

This is being provided in a rough-draft format. Speech-to-Text or CART (Communication Access Realtime Translation) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings. The consumer should check with the moderator for any clarifications of the material.

RI World Congress
26 October 2016
Parallel B Carrick
Modern Prosthetics and Orthotics

>> Hi. We'll just wait. We'll just wait a couple more minutes and for people to finish off their coffee and tea downstairs. There were three different options-- hopefully we hear from a modern prosthetics and orthotics. If that's not what you're here to hear about,-- you're welcome to stay. We have a couple of minutes, and then we'll introduce our first speakers.

>> Okay, I think we'll probably just get started so we can allow sufficient time for Q&A and engagements. Et cetera. I'm Allison Roe. I'm from the department of health. I'm delighted to be here as prosthetic and orthotics that I represent. This is a state of the art prosthetics and orthotic. And it can be driven from a user's perspective. We're also going to hear from-- prosthetic user and experiences of both limb loss and the careers of prosthetists. We present the latest development and prosthetic fitting and the aspects of prosthetic use and rehabilitative approaches. Public and patient partners and trial designs. A Rae research network which aims to bring scientists, clinicians, industries and users to create a circular of musculoskeletal device development. We have speakers and questions and have the next series of speakers, and then-- the end we'll be open to the floor for anybody that has any burning things to ask. So without much further ado, I'm going to introduce Alex.

>> Thank you very much for the kind introduction. I'm from the University of Southampton. I'm going to introduce our first speaker who is-- our expert prosthetist. Thank you very much.

>> As Alex said, my prosthetics and orthotic in the University of Southampton-- I work as a prosthetist. I have been an amputee all my life. I have the perspective of being both service user and service provider. And I'll speak to you today about my personal experience as a prosthetic user and how it has affected my work as a prosthetist. I was born with a condition called fibular hemi-hypoplasia I can't. Where all of the fibular bone is absent. The condition has associated leg discrepancy and first and ankle deformities and knee deformity. I was born with all of the above. And my knee joint was in a flex position and had range of motion--little function and four toes with each pair of toes fused together. This coupled with leg length discrepancy meant I couldn't walk without prosthesis. In order for me to learn to walk, I was fitted at age

two. My anatomical foot made it difficult. At age 3 I had an amputation from the ankle. This left me with an ion form shape that was easy to fit prosthetically. There were attempts to straighten my knee. Then at age 8 I had my knee fused in the straight position with a metal plate. This was to create a more uniform shape that was easier to fit prosthetically. I walked with straight knee gait. As I got older and grew taller it became difficult to sit comfortably without taking my limb off. I became aware how different I looked walking. With 16 I was given the option of further amputation which allowed me to be fitted with prosthetic limb with functioning knee joint. I had had the amputation and that was the last surgeon I ever had and I now wear what is an above knee prosthesis. I grew up in the southwest of Ireland. That's effectively my backdoor. So, um, as you can imagine, there weren't many clinics close by. It was an hour drive to the next large town, and I had many journeys to the hospital. I had my limb refitted and it involved many more limb fitting. I had a normal and happy childhood. I played sports, climbed trees, jumped in puddles and rode bicycles. Although there were a lack of services where I grew up it was a close and tightknit community that provided me with supportive upbringing. Preparing for this encouraged me to delve deeper how my amputation affected me as a child. It there were traumatic days. Last count I had no fewer than nine major surgeries two of those were amputations. There were many days of pain, emotional and physical days and hard days for me and my family. I have no doubt growing up with disability left with psychological scars and left a positive mark on me as a person. The national scientific council of the developing child describes three types of stress that can affect the child, positive stress, tolerable stress and toxic stress. With the support of caring adults children learn to manage and overcome positive and tolerable stress. This stress is considered normal and coping with them is important in development of the child. It's adverse experiences but this type of stress can be overcome with support of adults. I had plenty of that from parents, uncles and aunties, football coaches to the doctors, nurses, physiotherapists I received encourage is from people. This support allowed me to-- had a negative effect on my life into something positive to help shape me as a person. Growing up with the disability gives you a different perspective on life. Days of pain and discomfort make you appreciate days without and days away from family and friends make you cherish the days with them. Learning how to cycle a bike to managing to make it up that mountain, tend to be amplified when you have disability. I learned to make use of what I had and work hard at what I wanted whether that be getting on the football team or keeping up with my friends in the school yard and going to the university to get a degree. You might think that my younger years might have been the toughest. In any first 17, 18 years were a lot of surgeries. However in hindsight I think I dealt with my disability a lot better when I was younger. I was resilient and carefree and the hard times were quickly forgotten. I struggled the most in the late teens. When I moved away from home and became independent, I lost some of the support system that got me through the younger years. I became more aware of my disability and more self-conscious. As a teenager the last thing you want is to

be different. I became reclusive and lost the confidence as a young boy. It was less likely challenge to my abilities for that matter. It was when I was around 21 that I was given advice that helped turn things around. I was walking back home, Ireland, by boss told me this, I needed to find a vocation that helped. She noticed I-- I had been there 7 years and-- she suggested I try volunteering at the nursing home. I didn't actually do that. And I didn't take heed of her advice for a couple of years. But eventually that advice began to dwell only my conscious. When I was 23 I studied in the University of Strathclyde. And thankfully they accepted. I must say it was one of the best decisions I ever made. After four years I graduated and went straight to work. For me this is a great achievement. Now's I work was a prosthetist and I've done so for the last three years.

