TELEMEDICINE FOR ADULTS WITH COCHLEAR IMPLANTS IN THE UK: EMPOWERING PATIENTS TO MANAGE THEIR OWN HEARING HEALTHCARE

A team from University of Southampton Auditory Implant Service (USAIS) has been selected by the Health Foundation, an independent charity, to be part of a £3.5 million improvement programme. The Scaling Up Improvement programme supports seven projects in the UK to take their proven health care interventions and approaches and make them work at a larger scale to have a positive impact on patient outcomes.

The initiative from the USAIS will roll out successful telemedicine tools for adults with cochlear implants across the UK. Helen Cullington, Clinical Scientist at USAIS and Project Lead said, “People with cochlear implants need lifelong follow-up at one of only 18 centres in the UK. We are going to scale up a successful remote care pathway, and offer the improvement to all centres across the UK. Patients can choose to use a personalised online support tool, home hearing test and support to adjust devices. We hope to see more empowered and confident patients, better access to care, stable hearing and a more efficient clinic.”

The programme will run for two and a half years and each project will receive up to £0.5 million of funding to put their project into practice and evaluate it.

Sarah Henderson, Associate Director from the Health Foundation said: “We are very excited to support seven outstanding project teams who have been selected because of their expertise in scaling complex improvement projects, and their ambition to achieve impact by improving care for patients. Working together, as part of the Scaling Up programme, we aim to make sustained improvements to health care by testing out proven interventions at a scale. We hope to see the interventions being widely adopted across the UK.”

The University of Southampton Auditory Implant Service will lead the telemedicine project and will work in partnership with a wide range of organisations to deliver the project, including the University of Nottingham, Newcastle University, Wessex Academic Health Science Network, The Ear Foundation and the National Cochlear Implant Users Association.

Find out more: http://ais.southampton.ac.uk/research-consultancy/remote-care/
Yesterday I attended the Auditory Implant Service and my implant was activated. I had set no expectation level as I am very aware that every implantee has an ‘individual’ response to ‘switch on’. Some only hear ‘beeps’ for a number of weeks; some only hear ‘white noise’. Some hear ducks and others chipmunks and some echoes. This is what happened to me:

The first revelation was hearing my own voice – it is like ‘Sparky’s Magic Piano’ for those of you who remember that. BUT whatever it is, it sounds like words!

I also knew that in time, the electronic sounds will become more natural (thank goodness for that as it is hard to take Paul seriously with a voice like Sparky’s Magic piano!)

I am truly amazed, feel very lucky, and am hugely motivated by my experience. I know I am a half-full gal and tend to see the positive where possible. I also know that I am one of the lucky ones who is getting immediate benefit. HOWEVER, attitude and luck aside, it really is wonderful just to hear.

On a light-hearted note: after two hours of CI stuff, I needed to visit the ablutions and what a shock to hear ‘wee!!!!’ (sorry) and then to jump out of my skin at the sound of the hand dryer. A loosie’s reversing alarm had me running for cover, I suppose that is the idea.

At home now I am enjoying the sounds that a home make but I am under no illusion that the electronic sounds it sounds like words!

The confidentially quiet remark of a passing colleague.

In the world outside you forget the noises. No-one else can hear them. The noises are inside your head.

Deafness creeps up on you. Slowly it seeks to silence you. And yet in solitude all is silent.

The wind whistles in the wires above and rattles in the rigging. You are alone.

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The wind whistles in the wires above and rattles in the rigging. You are alone.

When others laugh, you smile lest they think your humour is lacking. You hesitate when the phone rings and relax when the voice is clear.

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NEW HEARING AID TECHNOLOGY FOR Naida Cochlear implant users

The Naida Link hearing aid has been designed for single-sided Advanced Bionics Naida CI users who have some aidable hearing in the other ear.

For single-sided Advanced Bionics Naida CI users who have an unable hearing loss in the other ear the Naida Link CROS captures sound from the non-implanted side and transmits it to the cochlear implant.

Both of the above devices work together with the Naida CI, and share features and controls to create a sense of binaural hearing. These include new features ‘duo-phone’ (which streams a telephone signal to both ears) and ‘Stereo-zoom’ (for listening in noisier environments).

