PROSTHETIC CHARITIES: PROSTHETIC REHABILITATION PROFESSIONAL’S OPINIONS ON THEIR FUNCTION & ROLE

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1. Abstract

Title: Prosthetic Charities: Prosthetic Rehabilitation Professionals Opinions on their Function & Role

Methods: This study utilised a nine question survey. The survey aimed to gain an insight into clinician’s opinions regarding various aspects of prosthetic rehabilitation charities. It also attempted to gauge the level of interaction currently and possible interactions in the future between clinicians and charities. Four of the questions were audio recorded to ensure all qualitative information was documented. All information was put into the analysis software Qualtrics. Qualitative data was analysed using Grounded theory and open coding to form themes in the information.

Results: 22 participants took part in the study from 4 of the prosthetic rehabilitation centres in NHS Scotland. Of these; 16 prosthetists, 2 prosthetic managers, 2 physiotherapists, a prosthetic technician and a clinical nurse were included.

Conclusion: Charities want to be more involved in supporting professionals and clinicians, but taking the participants opinions into account, this does not seem to the happening effectively at the moment. There is a need for charity run events, but these could be better tailored to the general amputee population for them to be more successful. Charities also need to better advertise their services and availability of grants for patients and clinicians to interact more easily with them. Charities are key to amputees and clinicians and the future is bright if these, and other, minor alterations are made.

KEYWORDS: questionnaire, NHS Scotland, PORT-ER, Raising the Bar, interview, prosthetics.
2. Acknowledgements
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3. Introduction

Amputation affects hundreds of new patients in Scotland every year. Scottish Physiotherapy Amputee Research Group (SPARG) have been collating and publishing data on amputees in Scotland for the last 18 years (Scott et al., 2011). From their most recent publication in 2009, there were 746 lower limb amputees in Scotland, consisting of 773 amputations (Scott et al., 2011), including bilateral and revision surgeries to amputate at a higher level. Of these 323 amputations were due to peripheral arterial disease (non-diabetic), 284 were a direct result of diabetes and 33 were due to other orthopaedic reasons. These amputations were at various levels with the majority (n=410) being trans-tibial. The other major levels of amputation were 321 trans-femoral and 30 knee disarticulation (Scott et al., 2011). It was recorded that 41% of all patients were fitted with an artificial limb. Those fitted with a prosthesis consisted of 68% trans-tibial and 24% trans-femoral patients (Scott et al., 2011). This highlights the demand and importance of the limb fitting service provided by the NHS in Scotland. These figures do not take into account the number of upper limb amputees or the patients that suffer a congenital loss of a limb or limbs.

A primary amputee is treated by a multi-disciplinary team (MDT). The main members of the rehabilitation MDT are the prosthetist, physiotherapist, rehabilitation consultant and often an occupational therapist. This is a non-exhaustive list as often other specialisations are called upon. Each member of the team has a key role to play in the provision and fitting of a limb, rehabilitating the patient, and training them in the use of the limb. The team must see that all the patients’ needs and wishes are taken into consideration when making any decisions about their treatment. This may include putting patients in touch with charities or user groups for further support after their initial care is complete. It is documented that in any area where treatment of ill health is concerned, charities are founded to help support patients and their families.

Charities aim to help the patients involved and support the health service wherever possible. A major example of this would be the Chest Heart and Stroke Scotland charity. Information from their website shows that this charity runs and assists chronic obstructive pulmonary disease (COPD) support services in Greater Glasgow.
and Clyde National Health Service (NHS). They provide one-on-one support for people suffering from COPD and organise information, education, outings and friendship for these patients (Stewart, 2012).

Mental health charities have also supported NHS services in many ways from fundraising to information leaflet production. In the Mental Health Foundation’s (MHF) publication on peer support (2012), they worked in partnership with NHS Lothian and NHS Lanarkshire. Together they produced a set of guidelines and support strategies to give peer support to people with long term health conditions. This was founded on evidence-based practice and personal experience from experts in the mental health field (Woodhouse, 2012).

As the role and function of many other charities that support different sectors of the health service are so widely understood, it is important to grasp the current situation that surrounds prosthetic charities. Much of the literature related to prosthetic charities and their role involves patient’s satisfaction of their care. No literature exists that takes into account the prosthetic rehabilitation professionals opinions of the charities. It is also important to comprehend how the Government see charities and how they see the partnership of the NHS and charities growing in the future.

3.1 Literature Search Methodology
During the review of the literature four key terms were searched. These terms were: charity; questionnaire and survey; service provision; and artificial limb. Initially the term prosthesis was used instead of artificial limb but this was later changed as the results generated by this search focussed on maxillo-facial and plastic surgery.

These terms were searched in 5 databases; Medline, Science Direct, the Cochrane Library, Web of Knowledge and the Health Management Information Consortium (HMIC). NHS Knowledge Network was also searched but following expert opinion on literature searching, this was dropped due to the lack of accessible papers.

Only journal articles were searched for in these databases. Every derivation of these terms was searched and these can be seen in APPENDIX A. The results of these searches were then transferred into End Note Web and duplicates were removed.
The key terminology searches that were focussed on when scan reading the titles were:

1. Questionnaire and survey + artificial limb
2. Service provision + artificial limb
3. Charity + artificial limb

This resulted in 248, 13 and 532 hits respectively. The titles of these searches were read to assess suitability with regards to pre-determined inclusion and exclusion criteria. The inclusion criteria included papers that referred to Europe or Britain, charities, services with regards to health service and surveys or questionnaires. The exclusion criteria were papers that referred to America, developing countries, patient’s opinions on services or treatment and papers that were concerned with military research or funding. With these in mind the number of papers suitable was reduced to 22, 1, and 23 respectively.

The abstracts of these papers were read and, again, bearing the inclusion and exclusion criteria in mind, the number of papers suitable for the study was reduced to 10. Two papers were excluded as they were not written in English, resulting in 8. These 8 papers formed the basis of the literature review.

The citations of the selected papers were also located and read, and these formed the secondary papers.

Addition papers were found by searching the above keywords in the following sources:

- Scottish Government website
- UK Government website
- Scottish Health on the Web website
- Home Office website

4. Background

4.1 Charities in Collaboration with the NHS
The demand on the prosthetic rehabilitation and limb fitting services in Scotland is at an all-time high (Scott et al., 2011). Despite the large and increasing demand, the
prosthetics service is subject to the financial constraints and cutbacks much like all other sectors of the NHS. For this, and other reasons, many believe that there must be a shift of emphasis in health care to take a more holistic approach and include the voluntary and charitable sectors, to give the best possible care (Coid et al., 2003, Crombie and Coid, 2000). Currently, voluntary, charity and private sector organisations are regulated by the Nation Care Standards Commission (NCSC) as dictated by the NHS executive report, regulating private and voluntary healthcare (Department of Health NHS Executive, 2000). This is an independent body set up to focus health care and ensures the best possible care is given to patients within the NHS.

Many would agree that to be classified as a charity, the group in question must fulfil certain criteria. The general consensus is that charities must be independent of any Government department, and therefore, able to govern itself and employ whomever it chooses (Edelman, 2004, Coid et al., 2003). They are also non-profit making and rely on financial donations from external sources (Edelman, 2004, Coid et al., 2003). Finally, they must have a specific patient group or cause that they support (Coid et al., 2003).

Edelman (2004) quoted ‘joined up’ service provision in his work with speech and language therapy. Edelman expresses a need for a “collaborative model of service delivery and professional practice” especially when working with children. The same can be said when working with vulnerable adults, therefore the information proposed by Edelman is comparable to, in this case, amputees. The paper goes on to describe a charity that works in the speech and language field called ‘I CAN’. This charity helps children with speech and language difficulties in the UK and has had two key goals. The first is to provide the best therapy and education for children with speech and language problems, but more importantly to improve the services that already exist. Methods by which this can be achieved were laid out in the study as being “through research and development activities, policy work, and provision of information and training,” (Edelman, 2004).

Edelman, however, does make clear that his research and proof of the great work of I CAN in supporting existing services is not an attempt for charities to replace the
service, but rather work together and enhance the service (2004). Completely relying on charities would be a backwards step in service provision and is not wanted by managers who are “wary of extra costs”, or the charity workers who worry they would be used as a cheap alternative to proper care (Black, 1988). Crombie and Coid (2000) go as far as saying that health professionals can feel intimidated by the affect that voluntary work will have on their job potentials and level of pay. It seems that this is fear of the unknown, as the literature here shows that voluntary work has a positive impact on the NHS. Black (1988) also highlighted where charities can be of benefit to the NHS. It is thought that where the NHS provides a service, charities and the voluntary sector can help by providing where the NHS lacks. The two services should work in unity with each other. The paper goes on to state “they can fill gaps in services by raising extra funds or redirecting public spending” (Black, 1988). Interestingly charities are also seen as acting as a communication tool between patients and the service providers.

The idea that charities and the voluntary sector are ‘innovative’ in their approach to providing services to the public is one that sets charities apart from the public sector (Black, 1988, HM Treasury, 2002). Innovation is one of the main ways that charities have been successful in providing services and support to many different aspects of public life. It is a beneficial trait that UK Government wants to nurture and support (HM Treasury, 2002).

However, it is documented that even although the ideal situation is synchronicity between the NHS and charities, the partnership does have its flaws, and many would argue the system does not work. One reason is the lack of structured organisation and official partnership agreements (Coid et al., 2003, Edelman, 2004, Black, 1988). There is a lack of knowledge between the services on the work they do and the environment in which they operate. One solution suggested by the literature is to legitimise the link between the charity and the NHS by making simple administrative changes (Coid et al., 2003). Another issue is charities feel over powered by the rigid format that the service tries to make them work within. Charities do not work well with the current model of auditing and recording accountability (Coid et al., 2003).
With an increasing role in health care, comes an increasing responsibility to show and prove the benefits of this (Crombie and Coid, 2000).

Another issue that may prevent a smooth relationship between charities and public health care systems is the bureaucracy that is involved in funding and grant application processes (Coid et al., 2003). Her Majesty’s Treasury highlighted this in their report in 2002, and attempted to put a common route for funding application via central Government (HM Treasury, 2002). Crombie and Coid (2000) again stated that the voluntary sector may bring as much as £12 billion pounds a year into the health care service.

The paper by Harris and Ward (2011), shows the linkage between the cancer charity Breast Cancer Care, and supporting not only patients but also related health care professionals, mainly genetic counsellors. It is stated that collaborative working with care support and the cancer treatment centres is positive but that the information provision and psychological counselling of the patient must be evenly split between the charity and the service (Harris and Ward, 2011). The authors showed how a charity can improve the service by running a psychological pilot study. The day was arranged by Breast Cancer Care, and was described by all participants as a success.

Having placed how charities can aid the NHS into some perspective, it is important to understand the other views on charitable organisations. How charities are seen by the Government and how charities see themselves are just as important when putting the opinions of prosthetic rehabilitation professions into context.

The Government have very strong views with regards to the role of the charitable sector and providing support to the NHS. They see the work of charities as being critical in the provision of the best possible care for patients.

4.2 Government Literature
Due to the increased strain on resources and finances, there could be an increased call for charitable organisations to fill gaps in health service provision (Coid et al., 2003). The Scottish Government groups all non-governmental, voluntary and charitable organisations under one collective term, the third sector. On the Scottish Government website, the third sector is defined as “community groups, voluntary
organisations, charities, social enterprises, co-operatives and individual volunteers” (The Scottish Government, 2012). It is evident that the Government sees benefit in cultivating the relationship between the third sector and the public sector as it pledged to give £73.5 million worth of funding in the three years between 2012-13 and 2014-15 (The Scottish Government, 2012). The UK Government sees that working together with the charitable sector will reinvigorate health care, and allow the NHS to push boundaries (HM Treasury, 2002).