So the prosthetist-- what I make is a process thesis or artificial limb this is the device that replaces the miss body part. I fit the artificial limbs lost through amputation. My main duties include assessing the patient's needs, taking measurements and plaster cast or CAT-CAM to proceed the design of the prosthesis.

Produce the final product, carrying out follow-up checks with patients 0 to see how they're coping with the device, functioning properly and carrying out adjustments or repairs if needed. I also work as the part of the multidisciplinary team, clinicians, three physiotherapists, two nurses, one occupational therapist, to practitioners, basically physiotherapist that have taken the place of the consultants that make bigger decisions. We have an NHS clinical lead and recently acquired psychologist one day a week, integrating her into the team. We're not seeing many results from her yet, buff hopefully that will make a big difference. Week two weekly meetings and discuss primary patients and discuss ongoing patient plans and changes in prescriptions. We're compact compartment so it's easy to have I know formal discussions with various members of the team. The reason I listed all the people in the team, the agency, how many different professions are involved in the care of one patient. There's a lot going on there. And so my clinic, I generally see five patients per day. Some patients require half an hour, others half a day. Afternoons are reserved for plaster work or the CAT-CAM model or paperwork. My clinics are varied, appointments start with a general assessment. And I'll ask a few questions to get to the root of diagnosis and issues. This leads to adjustments and repairs or taking plaster cast or computer scan if a new limb is required or socket. The majority of my primary patients are over 65 years of age and suffer from vascular disease. Others will have health issues. We have a population of young and fit amputees. After a patient has had an amputation, they will have an initial assessment to determine their suitability or prosthetic limb. A lot of patients don't progress to prosthetic limb.

Trying to give you any figures off my head just now. If the patient is suitable for prosthetic limb use, then go to primary assessment. That will be with myself process they sift and a nurse. The nurse will access the patient and general health. If well health the prosthetist will complete the assessment and take a plaster cast, computer scan. The prosthetist will design the prosthetic lick limb and choose the components. A

limb can usually be manufactured by technician and fit the patient within one to two weeks. Prosthetist will fit the prosthetic limb and make adjustments needed to make the limb as comfortable as possible. At this stage all going well, the patient is ready to start the day rehab with physiotherapist and prosthetist will be close by and make any adjustments and help out.

Effectively you have a patient for life. Prosthetic limb is a rigid and constant device. A patient may change in shape, weight and height and this will require regular adjustments to the prosthesis. Changes from prescription and lots of problem solving. Quite often a patient may have relatively simple prosthetic issues that on paper are easily solve. Buff it's the psychological aspect that can be hardest to remedy. The patient reacts differently. Some unrealistic expectations while others may lack motivation needed to make the most of their prosthetic limb. You have patients who live comparatively normal lives and rarely come to the center. I became a prosthetist because I think I can help others in a similar situation. I have the same training and professional knowledge as most other prosthetist. And I think it would be unfair for me that I have any more compassion and care than any other prosthetist. I think many patients will gain in the solace and knowledge that I have been through the similar situation as they have. Any healthcare professional will know that getting the trust of your patient will go a long way in helping treat them and solve issues. When a patient finds out I have a prosthetic limb and amputee it helps me gain their trust and from there often to keep it basically.

Patients may get encouragement that I lead quite a normal life. And having a disability isn't the end of the world and shouldn't limit you. I also have the unique position where I can try different components and give valuable feedback to my colleagues and patients. This can help when trying to slain how components work or any specific outcome the patient might need to expect. As mentioned before, we treat our patients over their entire lifetime. People can chafe a lot through their lives both mentally and physically as I did as I grew up and although disability might stay the same for many years, how far that person learns and manages to deal with that can change a lot. That's it, thank you very much for listening

>> [applause]

>> Gosh, that was fabulous. Thank you very much. Does anyone have any burning questions to ask now? Or we can wait after our speakers at the end. If you can write and speak into the mic, that would be lovely.

>> Hello. I'm from Pakistan. And we also have an orthotic and prosthetics unit where I come from. I just wanted to find out, you only spoke with lower limb prosthesis. How about upper limb? They're difficult but equally important. Missing upper limbs.

>> You're right. It can be a lot more difficult to fit an upper limb. Your hand has a lot more function than let's say a foot, relatively simple in comparison. And we do upper limb prosthetic as well. We try to spread it out. But because it's not as common and a lot of people who have lost an arm, whether it's an accidents on congenital will find better ways than using a prosthesis to do their regular jobs or get around the house.

It can often become something that's uncomfortable that's not useful for them. And we have one prosthetist who does most of the upper limb work. We're trying to take some of that away from him. He's created his own crazy miniature job for him several. It's hard because you're not get seeing most of it to get the knowledge base that he has developed.

>> I have one follow-up question. Which is that you are right that most people with missing upper arms have managed to get around their problem, you know. But downstairs, in the hall, there is a stall which was showing a functional or upper limb. Buff the cost is quite prohibitive. I was wondering how is this funded? The internet told me that it costs \$40,000. I was wonder, the lower limb is probably funded by a national health. Is the upper limb also funded by national health?

