture is wrong
OTs	• not secure enough

Table 18: Responses to pen holder.

Whilst professionals could identify potential benefits of this device for their clients, the children and young people felt that it would not really be necessary for them. All user groups, however, felt it could benefit bilateral amputees and could be adapted for use in a range of activities (such as typing and arts/crafts).

3.4.2.8 Summary of prototypes developed

Six terminal devices with specific functions were developed alongside an adjustable wrist device into which each of the terminal devices is interchangeable. Devices were developed both in response to the views expressed by the children and young people and as a result of the engineer's technical expertise, enabling the presentation of options that the participants may not otherwise have considered as feasible. The responses of the user groups to the prototypes included the identification of both positive and negative attributes of the designs. This feedback can be used to further develop these particular prototypes. The feedback can also be used to identify broad themes regarding improving upper limb prostheses for children that may complement themes earlier identified or provide new insights.

3.4.3 Themes identified from participants' responses to the prototypes

The following section presents the five broad themes that were identified from participants' responses to the prototypes developed.

3.4.3.1 Theme one: Quick and easy to use

Children and young people explained that the device has to be quick and easy to use because it has to make performing the task more convenient than doing it using their residual limb. Some felt that the cycling device would be quicker to use than other devices or their usual prosthesis. Professionals echoed this, explaining that anything that is a 'hassle' to use is likely to be unsuccessful for children. Participants felt that the method of screwing devices in and out of the wrist device was too time-consuming and that operating the wrist device and the dial-operated grip could be too complicated and tiring.

3.4.3.2 Theme two: Inconspicuous

Some participants felt the Smartphone holder looked 'cool' and would not draw attention as it looks similar to other Smartphone covers. Others, however, felt due to its size it may in fact draw attention. Participants also reported the 3-point grips, writing device and cycling appliance looked unrealistic and felt they could be improved if they looked more like a hand or had the suggestion of fingers. Participants believed this would prevent them from attracting unwanted attention from strangers.

3.4.3.3 Theme three: Less is more

The interchangeability of the terminal devices in the wrist unit was seen as positive by some participants as it was felt this was an improvement on needing to have more than one prosthesis (for different functions). Some participants (particularly the professionals) reported, however, that having a range of terminal devices may be difficult for a child to manage as they may potentially have several to carry around. Professionals and parents suggested this could be burdensome for children and may result in them forgetting or losing their devices. Terminal devices that were versatile for use in several activities were viewed more favourably by professionals. However the child participants did not reflect this view as they felt the different devices could be kept in different places depending on where they would be used, reducing the necessity to carry a range of devices at all times.

> *"You wouldn't always have to carry them around, only if you needed to use them. The iPhone one could just go in a pocket… I guess you could wear one on your hand that was for general things and carry the more specific ones with you. And the writing one you could just keep it in your locker at school or work so you wouldn't really need to carry it around."* (Anna, 14).

3.4.3.4 Theme four: Natural movement

Participants liked the natural movement of the jointed hand. They reported that devices that require operation with the unaffected hand are less appealing (such as the wrist device and dial-operated 3-point grip) because it is not natural or instinctive to operate them in this way. They expressed a preference for devices which can be operated with the residuum only. It was reflected by professionals that children tend to prefer devices they can use in an instinctive, spontaneous manner rather than those that require planning and higher cognitive processes for operating. Professionals' suggestions that devices should be instinctive to use may reflect the desire for them to be quick and easy to use, as expressed by the children and young people (see section 3.4.3.1, p.193).

3.4.3.5 Theme five: Safe and secure

Participants reported that it is important that the device they are using can be relied upon to securely hold an item. They felt that the dial-operated 3-point grip and Smartphone holder provided this, but that anything spring-loaded has the possibility of being less durable. All participants were concerned about the safety of the cycling appliance and expressed a need for it to have a quick release mechanism in case the user fell off their bicycle when using it. If this were to happen when using the current prototype, the child may remain attached to the bicycle which could lead to injury.

3.4.4 Section summary

The previous section has presented findings relating to the combined expertise of all major stakeholders (children, parents, professionals and engineer). This included consideration of subthemes distinct to one particular user group before presenting the prototypes developed by an engineer and the user groups' responses to them. Finally, key themes apparent throughout the user groups' responses to the prototypes were presented.

3.5 Chapter summary

This chapter has presented the findings from the focus groups and interviews conducted with children/young people, parents and professionals. The current situation with regard to upper limb prosthetics for each of the distinct user groups was presented prior to providing information on the prototypes developed and the feedback from participants on these prototypes.

Two overarching themes were identified from the data from children and young people: 'A Love-Hate Relationship' and 'Room for Improvement', explaining the ambivalent relationship participants have with prostheses and their evident dissatisfaction with devices that have been available to them. Two overarching themes were derived from the data from parents: 'Accepting your child's 'difference'' and 'What a prosthesis should be'. Within these themes, the complex phenomenon of adjusting to having a child with a disability was discussed with reference to the relationship parents have with prostheses.

Three major themes were developed from the data from professionals: ‘Client factors’, ‘Device factors’ and ‘Institutional and professional factors’. These themes explained the major factors that are taken into account by professionals when prescribing upper limb prostheses for children.

Findings relating to the combined expertise of all major stakeholders were then presented. This included a discussion of subthemes distinct to a particular user group, a description of the prototypes developed by the engineer and the user groups’ responses to them.

4. Discussion

The discussion chapter begins with a brief overview of the study, including a brief summary of the purpose of the study and a review of the methodology and results. Next, each of the study's objectives will be considered in turn with regard to how the study met the objectives and what was learned. The findings will then be discussed in relation to the theoretical concepts used, with consideration given to the impact of the results on knowledge growth in the subject area. A discussion of the methodologies used will then be presented. Implications of the findings will be considered with recommendations provided for professional practice, device development and research with children. Finally, reflections on the strengths and limitations of the research design and interpretation of results (and how they may have impacted the findings) and suggestions for future research are included.

4.1 Overview of the study

Upper limb difference can have both a physical and psychological effect on a child (Smith 2006). Prosthetic treatment is widely used and children may be prescribed prostheses for functional benefit, cosmetic restoration and for performance of particular activities. The availability of devices does however, vary between geographical areas. Although prosthetic treatment appears to be the favoured option, some studies have reported prosthesis 'rejection' rates amongst children to be as high as 50% (Shida-Tokeshi et al 2005). Previous research has explored reasons for this highly reported 'rejection' through examining children's use of and satisfaction with prostheses. This, however, has largely happened by way of quantitative methodologies or proxy measures. Therefore there is therefore limited research that directly explores children's views on the subject.

The current study aimed therefore to contribute towards the design and development of new prosthetic devices for children through developing an understanding of users' perceptions of their current situation, and drawing upon the unique expertise of all users. Approaching the study from a transformative paradigm perspective, it was viewed essential that children themselves were given the opportunity to share their views on the subject. It was also felt that the views and experiences of parents and professionals were necessary to develop a full understanding of the relationship users have with prostheses for children.

This aim was addressed through a multistage study which involved combining the views and expertise of children, parents, professionals and an engineer to develop a range of prototype devices. Input from the different users was gained through focus groups, interviews and direct design work (in the case of the engineer). The study followed an iterative design and lends itself to future iterations being carried out to further develop the prototypes.

All three user groups identified that prostheses can be used for dealing with unwanted attention, improving function and having fun. The areas for improvement of devices common across the user groups were weight, comfort, durability/reliability, ease of use and functional capabilities. There were also many factors affecting prosthesis use, some of which were shared across user groups and some which were distinct to a particular user group.

4.2 Study objectives

The following section will address each of the study objectives and explain how the objectives were met and what was learned from this.

4.2.1 Objective one: To identify and explain children's perspectives of currently available prostheses and examine their priorities for developing devices.

Children's perspectives on currently available prostheses have been explained through identification of both positive and negative feelings towards prostheses which are reflected in the areas they would like to see improvements made. These are summarised in table 19.

	Positive	**Negative**	**Improvement**
Appearance	Prevents unwanted attention from strangers.	Attracts attention because of how it looks.	More realistic or attractive/desirable appearance.
Play	Useful for fun and games.	Can be a hindrance in sports (due to weight or possibility of it falling off).	Improve fit. Reduce weight.
Function	Useful for some activities.	Many activities are easier without. Restricts movement/doesn't move enough to be useful.	Improve ease of use. Devices for particular activities not everyday use. Improve movement at wrist and elbow joints. Better range of grips.
Comfort		Uncomfortable. Heavy.	Improve comfort. Reduce weight.

Table 19: Children's positive and negative feelings towards prostheses and areas for improvement.

The issues children and young people identified as being either positive or negative about their prostheses can be understood with regard to the impact of limb difference, the desire for a prosthesis to reduce this impact and the ability of the devices that are currently available to them to do this.

4.2.1.1 Improving the appearance of prostheses

As discussed in chapter one (see section 1.1.3.3.2, pp. 22-24), children with limb difference and other physical disabilities are at an increased risk of developing self-esteem and body image issues (Wallander et al 1998). Body image can be impacted by social factors and life experiences, as well as an individual's internal psychological response to their body (Winchell 1996). It seems to follow, therefore, that a person with limb difference may want to reduce the attention their difference receives from peers and society by disguising that difference through cosmetic restoration using a prosthesis. This is also one of the main aims of prostheses reported widely in the literature – to improve a person's appearance (Spires et al 2000). Using a prosthesis in this way (to reduce attention) supports the notion of disability as a social construct, and the participants' desire to deal with stigma from society as a way of combating disability.

However, as expressed by the young people participating in the present study, the prostheses children are being prescribed do not always succeed in preventing attention and, in fact can even increase attention (*"...I feel more... self-conscious if I do wear one, especially if I have short sleeves..."* [Laura, 14]). This could potentially lead to negative social experiences which may contribute to body image issues. As explained by the professionals participating in the study, lifelike prostheses are very expensive and justifying the expenditure for a client who is still growing is difficult so it is often not possible to prescribe these for children.

If the prescription of high-end passive prostheses is considered in terms of its potential impact on body image issues, rather than factors associated with money or growth, it could be argued that adolescents (who may still be growing) would benefit more from high-end passive prostheses than adults. Participants in the current study identified that the passive prostheses they had been prescribed were not realistic-looking due to poor matches to skin tone, lack of aesthetic detail (such as veins and freckles) and lack of lifelike movement. Desmond & MacLachlan (2002) argued that during adolescence, a young person may become more aware of their sexuality and physical appearance, leading to body image difficulties in a previously well-adjusted child. This may suggest that it is at this time that cosmetic restoration is most important, advocating that resources for high-end passive prostheses should be focussed on an adolescent, rather than adult client group as the benefits gained at this time may contribute to the young person's healthy psychosocial development.

4.2.1.2 Improving the function of prostheses

In line with one of the main reported purposes of upper limb prostheses, the participants talked about using their prostheses to increase their ability to perform functional tasks (Spires et al 2000). The introduction chapter referred to the impact of limb difference on function, explaining that unilateral limb difference can lead to difficulties with balance and mobility in the early years and mastery of activities which are usually carried out bimanually in later years. Upper limb difference can impact on a person’s ability to use cutlery, tie shoelaces and perform self-care tasks, for example (Jones & Davidson 1995). Furthermore, participation in leisure activities may also be affected as many sports, musical instruments and craft activities require bimanual hand use. It should, however, be noted that the activities identified through exploration of previous literature and through discussion with the participants in the present study are all specific activities that traditionally require the use of two hands to be performed optimally. These activities included participating in sports and playing musical instruments. Female adolescent participants also identified that they required help with grooming activities, such as applying make-up and brushing hair. This desire to be able to perform self-care tasks independently may be related to the age of these participants and the value placed on developing independence and skill mastery in adolescence (Fisher & Hanspal 1998). Furthermore, the desire to perform grooming tasks independently may be related to the prevalence of body image development during adolescence, leading to appearance and attractiveness being attributes held in high esteem (Jain 1996).

There are however, many tasks encountered in daily life that can be carried out unilaterally or with the manipulation of one hand with the support of the other. This may explain why several of the participants reported finding it easier to perform activities without a prosthesis, such as picking items up. The identification of a prosthesis as useful for specific tasks as opposed to the functional restoration of a hand complements the recommendations from previous research that children may opt to use different prosthetic devices dependent on the task and environment (Crandall & Tomhave 2002, Buffart et al 2007, James et al 2006, Egermann et al 2009).

This suggests that the quest to replicate the movement of a human hand in a prosthesis is unnecessary for children and young people with unilateral limb difference. Furthermore, prescribing generic functional devices (such as body-powered gripping devices) may not be helpful for this client group as they have developed their own methods for performing the activities in a functional way. Prosthesis development and prescription for children and young people may therefore be more beneficial if it focused on what the clients wish to gain from the use of a device (i.e. their activity goal) as opposed to trying to ‘treat’ their ‘deficiency’ or replace the function they are (perceived to be) lacking. Fisher (1998) argued that a top-down approach that focuses on occupation, enables the focus of therapy to be what is really important from the perspective of the person, resulting in more successful adaptation and equipment provision. Focusing treatment on minimising a ‘deficiency’ or ‘impairment’ represents both a medical model of disability and a ‘bottom-up’ approach to healthcare assessment and intervention (Hocking 2001). Section 4.5.1 (pp. 231-233) discusses these in further detail, presenting an argument for why these traditional approaches are no longer satisfactory and why a ‘top-down’ approach, influenced by a social model, is more appropriate for contemporary healthcare and ‘treatment’ of limb difference.

4.2.1.3 Improving the comfort of prostheses

For several years studies have identified that a contributing factor to children and young people’s dissatisfaction with prostheses is that they cause discomfort, both in terms of being hot and sweaty and because young people feel they are heavy to wear (e.g. Wagner et al 2007). Despite this, it appears that many heavy and uncomfortable prostheses, largely body-powered devices with a harness system and myoelectric prostheses, are still being prescribed to children and young people. It has been argued that the heat and sweating on the residuum and the heaviness of prostheses are a necessity when providing functional devices as a result of the nature of the technology available to create these (Amputee Coalition of America 2008). Professionals participating in the current study felt that heat and sweating resulted from the closeness of fit to the skin, and lack of options for wearing a sock, when using a myoelectric device. They also felt that the weight was inevitable due to the motors and batteries needed to make the device work.

If these devices are considered in light of the previous assertion, that prostheses should be designed/prescribed based on an activity-specific goal as full functional restoration is unnecessary, then this trade-off between function and comfort is no longer an issue. It could be argued that, when designing a device to perform one particular activity or function, more simplistic and lightweight designs could be used, minimising the need for heavy mechanical parts to be included. Furthermore, this may also result in more reliable devices, requiring less maintenance.

4.2.2 Objective two: To identify and explain parents’ perspectives of currently available prostheses and examine their priorities for developing devices.

Parents’ perspectives on currently available prostheses have been explored through examining the experience of parenting a child with limb difference, examining the role of the prosthesis within that and identifying what parents feel prostheses should offer and where they fail in meeting these expectations. Table 20 describes the themes identified relating to the impact on a parent of having a child with limb difference, coping strategies to manage this impact and ways identified that these coping mechanisms could be improved. Parents identified coping strategies that are inherent characteristics of themselves, their child or the family unit (intrinsic strategies) and those that involve some external input (extrinsic interventions). Coping strategies are divided into these two categories in the table.

Impact of limb difference on parents	**Intrinsic coping strategies**	**Extrinsic coping strategies**	**Improvements**
Grief and guilt	Fun and humour		
		Peer and professional support	• Information at birth/diagnosis • Better availability of counselling for parents • Recognition that peer support is not always right for parents (feeling the need to be positive all the time)
		Prosthesis	• More realistic looking • More functional • More choices for children • More durable • Safer • More lightweight • More comfortable • Easier to use • More equitable service provision between centres

Table 20: Impact of limb difference on parents, coping strategies and areas for improvement.

Many of the issues identified by parents as requiring improvements are similar to those identified by the children and young people. Some issues, however, are important to parents that may not be of importance to children, and warrant more in-depth discussion. The importance of the safety of prostheses, the postural benefits of prosthesis use and the need for a prosthesis for parents when adequate psychosocial support (e.g. counselling) is not provided are some of these issues and will now be discussed in further detail.

4.2.2.1 Safety of devices

Children with unilateral limb difference may be heavily reliant on their unaffected upper limb for carrying out activities of daily living (Gambrell 2008). Even for an extremely proficient prosthesis user, the prosthesis is not capable of replicating the full dexterity of the natural fingers, meaning an injury to the unaffected upper limb can be significantly debilitating (Gambrell 2008). Any device that may increase the risk of injury to a child (such as, the cycling appliance without a quick release mechanism) is, therefore, understandably of concern to parents.

4.2.2.2 Posture/healthy physical development

Parents expressed a need to use a prosthesis for postural symmetry (when, for example, learning to crawl). Professionals were in agreement with this, suggesting that a prosthesis may be necessary when writing to prevent postural asymmetry. Research suggests that unilateral limb difference can cause scoliosis in direct correlation to the amount of weight lost from the affected side of the body due to the absence of (part of) a limb (Greitemann et al 1996), which supports this view. Parents were also, however, concerned that, if a prosthesis was heavier than the unaffected limb, it could have a detrimental effect on postural symmetry. This seems logical considering Greitemann's (1996) findings as, if the prosthesis weighs more than the affected arm, it could also present an imbalance in weight distribution. It can be seen, therefore, that the weight of prostheses should be considered carefully with regard to a child's on-going healthy growth and development.

4.2.2.3 Prosthesis in place of psychosocial support

As outlined in the results chapter parents identified the child's first prosthesis as being necessary for the parents, to help with their adjustment to the limb difference, as opposed to being needed by the child. Parents reflected that this need may not have been apparent had they been offered counselling to help them deal with the emotions of grief and guilt that they were experiencing. Kerr and McIntosh's (1998) study of parental experiences of the disclosure by health professionals of a child's limb difference revealed similar reactions: feelings of shock, numbness and loss were found to be common at the time of disclosure. There is a substantial body of literature describing the emotional and psychological stresses parents of a disabled child may experience including feelings of grief, loss and guilt (Pahl and Quine 1987). Theories explaining parents’ reactions to the birth of a disabled child propose that when a child is born with some kind of difference or disability it can be a shock to parents, resulting in these feelings (Younghusband et al 1970). Hornby’s (1995) model of loss argues that the process of adaptation to a significant loss, such as a child being born with a disability, can be viewed as a continuum of reactions through which people pass in order to reach acceptance of the loss. Parents of disabled children are particularly vulnerable to stress (Sloper & Turner 1993) and parental distress and family functioning affects a child’s cognitive, behavioural and social development (Wallander & Varni 1998). Therefore, a lack of psychosocial support for parents may result in high levels of parental distress, affecting the child's well-being (Middleton 1995). As a temporary coping strategy, denial (such as using a prosthesis to disguise the limb difference) can give parents time to adjust to the situation (Hornby 1995).

Participants described using the prosthesis as a tool to disguise, and therefore avoid confronting, their child’s condition. This is interesting as it places parents in the position of end user of the device (although not the person wearing it) as it is ultimately for the benefit of them, in this instance, and not the child. It should be noted, however, that there is a belief within the clinical community that early fitting of a prosthesis is beneficial to the child. As early as 1972, it was recommended that prosthetic management should begin at birth to support healthy physical and emotional growth and development (Sypniewski 1972) and this belief is still largely upheld (Patton 2002).

If parents were given the opportunity to discuss, and come to terms with difficult emotions, this may have been a more positive experience for them. The evident lack of counselling for parents of children with limb difference (many centres having neither a counsellor nor access to a counselling service) may once again represent a medical model approach to childhood limb difference. Practicing within the medical model would involve focusing on the child's impairment and the prevention of disability resulting from this impairment, rather than considering the broader needs of the child and family. Family/parental stress is viewed as directly occurring as a result of the impairment: treating the impairment is, therefore, viewed as treating the stress

(Sloper & Turner 1993). Taking a social model perspective, however, requires a broader focus that takes account of social and environmental factors, societal attitudes towards impairment and inadequacies in support.

A significant number of parents of disabled children do not receive professional counselling, despite feeling that it would be of benefit to them for reasons such as helping them to ‘come to terms’ with their child’s impairment, alleviating uncertainty about the future, offering practical advice and providing emotional support (Case 2001). This was echoed in the findings of the current study with parents expressing that being offered counselling at the time of diagnosis, whether this was *in utero* or following birth, would have been a positive experience for them. Some parents in the current study, however, reported that they should have received a diagnosis whilst pregnant, but that failures in the antenatal healthcare system had resulted in a missed diagnosis.

Hornby (1994) argued that parents need supportive counselling soon after diagnosis (Hornby 1994) to help them to express and clarify their feelings, and to understand their reactions and the reactions of others, resulting in positive adjustment to, and mature emotional acceptance of, their situation (Hornby 1994). Setoguchi (1991) recognised the significance of early support for parents, advocating that parents need to have their questions answered as soon as possible and to be given the opportunity to express their feelings.

Many of the parent participants mentioned the value of peer support received through Reach Charity Ltd. This is in line with Kerr and McIntosh’s (1998) findings from their qualitative study into the impact of parent-to-parent support on coping with having a child with limb difference. They found that social support from people in a similar situation was an effective buffer against stress due to the positive effects of experiencing a sense of belonging to a group (of similar others) and a feeling of being understood by these people.

A common reason given for lack of psychosocial support, voiced both by professional participants in the current study and colleagues at conferences, is that services do not have the available finances to fund a counsellor or to access a counselling service within their centre. A frequently voiced opinion anecdotally is that spending is prioritised for equipment and devices with professionals such as psychologists and counsellors being viewed as unaffordable luxuries. It could be argued, however, that this once again stems from a medicalised view of limb difference, suggesting that the difference needs to be ‘corrected’ or ‘disguised’ through use of a device. Providing appropriate psychological support to parents and families may, however, reduce the need for a prosthesis, subsequently reducing expenditure on equipment and devices. This may also facilitate the engendering of a culture of acceptance of limb difference, moving away from a stigmatised medical view.

4.2.3 Objective three: To identify and explain professionals’ perspectives of currently available prostheses and examine their priorities for developing prostheses

Professionals’ perspectives on currently available prostheses were explored through examining the various factors that impact on the prescription and treatment decisions they make. These are summarised in table 21.

Client Factors	**Device Factors**	**Institutional/ professional factors**	**Improvements that could be made**
Goals			• Client-centred goal-orientated assessment • Task-specific devices
Attributes			• Appreciation of changing needs • Growth not just physical
	Appearance		• More realistic • More child-centred • Silicone more widely available
	Comfort		• Less hot and sweaty • Less discomfort from straps
	Ease of use		• More intuitive operation
	Movement		• Improved wrist movement • More grips
	Durability		• Less likely to break down • able to carry out repairs on-site
	Environmental compatibility		• Suitable for use in messy and outdoor play
	Weight		• More lightweight
		Involving clients	• More options of devices • Custom-making and prototyping devices
		Financial considerations	• More equitable funding distribution
		Multidisciplinary team	• More equitable staffing across centres • Less hierarchical structure • Better networking and sharing between services

Table 21: Factors affecting prosthesis prescription and areas for improvement.

Many of the device attributes identified by professionals as requiring improvements are similar to those identified by the parents and children/young people. Identified functions of prostheses were also very similar. Gesture/communication as a function of prostheses was, however, something that was identified uniquely by an OT. People gesture frequently when talking and, although there is limited evidence to suggest this gesturing enhances or modifies the spoken word (Krauss et al 1995), it is widely assumed that gesticulation is an integral part of communication. Conversational hand gestures are assumed to be synchronised with, and related to, the meaning of the speech they convey (Kendon 1983).

Issues relevant to the working environment are uniquely important to professionals. Participants' insights into current treatment practices in paediatric prosthetics and the 'postcode lottery' of services may be particularly pertinent and, therefore, warrant further discussion.

4.2.3.1 Current treatment practices

Prosthesis viewed as 'replacement' of deficient limb

Much research has suggested that children should be provided with prostheses to serve specific purposes and for use in particular activities so that they can select the device that will be most appropriate for the desired use. (James et al 2006; Buffart et al 2007; Egermann et al 2009). Despite this, it was evident in the current study that it is still common practice to prescribe a child with a general purpose body-powered prosthesis and/or a passive device. Approaching device prescription in this way implies a treatment regime which aims to either 'replace' some function or cosmesis which is perceived to be 'lacking' or to attempt to replicate a human hand. The current study has shown that this is largely unnecessary, with children reporting that they feel comfortable with their difference and are able to complete their daily activities, only requiring a device to assist with specific tasks. Some participants even reported that wearing something which mimics a real hand feels disingenuous to them, suggesting that a device does not have to be inconspicuous to be aesthetically pleasing.

Furthermore, an approach to prostheses as replacement or compensation for something that is 'missing' strongly suggests an impairment-based approach to treatment, implying that it is the medical condition that is causing disability and needs to be corrected, rather than addressing the social, cultural and environmental factors that may be leading to disability. The children and young people who participated challenged a compensatory approach to prostheses, with their identification that they would not always want a prosthetic device to mimic a real hand. They suggested that prostheses could have the potential to enhance appearance, represent self-expression and be aesthetically pleasing for their own merit as opposed to as a substitute or replacement for a human hand.

Approaching prosthetic treatment as providing a ‘replacement’ for limb difference can be detrimental to a person’s ongoing rehabilitation and personal independence (Gallop 2012). By providing appropriate tools for completing particular activities (rather than a general purpose prosthesis) emphasis is placed on adapting the physical demands of the environment to enable a young person with limb difference to participate in the task. This is in contrast to a medical rehabilitative approach, which would attempt to ‘treat’ the deficiency to enable the young person to perform it in the same way as their able-bodied peers.

Non-use viewed as ‘rejection’

The term ‘rejection’ is used throughout literature on children’s upper limb prostheses to describe a child who does not use a prosthesis. The Oxford Dictionary (2010) definition of the word is “the dismissing or refusing of a proposal”, implying non-use of a prosthesis represents a negative response rather than a positive assertion or decision. This suggests that the correct response is to use a prosthesis, signifying that those children who do not use a prosthesis are in some way incorrect. This again inflicts an adult-imposed medicalised view on prosthesis use instead of accepting children’s choices and decisions as having equal merit. Furthermore, this term continues to be used, despite research as far back as 2007 reporting that children and young people may go through periods of non-use of prostheses due to a lack of functional benefit (Wagner 2007).

In the current study, professionals reported changing use patterns relating to times of change or transition, such as moving to secondary school or university or starting a new job. It seems evident therefore that use and non-use can be a regularly changing pattern throughout a child or young person's development.

Furthermore, children's decisions to not use a prosthesis should not be viewed as them 'rejecting' a device but rather failure of the device to meet the child's needs or expectations. Delays in children receiving devices or having to spend periods of time without the device due to maintenance issues may result in them choosing not to use a device. A prosthesis breaking down, particularly if this results in a lengthy repair process, could result in reduced motivation, increased frustration and even the child believing that they are in some way to blame for the device's failure. This would be compounded if their subsequent non-use of the device was then described in blame-laden language such as 'rejection'. Therefore the term 'rejection' should be used with great caution when describing use or non-use of prostheses as it is laden with judgement about the decision not to use a device and implies a permanent stance rather than what is likely to be a more complex, changing and situation-specific pattern. A further issue is that services need to be more responsive to children's needs and goals in order to recognise and respond to their motivation at the correct time. Children's needs and interests may change rapidly as they are growing and developing: prolonged periods waiting for an appropriate device may result in the device, when eventually issued, no longer meeting the child's needs or expectations.

4.2.3.2 'Postcode lottery' of services

The options available to different services as a result of the funding available to them varied hugely between the participants interviewed, confirming Murrison's (2011) findings that there is a 'postcode lottery' of services. This is also reflected in the Standards for Best Practice for prosthetists, which states prosthetists are required to "make best use of available resources" (BAPO 2013, p.4), suggesting a recognition that financial considerations are relevant to prosthetists.

Murrison (2011) observed that there is a 'postcode lottery' across NHS prosthetic services, resulting from discrepancies in funding levels across individual Primary Care Trusts (PCTs) and perpetuated by a lack of national guidelines for prosthesis provision. This implies a huge disservice is being done to children living in these areas as opportunities for them to "enjoy and achieve" (Department for Education and Skills 2003) may not be provided despite the fact this would be possible given the right equipment and professional expertise. This postcode lottery is evident in the findings from the current study in the following ways.

1. Device factors which some participants reported as unsatisfactory were not an issue for others.

An example of this is that some participants reported difficulties with getting the prosthesis on and off, whereas others reported that this was not an issue due to a particular design feature of their device. Becky (8) talked about not being able to get her prosthesis on and having *"to use talcum powder"*. She also, however, talked about being *"worried if it's gonna… fall off"* when playing in the playground. In contrast, Chris (12) reported he did not have any issues with getting his prosthesis on and off because of having *"a button which I press and… grooves... And you put it in and then it sticks and then when you wanna get it off you press the white button and it comes back…"*. This may suggest that some of the attributes of prostheses that participants are dissatisfied with result from disparity between what young people are offered depending on the geographical area, as opposed to design faults within the devices themselves.

2. Some participants reported receiving adequate training whereas others did not.

One issue participants described having with their myoelectric prostheses was the device getting stuck in a closed position. This was felt to result from the user not being adequately trained or competent in using the prosthesis as opposed, again, to a design fault of the device. Some parents described receiving appropriate training, which incorporated activities that are motivating and meaningful to the child. Others, however, hadn't received any specific training. Provision of training by an OT is in line with the key treatment approaches employed by OTs: working with clients to develop strategies to overcome aspects of impairment, adapting equipment used to complete a task and adapting the environment to better meet the client's needs (Canadian Association of Occupational Therapy, CAOT, 2012). Furthermore, when doing so OTs use activities that are meaningful to the client in terms of their own preferences, personal goals, and needs (Hinojosa and Kramer 1998), suggesting they are the most appropriate practitioners to engage and motivate children and to ensure activities remain meaningful to them.

3. Variances were reported in service flexibility.

Some participants praised services for their flexibility and understanding that appointments need to fit in around family life. Other participants, however, reported not being able to get to appointments due to lack of dates and times that are appropriate to family life or appointments only being available in the school holidays, which had been a factor in them visiting less. This is an important issue as children with limb difference (and other physical disabilities) use health services frequently, which can impact on their ability to participate in school and extra-curricular activities (Weir & Mackenzie 2010). This can result in reduced opportunities for participation in life situations vital to their healthy development (Department for Education and Skills 2003).

4. Variances were reported in level of choice available.

Some families reported having options with regard to equipment, staff and therapy available to them. Some centres in the study described being able to provide myoelectrics, silicone cosmeses and custom-made devices, whereas others were limited to providing only either a passive prosthesis or a body-powered device. This was related to both the funding available for the purchasing of equipment and the range of expertise of staff working at the centre.