The overwhelming message in all the governmental literature is that the third sector and charitable foundations have a key role in the provision of health care in Scotland. The report by Barclay (2011) starts off with a statement of how important the charitable sector is in the provision of health and social care. The author goes on to say that the role of the third sector in health and social care can only increase from now on (Barclay, 2011). This will ease the financial strain placed on the NHS as funds decrease.

The importance of the third sector in provision of health care in the modern day NHS Scotland is highlighted in the Health Care Quality Strategy, written by NHS Scotland in 2010. The NHS outlines how it will make the Scottish health care system one of the best in world. It states that it will achieve this by not only initiating new policies, but also modifying existing policies so that they prove the best care possible (The Scottish Government, 2010). One way in which the Government is attempting to maintain this innovative approach to service provision is to include the charities and voluntary service in any decision making and planning early on in the process (HM Treasury, 2002).

In this report, the Scottish Government sees four ways in which it can achieve its goal. One route involves strengthening its partnerships with private and third sector groups (The Scottish Government, 2010). The Government recognised that the third sector have a unique insight and access to specific patient groups and therefore have a large role to play in implementing the aims of the healthcare strategy (The Scottish Government, 2010). The Government has come to realise that the third sector is a resource that, if used effectively, can aid in achieving the best health care possible. Also in this report, the Government calls for a closer working relationship between
charity/voluntary foundations and independent private contractors, especially in the role that they play education of patients in self-management (The Scottish Government, 2010). Communication is also heavily highlighted in this report as the charitable sector has direct access to the patient groups. This means that they are the perfect channel for communication between the patient and the health service. However, this is not the only communication that they can be involved in. The Quality Strategy also sees charities as being able to promote NHS Scotland to the public, inspiring employees to strive to achieve their best (The Scottish Government, 2010).

However, the relationship between the public sector and the charitable sector is not perfect. The voluntary workers can be made to feel frustrated. As they see it, they are unable to make wholesale changes to service. This is where the NHS Scotland Chief Executive’s Annual report of 2011/12 comes in. In this report, the NHS in Scotland wanted to support the third sector and make them feel “part of the bigger picture” (NHS Scotland Chief Executive, 2012). It is hoped that this will help motivate the sector.

There are also many examples of the public and third sector working together to the benefit of the Scottish public. The first is the ‘Keep Well’ initiative, where the partnership between the third sector and the NHS is aiming to promote healthy lifestyle and educate people on the benefits of a healthy diet (NHS Scotland Chief Executive, 2012). Another example of charities and the health service working together is diabetic lower limb amputees. The Scottish Diabetes Group and Diabetes UK work in conjunction with the NHS to increase awareness and monitoring of diabetic feet. This was done by forming an initiative that ensured all at risk patients feet were checked regularly. Although the findings have not yet been published, it is hoped that this has lowered the number of amputations carried out due to diabetes (NHS-Scotland-Chief-Executive, 2012). The final example mentioned in the report showed ‘joined up’ service provision worked effectively in the treatment and care of sexual health and blood borne diseases. The partnership included the NHS, local/national governments and education campaigns (NHS Scotland Chief Executive, 2012).
The nature of the charitable sector is seen as being fluid. This gives the charity the ability to adapt to best suit its user’s needs. This is a positive attribute to have, especially in the current climate. However, this fluidity sometimes has issues when it meets the public sector’s business-like model of operation. Barclay (2011) highlighted this as an issue and more effort must be put into making the two sectors work together.

The Scottish Government is committed to making the partnership between public sector and private/third sector groups work. One way in which they have tried to strengthen the relationship between the two is to set up the Joint Improvement Team (Joint Improvement Team, 2012a). The Joint Improvement Team was established in 2004 with the premise of easing any challenges that partners, working in public and private services, may encounter (Joint Improvement Team, 2012b). They do this by supplying extra time and funds to ensure that the partnership is working to the best of its ability to allow them to provide the best possible care (Joint Improvement Team, 2012a).

Having gained an insight into how the Government view charities and their role in the future of the NHS, it is important to understand how prosthetic charities see themselves and how they are perceived by the public, before taking into account the prosthetic rehabilitation professional’s views.

4.3 Current Prosthetic Charities
Currently there are eight prosthetic charities that work in Scotland; BLESMA, The Douglas Bader Foundation, The Limbless Association, Limb Power, Reach, STEPS, The Murray Foundation and PORT-ER. Other, smaller charities do exist, but this study will focus on these main charities, as these are most well known and most likely to have had contact with prosthetic centres in Scotland. APPENDIX B gives information in greater depth on these charities.

4.3.1 BLESMA
BLESMA in an acronym of: British Limbless Ex Service Men’s Association. This charity was founded to support injured servicemen and their families. Their main aim is to help rehabilitate wounded soldiers suffering from the loss of limbs (BLESMA, 2013). The charity helps by providing grants and residential accommodation for
servicemen and their families. They also provide a communication route, by representing soldiers and their views in parliament. They work closely with other charities such as Help for Heroes.

4.3.2 Douglas Bader Foundation
The Douglas Bader Foundation (DBF) was established in memory of the famous World War Two pilot Sir Douglas Bader. The DBF helps amputees in different ways including grants, information provision and activity days. The DBF is responsible for setting up the prosthetics clinic in Roehampton. By way of fund raising and publicity, the DBF run annual large scale events such as the Bader Cup golf tournament (The Douglas Bader Foundation, 2013).

4.3.3 Limbless Association
The Limbless Association is one of the biggest prosthetic charities in the UK. They have a large network that links centres, charities and patients allowing them to efficiently distribute information and support to amputees, their families and carers. They too offer grants and funding to centres, patients and their families. Due to the size of the Limbless Association, they are able to provide legal advice to amputees by solicitors that specialise in traumatic injury resulting in the loss of limbs (Limbless Association, 2010).

4.3.4 Limb Power
Limb Power’s main goal is to get amputees to take part in sporting activities for the health, psychological, and social benefits it gives. Limb Power inaugurated and run the annual Amputee Games at Stoke Mandeville. They launched the Amputee Winter Games and the Junior Games both in 2011 (LimbPower, 2010).

4.3.5 Reach
Reach is a charity specifically set up to help and support children and their families affected by upper limb loss. Their main aims are to highlight needs of children with upper limb deficiencies and help support them and their families. Reach donate money and fund development of upper limb prostheses, but also carry out research into the causes of congenital limb loss and its prevention. One unique aspect of the charity is that they are able to provide insurance for the patient’s unaffected limb (Reach, 2012).
4.3.6 STEPS
STEPS is an acronym of:

Supporting & guiding
Training & educating
Empowering & enabling
Providing & connecting
Seeking & campaigning

They are a small charity supporting people affected by congenital lower limb conditions. This does not necessarily mean limb loss, but includes all pathologies such as Talipes Equinovarus and Developmental Dysplasia of the Hip (DDH). STEPS give information, produces newsletters, information leaflets and forums online (STEPS, 2011).

4.3.7 The Murray Foundation
The Murray foundation was founded in Scotland with the sole aim to support those who have suffered the loss of a limb, and to reassure them that they are not alone through their rehabilitation. The charity provides counsellors to those that are in need but also provides training for those with an amputation to become counsellors themselves. One invaluable service provided is a network of volunteer amputees that are able to visit and speak to patients, to help them come to terms with their situation. Using his sporting links Sir David Murray also started the Sports Master Classes (The Murray Foundation, 2013).

All of the charities offer the public the opportunity to become members of the group in return for membership fees. This allows people to take part in event days and is one route by which the charity can raise funds.

4.3.8 PORT-ER
PORT-ER is an acronym of Prosthetic and Orthotic Rehabilitation Technology-Education and Research. PORT-ER undertakes work both domestically and internationally. In the UK they are responsible for promoting rehabilitation through master classes and training workshops as well as funding clinicians to further their knowledge. Internationally they promote better prosthetic and orthotic care through the sharing of information and experience between clinicians.
They offer grants for associations and individuals to further their knowledge and experience in the field of prosthetic and orthotic rehabilitation (PORT-ER, 2013).

PORT-ER approached the National Centre for Prosthetics and Orthotics (NCPO) at the University of Strathclyde with an idea for an investigation. After much discussion a research question was decided upon and a project was formed.

4.4 Aims of Study
This study aims to qualitatively explore the opinions and thoughts of prosthetic rehabilitation professionals, and members of the MDT, working within the NHS in Scotland. Their opinions on charities and their possible role in the support of patients being treated in their clinics will be sought. As part of this, current prosthetic charities and how they market themselves will be investigated.

5. Methodology
5.1 Methodological Approach
The data acquired on prosthetic professionals opinions of charities and their links to the health service will be investigated using qualitative analysis and utilising a grounded theoretical approach. Glaser and Strauss state that grounded theory is the discovery of theory from data (2008) and is a method for comparative analysis. There are many approaches to grounded theory and qualitative analysis but the decision was made to use the method outlined by Glaser (1992).

Grounded theory is regularly used in the social sciences as a method of data analysis (Glaser and Strauss, 2008); however, it is being used with increased regularity in health service research methods (Bradley et al., 2007). It forms the perfect method of analysis when comparing opinions and qualitative information. This information can be collected in many ways including focus groups, case studies, institutional & cultural ethnography, historical analysis, participant & non participant observations, and interviews (Bradley et al., 2007).

Grounded theory is a method of forming ideas based on general information brought together from many sources and allows for clear themes and concepts to form (Glaser and Strauss, 2008). It produces hypotheses that would not be produced by
simple quantitative and statistical analysis (Glaser, 1992). Analysis and formation of hypotheses is an on-going process (Bradley et al., 2007) that spans the length of data collection and occurs gradually as more information is collated.

One of the most important aspects of Glaser’s description of grounded theory is that no preconceived hypothesis should be formed. This will cause the researcher to force a hypothesis on the data (Glaser, 1992) and bias the data towards an end result that was already predetermined. In his book, Grounded Theory 1984-1994 (1995), he emphasises the fact that qualitative researchers should be open to the information collected and receptive to emerging themes and trends which would not be evident to the closed mind.

In this study, the information will be collected in the form of interviews and short quantitative questions. Interview is a solid and proven form of data acquisition (Coid et al., 2003, Flick, 2009). It allows opinions to be recorded more freely than they would be within the confines of closed questions (Flick, 2009). The questions that will be used in this study were designed to take the form of core, open ended questions, supplemented by prompt questions in order for the interview to flow. The original core question framework was developed by experts from the charity PORT-ER, in the form of the ‘Raising the Bar’ survey. These core questions were then modified slightly by the researcher and supervisor to allow more qualitative information to be gathered. The researcher’s supervisor has an extensive background in qualitative analysis and grounded theory.

As an extensive literature search has been completed and no previous research being found, no preconceived ideas were formed, in keeping with true grounded theory and further justified the use of grounded theory. Glaser once said “Qualitative methods can be used to uncover the nature of people’s actions and experiences and perspectives which, as yet, little is known in the world of research products”(Glaser, 1992).