>> It is funded but like a lot of lower limb components that are kind of getting up to the higher expense categories and the one that you probably saw down there was an electronic one, you won't see any of our patients wearing them because we can't fund it. The cost of one of them is probably about one's budget for us. That's for one patient. Unfortunately we can't. And to be honest, even that component considering the cost of it, even though they will find great enjoyment using it. It's hard to get right. They will-- getting the fit of the cast and the sensors to read the buy graphical signals and getting it to do what you want to do is difficult. And it's by no means perfect yet. Yeah, and that's it. And the amount dark dash you can only wear one if you have a certain length of residual limb. Because there's so much componentry in there that you're trying to fit so much into a small space. It's quite difficult.

>> Sorry could you speak into the micro phone so we can get it on the screen?

>> You have such an expensive device for upper limb. The expectation of the patient is even higher.

>> Yeah, I think so. As well as that what we can do to meet that expectation, we can't really-- we can't come close to meeting it. Often people-- I find that people that do have them it's a novelty because it can do so many few jobs. I'll say this from when I've seen. That people who have had had it wear it for certain things. When they're going out they don't wear it for most of their daily jobs. You can do most things with one hand. You don't use the other one. The jobs you do need them for and what we can provide them isn't really you have E. up to scratch.

>> One last question and we must move onto our next speakers. We will have time to come back in the end. Thank you very much for that.

>> I'm Leslie from the University of Southampton. I ask my question as a fellow person who's lost a bit of limb. I had a traumatic injury and the thing that shocked me as a was recovering from the language people use. I was wondering have you changed your language you use with the patients. I struggle with terms like stump.

>> The only time I struggled was when I went to the university. I never heard of residual limb. I was born-- these words are the norm. So I didn't struggle with it. I can see how somebody might. Because stump.

It's really abrupt word and doesn't positively describe the way you want it. To me--

>> These are my fingers, not stumps.

>> And even being called an amputee or people who have diabetes are called diabetic, but you're not a diabetic. It lumps you into something you don't feel you are.

>> Thank you. Thank you.

>> [applause].

>>

>> I'll pause it to my colleague to Peter. He's going to tell us about some of the technologies that are available for prosthetic limbs and some of the work we've done together at the university.

>> bear with us.

>> Good morning, ladies and gentlemen. My name is Pete Wesley. I'm a physiotherapist by background. I work with a network that works with medical devices and is vulnerable-- it goes from masks to prosthetic tubes and anything attached to body. What I've been doing, with Alex Dickinson is looking at clinical engineering or healthcare issues. For healthcare issues.

Thank you. So the argument for doing research into prosthetics is an easy one to make. A growing population with individuals living with amputation. One of the big issues tends to be those who have vascular disease, some who suffered with diabetes who would have peripheral vascular disease that can progress into the need for having amputation. We have a large population of individuals who have undergone trauma. Trauma through traffic accidents but more frequently now through war-torn countries individuals are surviving with very complex wounds and complex poly-trauma. And previously if you'd had a trauma to an individual limb or two limbs, your survival rates were relatively low in the early 1900s. With modern medicines and tourniquet systems. If you lose limbs, your chance of survival is high. That leads a lot of individuals with very complex wounds and complex residual limbs to try to fit with prosthetics. As you can see, amputation can affect many body locations. Actually you need a lot of types of prosthesis and prosthetic fitting in order to provide service that can effectively return these individuals to function. That could be a finger, toe or full limb amputation.

In order to cater for these individuals, there's been huge advances in prosthetic technology. We've come from a situation where we had a simple prosthetic design all the way through prostheses that are with complicated materials and robotics. And they become a complex series of biomedical interactions to try to promote return. The challenge with this increased technology is the associated increase in cost. You'll find much of the western world has accessibility for advanced prosthetics.

Those in mid and lower income countries don't have the same accessibility. Componentry for these are getting cheaper. You're starting to see manufacturing come down in cost. You're seeing middle and low income countries having these prosthetics available. There's one critical element in prosthetics.

Regardless of how much it costs or how much technology is involved, the critical element for the prosthetic is the socket that sits at the top.

Now the socket transmits the load from the residual limb to the rest of the progression thesis for the individual to be ambulatory or be able to stand and function. A lot of the time there's a number of problems in the socket residual limb interface. A third of patients will experience pain, forfeiting, and this will potentially limit their ability to wear the prosthesis on a regular occurrence. As part of our research group, we're interested in skin health.

And the loading conditions between the socket and the residual limb can cause skin irritation and even skin wounds. And if the skin does break down in this interface, a lot of individuals will have to abandon their prosthetic limb or spend long periods without wearing it which has significant consequences in the ability to function and lead a good societal life.

So we know that this interface is absolutely critical and we know that we use expert prosthetist to try to design the best type of socket. This involves casting a residual limb and creating a mold of the residual limb to transmit the load between the residual limb and prosthesis. And depending on the fitting, often this can be a process. The first socket you create for an individual may need to be adopted one or two times. As we eluded to you before much the residual limb changes size over time. After someone has gone through amputation, the muscles that surround the residual limb will change and changes the contact conditions between the socket and the individual.

So the challenge we have is how can we use clinical engineering to help inform prosthetic fitting? At the University of Southampton, we use a multidisciplinary approach, we connect with clinicians, academic from the University and companies as well. We have an ongoing relationship with opt care and work with academic partners to transmit our findings and improve patient outcomes.