5. Differences in the impact of breakdowns of equipment.

The impact on the user of device repairs was seen to vary between centres. Some centres have a workshop on site and are therefore able to carry out same day repairs, whereas others have to send the device to another country for repair resulting in the child being without their prosthesis for a long period.

A ‘postcode lottery’ was observed to exist within the services represented by participants in the present study, as exemplified in the five specific instances described. The NHS was formed with equality of access to healthcare as a central tenet, yet inequities still persist in services including those for limb difference, as highlighted in the current study. Goddard and Smith (2001) suggest the reasons these inequities still exist include expertise/propensity of clinicians, variance in quality of services, lack of information provided to the population (to enable choice) and financial reasons. Wonderling et al (2005) expanded on this to state that for equality of access to healthcare to exist travel distance to facilities, transport and communication services, waiting times, charges and provision of information must be equitable.

This has clear ethical and professional implications for clinicians working in these services as decisions about which treatments to fund are passed on to the healthcare professionals within the NHS due to the NHS being unable to afford to pay for every appropriate treatment for each person accessing services (Jones & Irvine 2003). This may mean that professionals feel unable to suggest an intervention despite believing that it would be of benefit to the patient.

Furthermore, it seems probable that the prevalence of a ‘postcode lottery’ may worsen as a result of the current economic situation. However, improving services does not necessarily require financial investment but rather reconsideration of how funding is spent. It could be argued that investing in a full staff force which includes OT and psychological support services reduce the expenditure that is required on devices and equipment. In addition, national guidance, such as National Institute for Health and Clinical Excellence (NICE) guidelines, is designed to eliminate inequities (Jones & Irvine 2003). The development of national guidelines for the treatment of paediatric upper limb difference could result in a reduction in the presence of a ‘postcode lottery’. National guidelines may prevent treatment decisions being made at a local level as prescription decisions would be guided by the same national guidelines for all centres (Jones & Irvine 2003). However, Jones & Irvine (2003) caution that low incidence conditions, such as paediatric upper limb difference, are less likely to receive assessment from NICE, as decisions about which conditions are assessed are made by the Department of Health. These decisions may be politically motivated, favouring more ‘topical’ treatments (Jones & Irvine 2003).

4.2.4 Objective four: To practically apply the findings from the study

As a study operating within a transformative framework, it is vital that objectives relating to the practical use of the findings are included (Mertens 2003). Of particular importance, is that these practical applications should have benefit for the under-represented (in research) societal group that have participated in the study. The following section describes how the findings have and will be used to bring about improvement to paediatric upper limb services.

4.2.4.1 Informing the design of prototype devices that can be presented to industry for further development

Section four of the results chapter described the prototypes that were developed using RPT and based on the findings of the study. The feedback on the prototypes was used by an engineer to produce further iterations of the prototypes which can be continually developed until suitable to be presented to industry for development into working prostheses. This study represents the first stage in the development of new prosthetic devices: continual, iterative development will be required to reach the stage at which they can be commercially manufactured. However, involving users from this early stage ensures that the point of departure for the design is the users own views, experiences and expertise.

4.2.4.2 Identifying key extrinsic factors that impact on the use of prostheses that can contribute to the development of guidelines for the profession

Through consideration of the findings, several non-device-specific factors have been found to impact on prosthesis prescription and use. They are presented in the below table. A discussion of the implications of these for practice guidelines can be found in section 4.5 (pp.231-237).

Area of practice concerned	**Non-device-specific factors affecting prosthesis prescription and use**
Assessment	Client goals Client attributes
Treatment	Client involvement Parental needs
Higher level service delivery decisions	Financial considerations MDT

Table 22: Non-device-specific factors that impact on prosthesis prescription and use.

4.2.5 Section summary

The previous section has demonstrated how the study met the four key objectives, explaining children’s, parents’ and professionals’ perspectives and practically applying these findings. Exploring all three user groups has resulted in a rich understanding of factors impacting on prosthesis use for the three main user groups.

4.3 Relating the findings to the theoretical concepts used

The following section will explain the findings from the study in relation to theoretical concepts used to guide the research process, approach product development with children and understand the concepts of childhood and disability.

4.3.1 The BRIDGE methodology through a transformative lens

The evident exclusion of children from decisions affecting their treatment and the marginalisation inflicted on them, not only by society but by an impairment-based treatment regimen, has justified the use of a transformative stance in the present study (Mertens et al 1994). Children have been enabled to express their views on matters they may not routinely be consulted on, allowing them to exert more control over matters affecting them, as well as recognising them as equally able to impart insightful knowledge and experience. Iversen & Brodersen (2007) used the BRIDGE method to involve children in the design process for information technology applications. The current study has demonstrated how this method can be successfully applied to a range of stakeholders and in a health technology domain.

A central tenet of the BRIDGE methodology is that designing a new technology requires active participation of members of the community of users (Iversen & Brodersen 2007). The current study has addressed this through involving children, parents and professionals in conversational and participatory research to explore their views and experiences, and develop an understanding of their expertise. The current study began with involving children, recognising them as experts in their daily lives.

Understanding the daily lives of the end users of prostheses (children and young people) has enabled an identification of an ambivalent relationship with the device and allowed children to express that they may not see the necessity for a prosthesis both because they can manage functional tasks without one and because they have accepted their difference so have no desire to conceal it. Without exploring this directly with children this issue may not have been highlighted as it requires an understanding of the everyday practices and experiences of these children that could not have been assumed by proxy representation. Providing participants with an opportunity to express their own personal realities has resulted in this clear challenge to a traditional, medical model view of limb difference as an unfortunate occurrence, providing evidence against what may be a commonly held assumption.

The children and young people who participated in the study also highlighted an important function of prostheses as something to have fun with and include in play with friends and family. This supports our understanding of play as an important occupation for children and young people (Case-Smith 2005). Play is recognised as a central occupation of childhood, an essential part of children's development (Larson 2004). It has been argued that play in childhood has the capacity to encourage personal development and provide opportunities for formative experiences in the same way that work does in adult life (CAOT 1991). Furthermore, using prostheses in a fun and humorous way may be an appropriate coping strategy for children in managing stressful events (Dowling 2002). It can enable a child to view an upsetting or stressful event from a different perspective and reappraise it as less threatening (Martin 1989). This can lessen feelings of anxiety, fear, anger and frustration (Boyd and Hunsberger 1998) and help children to gain control of the situation (Bennett 2003).

The importance of fun and play in paediatric prostheses also highlights the importance of revealing different versions of reality through adopting a transformative ontological stance. It is generally recognised that the two main functions of a prosthesis are to improve a person's appearance and to increase their ability to perform functional tasks (Spires et al 2000). By directly exploring the views of children, however, it has been revealed that there is a third important function of prostheses for children, which is as something to have fun with and include in play with friends and family.

It is evident, therefore, that the occupations of children and adults may differ, making it hugely important to explore children's views. Adults' everyday experiences are likely to be very different from children's, inhibiting their ability to assume a child's viewpoint and therefore act as their proxy.

In addition to the evident importance of employing a philosophical approach that values the participation of historically marginalised groups, an approach which recognised the importance of power differentials was also justified. Parents who participated in the study described an inequality in service provision resulting from better services being received by those families who are more vocal about their needs. This suggests that services have some power over families that can only be redressed if users of the service are willing and able to communicate in the language and manner required of that service. This was also echoed in participants' use of combative language, such as talking about 'fighting' to get what they need, suggesting the need to overcome a struggle against a more powerful opponent. By reversing this hierarchy through consulting with children first, then parents and lastly professionals, recognition has been given to the importance of this power imbalance. Methodologies have therefore attempted to minimise the influence of this in the current study.

Moving on to explore the daily lives of parents of children with upper limb difference has brought to consciousness other issues, which although perhaps previously known anecdotally, have not been explored through formal research. Of particular note are parents' discussions of feelings of grief and guilt they have experienced. These related to the need to use a prosthesis to buffer these emotions (in the absence of appropriate psychosocial support to address these feelings) and the need to feel they are 'doing their best' to atone for their child's difficulties. Without having involved parents in the study it would not have been possible to understand these complex emotions which may impact prosthesis use.

The issues discussed by the professionals were largely focused around the work or clinic environment (as opposed to home, school or social settings as described by children and parents). Therefore exploring professionals' views introduced aspects of prosthesis use that children and parents may not have been aware of, such as budget pressures and lack of specially trained staff.

Having an awareness of the issues relevant to all users is important to prosthesis design because they can impact on the use or non-use of the devices. For example, being aware that many children feel they manage just as well or even better without a prosthesis may prevent the prescription of an unnecessary and, subsequently ‘rejected’, device. Having a fuller understanding of the need for the first passive prosthesis, as a coping tool for parents, can enable the design of this prosthesis to be guided by a parental rather than child need. Alternatively, it may encourage the provision of other non-device-dependent coping mechanisms, such as counselling, to minimise the need for that first device. Finally, an exploration of the complexities of the competing pressures on professionals, from financial constraints of device provision to working with a minimal staff team and within one’s own philosophical ethos (such as a medical model or social approach to disability) develops our understanding of factors that ultimately impact on what is prescribed. Taking the views of any of these user groups in isolation would, therefore, lead to a neglect of important cultural, social and historical influences that impact on prosthesis use.

Also vital to the BRIDGE method is Technological Immersion. The engineer in the current study introduced this to the participants through the design of devices not specifically requested by the children and young people, such as a Smartphone holder or an anthropomorphic hand. These devices were founded on broader areas of dissatisfaction expressed by the children, such as a lack of natural movement and difficulties with technology use, and developed through technological expertise and awareness of the options opened up by the use of RPT. Many of the young people participating in the study would not have seen a fully articulating device before and may, therefore, been unable to imagine such a device was possible. Using these prototypes challenged the participants’ understanding of what upper limb prostheses can be like, stimulating further discussion.

4.3.2 Theories of childhood

Chapter 2 outlined the researcher’s stance regarding theories of childhood, advocating a sociocultural view which purports that learning occurs as a result of experiences and social and cultural influences as opposed to seeing knowledge as something adults possess and children lack. The findings from the study provide some insight into the way children are viewed in the healthcare setting, particularly with regard to prosthetics services.

Parents expressed recognition of children as experts in their own lives and reflected that they feel treatment choices should be made by children. Some parents did, however, suggest that younger children are unable to make informed choices about their treatment and that parents then have to take on that decision-making for their children. This seemed to entail parents choosing prosthetic treatment for their children, the argument being that if children did not have experience of using prostheses they would not be able to make informed decisions about their treatment when older. Although this may suggest the ability to make decisions about treatment is seen by parents to be related to a child’s age, the age at which a parent decides their child has the capacity to make these decisions may vary. This may be affected by the experiences the child has had, their desire to be involved in decision-making and the efforts made by professionals to enable children to be involved.

Professionals’ efforts to involve children may be particularly relevant as the study findings suggest that parents have experienced situations in which professionals regarded themselves as the experts and attempted to fit the child to the technology rather than listening to and respecting the child’s views. Furthermore, it was apparent that the information provided to families about prostheses is aimed at parents. The information is not, therefore, being provided to children in a format that would enable them to make informed decisions.

Despite this, the professionals did appear to believe that it is important to involve children as much as possible in treatment decisions. It seems that whilst professionals may be exhibiting a belief that children have the propensity to be involved in decisions about their own treatment, limited resources impact on their ability to fulfil this.

The suggestion that children’s capacity for decision-making is affected by the information they are provided with was complemented by a view expressed by parents that children’s capacity to learn is always dependent on a child-friendly approach to their learning. The way prostheses operate was viewed as being inappropriate for children because they are not instinctive to use and do not fit comfortably into children's everyday activities. This may be as a result of prostheses not being designed from the perspective of children but rather with the emphasis on what is technically feasible.

Marginalisation within the prosthetic treatment centre appears to extend beyond children to parents being excluded from decisions and may reflect a broader hierarchical structure of treatment decisions. Parents in the current study described being dismissed by professionals, excluded from treatment decisions and pressurised into following the treatment recommended by the professionals. This hierarchy was also seen to extend to the professional setting with consultants being viewed as the ultimate decision makers. The professionals interviewed felt that a less hierarchical structure would be a more positive way of working in order to respect the different expertise of the professionals and maintain positive morale.

It can be seen from the current study that parents and professionals believe that ideally children should be involved in decisions affecting their treatment and that they should be viewed as experts in their daily lives. This would suggest a sociocultural view, in which children are not viewed as cognitively less competent. However, in practice, younger children may be being excluded by both parents and professionals from decision-making, and approaches which enable their participation may not be being used. Children, therefore, may be being viewed as less able to be involved in decisions because they are being presented information in a format more suited to adults.

4.3.3 Theories of disability

Chapter two argued the appropriateness of a sociocultural, as opposed to medical, view of disability. In this approach disability and impairment are viewed as distinct constructs, with the focus being on the social, rather than the biological factors, in understanding disability (Mertens 2010a). In the current study much reference was made by all three participant groups to the (positive and negative) responses of society to limb difference and the impact of this on prosthesis use.

Many of the young people in the study described using their prostheses to deal with unwanted attention. Parents also described using prostheses to prevent attention from other people or being treated differently. Being viewed as different as a result of their impairment could result in feelings of embarrassment and isolation for the children and their parents. This suggests a need to wear a prosthesis in order to conform to societal regulations as opposed to a way of making the activity easier for the person, highlighting the prominence of socially constructed disability.

Societal norms and regulations were also seen to impact on this. For example, hand shaking as an expected part of sociocultural etiquette can increase attention and unwanted questions. Additionally, the need to use a prosthesis to conform with what is considered the safe or correct use of an item designed for use by an able-bodied person (such as a car or a bicycle) also reflects the disabling of a person by their environment (both physical and institutional).

The social environment was, however, also viewed as having the power to reduce stigma and socially-constructed disability. The media was seen to be particularly influential in this. All groups of participants made reference to a television presenter who has limb difference and expressed a view that this has a positive influence on young people, facilitating an acceptance of limb difference as something that is ‘normal’. These views that the media can present positive role models and influence the stereotypes held by society is supported by the argument that media representation of people with disabilities have the power to perpetuate or challenge stereotypes of disability (Auslander & Gold 1999). Furthermore, if stereotypes presented in the media are negative these can have a detrimental effect on the developing self-confidence of disabled young people whose identity development may be influenced by messages presented in the media (Boston Women’s Health Book Collective 2005). In addition to this, those who do not have interpersonal contact with disabled people in their daily lives may be exposed to views of disability almost exclusively through mass media (Haller 2000).

The Paralympic Games (held in London in 2012) was widely referred to by participants as something which challenged traditional, medical model views of disability as a tragedy that requires pity, resulting instead in a perceived celebration of difference and achievement. The traditional views of disabled people as victims of tragedy in need of care and pity has been challenged by a shift to focusing on equality and the achievements of disabled athletes in the Paralympics (Scambler 2013). Professionals also reflected how prosthesis prescription changes over time in relation to the impact of these cultural and media events, suggesting that the nature, meaning and impact of impairments are seen to be influenced by social and cultural trends.

Despite the insight by all user groups into the influence of society and environment on disability, there was some evidence of professionals working within prosthetics services operating within a medical model. This can be seen within a treatment approach that prescribes prostheses as a ‘replacement’ for the ‘missing’ limb (as previously discussed in section 4.2.3.1, pp.210-212) as well as the suggestion that children need to be educated about how delicate their prosthesis is and the need to be careful with it. This may suggest that children are provided with a prosthesis that is not suitable for the environments and activities they encounter in their daily lives and that they are therefore required to adapt themselves to the environment or equipment.

4.3.4 Section summary

The previous section has provided justification for the use of the BRIDGE methodology through a transformative lens, identifying how this approach enriched the study. Findings were then discussed in relation to perspectives on childhood and disability.

4.4 Discussion of the methodologies used

It was proposed within the objectives for the study that conversational and creative methods would be used to enable participants to express their views and that prototypes would be used in this process. The following section will therefore reflect on the success of the methodologies used in meeting these objectives. Some elements of this section will be presented as personal reflections and in first person. These sections can be identified by their presentation in ‘thought bubble’ text boxes.

4.4.1 Use of interviews and focus groups with children/young people

As previously discussed at length in the methods section (see section 2.5.1, pp. 74-80), focus groups and interviews are appropriate tools for the collection of qualitative data with children, which can be enhanced with the inclusion of options for non-verbal communication. Qualitative, conversational methods appreciate individual perspectives of participants as they are able to influence the agenda of the research interview or direction of focus group discussion (Crow 2000). This enables participants to ensure that the factors that are important to them are highlighted to the researcher in the participants' own words. This is especially important when researching such a personal experience as the impact of impairment and technology on an individual.

Using quantitative methods to try to address the aims of this study would not have been satisfactory as participants would have been confined in their answers to categories imposed on them by the researcher (Mack et al 2005), which would have impeded them in expressing their individual realities and may have affected the priorities they selected as important to them (Crow 2000).

Parent proxy reports would have been similarly unsatisfactory as adults experience the same situation differently to children and are not capable of assuming the child's perspective (Lightfoot & Sloper 2002). Furthermore, from a transformative stance, which places emphasis on rights-based, emancipatory measures, both quantitative and parent-proxy methods would be ethically incompatible.

It is argued that research (both quantitative and qualitative) is impacted on by the researcher's own personal views and experiences. One way of managing this influence is to maintain a field journal, containing thoughts, feelings, ideas, questions and problems. In writing these personal thoughts and feelings about the research process, the researcher may become aware of biases and preconceived assumptions, allowing the researcher to alter the way that he or she collects the data or approaches the analysis (Krefting 1990). Throughout the current research, reflections and ideas were kept in a research journal (some excerpts of which are included in the data analysis section – see figures 10 & 11, pp. 103-104). Meetings with an advisory group were also used as a way to broaden influences on the study and minimise the possibility of the bias of one voice. These methods resulted in the study being expanded from examining the views and experiences of children to include developing an understanding of the parents of children with limb difference and the professionals working in the field.

Triangulation of data in this way is argued to be a powerful strategy for enhancing credibility as multiple perspectives are sought, helping to ensure that all aspects of a phenomenon have been investigated and not just those favoured by the researcher's own beliefs and philosophies (Knafl & Breitmaye, 1989). Study credibility can also be influenced by the expertise of the researcher. When conducting focus groups, the facilitator's role is crucial to the quality of data collected, suggesting that practicing, in order to improve skills, is a critical part of focus group research (Kennedy et al 2001). In the current study, researcher expertise was developed through conducting a pilot focus group to develop the focus group facilitation skills of the researcher.

A pilot study can refer to a small-scale version of the main study, conducted as a trial run or the pretesting of particular methods or instruments (van Teijlingen & Hundley 2001). One of the benefits of conducting a pilot study is that it might draw attention to issues that may have the potential to impact on the success of the main study, such as whether proposed methods or instruments are inappropriate or too complicated (van Teijlingen & Hundley 2001). Being aware of these issues prior to conducting the main study provides the researcher with an opportunity to redesign parts of the study in order to overcome difficulties that the pilot study reveals (van Teijlingen & Hundley 2001). Appendix C contains a discussion of the impact the pilot focus group had on the data collection for the main study.

4.4.2 Use of interviews and focus groups with parents

Interviews and focus groups were found to be appropriate methods for enabling parents to express their views. I used a semi-structured approach which allowed me to ensure key areas were discussed whilst keeping the conversation flow open. This enabled parents to discuss their views freely and gave insights into subjects that may not otherwise have been broached (such as the prosthesis as a tool for parents as opposed to children). Through reading the transcripts (see Appendices L & M) of these interviews, it can be seen that parents were open and honest with me, sharing views that may be in contrast to the usual attributes they present to the outside world. An example of this is one participant who became emotional during the interview and discussed the difficulties of needing to present a "relentlessly positive" facade to the outside world. She also shared concerns about her daughter's delayed independence when compared with her siblings. I found use of prototypes effective in stimulating ideas regarding prosthesis development, but, as previously stated, an audio-visual approach to collecting data using prototypes may have been beneficial.

Figure 29: Reflection on use of focus groups and interviews with parents.

4.4.3 Use of interviews with professionals

Interviews alone, as opposed to in conjunction with focus groups were used for gaining an understanding of the views of professionals. This decision was taken as it was felt professionals would be better enabled to express their own personal views in the absence of their peers. Due to the hierarchical nature of the limb centre, as expressed by participants, a focus group may have been inappropriate: Kitzinger (1995) advises it is important to be aware of how hierarchy within the group may affect the data. Had such dynamics been introduced to the data collection procedure, factors relating to difficulties resulting from financial constraints and multi-professional working may not have been raised by participants. Additionally, arranging focus groups in a location central to all participants would have been extremely difficult due to the geographical spread of the participants.

Despite my attempts to minimise participants withholding views by providing them with a safe and confidential environment to express themselves, there was still evidence of participants being wary about what information they shared. This may have been because they were nervous that their views may be shared with their managers. Some participants began the interview by seeming to defend both prosthetic devices and the service in which they work but later expressed dissatisfaction with both (see Appendix N for an example). Such participants required assurance that their views would be treated in the strictest of confidence. I also shared my own professional background as an OT working within the public sector, which seemed to alleviate participants' perceived defensiveness. This may have been because their perceptions about my credibility were raised, as well as engendering a feeling that I could understand and empathise with the challenges they may be facing in their clinical practice.

Figure 30: Reflection on use of interviews with professionals.

4.4.3.1 Developing an understanding of the views of both prosthetists and therapists

As discussed in section 1.3.6 (pp. 46-47) it was felt necessary to have both prosthetists and OTs represented in the study due to the differences in their professional training and the roles they undertake within the limb centre. Despite these clear differences, the themes identified from the two professions cohered closely. There were, however, some notable differences, as described in chapter 3, which validates the inclusion of both of these professions.

4.4.4 Use of prototypes

Prototypes were used as a way of implementing the technological immersion element of the BRIDGE methodology, enabling the engineer to input his own expertise and introduce new ideas to participants regarding what could be achievable. These prototypes served not only to assure the children participating in the study that their ideas had been listened to and acted upon, but also to stimulate further discussion and idea generation amongst participants. Although valuable data regarding participants' views on the prototypes was gained through conversational methods, the data gathered may have been enhanced with audio-visual recording. This may have facilitated understanding of participants' feedback (as instances in which non-specific references are made such as, *"this bit"*, could have been more fully understood), as well as providing information on the way participants interacted with the prototypes and how easy they found them to operate in practice. Use of audio-visual data in participatory design research will be discussed in further detail in section 4.8.3 (pp.246-247).

4.4.5 Section summary

The previous section has discussed the appropriateness of the data collection methods used and how successfully they were applied in the study. Techniques used to enhance the success of the data collection methods (such as piloting the methods) were also discussed.

4.5 Recommendations for professional practice

The following section presents recommendations for improving the experiences of children and parents when accessing services for children with limb difference. Recommendations relating to assessment and approaches to treatment will be outlined, as well as more general recommendations regarding challenging the current service culture.

4.5.1 Reviewing how and what is assessed

There was a view expressed by parents participating in the research that professionals approach prosthesis prescription from the standpoint of attempting to fit the child to the technology available rather than listening to the child and attempting to address their needs and wants. If occupationally-focused assessments were carried out, the child's needs and wants in terms of their activity participation could be identified and addressed. Furthermore, research suggests that occupationally-focused assessments, based on how disabilities affect everyday activities, are more likely to have meaning and worth to families than impairment-based assessments, such as measures of motor coordination, for example (Tam et al 2008). Assessment that starts with the client and focuses on daily occupations and environmental context reflects a top-down approach to healthcare assessment and intervention. A top-down assessment begins with assessing the meaning of occupations for the client prior to examining the tasks that are required in fulfilment of those occupations. Lastly, the underlying performance components that may be impacting on both task and occupational performance are assessed (Trombly 1993).

A bottom-up approach to assessments, in contrast, begins with assessing the underlying performance components and deficits within these, making assumptions about occupational performance based on the deficits and strengths identified (Trombly 1993). It is assumed within a bottom-up approach, therefore, that improving underlying motor, cognitive or psychological skills will result in improved performance of activities of daily living. The bottom-up approach to assessment and intervention arose in reaction to the emergence of the medical model in the 1920s and a perception that a medicalised view was the gold standard of healthcare provision. However, in line with the gaining prestige of the social model of disability, it has been acknowledged that the OT profession is in the process of refocusing on the value of the occupational needs of clients (Morress 2006). Furthermore, a top-down approach to assessment involves engaging in therapeutic problem-solving, which is in-keeping with the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) (2001) (Rodger 2010). The top-down assessment approach can therefore ensure that healthcare professionals focus on realistic and meaningful occupational issues for clients.

Outcome measures used in upper limb difference have traditionally related to the areas of satisfaction with prosthesis use, hand/upper limb function and prosthesis wear time (Wright 2009). This reflects a traditional bottom-up, impairment focused approach to the assessment and treatment of upper limb difference. Outcome measures examining activity participation and psychosocial well-being are limited. Wright (2009, updated in 2013) carried out a systematic review of outcome measures for upper limb prostheses, identifying nine measures for use with children. Of these nine, four were classified as assessing hand function, three as assessing upper limb functional ability; one was a measure of participation and one of quality of life. With seven measures focusing on function, it could be argued that the emphasis is on a deficit-based approach with limited tools available that facilitate professionals adopting a top-down, client-centred model.

In order to maintain a client- and occupation-focused approach to assessment in paediatric limb difference it may be most appropriate to begin with an individualised measure, such as the Canadian Occupational Performance Measure (COPM, Law et al 1990), to first identify priority areas for intervention for the client. The COPM is the most frequently used individualised outcome measure with children in OT and has satisfactory to good psychometric properties (Tam et al 2008). It can be used with the child and their parents individually, and goals compared in order to reach a compromise both parties are happy with, which is important as children and parents may have different goals (Tam et al 2008).

Following the use of an individualised occupationally-focused measure, more specific measures could then be selected as appropriate to the client-centred goals identified. An observational measure of function that has potential for the professional to select tasks that are most relevant to the client's goals would be of value in this instance. There isn't currently a measure for paediatric prosthesis use which appears to address this need and have strong psychometric properties. The adaptation of an adult tool, such as the Southampton Hand Assessment Procedure (SHAP), to address child-centric occupations may serve to fill this gap. The SHAP is recommended by the Upper Limb Prosthetic Outcome Measures group for assessing performance in activities of daily living and in tasks with abstract objects, for an adult population (Bouwsema et al 2012). Additionally, as previously discussed measures of psychosocial well-being for this client group are also limited and lacking in supporting evidence. Again, it may therefore be necessary to adapt an adult developed tool to suit this purpose. The Trinity Amputation and Prosthesis Experience Scales (TAPES) is a self-administered questionnaire comprising psychosocial adjustment, activity restriction, and prosthetic satisfaction domains that is well-validated in an adult population (Gallagher & MacLachlan 2004). It may, therefore, be suitable for adaptation for use with children (Wright 2009).

4.5.2 Involving children and families

The parents in the current study expressed a desire for more choices within the treatment offered to them and their children. Some of them expressed a feeling that neither they nor their child had been sufficiently involved or consulted in decisions about the treatment received, feeling at times excluded from decisions. One parent even expressed a feeling of being *"pressurised"* by professionals into using prostheses. This is in line with previous research on children's experiences of out-patient clinics, which found that even older children were routinely excluded from discussions and given limited autonomy (Carter 2002). This is important as legislation that guides working with children (United Nations Convention on the Rights of the Child 1990 and Children Act 1989, 2004) states that children must be given the opportunity to say what they think about matters that affect them and that their views should be sought and listened to. Furthermore, building and maintaining strong rapport with clients has been found to lead to positive outcomes (Cole and McLean 2003).

Family-centred practice is an approach to providing services to children with additional needs which considers the family to be at the centre of the services (Law et al 2003). Traditional child-focused approaches emphasise the professionals as the decision-makers with regard to the service a child receives (Law et al 2003). Family-centred practice appreciates the uniqueness of families and places emphasis on the family as the constant social environment in the child's life and expert in the child's needs (Law et al 2003). Decision-making happens as a negotiation between the child, the family and professionals and the strengths and needs of all family members are considered (Law et al 2003). Iwama (2006) argues that the experience of disability may be collective rather than limited to and contained within the individual. The lives of the family members of people with disabilities may therefore be affected and changed profoundly, emphasising the need to involve the whole family unit in intervention.

Family-centred care has been found to result in better psychological adjustment of children with disabilities (Stein & Jessop 1984, 1991) and their parents (King et al 1999). In Stein & Jessop's (1984, 1991) research, families were encouraged to make informed decisions in partnership with service providers and have increased responsibility for managing their child's therapy. Family-centred care was found to result in better parental emotional well-being and less depression and distress. This suggests it is very important that services address parents' needs for information, support, understanding and positive relationships with professionals (King et al 1999).

Family-centred practice advocates that the families of children should work collaboratively with professionals, with mutual respect for the skills and expertise brought to the relationship and joint decision-making (National Centre for Cultural Competence 2007). A practical way to implement this may be to ensure appropriate information about treatment options is provided to children and parents in the most appropriate format for them.

4.5.3 Child- and family-centred training for prosthesis use

Parents in the current study described the difficulty of attending all the appointments required for prosthetic training due to the other demands on them in caring for their family and working. Professionals also demonstrated awareness of the commitment required of families when the child received a myoelectric prosthesis and reflected on some of the difficulties this can present. The importance training has on the success of myoelectric use in children is well-documented (e.g. Hubbard et al 1985; Hermansson 1991; Egermann et al 2008). The current study has evidenced the need for this training to be relevant and meaningful to the child and incorporate the needs of the family unit. One way to manage this may be to deliver a training regime that is incorporated in the everyday lives of children and families and through therapy that occurs in the child's home environment rather than the clinic setting, but the therapist hours required to implement this may make it unrealistic within an NHS setting. An alternative may be to develop computer based training programmes that children can carry out in the home setting, reducing the number of appointments that children and families will be required to attend at a limb centre. Several computer training packages for myoelectric use are already in existence (e.g. Lovely et al 1990, Armiger & Vogelstein 2008, De La Rosa et al 2009, Oppenheim et al 2010, Ottobock 2013). However, they present issues with affordability and availability, generally being used in clinic settings as opposed to in people's own homes. Furthermore, they focus on developing competency in the use of myoelectric devices only. There may, therefore, be a need for an affordable and portable training package that is fun and motivating for children and suitable for use with both mechanical and electric devices.

4.5.4 Challenging service cultures

In order to achieve family-centred and occupationally-focused assessment and intervention in paediatric limb clinic settings, it is necessary to challenge some of the existing cultural norms

4.5.4.1 Moving away from 'rejection': accepting non-use as an option

As previously discussed, in section 4.2.3.1 (pp.210-212), using the term 'rejection' to describe children's non-use of prostheses in inappropriate and unhelpful. Changing the language used in clinical settings to describe children's choices with regard to using or not using prostheses will help to recognise not using prostheses as a legitimate treatment choice. Professionals need to have the confidence to recognise that prosthetic management is not always the best treatment for children and young people. Other interventions, such as adaptive devices, adapting tasks/environments or finding alternative ways of completing activities can then be explored.

