

Raising the Bar: Survey Results



Background:

We were interested in finding out about development needs for the field of prosthetics and orthotics and so we designed an online market research survey questionnaire which was sent as an email link to 240 contacts and was made available via the PORT-ER website for an 8 month period in 2013.

The survey was intended for anyone with an interest in prosthetics and orthotics whether a client using a prosthetic limb, orthotic brace or prescribed footwear, a rehabilitation professional, a disability sports professional or acquaintance.

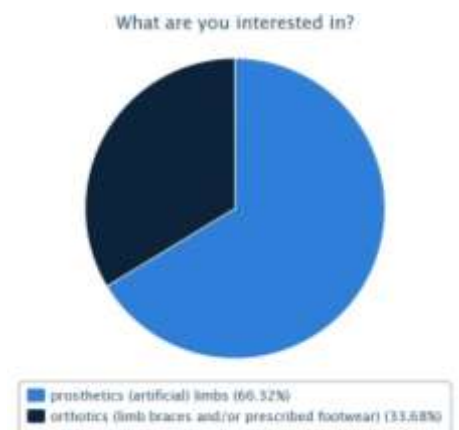
Because many of our key contacts include persons with limb amputation or limb or mobility impairments, the survey was developed following the advice given by the NHS Health Research Authority in their document *"Does my project require review by a Research Ethics Committee"*. We determined that the survey did not require such review. Instead, in developing our method and survey questions, we followed the advice given by the British Healthcare Business Intelligence Association in their document *"Legal and Ethical Guidelines for Healthcare Market Research"*. The survey had 12 questions and took about 5 minutes to complete. Respondents could withdraw at any time. Responses to the survey are anonymous and we have no way of telling who has responded.

Results:

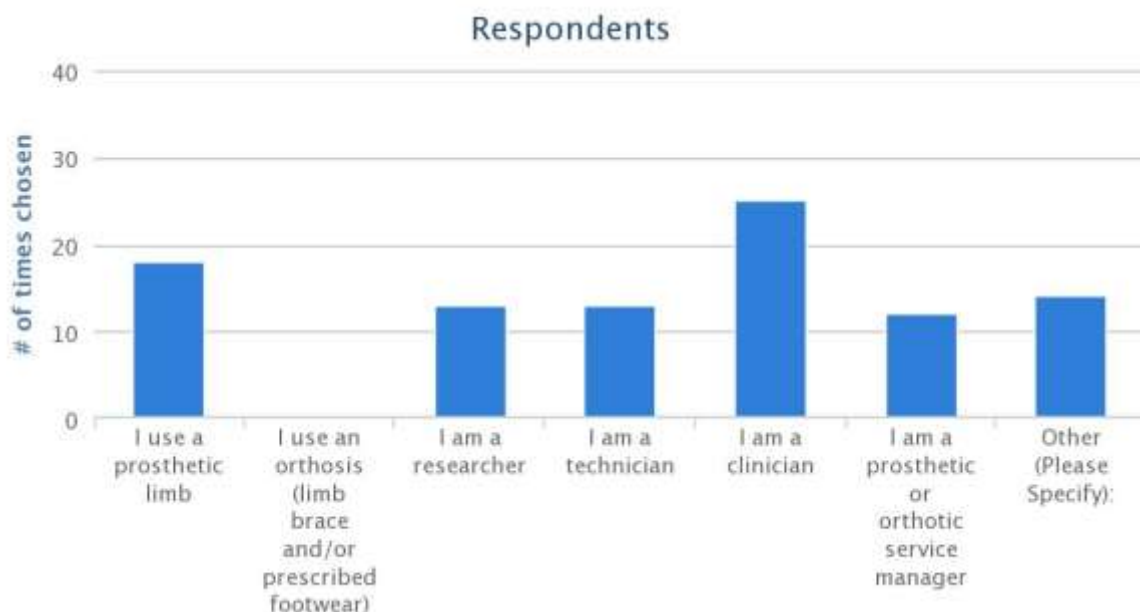
ABOUT RESPONDENTS

67 full online responses were received.

Most respondents were professionals. More respondents were interested in prosthetics than orthotics.