5.2 Ethics
Ethical approval was sought and obtained from the University of Strathclyde’s Departmental Ethical Committee (DEC) APPENDIX C. The full ethics forms can be seen in APPENDIX D. In keeping with the ethical limits, each participant signed a
consent form APPENDIX F after reading and agreeing to the participant information sheet (P.I.S) APPENDIX E. All information was pseudo-anonymised to allow participants to withdraw their data at any point. As stated in the ethics approval, all data was stored on a password protected pen drive that remained inside the NCPO at all times. All interview tapes were destroyed after transcription. In accordance with ethical approval, all data will be kept for 5 years and then safely destroyed in agreement with the University of Strathclyde’s data protection protocols.

5.3 Sample/participants
The participants used in this study were chosen due to their relevance to the research subject (Flick, 2009). All participants were professionals within the NHS and involved in prosthetic rehabilitation. In total, 22 participants took part in this study (n=22). It was important to get a broad range of members within the MDT involved to ensure the emergent themes were as accurate and representative of the population as possible.

5.4 Data Collection
A formal standardized email APPENDIX G was composed and sent to the respective prosthetic centres to make them aware of the project and gauge interest to recruit participants. One week was given for participants to consider their involvement in the study. If the centres wished to be included in the study a second email APPENDIX H was sent. This included a P.I.S APPENDIX E, and detailed what was involved and required of the potential participant. Following this, interview dates and times were organised at the centres convenience for the researcher to visit and conduct the survey and interviews.

The prosthetic rehabilitation centres approached in this study were:

1. **Aberdeen**- Mobility and Rehabilitation Services (MARS), Woodend Hospital
2. **Dundee**- Tayside Orthopaedic Rehabilitation Technology Centre (TORT), Ninewells Hospital
3. **Edinburgh**- Southeast Mobility and Rehabilitation Technology (SMART) Centre, Astley Ainslie Hospital
4. **Glasgow**– West of Scotland Mobility and Rehabilitation Centre (WESTMARC), Southern General Hospital

5. **Inverness**– Raigmore Hospital

5.5 **Interviews**
All interviews were conducted in a similar fashion by the same researcher. The interview started with the interviewer introducing themselves and explaining the process, the types of questions asked, and the expected time frame. It was also clarified that they should express as much or as little as they wanted and there would be no repercussions for expressing these views. It was clarified that, should the participant want to withdraw from the study, they could do so and their data would not be included in the results. If the interviewee was happy, the interview was started.

Interviews took between 10 and 15 minutes. Questionnaires APPENDIX I were filled out and marked with a randomly selected participant number to allow its removal, if necessary.

At the end of the process the participant was reminded that, should they be interested, a copy of the investigations findings in the form of a poster could be requested.

5.6 **Qualitative Analysis and Software Package**
All information collected from the questionnaires and interviews was then transcribed. All information transcribed was checked and verified by the researcher’s supervisor to ensure that it was transferred accurately.

The questionnaire was input into the computer package, Qualtrics. Qualtrics was chosen as it is an analysis software package supported and licensed by the University of Strathclyde. It allows users to create detailed online questionnaires and can be used in market research and satisfaction studies. In this investigation, it was used to quantitatively analyse the questionnaire responses, and display them in a user friendly format.
Thematic analysis was carried out to qualitatively analyse the interviews. Each transcript was read and common themes and topics were openly coded, to draw them together, for each question. These themes were then collated in the results. In order to justify a theme, a minimum of three participants must share a view.

6. Results
All transcribed data can be found in APPENDIX J.

The results will be displayed in the order that they were gathered in the questionnaire. The first two questions of the survey explored the demographic information of the participants. Table 1 shows the geographical sites of the participants. As is shown, only four of the five prosthetic rehabilitation sites were visited in NHS Scotland. No response to the initial email was received from NHS Highlands, therefore further P.I.S were not requested or sent. The majority of the interviews were carried out in GG&C with twelve practitioners taking part. The least number of participants were interviewed at NHS Tayside, with only two individuals being available for participation.

Table 1 Geographical location of participants

<table>
<thead>
<tr>
<th>Answer</th>
<th>Response</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grampian</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Tayside</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Greater Glasgow and Clyde (GGC)</td>
<td>12</td>
<td>55%</td>
</tr>
<tr>
<td>Highlands</td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Lothian</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>22</td>
</tr>
</tbody>
</table>

22 participants took part in the study (n=22). The chart below (Figure 1) shows how they were split by profession. Of the 22, 16 were prosthetists, 2 prosthetic service managers, 2 physiotherapists and 2 classified under the ‘other grouping’. The other group included one prosthetic/orthotic technician and one clinical nursing assistant that worked in both prosthetics and orthotics.
Question 3 investigated what specific information on prosthetics could be improved for people directly related to prosthetic rehabilitation and question 4 established methods of information dissemination to the public, and which ones could be developed in the future. The themes that emerged from the responses to question 3 can be seen in Figure 12. The majority of professionals agreed that patient information should be improved (n=19) with eleven clinicians suggested that information regarding professionals should be made better (n=11). The sub-themes that arose from this can also be seen in Figure 12 and will be discussed later. The results of question 4’s responses can be seen in Figure 2. It can be seen that the majority of the participants regarded information distributed through websites and conveyed through conversations with health care professionals as being the most important and should be developed more.
Question 5 investigated if the participants thought that the Amputee Running Master Classes, which have been run by PORT-ER, or other similar type events were worthwhile and should continue occur. The results can be seen in Figure 3. The participants were then asked to make suggestions as to other events, they felt, should be run. The responses were wide ranging, but themes of the types of events that should be run can be seen below (Figure 13). The main types of events that were suggested were sports events suitable to all amputees (n=10) and social events run for the patients (n=6). Sports days were further described as being suitable for those in wheelchairs (n=4) and swimming (n=5). A number of participants suggested that whatever the event was it should be age appropriate (n=6).
Based on these suggestions, the participant was then asked how often these events should be run and where, either geographically or otherwise, they should be held. The results are displayed in Table 2 and in Figure 14, respectively. If the event being held is a sports event, then the majority of professionals agree that the event should be run annually. Social events received a greater variety of responses with suggestions ranging from annually to every 3 months. No specific frequency was shown to be a consensus. The regularity of organising information days was much the same, with no clear frequency being suggested.

**Table 2 Main themes based on how often events should be run**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Sports</th>
<th>Social</th>
<th>Information/ training days</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frequency</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annual</td>
<td>7</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Biannual</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Quarterly</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Every 3 months</td>
<td></td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

The sixth question explored the participant’s personal experience and/or interactions with charities and whether they had applied for funding in the past. The question also tried to ascertain if they were successful in any previous bids for funding and if they would apply for funding again in the future. The initial result of whether the participant has applied before or not can be seen in Figure 4. 8 said yes and 14 said no (n=8 and n=14 respectively).
Of the eight that have applied for funding before, one candidate was unsuccessful in their bid for financial backing. The successful candidates applied for funding for a variety of reasons, which can be seen in Figure 5.

Those that have not applied before were asked why they had not applied and the themes that came to the forefront are displayed in Figure 6.

The final part of question 6 asked the participants if they would consider applying for funding from a charitable organisation in the future, and if so, was it for anything...
specific (Table 3). Most professionals agreed that they would apply for funding in future (n=17), and a general trend that arose was that they would only apply for funding if there was a specific need (n=7).

<table>
<thead>
<tr>
<th>Answer</th>
<th>Response</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes then for what areas?</td>
<td>17</td>
<td>77%</td>
</tr>
<tr>
<td>No- why not?</td>
<td>5</td>
<td>23%</td>
</tr>
</tbody>
</table>

Question 7 asked the professionals how best charities should advertise funding opportunities and applications for funding. It began with a closed question to ascertain if the professionals had heard that small grants were available for them to apply for. The results were again, fairly even, with 41% having heard of them and 59% not (Figure 7).

![Figure 7 Graph showing number of participants that had and had not heard of grants available to apply for](image)

Participants were also asked how they found out about the grants, or the best way charities could advertise these grants. The themes can be seen in Figure 8.
Figure 8 Map showing the best ways that professionals can hear about grant availability

The majority said the best way to advertise the grants availability was for the charities to directly contact the professionals or centres (n=12). During the interviews, there were a number of suggestions as to how the charities could improve their advertising which also became apparent and can be seen in Figure 9.

Figure 9 Map showing the main themes that arose when participants suggested how to improve grant information dissemination

Question 8 gave the participants a list of areas of prosthetic device design and asked them to rank them in preference from 1 to 7 with 1 being the most important to research and 7 being the least. The professionals were also asked if these topics covered all aspects of research in their eyes or if there was anything that was missed. The results can be seen in Figure 15.

A clear emphasis has been put on comfort and fit, as it was voted the most important by 19 participants. Other suggestions for research topics included; the comparison of components- e.g. knee joints; socket material; psychological support to deal with limb loss; and liner donning aids.

Finally, question 9 was a summary of what has been discussed before, namely, would they consider interactions in the future (Figure 10), and what would they consider interacting with them for (Table 4).
Most participants would consider interactions with prosthetic charities in future (n=21), and there was similar feelings as to what they would interact with them for (Table 4), but there was no outright majority.
Figure 11 Map showing the main themes that emerged when participants were asked what information about prosthetics could be better
Figure 12 Main themes based on what other events that should be run.
Figure 13 Main themes based on where events should be run.

- Where should these events be run?
  - At hospital or clinic
  - Community centre
  - Away from clinical setting
  - Regionally
  - Venue that is appropriate to activity
Figure 14 Graph showing participant's preference on what area of prosthetic device design research is most important
7. Discussion
The direct quotes from the participants used in this section are examples used to highlight the themes that emerged.

One of the first findings in the demographic data was that no participants were from NHS Highlands (Table 1). The prosthetics centre in Inverness is one of the smallest in Scotland and so the lack of participants would not have had a large influence on the results. The majority of the participants came from NHS GG&C. This makes sense as this is the largest prosthetics centre in Scotland.

Only 22 participants could be interviewed, questioned and transcribed in the given time frame of an undergraduate study (Figure 1). Not all the prosthetists in Scotland were included in this, due to unforeseeable circumstances, despite every effort being made to include them. As seen in the results, different members were seen- including a prosthetic technician, physiotherapists, prosthetists and a clinical nurse.

When it came to the professional’s opinions, 86%, felt that patient information should be improved in some form (Figure 12). Half (50%) believed that information leaflets given to patients should be made better.

"We try to develop patient information sheets..." pt7

"...in the leaflets should be general information” pt8

"Maybe it should be written down and given to patients” pt9

When asked further what these leaflets should contain, a common view emerged. This included: a frequently asked questions section; how to care for your limb; how to re-access the service; what to do if problems arise; and important contact details. 45% of clinicians felt that cleanliness was of great concern and that hygiene and maintenance were key issues that must be reiterated.

“...care for your prosthesis and hygiene and general cleanliness” pt11

“...as to how they should clean/care for their limb” pt19
“…looking after their prosthesis…” pt18

One participant went on to say:

“That would then give recourse that if things are mistreated……we know they have it in written form” pt19

26% suggesting improvement in patient information felt another issue that should be better addressed is the definition of a time scale of rehabilitation, as they are often asked when things will happen or have patients frustrated at a perceived lack of progress.

“Timescales are always a thing that patients are a bit unsure about” pt10

“That’s not just about what they can expect straight away, but timescales…” pt17

However, they do realise that this is a process which is not necessarily quantifiable.

“I think this is because we are unsure about how their progress is going to go” pt10

The patient information could be improved if a full pre-amputation consultation was carried out for each patient. This point was raised by 4 prosthetists involved, but again it is understood that it is not always possible.