4.5.4.2 Less hierarchical structure

Evidenced throughout the findings was the existence, at least in some settings of a hierarchical structure to treatment decisions, with consultants being at the top of the hierarchy, followed by prosthetists. Parents and children expressed feeling they were not consulted in decisions, suggesting they are positioned at the bottom of this hierarchy. If services are to practice in a family-centred way a hierarchical structure cannot be maintained: professionals from different disciplines, children and families need to work together on an equal basis to achieve the best outcome for the child and their families.

4.5.4.3 Minimum service requirements (to reduce inequality)

In order to reduce the inequity that exists between services, minimum service requirements should be placed on centres, with relation to the staffing required and the services offered.

- **Core staffing requirements**

As previously discussed, huge discrepancies exist between services, with some services having no OTs, no counsellors and prosthetists that have limited experience working in upper limb prostheses or with children. If services are to offer family-centred treatment that focuses on the participatory needs of children, OTs and counsellors are essential team members. OTs are the professionals best placed to carry out the assessment and goal setting required to fulfil these needs and counsellors are essential to ensuring the psychosocial needs of children and families are being met by services.

- **No blanket policies of non-prescription**

It was evident in the interviews with professionals that some services did not offer certain devices (such as myoelectric prostheses and silicone cosmeses) to children. Blanket policies such as these, whether official or unwritten, serve to reinforce the ‘postcode lottery’ and, if challenged by clients, may represent maladministration of services, which could result in serious financial consequences for NHS Trusts.

4.6 Recommendations for device development

Based on the findings from the current study, several recommendations regarding the development of prosthetic devices for children and young people are proposed. These include developing cost-effective task-specific devices, exploring modularity and improving comfort and weight.

4.6.1 Off the shelf task specific devices

Having cost-effective task-specific devices that are not custom-made will reduce the impact of the diversity in skills of professionals at different centres. Professionals working in centres which do not have access to an onsite workshop with highly skilled technicians will still be able to offer children and young people devices that meet their identified activity goals. These devices should aim to be as easy, natural and intuitive, to use as possible. Activities that it would be useful to have off-the-shelf prosthetic devices available for include cycling, writing/typing/computer use and self-care/grooming. Devices should also be designed with durability in mind due to the environments in which children use prostheses and the activities for which they use them.

4.6.2 Modular devices

More technically, advanced devices should be designed with modularity as a key feature. Modularity within upper limb prosthetics could include standardised and individually removable fingers, for easy repair or flexible arrangement and use. As identified by the project advisory group, modular devices will reduce the impact of breakdowns and repairs as children and young people will not need to be without their prostheses for long periods whilst it is being repaired. Additionally, modular devices can be more adaptable to a child’s growth and development, as certain aspects can be altered without the need for an entirely new device. This may also increase the propensity for services recycling devices or parts (Supan 2002). Lack of recycling/reusing prosthetic devices was an element of practice many of the professional participants found to be unsatisfactory. The lack of options for recycling devices not only has clear cost implications but it is also concerning when considering the NHS commitment to reducing carbon emissions as governed by the Carbon Reduction Commitment Energy Efficiency Scheme (CRC): a mandatory energy efficiency scheme affecting the majority of NHS organisations (Sustainable Development Unit 2013). Sixty percent of the NHS's current contribution towards climate change comes from procurement, including medical devices and equipment, such as prosthetics (The Climate Connection, 2009). The Climate Connection (2009) advises that health trusts should minimise waste when buying devices and equipment through making decisions based on the whole life-cycle costs of the device/equipment.

4.6.3 Socket comfort

Socket comfort was identified as a highly important feature of prostheses. Heat, sweating and discomfort were found to result in children choosing not to wear prostheses. The scope for the current study was to develop terminal devices, but future device development needs also to focus on improving comfort for the wearer: an otherwise highly useful device may go unworn if it causes pain or discomfort to the wearer. An area that may warrant further exploration is the use of materials that are more malleable, to prevent damage to the wearer and others through accidental contact. It would also be beneficial to improve the wear temperature and the comfort of the material against the skin of the residuum. Improving flexibility at the elbow may prevent restriction of movement for the wearer.

4.6.4 Reduced weight

Weight was another highly important issue identified in the current study. Device development may benefit from focusing on reducing the weight of particular components. However, another way of addressing this concern maybe to provide appropriate training that gradually prepares a child for the increased weight of a prostheses. Some professional participants shared low-tech methods they have used for doing this, such as attaching gradually increasing weights to a child's current passive or body-powered device to prepare them for the increased weight of their next body-powered or myoelectric prostheses. Prosthesis training that is more appropriate to children and families (as discussed in section 4.5.3, pp.234-235) could take account of the need for children to develop their muscle strength to manage increased prosthesis weight. Research exploring innovative home-based therapy for children with other conditions (such as cerebral palsy) has suggested computer technology has great potential due to it being intrinsically motivating for children and young people, and something they are very familiar with (Snider et al 2010). Incorporating wearing graded weight increased prostheses with carrying out computer game-based activities could not only help the child to adjust to the weight difference but also improve their competence and confidence in motor tasks (Snider et al 2010). Sugumaran & Prakash (2011) suggest that, when playing games, children may become so engrossed in the activity that they ‘forget’ they are taking part in therapy, increasing the likelihood they will adhere to the therapy programme prescribed.

4.7 Recommendations for research with children

The current research has provided support for involving children as active participants in research. Four specific recommendations have originated from reflections on the execution of the current study:

- That children should be involved in research into medical device development;
- That they should be provided with a variety of ways to express themselves (in the absence of their parents if possible);
- It should be evidenced to the children that their views have been listened to.

4.7.1 Children can and should be involved in medical technology development.

The current study has demonstrated the value of involving children in the development of prostheses and medical technology generally. The participants demonstrated an ability to engage fully in the study and share unique insights which may not have been gleaned through other methods. Appreciating the involvement of children reflects the ethos of the BRIDGE methodology: children are experts in their daily lives and design cannot happen without the involvement of these experts (Iversen & Brodersen 2007).

Furthermore, Iversen & Brodersen (2007), argue that adopting a sociocultural view of learning necessitates an acceptance that children's involvement can be treated as equal to the involvement of adults. The current study has demonstrated that this approach to participatory design can produce rich and relevant data. Additionally, a consequence of involving children in the design process is that they will gain experience of these ways of working with adults, which will enable their learning and development for future participation (Iversen & Brodersen 2007).

4.7.2 Children should be provided with a range of ways to express themselves but these should be used at their discretion.

As a result of theoretical underpinnings within the BRIDGE methodology, coupled with learning achieved through the pilot focus group, the decision was taken to use the same conversational data collection methods with both children and adults. Creative methodologies were considered, and some practical and craft activities devised, as well as arts materials made available for children's use. No creative activities were enforced within the data collection: the use of other methods for self-expression was left totally to the discretion of the participants. It is interesting to note that none of the participants used the arts materials, choosing to express themselves through words and occasionally demonstrations.

Bagnoli & Clark (2010) suggest that creative methodologies enable children to communicate words they cannot otherwise say, use metaphors, demonstrate ambiguous or ambivalent feelings, and remain engaged in the task. They also suggest that creative activities are engaging. Their research indicated that children did not want to take part in research which required them to just sit and talk (Bagnoli & Clark, 2010). The participants in the current study remained engaged throughout, however, reflecting that they enjoyed talking about their prostheses and having their opinions listened to. This may suggest that children and young people may be more likely to remain engaged with a study when the research concerns an issue that is important and meaningful to them.

4.7.3 Participation in the absence of their parents

In the current study, efforts were made to provide children with an opportunity to share their views in the absence of their parents. This was facilitated by providing parents with a chance to express their own views by participating in an interview or focus group themselves.

It was felt this was important as children may withhold information in the presence of their parents (Garth 2009), particularly when discussing a subject that is emotive for parents. Some parent participants became emotional when sharing their experiences of their child's disability. If they had been present during the interview with their child, their emotions may have become evident and prevented the child from feeling able to express their views honestly for fear of upsetting their parent. Additionally, it may have made the experience of participating in the interview unnecessarily distressing for the child.

Furthermore, the presence of parents could result in coercion for the child to cooperate in the research: parents may feel embarrassed or unhelpful if their child chooses not to participate. Indeed, this may have become an issue in the current study. One child participant, Lauren (14), was two hours late for the arranged time for her interview. Her parents appeared embarrassed and were very apologetic, and both participated in interviews of their own prior to Lauren's arrival. When Lauren did arrive, her parents made it clear that Lauren would be participating in an interview with the researcher regardless of what her preference was. Lauren's parents were then asked to leave the room so the interview could begin and it was explained to Lauren that she did not have to participate and that her parents did not need to know that she had not participated. The researcher engaged Lauren in general conversation about her interests in order to create the impression to her parents that an interview had taken place. After some time, and having been able to build trust and rapport, Lauren voluntarily said that she would like to participate in the research interview. It was reiterated to Lauren that she did not have to answer any questions she did not want to and she could end the interview at any time and the interview then commenced. This demonstrates two important factors influencing the decision to interview children in the absence of their parents: it reduces the possibility of coercive participation and enables the researcher to build rapport with the participants.

4.7.4 Listening to children and young people's views and demonstrating this.

It is not sufficient to assume that by carrying out interviews and focus groups with children and young people that they have automatically been listened to or, indeed, that this is their perception. Clark (2005) advises that listening is an active process of communication, which combines hearing, interpreting and constructing meanings from the information shared by participants. This active listening is an essential element of participation and implies a sharing of power (Miller, 1997).

Using prototype devices and requesting feedback on them is a tangible way of demonstrating to participants that this listening has occurred. If prototypes are in line with children's expectations, they can provide validation that appropriate interpretations have been made from the information shared by the participants.

4.7.5 Section summary

The previous section has outlined recommendations that have originated from the findings from, and reflections on, the current study. These recommendations encompass clinical practice, device development and research with children. They include such issues as changing approaches to assessment and treatment; focusing on task-specificity, modularity, comfort and weight in device development; and involving children as equal partners in research into medical device development.

4.8 Reflections on the strengths and limitations of the research design and interpretation of results

The following section will focus on any potential weaknesses in the way the study was carried out and identify any improvements that could have been made. Three main issues have been identified and will be discussed: the potential for researcher bias, limitations to the participatory element of study design and difficulties encountered by not having video data for the interviews and focus groups that involved reactions to prototypes.

4.8.1 Potential researcher bias

It is important that the results are considered in relation to the researcher's professional background. As an OT, there may have been a tendency to focus on elements of the discussion that related to daily activities, participation and the disabling impact of unsuitable environments, for example. Whilst the influence of the researcher's own professional identity is likely impossible to fully eliminate it could be argued that the multi-professional nature of the research team may have helped to ensure a balanced interpretation of the findings. With input from engineering and psychology a more holistic approach to the data could be taken.

Myers (2000) suggests that objectivity in qualitative data is made more difficult due to the sheer volume of data. Presenting the data in a readable format, inherently involves summarising the data which can present the possibility of presenting a subjective rhetoric. Myers (2000) suggests that one way of managing this is to triangulate the data in some way. In the current study, triangulation of users (children, parents and professionals) lends support for the notion that the views presented represent those of the participants and not the researcher. One example is the views of participants' on prosthesis weights: children, parents and professionals all described prosthesis weight as an issue and independently both a child participant and a professional participant provided an example of children having to support their prosthesis with their other hand.

There were some additional issues with the execution of the study's methods that may have impacted on the truthfulness of the data collected, including the challenge of being a researcher and a practitioner (and resisting the urge to problem-solve and provide advice during interviews). This was addressed through discussion and debriefing during supervision sessions. Other issues were participant attrition in the second stage of data collection and the inclusion of an engineering PhD student (inexperienced in qualitative research) in the second focus group. A personal reflection of this is presented in a 'thought bubble' text box to indicate it is written in first person (see figure 31).

It was planned that Dr Andy Cranny would attend the focus groups to explain the prototypes he had developed and answer any technical questions. However, unfortunately Dr Cranny was unable to attend on the day. A fellow PhD student (in engineering) from the research team kindly agreed to fulfil this role on the day. My understanding of his role in the focus group was to explain/demonstrate the prototypes to participants and answer any questions they had about them. However, perhaps due to his enthusiasm for the prototypes, he became involved a lot more as a group facilitator, posing questions to participants. These were largely closed questions, some of which appeared to seek validation of his ideas rather than the ideas of the children themselves being explored.

What could I have done differently?

- Provided a better explanation to all members of the research team (at team meetings) about the purpose and methods of qualitative focus groups in case of unforeseen changes in those involved.
- Suggested training for this particular member of the research team in qualitative methods.
- Spent more time on the day discussing the focus groups with him and more clearly defined for him what his role would be.
- Managed the focus group better by applying facilitation techniques to help manage the input of this team member in a professional manner.

Figure 31: Reflection on involvement of an engineering PhD student in the second focus group.

A way to further enhance the truthfulness of the data, and reduce the possibility of subjective interpretation, would have been to include children with upper limb difference, parents of children with upper limb difference and professionals working in the setting on the project's advisory board.

4.8.2 Research designed by researcher (not co-designed with participants)

In the current study, child participants were involved by being invited to share their views and having those views impact on the design process of upper limb prostheses. Jardine & James (2012) suggest that the participation of children and young people can occur at eight different levels. This ranges from non-participation to true participation (which includes research initiated by young people or shared on equal terms with adults). Jardine & James (2012) suggest that involving young people directly in research on issues relevant to them (such as the current study) is a means of promoting participation.

Although the current study did directly involve children and young people as participants, they were not engaged as researchers themselves, which would have further confronted issues of power, whilst benefiting both the young people and the quality of the data obtained (Jardine & James 2012). Ideally, in the current study the whole research process would have been co-constructed by the researcher and children with limb difference. However, it was not possible for this to occur for several reasons, such as the complex ethical issues participatory research with children raises and the researcher's lack of experience and confidence in dealing with these.

In participatory research the boundaries between different stages of research can become blurred, creating difficulties in identifying the appropriate time to obtain informed consent (Durham Community Research Team 2012). This is particularly when working with groups who may be deemed vulnerable, such as children and young people (Durham Community Research Team 2012). Consent as a formal, discrete criterion becomes marginalised, which can result in consent being presumed by a lack of withdrawal rather than sought as a positive assertion (Durham Community Research Team 2012). Furthermore, gaining the appropriate ethical approvals to begin the research may have proved extremely difficult, both due to the complexities of consent issues, and as a result of the potentially unpredictable nature of the overall research process.

4.8.3 Lack of video data

In the current research, interviews and focus groups were recorded using audio equipment. It became apparent, however, that in the focus groups and interviews which involved participants giving feedback on the prototypes that visual data would have been useful. Visual data would have aided in recall and comprehension of the participants' opinions as at times they would refer to 'this bit' or 'that bit' of a prototype. Furthermore, having data on the way the children and young people physically responded to and interacted with the prototypes might have added another element to understanding their relationships with the devices.

The use of video recordings in design research with children is widely discussed with regard to how children respond to the use of a video camera and whether the video camera interferes with the process (Druin 1999). Druin (1999) argued that the difficulty of using video cameras in design research with children is that they tend to either 'perform' or 'freeze'. Iversen & Brodersen (2007) found that children did react to the video camera by, for example, making faces and trying to ensure they are captured by the camera. They argue however that this is no different to adult users' reactions to the presence of a video camera; children are just more explicit in their reactions (Iversen & Brodersen 2007). Iversen & Brodersen (2007) also suggest that this is not necessarily a problem in research that focuses on design as the process of designing is a somewhat artificial one that is not part of children's everyday lives. Their 'performance' in front of a camera is, therefore, 'normal' behaviour for this unusual situation.

Furthermore, Iversen & Brodersen (2007) suggested that the use of a video camera in research that focuses on design can encourage the sharing of tacit knowledge. In their collaborative design workshops with children and adults, they found that those members of the groups that were less vocal and, subsequently not given opportunities to share ideas by their peers, used the video camera as a way of having their voice heard, sharing their ideas directly with the camera. Without the presence of the camera they may not have had an avenue for sharing their ideas, suggesting that 'performing' for a video camera can be beneficial in research if it enables the 'quieter' voices to be heard as equals to those that are more powerful. Video can, therefore, be applied within the BRIDGE methodology as a powerful documentation tool (Iversen & Brodersen 2007). Other benefits of the use of video recording in qualitative data collection may be having non-verbal communication and the physical context of the interview/focus group captured for repeated viewings by the researcher, reducing the reliance on field notes and memory (Kreuger 1994).

4.8.4 Section summary

The previous section presented some potential weaknesses in the way the study was conducted and made some suggestions for how these weaknesses could have been minimised. These suggestions include:

- Ensuring appropriate training for all members of the research team;
- Having representatives from the participant groups on the project advisory board;
- Using audio-visual recording devices to capture data regarding participants' responses to the prototypes.

4.9 Suggestions for future research

In the following section, suggestions for further research in prostheses for children are outlined. These suggestions have been formulated through reflecting on issues highlighted in the current study's findings, the contribution of these to understanding paediatric prosthetics, and those areas in which further knowledge is needed.

4.9.1 Observational study of prosthesis use/non-use

The current study has explained in depth the *meaning* of prosthesis use for children/young people, their parents and professionals, where meaning refers to significance within a person's life and culture (Reed & Sanderson 1999). The findings have strongly indicated prostheses are valued as a tool/assistive device for participation in occupations. To fully understand the *form* of occupations using prostheses, observational information is necessary. 'Form' refers to the environmental and task demands of performing the occupation

(Reed & Sanderson 1999). It would be useful, therefore, to conduct an ethnographic study of prosthesis use in children's daily occupations. Furthermore, this would build on other research that is being conducted within the research team that is attempting to develop a classification of the most common hand grips in children. In this study, the researcher is collecting observational data on children's hand grips whilst carrying out daily occupations: it could, therefore, be viewed as a focused activity analysis, concentrating only on hand use. An observational study of children carrying out preferred occupations with and without their prostheses could, therefore, be viewed as a focused performance analysis, identifying the factors that are impeding on a child's occupational performance in these areas.

Observing children carrying out these activities both using their current devices and without using a device could provide insight into the ways in which the device may be inhibiting, or at least not facilitating, performance of the activity. Analysis of this information could then be used to further develop the prototypes from the present study or to design additional prototypes. A follow-up observational analysis could then be carried out with the children using the prototype prosthesis to carry out the activities (subject to thorough risk assessment) to determine whether the prototype devices better facilitate performance in the activities than current devices.

4.9.2 Development of client-centred assessment tool for use in paediatric prosthetics

As discussed earlier there is a need for client-centred assessment tools for use in paediatric limb difference. An observational measure of function which includes client identified activities and a measure of psychosocial well-being for this client group would be beneficial. The data collected in the current study could be reanalysed to inform the development of adult outcome measures into appropriate tools for use with children and young people. A small-scale feasibility study would then be required to refine the questions/activities to ensure they are appropriate to the children and not too difficult or time-consuming for clinicians to use in practice. Psychometric testing and development of the tool can then occur. This will provide clinicians and researchers with appropriate and robust tools for use with children and young people with limb difference that can be used in practice. The tools when used in conjunction with an interview-based assessment measure, such as the COPM, will ensure that client-centred, occupationally-focused assessment, that takes account of both physical and mental health needs, can be carried out with children and young people with limb difference.

4.9.3 Longitudinal study exploring impact of limb difference and patterns of prosthesis use across ages.

As discussed previously, participants in the current study identified that prosthesis use amongst children and young people follows certain patterns that reflect changes in their physical and psychosocial development, as well as changes to their environment (such as using a prosthesis when first attending a new school). Having an in-depth understanding of the patterns of prosthesis wear would support professionals in predicting a child's changing need for prosthetic devices and provide evidence for presentation to service funders to assist with ensuring services have the appropriate levels of funding to meet the needs of their service users. In addition, having information about children and young people's use and non-use of prostheses would provide evidence against the notion that children 'reject' devices.

It may be possible to gather the necessary data by reviewing records at limb centres regarding which devices have been prescribed at different ages for children and young people. This may also highlight the differences in provision between the different centres, adding weight to the argument that there is a postcode lottery in this setting.

4.9.4 Views and experiences of siblings

Due to the scope and time constraints of the current study, it has not been possible to involve siblings. If, however disability is understood as a collective rather than individual experience, as suggested by Iwama (2006), the experiences of siblings are vital for a full understanding of the experience of limb difference and prosthesis use for children. The lives of the family members of people with disabilities may be affected and changed profoundly when understood from this collective perspective, thus emphasising the need to involve the whole family unit in studies that seek to explain experiences of disability.

Furthermore, research into siblings of children with limb difference is missing from the evidence base for this client group. However, research into the experiences of siblings of children with disabilities has found that growing up with a sibling who has a disability can present difficulties for a child. The tendency for parents to focus on the needs of the disabled child can affect a child's development of identity (McHale & Gamble 1987). Additionally, societal stigma surrounding the issue of disability (which was evident in the findings of the current study) also impacts on siblings and can impact on the developing relationship between siblings (Philip & Duckworth 1982). Furthermore, the elevated stress described by parents in the current study has also been found to be evident in siblings of children with disabilities (Sharpe & Rossiter 2002).

It would be beneficial, therefore, to develop and understanding of children's experiences of having a sibling with limb difference. Using conversational methods, such as focus groups and interviews, would be appropriate for developing an in-depth qualitative understanding of their experiences. They may also benefit the participants by providing an opportunity for this rarely consulted group to express their views and feel listened too.

4.9.5 Section summary

The previous section has suggested some useful future research avenues in the field of paediatric prosthetics, specifically:

- An observational study of prosthesis use;
- Developing appropriate paediatric outcome measures;
- A longitudinal study of patterns of prosthesis use;
- A qualitative study to improve understanding of the experiences of siblings of children with limb difference.

These studies would all add valuable insight into issues which could improve the experiences of children and families accessing limb centres.

4.10 Chapter summary

In spite of highly reported non-use rates of upper limb prostheses in children and young people, research directly addressing children's views of, and relationships with, upper limb prostheses has been neglected. This has been in favour of quantitative and parent proxy studies on children’s satisfaction with, and use of, devices.

Using qualitative methodologies, employed through the BRIDGE approach to designing with children, has enabled the development of our understanding of the phenomenon of paediatric prosthetic use from the perspective of three main user groups. This highlighted similarities and differences in the experiences of the different prosthesis users in the social scene, enabled the development of new devices and suggested that much could be done to improve the provision of services to children with limb difference and their families.

It is hoped that this study has demonstrated that children can and should be treated as equals in research and design, and that other researcher and designers will be encouraged to involve users, particularly children, in the development of future assistive devices and health technologies.

Conclusion

This thesis has attempted to identify and explain factors related to prosthesis use for children and young people in order to provide recommendation for service improvement and to develop devices that may better meet their needs. A participatory design approach, specifically the BRIDGE method, was used to examine the current situation with regard to upper limb prostheses for children, their parents and the relevant professionals working in the area. Current service provision varies greatly across the country in terms of the staff working in the services, the devices they provide, and the ongoing training and therapy carried out.

The study has identified key factors that if addressed may help to rectify the current inequities, including reviewing how and what is assessed, implementing family-centred treatment practice and challenging service cultures. The study has also led to the development of several cost-effective task-specific prosthetic devices that are suitable for further development and refinement either by the current research team or by an industry partner, which requires further exploration. However, implementing such changes as recommended in this thesis and making new devices available does not necessarily guarantee the improvement of services. The study has identified many and varied factors impacting on upper limb prosthetic services for children. Some of the issues identified require addressing at a national level in order to enable changes to be made at a service level (for example improvement of staffing levels will require investment of funding). Furthermore, any changes should be brought in in partnership with the health professionals and service users involved and should respect the culture of the organisation. It is widely recognised that changes to practice in response to research findings or insights relating to improved service-user experiences occur slowly and that healthcare professionals learn and adopt new information gradually (Grol & Winseng 2013). Furthermore, there are many and varied approaches to implementing change in healthcare, based on differing philosophical assumptions (Grol & Winseng 2013), a discussion of which is beyond the scope of this thesis.

It is intended that this thesis offers insight into current factors affecting prosthesis use and non-use in children and young people as well as outlining a method for successfully developing healthcare technology involving users, whether children or adults.

Closing reflection

When I began this study in October 2010, it was in fulfilment of a desire not only for higher academic achievement but also in response to my frustration at being unable as a health professional to enact service-level changes for children with disabilities and their families. As I became more immersed in the field of paediatric upper limb prosthetics it became apparent that the users of the devices were also the professionals themselves and that, they too, were dissatisfied and frustrated with their current situation and the services they were able to offer their clients.

As an experienced practitioner working on a day-to-day basis with children and families, my ability to develop skills in qualitative research with these client groups was, perhaps surprisingly, less challenging than developing my skills in conducting research with other professionals. Interview experiences, in which fellow professionals were reluctant to share their views openly with me and appeared suspicious of my skills and agenda, led to moments of self-doubt and loss of confidence about my ability to carry out this important research effectively. However, once I recognised that my skills in empathising with, and actively listening to, children and parents were transferrable to professional participants I was able to overcome these doubts and develop my research skills with this participant group also. In this way it can be seen that by applying skills gained through clinical work to the research setting, the processes of conducting qualitative research has influenced my own professional development.

Although this represents the conclusion to this current study, I believe it contributes significantly to the understanding of children’s use of upper limb prostheses and opens up avenues for further exploration and knowledge development within the field. Furthermore, the iterative nature of participatory design implies a continual evolution towards improved products and improved outcomes, of which it is hoped this is just the beginning.

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Appendices

Appendix A

Papers, Posters and PowerPoint Slides from Conferences

Paper from the MyoElectric Controls/Powered Prosthetics Symposium.
August 2011: Fredericton, New Brunswick, Canada.

THE DESIGN OF A MYOELECTRICALLY CONTROLLED HAND WITH MULTIPLE ACTUATORS FOR FIVE-YEAR OLD CHILDREN

Thomas Redman[1], Tara Sims[2], Paul Chappell[1], Maggie Donovan-Hall[2], Andy Cranny[1], Cheryl Metcalf[2] and Neil White[1]
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ABSTRACT

Myoelectric prosthetics are complex functional devices that can improve significantly a person's quality of life. This paper describes the development of a myoelectrically controlled prosthetic hand for a five-year old child. A key consideration in the design of upper-body prostheses is to use information from studies highlighting the main causes of rejection. These studies emphasise that in order to reduce rejection, it is necessary to include the opinions of the users in the design process. Additional constraints are introduced due to the small size and mass of a five-year old child's hand compared to that of an adult. The main points of the final design are detailed, including the areas where these constraints were overcome. Modularity was used throughout the design; it allows the hand to be configured for the individual user, and also helps to reduce the potential cost of the hand. The final design has three actuators controlled individually through the use of a master-slave microchip combination. This design has a final mass of 105.8g and produces a pinching force of 4.35 N.

INTRODUCTION

There have been greater advances in the design of prosthetic hands for adults compared to those for children. Although there have been developments to child prostheses, they have not always been in line with those made to adult prostheses. Acceptance of the user is a key consideration in the design of upper-body prosthetics. It is generally recognised that the younger a user is introduced to a myoelectrically controlled prosthesis, the greater their acceptance of the technology [1]; this is encouraging the fitment of functional and adaptable prosthetic limbs to young children. To provide choice, hands designed specifically for the needs of children are required. Currently there are two commercially available upper-limb prostheses specifically designed for children: the Otto Bock 2000 Electric Hand, and the RSL Steeper Scamp Myo Electric Hand. Both of these hands are single degrees of freedom devices that are available in various sizes, and driven by a single actuator that closes the first and second fingers onto the thumb. Improvements in child prosthetics could be made with improved adaptability and an increased number of individually driven axes. To address this, the development of prostheses for children that are produced in conjunction with research into the acceptance and needs of children is needed. This paper describes how a prosthesis for young children was designed with multiple degrees of freedom, modularity and functionality, taking into account considerations from both a user's perspective and from technical constraints. (A final prototype can be seen in figure 1.)

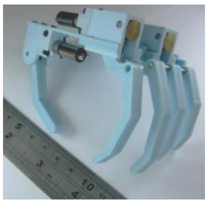

Figure 1 – A Prototype Myoelectric Hand.

USER CONSIDERATIONS

Rejection rates of upper limb prostheses amongst children have been reported to be as high as 50% [2]; indicating that upper limb prostheses that are currently being prescribed are not meeting the needs of young people [3]. Research into rejection of prostheses amongst adult users found dissatisfaction with the prosthesis to be linked to rejection [4], therefore highlights the importance of including the views of users when developing new prosthetic devices. This is supported by Biddiss & Chau's [3] historical review of upper limb prosthetic use and abandonment, which concluded that “increased emphasis on participatory research and consumer satisfaction is needed” Biddiss et al [5] involved prosthetic wearers of all ages to inform prosthetic design by identifying their key development priorities. These were reduced weight, lower cost, life-like appearance, improved comfort, enhanced wrist movement and better grip control/strength. The design priorities varied substantially across age groups, suggesting that upper limb prostheses designed from the users’ perspective would be different for children compared to those designed for an adult. This supports the need for prosthetic hands for children designed alongside studies into the views of the users. Before this user-led design, it is necessary to explore the technical feasibility of designing a hand of this size and mass.

At Southampton University a study (Our Bodies Our Views) used questionnaires and interviews to examine satisfaction with prostheses and reasons for prosthesis rejection in young people with upper limb loss aged 5-18 years. Three factors were identified as important amongst the participants. They were: the look of the prosthesis; the functional ability, and being involved in the selection of the prosthesis. Reasons identified for not wearing the prosthesis were: it was uncomfortable (including being too hot and too heavy); that it is only useful for specific tasks; the artificial appearance of the prosthesis (attracting unwanted attention), and wear and staining. This study also highlighted the importance of communicating with children when designing prosthetic devices.

TECHNICAL DESIGN CONSTRAINTS

Table 1: Hand Measurements of 5 and 16 Year Olds [6].

When designing prostheses for children there are issues introduced due to the differing size and mass requirements. Table 1, for example, shows average hand measurements for 5 and 16 year olds [6]. The data in rows E & F, shows that irrespective of age, certain proportions of the hand are virtually unchanged. However, the natural hand of a five year old child is two thirds smaller than that of the average 16 year old (approximately equivalent to an adults hand); suggesting a similar difference in the overall mass. The effect of this constraint is most prevalent in the design of the drive system, where the consideration of output power and speed are equally important. However larger actuators are typically heavier. Including multiple functional axes means that multiple drive systems are required; as a result there is a summing effect of the significance of the drive system weight.