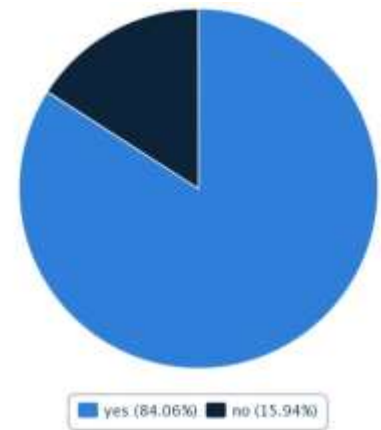
Respondents noted why they are interested in prosthetics and orthotics:



INFORMATION ABOUT PROSTHETICS AND ORTHOTICS

Do you think information about prosthetics and/or orthotics should be better in terms of content and availability?

84% of respondents thought that information should be better.



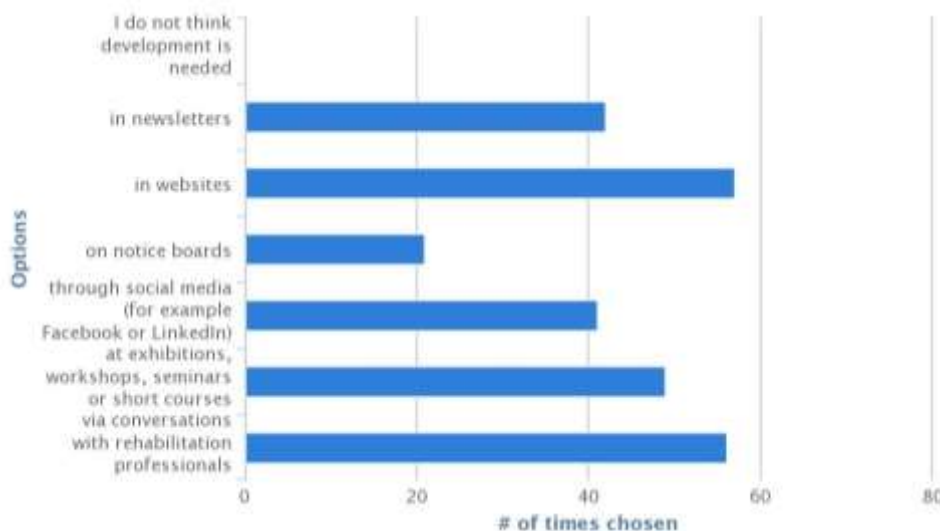
What kind of information content needs to be developed?

- A data base of all available limbs divided by use not make i.e. running, skiing, long distance etc.
- Awareness to people running courses for NHS like I do
- There is a lot of information available through various disparate sources - finding and accessing it all can be hard for prosthetic users and staff also. Info such as benefits, funding sources, vocational information, access to community resources etc.
- Advantages, side effects of braces available and how to use them, protect them from harsh climatic conditions and their durability.
- New socket solutions
- Better publicised points of contact displayed at rehab centres where amputees regularly attend.
- Online information in a standardized format to compare different products.
- General awareness in public about what all things available in market.
- The prostheses provided by the NHS in Scotland should be promoted positively. Role of amputees in being responsible for their own wellbeing: weight control (how this affects limb fit, difficulties this poses prosthetists), importance of general activity levels and fitness etc. This is something that clinicians should be aware of too.
- More needs to be developed in what is available and the very real objectives that can be expected. Too much is emphasized on "High Tech" and not enough and the interaction with the patient.
- The availability of prostheses i.e. if the amputee user is interested in sports he or she should be able to find out the best prostheses available
- Contents on modern and accepted developments in prosthetic and orthotics field please bearing in mind affordability especially to the developing world where many cannot be able to access the services. The concepts should be easily available and comprehensive to us as practitioners in this environment.
- Emphasis on custom-made products rather than universal
- The information content should be based and focused on amputees need and offer multiple choices to encourage them hope for their future.
- I am a practitioner in Africa and the field of P&O is not yet fully understood by Governments, the general public as well as the affected clients.
- 1. Patient /user information 2. Innovation content suitable for less resourced Countries 3. Research on impact of P&O devices on the quality of life particularly in Less resourced settings
- There is a lot of company different technical
- There is a high demand for understanding the degrees of posting to place intrinsically or extrinsically on an orthosis and little literature to utilize in applying theory to various pathologies.
- Awareness of profession
- Patient instructions
- Simpler solutions to prosthetic needs. Current types may not offer optimal solutions especially to developing countries.
- Material science references.
- Realistic information with regards to potential functional achievements as well as information on limitations that may be caused by multiple medical issues, Age, reason for amputation etc. Making sure that information is as relevant and available as early as possible. Information not only on the physical impact of amputation but also psychological, social etc.
- Awareness on prosthetic/orthotic services. -provision of services to quality standards ,and availability of services, types of technology, - importance/advantages of prosthetics and orthotics -availability and location of P/O schools
- There is a lot of information available through many different routes but it could be better organised
- General information, protocols, explanation of provision, possible provision available explained.
- General topic area reviews
- What's available via NHS in towns of leading technology