“We try to do that through pre-amp consultations but very often we don’t actually get the opportunity to do that, and I think it helps the patients a lot” pt7

“…we do a lot of pre-amp consults and there is a lot of information gets thrown at that patient, too much for one person to take on board” pt16

“…patients should be given a bit more information at the start so they don’t panic…” pt9

The “sticky water”(pt13) of prescription guidelines was raised by 36% of the participants. It was thought that there should be a clear layout of why patients have been given a limb and a list of requirements each patient must fulfil to be prescribed a certain component.
“Prosthetic prescription criteria could be more explicit for patients and documented...” pt6

“...patients is to realise what they are getting from the NHS is a suitable prescription....So prescription guidelines and why they have been given things” pt11

The ideal situation for one prosthetist would be:

“What I’d love to see would be a constantly updated, evidence based, prescription guidelines, available to everybody.” pt18

Any information that is given to either patients or professionals should be current.

“...I suppose it could be updated...” pt9

50% of those asked felt that information for professionals could be better (Figure 12). Those who raised this as being inadequate commented that the main aspect that could be improved was communication (63%). Three main themes arose from this; within the MDT, educating other professionals about the service, and ensuring all professionals worked together- regarding information given to patients or referrals within NHS.

“We work as a team, so communication within the MDT and the professionals in a bigger context” pt14

“I think there is a lack of knowledge within the health profession about what our service does” pt15

“...so developing communication with the consultants, to say, if you are thinking of doing an amputation...” pt16

“I guess professionally, right from the get go, doctors, nurses, physios.....We need to give them realistic goals” pt9

“...rehabilitation professionals are concerned, communication is a big thing...especially referrals” pt10
“For professionals...how to refer, what information is needed, at what stage you should refer...” pt18

This opinion has long been shared with NHS managers and is supported in the literature by Tourish, where he states that “effective internal communication between managers and staff is vital to organizational success” (1998).

One main theme from question 4 (Figure 2) was the use of social media as a medium for knowledge dissemination. There were two schools of thought on this subject. Some thought it was ‘the way things were going’ although they ‘weren’t on Facebook’ themselves. Others more familiar with Facebook saw it as ‘too vague’ a medium. The issue that joining a group on Facebook could give away personal information and other people were able to see that a patient was an amputee was broached. Many professionals said that it would not be the ‘first port of call’ when seeking hard facts, as it is too open. Although just under half the participants (45%) voted that newsletters should be improved, those that did not vote for it commented that they felt newsletters had been overdone in recent times and that other avenues of distribution should be investigated. Some professionals made a link between the conversations with professionals (63%) and the previous idea of information in leaflets for patients to take away. 72% of participants said that information presented on websites should be improved (Figure 2). This relates to information available on other charities which was highlighted at the beginning. Cancer, stroke and other pathology based charities already offer considerable free advice to patients whenever needed. The Limbless Association has a directory of contact details for charities, centres and important resources already on their web page. However, websites should be used with caution. One prosthetist was wary of what information was on websites and therefore what information patients could gain and use. As websites are not peer reviewed any information, true or false, can be found.

95% of participants agreed that charity run events were worthwhile and that more should be offered (Figure 3). Some (28%) suggested that ‘Master Class’ was a poor choice of name as it made the event too niche and excluded people.

“So I do think the running master class sounds a bit elite” pt22
“I would say running is quite specific...” pt17

“...unfortunately the number of amputees that can actually take part in this are relatively small...” pt7

“I’m not sure that a snap shot of these master classes is the way forward” pt9

“...so I think you are narrowed to a small field wanting to do running master classes.” Pt16

The suggestions for the types of events that should be run are in Figure 13. Sports events proved a popular choice of event to run with 66% indicating their use. Of these, 71% believed sports should be more accessible to all, which meant making them less high impact.

“I think sport is suitable for all...” pt12

“I have more patients that want to cycle than I have that want to run.” pt16

“...activity must be open to all” pt16

“I think activities that are a bit lower on the activity level would be better for our amputee population” pt17

“I also think it doesn’t need to be just aimed at sporting and at high end...” pt19

4 participants said there should be an emphasis on sports that could be partaken in wheelchairs, with specific events such as archery and bowls being mentioned. The general consensus (50%) was that if sports events were to be run, that the enthusiasm for the Paralympics and upcoming Commonwealth Games should be harnessed.

“I think the Paralympics, we need to get on the back of that...” pt20

“Paralympics has certainly increased the amount of awareness...” pt21

“Paralympics...it was a great thing for the disabled world” pt8

Irrespective of event, they should be age and ability appropriate. One participant specifically identified the lack of paediatric sporting events currently in existence.
“I think they should try and target different age groups...” pt5

“...possibly events should be age relevant...” pt8

“I think the general population is too big a group to cater for...” pt9

“...a bit of a gap in getting these amputee children into sports.” pt9

Swimming was a sport that was mentioned by 35% as being ideal due it being low impact, cheap to run and beneficial to all round fitness.

“That’s one thing I find is that, amputees are often quite anxious about returning to swimming after amputation. How will it work, who's going to help me, how will I get in the pool, what are the changing facilities going to be like now as a disabled person, all that sort of stuff.” pt22

“Maybe just swimming...activities where you have amputees where they can meet each other...” pt20

“...a lot of people are asking about....swimming and more sports...” pt 8

Although many suggested that sports were more suitable for younger amputees, presuming that sport isn’t suitable for older patients would be grossly inaccurate. One prosthetist went on to say.

“...sports is suitable for all, as we have some that are into curling and bowling and stuff so it's clearly an all age thing.” pt12

Other suggestions of events to run included social days - with an emphasis on healthy living/wellbeing - and information sessions make patients more knowledgeable. Such events would allow them ‘to communicate with professionals’. Training days could show patients what they can do with and without a prosthetic limb, so would be open for more than just those who have been limb-fitted.

“I think information for our general population of amputees on perhaps what they can do with or even without their prosthesis following their amputation would be good.” pt7
The fact that not all patients are fitted with a prosthesis was also raised at this point, and holding events for amputees in general was mentioned. Although this is not a theme in itself, as not many clinicians mentioned it (14%), this is an issue that charities should note when designing events in the future. This is also reflected in the literature with SPARG (2011) reporting that 41% of amputees are fitted with a prosthesis.

“...after all only 40% of the patients are actually limb fitted, so there are 60% of the amputee population sitting out there that don’t wear limbs anyway.” pt7

“...they won't necessarily get a leg, as there is a lot of assumption that they are definitely getting a leg after their amputation and are very shocked if they don't get one...” pt9

“Everybody tends to think they will either get a sports limb or nothing, and perhaps there's not enough literature there to explain the process by which we decide whether somebody does or doesn't achieve limb fitting, or what sort of limb is prescribed.” pt13

This is supported by an increased call for more wheelchair based activities, although this is not a view shared by all.

“...unless it was maybe something you could do from your wheelchair...” pt10

“...wheel chair based activities as well as limb based activities...” pt13

When asked where these events should be held there were multiple suggestions depending upon the type of event. Most participants admitted they should be held at an event appropriate venue (Figure 14). 54% argued that it should held at a location accessible to most amputees i.e. the central belt. However, travel was brought up by numerous participants as a stumbling block to running an event. Those based in Aberdeen have a local charity called L.O.O.N.S that is able to provide transportation to events

“...our local charity are not averse to putting on a bus to go here there and everywhere...” pt13
Those relying on hospital transport may find this an issue. A connection was made, with the feeling that patients may prefer for events to be held at hospitals as they are familiar with the surroundings and could take advantage of transport links.

“It will also need to be run during the day while the patients were perhaps getting treatment anyway. Transport and things become an issue then as well.” pt7

“A number of them come in here by ambulance or ambulance car, so transport is going to be a problem.” pt10

One participant said that from her personal experience, events should be run

“But if it’s run in the evening then at least he could go and join.” pt14

Generally people felt they should be run regionally (36%). Charities would need to get many people involved in an event to ensure it was worthwhile and well attended- without running them too regularly that it became too expensive (Table 2).

Just over a third of the clinicians asked had applied and were successful in receiving financial support from a charity (Figure 4). They applied for this for a range of reasons - from teaching to equipment (Figure 5). Of those participants that applied for financial help from a charitable organisation, only one applicant was unsuccessful. No feedback was given to this participant as to why their application was unsuccessful. This was not found to be helpful by the participant in question.

“Unsuccessful grant application, it was applied for around the time of the economic slowdown, but I wasn’t given any feedback that you would expect...” pt2

Ideally if applicants were not successful in their application, charities should give explanatory feedback. This will aid further applications, and strengthen bonds between professionals and charities further, which is one of the key aims for the government (HM Treasury, 2002). Most of the interviewees have not applied for funding, and various reasons for this became apparent (Figure 6). The main themes that developed were: professionals having a distinct lack of time and have not had any direct need to do so presently. Clinicians working in the prosthetics service report being very busy with little time to do anything other than direct patient care.
“Sometimes in our clinical environment, we can’t spend enough time to go over that kind of stuff…” pt20

This correlates to what was found by SPARG’s regarding the number of amputees accessing the prosthetics service in Scotland (2011). The time constraints put on clinicians in the NHS is highlighted when one prosthetist said of research:

“…people generally don’t do that is because they don’t have the time to do research…. Your job would need to be restricted and your job would need to be research.” pt9

77% would apply for funding in the future (Table 3), although there should be a specific call to apply, so that money was not wasted. Two participants specifically highlighted the lack of funds available in general in the NHS.

“Funding is an issue…. It’s for everyday runnings and maintaining…” pt6

Those that said they would not apply again gave a lack of time or interest as reasons.

More participants had never heard of available grants (Figure 7). Of those that knew about the grants some heard through ‘word of mouth’ from colleagues and other professionals (Figure 8). This is not a very efficient method of advertising. Both groups were asked how they would like to be informed, and what the best way to reach the clinicians would be (Figure 9). 12 wanted active, direct contact from the charities to the clinics.

“…emailing prosthetic service managers and getting directly in contact…” pt12

“So direct contact from the charities” pt13

“…would get in touch directly with the clinical team…” pt14

“so direct contact in some capacity” pt20

This should take the form of emails or newsletter sent from the professional body BAPO (British Association for Prosthetists and Orthotists).

“…develop some sort of way through email or through letter…” pt21
“I guess they could let us know through email…” pt22

This was countered when one prosthethist said:

“…contact would be through BAPO and their newsletters but then again, not everyone is a member of BAPO” pt11

However, another said:

“…it would encourage everyone to be a member of BAPO” pt18

5 clinicians wanted detailed criteria sent well in advance of the application deadline.

“…what deadlines are and what you need to apply are... it’s good to hear what their criteria are.” pt6

“…with focussed information, because it’s a bit pointless if it’s vague...” pt16

Having detailed criteria would reduce the amount of time when looking for suitable funding, reduce time taken to apply and give the clinician more time to get a full proposal written and submitted. It may also make clinicians more likely to apply in the future. This viewpoint was supported in the literature by Coid (2003). One person suggested that developments could be made in producing a website resource to access all available grants. This would require all prosthetics charities co-operating, which may not be possible at the current time.

Next, participants were asked where they felt research into prosthetic devices should focus (Figure 15). An outright majority (86%) thought research should focus on comfort and fit, as without comfort and fit ‘everything else is pointless’. Some clinicians made links between the different topics of research. Two clinicians felt that ‘security and comfort & fit are one and the same thing’. Another said that there should effectively only be 3 topics as function & weight were linked and cost & durability were also joined. A separate professional related function with security. This is summed up by one participant saying, apart from comfort and fit being first, on any given day the order of the rest could be different depending on clinician or patient. This is supported by another when they said ‘cosmetic appearance can
become very important depending on the patient’. Cost & availability were said to connect with all other areas as ‘everything we do should be cost effective’.