We are working with the manufacturing company to have this technology as an option for new patients in the device kit. For existing patients the technology is available at some local audiology departments (we are able to offer support in obtaining and fitting the devices) and we are currently finalising a pathway at USAIS. You are welcome to contact us to see if the technology is appropriate for you.

For more information contact:
Robert Baughar (NHS Lead for Naida technology) or Nicci Campbell (Self-funded CI Team Lead) E: ais.plus@soton.ac.uk

SELF-FUNDED UPDATE: GOOD NEWS

We are delighted to inform you that:

1. The NHS England Specialised Commissioners have agreed to fund the yearly care and maintenance of our self-funded cochlear users after the first 12 months; provided you are registered with a GP in England. After the 12 month review appointments you will be transferred from the Self-funded Team to one of our NHS Locality Teams at USAIS, based on your address. The care you receive will be exactly the same but you may have different staff members assigned to your care.

2. We are now also offering a second side self-funded cochlear implant to adults at USAIS who already have a cochlear implant and meet our self-funded cochlear implant criteria.

For more information contact: Nicci Campbell (Self-funded CI Team Lead) E: ais.plus@soton.ac.uk

TECHNOLOGY, STOCK AND EQUIPMENT

NEW COCHLEAR PROCESSORS

Cochlear have introduced two new cochlear implant speech processors which we will soon be offering to suitable adult and paediatric patients. The first is a behind-the-ear processor called NuCluse 7x which is able to stream music and telephone calls directly from compatible Apple devices such as the iPhone. The second processor – Kanso – is an off-the-ear solution. Both new processors can be used in tandem with an iPhone. The second processor – Kanso – is an off-the-ear solution.

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LOST OR DAMAGED PROCESSORS

We love hearing about the busy lives of our patients. Shirley and Davelin in Spares and Repairs have regular updates via email from some of you whilst out and about and we’re always happy to supply you with equipment when needed.

We do though have one request. Please protect the processor as much as possible from loss or damage. Normal wear and tear is covered by manufacturer guarantees but damages deemed outside of warranty conditions, and all lost processors, have to be replaced using the same money that we have set aside for our normal spares and repairs service. The average processor costs £6000 to replace and over the year this can really eat into our budget. In September 2017 alone the spares and repairs team had to send out 60 replacement cochlear implant processors.

Most processors have extra retention and waterproof options that will help if you are taking part in sport or outdoor activities. Please get in touch if you want to investigate these for your processors.

BCHI NEWS

As an alternative to using a softband long term the Cochlear Sound Arc is now available for Baha 5 series users. Patients can contact us if they wish to consider this wearing option but will need to come to the clinic to have the Sound Arc fitted.

MY JOURNEY TO SYNCHRONISED HEARING

BY CHRIS SATCHWELL

MY JOURNEY TO SYNCHRONISED HEARING

By Chris Satchwell

My hearing failed with age. An NHS referral to ATS for a CI failed, because residual hearing in one ear was too high. After three more years of fully-sustained residual hearing I swallowed hard and went down the self-funded pathway. This began with conversations with USAIS. I knew of longer-term work to try to find a biological cure for my type of age-related deafness, so was interested in a single implant only. These conversations also covered the choice of implant, which included the idea of a synchronised hearing aid (Phonak Nadia Link Hearing Aid) which was being designed to work with the Advanced Bionics (AB) implant to improve binaural hearing.

After implantation, I wanted to benefit as quickly as possible. Experience with mathematical brain models leads me to believe that efficacy in training depends on the ability to associate sounds with words and, for fast learning, the quantity of training is more important than the time over which it takes place. With those thoughts in mind, for around three hours a night, I used proprietary devices to stream very clear sound signals from a TV to my hearing aid and CI, sub-titles and lip-reading to associate those sounds with words. Views on how CI training should best be conducted vary, but this regime worked for me.

I later followed USAIS’s advice to listen to a car radio (when safe to do so) to improve the ability to cope in noisy environments. I’ll say more about these environments when I come to the Nadia Link Hearing Aid’s stereo-zoom, which brings me to a good point to introduce the capabilities of this exceptional hearing aid.