- Patients need to be better informed about ALL products available not just products supplied by a particular contractor in charge of a particular limb centre.
- What's available and what other people are using to help to be more mobile. especially with regard to sports
- An honest picture of what is available in prosthetics to amputees
- Information regarding prosthetic limbs is not easily available to the user unless through a third party, i.e. prosthetic, limb centre
- National or regional rehabilitation plans focusing on service delivery to people with physical disabilities. research so as to obtain the number of people with disabilities (PWD) availability of services in context to needs raise awareness to governments on PWD's rights, availability of services, accessibility and sustainability of services
- Prosthetics is doing ok, what with the recent Paralympics. Orthotics needs more coverage especially post-polio treatment. It's not all insoles!!
- Raising the profile of advances by better dissemination
- Clear and accessible information for patients and professionals which is free of sales bias and based in evidence. Regularly updated evidence based prescription guidelines would be ideal.
- Easy to understand and access. Current information is too clinician orientated and potential users are sometimes blinded by science.
- Please see our website xxx and see that there is real information about the product, comparatively and about its objectives and history.
- More about the various types of limb, foot, socket, suspension, cosmesis and particular needs they meet - on Voluntary websites
- General public know very little about orthotics (often think it means insoles if they have heard of the word at all). Need more media coverage to raise the profile
- Prescription guidelines
- In addition to written data sheets maybe access to some video seminars, end users or clinicians discussing issues, and the benefits v potential problems with use of prosthetics and/or orthotics
- There needs to be one place where athletes can go to find info about specialist providers, the process (including gate/biomech analysis), approximate costings and also all available grants and funds for individuals to access limbs to assist with their sporting career or for their health and wellbeing. the need for this is on an ad hoc basis, so when we come across people wanting to take part in sport who are restricted due to them not being able to access a running leg through their NHS prosthetist. It would be great to direct them to one place to get all the information they need.
- Wider information on what a user can expect in terms of limbs, developments and access to good web sites
- 'How to' instructions for amputees and health care professionals to demystify the science behind movement
- I like the US Amputee Coalition and Limb Loss model and resources, would like to see better collaboration internationally and additional language options.
- Types of prosthesis available and uses. Types of socket, why some are better than others.
- Some basic info for family members to give an overview of what will happen following amputation, i.e. going back for fittings etc. so everyone has a good understanding of the process
- Information in layman's terms that don't require a degree in anatomy or engineering to understand. It could be on charity websites or in limb fitting centres. GP's appear to have no information at all on the subject.
- more online info for patients
- information on what devices are available

Where do you think information about prosthetics and/or orthotics should be developed?

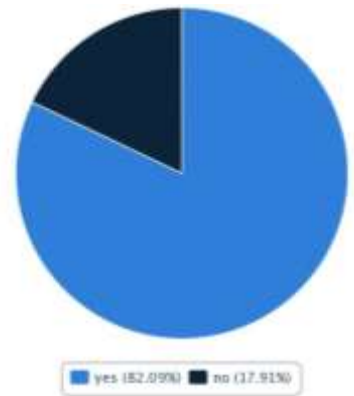
The most frequent response was about website information development.



DISABILITY SPORTS EVENTS

In the past, PORT-ER has 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 for PORT-ER to do this?