One of the areas that we're interested in and was alluded to earlier is the adoption of CAT-CAM. This is where we can use cameras to change the shape of the residual limb. These technologies have been around for many years. Buff the adoption of the technology has been relatively poor across both western countries and lower middle welcome countries. And the challenge we face is how do you create a geometry and make that information user friendly and make it have an impact on patients? The other issue we have is traditionally scanning technologies have been very expensive. So you can easily spend 25,000, 30,000 on a scanner. New scanners are becoming much cheaper so you can pick up a scanner for 300. But are those scanner accurate and repeatable. And more accuracy is required at a clinical level. We need to be measuring these residual limbs. Alex and I have worked with opt care. And we looked at five or six different scanning technologies and show that these scanners are highly repeatable and highly accurate. They can measure the shape of the residual limb in sub millimeter accuracy. The cheaper scanners lose some of the accuracy. It's still in a tolerance to be meaningful. A 300 scanner can measure--

that technology is probably applicable in the prosthetic setting.

We also want to use the scanner information to provide additional feedback to the clinicians. So we want to try and use the shape of the residual limb to inform prosthetic fitting. We can define certain points as low bearing surfaces. And we know we can trace a residual limb over time. We can track the way the limb changes to try to tie that limb with the rehabilitation and the prosthetic fitting process.

We can have a look to see if there were particular subgroup of patients, patients with residual limbs, different shape limbs and see how that relates to ambulatory or status after the operation and try to guide the clinicians and particularly the surgeons into targeting a certain shape of residual limb where possible. The other complimentary research in Southampton is to try and look at the conditions between the socket and the residual limb. So we know these tissues aren't used to taking high loads and often they breakdown because the pressure and the sheer forces are too high for the skin and soft tissues to take. So our colleagues at the University of Southampton have developed sensors that can measure the pressures between the socket and residual limb and the shear-- how much rub there is against the residual limb. And these sensors can be incorporated into a liner, typically used between the socket and the residual limb. And the ultimate goal with sensing at the residual limb interface is that can we provide some kind of early warning system to stop individuals there having their tissues breakdown? If we can create sensors that measure pressure and shear accurately, can we create a traffic light system that say, the shears are too high, you need to stop using your prosthesis for a period of time so the tissue can recover. These sensors are becoming available within certain industries and becoming much more widely available are to prosthetists as well. When they originally fit the socket, they see what pressure and forces that socket fit is transmitting and inform them to make changes.

Inform the process they sift and inform the patients as to the forces that can be a danger to them.

So to summarize, we've had great advances in prosthetic and orthotics in terms of componentry. The essentially that's important is we get the socket right with the residual limb. We have engineering solutions to CAT-CAM technology to shape the residual limb and developed sensors to have biofeedback to the patient and the process they sift to make informed decisions to when tissues might be at risk.

Hopefully as the technologies become cheaper and more available, there's far more opportunity for us to expand this technologies outside of the U.K. and around the world. Thank you for your attention.

>> [applause]

>> Thank you, that was really interesting, Peter. Do we have any burning questions at the moment? And again if you can introduce yourself and speak into the mic. Thank you.

>> Hi, my name is-- I was going to ask, you're talking about sensors that can protect the patient and the socket so that skin doesn't breakdown. Can it be used in pajamas for people who spend a lot of time in bed so they don't get sores?

>> Yes, I also work in the pressure field as well. We're very much interested in pressure mapping. It's been around a long time. But sensor that can measure pressure. The spin-off of these sensors will be in sitting and bed environment.

>> Can I ask a question? Is there such-- any space for-- new technology in this area?

>> I would even say it's a new technology. A lot of-- a lot of prosthetics are being 3D print. They are still restricted in terms of the terms that can be used and the time the print can be made from a scanning image. The milling machines that are used can CAT-CAM don't have the same accuracy as 3D printers but potentially a lot cheaper and faster at producing.

>> Thank you.

>> Questions-- in terms of timing-- we're going to be late for lunch. So hopefully-- that the questions are much more enjoyable.

>> Okay, my name is-- you dash the socket is the most crucial part of a prosthesis. We have high end-- but how the prosthetist is fitting the prosthesis is-- I would be interested in these technique you are saying. Is it already to market product? The sensors underliner?

>> The product has been validated and is becoming commercially available. The partner for that project is Blatchford. There's a strong chance it will be marketed through Blatchford.

>> Thank you. Thank you, Peter. [applause]

>> Thank you very much.

>> Thank you very much. Yes, I'm a whatever psychologist by background. And I have worked in the field of rehabilitation for quite sometime now. I have interest in prosthetic rehabilitation. I'm going to spend a few minutes. We had a little bit about the-- amputations and-- the cause of amputation. I'm just going to provide a little bit of background and think about some of the demographics within the U.K. And we can think about that more globally as well. Following on from the importance of interdisciplinary teams that we already heard about and the work that Pete has done. I'm going to talk about the holistic perspective. And use the psycho social approach as a framework for this and expand and think of issues to think about when we think about limb loss.

I'm going to provide two examples of work we used using holistic approach request in the University. Working with external companies, stakeholders, clinicians and examples in the educational research. So you've already had the different causes of limb loss.

We know that it can be congenital issues, people born with limb deficiencies. It could be through traumatic injuries. People can have infections which can cause an amputation as well as tumors and other aspects.

But within the U.K., as Pete already alluded to, the biggest cause is vascular disease and diabetes. This vascularity relates to large number of amputations that we see in the clinics there.