Although it is not directly related to research into device design, two clinicians wanted to express the opinion that the psychological wellbeing of the patient is an area of care which should be improved in the future, and this is something charities can help with. In the literature, charities such as The Murray Foundation have helped in the past with amputee counsellors. A Grampian based charity, L.O.O.N.S, also provides such a service. One professional raised the point that psychological wellbeing directly related to research.

“No amount of money you could throw at it (a perceived problem with a limb) would solve it; if the patient’s psychological state isn’t right.” pt19

Durability was quite low on people’s preference list and it was mentioned that most prosthetic components are very durable and the socket generally needs replaced before components. Although one participant did state that in future research it would be a good idea to develop extended warranties as they would be more likely to choose one component over a competitor if they were confident enough to extend the warranty. Leading on from this, socket material, socket shape capture and cheap manufacture costs were also brought up by two participants independently. One final suggestion was to increased research into donning aids. One participant recounted how a patient manufactured their own liner donning device due upper limb issues. The clinician felt that this would be a good idea and could open up new prescription corridors, generally contraindicated for certain patients.

Further themes emerged when the participants were asked, if they would have interactions with a charity again (Figure 10), what they could foresee as a possible reason to do so (Table 4). Some combined earlier feelings of increasing patient information by suggesting hot line development for patients to use for knowledge or peer group development. One clinician reported such information as being ‘less over recent years’. Clinicians are also aware of current trends in the field by identifying the increase in military personnel entering the NHS service, and feeling that forging direct links with forces charities, e.g. BLESMA and Help for Heroes, would be
useful. Others wanted to increase the amount of counselling run by charities for their patients, as it was seen as an invaluable resource in the past which should be further developed and more widely available.

7.1 Summary
In general, the sample of professionals approached felt that charities were a necessary resource and that more could and should be made of them. This could range from organising events for patients to developing resources available for knowledge and psychological wellbeing. The need for sporting, healthy living and daily life events are important but should not be run at the expense of information and social events. Sporting activities should be more open to all rather than aimed at the niche, high activity population. Grant availability and funding options should be better advertised and clearer for applicants. General information about prosthetics should be well defined, current and freely available to all.

7.2 Importance of the Study
This study is of great importance to any prosthetic charity involved in providing care and support for prosthetic users as well as being useful for the wider prosthetics community. It is important that prosthetic charities are given a voice in the greater health community because, although they are smaller, the work they do is no less important. This study also gives a medium for professionals to engage directly with charities and report back on how they feel issues can be improved. Charities can also use this constructive feedback to tailor their research and how they spend funds in the future to better support users and professionals in the field.

7.3 Limitations of Study
A number of limitations have been identified in the current study. Firstly all of the professionals recruited as part of this study were from NHS Scotland. This means the results generated from the questions stand alone and must be put into further context before being used in a wider study. The opinions may be indicative of other AHP’s but may not represent the exact point of view for the whole of the United Kingdom.

It relies a great deal on the nature of the interviewer and their ability to form a rapport with the interviewee (Sociology Research Skills, 2012). Coaching was given to the researcher by an experienced professional to rapidly up-skill in semi-structured
interview techniques to ensure that no leading questions were asked and the interview was carried out in a neutral manner.

Use of semi-structured interview carries inherent drawbacks. Aside from the time consuming transcription, an interview is unrepeatable and therefore each one carried out was slightly different from the last (Sociology Research Skills, 2012). It is also difficult to judge exactly what information is relevant and what is superfluous (Sociology Research Skills, 2012). As each interviewee answered in a different way it was a challenge to group answers into themes for the grounded theory.

Charities were not consulted on their aims and aspirations for research and future activities. Given more time, this should also be considered. This, coupled with future governmental plans, would be an interesting view to include.

Despite the limitations, and having taken the shortcomings into account, this is the first piece of work of its kind. There is no other literature that investigates the way in which professionals view prosthetic charities and their previous experiences in working with them. This makes this work valuable in its own way and provides an initial insight into a much larger, and as yet, undocumented subject.

7.4 Recommendations for Future Research
One area that this study does not touch on is the perceptions of patients that utilise prosthetic charities. It would be interesting to compare the viewpoints of professionals with those of users and establish where their opinions correlate. This could be used as a tool for the development of better service provision by the charities that would benefit both groups.

Another way in which the current study can be further developed would be to employ the help of every health professional involved in amputee care in Scotland or take a suitable sample from the UK wide professional group. The semi-structured interview could take a more exhaustive questioning form. The current study was unable to investigate in this depth due to time constraints.

It would also be interesting to put the results from Scotland in a broader context by comparing them to similar results from England and Wales. As part of the ‘Raising the Bar’ study PORT-ER has developed, an almost identical questionnaire is being
utilised UK wide. This questionnaire is also available to orthotists and would give a comparison between perceptions of prosthetic and orthotic. Such a project would entail a large body of work, as there are no specifically orthotic based charities.

7.5 Conclusion
Having looked at the Government policies on the third sector, how the charities portray themselves, and what the professionals on the front line of prosthetic rehabilitative care really think, it is now essential to integrate the information from the three sectors. The Government sees charities playing an increased role in the provision of health care in Scotland (Barclay, 2011). The Government also wants to strengthen the bond between the private sector and the third sector, all for the benefit of the patients using the NHS (The Scottish Government, 2010). Although this is with regard to charities in general, it would be reasonable to assume the same could be applied across the prosthetic charities.

Charities themselves want to have a larger role in supporting patient care and, with the increased number of amputees in Scotland (Scott et al., 2011), it is reasonable to accept this. Charities are not attempting to take over health care, but rather support and augment where they can (Edelman, 2004). The over-whelming feeling is that charities can play a larger role in supporting amputees and professionals in Scotland but, at the moment, this may not be happening in the best or most effective way. Charities must be more active in their advertising to professionals about the prospects of grants, and must tailor events they run to be more accessible to greater numbers of amputees. If charities work together with professionals in the NHS on developing such events then they may be better received and will have a greater attendance in the long run. Charities must highlight the good that they do and state the benefits that this can have for all involved. One way this can be achieved is by direct contact with centres. Clinicians appreciate the role of charities and would consider interacting with them; however charities are not effective enough at marketing themselves. This must improve if the hope of the Government is to be realised.

However, in this utopia, the voice of realism must be heard. Advertising and self-promotion requires time, money and man-power on behalf of the charities. Often
these are features that charities simply do not have. Charities rely on volunteers and financial donations to exist. Professionals are very busy and help in every way they can, but due to busy clinics and a large patient base, often cannot afford the time to give to charities or see the benefit in doing so.

This thesis has attempted to illustrate the feelings of professionals and how they see prosthetic rehabilitation charities. The need for more effective communication between the government, charities and professionals has been highlighted and if all three can work together, a bright future for the amputees of Scotland is achievable.
8. Appendices

Appendix A
Search Terms and Derivations

The terms searched to form the basis of the background literature were as follows:

1. Charity*
2. Question* and survey*
3. “service provision”
4. “artificial limb”

These terms were searched individually then in the following combinations:

<table>
<thead>
<tr>
<th>Two terms</th>
<th>Three terms</th>
<th>Four terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>1+2</td>
<td>1+2+3</td>
<td>1+2+3+4</td>
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<tr>
<td>1+4</td>
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<td>2+3</td>
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<td>2+4</td>
<td></td>
<td></td>
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<tr>
<td>3+4</td>
<td></td>
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</tr>
</tbody>
</table>

Appendix B
CHARITIES LIST

BLESMA

Established
1932

Director
Jerome Church = General Secretary and amputee member of board

Aims
Rehab those that have recently lost a limb in the line of service

Provide residential care in 2 care homes

Provide grants for those that have lost a limb

Provide welfare services to amputees and or widows

Represent members and or widows to government

Activities
Run fundraising events e.g. Fall for the Fallen (skydive) and Bike for BLESMA (sponsored motor cycle ride on Route 66)

Also petition Government and champion the thoughts of their members e.g. responsible for Headley Court being set up.

**Douglas Bader Foundation**

**Established**

1982

**Director**

Keith Delderfield

**Aims**

NONE VISABLE

**Activities**

Set up Douglas Bader Rehab Centre in 1993 in Roehampton

Grant scheme set up in 1995

Set up Limb Loss Information Centre website in 2005

Bader Braves - side project to help children with limb loss

**Limbless Association**

**Established**

1983

**Director**

John Reid = chair of trustees

Lady Rix = Patron

**Aims**

Support all people with limb-loss through various centres

Newsletters and magazines, one to one visits from volunteers, membership to charity, info on sport and teams to play in.
Support and assistance pre and post amputation/ congenital loss

Information for patients, carers and families

Legal advice

Grants and funding

**Activities**

Lots of sports clinics and fundraising through marathons, and runs etc.

No funding from government, all grants, donations and membership money

---

**LimbPower**

**Established**

2007

**Director**

Kiera Roche = chairman

**Aims**

Aid rehab and QOL through medium of sport and arts

Give information, access to facilities and opportunity to try out new things

**Activities**

Amputee games at Stoke Mandeville

Amputee winter games

Junior games

---

**Reach**

**Established**

1978

**Director**

Nigel Tarrant = Chairman
Laura Hamilton= patron

Aims
Promote interests of children with upper limb deficiencies
Support and educate families and carers
Encourage and support research in upper limb P&O, surgeries/medicine and cause of deficiencies

Activities
Publish newsletters
Provide insurance for good arm
Donate money to research and development

STEPS
Established
1980 became charity in 1988

Director
Sue Banton

Aims
Give information and support to families whose child is affected by lower limb congenital deformity
Talipes, DDH, lower limb deficiency

Activities
n/a

The Murray Foundation
Established
1996

Director
Susan Shaw
**Aims**

Support those with lower limb loss

**Activities**

Provision of BACP accredited counsellors

Training in counselling skills

Hospital Visitors Scheme

Freephone Helpline

Information

A Scotland wide network of support groups

Events

Sports master classes, quizzes and social events

**PORT-ER**

**Established**

2006

**Director**

Diana Corrick

Sandy Sexton

**Aims**

To encourage safe standards of prosthetic and orthotic care to internationally recognised standards;

To support the advancement of knowledge in prosthetics and orthotics by sharing information;

To support innovation in prosthetics and orthotics.

To provide funding to communities of patients/users to enhance patient/user education.

**Activities**

Amputee Running Master Class
Fund raising events

Raising the Bar Survey
Appendix C

memo

To: Elaine Figgins
From: Departmental Ethics Committee
Copy: 

Date: 7 March 2013
Ref: 

Paper DEC/BioMed/2013/06
Prosthetic Rehabilitation Service Provision professionals’ opinions of charitable bodies’ function/roles

Thank you for the above revised ethics application.

The Departmental Ethics Committee is satisfied with all changes in the revised application and gave their approval for this project with immediate effect.

Good luck with your project and remember you must inform us in writing of any changes to the project and any unforeseen circumstances which arise during the project.