82% of respondents thought there was still a need to fund sports events.



Those that answered positively then answered:

What sporting events should we support in the future, and in which geographical location?

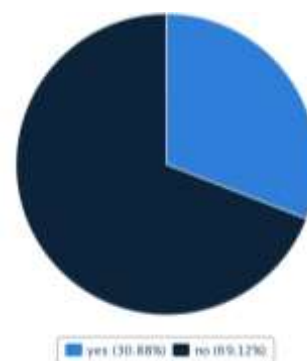
- As varied as possible and in as many locations as possible
- Running, but also a chance to try different sports eg cycling
- Triathlon
- Disability sporting events anywhere disabled people visit
- Anything further north!
- Golfers in tropic of Africa, bicycle riders in hilly areas, tennis players and basketball players in rough terrain.
- Water sports
- I wasn't aware of any other master classes being run. I think if a programme is developed there should be an attempt to make sure there is a good geographical spread of venues.
- The running master class could be repeated - it was excellent. Perth is fairly central if there are facilities to run something like that.
- All Types skiing hiking even activities for "non-athletes" to promote some exercise for older adults as well. Maybe just walking, getting outside, pushing their individual envelope. Maybe even dealing with diabetes and amputation.
- I would think events such as running classes and for beginners flat surfaces would be better
- In East Africa, we haven't yet had the opportunity to expose amputees who have been benefited with prosthetics and a chance to host this event will go a long way to mitigate on stigma associated with amputation or loss of limbs for that matter.
- BK tour, here at Balkans (EU)
- Sporting events for children and young amputees and further running and amputees with lower limbs loss. The location should be in Developing Nations or countries with real need of special events, in order to be helped in their economy and national image...
- I have not heard about the POR-ER sports event, and therefore I cannot answer on whether or not there still is a need for PORT-ER to do this. However, generally I think there is a need for funded sports training events like this, even though it applies only to a minority of the patients wearing prosthetic or orthotic devices.
- Any kind of sporting event involving disability in Africa especially Southern Africa.
- Amputee running, sports like table tennis and preferably in both primary and secondary school in less resourced Countries
- All of them location: Palestine, Gaza strip
- Not knowledgeable in this venue - better to leave this question unanswered. I am in the Region B area and would support any events.
- Any sport anywhere for individuals with a Disability - for O&P as well as actively using such
- I prefer to see support of local events rather than big events. This will bring more focused awareness on P&O.
- Cycling, rowing, heavy lifting, jumping
- Football/netball sports, and other games -swimming -mountain climbing
- Disabled cricket in Pakistan
- Further running classes - Perhaps aimed at more average amputees in Exeter
- Depends on your needs
- Whole of UK
- Any event which may encourage people to get out and exercise or share achievements with others. Start in Exeter but where ever there is demand by enough people.
- Common Wealth Games
- Running and other athletics, badminton, tennis, cycling in Plymouth
- Playing football(some clients), running, tri cycle riding etc.
- It really depends on the user.
- There could be more running events. (like road races and track events)
- Where appropriate as and when an opening allows. Major events are fine but those interested in sports don't start at that level
- Introduction to running, also Pilates - in central belt location

- Do not really know
- I am go so not directly interested but events are vital to personal goals/achievements and image
- something for orthotic users. I think prosthetic users have a good profile now esp following on from Olympics. Orthotic users have v little recognition. it would need to be general disabled as difficult to limit any events to only orthotic users.
- More in Scotland
- Scotland
- While others might be providing sports training events, PORT-ERs continued involvement provides vital contact with those with disabilities on a one to one basis during practical workshops, all parties attending can learn from these sessions based on observation, feedback and outcomes and so ensures that PORT-ER is better able to meet the needs of those that need support in the future.
- LIMBPOWER 'Learn to Run' clinics. These events have been linked into the UKA and England Athletics Introduction to athletics sessions and have proved invaluable to new runners or new amputees not ready to start sport. This gives them an opportunity to take part and get expert physio/coaching and advice on stump management, prosthesis management and learning to run. This sits below any sports governing body's responsibility (pre-sport) and is very specific to amputees, therefore essential to amputees. The feedback from the attendees at the clinics that have so far taken place is exceptionally positive.
- This should be focused on interest shown in regions by use of feedback from interested parties.
- Just basic Sports training
- Since you are based in the South West it would make sense for you to continue with your running master classes in your local area. Limb power run classes throughout the UK but I think they steer clear of the South West
- If possible look at other spots using our contacts, 5 a side football for example, is there a group for this?
- Across UK for different sports not just running but

GRANTS

Each year, PORT-ER awards small development grants to user groups or other organisations delivering projects aligned with our aims. Prior to this survey, were you aware of PORT-ER grant availability?