So what we're thinking about the percentage of the number people with limb loss, and things like that we can see that when we think about vascularity, diabetes and vascular disease, there's a lot of-- it's a huge range. It's between 3 and 9 and 7.2%, that's in 100,000. That's a quite large number of people. This equates to 60 to 65,000 people with limb loss which is approximately 5,000 new referrals a year. It's a large number of people within the U.K. If we combine this with global figures, we know that vascularity is the major cause but generally in countries suffer as Asia and the Middle East there's a growing number of people having amputation related to diabetes. So it's some component to consider. And when we think of this in terms of the statistics that we see, we have to be cautious because-- together we have problems like this in the U.K. And we're a small country compared to other countries. It's usually it's funding. People measuring limb loss at different levels. People who have congenital upper limb loss who don't access prosthetic services aren't included in the statistics. We see there's a larger referral for men. We can see that as suggested, we have a large number of older people related to vascularity. So 50% of people over the age of 65 and 20% of people over the age of 75.

So a large number of older people. Majority lower limb loss and smaller number into upper limb loss which relates to the things we've been talking about.

Forget about the demographics and think about limb loss as having an amputation or living with limb loss, we know that people can be confronted with a wide range of different factors. So when we think about it, it's the physical factors and the functional factors. We're thinking about the cause of amputation or the level of amputation is really important. Above the knee or below the knee. Whether they're-- issues related to skin integrity. All of those physical factors will impact on the functional outcomes. We talked about the not everyone will wear a prosthetic. And some of them will be down to the ability but down to choice. I recognize not everybody necessarily wants to go on and wear a prosthetic. And the individual choice is very important.

Obviously living with limb loss or having an amputation is a massive impact on body image. People will adjust differently. Parents are important as well. Important to different people. I'm thinking about the difference between upper and lower limb is important as well. People cope and adjust differently to limb loss. We've seen a research that the physical factors such as the level of limb loss doesn't necessarily impact on adjustment. It's very much an individual factor. And then of course the social situation and social support is important. We have to have that from-- I know what he was talking about, times that were difficult for him. And this can be linked to the sense of changes and self-identity and roles of people do. We talked about being a mother. Picking the child up from school. It can impact on the person's quality of life. And then we're in this world where we've got more growing sophistication and quality in prosthetic devices, the environment is important, what's available within the health care services or not. Making those predictions, thinking about it. Lower limb loss we have microprocessors available. It's not

available to everyone in the NHS he at the moment. It was supposed to be but it was put back. The environment itself is really important.

And then of course all of these factors impact on the psychological well being, thinks of levels-- we think about depression and anxiety and stress. But also more positive aspect of it, people drawing out positive meaning from their prosthetic and all those factors. So limb loss is a very individual experience. Being around for a long time now and it moves away from the biomedical where we look at things from a biological perspective and physical perspective and appreciate the fact that there's a complex interaction between these social psychological and physical factors. And we can look at it and start to think about all of the complexities. When we start to use this framework for individuals with, who have amputation or limb loss it brings to mind the person's sense of care and the approach that's really important.

Thinking about this when we look at the different factors, we can think of the biological factors, the levels and the cause. The outcomes related to prosthetic rehabilitation. The presence of-- pain in general, or phantom limb pain. It can be a huge thing for people to cope with. The support they get, all those aspects as well as general health and all of those other things, so in the U.K. when we think about the kind, the majority of people who are fitted with limb, majority of people being older and having vascularity that is important as well. The psychological factor is already talked about. Most of those but thinking about the coping and adjustment, the distress, all the different aspects as well as really taking a positive stance and thinking about motivations but also expectations. We've already talked about the fact that some people can have normal expectations. Where does it come from? There's a comment before downstairs when we were having the big talks, the fact that when people see other people with disability, there's an assumption that everyone can do it. Maybe we've seen that with the Paralympics since 2012. Societies got to see some of these fantastic prosthetics available. Everybody's different in thinking about the different needs. This is embedded in the associate logical factors when you think about the living situation. Whether people can go back to their homes or not. Prosthetic rehabilitation is an option for them. They decided to live in a wheelchair. Is their flat big enough for support sources they've got. Common sense as well that people can feel isolated. All of these cultural factors. All of the social realms and the social economic factors as well. All of this illustrates that holistic of patient is experience. We can develop the best prosthetics out there, but if the fit's not right, it's not going to be useful for people. You can say that as well. If the psycho social fit isn't right. Is it going to be useful for people?

The patient being key in all of these decision making. And we can't do that unless we really work in disciplinary approaches. And people talk about multidisciplinary. Is it-- are we working together? We might have multiple professions within a center. But how much do people interact to understand each other's worlds? This is all linked to the guidelines and the services. All things that we think about, all of the time.

What we've tried to do is not new. All of this is things that we think about when we think about limb loss and amputations anyway. But we've tried to work with our clinical partners, professional specialists, organizations to establish some care areas to work onto take forward. So once in education, we spent time developing some new courses at the University of Southampton, faculty of sciences. Facilities across the whole university. We try to make muscle did I disciplinary learning opportunities where you can do a single module and-- in amputation and rehabilitation. This provides an in-depth understanding of the patient journey right from causes for amputation all the way to prosthetic rehabilitation. And we work with our industrial partners. We have students to meet them. And our students range from experienced clinicians to the first cohorts. We have OTs, PCOs, prosthetists and bioengineering students. It brings people together to learn from each other.