Regards

Linda Gilmour (Secretary to)
Departmental Ethics Committee
# Appendix D

**OFFICE USE ONLY**

**UEC**

//12

Paper

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## Ethics Form

Please answer all questions

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>1. Title of the investigation</td>
<td>Prosthetic Rehabilitation Service Provision professionals' opinions of charitable bodies' functions/roles.</td>
</tr>
<tr>
<td>2. Chief Investigator (Ordinance 16 member of staff only)</td>
<td></td>
</tr>
<tr>
<td>Name:</td>
<td>Mrs Elaine Figgins</td>
</tr>
<tr>
<td>Status:</td>
<td></td>
</tr>
<tr>
<td>☐ Professor</td>
<td>☒ Reader/Principle Teaching Fellow</td>
</tr>
<tr>
<td>☐ Senior Lecturer</td>
<td>☐ Teaching fellow</td>
</tr>
<tr>
<td>Department:</td>
<td>Biomedical Engineering</td>
</tr>
<tr>
<td>Telephone:</td>
<td>0141 548 2051</td>
</tr>
<tr>
<td>E-mail:</td>
<td><a href="mailto:e.figgins@strath.ac.uk">e.figgins@strath.ac.uk</a></td>
</tr>
<tr>
<td>3. Other Strathclyde investigator(s)</td>
<td></td>
</tr>
<tr>
<td>Please provide details for all investigators involved in the study</td>
<td></td>
</tr>
<tr>
<td>Name:</td>
<td>Mark Currie</td>
</tr>
<tr>
<td>Status (e.g. lecturer, post-/undergraduate):</td>
<td>Undergraduate</td>
</tr>
<tr>
<td>Department/Institution:</td>
<td>National Centre for Prosthetics and Orthotics, Biomedical Engineering,</td>
</tr>
<tr>
<td>If student(s), name of supervisor:</td>
<td>Elaine Figgins</td>
</tr>
<tr>
<td>Telephone:</td>
<td>0141 548 3298</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:mark.currie@strath.ac.uk">mark.currie@strath.ac.uk</a></td>
</tr>
</tbody>
</table>
4. Non-Strathclyde collaborating investigator(s)
Name(s): Sandra Sexton
Status: Director PORT-ER
If student(s), name of supervisor: N/A
Contact Details: Telephone +44 7825775998
E-mail: sandy@rehabskills.com

5. Overseas Supervisor(s)
Name(s): None
Status: 
Department/Institution: 
Telephone: 
Email: 
I can confirm that the local supervisor has obtained a copy of the Code of Practice: Yes ☐
Please provide details for all supervisors involved in the study:

6. Where will the investigation be conducted
The investigation will be conducted at the National Centre for Prosthetics and Orthotics, Department of Biomedical Engineering, University of Strathclyde and at the five Prosthetic Services Centres located across Scotland
6. Aberdeen- Mobility and Rehabilitation services, Woodland Hospital
7. Dundee- TORT, Ninewells Hospital
8. Edinburgh- SMART centre, Astley Ainslie Hospital
9. Glasgow- WESTMARC, Southern General Hospital
10. Inverness- Raigmore Hospital

7. Duration of the investigation
Duration(years/months) : 2 months
Start date (expected): 08/03/13 Completion date (expected): 10/05/13

8. Sponsor (please refer to Section C and Annex 3 of the Code of Practice):
The University of Strathclyde

9. Funding body (if applicable)
Name of funding body: None
Status of proposal – if seeking funding (please click appropriate box):
☐ In preparation
☐ Submitted
☐ Accepted
Date of Submission of proposal: / / 
Date of start of funding: / / 
10. Objectives of investigation (including the academic rationale and justification for the investigation)

This work will be part of a 40 credit fourth year undergraduate project in prosthetics. This project seeks to improve the working relationship between charitable bodies and the Prosthetic rehabilitation service professionals that work in Scotland, through investigating the opinion of these professionals. Coid et al in 2003 showed through a qualitative study of face to face interviews with Scottish Health Board officials, that the relationships with voluntary organisations was not explicit, and that future initiatives would be required to improve the relationship. A literature search is currently being carried out. Only one paper on Speech and Language Therapy (Edelman 2004) documented the improved service provision through an active role of the voluntary sector. However the service provision of interest to this investigation is that of the prosthetic service in Scotland.

SPARG, the Scottish Physiotherapy Amputee Research Group, have been collating and publishing data on amputees in Scotland for the last 18 years (SPARG, 2009). From their most recent publication it was found that there were 746 amputees in Scotland, with 773 amputations in total. This data included bilateral amputees and revision surgery at a higher level due to complications. 323 of these amputations were as a result of peripheral arterial disease (with no related diabetes), 284 were as a result of Diabetes Mellitus and 33 were documented as due to other reasons. Amputations were at various levels with 410 trans-tibial, 321 trans-femoral and 30 knee disarticulation.

Prosthetic patients in Scotland can be seen and treated for in one of the five centres for prosthetic rehabilitation in Scotland. These are:

11. Aberdeen- Mobility and Rehabilitation services, Woodland Hospital
12. Dundee- TORT, Ninewells Hospital
13. Edinburgh- SMART centre, Astley Ainslie Hospital
14. Glasgow- WESTMARC, Southern General Hospital
15. Inverness- Raigmore Hospital

It is plain to see from these results that amputation and its prosthetic rehabilitation remains a significant function of the NHS.

As with any area where human welfare is involved, there are charities that are founded to support the people affected. These charities aim to help patients and support the health service where ever possible. A major example of this would be the Chest Heart and Stroke charity. It is evident on their website pages that they run chronic obstructive pulmonary disease (COPD) support services that have been piloted in Greater Glasgow and Clyde NHS service. They also provide one on one support for people suffering from COPD and organise information, education, outings and friendship for this patient group (Stewart, 2012).

Another example is mental health charities that support NHS services in many ways from fundraising to information leaflet production. In the Mental Health Foundation’s (MHF) publication on peer support (2012), partnership working with NHS Lothian and NHS Lanarkshire established guidelines and support for organisations giving peer support for long term health conditions was discussed. This was derived from evidence based practice and experience from experts in this specific field (Mental Health Foundation, 2012).

Harris and Ward (2011) showed the linkage between the charity Breast Cancer Care, and supporting not only patients but also related health care professionals, mainly genetic counsellors.

A literature search on prosthetic charities supporting the NHS service was conducted and there was very little evidence attainable. This vindicates the objectives of this study. The original idea was presented by PORT-ER, the Exeter based prosthetic rehabilitation charity who had noticed the lack of evidence to support and justify their work. This initiated this
investigation into how prosthetic charities can best function alongside the prosthetic rehabilitation services in Scotland. The chief investigator and the UG student met with Sandra Sexton a Director of PORTER and agreed to work in collaboration on this project. Time was spent on formulating a research question that met the objectives for a student project in a set time frame from March till May 2013. The objective was to align with the ‘raising the bar’ questionnaire that PORTER have put on line for England and Wales. Thus the order of the questionnaire remains unchanged so this alignment can occur once the project is completed. To enhance its effectiveness there has been added a qualitative element at the end of the interview to allow more detailed evidence to be gathered through core and prompt questions. These would be around the interactions that professional prosthetic rehabilitation staff in Scotland have experienced in interacting with charitable bodies, as well as their future plans to interact with such organisations. A literature search is being undertaken to support this study around the newly incorporated qualitative elements using a grounded theory approach. This has included the modification of the survey at the end to incorporate open questions and elicit more detailed responses from participants. The aim is to produce evidence to inform the practice of the voluntary sector and improved partnership working with the service providers in prosthetic rehabilitation.

References
11. Nature of the participants
Please note that investigations governed by the Code of Practice that involve any of the types of projects listed in B1(b) must be submitted to the University Ethics Committee for prior approval.

Are any of the categories mentioned in Section B1(b) (participant considerations) applicable in this investigation?
No

Please detail nature of participants: Experienced prosthetic rehabilitation service professionals from the five main prosthetic service centres in Scotland and from NCPO staff. To include prosthetists, Physiotherapists, Medical rehabilitation doctors, Occupational Therapists - but all must work at the Mobility and rehabilitation Centres in Scotland.

Number: Minimum of 5 maximum of 50 due to time constraints.

Age (range): 21-67

Please also include information on: recruitment methods (see section B4 of the Code of Practice); inclusion/exclusion criteria; and any further screening procedure to be used. A list of eligible and experienced prosthetists, physiotherapists, medical rehabilitation doctors and occupational therapists who currently work in Scotland will be accessed from the PORT-ER database. Relevant staff will then be informed by email about the study (Appendix B). They will then be given 1 week to consider if they would like to participate. Participants who express an interest will then be sent the participant information sheet (Appendix A). Participants may choose to participate in the project or not. They will be then be asked to make an informed decision as to whether or not they wish to participate by replying to the email. From the list of positive responses by email and participant information sheet, a date will be set for the student to attend each of the prosthetic service venues across Scotland that is suitable for the majority of respondents. Participants will be informed of the date set and individual appointments of 15 minutes set for the date.

Inclusion Criteria: The prosthetic rehabilitation professionals must be experienced in their profession and currently work in Scotland within the area of prosthetic rehabilitation.

12. What consents will be sought and how?
Please note that the information sheets and consent forms to be used should be attached to this for.

The participant will be provided with a participant information sheet (Appendix A) and asked to sign a consent form (Appendix A). Both of these documents are appended to this application. At this stage participants will be assigned a random participation number to ensure anonymity, yet allow for data to be removed at a later stage should the participant change their mind.

13. Methodology
Investigations governed by the Code of Practice that involve any of the types of projects listed in B1(a) must be submitted to the University Ethics Committee for prior approval. Where an independent reviewer is not used, then the UEC/DEC reserves the right to scrutinise the methodology.

Are any of the categories mentioned in the Code of Practice Section B1(a) (project considerations) applicable in this investigation?
No

Design: what kind of design/research method(s) is/are to be used in the investigation?
This methodology will use a questionnaire 'Raising the Bar' that had been modified very slightly (Appendix C) to allow qualitative feedback through open questions carried out by the named student who will conduct individual interviews. Each interview will be carried out by named UG student who can be seen as an independent since they have no personnel experience with the prosthetic service in Scotland. Mark Currie completed his clinical placement experience in Belfast - so this should eliminate any bias of the interviewer.

The study design is a simple 9 question questionnaire that asks the participants view of charitable bodies and their past involvement and potential future involvement. The
Participants will be asked the questions by the student and the multiple choice answered as in the original document of the raising the bar survey. The final section will then be the open questions with prompt questions to follow as required, that will be tape recorded at this point of the interview. The student will only tape this section of the interview. This tape will be transcribed by the student when back at the University. The paperwork and recordings will then be returned to the NCPO for transcription in the department as soon as feasibly possible. Following transcription taped interviews will be immediately deleted.

If participant cannot attend on the day set at that centre then a paper copy of the questionnaire will be left with a SAE for return, should the participant still want to be included. This will include the core and prompt questions for each participant to read. The data collected will be analysed using Qualtric software, which the University has a license for. All data will be anonymised by numbering the interviews randomly. The participant information sheets and the randomised numbers allocated will be stored in the NCPO safe, in case any participant may wish to withdraw their data at a later date. The questionnaire/survey is attached (Appendix C).

The student will then proceed to produce an individual thesis for his particular final year project. The methodology as described will be described and presented in the project thesis, Viva and poster presentation.

Techniques: what specific techniques will be employed and what exactly is required of participants?

Participants will be asked the questions in the attached survey. (Appendix C). The qualitative questions at the end of the interview will be open questions. These will also have prompt questions and an example is given on the form (Appendix C). These will be recorded using a University Dictaphone/recorder. Participants will be asked their opinions of charitable bodies as they relate to their clinical prosthetic rehabilitation service and their professional life.