DESIGN OF A PROTOTYPE HAND

To realise a design that is both cheap and flexible, the decision was made to include a high level of modularity. This would be split into two levels. The first level would be in the manufacture to aid in reducing the number of different parts and construction processes, therefore, reducing the cost of manufacture. The second is to provide technician level reconfiguration; to provide the user with flexibility and choice when choosing their exact specification. This permits easy setup, reconfiguration and maintenance of the hand; possibly allowing for reduced post-fitment costs.

An electric motor and gearbox was used to actuate the hand since it is the common method of actuating myoelectric prosthetic hands. The design of the gearbox arrangement is based on a scaled version of the Southampton Hand’s gearbox [7]. It uses Faulhaber DC-Micromotors (0816 with a 64:1 gearbox) to drive the fingers and thumb through a worm-wheel combination. The defining characteristics of a drive system are the output speed and torque. Both of these values are determined by the characteristics of the motor and gear chain. Equation B (Appendix A) shows that the gears have a linear effect on the output torque and an inverse relationship with the output speed.

The motor selected for this project produces 0.15 mNm and rotates at 15,800 rpm (263.3 rps). There are two gear combinations in the drive chain, the first has a ratio of 64:1 and the second has a ratio of 20:1, with respective efficiencies of 60% and 89%. The torque across a gear system increases proportionally by the ratio of the number of teeth on the gears in the system, the speed through the system decreases with the same relationship. This determines the output characteristics, of 0.12 N maximum force and a maximum speed of 0.13 rps.

Two essential considerations were identified for the design of the prosthesis: the speed for 90^{o} closure of the hand and the force produced at the fingertip. It is assumed that the fingers only rotate through 90^{o}. Equations C and D were used to convert the drive system output characteristics into prosthetic output characteristics. Equation C gives a closure time of 1.95 s. Equation D shows that to calculate the force at the fingertip, the length of the finger from the rotating axis is needed. This design has a middle finger measuring 55 mm which gives an output force of 2.17 N. This produces a theoretical combined finger closure force of 4.35 N. These characteristics are not optimal and improvements do need to be made in the speed and force generation. However, it was decided since the hand was for a preliminary study these characteristics would be acceptable.

The artificial metacarpophalangeal (MCP) joint is defined as the key component in the design, as it houses all of the driven components of the hand. As mentioned previously, the design is based on the Southampton Hand [7]. However scaling the design needed careful consideration to ensure adequate strength of the components. The design incorporates the axle for the motor and is split to allow the worm to be placed into the MCP joint. A key feature in this design is the connection slot to allow the MCP to fit into any of the four MCP locations on the palm.

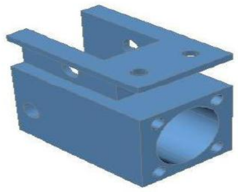

Figure 2 - Prosthetic Metacarpophalangeal (MCP) Joint

The shape of the fingers and thumb was chosen to mimic that of a human hand and to allow the first finger and the thumb to form an effective pinch. The base of the finger has a slot to allow for a strong and effective coupling to the wheel gear. The curved base of the finger is aligned with the MCP joint when straight; this allows the fingers to lie flat when fully extended.

The hand uses a microchip-based control system in a master and slave configuration. This design increases the modularity of the system; allowing for easy reconfiguration and motor addition. It uses an overcurrent device to regulate the force at the fingertips but has the availability to incorporate embedded force sensors into the fingertips. The current system though functional, does not provide closed feedback required for fine touch.

Figure 3: A Prosthetic First Finger.

DISCUSSION

This study shows that it is possible to build a prosthetic hand that incorporates multiple actuators for children aged five-years. The final prototype is 127 mm long and 60 mm wide; these values are comparable to the size of a five-year old human hand. The mass of this design is 105.8g; this value is similar to that of existing prosthetic hands for children. However, the mass can be reduced through material changes and design alterations. All of the components of the drive are interchangeable throughout the system; including the motors, gears and all drive shafts. The hand has only 22 different mechanical parts; including 7 drive shafts, screws and pins that all require minimal manufacturing. The second level of modularity allows for the hand to be reconfigured to fulfil the exact requirements of individual users without any adjustment to the design. An example of this is that the middle finger for one user may be the index finger for another. This would reduce the total amount of components that a fitment centre stocked, therefore, potentially reducing the costs.

CONCLUSION

This novel, child prosthetic hand is fully adaptable, whilst, still providing a high level of functionality. The design confirms that it is feasible to provide hands for children that are able to deliver choice, without compromising on the size or mass. The power of the drive system may be increased without affecting the target age and functionality and can be achieved by changing the motor and the design of the MCP joint. The modularity in the design added significant functionality and showed that it could increase the choice given to the users, whilst reducing pre- and post-fitment costs. This area of research calls for further development.

FUTURE WORK

This study highlights several areas for possible improvements, the first of which would be to increase the speed and force characteristics. Further studies will be undertaken to improve the control system by including force and position sensors allowing for the development of a hybrid force-position control system. This could be implemented with the use of encoders on the motor shafts to infer position of the fingers. During a redesign, the mass of the hand could be reduced further with the use of different materials and an altered drive system. The modularity incorporated into the design could be adapted to provide in-service reconfiguration. This would further increase the functionality and could reduce the need to service the entire hand.

Having confirmed the feasibility of producing a hand with suitable size and mass characteristics, research focusing on the users' views is needed. Although this study begins to address user considerations and reasons for rejection this was not extensive. Therefore further research will be conducted to investigate the aspects of prostheses that are important to children, and to explore their views on new designs for future devices.

ACKNOWLEDGEMENTS

The authors of this paper would like to thank Mark Long and ECS Zepler Mechanical workshop M.S. Abd Rahman, A.M. Abdullah, A.G. and M.H. Mat Saman for their advice and work in the manufacture of the hand.

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From "MEC 11 Raising the Standard," Proceedings of the 2011 MyoElectric Controls/Powered Prosthetics Symposium Fredericton, New Brunswick, Canada: August 14-19, 2011.

Appendices

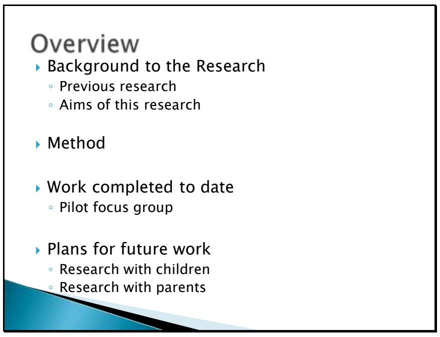
Presentation slides for ISPO: Psychosocial Impact of Disability and Limb Loss. November 2011: Sydney, Australia.

Slide 1

Involving children in the development of upper limb prostheses

Tara Sims, Dr Maggie Donovan-Hall, Dr Cheryl Metcalf
4th November 2011
ISPO 2011 - Psychosocial Impact of Disability and Limb Loss
Sydney, Australia

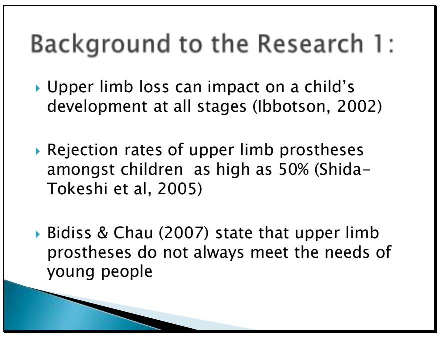
Slide 2



Overview

- Background to the Research
  - Previous research
  - Aims of this research
- Method
- Work completed to date
  - Pilot focus group
- Plans for future work
  - Research with children
  - Research with parents

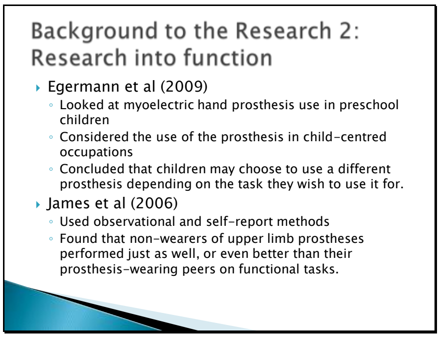
Slide 3



Background to the Research 1:

- Upper limb loss can impact on a child’s development at all stages (Ibbotson, 2002)
- Rejection rates of upper limb prostheses amongst children as high as 50% (Shida-Tokeshi et al, 2005)
- Bidiss & Chau (2007) state that upper limb prostheses do not always meet the needs of young people

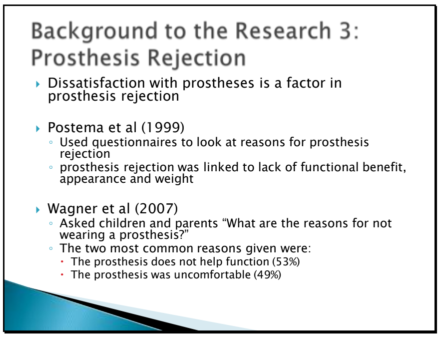
Slide 4



Background to the Research 2: Research into function

- Egermann et al (2009)
  - Looked at myoelectric hand prosthesis use in preschool children
  - Considered the use of the prosthesis in child-centred occupations
  - Concluded that children may choose to use a different prosthesis depending on the task they wish to use it for.
- James et al (2006)
  - Used observational and self-report methods
  - Found that non-wearers of upper limb prostheses performed just as well, or even better than their prosthesis-wearing peers on functional tasks.

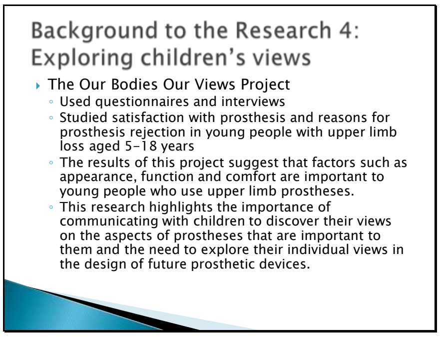
Slide 5



Background to the Research 3: Prosthesis Rejection

- Dissatisfaction with prostheses is a factor in prosthesis rejection
- Postema et al (1999)
  - Used questionnaires to look at reasons for prosthesis rejection
  - prosthesis rejection was linked to lack of functional benefit, appearance and weight
- Wagner et al (2007)
  - Asked children and parents "What are the reasons for not wearing a prosthesis?"
  - The two most common reasons given were:
    - The prosthesis does not help function (53%)
    - The prosthesis was uncomfortable (49%)

Slide 6

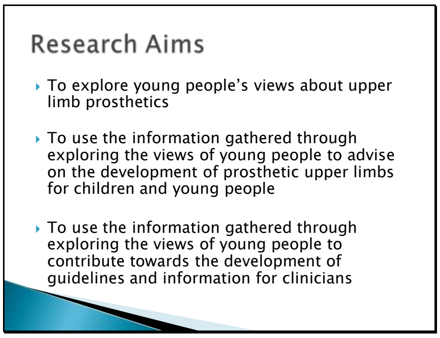


Background to the Research 4: Exploring children's views

- The Our Bodies Our Views Project
  - Used questionnaires and interviews
  - Studied satisfaction with prosthesis and reasons for prosthesis rejection in young people with upper limb loss aged 5-18 years
  - The results of this project suggest that factors such as appearance, function and comfort are important to young people who use upper limb prostheses.
  - This research highlights the importance of communicating with children to discover their views on the aspects of prostheses that are important to them and the need to explore their individual views in the design of future prosthetic devices.

Appendices

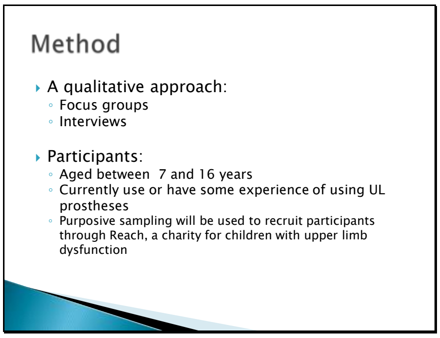
Slide 7



Research Aims

- To explore young people's views about upper limb prosthetics
- To use the information gathered through exploring the views of young people to advise on the development of prosthetic upper limbs for children and young people
- To use the information gathered through exploring the views of young people to contribute towards the development of guidelines and information for clinicians

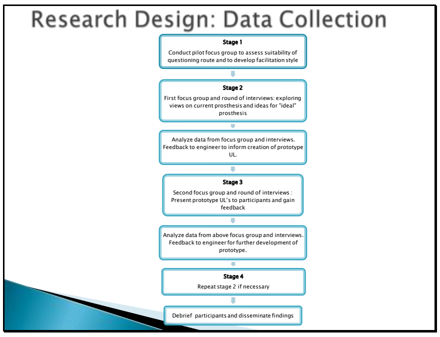
Slide 8



Method

- A qualitative approach:
  - Focus groups
  - Interviews
- Participants:
  - Aged between 7 and 16 years
  - Currently use or have some experience of using UL prostheses
  - Purposive sampling will be used to recruit participants through Reach, a charity for children with upper limb dysfunction

Slide 9



Research Design: Data Collection

Stage 1

Conduct pilot focus group to assess suitability of questioning route and to develop facilitation style

Stage 2

First focus group and round of interviews: exploring views on current prosthesis and ideas for "ideal" prosthesis

Analyze data from focus group and interviews. Feedback to engineer to inform creation of prototype UL.

Stage 3

Second focus group and round of interviews : Present prototype UL's to participants and gain feedback

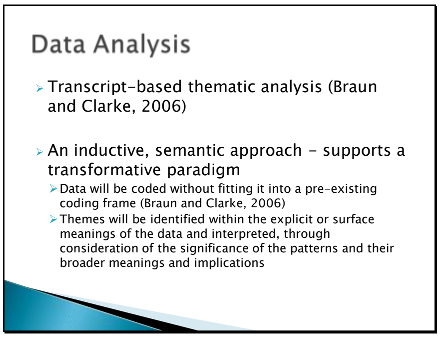
Analyze data from above focus group and interviews. Feedback to engineer for further development of prototype.

Stage 4

Repeat stage 2 if necessary

Debrief participants and disseminate findings

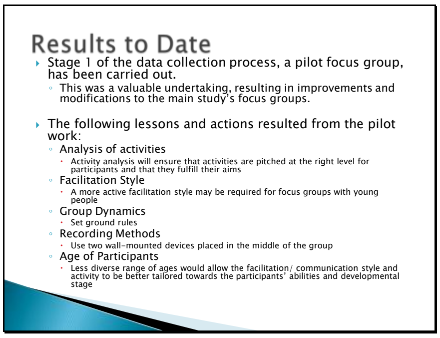
Slide 10



Data Analysis

- Transcript-based thematic analysis (Braun and Clarke, 2006)
- An inductive, semantic approach - supports a transformative paradigm
  - Data will be coded without fitting it into a pre-existing coding frame (Braun and Clarke, 2006)
  - Themes will be identified within the explicit or surface meanings of the data and interpreted, through consideration of the significance of the patterns and their broader meanings and implications

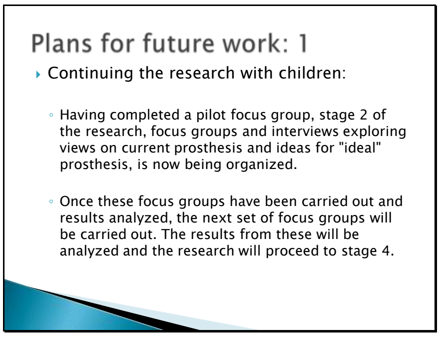
Slide 11



Results to Date

- Stage 1 of the data collection process, a pilot focus group, has been carried out.
  - This was a valuable undertaking, resulting in improvements and modifications to the main study's focus groups.
- The following lessons and actions resulted from the pilot work:
  - Analysis of activities
    - Activity analysis will ensure that activities are pitched at the right level for participants and that they fulfill their aims
  - Facilitation Style
    - A more active facilitation style may be required for focus groups with young people
  - Group Dynamics
    - Set ground rules
  - Recording Methods
    - Use two wall-mounted devices placed in the middle of the group
  - Age of Participants
    - Less diverse range of ages would allow the facilitation/ communication style and activity to be better tailored towards the participants' abilities and developmental stage

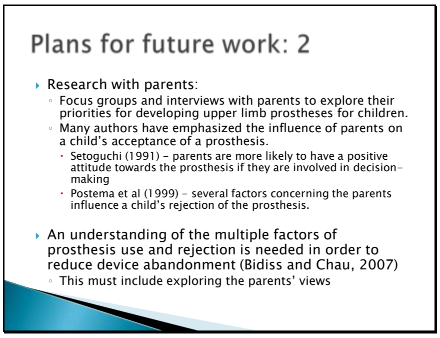
Slide 12



Plans for future work: 1

- Continuing the research with children:
  - Having completed a pilot focus group, stage 2 of the research, focus groups and interviews exploring views on current prosthesis and ideas for "ideal" prosthesis, is now being organized.
  - Once these focus groups have been carried out and results analyzed, the next set of focus groups will be carried out. The results from these will be analyzed and the research will proceed to stage 4.

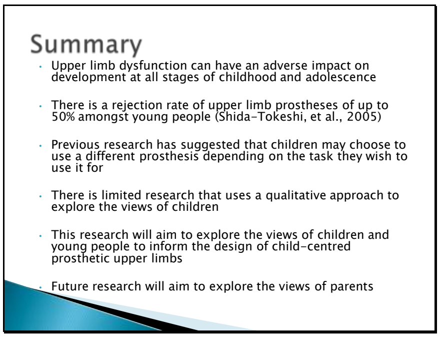
Slide 13



Plans for future work: 2

- Research with parents:
  - Focus groups and interviews with parents to explore their priorities for developing upper limb prostheses for children.
  - Many authors have emphasized the influence of parents on a child's acceptance of a prosthesis.
    - Setoguchi (1991) – parents are more likely to have a positive attitude towards the prosthesis if they are involved in decision-making
    - Postema et al (1999) – several factors concerning the parents influence a child's rejection of the prosthesis.
- An understanding of the multiple factors of prosthesis use and rejection is needed in order to reduce device abandonment (Bidiss and Chau, 2007)
  - This must include exploring the parents' views

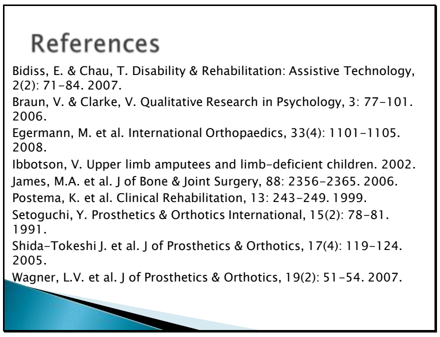
Slide 14



Summary

- Upper limb dysfunction can have an adverse impact on development at all stages of childhood and adolescence
- There is a rejection rate of upper limb prostheses of up to 50% amongst young people (Shida-Tokeshi, et al., 2005)
- Previous research has suggested that children may choose to use a different prosthesis depending on the task they wish to use it for
- There is limited research that uses a qualitative approach to explore the views of children
- This research will aim to explore the views of children and young people to inform the design of child-centred prosthetic upper limbs
- Future research will aim to explore the views of parents

Slide 15



References

Bidiss, E. & Chau, T. Disability & Rehabilitation: Assistive Technology, 2(2): 71-84. 2007.

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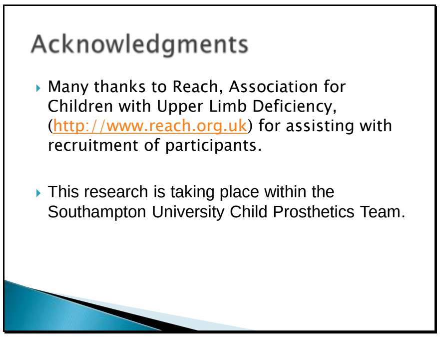
Wagner, L.V. et al. J of Prosthetics & Orthotics, 19(2): 51-54. 2007.

Slide 16



Acknowledgments

- Many thanks to Reach, Association for Children with Upper Limb Deficiency, (http://www.reach.org.uk) for assisting with recruitment of participants.
- This research is taking place within the Southampton University Child Prosthetics Team.

Slide 17

Contact Details

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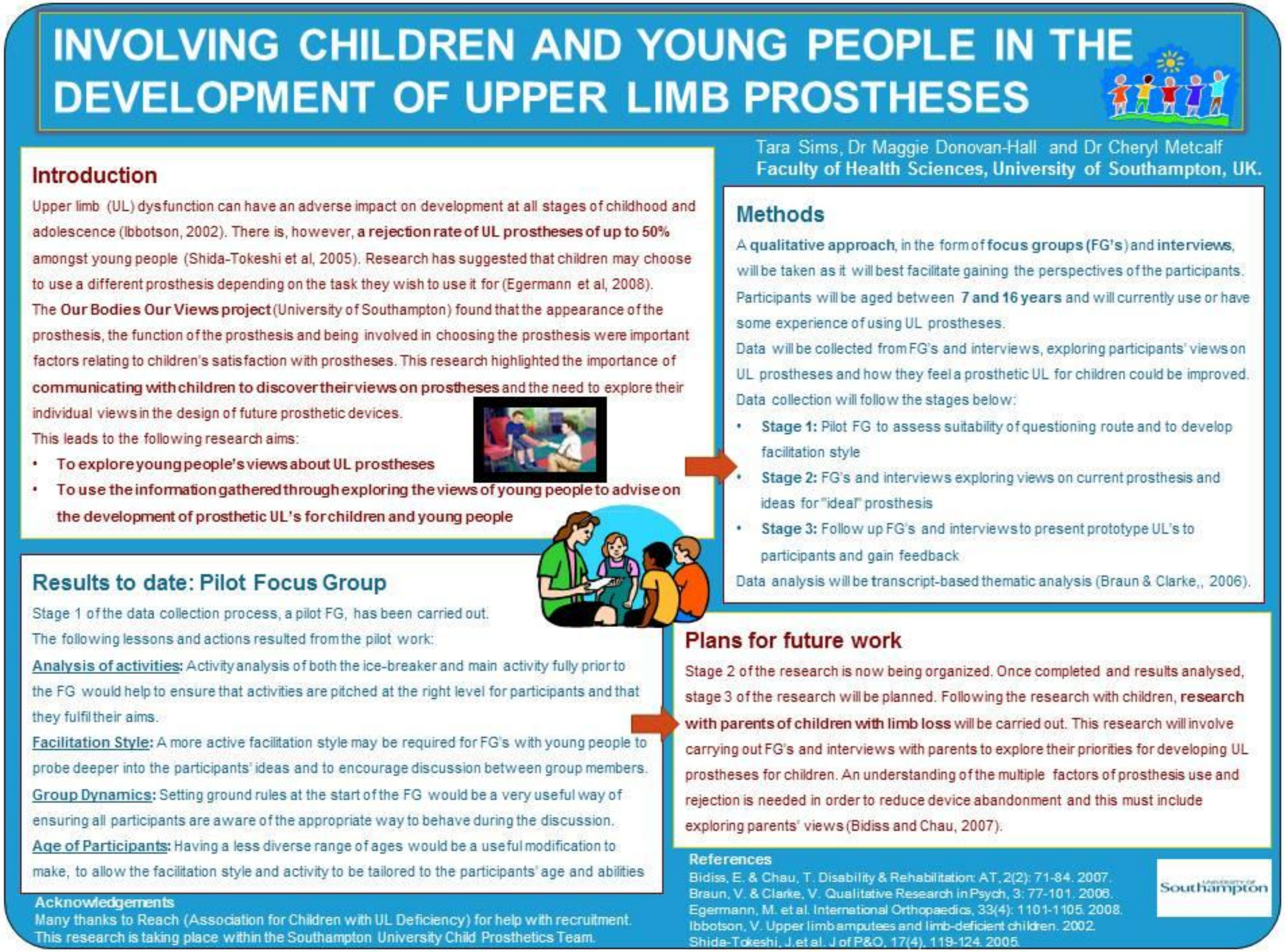
Supervisors: Dr Maggie Donovan-Hall; Dr Cheryl Metcalf

Poster for Children Young People and Families (COT specialist section)



INVOLVING CHILDREN AND YOUNG PEOPLE IN THE DEVELOPMENT OF UPPER LIMB PROSTHESES

Tara Sims, Dr Maggie Donovan-Hall and Dr Cheryl Metcalf
Faculty of Health Sciences, University of Southampton, UK.

Introduction

Upper limb (UL) dysfunction can have an adverse impact on development at all stages of childhood and adolescence (Ibbotson, 2002). There is, however, **a rejection rate of UL prostheses of up to 50%** amongst young people (Shida-Tokeshi et al, 2005). Research has suggested that children may choose to use a different prosthesis depending on the task they wish to use it for (Egermann et al, 2008).

The **Our Bodies Our Views project** (University of Southampton) found that the appearance of the prosthesis, the function of the prosthesis and being involved in choosing the prosthesis were important factors relating to children's satisfaction with prostheses. This research highlighted the importance of **communicating with children to discover their views on prostheses** and the need to explore their individual views in the design of future prosthetic devices.

This leads to the following research aims:

- **To explore young people's views about UL prostheses**
- **To use the information gathered through exploring the views of young people to advise on the development of prosthetic UL's for children and young people**

Methods

A **qualitative approach**, in the form of **focus groups (FG's)** and **interviews**, will be taken as it will best facilitate gaining the perspectives of the participants.

Participants will be aged between **7 and 16 years** and will currently use or have some experience of using UL prostheses.

Data will be collected from FG's and interviews, exploring participants' views on UL prostheses and how they feel a prosthetic UL for children could be improved.

Data collection will follow the stages below:

- **Stage 1:** Pilot FG to assess suitability of questioning route and to develop facilitation style
- **Stage 2:** FG's and interviews exploring views on current prosthesis and ideas for "ideal" prosthesis
- **Stage 3:** Follow up FG's and interviews to present prototype UL's to participants and gain feedback

Data analysis will be transcript-based thematic analysis (Braun & Clarke,, 2006).

Results to date: Pilot Focus Group

Stage 1 of the data collection process, a pilot FG, has been carried out.

The following lessons and actions resulted from the pilot work:

Analysis of activities: Activity analysis of both the ice-breaker and main activity fully prior to the FG would help to ensure that activities are pitched at the right level for participants and that they fulfil their aims.

Facilitation Style: A more active facilitation style may be required for FG's with young people to probe deeper into the participants' ideas and to encourage discussion between group members.

Group Dynamics: Setting ground rules at the start of the FG would be a very useful way of ensuring all participants are aware of the appropriate way to behave during the discussion.

Age of Participants: Having a less diverse range of ages would be a useful modification to make, to allow the facilitation style and activity to be tailored to the participants' age and abilities

Plans for future work

Stage 2 of the research is now being organized. Once completed and results analysed, stage 3 of the research will be planned. Following the research with children, **research with parents of children with limb loss** will be carried out. This research will involve carrying out FG's and interviews with parents to explore their priorities for developing UL prostheses for children. An understanding of the multiple factors of prosthesis use and rejection is needed in order to reduce device abandonment and this must include exploring parents' views (Bidiss and Chau, 2007).

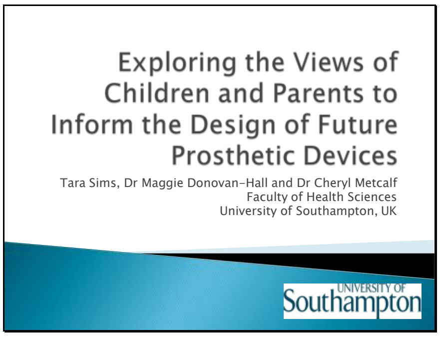
Acknowledgements
Many thanks to Reach (Association for Children with UL Deficiency) for help with recruitment.
This research is taking place within the Southampton University Child Prosthetics Team.

References

Bidiss, E. & Chau, T. Disability & Rehabilitation: AT, 2(2): 71-84. 2007.
Braun, V. & Clarke, V. Qualitative Research in Psych, 3: 77-101. 2006.
Egermann, M. et al. International Orthopaedics, 33(4): 1101-1105. 2008.
Ibbotson, V. Upper limb amputees and limb-deficient children. 2002.
Shida-Tokeshi, J. et al. J of P&O, 17(4), 119-124. 2005.

Presentation slides for Trent International Prosthetics Symposium (TIPS). May 2012: Loughborough, UK.

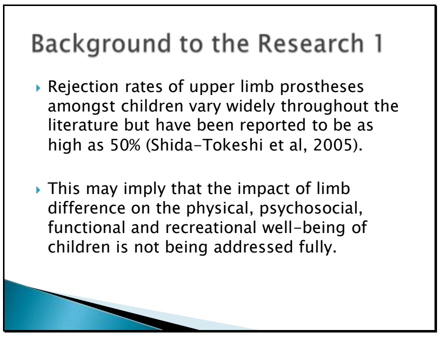
Slide 1



Exploring the Views of Children and Parents to Inform the Design of Future Prosthetic Devices

Tara Sims, Dr Maggie Donovan-Hall and Dr Cheryl Metcalf
Faculty of Health Sciences
University of Southampton, UK

Slide 2

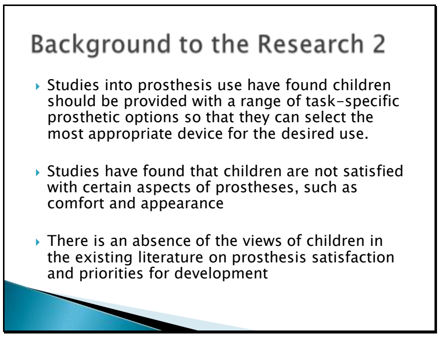


Background to the Research 1

- Rejection rates of upper limb prostheses amongst children vary widely throughout the literature but have been reported to be as high as 50% (Shida-Tokeshi et al, 2005).
- This may imply that the impact of limb difference on the physical, psychosocial, functional and recreational well-being of children is not being addressed fully.

Appendices

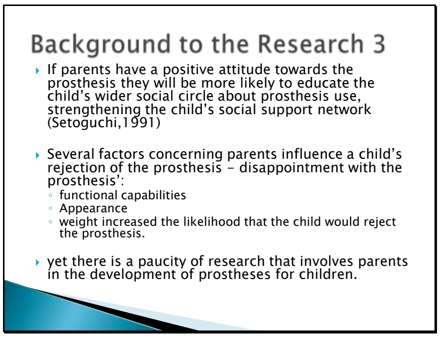
Slide 3



Background to the Research 2

- Studies into prosthesis use have found children should be provided with a range of task-specific prosthetic options so that they can select the most appropriate device for the desired use.
- Studies have found that children are not satisfied with certain aspects of prostheses, such as comfort and appearance
- There is an absence of the views of children in the existing literature on prosthesis satisfaction and priorities for development

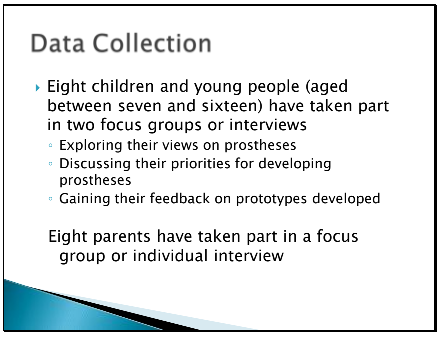
Slide 4



Background to the Research 3

- If parents have a positive attitude towards the prosthesis they will be more likely to educate the child's wider social circle about prosthesis use, strengthening the child's social support network (Setoguchi,1991)
- Several factors concerning parents influence a child's rejection of the prosthesis – disappointment with the prosthesis':
  - functional capabilities
  - Appearance
  - weight increased the likelihood that the child would reject the prosthesis.
- yet there is a paucity of research that involves parents in the development of prostheses for children.