We can't do isolation. It's important that we work with our external article partners and stakeholder and understand the aspect of it. And quickly the last example is the growing of interdisciplinary projects we've got that embrace this holistic framework. We come together in different groups and we've carried out work with children with limb loss and engineers, we came together as a group. Carried out a piece of research where we asked children to develop, provide us their ideas. And we manufactured prototypes of devices that they wanted. And we took them back to the children. And they looked at them in a focused group setting and that's what we're publishing now. That's really important.

We've also tried to understand a relatively small group in terms of statistics. But the lives of people who have lost multiple limb loss. We've done that in a holistic way, using participation research where the person has helped us come up with all the questions. Carrying out research while we're looking at the use of any technologies such as CAT-CAM in developing countries where we really need to understand the cultural and social needs of the group and we're using flexible approaches to do that.

So I have to illustrate the importance of holistic framework. For us it really is the force of what we're doing and what we hope to do in the future is a close integration of research and clinical practice. We work closely with clinical partners and people in industry as well. And it's the importance of this interdisciplinary approach and working and living together. Thank you very much. [applause]

>> I've used this opportunity to bring leaf let's. If anybody's interested and as well as international focus.

>> We've got time for a quick question or so before we go to our next speaker. If anybody has anything to ask, raise-- highlights. Great. There might be something at the end. Thank you very much.

>> Thank you very much. That's brilliant. Next, I'd like to introduce Joe Adams. And clinical occupational therapist. And-- examples of patient partners and developing--

>> Step away from the computer.

>> Thank you. Thank goodness for-- thank you very much. That's our first thank you.

Perfect. Um, just-- thank you very much for coming today. And I'm delighted to talk to you. My name is

Joe Adams. And I am an occupational therapist by background. But now have a professorial role. A lot of my day job is involved with doing clinical effectiveness of the control trials of the rehabilitation that is going on within the NHS on a day-to-day basis. All of our research is funded externally. So the government and charities will be funding our work. The talk I'll be giving this morning is funded by arthritis research U.K. I also have a national role with the charity as a patient and public involvement lead for a center of excellence and osteoarthritis. And this talk is being established with our leading public engagement officer who's called gem. And gem is with me-- he worked with me to produce this presentation.

I'm going to be talking about an approach to developing clinical research that starts off with our patients and our service users. And the route that we went-- the route we went through to design the control trial. And I'd like to share how we've done that. I'm going to be talking about why we engage patients in public partners in designing musculoskeletal research. Examples of how we managed to do that successfully and the benefits and challenges to that.

So why should we engage our service users in helping us to design clinical research? Now, sometime ago, professor dame Sally Davis was a chief medical officer here in the United Kingdom. And she was responsible for allocating funding for research that went into the NHS. We were delighted when she started by saying, no matter how complicated the research, brilliant the academics and researchers, patients and carriers and the public will always offer unique and valuable insights. Their advice whether designing, implementing, and evaluating research, makes research studies more credible and often more cost effective. She really led the way about involving patients and service users from the start of our research programs. And at its best, patient and public involvement in our clinical research is essential for good quality research. We know that it will lead to better questions that patients and service users have identified as being meaningful for them. We know potentially if we engage people in the start of our research design, we have studies that are designed that people want to be a part of and they agree to be a part. We can involve our service users to help us analyze the data about user experience. We know it will improve the quality and relevance for a very competitive area. We know that we are very strong in the U.K. already in patient and public involvement. And that strengthens the research that's coming out of the universities and the NHS.

And ultimately we also know that if the NHS is willing to be engaged in that research, those departments engaged in clinical research will also produce better patient care. There's lots of reasons why involving patients in the beginning of our research leads to very good outcomes. I'm going to give you examples now of a current trial that are running on thumb base-- thumb based host yo arthritis. And the host yo arthritis. The examples from the beginning when we designed clinical effectiveness of randomized clinical trial in the effectiveness of improving orthotics for people who have osteoarthritis in the right of the base of their thumb.

I'm looking to our leader here because I've noticed that she's wearing a splint. We wanted to design a randomized control trial that was able to identify what patients and our service users said really mattered to them.

Now in clinical research we can offer, measure things very reliably, very precisely and effectively but they're not always the things that matter to patients who have the condition. So we wanted to start off. We wanted to say to the people who had thumb based osteoarthritis what is important to you in this clinical random trial?

We also wanted our patients, we wanted to test interventions. We knew what the NHS was already providing. But we wanted to ask our patients, what do you think should be provided so we can test what you think should be there right from the very beginning. And for the very first time, in a randomized controlled trial. We wanted to develop a venue type of splint that wasn't going to use biomechanical to mobilize hand joints. We wanted to design a splint that was allowing the joint to move. And I don't have thumb based osteoarthritis. So the first thing that I wanted to do, very beginning was to run focused groups with patients to ask them A, what they wanted us to measure; B what type of intervention they wanted us to evaluate for the NHS and help us design new splints for our trial. The first stage we wanted to run focused groups. The second stage, I wanted to get a national group of patients who were interested oncoming onboard with your reserve.

And I wanted to hone down one intervention and do that with clinicians but also with patients. It's not just clinicians saying, this is what we should be researching. We had an equal voice for patients to say, this is what we think you should be researching as well. The final change is trialing a randomized trial.

Right from the beginning we published this in health expectations. It's the first time that we are aware that it's been the patients that have designed right from the outset. We didn't have any engagement with industry at that time. We started with patient. Asking what do you want? Can you help us design it? That was our starting point. Before anything else we went to our patient groups.