The entire interview process will take between 10-15 minutes. It is hoped that at each centre a number of staff will be interviewed on the same day. Only one day per centre is planned due to cost and time restraint of the project timeframe.

PORT-ER a UK prosthetic based charity has agreed to allow access to their database of professionals and also to fund the student travel to each of the 5 prosthetic rehabilitation service centres across Scotland.

After statistical analysis and write up, participants involved in the study will be offered a copy of the poster created that will summarise the survey results.

Has this methodology been subject to independent scrutiny?

☒ No

Please provide the name and contact details of the independent reviewer:

14. Data collection, storage and security

Explain how data are handled, specifying whether it will be fully anonymised, pseudo-anonymised, or just confidential, and whether it will be securely destroyed after use:
All data collected will be pseudo anonymised and kept confidential. It will not contain any participant information. Following research completion all data will be destroyed within 5 years of the project. Participants will be assigned a randomly allocated identifier in a sequential order- through the random arrangements of interviews, which will numbers 1-20 etc. No one will know the identity of the participant except the student at the time and the participant themselves. Each participant will be asked to write their name next to their unique identifier and place this in a sealed envelope with their name on the outside of the envelope. Envelopes will be stored by the chief investigator in a locked safe at the NCPO and will be opened only in the event that a participant requests their data be removed from the survey. After the project completion all envelopes will be destroyed without opening. All interviews completed will have anonymised numbers, and they will be kept in a locked
cabinet and input into a computer at the NCPO- saved on a password protected pen drive – and this pen drive will be worked on at the NCPO. The pen drive will be locked away when not being used for analysis by either the chief investigator or the named student. Explain how and where it will be stored, who has access to it, and how long it will be stored: All data will be stored in the same locked cabinet at the NCPO and kept on a pen drive that will be password protected. Data will only be accessible by the named Strathclyde investigator, and the named student. The recording system used for the interview process is the property of the National Centre and will be stored in the National Centre, as will any returned forms through the postal service.

Will anyone other than the named investigators have access to the data. ☑ Yes If ‘yes’ please explain: This student project was initiated through an approach from one external collaborator, Mrs Sandra Sexton as one of the Directors of the charity/voluntary organisation PORT-ER. PORT-ER had received lottery funding to carry out a needs assessment of their users both professional and patients in the field of prosthetic rehabilitation. The chief investigator and student are carrying out this work and will present to this external stakeholder only once completed and anonymised as data in the final report and presentation. This may be used to inform the voluntary organisation of the needs and opinions of the prosthetic rehabilitation service professionals within Scotland.

<table>
<thead>
<tr>
<th>15. Potential risks or hazards</th>
<th>No risks have been identified.</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. Ethical issues</td>
<td>Ethical issues relate to protection of participants anonymity. The full anonymity of participants will be protected at all times throughout the study as each participant will be allocated a unique identifier which is only known by the participant and UG student- this detail will be locked in a safe and destroyed as soon as the project is complete.</td>
</tr>
<tr>
<td>17. Any payment to be made</td>
<td>No payments shall be made throughout this study/ project. Although the student will be reimbursed for economy travel to the prosthetic services centre across Scotland to conduct the face to face interviews.</td>
</tr>
<tr>
<td>18. What debriefing, if any, will be given to participants</td>
<td>Participants will be given access to final results upon request through a poster presentation.</td>
</tr>
<tr>
<td>19. How will the outcomes of the study be disseminated (will you seek to publish the results)</td>
<td>Outcomes will be presented in the thesis submitted for assessment as part of the student’s honours degree. The results may also be disseminated through a scientific/professional conference or journal.</td>
</tr>
<tr>
<td>20. Nominated person to whom participants’ concerns/ questions should be directed before, during or after the investigation (please also provide contact details)</td>
<td>Participants will be advised through the information sheet provided to address concerns and questions to Mrs Elaine Figgins, NCPO, Department of Biomedical Engineering; Tel 0141 548 2051; email <a href="mailto:e.figgins@strath.ac.uk">e.figgins@strath.ac.uk</a></td>
</tr>
</tbody>
</table>
21. Previous experience of the investigator(s) with the procedures involved

Mrs Elaine Figgins has extensive teaching and research experience with prosthetic and orthotic projects, as well as extensive experience in project supervision, questionnaire analysis and results dissemination through her own on-going PhD. She has extensive recent experience and training from Glasgow Caledonian University on qualitative methodologies which were compulsory elements for her on going Professional Doctorate qualification.

Mark Currie is an undergraduate student in his last year of a 4 year BSc Honours degree and has completed two four month placements in NHS prosthetic and orthotic centres at the time of research.
22. Chief Investigator and Head of Department Declaration

Please note that unsigned applications will not be accepted and both signatures are required.

I have read the University’s Code of Practice on Investigations involving Human Beings and have completed this application accordingly.

Signature of Chief Investigator

Please also type name here: Elaine Figgins 20/02/2013

I confirm I have read this application, I am happy that the study is consistent with departmental strategy, that the staff and/or students involved have the appropriate expertise to undertake the study, that the study makes appropriate use of available resources and facilities within the department and that there are no other departmental-specific issues relating to the study of which I am aware.

Signature of Head of Department

Please also type name here Prof Bernie Conway

Date: 20th Feb 2013 20 / 02 / 2013

23. Only for University sponsored projects under the remit of the DEC/SEC, with no external funding and no NHS involvement.
Head of Department statement on Sponsorship

This application requires the University to sponsor the investigation. This is done by the Head of Department for all DEC applications with exception of those that are externally funded and those which are connected to the NHS (those exceptions should be submitted to R&KES). I am aware of the implications of University sponsorship of the investigation and have assessed this investigation with respect to sponsorship and management risk. As this particular investigation is within the remit of the DEC and has no external funding and no NHS involvement, I agree on behalf of the University that the University is the appropriate sponsor of the investigation and there are no management risks posed by the investigation.

If not applicable, click here ☐

Signature of Head of Department

Please also type name here

Date: / / 

For applications to the University Ethics Committee the completed form should be sent to ethics@strath.ac.uk with the relevant electronic signatures.
Management Risk Assessment and Sponsorship

You are required to complete this form when:

- Your application is going to University Ethics Committee (UEC). You should attach it with your application when you send the application to the ethics mailbox.
- Your application is going to Departmental Ethics Committee (DEC), or the School Ethics Committee (SEC) in the case of HASS, and there is no NHS involvement or external funding. The CI should complete and submit the form to the Head of Department/School General Application Forms.

The Code of Practice on Investigations involving Human Beings requires that all investigations involving humans as subjects should be subject to management risk assessment as well as ethical scrutiny. For those investigations that fall within the remit of the University Ethics Committee, and/or involve the NHS, and/or are externally funded then this form should be completed and submitted to Research & Knowledge Exchange Services. For those investigations that fall within the remit of the Departmental Ethics Committee, and do not involve the NHS, and are not externally funded then this form should be completed and submitted by the Chief Investigator to his/her Head of Department.

1. Title of investigation: Prosthetic Rehabilitation Service Provision professionals’ opinions of charitable bodies’ functions/roles.

2. Chief Investigator: Mrs Elaine Figgins

3. Is it proposed the University will sponsor the investigation (i.e. have responsibility for overall management of the investigation)?
   Yes ☒ No ☐ If no, who is the Sponsor? ………………….

4. Are you aware of any issues relevant to the University’s insurance cover? For example is this a clinical trial and/or are you offering no-fault compensation to volunteers?
   Yes ☐ No ☒ If yes, what are those issues? …………………

5. Are you aware of any issues relevant to the University’s assessment of management risk of this project? Please see attached for examples of possible management risk issues.
   Yes ☐ No ☒ If yes, what are those issues? …………

Signature of Chief Investigator:

Date: 11/02/13.

For investigations that fall within the remit of the University Ethics Committee, and/or involve the NHS, and/or are externally funded please send this completed form with the appropriate ethics application form to Helen Baigrie, Contracts Manager, Research and Knowledge Exchange Services.
Management Risk Assessment Issues

When considering management risk Research and Knowledge Exchange Services and Senior Officers will consider factors including, but not limited to, the following.

1. Risk to reputation of University and risk of litigation and/or insurance claims. This risk maybe caused by:
   - harm to volunteers and wider community
   - poor research strategy
   - breach of statutory framework or contractual obligations
   - project not being carried out according to protocol
   - inadequate or inappropriate insurance cover.

2. Risk to research completion. This risk maybe caused by:
   - failure to properly carry out research
   - failure to proper supervise students
   - inadequate resources and/or facilities
   - inexperienced staff.

3. Risk to dissemination and use of research results. This risk maybe caused by lack of resources or failure to identify and act upon intellectual property in results.

4. Risk to researchers – career and reputation. This risk maybe caused by misconduct or non-completion of research.

The management risk assessment will consider the University’s context, in particular:

- Research and Development Strategy, including the objective of the University in general, and the objective of University research generally and within the relevant faculty/department.
- Research and Development Structure and Systems. In particular the support provided by the University’s structure to reduce the risks posed by research and by this investigation, and the systems in place to monitor and respond to the risks.
Appendix E

Participant Information Sheet

Name of department: Biomedical Engineering

Title of the study: Prosthetic Rehabilitation Service Provision professionals’ opinions of charitable bodies’ functions/roles.

Introduction

This work will be part of a 40 credit fourth year undergraduate project in prosthetics.

What is the purpose of this investigation?

This project seeks to improve the working relationship between charitable bodies and the Prosthetic rehabilitation service professionals that work in Scotland, through investigating the opinion of these professionals. Coid et al in 2003 showed through a qualitative study of face to face interviews with Scottish Health Board officials, that the relationships with voluntary organisations was not explicit, and that future initiatives would be required to improve the relationship. A literature search is currently being carried out. Only one paper on Speech and Language Therapy (Edelman 2004) documented the improved service provision through an active role of the voluntary sector. However the service provision of interest to this investigation is that of the prosthetic service in Scotland, and currently this has no evidence available in the literature.

As with any area where human welfare is involved, there are charities that are founded to support the people affected. These charities aim to help patients and support the health service where ever possible. A major example of this would be the Chest Heart and Stroke charity. It is evident on their website pages that they run chronic obstructive pulmonary disease (COPD) support services that have been piloted in Greater Glasgow and Clyde NHS service. They also provide one on one support for people suffering from COPD and organise information, education, outings and friendship for this patient group (Stewart, 2012).

Another example is mental health charities that support NHS services in many ways from fundraising to information leaflet production. In the Mental Health Foundation’s (MHF) publication on peer support (2012), partnership working with NHS Lothian and NHS Lanarkshire established guidelines and support for organisations giving peer support for long term health conditions was discussed. This was derived from evidence based practice and experience from experts in this specific field (Mental Health Foundation, 2012). Harris and
Ward (2011) showed the linkage between the charity Breast Cancer Care, and supporting not only patients but also related health care professionals, mainly genetic counsellors.