Traditional un-syncronised aids typically deliver sound at a slightly different time to the CI, leaving the brain to try to make sense of separate sounds in separate ears at any instant in time. A synchronised aid communicates with the CI such that both deliver the same sound at the same time, just like natural hearing. For me, this was a case of not realising how much I had lost until I discovered synchronised hearing. I could see the world clearly. It may seem trivial, but it isn’t, and when combined with the aid’s other features, my hearing experiences have been greatly enhanced.

Unlike my previous aids, when the new technology Nadia Link Hearing Aid was being fitted, there was a great deal of unstorted amplification available beyond any level I needed for comfortable hearing. Within a few days I was getting used to it: living in a much noisier world, hearing how badly my floorboards creaked, picking up the middle two consonants of the BBC South presenter Anjana Gadg’s surname and understanding my car radio at a lower volume. In conversation when walking in company, I no longer needed a companion to walk on the side of my CI.

About five days after fitting, situations that normally found difficult through echoes became much easier.

The Nadia Link Hearing Aid offers a number of ways to improve musical appreciation, synchronisation and better amplification for melody and more unstorted amplification to capture a much truer sense of volume. Its features include a duo-phone (to enable a phone to be heard in both the CI and aid), echo block and stereo-zoom. The aid is so good that the echo block is rarely needed. Stereo-zoom is far ahead of anything I have used in the past. Three weeks after fitting, I used it to enjoy a seventy-five minute conversation in a noisy coffee shop. I was listening to the CD output whose inputs were primarily the TV but occasionally the output of a “noise” CD from a CD-ROM player. USAIS and AB looked into my problems, for which I am grateful. These problems were all resolved by plugging the TV Link directly into the TV’s analogue sound output. Among lessons learned were (i) when a TV Link takes its output from a sound system, it may work well when streaming to a CI alone but not when streaming to both a CI and aid, and (ii) when building or changing a sound system, start by connecting the TV Link to the TV directly and check for any degradation of performance as it is built or changed.

In summary the combination of CI and Naida Link Hearing Aid is a very long way to recapitulating the natural sense of hearing I enjoyed when I was young.

“My journey to synchronised hearing brought me to a good point to introduce the capabilities of this exceptional hearing aid. Traditional un-syncronised aids typically deliver sound at a slightly different time to the CI, leaving the brain to try to make sense of separate sounds in separate ears at any instant in time. A synchronised aid communicates with the CI such that both deliver the same sound at the same time, just like natural hearing. For me, this was a case of not realising how much I had lost until I discovered synchronised hearing. I could see the world clearly. It may seem trivial, but it isn’t, and when combined with the aid’s other features, my hearing experiences have been greatly enhanced.”

A SELF-FUNDED CI USER’S EXPERIENCE

At USAIS we also offer a self-funded service for adults who could benefit from cochlear implantation but do not meet current NICE criteria. Their journeys show many similarities but also differences to the majority of our NHS-funded patients.
Hi, I’m Michael, I work in the assistive technology field, part of my role is helping people with hearing loss by providing information about wireless accessories that might help in a work or educational environment. This includes evaluating new products and finding solutions to overcome communication barriers which are mostly connectivity issues.

Prior to having a cochlear implant I wore hearing aids as I am profoundly deaf in both ears but I had to stop wearing one of my aids eventually as I was gaining very little benefit. I really struggled with listening, so I stopped talking with most people and found the wireless accessories I had previously used were not giving me any benefits either. Since having my cochlear implant and the Cochlear Nucleus 6 sound processor fitted I’ve experienced amazing changes, I can now communicate with almost anyone and I hear lots of new sounds which I find fascinating. Recently I finally went under water using the silicone coat (Aqua+) and was amazed to hear bubbles and muffled voices.

The only downside to using my cochlear implant is that it’s even communicating in noisy environments or making voice calls but I find the MiniMic is very useful in these types of situations, particularly at work. The MiniMic allows me to connect with Skype, webinars or online videos, small meetings and presentations.

One time I had a Skype call with a client to discuss a technical issue on software which was brilliant as I was able to understand most of what the client was saying. I explained to the client about my hearing loss and asked him to speak a bit slower - he was a Londoner who was used to speaking quickly. I was on a noisy platform at a train station, talking to a member of staff at my work office, and I was able to hear the main key points of the conversation after I set the Phone Clip up correctly. The other benefit I found with the Phone Clip was listening to music wirelessly as previously, if I used ear hooks or headphones, they would pull my ears. I do still struggle to hear all the lyrics unless I re-arranged them and if the conversation was random I would probably struggle a little bit unless I’m familiar with the topic.