Slide 5

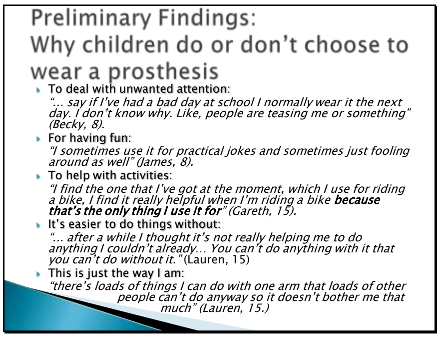


Data Collection

- Eight children and young people (aged between seven and sixteen) have taken part in two focus groups or interviews
  - Exploring their views on prostheses
  - Discussing their priorities for developing prostheses
  - Gaining their feedback on prototypes developed

Eight parents have taken part in a focus group or individual interview

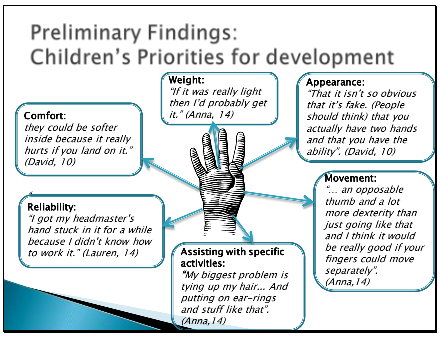
Slide 6



Preliminary Findings:
Why children do or don't choose to wear a prosthesis

- To deal with unwanted attention:
  "… say if I've had a bad day at school I normally wear it the next day. I don't know why. Like, people are teasing me or something" (Becky, 8).
- For having fun:
  "I sometimes use it for practical jokes and sometimes just fooling around as well" (James, 8).
- To help with activities:
  *"I find the one that I've got at the moment, which I use for riding a bike, I find it really helpful when I'm riding a bike **because that's the only thing I use it for**" (Gareth, 15).*
- It's easier to do things without:
  "… after a while I thought it's not really helping me to do anything I couldn't already… You can't do anything with it that you can't do without it." (Lauren, 15)
- This is just the way I am:
  "there's loads of things I can do with one arm that loads of other people can't do anyway so it doesn't bother me that much" (Lauren, 15.)

Slide 7



Preliminary Findings:
Children's Priorities for development

Weight:
"If it was really light then I'd probably get it." (Anna, 14)

Appearance:
"That it isn't so obvious that it's fake. (People should think) that you actually have two hands and that you have the ability". (David, 10)

Comfort:
they could be softer inside because it really hurts if you land on it." (David, 10)

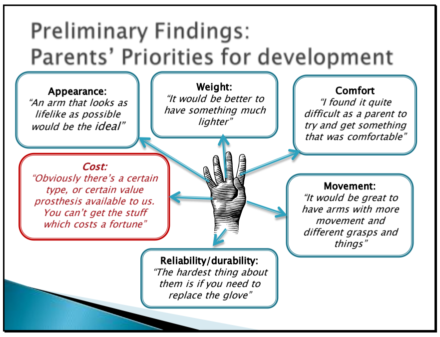
"

Reliability:
"I got my headmaster's hand stuck in it for a while because I didn't know how to work it." (Lauren, 14)

Movement:
"… an opposable thumb and a lot more dexterity than just going like that and I think it would be really good if your fingers could move separately". (Anna,14)

Assisting with specific activities:
"My biggest problem is tying up my hair… And putting on ear-rings and stuff like that". (Anna,14)

Slide 8



Preliminary Findings:
Parents' Priorities for development

Appearance:
"An arm that looks as lifelike as possible would be the ideal"

Weight:
"It would be better to have something much lighter"

Comfort
"I found it quite difficult as a parent to try and get something that was comfortable"

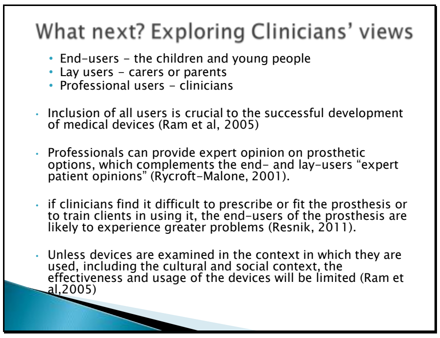
Cost:
"Obviously there's a certain type, or certain value prosthesis available to us. You can't get the stuff which costs a fortune"

Movement:
"It would be great to have arms with more movement and different grasps and things"

Reliability/durability:
"The hardest thing about them is if you need to replace the glove"

Appendices

Slide 9

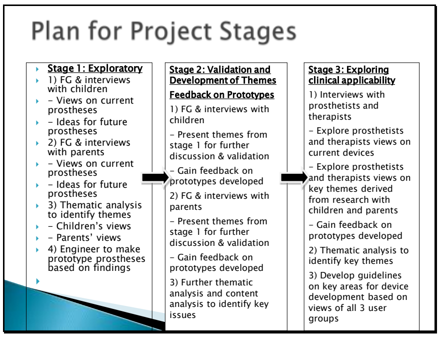


What next? Exploring Clinicians' views

- End-users – the children and young people
- Lay users – carers or parents
- Professional users – clinicians

- Inclusion of all users is crucial to the successful development of medical devices (Ram et al, 2005)
- Professionals can provide expert opinion on prosthetic options, which complements the end- and lay-users "expert patient opinions" (Rycroft-Malone, 2001).
- if clinicians find it difficult to prescribe or fit the prosthesis or to train clients in using it, the end-users of the prosthesis are likely to experience greater problems (Resnik, 2011).
- Unless devices are examined in the context in which they are used, including the cultural and social context, the effectiveness and usage of the devices will be limited (Ram et al,2005)

Slide 10



Plan for Project Stages

- **Stage 1: Exploratory**
- 1) FG & interviews with children
- – Views on current prostheses
- – Ideas for future prostheses
- 2) FG & interviews with parents
- – Views on current prostheses
- – Ideas for future prostheses
- 3) Thematic analysis to identify themes
- – Children's views
- – Parents' views
- 4) Engineer to make prototype prostheses based on findings

Stage 2: Validation and Development of Themes

Feedback on Prototypes

1) FG & interviews with children

– Present themes from stage 1 for further discussion & validation

– Gain feedback on prototypes developed

2) FG & interviews with parents

– Present themes from stage 1 for further discussion & validation

– Gain feedback on prototypes developed

3) Further thematic analysis and content analysis to identify key issues

Stage 3: Exploring clinical applicability

1) Interviews with prosthetists and therapists

– Explore prosthetists and therapists views on current devices

– Explore prosthetists and therapists views on key themes derived from research with children and parents

– Gain feedback on prototypes developed

2) Thematic analysis to identify key themes

3) Develop guidelines on key areas for device development based on views of all 3 user groups

Slide 11

Clinicians' Views of Upper Limb Prostheses

Are you a clinician working in the field of paediatric UL prosthetics? If so, we would like to invite you to join our study...

We are hoping to gain a better understanding of what clinicians think and feel about upper limb prosthetics for children.

We are carrying out one-to-one interviews lasting approximately 1 hour.

It is hoped that our findings will help develop upper limb prostheses for children that take into account the views of children, parents and clinicians, in order to reduce the current high rates of reduction.

For more information about the study please contact:
Tara Sims (PhD Student)
Faculty of Health Sciences
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Highfield
Southampton SO17 1BJ
Email: tss1e10@soton.ac.uk

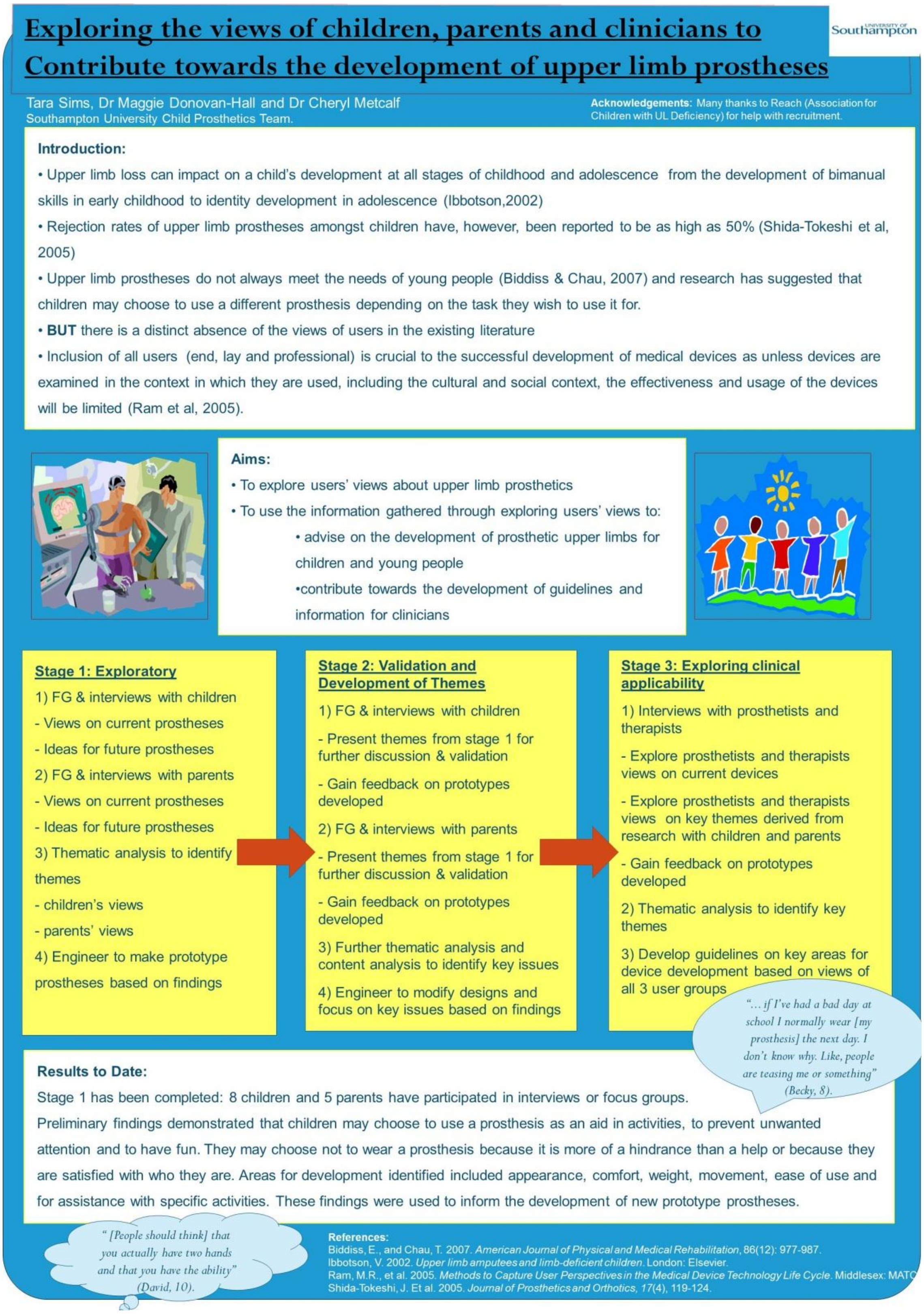
UNIVERSITY OF Southampton

How to get involved

Interviews with clinicians working in paediatric UL prosthetics – gain feedback on prototype designs

Contact the researcher:
Tara Sims
Email: tss1e10@soton.ac.uk

Poster for TIPS (May 2012: Loughborough, UK) and Faculty Postgraduate Research Conference (June 2012: Southampton, UK)



Exploring the views of children, parents and clinicians to Contribute towards the development of upper limb prostheses

Southampton

Tara Sims, Dr Maggie Donovan-Hall and Dr Cheryl Metcalf
Southampton University Child Prosthetics Team.

Acknowledgements: Many thanks to Reach (Association for Children with UL Deficiency) for help with recruitment.

Introduction:

- Upper limb loss can impact on a child's development at all stages of childhood and adolescence from the development of bimanual skills in early childhood to identity development in adolescence (Ibbotson,2002)
- Rejection rates of upper limb prostheses amongst children have, however, been reported to be as high as 50% (Shida-Tokeshi et al, 2005)
- Upper limb prostheses do not always meet the needs of young people (Biddiss & Chau, 2007) and research has suggested that children may choose to use a different prosthesis depending on the task they wish to use it for.
- **BUT** there is a distinct absence of the views of users in the existing literature
- Inclusion of all users (end, lay and professional) is crucial to the successful development of medical devices as unless devices are examined in the context in which they are used, including the cultural and social context, the effectiveness and usage of the devices will be limited (Ram et al, 2005).

Aims:

- To explore users' views about upper limb prosthetics
- To use the information gathered through exploring users' views to:
  - advise on the development of prosthetic upper limbs for children and young people
  - contribute towards the development of guidelines and information for clinicians

Stage 1: Exploratory

1) FG & interviews with children
- Views on current prostheses
- Ideas for future prostheses

2) FG & interviews with parents
- Views on current prostheses
- Ideas for future prostheses

3) Thematic analysis to identify themes
- children's views
- parents' views

4) Engineer to make prototype prostheses based on findings

Stage 2: Validation and Development of Themes

1) FG & interviews with children
- Present themes from stage 1 for further discussion & validation
- Gain feedback on prototypes developed

2) FG & interviews with parents
- Present themes from stage 1 for further discussion & validation
- Gain feedback on prototypes developed

3) Further thematic analysis and content analysis to identify key issues

4) Engineer to modify designs and focus on key issues based on findings

Stage 3: Exploring clinical applicability

1) Interviews with prosthetists and therapists
- Explore prosthetists and therapists views on current devices
- Explore prosthetists and therapists views on key themes derived from research with children and parents
- Gain feedback on prototypes developed

2) Thematic analysis to identify key themes

3) Develop guidelines on key areas for device development based on views of all 3 user groups

"… if I've had a bad day at school I normally wear [my prosthesis] the next day. I don't know why. Like, people are teasing me or something" (Becky, 8).

Results to Date:

Stage 1 has been completed: 8 children and 5 parents have participated in interviews or focus groups.

Preliminary findings demonstrated that children may choose to use a prosthesis as an aid in activities, to prevent unwanted attention and to have fun. They may choose not to wear a prosthesis because it is more of a hindrance than a help or because they are satisfied with who they are. Areas for development identified included appearance, comfort, weight, movement, ease of use and for assistance with specific activities. These findings were used to inform the development of new prototype prostheses.

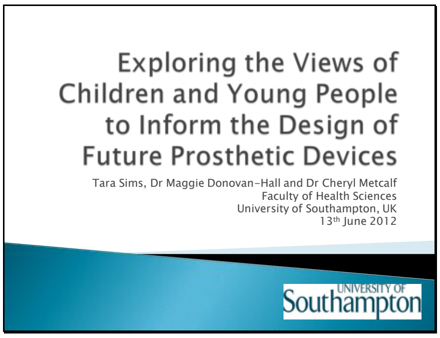
" [People should think] that you actually have two hands and that you have the ability" (David, 10).

References:
Biddiss, E., and Chau, T. 2007. *American Journal of Physical and Medical Rehabilitation*, 86(12): 977-987.
Ibbotson, V. 2002. *Upper limb amputees and limb-deficient children*. London: Elsevier.
Ram, M.R., et al. 2005. *Methods to Capture User Perspectives in the Medical Device Technology Life Cycle*. Middlesex: MATC
Shida-Tokeshi, J. Et al. 2005. *Journal of Prosthetics and Orthotics*, 17(4), 119-124.

Appendices

Presentation slides for College of OT (COT) Annual Conference. June 2012: Glasgow, UK.

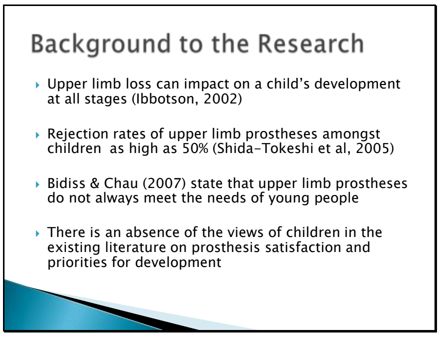
Slide 1



Exploring the Views of Children and Young People to Inform the Design of Future Prosthetic Devices

Tara Sims, Dr Maggie Donovan-Hall and Dr Cheryl Metcalf
Faculty of Health Sciences
University of Southampton, UK
13th June 2012

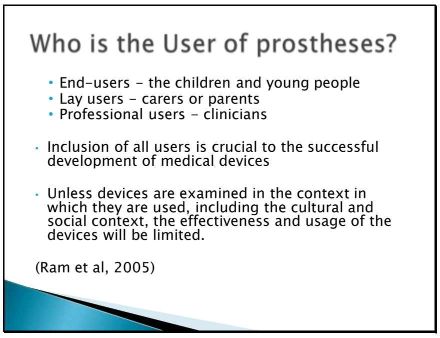
Slide 2



Background to the Research

- Upper limb loss can impact on a child's development at all stages (Ibbotson, 2002)
- Rejection rates of upper limb prostheses amongst children as high as 50% (Shida-Tokeshi et al, 2005)
- Bidiss & Chau (2007) state that upper limb prostheses do not always meet the needs of young people
- There is an absence of the views of children in the existing literature on prosthesis satisfaction and priorities for development

Slide 3



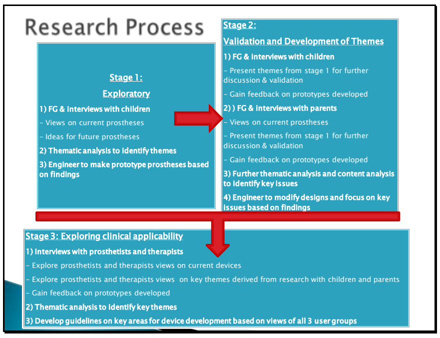
Who is the User of prostheses?

- End-users – the children and young people
- Lay users – carers or parents
- Professional users – clinicians

- Inclusion of all users is crucial to the successful development of medical devices
- Unless devices are examined in the context in which they are used, including the cultural and social context, the effectiveness and usage of the devices will be limited.

(Ram et al, 2005)

Slide 4



Research Process

Stage 1:

Exploratory

1) FG & interviews with children

- Views on current prostheses

- Ideas for future prostheses

2) Thematic analysis to identify themes

3) Engineer to make prototype prostheses based on findings

Stage 2:

Validation and Development of Themes

1) FG & interviews with children

- Present themes from stage 1 for further discussion & validation

- Gain feedback on prototypes developed

2)) FG & interviews with parents

- Views on current prostheses

- Present themes from stage 1 for further discussion & validation

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3) Further thematic analysis and content analysis to identify key issues

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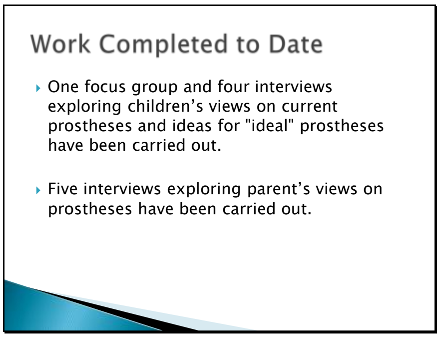
3) Develop guidelines on key areas for device development based on views of all 3 user groups

Slide 5

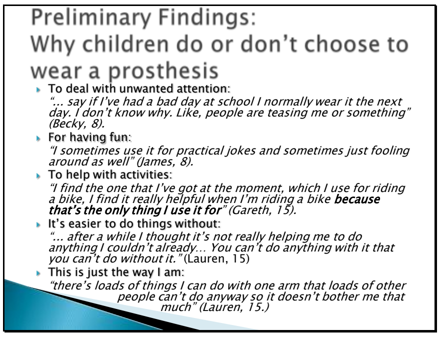


Work Completed to Date

- One focus group and four interviews exploring children's views on current prostheses and ideas for "ideal" prostheses have been carried out.

- Five interviews exploring parent's views on prostheses have been carried out.

Slide 6

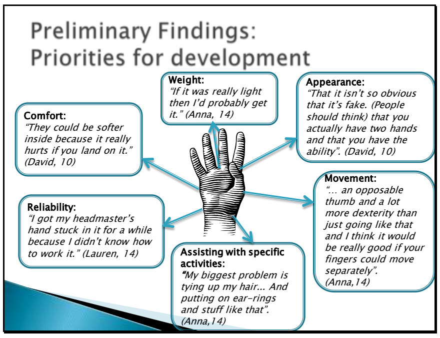


Preliminary Findings: Why children do or don't choose to wear a prosthesis

- To deal with unwanted attention:
  "... say if I've had a bad day at school I normally wear it the next day. I don't know why. Like, people are teasing me or something" (Becky, 8).
- For having fun:
  "I sometimes use it for practical jokes and sometimes just fooling around as well" (James, 8).
- To help with activities:
  *"I find the one that I've got at the moment, which I use for riding a bike, I find it really helpful when I'm riding a bike **because that's the only thing I use it for**" (Gareth, 15).*
- It's easier to do things without:
  "... after a while I thought it's not really helping me to do anything I couldn't already… You can't do anything with it that you can't do without it." (Lauren, 15)
- This is just the way I am:
  "there's loads of things I can do with one arm that loads of other people can't do anyway so it doesn't bother me that much" (Lauren, 15.)

Appendices

Slide 7



Preliminary Findings:
Priorities for development

Weight:
"If it was really light then I'd probably get it." (Anna, 14)

Appearance:
"That it isn't so obvious that it's fake. (People should think) that you actually have two hands and that you have the ability". (David, 10)

Comfort:
"They could be softer inside because it really hurts if you land on it." (David, 10)

Movement:
"… an opposable thumb and a lot more dexterity than just going like that and I think it would be really good if your fingers could move separately". (Anna,14)

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"I got my headmaster's hand stuck in it for a while because I didn't know how to work it." (Lauren, 14)

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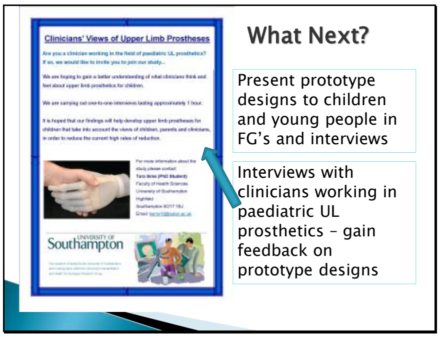
Slide 8



Clinicians' Views of Upper Limb Prostheses

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It is hoped that our findings will help develop upper limb prostheses for children that take into account the views of children, parents and clinicians, in order to reduce the current high rates of reduction.

For more information about the study please contact:
[illegible]
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Email: [illegible]

UNIVERSITY OF Southampton

What Next?

Present prototype designs to children and young people in FG's and interviews

Interviews with clinicians working in paediatric UL prosthetics – gain feedback on prototype designs

Presentation for ISPO, BAPO and BACPAR Conference. September 2012: Sheffield, UK.

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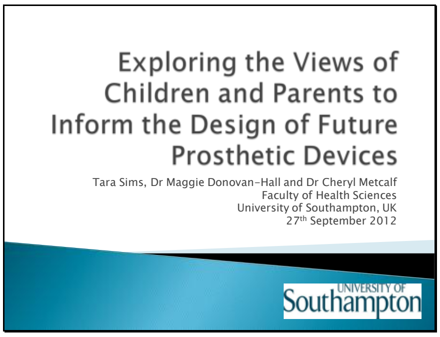

Exploring the Views of Children and Parents to Inform the Design of Future Prosthetic Devices

Tara Sims, Dr Maggie Donovan-Hall and Dr Cheryl Metcalf
Faculty of Health Sciences
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27th September 2012

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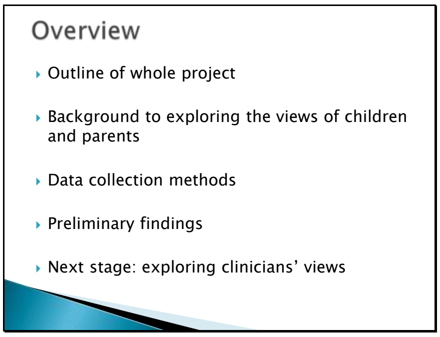
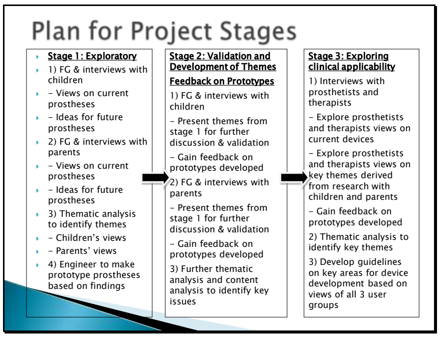


Overview

- Outline of whole project
- Background to exploring the views of children and parents
- Data collection methods
- Preliminary findings
- Next stage: exploring clinicians' views

Appendices

Slide 3



Plan for Project Stages

- **Stage 1: Exploratory**
- 1) FG & interviews with children
- – Views on current prostheses
- – Ideas for future prostheses
- 2) FG & interviews with parents
- – Views on current prostheses
- – Ideas for future prostheses
- 3) Thematic analysis to identify themes
- – Children's views
- – Parents' views
- 4) Engineer to make prototype prostheses based on findings

Stage 2: Validation and Development of Themes

Feedback on Prototypes

1) FG & interviews with children

– Present themes from stage 1 for further discussion & validation

– Gain feedback on prototypes developed

2) FG & interviews with parents

– Present themes from stage 1 for further discussion & validation

– Gain feedback on prototypes developed

3) Further thematic analysis and content analysis to identify key issues

Stage 3: Exploring clinical applicability

1) Interviews with prosthetists and therapists

– Explore prosthetists and therapists views on current devices

– Explore prosthetists and therapists views on key themes derived from research with children and parents

– Gain feedback on prototypes developed

2) Thematic analysis to identify key themes

3) Develop guidelines on key areas for device development based on views of all 3 user groups

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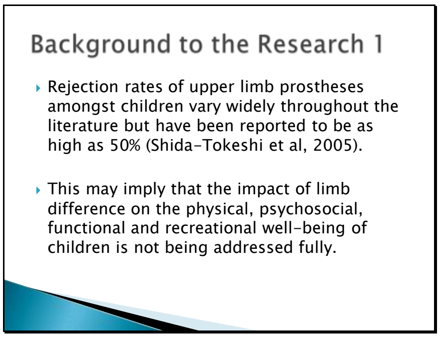

Background to the Research 1

- Rejection rates of upper limb prostheses amongst children vary widely throughout the literature but have been reported to be as high as 50% (Shida-Tokeshi et al, 2005).
- This may imply that the impact of limb difference on the physical, psychosocial, functional and recreational well-being of children is not being addressed fully.

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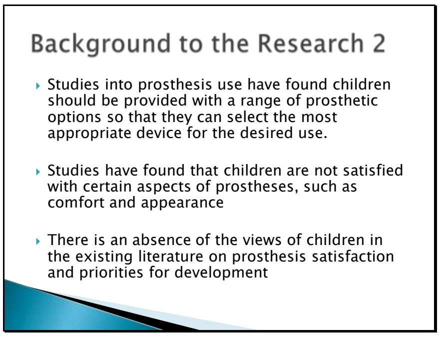

Background to the Research 2

- Studies into prosthesis use have found children should be provided with a range of prosthetic options so that they can select the most appropriate device for the desired use.
- Studies have found that children are not satisfied with certain aspects of prostheses, such as comfort and appearance
- There is an absence of the views of children in the existing literature on prosthesis satisfaction and priorities for development

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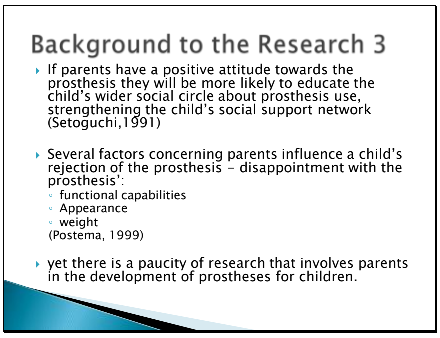

Background to the Research 3

- If parents have a positive attitude towards the prosthesis they will be more likely to educate the child's wider social circle about prosthesis use, strengthening the child's social support network (Setoguchi,1991)
- Several factors concerning parents influence a child's rejection of the prosthesis – disappointment with the prosthesis':
  - functional capabilities
  - Appearance
  - weight

  (Postema, 1999)
- yet there is a paucity of research that involves parents in the development of prostheses for children.

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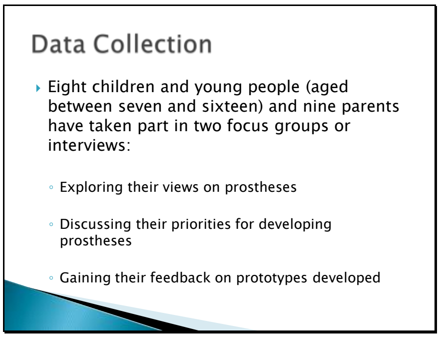

Data Collection

- Eight children and young people (aged between seven and sixteen) and nine parents have taken part in two focus groups or interviews:
  - Exploring their views on prostheses
  - Discussing their priorities for developing prostheses
  - Gaining their feedback on prototypes developed

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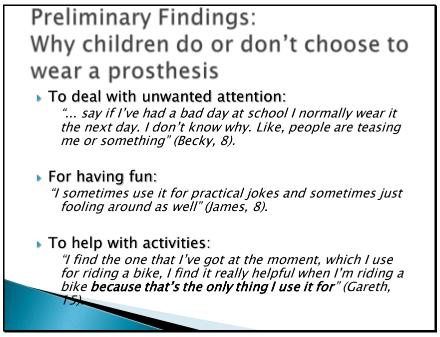

Preliminary Findings: Why children do or don't choose to wear a prosthesis

- To deal with unwanted attention:

  "… say if I've had a bad day at school I normally wear it the next day. I don't know why. Like, people are teasing me or something" (Becky, 8).
- For having fun:

  "I sometimes use it for practical jokes and sometimes just fooling around as well" (James, 8).
- To help with activities:

  "I find the one that I've got at the moment, which I use for riding a bike, I find it really helpful when I'm riding a bike ***because that's the only thing I use it for****" (Gareth, 15).*

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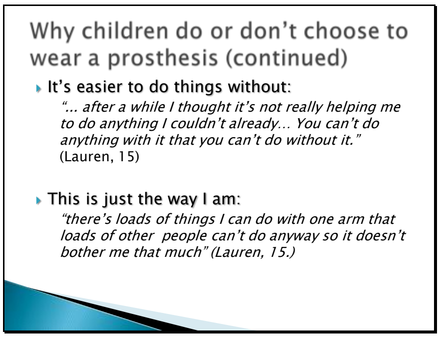

Why children do or don't choose to wear a prosthesis (continued)

- It's easier to do things without:

  "… after a while I thought it's not really helping me to do anything I couldn't already… You can't do anything with it that you can't do without it." (Lauren, 15)

- This is just the way I am:

  "there's loads of things I can do with one arm that loads of other people can't do anyway so it doesn't bother me that much" (Lauren, 15.)