The next stage, I went into a little arthritis magazine that tends to sit in doctor dash calendar in the waiting rooms. I put a two line in there and I asked, do you have thumb based osteoarthritis. And would you like to design research. I was inundated. I had 150 people respond. Yes, I have hand pain and I would like to help you. I had automatically established a national database of people who were really willing to help us as researchers carry out our research.

We engaged those people alongside our professional colleagues who were treating these individuals in the NHS to define how our trial should look. And we gave equal weight to whether or not somebody was highly skilled, extended scope practitioner in osteoarthritis or whether or not they're an individual who just started osteoarthritis to help us define our interventions.

The final stage, when you do a clinical trial in the NHS, there's a lot of information that has to go out to

patients who agree to take part in the study, to consents. We wanted to make sure that all of our information was written in clear, simple language that people could understand. And as academics we're very bad, we're good at making scientific things very complicated. We're very bad at making that language simple and straightforward so everybody can understand it. And our patients groups helped review our information to make sure it was written on an appropriate age.

I just want to finish off to summarize that some of the benefits and challenges that have been identified from doing PPI. Some of the challenges, and I have to say the group I work a lot with, rheumatologists, and I have a huge respect for my rheumatology clinicians I'm working with the occupational therapist is and physiotherapist because they're signed up in engaging patients in our clinical design. There's work done that look at other people's responses to engaging service users. These are some of the things that people say, some of barriers that we would face as researchers to engage in people.

Sometimes some individuals will say that we can't have service users helping us design this very expensive clinical research. They're not academically able to do so. They haven't done a PhD. They're not trained as a researcher. They may be bias. And the patients involved are not representative. So we would tend, and I agree with this one, that we very often will tend to recruit people with bright, articulate, rather than being very accessible to people with different backgrounds. And the traditional barriers within the NHS and medical-- about giving equal rights to patients to participate. The benefits we have, I see this ten fold, if we design our clinical research with patients and service users right at the beginning, we have research that is meaningful to the people that it's purporting to serve. It's not what I think as a professor. It's about what the individuals with the condition feel is important. We're more likely to recruit time and target for our trials. We get heavily penalized if we have public funding to support our trials. We have to deliver in time and target. We have much more representative research findings, are able to recruit patients into the trials that are not just the bright, intellectual individuals. We have a range of individuals. And we work closely with our patient reps to help us disseminate clinical complex-- to lay groups and lay summaries. We're indebted to our service users for helping us with that.

And I'm absolutely convinced and sold on the idea. But I think right away through the research process, if we involve our patients and service user from the beginning, we know that our research is going to be meaningful, accurate and able to engage more patients and service users to come onboard clinical effectiveness trials which will support our rehabilitation continue to be funded by the government in the NHS.

That is-- I'll be happy to talk to people after the session if anybody would like to ask questions. And I just want to finish with that quote. Because when I was thinking about something to round off, I really like this Henry Ford quote. Coming together is the beginning, keeping together is progress, and working together is success. Thank you very much.

>> [applause]

>> Very interesting. So have we got any questions for Jo before I bring us onto our final speaker? We do have time for one or two. Can you introduce yourself and speak into the microphone. Thank you.

>> Thank you for your excellent presentation. And orthopedic surgeon from Bangkok Thailand and a hand specialist and hand surgeon. I think it's something different to have public and patient to be involved in the kind of research. I wonder, this research has going on and you have the results of this research right now?

>> We have the result of our-- this preliminary was funded for two years to design and develop national randomized trial. We have our pilot results. I'm happy to talk about our pilot results. And we're funded for another half a million pounds to conduct-- we start recruiting in January to carry out a full round randomized control trial at the-- looking at the clinical effectiveness of mobilizing in osteoarthritis. We're threw ethics. We'll start recruiting for that in January.

>> That's very exciting. Thank you very much.

>> I'm looking forward to talking to you afterwards as well.

>> Bring on our last speaker, Alex.

>> So we're going to time-- we're going to finish just in time for lunch.

>> Thank you very much. On behalf of the institute of life sciences at the University of Southampton. I want to tell you how to coordinate on musculoskeletal schedule across the university. It's a unique network connecting clinicians and researchers and end users to improve musculoskeletal schedule health. This talk will-- developed model and example of the prosthetic and orthotic research we have underway. So we're faced with a major challenge in musculoskeletal schedule disease. It's a burden on society and economy and individuals of all ages around the world. Conditions include osteoarthritis and-- it's a growing-- we heard the statistics on amputation. In the U.K. alone we have rip-- we need to replace the replacement and revision surgery. That's common replacement in younger patients. In osteoporosis. The cost of the NHS is 2 billion pounds a year for treating hip fractures. One women in three and one man in five is to experience this. We've had had Santa tick ticks in diabetic amputations. It's estimated by WHO that over 100 million all over the world is treated. WHO also suggests that between 85 and 95 percent of these people don't have the access to the PNO they need. In the University of Southampton we have a unique capability in musculoskeletal schedule research. And our target in this activity was to coordinate 50 researchers and clinicians in University and hospital and many more in the local area. At the institute of life sciences our-- interdisciplinary vocational network in orthopedics, prosthetic and assistive technologies. The first thing we did is have musculoskeletal schedule research in the university. Engineering health sciences, medicine and electronic-- we grouped the research activities in representing components which is the fundamental science levels. Limbs in the psychological level and the individual

which is the human device interactions level. The key activities include growing and replacing hardened tissue. 3D scaffold is a way to deliver those stem cells. Analyzing failed implants and advanced imaging technologies how to understand how they're interacting with the body.