The other advantage of using the MiniMic is connecting miniature receivers such as the Roger X6s the eustropia when evaluating or testing equipment. Also it allows me to expand the wireless microphone range if I were to attend a large meeting.

The USAIS Telephone Handling Handbook is a file containing all kinds of tips and advice and a series of practice exercises that you can try out, either with family and friends or with a member of the USAIS team. The Handbook also outlines the different technology that is available, for example, specialist telephones or items in your kit, and gives a rundown of listening strategies that you can use to help manage calls more effectively. You may find a phone with amplification and tone control helpful or maybe using your telecoil (T setting) with a compatible telephone improves the incoming signal for you. Some people who use cochlear implants with the telephone like to use a Bluetooth streamer or a headset/phones. Speakerphone is also a good option, particularly if you also have a hearing aid.

Telephone Handling Workshops run regularly throughout the year and a number of different telephones are available for you to try in small group. Learning with others in this way and having the opportunity to practise a short telephone call really helps to boost confidence - let us know if you would like to come along and we will add you to our waiting list, we will be organising the workshops for the first time next year.

One way of building your confidence is to listen to recorded messages or on the telephone where you don’t have to actually have a back and forth conversation. You can practice finding the right positioning - remember where your processor’s microphones are and hold the receiver to this area, it can be quite tricky until you get the hang of it. You could try ringing the Speaking Clock or this specially recorded message on 02380 76598617. You will hear the dulcet tones of our Customer Service Manager, Ed Heard and the following passage. Why not give it a go!

You will hear one ring and then the following passage:

A large, strong dog was specially raised in the Swiss Alps in Europe. It grew to have a thick brown and white coat. The dog was called a Saint Bernard. It was first trained by monks. They lived in a mountain shelter called the Lodge of St Bernard. The shelter was for hikers and skiers.

The dogs were trained to help patrol the snow covered trails. They were trained to search for people lost in the mountains. They would drag or lead them back to the shelter. There they would be taken care of by the monks.

The monks soon learned that walking or lying cold in the snow caused people to become very thirsty. So they tied small kgs of water or not of alcohol around the neck of the Saint Bernard. In the case of the person being able to walk, a tsp could be taken to restore energy. If the last person was not awake, the Saint Bernard would drag them to the lodge. If the person woke up during the journey, he or she would take a sip from the keg while being taken to the lodge.

Congratulations to Harry Sherman who was selected as the mascot for Southampton Football Club in their match against Manchester United in May. Football fan Harry was joined at the game by his family who described the whole day as a “wonderful experience.”
The latter aspect is what allows children to access speech, language and optimal communication in all areas of life: education, social, home. We need to ensure that changes to Audiology pathways do not adversely impact the Rehabilitation elements of the service.

This project has the potential to alter the paediatric cochlear implant service to make it more specific, individualised and needs-led. For the service users and families that may want an alternative care pathway, they could benefit greatly from having to make fewer trips to the implant centre. This would limit the amount of disruption to work, school and family life, while still providing support to those service-users. Also, by encouraging and supporting self-management, this could empower and motivate parents to manage their child’s hearing.

The information gathered from this project will give an understanding of the first-hand experiences and needs of those who use the service (i.e. parents and carers). This will ensure that any steps taken to alter the current pathway is shaped and guided by those needs. By finding out the views of parents, we gain an insight into the real-life application and experiences of the service.

Future plans
We aim to use focus groups to get a broad view of parents’ thoughts on alternative pathways and the potential impact of technology. We will then create a questionnaire and parents will be asked to indicate whether they would choose the alternative care pathway or usual care. Of course, we realise that remote care is not for everyone. We would like to offer care to people in the way that suits them best.

TELEMEDICINE AND REMOTE CARE FOR PEOPLE USING COCHLEAR IMPLANTS

COCHLEAR IMPLANT CARE: PUTTING PATIENTS IN CHARGE

This summer has been very busy for the team behind the CIRCA project. The head of the team, Helen Cullington, has presented at numerous conferences and received much interest about the work in remote care for people with cochlear implants.