69% of respondents were previously unaware of PORT-ER grants

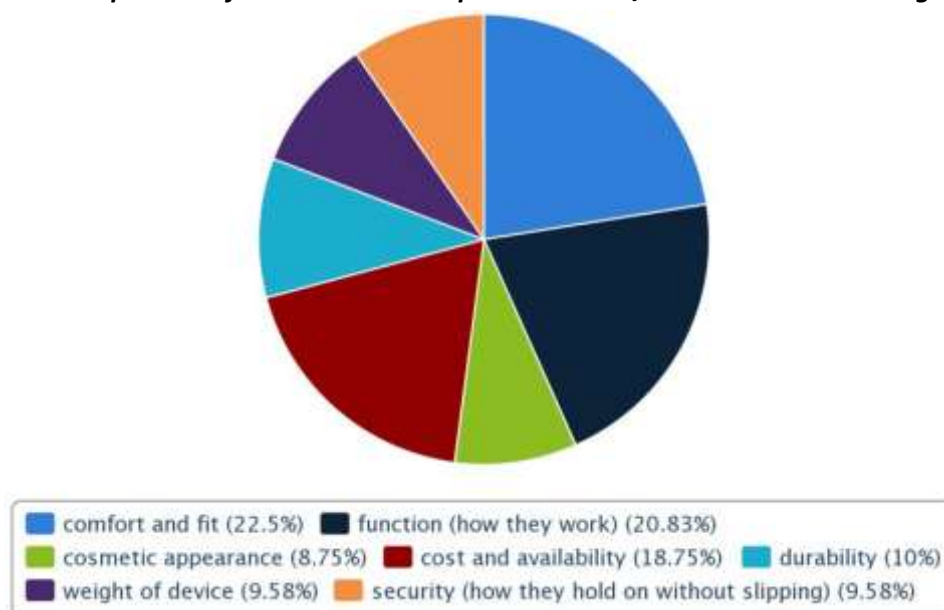


If you have applied for project grant funding from PORT-ER or from other charities or sources, please summarise what you applied for and if this was successful or not:

Respondents reported receiving grant funds from 5 organisations, including PORT-ER

RESEARCH PRIORITIES

What do you think are the priorities for research about prosthetic and/or orthotic device designs?



Other comments about research priorities.

- Places where they are going to be used, weight of a client, sex, age, number of disabilities and severities are some of the factors that affect choice bracing
- I would be so glad if more research conducted also feature challenges the prosthetists in the developing world face while discharging services .
- Professionals who design and create prosthetics and orthotics should have a special education
- Comfort and fit also implies improving patient outcomes. I believe "improving patient outcomes" is one of the most important goals. When this is achieved, most of the other objectives will fall in place.
- EFFICACY STUDIES
- I like to continue my research on socket less prosthetics which offers much higher degree of comfort, costless solutions to prosthetics.
- The device is better when a technician can modify the function easily.
- Research needed into the psychological impact of amputation, real patient experiences and ways to integrate these into clinical care.
- More info needed on what's new, how to get it and where. Arms need more focus
- Socket fit is most important to ensure comfort followed by security of fit.
- As a manufacturer it would be good to know of unmet needs in prosthetic components, even things that are believed to be not possible...
- Need research into how often orthotic devices are being worn, and how it compares to treatment times of appointments and whether there were review appointments offered. Need research into cosmetically pleasing orthopaedic shoes. Research into dynamic movement orthoses (lycra garments), independent of the company manufacturing them.
- Appearance should be the lowest priority as function has to be its purpose. If the appearance is poor clothing could be worn to hide it.
- Materials development needed