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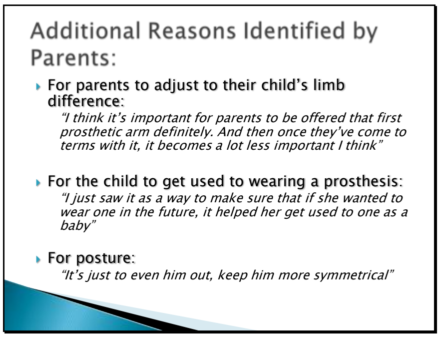

Additional Reasons Identified by Parents:

- For parents to adjust to their child's limb difference:

  "I think it's important for parents to be offered that first prosthetic arm definitely. And then once they've come to terms with it, it becomes a lot less important I think"

- For the child to get used to wearing a prosthesis:

  "I just saw it as a way to make sure that if she wanted to wear one in the future, it helped her get used to one as a baby"

- For posture:

  "It's just to even him out, keep him more symmetrical"

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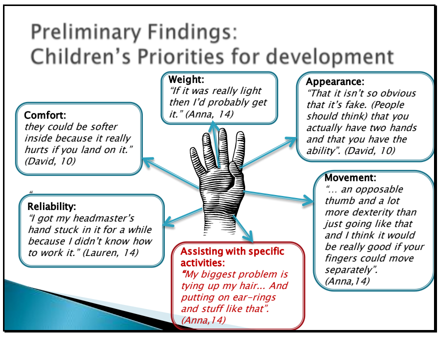

Preliminary Findings: Children's Priorities for development

Weight:
"If it was really light then I'd probably get it." (Anna, 14)

Appearance:
"That it isn't so obvious that it's fake. (People should think) that you actually have two hands and that you have the ability". (David, 10)

Comfort:
they could be softer inside because it really hurts if you land on it." (David, 10)

Movement:
"… an opposable thumb and a lot more dexterity than just going like that and I think it would be really good if your fingers could move separately". (Anna,14)

"

Reliability:
"I got my headmaster's hand stuck in it for a while because I didn't know how to work it." (Lauren, 14)

Assisting with specific activities:
"My biggest problem is tying up my hair… And putting on ear-rings and stuff like that". (Anna,14)

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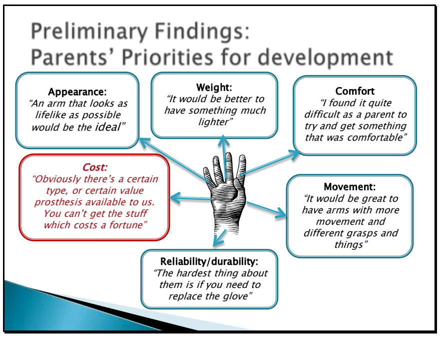

Preliminary Findings: Parents' Priorities for development

Appearance:
"An arm that looks as lifelike as possible would be the ideal"

Weight:
"It would be better to have something much lighter"

Comfort
"I found it quite difficult as a parent to try and get something that was comfortable"

Cost:
"Obviously there's a certain type, or certain value prosthesis available to us. You can't get the stuff which costs a fortune"

Movement:
"It would be great to have arms with more movement and different grasps and things"

Reliability/durability:
"The hardest thing about them is if you need to replace the glove"

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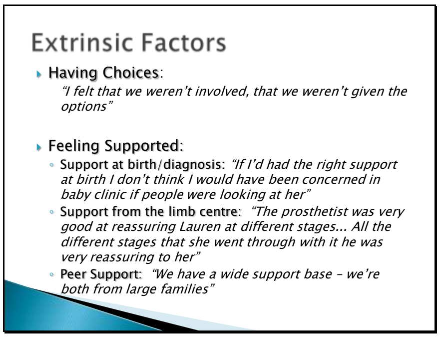

Extrinsic Factors

- Having Choices:
  "I felt that we weren't involved, that we weren't given the options"

- Feeling Supported:
  - Support at birth/diagnosis: *"If I'd had the right support at birth I don't think I would have been concerned in baby clinic if people were looking at her"*
  - Support from the limb centre: *"The prosthetist was very good at reassuring Lauren at different stages… All the different stages that she went through with it he was very reassuring to her"*
  - Peer Support: *"We have a wide support base – we're both from large families"*

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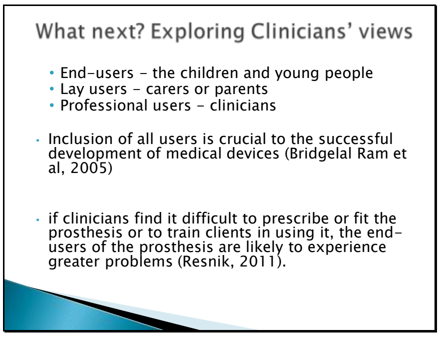

What next? Exploring Clinicians' views

- End-users – the children and young people
- Lay users – carers or parents
- Professional users – clinicians

- Inclusion of all users is crucial to the successful development of medical devices (Bridgelal Ram et al, 2005)

- if clinicians find it difficult to prescribe or fit the prosthesis or to train clients in using it, the end-users of the prosthesis are likely to experience greater problems (Resnik, 2011).

Appendices

Slide 15

Clinicians' Views of Upper Limb Prostheses

Are you a clinician working in the field of paediatric UL prosthetics?
If so, we would like to invite you to join our study...

We are hoping to gain a better understanding of what clinicians think and feel about upper limb prosthetics for children.

We are carrying out one-to-one interviews lasting approximately 1 hour.

It is hoped that our findings will help develop upper limb prostheses for children that take into account the views of children, parents and clinicians, in order to reduce the current high rates of reduction.

For more information about the study please contact:
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Southampton SO17 1BJ
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How to get involved

Interviews with clinicians working in paediatric UL prosthetics – gain feedback on prototype designs

Contact the researcher:
Tara Sims
Email: tss1e10@soton.ac.uk

Presentation slides for ISPO World Congress. February 2013: Hyderabad, India.

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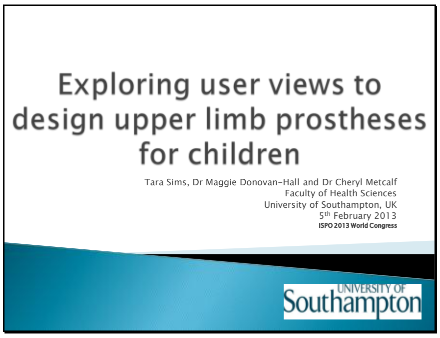
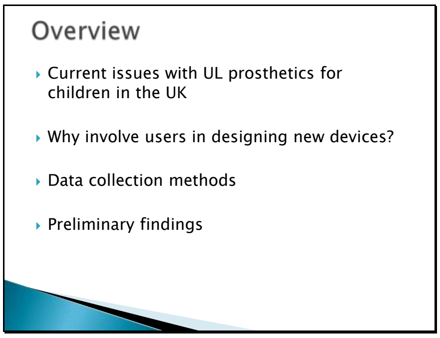


Exploring user views to design upper limb prostheses for children

Tara Sims, Dr Maggie Donovan-Hall and Dr Cheryl Metcalf
Faculty of Health Sciences
University of Southampton, UK
5th February 2013
ISPO 2013 World Congress

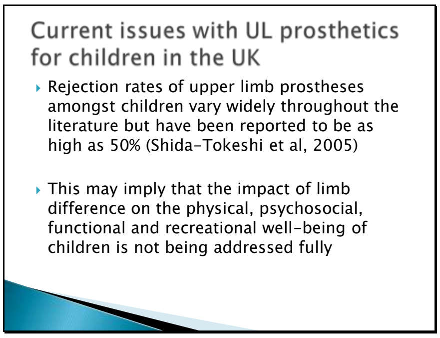
Slide 2



Overview

- Current issues with UL prosthetics for children in the UK
- Why involve users in designing new devices?
- Data collection methods
- Preliminary findings

Slide 3



Current issues with UL prosthetics for children in the UK

- Rejection rates of upper limb prostheses amongst children vary widely throughout the literature but have been reported to be as high as 50% (Shida-Tokeshi et al, 2005)
- This may imply that the impact of limb difference on the physical, psychosocial, functional and recreational well-being of children is not being addressed fully

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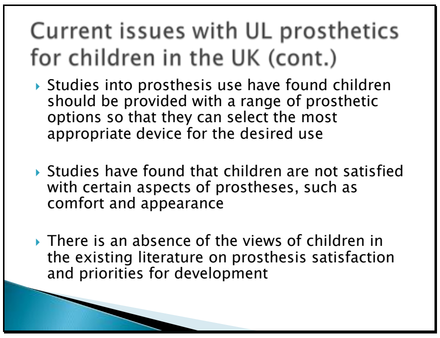

Current issues with UL prosthetics for children in the UK (cont.)

- Studies into prosthesis use have found children should be provided with a range of prosthetic options so that they can select the most appropriate device for the desired use

- Studies have found that children are not satisfied with certain aspects of prostheses, such as comfort and appearance

- There is an absence of the views of children in the existing literature on prosthesis satisfaction and priorities for development

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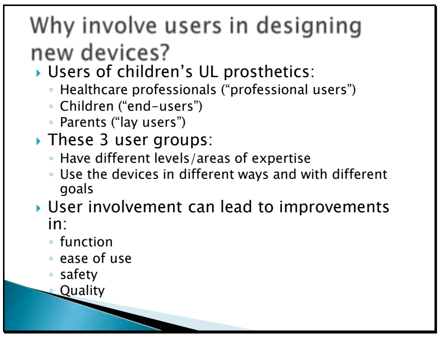

Why involve users in designing new devices?

- Users of children's UL prosthetics:
  - Healthcare professionals ("professional users")
  - Children ("end-users")
  - Parents ("lay users")
- These 3 user groups:
  - Have different levels/areas of expertise
  - Use the devices in different ways and with different goals
- User involvement can lead to improvements in:
  - function
  - ease of use
  - safety
  - Quality

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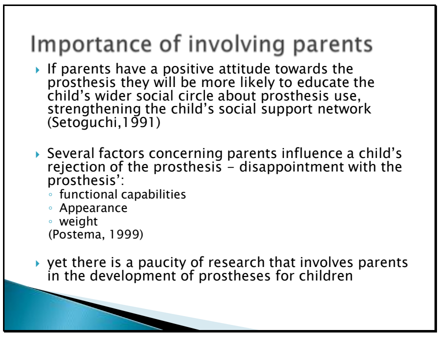

Importance of involving parents

- If parents have a positive attitude towards the prosthesis they will be more likely to educate the child's wider social circle about prosthesis use, strengthening the child's social support network (Setoguchi,1991)

- Several factors concerning parents influence a child's rejection of the prosthesis – disappointment with the prosthesis':
  - functional capabilities
  - Appearance
  - weight

  (Postema, 1999)

- yet there is a paucity of research that involves parents in the development of prostheses for children

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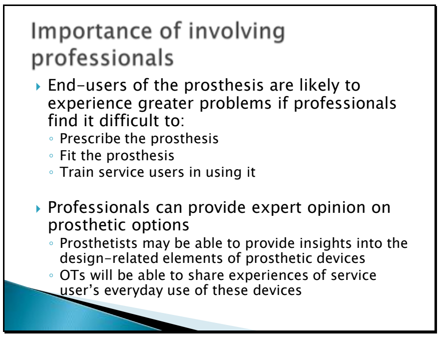

Importance of involving professionals

- End-users of the prosthesis are likely to experience greater problems if professionals find it difficult to:
  - Prescribe the prosthesis
  - Fit the prosthesis
  - Train service users in using it
- Professionals can provide expert opinion on prosthetic options
  - Prosthetists may be able to provide insights into the design-related elements of prosthetic devices
  - OTs will be able to share experiences of service user's everyday use of these devices

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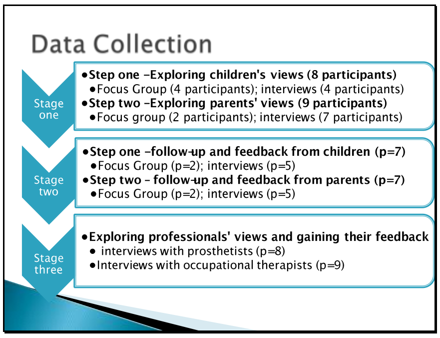

Data Collection

Stage one
- **Step one –Exploring children's views (8 participants)**
  - Focus Group (4 participants); interviews (4 participants)
- **Step two –Exploring parents' views (9 participants)**
  - Focus group (2 participants); interviews (7 participants)

Stage two
- **Step one –follow-up and feedback from children (p=7)**
  - Focus Group (p=2); interviews (p=5)
- **Step two – follow-up and feedback from parents (p=7)**
  - Focus Group (p=2); interviews (p=5)

Stage three
- **Exploring professionals' views and gaining their feedback**
  - interviews with prosthetists (p=8)
  - Interviews with occupational therapists (p=9)

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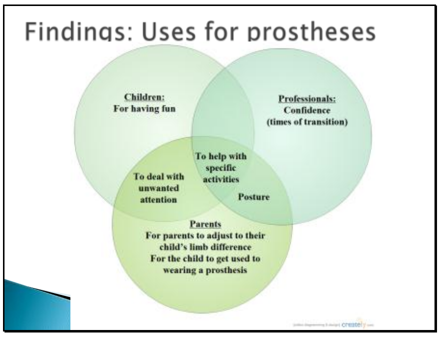


Findings: Uses for prostheses

Children:
For having fun

Professionals:
Confidence
(times of transition)

To help with specific activities

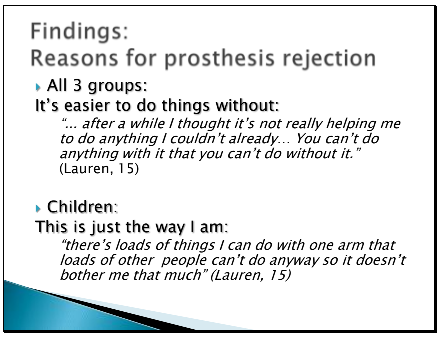
To deal with unwanted attention

Posture

Parents
For parents to adjust to their child's limb difference
For the child to get used to wearing a prosthesis

Appendices

Slide 10



Findings:
Reasons for prosthesis rejection

- All 3 groups:

It's easier to do things without:

> *"... after a while I thought it's not really helping me to do anything I couldn't already... You can't do anything with it that you can't do without it."* (Lauren, 15)

- Children:

This is just the way I am:

> *"there's loads of things I can do with one arm that loads of other people can't do anyway so it doesn't bother me that much" (Lauren, 15)*

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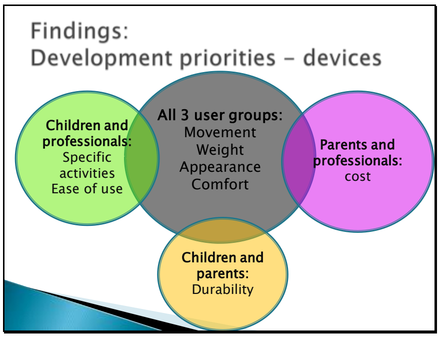

Findings:
Development priorities – devices

Children and professionals:
Specific activities
Ease of use

All 3 user groups:
Movement
Weight
Appearance
Comfort

Parents and professionals:
cost

Children and parents:
Durability

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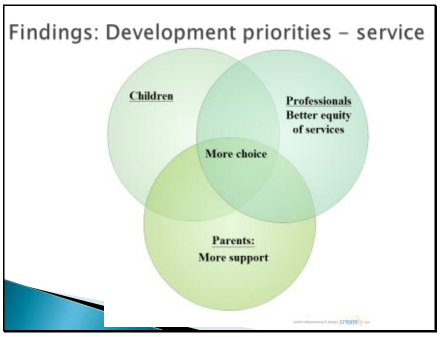

Findings: Development priorities – service

Children

Professionals
Better equity of services

More choice

Parents:
More support

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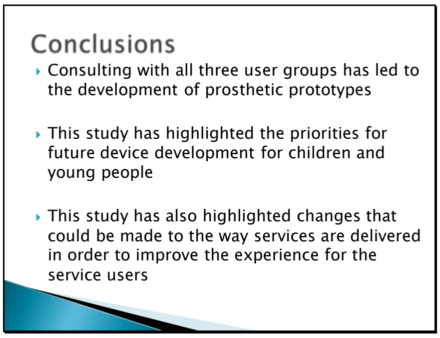

Conclusions

- Consulting with all three user groups has led to the development of prosthetic prototypes
- This study has highlighted the priorities for future device development for children and young people
- This study has also highlighted changes that could be made to the way services are delivered in order to improve the experience for the service users

Slide 14

Thank you for listening

For further discussion, please get in touch:

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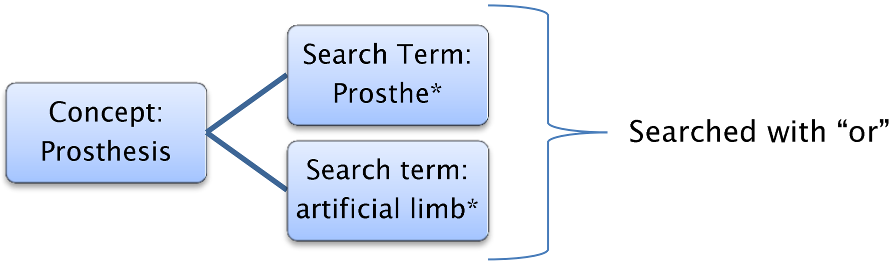
Appendix B

Details of search strategy: EBSCO and AMED

Search dates: 2000-present

Languages: English

Search Terms:



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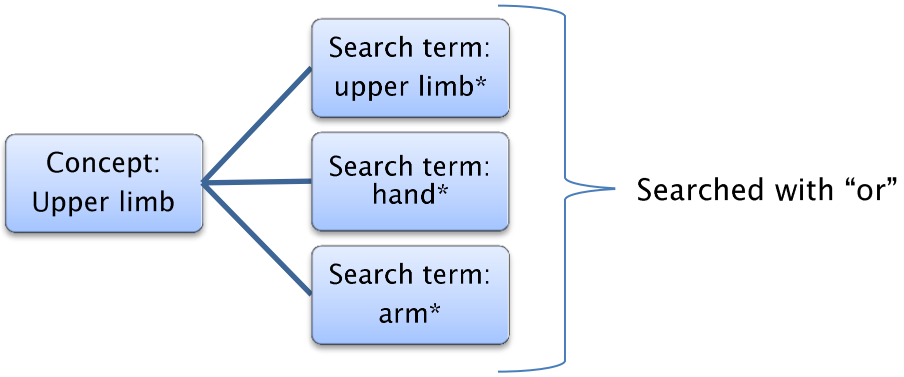

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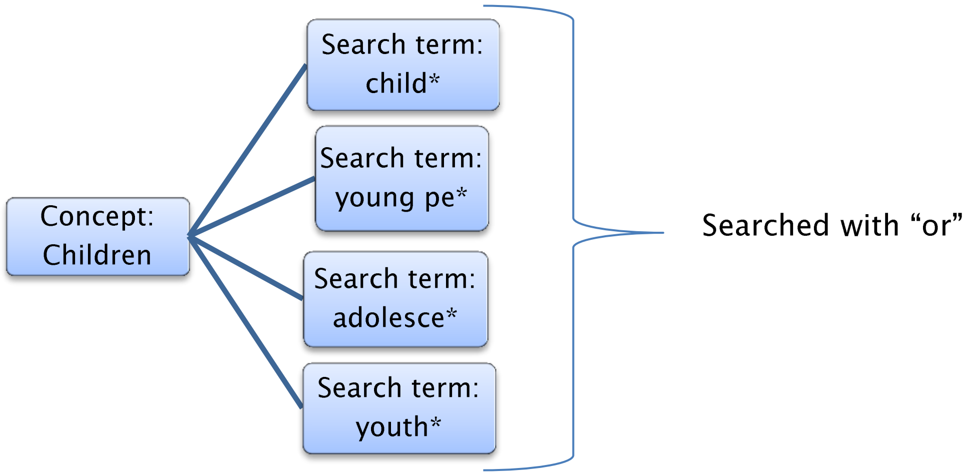


Appendix C

Pilot Focus Group Report

Method for pilot study

Participants:

The decision was taken to carry out the pilot work on children without limb difference in order to maximise the availability of participants for the main study. As limb difference amongst children is rare, it was felt that recruitment of sufficient numbers of participants to the main study may be a challenge and using a different cohort of participants for the pilot focus group would not exacerbate potential recruitment difficulties. Six participants took part in the pilot focus group. The participants were aged between five and ten years old with a mean age of seven years old. Three participants were male and three were female. Participants were recruited through staff members of the Faculty of Health Sciences at the University of Southampton. Participant packs containing participant information sheets and reply slips were put in pigeon holes of colleagues in the Faculty of Health Sciences. Informed consent was sought from the participants' parents, whereas assent was required from the participants themselves.

Materials:

A focus group schedule was designed to guide a discussion on participants' views of television programmes and their ideas for developing new programmes. Due to the participants not having limb difference or experience of prosthesis use it was necessary to choose a different topic for discussion than that of the main study's focus group. Television programmes was chosen as a suitable topic for the pilot focus group as television is something children are very familiar with and have experience of. Research has shown that children watch an average of 2.7 hours of television a day and three in five five-16 year olds have their own television (Childwise 2012). Furthermore, using something product based (television programmes) enabled the focus group guide to be tailored to mirror the questioning route of the focus groups in the main study, moving from general opinions to ideas for improvement and product development. Other materials required for the focus group included refreshments, art materials and a recording device. Healthy snacks and drinks were provided, as refreshments can help to create a relaxed atmosphere (Kitzinger 1995). Certificates thanking the participants were also provided.

Setting:

Prior to the focus group a quiet room was identified and prepared by positioning chairs in a horseshoe arrangement to facilitate discussion (Health & Safety Executive, HSE, 1998).

Procedure:

On arrival at the focus group, participants were encouraged to make a name sticker for themselves, as did the facilitators, and were offered a drink and a snack. The format of the group then proceeded as follows: ice-breaker activity, opening discussion, main activity and closing discussion.

Reflection on Pilot Study

As previously mentioned, the rationale for carrying out a pilot focus group was to provide the facilitator with an opportunity to reflect on and evaluate the process prior to carrying out the main study's focus group, in order to enhance facilitation skills. The following section will, therefore, be presented as a reflective piece.

Arrival at the group and ice-breaker activity:

On arrival at the session, participants and their parents were given consent forms to read and sign and any questions they had were answered – some of the participants wanted clarification/reassurance about what was going to be discussed and what we were going to do during the session. Participants were then asked to make a name sticker for themselves using the art materials provided. To begin the session, participants took part in an ice-breaker game in which they had to organise themselves into a line in alphabetical order. Participants seemed to enjoy this and it appeared to be helpful as a warm-up activity to encourage the participants to feel relaxed. Lightfoot & Sloper (2002) recommend the use of an ice-breaker exercise to create a more relaxed environment and encourage participation in the conversation. Some of the younger participants, however, found the activity quite difficult. The ice-breaker exercise could have been made easier if all participants were asked to say their name aloud at the start. This would have been helpful in the activity of alphabetising names for those younger or less literate participants and also may have encouraged participants to listen to each other. Despite this, the activity seemed to work well as participants appeared to enjoy it and it enabled participants to move around before the discussion without being so stimulating that it impacted on their ability to settle down for the discussion. The particular activity used also encouraged participants to learn each other's' names. To improve the activity, an activity analysis of the ice-breaker prior to the focus group would help to ensure that activities are pitched at the right level for participants' age and developmental stage.

Participants were then asked to sit down so that the discussion could begin. Participants chose to sit on the floor as the facilitator did not make it clear that the chairs had been arranged for them. The facilitator then introduced herself and the two co-facilitators and recapped on the purpose of the discussion and outlined the process. Participants were assured that, despite tape recording the conversation, principles of confidentiality and anonymity would be upheld. This was explained to them by stating that the tape recording was necessary to help the facilitators remember what the children had said, but would not be shared with other people. Despite being experienced in group work with children through clinical practice, this was the facilitator's first experience of conducting a focus group, which may explain some of the apprehensions that existed prior to conducting the group. See Figure below for examples of these concerns.

Concerns about practical issues:

- Will the participants turn up?
- Will the recording device capture every voice (even those who are quietly spoken)?

Concerns about the participants' behaviour:

- Will all the participants join in and answer the questions?
- Will some participants be very shy and remain silent throughout?
- Will some participants be very outgoing and dominate the discussion?
- Will all the participants be well behaved or will there be challenging behaviour to deal with?

Concerns about my skills as a facilitator:

- Will the questions on the interview schedule make sense to the participants?
- Will I be able to time the group correctly – will the conversation dry up too quickly or run over time?
- Will I be able to ensure the young people feel comfortable in the environment and enjoy the experience?
- Will my inexperience result in leading questions being asked?
- Will I be able to maintain the focus of the discussion
- Will the content of the interview guide gain sufficient information from participants?

Opening Question:

The opening question asked participants to say their name and their favourite television programme. This question required only a brief answer that would reflect a preference of the participant. Kennedy et al (2001) suggest that this is useful for demonstrating to the participants that the facilitators are not seeking 'right' or 'wrong' answers, making the participants feel more comfortable through decreasing performance anxiety. The first participant didn't, however, say her name before talking about her favourite television programme and this set a precedent for the other participants when answering the opening question. Not having the participants introduce themselves at the start of the discussion made distinguishing voices, when listening back to the recording, more difficult and may also have inhibited discussion between participants due to not knowing each other’s names. Prompting each participant to give his/her name at the start would have resolved this issue.

Interview Guide:

The pre-designed semi-structured interview guide helped to ensure the facilitator had covered everything that she had intended to and enabled keeping the discussion focused on the topic. A drawback of the guide, however, was that, if adhered to too rigidly, it may have made the facilitator less open to unexpected insights of the participants and less confident about probing further when the conversation took an unexpected direction (Morgan 1995). During the interview, the facilitator felt conscious of making contributions outside of the interview guide, which may suggest that rigid adherence to the guide was indeed an issue.

Group Dynamics:

The facilitator was also aware of the need to encourage participants to talk with one another and not directly to the facilitator (Gates & Waight 2007), which was challenging. Additionally, the facilitator was conscious of not breaking pauses in conversation too quickly as these gaps may provide opportunities for quieter participants to contribute (Krueger & Casey 2001). It was felt that confidence to divert from the focus group schedule would develop with growing confidence at facilitating.

Some participants were quieter than others but joined in with gentle encouragement and direct questions. Two of the participants were twins. They were the youngest of the participants (at 5 years old) and it was evident that one of the twins had a dominant role in the relationship. At times, this made it difficult for the quieter twin to express his opinion. The more assertive twin also occasionally interrupted other participants and dominated the discussion. Stafford et al (2003) suggest that the presence of both monopolising characters and shy personalities can result in difficulties eliciting minority viewpoints. These personality dynamics could be managed better if ground rules are set and agreed by the group before the discussion begins.

The youngest participants were 5 years old, which may have had an impact on the depth of information obtained as, if focussing questions at a level suitable for 5 year olds, the older participants may not have had a forum to discuss their more complex ideas. Conversely, when discussing more complex ideas, the younger participants may not have understood and, therefore, may have found participation too challenging. This observation is supported by Kennedy et al's (2001) recommendation that the discussion should be designed according to the participants' level of comprehension. Furthermore, they suggest that up until the age of 10, questions should be short, concrete and specific (Kennedy et al 2001), which may explain why the activity of creating a poster for an imaginary television programme seemed to be too difficult for younger participants, possibly due to the level of abstract thought required.

Creative Activities:

The main activity of making a poster seemed to be enjoyed by all participants. Hennesy & Heary (2005) recommend using activities in order to maintain children's concentration and interest. Everybody participated in this and had an opportunity to share their ideas. Some interesting ideas emerged, which may not have been shared without the use of a creative activity, as Kennedy et al (2001) recommend giving children opportunities to express their ideas in a variety of ways, not just through discussion. The activity did, however, result in a series of individual presentations rather than promoting group discussion. Some of the participants shared their ideas in a very descriptive format without explanation of the reasons they had included certain ideas in their posters. As discussed earlier, some younger participants also seemed to find the activity quite challenging and the concept of designing a poster may have been too abstract. These drawbacks could be addressed in future focus groups by the facilitator taking a more active role in probing the participants to draw out the reasons behind their ideas. It would also be beneficial to complete an activity analysis of the main activity to ensure it is graded at a level that is suitable for the participants' ages and abilities (Miller-Kuhaneck et al 2009).

Comfort of participants:

Participants were offered a healthy drink and snack before the discussion began. These refreshments were provided as several researchers recommend the use of food and drink to promote a relaxed atmosphere (e.g. Mansell et al 2004; Morrison & Peoples 1999). Some of the snacks were in packets, which at one point in the recording can be heard being rustled very loudly, hindering the ability to hear participants' voices. Considering the noise that the snacks may create, as well as their suitability for young children (e.g. healthy), is important. It should not, however, prevent the use of snacks in future focus groups, as providing snacks and drinks seemed to result in the majority of participants feeling more relaxed. Some participants did not, however, choose to have a drink or snack and they may have felt uncomfortable being offered them. For this reason, it may be more effective in future focus groups to leave the drinks/snacks in a place where participants can help themselves.

Kennedy et al (2001) identified that location is an important consideration when conducting focus groups with children, as unfamiliar settings can be anxiety-provoking. The location for the pilot focus group was the participants' parent/guardian's place of work. It was, therefore, convenient and familiar to the participants and they were aware that their parents/guardians were close by. This may have contributed to the participants feeling relaxed and comfortable during the discussion.

Blank stickers and art materials were provided for the participants to make their own name tags, enabling participants to maintain some ownership of the process, helping to counteract any potentially inequitable researcher-participant power balances (McNaughton & Smith 2005). The participants seemed to enjoy making their own name stickers and having the facilitators also wear name stickers they had made enabled a commonality between participants and facilitators and, hopefully, reduced any anxieties about talking to the facilitators. Certificates of thanks were given to all participants at the end of the discussion and, following the focus group, one of the parents fed back that her daughter was very pleased with her certificate.