A literature search on prosthetic charities supporting the NHS service was conducted and very little evidence was attained. This vindicates the objectives of this study. The original idea was presented by PORT-ER, the Exeter based prosthetic rehabilitation charity who had noticed the lack of evidence to support and justify their work. This initiated this investigation into how prosthetic charities can best function alongside the prosthetic rehabilitation services in Scotland. The chief investigator and the UG student met with Sandra Sexton a Director of PORTER and agreed to work in collaboration on this project. Time was spent on formulating a research question that met the objectives for a student project in a set time frame from March till May 2013. The objective was to align with the’ raising the bar’ questionnaire that PORTER have put on line for England and Wales. Thus the order of the questionnaire remains unchanged so this alignment can occur once the project is completed. To enhance its effectiveness a qualitative element has been added at the end of the interview to allow more detailed evidence to be gathered through core and prompt questions. These will be around the interactions that professional prosthetic rehabilitation staff in Scotland have experienced in interacting with charitable bodies , as well as their future plans to interact with such organisations. A literature search is being undertaken to support this study, around the newly incorporated qualitative elements using a grounded theory approach. This has included the modification of the survey at the end to incorporate open questions and elicit more detailed responses from participants. The aim is to produce evidence to inform the practice of the voluntary sector and improved partnership working with the service providers in prosthetic rehabilitation.

References


Do you have to take part?

Your participation in this project is entirely voluntary and all of your responses will be anonymised. If you change your mind you are completely free to withdraw from the project at
any time without having to give a reason. Participants can withdraw their data from the project at any time without having to give a reason. Not participating in this project will in no way influence your standing or relationship within the University or your workplace.

**What will you do in the project?**

This methodology involves a short qualitative questionnaire which will be carried out by a 4th year student at your place of work. It should take between 10-15 minutes. We require your permission to voice record the final section of the interview where you will be asked your experiences and interactions with charitable organisation through your professional work. The survey will be carried out by one student and the content of your interview will be transcribed and kept anonymous. This final year student will then proceed to produce an individual thesis for his particular project. After statistical analysis and write up, clinicians involved in the study will have the opportunity to request to have a copy of the poster sent to them. This will detail and explain a summary of the project results from the Chief Investigator. No access to individual data will be given just group data and no-one will be made aware at any stage of who has agreed to participate.

**Why have you been invited to take part?**

You are an experienced professional working in the field of prosthetics rehabilitation services in Scotland and we are seeking your views and opinions.

**What are the potential risks to you in taking part?**

There are no known risks associated with your participation in this project. All data collected will be pseudo anonymised, confidential and will not contain any participant information.

**What happens to the information in the project?**

All information we gather will be treated as confidential and securely stored. All information will be stored on a password protected pen drive. This will be kept securely in a safe within the National Centre for Prosthetics and Orthotics. All tapes of the interview will be destroyed immediately after transcription. Any future reporting of the work will exclude your name.

The final collated information will be shared with the charity PORT-ER, who have kindly supported this project through funding travel to each of the venues by the student.

The University of Strathclyde is registered with the Information Commissioner’s Office who implements the Data Protection Act 1998. All personal data on participants will be processed in accordance with the provisions of the Data Protection Act 1998.

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

**What happens next?**

Since you have responded to the original email we are sending you this information sheet. Please take one week to consider this. If you are willing to participate in this project please email both Mark Currie and Elaine Figgins at mark.currie@strath.ac.uk and e.figgins@strath.ac.uk respectively. When we have received your email we will then ask if you wish to proceed and arrange a suitable date to attend your Prosthetic Centre if this is the
case. Prior to commencement we are required to ask you to sign a consent form. You will be given a unique randomised number that only you will know to identify you. The actual interview will take around 15 minutes to complete. We hope that you will find this project interesting and enjoyable. Whether or not you agree to participate, we should like to thank you for taking the time to read this information sheet.

The results of this project will be presented by the student in a thesis which will be assessed and examined. The results may also be presented at a professional conference or in a scientific journal. In all of this, your anonymity will be respected.

**Researcher Contact Details:**

Mr Mark Currie, 4th year student, Department of Biomedical Engineering, University of Strathclyde.

Telephone: 0141 548 3298

Email: mark.currie@strath.ac.uk

**Chief Investigator Details:**

Mrs Elaine Figgins, Department of Biomedical Engineering, University of Strathclyde.

Telephone: 0141 548 2051

Email: e.figgins@strath.ac.uk

This investigation was granted ethical approval by the University of Strathclyde Departmental Ethics Committee. If you have any questions/concerns, during or after the investigation, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the Departmental Ethics Committee
National Centre for Prosthetics and Orthotics
Department of Biomedical Engineering
University of Strathclyde, Curran Building
131 St James Road, Glasgow G4 0LS, Scotland, UK
Tel: (+44) 141 548 3298
Fax: (+44) 141 548 3295
www.strath.ac.uk/biomedeng

Email: linda.gilmour@strath.ac.uk
Appendix F

Consent Form

Name of department: Biomedical Engineering
Title of the study: Prosthetic Rehabilitation Service Provision professionals’ opinions of charitable bodies’ functions/roles

- I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences.
- I understand that I can withdraw my data from the study at any time.
- I understand that any audio recordings made in the investigation will be destroyed immediately after transcription and no information that identifies me will be made publicly available.
- I consent to being a participant in the project
- I consent to being audio recorded as part of the project

In agreeing to participate in this investigation

(PRINT NAME)                          Hereby agree to take part in the above project

Signature of Participant:                                             Date
Appendix G

Attention all Prosthetic Rehabilitation Professionals

Prosthetic Rehabilitation Service Provision professionals’ opinions of charitable bodies’ functions/roles.

Introduction

We would like to ask for your opinion and views on voluntary organisations such as charities involved with the prosthetic rehabilitation service in Scotland.

What is involved?

The investigation is a survey where the participants will be asked to be interviewed for 10-15 minutes at your place of work by a fourth year student from the National Centre for Prosthetics and Orthotics at the University of Strathclyde. There are a total of 9 questions followed by a semi-structured open question interview on this topic which we would ask your permission to tape record the final part of the interview. All data will be kept anonymous. You will be allocated a project number so no names are documented during the interview or in future presentations of the collated data.

We hope to capture the views of the professional staff working within the field of prosthetic rehabilitation in Scotland around the role and function of voluntary organisations to aid and develop partnership working between the two.

To participate in this study you must be

- A professional in the field of prosthetic rehabilitation in Scotland

To take part in this study or for further information please email: either: mark.currie@strath.ac.uk or his supervisor: e.figgins@strath.ac.uk
If you are interested then a participant information sheet will be emailed to you. You will then be given one week to consider the details and to decide if you wish to take part. If you do wish to take part, inform the investigators and following this an interview date and time with the student undertaking this project will be emailed to you. If this time is suitable for you, the survey which will take 10-15 minutes will be completed at your place of work.
Appendix H

Follow up email sent with copy of Participant Information Sheet to interested party.

Thank you very much for replying and for showing an interest in my study. Please find attached the participant information document and consent form with more in depth information on the study. Essentially, I am looking to gather information on the expert opinions of prosthetic rehabilitation professionals on prosthetic charities. I will be looking at previous interactions with such organisations and your knowledge and experience of them.

It will take the form of a short survey of 9 questions, some of which you are able to express more in depth views, and these will be audio recorded so I don't miss any of the information.

If you have any further questions regarding the investigation or want any further information, please don't hesitate to ask.

If you are happy to be involved then please let me know, and I can organize a suitable time to come to your centre and see you. If you know of anyone else in the centre that may be interested and is involved in prosthetic rehabilitation then please make them aware of the study, as if they are interested, I can coordinate my visit to carry out multiple questionnaires in the one day.

I would really appreciate you asking the technicians to take part, as they are an integral part of the team! You can forward this message on to them or I can send them their own copy if you would prefer.

Many thanks again for taking the time to read this,

Mark Currie
PROSTHETIC REHABILITATION SERVICES SURVEY SCOTLAND
(in collaboration with ‘Raising the Bar Project’ PORTER)

This survey:
At the NCPO University of Strathclyde we are interested in finding out about development needs for the field of prosthetics in Scotland and hope you will complete our market research survey questionnaire. The survey is anonymous. Once completed, we will share the summary information with the charity PORT-ER. They may use it in their newsletter, website, with different organisations, researchers and funders and to be able to prioritise activities and grants.

Scope of this survey:
The survey is intended for professionals working in the field of prosthetic rehabilitation in Scotland.

We are working with PORT-ER- who are they?
PORT-ER is a small charity. who award small development grants and deliver activities relating to their aims:
- to encourage safe standards of prosthetic and orthotic care through the education of clinicians to internationally recognised standards;
- to support the advancement of knowledge in prosthetics and orthotics through the dissemination of information;
- to support innovation in prosthetics and orthotics .
- to provide funding to communities of patients/users to enhance patient/user education.

9 questions: Please tick or comment where appropriate

Question 1: What area on NHS Scotland do you practice in? tick one or more
- Grampian
- Tayside
- Greater Glasgow and Clyde (GGC)
- Highlands
- Lothian

Question 2: What is your profession? tick one or more
- I am a prosthetist
- I am a physiotherapist
☐ I am a medic/ rehabilitation consultant

☐ I am a prosthetic service manager

☐ Other (Please specify)…………………….

**Question 3:** What information about prosthetics could be better in terms of content and availability?
Prompt question (patient information, professional staff, service information as examples)

What kind of information content needs to be developed or improved? Please comment:

**Question 4:** Where do you think information about prosthetics should be developed: *tick all that apply*

☐ in newsletters

☐ in websites

☐ on notice boards

☐ through social media (for example Facebook or Linked In)

☐ at exhibitions

☐ at workshops

☐ at seminars or short courses

☐ via conversations with rehabilitation professionals

☐ Other………. Please comment

**Question 5:** In the past charities have funded sports training events like Amputee Running Master Classes. Other organisations are doing this more frequently now. Do you think there is still a need to do this or similar?  ☐ yes ☐ no
If yes, what events should be supported in future, for your amputee population, and in which geographical area? Please comment:

How often should this be? Please comment on frequency of events for them to remain effective?

**Question 6:** Have you ever applied for grant funding from any charity or from elsewhere? □ yes □ no

*If Yes, please explain and give details of:*

Successful or unsuccessful  
*Purpose of funding - for service provision or patient education as examples?*  
Would you consider applying in the future?  
If yes then for what areas?  
If no then why not? (Restrictions of amount of funding available as an example?)

**Question 7:** Each year, charities awards small development grants to user groups professionals or other organisations delivering projects aligned with prosthetic rehabilitation.

Are you aware of such grants availability? □ yes □ no

*Prompt questions (how best is information disseminated to your professional service):*

**Question 8:** What do you think are the priorities for research about prosthetic and/or orthotic device designs? *Tick one or more*

□ Comfort and fit  
□ Function (how they work)  
□ Cosmetic appearance  
□ Cost and availability  
□ Durability  
□ Weight of device
| Security (how they hold on without slipping) | Other………… |

*Comments and prompt questions- which would have highest priority? Are there other topics that should be included?*

| Question 9: Have you had previous interactions with any prosthetic related charity? | ☐ yes ☐ no |

Would you consider further interactions? ☐ yes ☐ no

If yes, in which areas:

- ☐ Research
- ☐ Grant funding
- ☐ CPD- Short courses/ seminar
- ☐ Amputee master classes
- ☐ Other……… *Please comment:*
APPENDIX J

All transcribed information can be found in an electronic format on the Compact Disc attached to the back page of this thesis. This is due to large amount of data and text it contains.

SEE BACK PAGE.
9. References


HARRIS, J. & WARD, S. 2011. A UK collaborative 1-day pilot information and support forum facilitated by a national breast cancer charity and NHS cancer genetic counsellors,
for women at high risk, BRCA 1/2 gene carriers and hereditary breast cancer.  
*European Journal of Cancer Care, 20, 818-824.*