Looking at limbs in prosthetic and augmentation, we're involved in the design. And the work Peter presented earlier. Which is optimizing prosthetic limb fitting. Terms-- presenting what happens in the prosthetic phase and computation engineering. So we can reduce the clinical and animal tests we need to perform.

Finally looking at the individual. We're interested in biomedical mechanics. And worn sores and these devices in robotic therapies. And user driven design and psycho social issues. Next we conducted a matching exercise. Within one hour of Southampton.

We found the central south of England-- 30 companies, five governmental research organizations and a range of bodies providing enterprise and support of government. And incubation to start our businesses. Try to harness this local network, we designed-- which is an ecosystem which we coordinate user needs driven musculoskeletal health product development.

So we want to create a virtual cycle of feedback to link the user and clinicians in these three main areas of expertise that we identified. Our first approach is to understand their needs. We link the needs to the expertise at the university, the hospital and local industry.

Third, we exploit a broad range of to ensure translation of clinicians and service users. This include policy makers and professional body to ensure the economic benefits can be achieved. These activities are interconnected to the product and patients, involvement concept. And we keep reiterating through this development process to make sure we work toward meeting that user need. To establish the network we contacted the local companies and surveyed the university researchers to understand their international and collaborative links. We invited them to launch events in six 2016. It indicated that they want to be part of that. And the momentum that we're able to build in the first six months. The center of gravity might be Southampton but we have partners across Europe and Southeast Asia and looking towards South America.

So with the input from our network we identified these are our core work streams. The core-- and these things give us the flexibility to address a broad range of new probes but retain focus for the objective, for the benefit of the service users.

So as one example, we were approached by the prosthetics industry. I'd like to tell you more about it. The industry and clinicians have identified the need for the-- this is by all the parties involved. As explained by previous speakers, it's an is-- there's great variation in the user's requirements. And the fact that we're combining a wide range of prosthetic together. You think you tested one to generate the number of individuals who are using that. Testing those components in the same way is very difficult.

It's difficult to untangle the benefits of any individual technology and take a more objective approach. So our argument was that a big data registry for lower limb prosthetic would help clinicians optimize their practice and monitor and monitor treatment selection for the individual patients. It would help the industry to iterate design for human trials and it would help the healthcare providers to access the benefits. So the case could be made for more funding for prosthetic limbs. Our industrial advisers recognize that this needs to be an independent exercise. One of the gentleman recommended this study to us, had a nice quote. The problems that users face is complex and multi-facetted that we need to pull in the expertise. The ideal organizations to address the problem.

So far we mapped the problem out and identified the system requirements to see how they would vary with the different users. This forms as part of a much more complicated diagram. I simplified this five times. It's an effective solution to this problem is complicated. But it depends on the participants. We use a data base that has four portals for the user, clinician, user and researcher.

and to view larger population reports so they can understand their rehabilitation progress. For example and take ownership of their prosthetic treatment. The clinician in the industry portals are separate but linked. Clinicians will be able to appraise their practice, take an evidenced based approach. And the industry will be able to obtain large cohorts in appraisal of their products help justify. There's a huge research in the database. Researchers often struggle to access information. This will provide-- reports easy to access access. This project is as a whole are in the early stages of development it shows the fundamental importance of combining the end users with the enterprise and clinicians in the research. If we keep our activities linked with input of the community we will be able to maximize our impact. This-- sums up the spirit of our approach. The greatest advantage is in the collaboration.

And that's where you come in. So we welcome, we're keen to welcome new members, if you're a researcher, clinician, a member of the public, a pom maker or if you work in the industry. If you share our vision, and you want to help the musculoskeletal schedule research, we want to hear from you. Visit us. As you can see-- directly outside the window to talk to us and leave us your details. And we have a website which is Southampton-- we've been chastised back home that we're not receiving much hits. We appreciate if you visit and you can take home a little bit of this information and see links to some of the research we've been talking about today. Thank you very much indeed. I'll hand it back over to Allison so you can continue moderating if you like.

>> Thank you very much. [applause]

>> Thank you, Alex.

>> That was greet to have all-- that was a really interesting talk. Thank you. So we do have a few minutes before lunchtime. If anybody has any questions for Alex our last speaker or indeed any of our previous

speakers. I'm sure you'll be happy to answer-- if you want to introduce yourself.

>> Hi. I'm here as a public-- osteoporosis. How do you likely that it will come together within the next two years or so to be-- adult models-- the hospital I was working with universities and industries, combine --.

>> The success is a challenge. But I think we're trying to talk broadly about the model as we possibly can and to involve as many people at the high level in policy as we can so that we make sure we're doing the right thing so that we have the best chance at that. If he anything to add to that.

>> So that is one of our next goals to try to get policy makers. We left it at this point because we thought we had a solid foundation. We're creating a dynamic foundation. So stay tuned.

>> Thank you.

>> Any further questions for any of the speakers that you heard this morning? Um, and if not, I'm sure you'll be able to catch them throughout the rest of the day here.

>> Can I just ask for a final-- to all our speakers who gave a wonderful insight this morning. Thank you.

[applause]

>>

>> I think we're finished with a couple of minutes to spare. Enjoy the rest of Congress. Thank you.

>> There's pamphlets in the front.