Technical Considerations:

The sound quality of the recording was quite poor in places, possibly due to the position of the recording device. The recording device was placed on a table outside of the group and at one end. This resulted in people who were sat on one side being heard very clearly on the recording but participants on the other side being very quiet and difficult to hear. McLafferty's (2004) recommendation of having a second method of recording the discussion may be useful to eliminate this issue. Positioning the recording device in the middle of the group may also help with sound quality. Furthermore, Kennedy et al (2001) reported that recording devices that are placed on a table pick up too many superfluous sounds and that hanging or wall-mounting a microphone can help with this.

Summary of Lessons learned from pilot focus group:

Analysis of activities: analysing both the ice-breaker and main activity fully prior to the focus group would help to ensure that activities are pitched at the right level for participants and that they fulfil their aims, whether this be encouraging the participants to relax and participate or facilitating more in-depth discussion of participants' ideas.

Facilitation Style: A more active facilitation style may be required for focus groups with young people to probe deeper into the participants' ideas and to encourage discussion between group members. Although it is useful to have an interview guide, having confidence to allow the discussion to digress to a certain degree is essential for enabling the emergence of unanticipated insights.

Group Dynamics: Setting ground rules at the start of the focus group would be a very useful way of ensuring all participants are aware of the appropriate way to behave during the discussion (Kennedy et al 2001). These can be decided jointly by the group, making it a collaborative process, helping to redress the power imbalance between adult researcher and child participants (McNaughton & Smith 2005).

Recording Methods: More careful consideration of the type, position and quantity of recording devices is required. In future, it may be more successful to have two hung or wall-mounted devices that are placed in the middle of the group.

Age of Participants: Having a less diverse range of ages would be a useful modification to make in future focus groups, as this would allow the facilitation/communication style and activity to be better tailored toward the participants' abilities and developmental stage.

Appendix D

Participant Information and Consent documentation:

Children and Young People

Letter to Reach Charity Ltd members

Reach
Association for Children with Upper Limb Deficiency
Patron: Laura Hamilton

Dear Reach Member,
Invitation to join the study:

"How can we improve provision of prosthetic upper limbs for children and young people?"

We are interested in finding out what young people think about upper limb prostheses and how we can make them better. We thought you (or your child if you are the parent) may be interested in helping us find this out.

The study, which is being carried out by the University of Southampton, aims to find out the views of children and young people aged 7-16 years who have some experience of wearing an upper limb prosthesis.

The study will involve each participant taking part in 2 focus groups. There will be a maximum of 10 participants in each focus group and the groups will be divided according to age. In the first group, participants will be asked to share their views on upper limb prostheses. In the second group, participants will be shown some examples of prostheses and asked to give their feedback. Some participants may be asked if they would be willing to take part in a one-to-one interview following the focus groups.

Depending on the number of people who respond to this invitation, you may or may not be selected to take part in the study, but we will contact you either way to let you know.

Thank you for considering the study. If you have any questions, please do not hesitate to contact the researcher, Tara Sims, at tss1e10@soton.ac.uk.

Yours sincerely,

Tara Sims.

Participant Information Sheet

For older children (12-16 years) and parents

Children and Young People's Views of Upper Limb Prostheses

We would like to invite you to join our study. Before making a decision about whether to be involved you should know what the study is all about. Please take time to read this information and talk about it with your family and friends to help you make a decision. Thank you for taking the time to read this information and consider taking part in the study.

What is the aim of the study?

There is not much information about what children and young people think and feel about their upper limb prostheses. We are hoping to gain a better understanding of this so that upper limb prostheses can be designed and made with children and young people's views in mind.

Why have I been chosen?

You have been contacted because you are between 7 and 16 years of age and have upper limb deficiency/loss. Up to 30 children and young people aged between 7 and 16 years will be joining the study. If you return the reply slip to tell us you are interested in taking part, you may or may not be chosen to take part depending on how many people respond. However, we will contact you either way to let you know.

Do I have to take part in this study?

No, it is up to you whether or not you join the study. If you decide you are interested in taking part in the study, keep this information sheet. You can change your mind and withdraw from the study at any time – you do not have to tell us why.

What will happen if I take part?

We will phone your parent/guardian to invite you to attend 2 focus groups. The first focus group will take place in July or August this year and the second focus group will take place in autumn/winter of this year. The focus groups will be carried out on a weekend. During the focus groups, your parent/guardian can stay with you in the room if you want them to, but there will be a room for all the parents/guardians to wait in if you are happy for them to do so.

A focus group is a discussion with a group of people concentrating on a particular topic (in this research, upper limb prostheses). Each focus group will last approximately 1 hour. You can participate in the discussion as much or as little as you like and you can stop taking part at any time.

The location of the focus groups will be decided on once we know where everybody taking part lives so that we can prevent anybody from having to travel very far. You will be reimbursed for all your travelling expenses for getting to and from the focus groups. This will be done by the researcher, Tara Sims.

We will be tape recording the focus groups to help us remember what everyone has said. No one will know who you are because all the details about you will be kept private.

What could be difficult about taking part in the study?

Some children and young people find this a difficult or upsetting topic to talk about. You can stop taking part at any time and it is up to you what you wish to share and how much you contribute to the discussion.

How could this study help me?

Although this study may not help you directly, you may enjoy sharing your views and opinions. It is hoped that our findings will help develop upper limb prostheses that take into account the views of children and young people.

What will happen when the study is finished?

When the study is over, you will be given the opportunity to talk about the findings with the researcher. The main findings from the study will also be shared with Reach so they can share this information with their members.

It is hoped that the main findings from this study will contribute toward the development of upper limb prostheses for children and young people.

What if there is a problem or I have a complaint about this study?

If you have a concern or a complaint about this study you should contact Susan Rogers, Head of Research & Enterprise Services, at the Faculty of Health Sciences (Address: University of Southampton, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 7942; Email: S.J.S.Rogers@soton.ac.uk). If you remain unhappy and wish to complain formally, Susan Rogers can provide you with details of the University of Southampton Complaints Procedure.

Will anyone else know I am taking part in this research?

No-one else will know you took part in this study. All the information you give will be labelled with a number, not your name, so you will not be recognised. This information will be kept in a locked cabinet which only the researchers in the study will be able to open. Any personal information (like your name and address) will be kept in a separate locked cabinet. The rules of the University of Southampton state that all information you give us must be kept for 10 years and then destroyed.

Who is organising and funding the research?

The research is funded by the University of Southampton and will be taking place within the university's Rehabilitation and Health Technologies Research Group.

Who has reviewed the study?

Before any research takes place it has to be checked by an Ethics Committee to make sure that it is acceptable to do. This study has been approved by the University of Southampton's Faculty of Health Sciences Ethics Committee.

Contact details of the researcher:

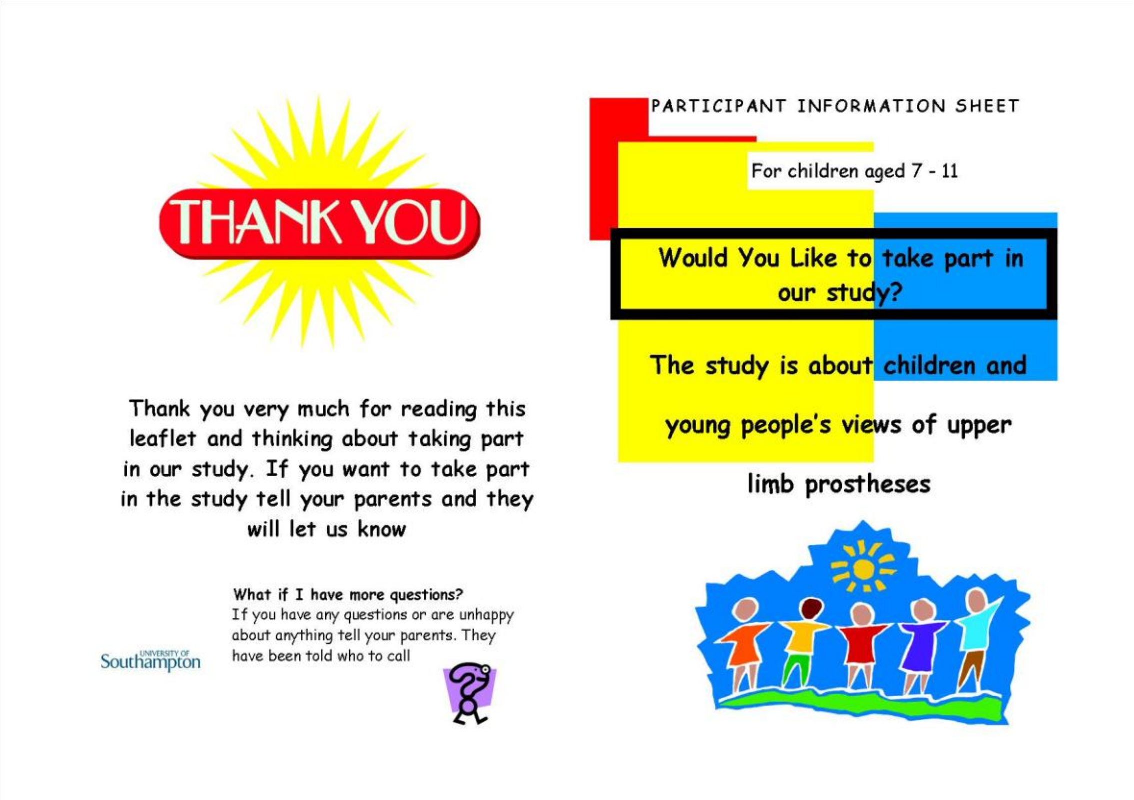
If you have any questions about the study, please contact the following person who will be happy to answer your queries:

Tara Sims (PhD Student)

Faculty of Health Sciences
University of Southampton
Highfield
Southampton
SO17 1BJ

Email: tss1e10@soton.ac.uk

Thank you for taking time to read this information and considering taking part in this study.



THANK YOU

Thank you very much for reading this leaflet and thinking about taking part in our study. If you want to take part in the study tell your parents and they will let us know

What if I have more questions?
If you have any questions or are unhappy about anything tell your parents. They have been told who to call

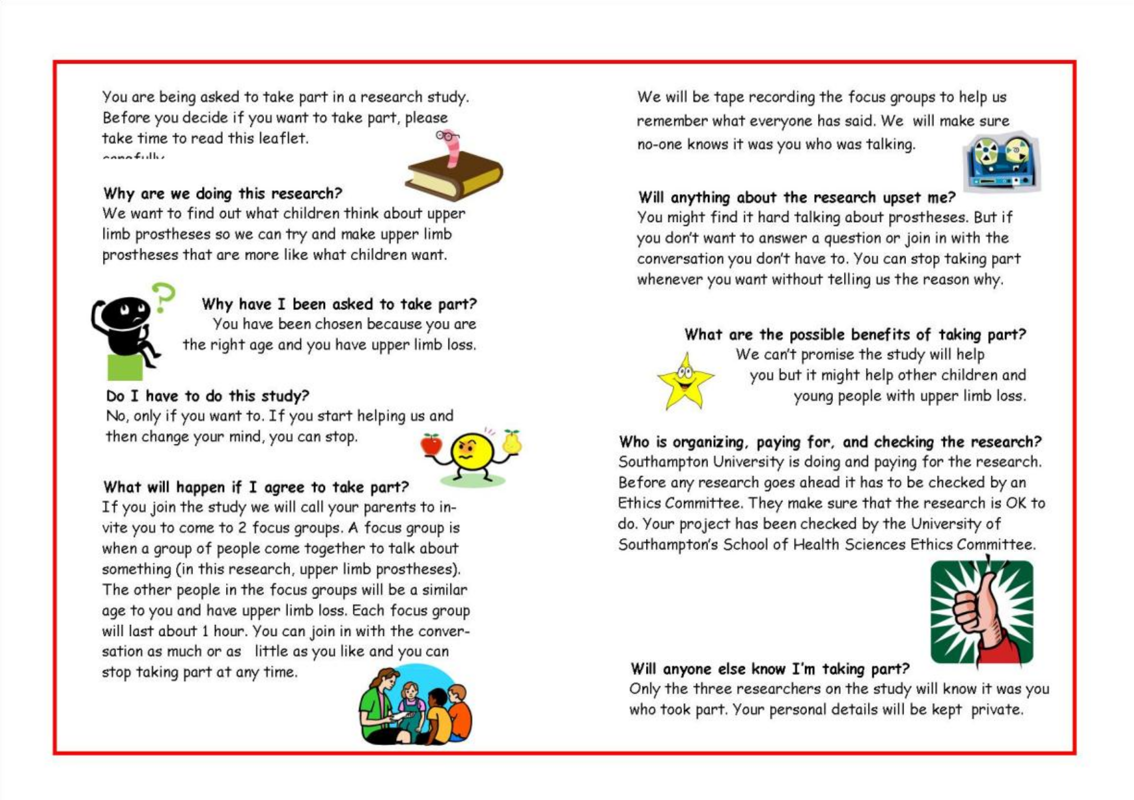
UNIVERSITY OF Southampton

PARTICIPANT INFORMATION SHEET

For children aged 7 - 11

Would You Like to take part in our study?

The study is about children and young people's views of upper limb prostheses



You are being asked to take part in a research study. Before you decide if you want to take part, please take time to read this leaflet.
carefully

Why are we doing this research?
We want to find out what children think about upper limb prostheses so we can try and make upper limb prostheses that are more like what children want.

Why have I been asked to take part?
You have been chosen because you are the right age and you have upper limb loss.

Do I have to do this study?
No, only if you want to. If you start helping us and then change your mind, you can stop.

What will happen if I agree to take part?
If you join the study we will call your parents to invite you to come to 2 focus groups. A focus group is when a group of people come together to talk about something (in this research, upper limb prostheses). The other people in the focus groups will be a similar age to you and have upper limb loss. Each focus group will last about 1 hour. You can join in with the conversation as much or as little as you like and you can stop taking part at any time.

We will be tape recording the focus groups to help us remember what everyone has said. We will make sure no-one knows it was you who was talking.

Will anything about the research upset me?
You might find it hard talking about prostheses. But if you don't want to answer a question or join in with the conversation you don't have to. You can stop taking part whenever you want without telling us the reason why.

What are the possible benefits of taking part?
We can't promise the study will help you but it might help other children and young people with upper limb loss.

Who is organizing, paying for, and checking the research?
Southampton University is doing and paying for the research. Before any research goes ahead it has to be checked by an Ethics Committee. They make sure that the research is OK to do. Your project has been checked by the University of Southampton's School of Health Sciences Ethics Committee.

Will anyone else know I'm taking part?
Only the three researchers on the study will know it was you who took part. Your personal details will be kept private.

Reply Slip

Children and Young People's Views of Upper Limb Prostheses

If you are interested in taking part in our study please read the statement below and tick the box if you agree. Please return the slip to the University of Southampton in the prepaid envelope provided.

After reading your information sheet I am interested in taking part in your study.

I would be happy for you to contact me to talk about it. ☐

Details of child/young person:

Name:____

Age:____

Gender: ☐ Male ☐ Female (please tick)

Please could you tell me the type limb deficiency/loss you have (please tick below):

☐ Left arm below wrist ☐ Right arm below wrist
☐ Both arms below wrist

☐ Left arm below elbow ☐ Right arm below elbow
☐ Both arms below elbow

☐ Left arm above elbow ☐ Right arm above elbow
☐ Both arms above elbow

Please could you tell me what your experience of using a prosthesis is:

☐ I have never used a prosthesis

☐ I have used a prosthesis in the past but do not use one now

☐ I currently use a prosthesis

I will NOT be available to take part on the following dates:

____

____

____

____

Details of Parent/Guardian:

Name:____

Address:____

____

____

____

_____________________Tel:_____________________________

Email:______________________________________

CONSENT FORM

For Parents/Guardians

Study title: How can we improve provision of prosthetic upper limbs for children and young people? Involving service users in the development of upper limb prostheses.

Researcher name: Tara Sims

Ethics reference:

Please initial the box(es) if you agree with the statement(s):

have read and understood the information sheet dated……. (version no…..). I have had the opportunity to ask questions about the study and any questions I had have been answered satisfactorily ☐

I agree to allow my child to take part in this research project and agree for his/her data to be used for the purpose of this study ☐

I understand that my child's participation is voluntary, that s/he can choose not to participate in part or all of the study, and that s/he or I can withdraw at any stage of the project without having to give a reason and without consequence ☐

I agree for my child to be audiotaped during the focus groups/interview ☐

I agree for my child to be directly quoted in the findings of the study but understand that any quotations will be anonymous ☐

I understand that only the three researchers on the study will have access to the information collected during the interview ☐

Participant’s Name: ……………………………………………………… (please print)

Parent’s/Guardian’s Name: ………………………………………………………………

Parent’s/Guardian’s Signature: ……………………………… ………………………

Date:………………………………………………………………………………………

Name of Researcher: ……………………………………………………………………

Signature of Researcher:…………………………………………………………………

Date: ………………………………………………………………………………

ASSENT FORM
For Children and Young People
(To be completed by child with their parent/guardian)

Project Title: How can we improve provision of prosthetic upper limbs for children and young people? Involving service users in the development of upper limb prostheses.

Please tick all the statements you agree with:

I have read (or had read to me) information about this research ☐

The research has been explained to me ☐

I understand what the research is about ☐

I have asked all the questions I want to and the researcher has answered them ☐

I understand that I don't have to take part and that I can stop taking part whenever I want without giving a reason. ☐

I am happy for the researcher to record what I say ☐

I am happy for the researcher to put some of the things I say in a report as long as my name is not used in the report ☐

I am happy to take part in this research ☐

If you haven't ticked all the boxes or you don't want to take part, don't write your name.

If you do want to take part, please write your name and today's date

Name: ....

Age:......................

Date……………………………

Appendix E

Focus Group Ice-breaker: Activity Analysis & Synthesis

(based on Lamport, Coffey & Hersch 2001)

Name of activity: Man-eating Yoghurt Swamp Game

Brief Description of the activity: Group participants are asked to stand in a straight line. They are then told they are standing on a bridge over a “man-eating yoghurt swamp” but that the exit of the bridge is closed and will only open if they are standing in alphabetical order of their names. They are asked to loudly tell the group their names and then rearrange themselves into the right order without stepping off the imaginary bridge (and into the swamp!).

If necessary, repeat the activity with other order, such as:

- Height, from smallest to tallest.
- Birthdays, from January through to December.
- Shoe size, from smallest to largest.

Tools/Equipment (non-expendable), Cost and Source/Materials/Supplies (expendable), Cost and Source: None, just imagination!

Space/Environmental Requirements: Space large enough to accommodate all group participants, free from furniture or other trip hazards.

Maximum total time needed: 15 minutes.

Special considerations: Activity will need to be adapted for young people with additional mobility or sensory needs.

Acceptable criteria for completion: All participants have interacted in the task and each other. Participants will be standing in the correct order according to the instruction given.

Performance Components

Sensory:

In order to be able to perform the activity as described above participants will need to have adequate vision and hearing – if not adaptations to the activity could be made to accommodate these (e.g. wider ‘bridge’ for participants to walk over (for visual impairment), all participants required to perform activity using gesture instead of speech (for hearing impairment).

Participants with difficulties with proprioceptive or vestibular processing may find it difficult to remain on the ‘bridge’. Again a larger ‘bridge’ would address this.

Participants who are tactile defensive may find it difficult to be in such close proximity to other participants.

Neuro-musculoskeletal:

Participants will require sufficient muscle tone, stamina and postural control to stand and move in a tight space over several minutes (up to 15). The activity could be adapted to accommodate those who need to sit for periods by using a row of chairs as the bridge.

Participants will require sufficient clarity of speech to make themselves understood to the other participants.

Motor:

Participants will require sound motor skills in order to walk around other participants within a small space.

Cognitive Integration and cognitive components:

Expressive and receptive language skills will be needed to share names with other participants.

Participants will need sufficient attention to listen to the instructions at the start of the activity. This will involve attending to and understanding several steps/components.

They will need to have adequate communication skills to speak to the other participants.

They will need an understanding of what ‘alphabetical order’ means and good knowledge of the alphabet.

They may also require memory skills to retain participants’ names for long enough in order to get the order correct.

Psychosocial Skills and Psychological Components:

Participants will require a sufficient level of self-confidence to feel comfortable saying their name aloud to other participants.

Social skills will be required in order to share information appropriately with other participants and to move appropriately around others in a small space.

Reference: Lamport NK, Coffey M and Hersch GI (2001) *Activity, Analysis and Application* (4th edition). Thorofare, NJ: Slack Inc.

Appendix F

Focus Group and Interview Guides

Questioning Route for First Focus Group with children/young people

Opening Questions

- Tell us your name and where you live
- Tell us your first name and your favourite colour

Introductory Questions

- Think about the first prosthetic arm you can remember having, what was it like?
    - What were the things you liked about it?
    - What were the things you didn't like about it?

Transition Questions

- What has been the best prosthetic arm you've had? – what made it the best?
- Thinking about all the different prosthetic arms you've had...
    - What's been good or bad about the way they've looked?
    - What's been good or bad about the things you could use them for/what you could do with them?
    - What's been good or bad about the way they felt?
    - Were they comfortable? What did or didn't help them to be comfortable?

Key Questions

- I want you to imagine that I have a magic wand and can conjure up your ideal prosthetic arm:
    - What would it look like?
        - Colour

        - Special features
        - Feel/texture of the surface
    - What activities would it help you to do?
        - at home
        - at school
        - with friends
    - How would you feel about it?
    - What would other people think about it?
    - How would it feel when you’re wearing it?
        - Would it be light/heavy

Ending Questions

- We’ve discussed lots of ideas for your ideal prosthetic UL: of all of these, which one is most important to you?
- Is there anything else that we haven’t already talked about that anyone would like to add about their ideal prosthetic UL?

Questioning Route for Focus Group with Parents

1st Half:

Opening Question

- Tell us your name and where you live

Introductory Question

- Think about your child's first prosthetic arm, what was it like?
    - What things were good about it?
    - What things weren't good about it?

Transition Questions

- What has been the best prosthetic arm your child has had and why?
- Thinking about all the different prosthetic arms your child has had...
    - How did they look – what was good or bad about their appearance?
    - What's sort of activities did it help/hinder them to do?
    - Did your child find them comfortable? What did or didn't help them to be comfortable?

Key Questions

- What would an ideal prosthetic arm for your child be like?:
    - What would it look like?
        - Colour
        - Special features
        - Feel/texture of the surface
    - What activities would your child be able to do with it?

  - at home
  - at school
  - with friends

Ending Questions

- We've discussed lots of ideas for your ideal prosthetic UL: of all of these, which one is most important to you?
- Is there anything else that we haven't already talked about that anyone would like to add about their ideal prosthetic UL?

2nd half:

Discussion around prototype prosthetic upper limbs and information gathered in FG's with children:

- Participants asked to give their opinions on the prototypes
- What do they think is good/bad about them?
- How could they be improved?

Questioning Route for one-to-one interviews with Parents

- Think about your child’s first prosthetic arm, what was it like?
    - What things were good about it?
    - What things weren’t good about it?

- What has been the best prosthetic arm your child has had and why?
    - What did it look like?
    - What’s sort of activities did it help/hinder your child to do?
    - Did your child find it comfortable? What did or didn’t help them to be comfortable?
    - How did your child feel about wearing it?

- Think about a prosthetic arm that hasn’t been so good:
    - What did it look like?
    - What’s sort of activities did it help/hinder your child to do?
    - Did your child find it comfortable? What did or didn’t help them to be comfortable?
    - How did your child feel about wearing it?

- What would an ideal prosthetic arm for your child be like?:
    - What would it look like?
        - Colour
        - Special features
        - Feel/texture of the surface
    - What activities would your child be able to do with it?
        - at home

        - at school
        - with friends
    - How would your child feel about wearing it?

- We’ve discussed lots of ideas for your ideal prosthetic UL: of all of these, which one is most important to you?
-
- Is there anything else that we haven’t already talked about that you would like to add about what an ideal prosthetic UL would be like?

Questioning Route for one-to-one interviews with Professionals

- What do you think about the prosthetic arms that are currently available for children and YP?
    - What things are good about them?
    - What things aren't good about them?

- In your opinion what's the best prosthetic arm for children and YP and why?
    - What does it look like?
    - What activities can it help children with?
    - Do you think children find it comfortable?
    - What do you think children and their parents feel about it?

- Do you think things can be done to improve prostheses for children?
    - If so, in what areas?
    - If not, why not?

- Children and YP have told us they would like prostheses to be improved in terms of:
    - Appearance
    - Comfort
    - Reliability/ease of use
    - Weight
    - Movement
    - For use with specific activities

What do you think about these?

- These prototype prosthetic devices have been made based on the ideas of children and YP:
    - What do you think about them?
    - What would encourage you to prescribe them to your clients?

  - What would be the barriers for you in using them with your clients?
  - What do you think we need to do to improve them?

- Is there anything that we haven't already talked about that you think needs to be taken into account when developing new prosthetic UL's for children and YP?

Appendix G

Participant Information and Consent documentation:

Parents

Participant Information Sheet

Parents' Views of Upper Limb Prostheses

Invitation to join the study:

"How can we improve provision of prosthetic upper limbs for children and young people?"

We are interested in finding out what parents think about upper limb prostheses and how we can improve them. We thought you may be interested in taking part in research that aims to find this out.

The study, which is being carried out by the University of Southampton, aims to find out the views of parents of young people aged 7-16 years who have some experience of wearing an upper limb prosthesis.

The study will involve each participant taking part in a focus group. There will be a maximum of 12 participants in the focus group. Participants will be asked to share their views on upper limb prostheses and will be shown some examples of prostheses and asked to give their feedback.

Depending on the number of people who respond to this invitation, you may or may not be selected to take part in the study, but we will contact you either way to let you know.

Before you decide whether to take part in the study, it is important for you to understand why the research is being done and what it will involve. Please take time to read this information to help you make a decision. Ask us if there is anything that is not clear or you would like more information. Thank you for considering taking part in the study.

What is the aim of the study?

There is not much information about what parents think and feel about upper limb prostheses. We are hoping to gain a better understanding of this so that upper limb prostheses can be designed that take into account parents' views.

Why have I been chosen?

You have been contacted because you are the parent of a young person who has upper limb deficiency/loss and who is participating in our research on children's views of prostheses.

Do I have to take part in this study?

No, it is up to you whether or not you join the study. If you decide you are interested in taking part in the study, keep this information sheet. You can change your mind and withdraw from the study at any time – you do not have to tell us why.

What will happen if I take part?

You will be invited to attend a focus group with other parents of children with upper limb loss/deficiency. A focus group is a discussion with a group of people concentrating on a particular topic (in this research, upper limb prostheses). The focus group will last approximately 1 hour and will take place at the same time as the focus group your child will be attending. You can participate in the discussion as much or as little as you like and you can stop taking part at any time.

You will be reimbursed for all your travelling expenses for getting to and from the focus groups. This will be done by the researcher, Tara Sims.

We will be tape recording the focus groups to help us remember what everyone has said. No one will know who you are because all the details about you will be kept private.

What are the possible risks of taking part?

There are no specific risks from taking part in the study, but you may find some things difficult or upsetting to talk about. You can stop taking part at any time and it is up to you what you wish to share and how much you contribute to the discussion.

What are the potential benefits of taking part?

It is hoped that our findings will help develop upper limb prostheses for children that take into account the views of young people and their parents.

What will happen when the study is finished?

When the study is over, you will be given the opportunity to talk about the findings with the researcher. The main findings from the study will also be shared with Reach so they can share this information with their members.

It is hoped that the main findings from this study will contribute towards the development of upper limb prostheses for children and young people.

What if there is a problem or I have a complaint about this study?

If you have a concern or a complaint about this study you should contact Dr Martina Prude, Head of Research & Enterprise Services, at the Faculty of Health Sciences (Address: Research Governance Office, Building 37, Room 4055, University of Southampton, University Road, Highfield, Southampton, SO17 1BJ; Tel: +44 (0)23 8059 5058; Email: mad4@soton.ac.uk). If you remain unhappy and wish to complain formally, Dr Martina Prude can provide you with details of the University of Southampton Complaints Procedure.

Will anyone else know I am taking part in this research?

No-one else will know you took part in this study. All the information you give will be labelled with a number, not your name, so you will not be recognised. This information will be kept in a locked cabinet which only the researchers in the study will be able to open. Any personal information (like your name and address) will be kept in a separate locked cabinet. The rules of the University of Southampton state that all information you give us must be kept for 10 years and then destroyed.

Who is organising and funding the research?

The research is funded by the University of Southampton and will be taking place within the university's Rehabilitation and Health Technologies Research Group.

Who has reviewed the study?

Before any research takes place it has to be checked by an Ethics Committee to make sure that it is acceptable to do. This study has been approved by the University of Southampton's Faculty of Health Sciences Ethics Committee.

Contact details of the researcher:

If you have any questions about the study, please contact the following person who will be happy to answer your queries:

Tara Sims (PhD Student)
Faculty of Health Sciences
University of Southampton
Highfield
Southampton
SO17 1BJ
Email: tss1e10@soton.ac.uk

Thank you for taking time to read this information and considering taking part in this study.

If you are interested in taking part in our study please complete the reply slip on the following page and return to the University of Southampton in the prepaid envelope provided.

Reply Slip

Parents' Views of Upper Limb Prostheses – Focus Group

If you are interested in taking part in our study please read the statement below and tick the box if you agree. Please return the slip to the University of Southampton in the prepaid envelope provided.

After reading your information sheet I am interested in taking part in your study. ☐

I would be happy for you to contact me to talk about it.

I will NOT be available to take part on the following dates:

____

____

____

____

Participant details:

Name:____

Address:____

____

_____________________Tel:______________________________

Email:_______________________________________

Participant Information Sheet – Interviews

Parents' Views of Upper Limb Prostheses

Invitation to join the study:

"How can we improve provision of prosthetic upper limbs for children and young people?"

We are interested in finding out what parents think about upper limb prostheses and how we can improve them. We thought you may be interested in taking part in research that aims to find this out.

The study, which is being carried out by the University of Southampton, aims to find out the views of parents of young people aged 7-16 years who have some experience of wearing an upper limb prosthesis.

The study will involve each participant taking part in a one-to-one interview. Participants will be asked to share their views on upper limb prostheses and will be shown some examples of prostheses and asked to give their feedback.

Depending on the number of people who respond to this invitation, you may or may not be selected to take part in the study, but we will contact you either way to let you know.

Before you decide whether to take part in the study, it is important for you to understand why the research is being done and what it will involve. Please take time to read this information to help you make a decision. Ask us if there is anything that is not clear or you would like more information. Thank you for considering taking part in the study.

What is the aim of the study?

There is not much information about what parents think and feel about upper limb prostheses. We are hoping to gain a better understanding of this so that upper limb prostheses can be designed that take into account parents' views.

Why have I been chosen?

You have been contacted because you are the parent of a young person who has upper limb deficiency/loss and who is participating in our research on children's views of prostheses.