Helen presented at the Third International Meeting on Internet and Audiology, held at the University of Louisville in Kentucky, USA. You can watch this talk by visiting http://v.ht/remotecarelouisville

She also visited Harrogate to attend the annual British Society of Audiology conference. You can learn more about remote care for people with cochlear implants from this presentation: http://v.ht/remotecareharrogate

In June, Helen headed over to Paris for the IFOS ENT World Congress, where she spoke about telemedicine and the purpose and outcomes of the remote care approach to Audiology pathways. You can find out more about how we are implementing this here: http://v.ht/remotecareparis

Helen also presented at the National Cochlear Implant Users Association, explaining the purpose and outcomes of the remote care study and what the next steps for the project are. We are delighted to have received funding from The Ida Institute for a study looking at how we can use online tools to help people prepare for their cochlear implant assessment appointments.

STAFF UPDATE

Stephen Wetherill has joined us as a PhD student in collaboration with the Electronics and Computer Science faculty at the University of Southampton. He will be exploring the computer science aspects of telemedicine for people with cochlear implants.
HOLIDAY LOANER SCHEMES

Are you planning to jet off over the holiday period?
Are you wondering what to do should your processor fail whilst you are away?
Just to remind you that there are Holiday Loaner Schemes available from each of the cochlear implant manufacturers so you can ensure you can enjoy your holidays every day you are away.

For more information contact:
E: ais.repairs@soton.ac.uk

MRI SCANS

Most of us will now have at least one MRI scan during our lifetime. If you or your child with a cochlear implant needs an MRI scan, it is important that the radiographer knows in advance about the cochlear implant as they will need to make some changes to the normal procedure. This is because the MRI scanner creates a large, powerful magnetic field which will act on the internal implant magnet.

When you are told you may need an MRI scan you should contact USAIS to check the safety requirements for your model of cochlear implant. Most of the newer models of implant have been tested to be safe to scan up to 1.5 Tesla without removing the internal magnet. However, some of the older models are not recommended for MRI scanning at all.

Each of the cochlear implant manufacturers has their own set of written guidelines that we can issue and it is important that their advice is followed carefully. Contact all manufacturers, the external processor will need to be removed before going in to the scanning.

REMINDERS

Vaccinations
All people with a cochlear implant should be fully vaccinated against pneumococcal bacteria. Current government advice:

→ Adults should be vaccinated with the PPV vaccine (pneumovax)
→ Children under 2 are covered by the vaccinations in the childhood immunisation programme (PCV series)
→ Children over 2 should be vaccinated with the PPV vaccine (pneumovax)

If you are unsure of your (child’s) immunisation status please contact your GP to check.

Is your child changing school?
Please let us know so we can ensure your contact details are up to date.

Facebook
If you would like to keep updated about our service please follow us on Facebook.

Unfortunately our staff are unable to accept personal friend requests from patients.

For more information:
Follow us on Facebook:
University of Southampton Auditory Implant Service

DO YOU HAVE ANY GOOD NEWS STORIES OR EVENTS FOR OUR NEXT NEWSLETTER?
Contact Coral: E: ais@soton.ac.uk

STAFF NEWS

CONGRATULATIONS

Dr Nicci Campbell who has been nominated for a prestigious Times Higher Education award for Most Innovative Teacher of the Year. Nicci has developed an unrivalled reputation for excellence for her education in the area of auditory implantation at Southampton, which enhances, and is enhanced by, her clinical patient care commitments.

GOODBYES

Farewell to Marie Langford, Clinic Secretary for the Central Team, who has retired after 10 years at USAIS. We wish Marie the very best for her retirement.

CHARITY OF THE YEAR

Last year USAIS raised over £700 to support their charity of the year, Fisherman’s Rest. The team have now voted for a new charity of the year for 2017/8.

We are pleased to announce we will be supporting DeafPLUS. We look forward to working with this wonderful deafPLUS charity which has already established strong links with the centre.

OUR MISSION, VISION AND VALUES

Our mission, vision and values are at the heart of everything we do. We recently displayed these in the clinic area with staff signatures alongside to show our commitment to them.

Find out more:
www.southampton.ac.uk/ais

LETTERS

Thank you
For more information contact:
E: ais@soton.ac.uk