Do I have to take part in this study?

No, it is up to you whether or not you join the study. If you decide you are interested in taking part in the study, keep this information sheet. You can change your mind and withdraw from the study at any time – you do not have to tell us why.

What will happen if I take part?

You will be invited to take part in a one-to-one interview with the researcher. The interview will last approximately 1 hour and will take place in your home or a venue of your choice. You can stop taking part in the interview at any time.

We will be tape recording the interviews to help us remember what is said. No one will know who you are because all the details about you will be kept private.

What are the possible risks of taking part?

There are no specific risks from taking part in the study, but you may find some things difficult or upsetting to talk about. You can stop taking part at any time and it is up to you what you wish to share.

What are the potential benefits of taking part?

It is hoped that our findings will help develop upper limb prostheses for children that take into account the views of young people and their parents.

What will happen when the study is finished?

When the study is over, you will be given the opportunity to talk about the findings with the researcher. The main findings from the study will also be shared with Reach so they can share this information with their members.

It is hoped that the main findings from this study will contribute towards the development of upper limb prostheses for children and young people.

What if there is a problem or I have a complaint about this study?

If you have a concern or a complaint about this study you should contact Dr Martina Prude, Head of Research & Enterprise Services, at the Faculty of Health Sciences (Address: Research Governance Office, Building 37, Room 4055, University of Southampton, University Road, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 5058; Email: mad4@soton.ac.uk). If you remain unhappy and wish to complain formally, Dr Martina Prude can provide you with details of the University of Southampton Complaints Procedure.

Will anyone else know I am taking part in this research?

No-one else will know you took part in this study. All the information you give will be labelled with a number, not your name, so you will not be recognised. This information will be kept in a locked cabinet which only the researchers in the study will be able to open. Any personal information (like your name and address) will be kept in a separate locked cabinet. The rules of the University of Southampton state that all information you give us must be kept for 10 years and then destroyed.

Who is organising and funding the research?

The research is funded by the University of Southampton and will be taking place within the university's Rehabilitation and Health Technologies Research Group.

Who has reviewed the study?

Before any research takes place it has to be checked by an Ethics Committee to make sure that it is acceptable to do. This study has been approved by the University of Southampton's Faculty of Health Sciences Ethics Committee.

Contact details of the researcher:

If you have any questions about the study, please contact the following person who will be happy to answer your queries:

Tara Sims (PhD Student)
Faculty of Health Sciences
University of Southampton
Highfield

Southampton
SO17 1BJ
Email: tss1e10@soton.ac.uk

Thank you for taking time to read this information and considering taking part in this study.
If you are interested in taking part in our study please complete the reply slip on the following page and return to the University of Southampton in the prepaid envelope provided.

Reply Slip

Parents' Views of Upper Limb Prostheses – Interviews

If you are interested in taking part in our study please read the statement below and tick the box if you agree. Please return the slip to the University of Southampton in the prepaid envelope provided.

After reading your information sheet I am interested in taking part in your study.
I would be happy for you to contact me to talk about it. ☐

I will NOT be available to take part on the following dates:

____
____
____
____

Participant details:

Name:____
Address:____
____
____
____
____________________Tel:___________________________
Email:__________________________________

CONSENT FORM

Study title: How can we improve provision of prosthetic upper limbs for children and young people? Involving parents in the development of upper limb prostheses.

Researcher name: Tara Sims

Ethics reference:

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet dated……. (version no…..). I have had the opportunity to ask questions about the study and any questions I had have been answered satisfactorily ☐

I agree to take part in this research project and agree for my data to be used for the purpose of this study ☐

I understand that my participation is voluntary, that I can choose not to participate in part or all of the study, and that I can withdraw at any stage of the project without having to give a reason and without consequence ☐

I agree to be audiotaped during the interview/focus group ☐

I agree to be directly quoted in the findings of the study ☐

but understand that any quotations will be anonymous

I understand that only the three researchers on the study will have access to the information collected during the interview/focus group ☐

Participant's Name: ....
(please print)

Participant's Signature: ....

Date:..

Name of Researcher: ....

Signature of Researcher:...

Date: ....

Appendix H

Participant Information and Consent documentation: Professionals

Study Flier

Clinicians' Views of Upper Limb Prostheses

Are you a clinician working in the field of paediatric UL prosthetics?
If so, we would like to invite you to join our study...

We are hoping to gain a better understanding of what clinicians think and feel about upper limb prosthetics for children.

We are carrying out one-to-one interviews lasting approximately 1 hour.
Interviews will be carried out between May and October 2012.
The researcher is happy to travel to a place of your choice to carry out the interview, but if you would like to come to the University of Southampton to take part, travel costs by bus, train or car will be reimbursed.

It is hoped that our findings will help develop upper limb prostheses for children that take into account the views of children, parents and clinicians, in order to reduce the current high rates of reduction.

For more information about the study please contact:
Tara Sims (PhD Student)
Faculty of Health Sciences
University of Southampton
Highfield
Southampton SO17 1BJ
Email: tss1e10@soton.ac.uk

UNIVERSITY OF
Southampton

The research is funded by the University of Southampton and is taking place within the University's Rehabilitation and Health Technologies Research Group.

Participant Information Sheet

Clinicians' Views of Upper Limb Prostheses

We are interested in exploring clinicians' views about upper limb prostheses and what the priorities for future device development should be. We thought you might be interested in taking part in research that aims to find this out. The study, which is being carried out by the University of Southampton, aims to find out the views of clinicians who have experience in the field on paediatric upper limb prosthetics. The study will involve each participant taking part in a one-to-one interview. Participants will be asked to share their views on upper limb prostheses and will be shown some examples of prostheses and asked to give their feedback. Depending on the number of people who respond to this invitation, you may or may not be selected to take part in the study, but we will contact you either way to let you know.

Before you decide whether to take part in the study, it is important for you to understand why the research is being done and what it will involve. Please take time to read this information to help you make a decision. Ask us if there is anything that is not clear or you would like more information. Thank you for considering taking part in the study.

What is the aim of the study?

There is a lack of research exploring the views of clinicians on upper limb prostheses for children and young people. We are hoping to gain a better understanding of this so that upper limb prostheses can be designed that take into account users' views. This is the third stage in a research study, which is exploring the views of users (children, parents and professionals) on prosthetic upper limbs for children and young people. Research exploring children's and parents' views has already been carried out.

Why have I been chosen?

You have been contacted because you are a clinician who works in the field of paediatric upper limb prosthetics.

Do I have to take part in this study?

No, it is up to you whether or not you join the study. If you decide you are interested in taking part in the study, keep this information sheet. You can change your mind and withdraw from the study at any time – you do not have to tell us why.

What will happen if I take part?

You will be invited to take part in a one-to-one interview with the researcher. You can choose where you would like the interview to take place – your home, your place of work, the University or another private location of your choice. The interview will last approximately 1 hour. You can end they interview earlier than this if you wish to. We will be tape recording the interview to help us remember what you have said. No one will know who you are because all the details about you will be kept private.

If you choose to travel to the University of Southampton to participate, you will be provided with an expenses claim form so that your travel expenses can be reimbursed. This will cover travel by:

- Car: car mileage will be reimbursed
- Train/Bus: Standard class train and bus fares will be reimbursed

If you choose for the interview to take place at your home, work or another location, the researcher will be willing to travel within the UK to carry out the interview.

What are the possible risks of taking part?

There are no specific risks from taking part in the study. You can stop taking part at any time and it is up to you what you wish to share.

What are the potential benefits of taking part?

There are no direct personal benefits, but it is hoped that our findings will help develop upper limb prostheses for children that take into account the views of young people, parents and clinicians. The findings may also be used as a starting point for future research or to help with the development of guidelines and information.

What will happen when the study is finished?

When the study is over, you will be given the opportunity to talk about the findings with the researcher. The main findings from the study will also be disseminated through conferences and journal articles. It is hoped that the main findings from this study will contribute towards the development of upper limb prostheses for children and young people.

What if there is a problem or I have a complaint about this study?

If you have a concern or a complaint about this study you should contact Dr Martina Prude, Head of Research & Enterprise Services, at the Faculty of Health Sciences (Address: Research Governance Office, Building 37, Room 4055, University of Southampton, University Road, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 5058; Email: mad4@soton.ac.uk). If you remain unhappy and wish to complain formally, Dr Martina Prude can provide you with details of the University of Southampton Complaints Procedure.

Will anyone else know I am taking part in this research?

No-one else will know you took part in this study. All the information you give will be labelled with a number, not your name, so you will not be recognised. This information will be kept in a locked cabinet which only the researchers in the study will be able to open. Any personal information (like your name and address) will be kept in a separate locked cabinet. The rules of the University of Southampton state that all information you give us must be kept for 10 years and then destroyed.

Who is organising and funding the research?

The research is funded by the University of Southampton and will be taking place within the university's Rehabilitation and Health Technologies Research Group.

Who has reviewed the study?

Before any research takes place it has to be checked by an Ethics Committee to make sure that it is acceptable to do. This study has been approved by the University of Southampton's Faculty of Health Sciences Ethics Committee.

Contact details of the researcher:

If you have any questions about the study, please contact the following person who will be happy to answer your queries:

Tara Sims (PhD Student) Email: tss1e10@soton.ac.uk
Faculty of Health Sciences
University of Southampton
Highfield
Southampton
SO17 1BJ

Thank you for taking time to read this information and considering taking part in this study. If you are interested in participating in this research please return the enclosed reply slip to the researcher at:

Tara Sims (Dr Maggie Donovan-Hall)
Faculty of Health Sciences (Building 45)
University of Southampton
FREEPOST (SCE9053)
Southampton
SO17 1YA

Reply Slip

Clinicians' Views of Upper Limb Prostheses

If you are interested in taking part in our study please read the statement below and tick the box if you agree. Please return the slip to the University of Southampton in the prepaid envelope provided.

If you would like further information before deciding whether you are interested in taking part, please contact the researcher, Tara Sims, at tss1e10@soton.ac.uk

After reading your information sheet I am interested in taking part in your study.

I would be happy for you to contact me to talk about it. ☐

I will NOT be available to take part on the following dates:

____

____

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____

I would like my interview to be carried out in the following location:

____

____

____

____

Participant details:

Name:____

Profession:____

I have worked in the field of paediatric upper limb prosthetics for

________years, ________months.

Address for contact by researcher:

____

____

____

Tel:______________________________Email:_____________________________________

Letter to Respondents not Selected to Participate

Tara Sims
Faculty of Health Sciences
University of Southampton
Highfield
Southampton
SO17 1BJ

[Date]

Dear [**Recipient Name**],

Thank you very much for showing an interest in our study about clinician's views about upper limb prostheses. Whilst we would be very interested in hearing your views, we now have all the participants needed for the current study. Unfortunately, this means your further participation in this study is not required.

We really appreciate you taking the time to think about our study and volunteering to participate and hope that you may be willing to participate in future studies we will be carrying out.

Yours sincerely,

Tara Sims
University of Southampton

CONSENT FORM

Study title: Exploring the views of clinicians to contribute towards the development of new upper limb prostheses for children

Researcher name: Tara Sims
Ethics reference:

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet dated……. (version no…..). I have had the opportunity to ask questions about the study and any questions I had have been answered satisfactorily	☐
I agree to take part in this research project and agree for my data to be used for the purpose of this study	☐
I understand that my participation is voluntary, that I can choose not to participate in part or all of the study, and that I can withdraw at any stage of the project without having to give a reason and without consequence	☐
I agree to be audiotaped during the interview	☐
I agree to be directly quoted in the findings of the study but understand that any quotations will be anonymous	☐
I understand that only the three researchers on the study will have access to the information collected during the interview	☐

Participant’s Name: .... (please print)

Participant’s Signature: ………………………………….. ....

Date:………………………..

Name of Researcher: ………………………………………………...

Signature of Researcher:……………………………………………………….............................

Date: ……………………………………………………………………………………………

Appendix I

Transcription Protocol

- **Labelling Transcripts**

Transcript shall include the following labelling information in the header of the document:

<u>Focus Groups</u>

Focus Group Location:

Date:

Number of Attendees:

Name of Facilitator:

Name of Transcriber:

<u>Interviews</u>

Interview Location:

Date:

Interviewee:

Name of Interviewer:

Name of Transcriber:

- **Documenting Comments**

Comments or questions by the Interviewer or Facilitator should be labelled as such in the left margin.

Any comments or responses from participants should be labelled with **their pseudonym:** at the left margin. A response or comment from a different participant should be separated by a return and **their pseudonym:** at the left margin.

- **End of Interview**

In addition, the transcriber shall indicate when the interview session has reached completion by typing END OF INTERVIEW in uppercase letters on the last line of the transcript.

- **Content:**

Audio data shall be transcribed verbatim including nonverbal sounds (such as laughter). Nonverbal sounds shall be typed in parentheses e.g. (laughter). Words shall be transcribed as the individual said them (including mispronunciations).

- **Inaudible Information**

The transcriber shall identify portions of the audiotape that are inaudible or difficult to decipher and type the phrase “inaudible” in square brackets.

- **Overlapping Speech**

If individuals are speaking at the same time (i.e., overlapping speech) and it is not possible to distinguish what each person is saying, the transcriber shall place the phrase “cross talk” in square brackets immediately after the last identifiable speaker’s text and pick up with the next audible speaker.

- **Pauses**

If an individual pauses briefly between statements or trails off at the end of a statement, the transcriber shall use three ellipses

- **Sensitive Information**

If an individual uses his or her own name during the discussion, the transcriber shall replace this information with the appropriate pseudonym. Any other sensitive information (such as, others’ names, locations, organisations) shall be removed at the time of transcription.

Appendix J

Example Focus Group Transcript: Children and Young People (excerpt)

Focus Group Location: London

Date: 19th November 2011

Number of Attendees: 4. 2 female, aged 8 and 14. 2 male, aged 10 and 12.

Name of Facilitators: Tara Sims (1) and Maggie Donovan-Hall (2)

Name of Transcriber: Tara Sims

Facilitator 1: So the first thing I want everyone to do is just to say their name and where they live. Ok.

David: I'm David and I live in XXXX.

Chris: I'm Chris and I live in XXXX.

Becky: I'm Becky and I live in XXXX.

Anna: I'm Anna and I live in XXXX.

Facilitator 1: Great. Thanks. Um. First thing I want us to think about today is the very first prosthetic arm that you ever got.

Becky: [whispered] Mine was teeny.

Facilitator 1: Can people remember what that was like?

Becky: Yeah, I still have it.

David: Yeah, same.

Anna: I still have mine.

Becky: I have a collection of my old hands.

Chris: I think I have mine.

Facilitator 1: What was it like?

Becky: Teeny.

David: Yeah, like that big.

Anna: And it was just a cosmetic one. It wasn’t an electric one. It was quite light. I think I used it when I was a baby for like crawling and stuff.

Facilitator 2: Was everyone else’s cosmetic or did it do anything?

Becky: I had a few which were like battery powered

David: Yeah I had one but I didn’t really use it.

Facilitator 1: You didn’t really use it?

David: It was too heavy.

Chris: I had one of those as well. I don’t know what they’re called but they were too heavy. I found I had to actually hold it with my other arm so it didn’t work.

Facilitator 1: Yeah. Did other people use theirs?

Anna: Um. I have had electric ones and I remember I used to have this, the battery was on a separate wire and I had to put it in the pocket of my school dress when I was in like reception or something.

Becky: I had one of them.

Anna: Yeah, it was annoying.

Becky: Yeah, um, the battery kept like not working.

Facilitator 2: So why did you stop using them?

Becky: Because, um they didn’t really last very long. My one, which is in my mum’s handbag, the glove has ripped. And like the nails have like flaked off.

David: Yeah.

Becky: That’s what happens sometimes.

Anna: I stopped using my electric one because I found it was more hassle than it was worth because all it did was that and it was really heavy so it ended up being less convenient than without.

Facilitator 2: Why did you stop wearing yours?

David: Just because it was too heavy and it was easy to break.

Facilitator 2: OK. So why is it a problem when it’s heavy?

David: Because it doesn’t actually help you much because you just have to carry it like that to change it.

End of excerpt

Appendix K

Example Interview Transcript: Children and Young People (excerpt)

Interview Location: Participants' home

Date: 21st December 2011

Interviewee: Male, aged 9.

Name of Interviewer: Tara Sims

Name of Transcriber: Tara Sims

Interviewer: Do you wear a prosthesis at the moment?

James: Not yet, no, because when you actually had one and then it actually goes to young you're like "ah no" because you really like it but it won't fit you anymore.

Interviewer: So did you used to have one that you grew out of?

James: Yeah.

Interviewer: Ok. What was the one that you used to wear like?

James: It was like a one that doesn't move, but it was still fun though.

Interviewer: Yeah? What did it look like?

James: It was a bit bigger than my right hand. A tiny bit bigger, so it wasn't exactly like my hand and you could notice it was fake. Long finger nails. Mum used to pretend she was trimming them for fun.

Interviewer: It had long finger nails?

James: Yeah.

Interviewer: When did you wear it?

James: Usually at school ‘cause my mum says if I use it there I can put my prosthetic arm onto the paper so that it will just hold it still.

Interviewer: Ok. Do you use it for anything else at school?

James: Sometimes practical jokes, sometimes just fooling around as well.

Interviewer: Yeah?

James: Well, one time I went behind a wardrobe, put the prosthetic arm around my neck and pretended I was being strangled behind the wardrobe.

[Laughter]

Interviewer: What did people think of that?

James: They thought it was hilarious.

Interviewer: It sounds funny. Did you ever wear it outside of school?

James: Not that much no ‘cause it doesn’t come in use then so I’m not that sure. It’s only useful at school.

Interviewer: Ok. Do you know how long you had it for?

James: A year or so.

Interviewer: Have you ever had one that moves?

James: Yes I did. It was like one where if I pulled my right shoulder blade then the arm would open and close and stuff.

Interviewer: What did you think about that one?

James: That one was quite cool, kind of freaky, but it was awesome.

Interviewer: What was good about it?

James: Because when it opened it looked really freaky and when we played games of tag, I used to use a prosthetic arm to actually tag the person or grab their t-shirt. And also it was good holding on to ropes.

Interviewer: Were there things that you didn’t really like about it?

James: No actually.

Interviewer: And your one that doesn’t move, what things do you like about that one?

James: Well, not that sure. That one because it is really heavy, so it holds things really well and if I push things into I, it won’t break.

Interviewer: Is that your one that doesn’t move?

James: Yeah, but the other one was quite heavy too and it was quite hard trying to lift things up.

Interviewer: So is it good or bad it being heavy?

End of excerpt

Appendix L

Example Focus Group Transcript: Parents (excerpt)

Focus Group Location: London

Date: 16th June 2012

Number of Attendees: 2. 1 female, 1 male.

Name of Facilitators: Maggie Donovan-Hall, Thomas Redman (2)

Name of Transcriber: Tara Sims

Facilitator: Thanks ever so much for coming along this morning. As you know, what we're trying to do with this project is to take forward some research that was carried out before which was looking at children's views, at our bodies our views conference, and this time we're working with engineers, developing devices, and the aim is to try and get prosthetics with the views of all the people involved in the child's life so the child will be in the centre as the user of the prosthetic but obviously parents are very important and healthcare professionals are very important. So it's looking at all of the actors within the situation so to speak. So the aim of the focus group is to gain your views, from your perspective, so not really trying to think of what your child wants, but how you feel as parents because that's a very important part. So what I'd like to do is just chat about some of your general views and then we'll have a little break and then we'll get the devices in that we've developed. Some of those devices have been developed on the views of what the children told us last time and then just talk about prosthetics for the future and how you would like things to develop and what you think is important from your own experiences. Is that ok?

Participant A: Yes.

Participant B: Yeah, that's fine.

Facilitator: So, to start off, do you want to talk about the background and what kind of prosthetics your children have had to date in your own experiences?

Participant B: Yeah, I'll go first. Chris doesn't really wear one. The only time he tends to wear it is when he's riding his bike. So in terms of what he has had since he had his accident, which was nearly nine years ago now, no I think it must be nearly 10 years ago. We started off with, I'm just trying to think, it was basically a prosthesis which had sort of the hook on it.

Facilitator: Split hook?

Participant B: Yeah, split hook. And he had like the sling that came over the shoulder and I think he had to move the shoulder and everything to make it work. But as I say it was such a long time ago. So we tried to get him to use that and we were having a bit of fun with it, you know going around playing with Lego, that sort of thing. And also with it you also had another attachment so you could put just like a hand on.

Facilitator: Passive?

Participant B: A passive one, yeah. So that was his sort of very first one and he would probably have had that one probably from about 3 and a half, about 6 months after he had his accident. And we tried with him trying to get him to use it and everything and he wasn't really that bothered. Every now and again he'd use it for a bit of fun or whatever. And then as he got older obviously your arm grows and that so he's had others. So we've always had one but as I say really it doesn't seem to bother him about needing to have one and I think one of the hardest things with it is they are so heavy. Or they certainly were so heavy. I'm not sure these days, I think they're probably getting lighter and things. But they are heavy, quite cumbersome and I think that just basically put him off. And like I say these days, in fact there is one other thing he does use it for, riding his bike, he'll just basically, he has the sock on here, the socket thing and it just sort of plugs on and he's got a hand that he can put on there.

And it’s just a passive hand that we can put on the handle bars and it’ll just hold on.

Facilitator: So that hasn’t been adapted for riding a bike?

Participant B: No, it hasn’t been adapted. The bike’s been adapted from the point of view that when he, well all the bikes he’s had, the back brake is where you pedal backwards, so when he was a younger kid they were quite easy to get, but as he’s become older, we’ve had to have them specially built. There was a shop in XXXX that did it for us and they were very kind they didn’t charge for the labour or anything like that, they were really happy to do it. So that, and also they adapted it because the gears tend to be, he’s lost his right hand, so the gears tend to be on the right side so he’s had to have it adapted so that it was on the left side, so they did all of that for free. So what he does is he just clamps it on to the handle bars and uses his left hand to do everything else. Now there’s always a possibility if you come off it could be a bit nasty, but generally I think, he has come off a couple of times, but the arm quite often will just come off at the socket. That’s probably not the safest, if you were looking at health and safety they’d probably say you should be doing that. So he uses it for that and then the other thing he also has with this arm, again if you take the hand off he’s got like a clamp which he uses for playing cricket. Because when he started out playing cricket, because again only having the one arm it’s pretty strong so he would play just one-handed, and he was playing ok, he doesn’t play so much cricket now it’s only to start off with he was in the a team at school and people were quite amazed by him. He’d come in to bat and people would just look at him. But now as he’s got older he’s started to use the clamp more to like guide the bat and things. So he tends to use it for cricket as well. But he certainly played cricket last season but I think he’s only had a couple of games this year. So that’s really the only time I think he uses it. And the rest of the time he just gets by without it. You know it really doesn’t, form what I gather, it really doesn’t bother him.

End of excerpt

Appendix M

Example Interview Transcript: Parents (excerpt)

Interview Location: Participant's home

Date: 4th September 2012

Interviewee: Mother of female, aged 8.

Name of Interviewer: Tara Sims

Name of Transcriber: Tara Sims

Interviewer: So I'll start by showing you these. The reason they're all blue and green is because he's got a 3d printer and he just had to print them out on whatever plastic they had in the printer on that day so they're just rough prototypes. So this is designed to be like a wrist because quite a lot of children said they didn't move enough at the wrist. So it's just a ball and socket and you loosen that and then you will have a device around so you can move it around into the position you want and then it locks in place.

Participant: Oh right, I see. That's quite clever. I'd be interested to see how... I mean this strikes me as far more functional than cosmetic, and my experience is that although there are times when she has a particular activity in mind and we go off to the prosthetic clinic and they make her a gismo as she calls it, the majority of her prostheses the emphasis has been on cosmetic appearance. In our experience the more cosmetic a prosthesis is the less functional it is because the glove hinders access to any buttons or anything like that. But it seems like a very simple but effect solution. And the fact that you can lock it and it's sturdy means that you can rely on it. And that's something else you have to bear in mind. For instance if somebody has a device for riding a bike you've got to think that they're going to put all their weight through it at some point and it's gotta not give.

Interviewer: What do you think about how it's operated?

Participant: Becky used to have a split hook with a button and a twist and a click and she managed that well so I think she would manage that. Obviously it would be too complex for somebody who's got bilateral limb loss but I can't see that being a problem for someone with unilateral limb loss.

Interviewer: Ok. Most of the things he has made are for specific tasks or functions. So this one is basically a grip.

Participant: Yeah, that looks very much like a traditional split hook type arrangement.

Interviewer: So you tighten it like that.

Participant: Oh I see. So it's effectively like a vice type arrangement.

Interviewer: What do you think of it?

Participant: I think it's an interesting idea but I don't know what advantage it would convey to a prosthesis user over a split hook. Although that said a split hook is usually just the top bit. I could see that could potentially be useful for something like bike riding. But then one of the challenges with bike riding which we're currently battling is that you don't want to be locked onto the bike otherwise you fall with the bike which isn't desirable. For somebody wanting to do a specific practical task or pursue a hobby that could be useful. And with a slightly different shaped grip it could be useful for holding things.

Interviewer: What kind of grip?

Participant: The typical thing that we usually have is needed to hold a bowl in that hand. I mean that would work for holding a saucepan handle type thing and possibly even a jug or a bowl with a handle. Something that sort of hooks over a bowl or a pan for steadying. But then one gets round those things with suction grips or Dycem matting. But you can't oppose with them as you can with your residual limb. But I think the concept of a lockable vice type arrangement is potentially very useful. I'm not very well qualified to comment in so far as Becky's age is such that she's not pursuing hobbies beyond the usual childlike sporting activities. If she were wanting to play snooker or something like that I'd probably have a bit more insight really. Obviously it's made of plastic but the mechanism seems quite reliable. And the fact that it's very adjustable makes me think it would have a multitude of uses. If you had one you'd probably find lots of things to use it offer. And that's the other tension – you don't really want to spend your life going around with a suitcase full of gadgets. There's a trade-off between usefulness and specificity.

Interviewer: Yes. This is a version of that, which is sprung.

Participant: I don't know what benefit you'd derive from this. I think you'd get more use out of the other one. You could probably use this for more delicate tasks; you could probably hold a piece of paper in it. But it's an interesting idea. I think that extra third hook is an interesting development because a traditional split hook is only two.

Interviewer: So this is what he came up with for cycling.

Participant: Oh, interesting.

End of excerpt

Appendix N

Example Interview Transcript: Professionals (excerpt)

Date: 4th September 2012

Interviewee: Prosthetist

Years of experience in UL prosthetics: 12

Name of Interviewer: Tara Sims

Name of Transcriber: Tara Sims

Interviewer: So I'd like to begin by finding out your views on upper limb prostheses for children that are available on the NHS.

Participant: There's not a huge selection available to be brutally honest. Well there is, a certain company does provide a lot of myoelectric limbs, but they're horrifically expensive, we don't use them at all at this centre. Then there's another company that provides a lot of cosmetic and body-powered limbs, but there isn't such a big range but the range of products available for upper limb across the board is nowhere near what is available for lower limb. Any myoelectric stuff is very expensive and we don't provide them currently for children as we haven't got an OT at the moment. OT's are pretty essential if you're going to have successful myoelectric use. When I first came here they had an OT that had worked here for a long time and they were supplying myoelectrics for children. But they were finding that many children didn't really progress with them, they would only use them for a couple of years. But when that OT left, provision got less and less but if you haven't got an OT there's no pint providing them because there's no-one to do the training. So currently we're not providing myoelectric limbs for children and we hardly do for adults either. If they've already got one we wouldn't take it away because they know how to use it. But if somebody new came and wanted one we'd have to think very closely about it.

Interviewer: Right. Are the issues to do with training?

Participant: Since I’ve been here, the success rate of the few they did prescribe wasn’t great. So there’s that, the expense of it and not having an OT.

Interviewer: Ok. So you’re prescribing cosmetic and body-powered limbs?

Participant: Yes.

Interviewer: What success do you have with those with children?

Participant: Depends on the age. We don’t have a huge number of children here. But what tends to happen is they come at about a year and we provide a cosmetic limb which they may or may not use. It depends on the level as well because if they’re trans radial they can use their little stump to do things and they get feedback as well. If you cover it up with something they lose that sensory feedback. So off the top of my head is what happened is we’ve prescribed them when they’re young and they’ve stopped using them. But then in their teenage years they’ve come back and wanted something prosthetic. If I think back, there have been a few little ones who I don’t see any more so I’d guess they’re not using them. A fair amount of trans radial children are provided with limbs and they don’t use them. Sometimes when we provide them we offer a review appointment or say come back if there’s a problem. They usually don’t want to make the appointment there and then so the onus is on them to make an appointment and come back to see us.

Interviewer: Do you have many children using body-powered limbs?

Participant: Less. We have a few, but less than cosmetic.. cosmetics are by far the most common.

Interviewer: You mentioned loss of sensation as a drawback. What other drawbacks do you think there might be?

Participant: Loss of sensation and like I say for trans radial they can manage without it. They can use their little stump to hold things and move things around. But some of the older ones come back because they need it for a purpose like riding a bike. It also feels really heavy to them and it's not hugely useful. Use and loss of sensation I think are the main reasons. But when they get holder and they want to do a particular activity then they might actually want one. I have another child in mind who wants something for archery so he needs something to help hold it so he came back because of that. And another little girl came back because she wanted to ride her bike.

Interviewer: So would you make them?

Participant: Yes, the socket bit is custom made for each patient obviously. We would adjust a hand to fit the task. For cycling, you can use a foam hand and bend the fingers round to hold on to the bars.

Interviewer: Ok. So what general things do you think we should be looking at to improve prostheses for children or not?

End of excerpt

Appendix O

Planned Publications

- Article submitted to Reach Charity Ltd for publication in their quarterly magazine “Within Reach” (for dissemination of the findings to their members).
- Co-writing two papers with Dr Andy Cranny:
    - The methodological aspects of the study – use of RPT within a Participatory Design framework (intended for the Journal of Medical Engineering and Technology).
    - Children and young people’s views of prostheses (intended for the Journal of Physical and Occupational Therapy in Paediatrics).
- Other papers currently in planning/writing stages:
    - The experience of parenting a child with limb difference and the role prostheses play (intended for Child: Care, Health and Development).
    - Current issues for OTs practicing in the field paediatric prosthetics (intended for the British Journal of Occupational Therapy).
    - Prosthetists views on NHS prosthetic services and devices for children (intended for the Journal of Prosthetics and Orthotics).

Upcoming Presentations

- “The Views and Experiences of UK Occupational Therapists working in Paediatric Upper Limb Prosthetics in the NHS –Priorities for the Development of Services and Devices” at the WFOT Annual Congress (Yokohama, Japan, 21st June 2014).
- “Current Issues and Developments in Paediatric Upper Limb Prosthetics” at the OT Show (Birmingham, UK, 26th November 2014).