

CUH Patient and Public Involvement Spring 2024 Newsletter

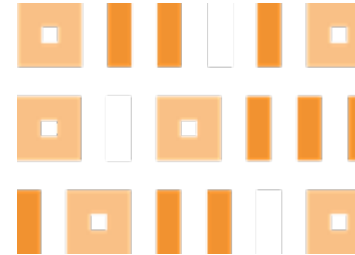
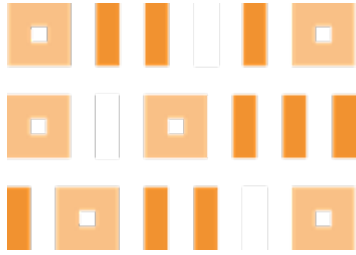
News and updates on PPI in the East of England



Welcome to the Spring 2024 edition

We invite you to mark your calendars for our upcoming events, webinars, and gatherings, whether they be virtual or in-person. This quarterly update is your key source for the latest news on local and national events, PPI developments, engaging research articles, and much more!

Please email cuh.ppi@nhs.net to update your choices if you would prefer to be removed from our subscriber list.



Research Information talks 2024

We recently hosted research information talks by Cambridge researchers on the following topics, which will soon be available on our YouTube channel:

- **Professor Roger Barker**
What Is Cell Therapy?
Delve into the promising field of cell therapy and its potential to revolutionise medical treatments.
- **Dr James Whitworth**
Identification of Genetic Cancer Predisposition and Why Mosaicism Can Make It Difficult
Understanding the challenges in identifying genetic predispositions to cancer, with a focus on the complexity introduced by mosaicism.
- **Dr Elena Raffitti**
What Are the Most Common Statistical Methods for Healthcare Research?
Gain insights into the statistical tools that drive contemporary healthcare research and how they are applied to real-world data.

These talks are open to anyone involved in research across Cambridge, and the links will be shared with both CUH PPI panel members and public involvement and engagement staff in our network.

What research information talks would you like to see next?

Please email cuh.ppi@nhs.net with any ideas, suggestions, or requests for information talks.

Check out videos of some of our previous talks:

Gut-brain interactions: hidden dialogues <https://youtu.be/FTa66Zhlhyk>

- Advances in our understanding of how the gut communicates with the brain have highlighted the importance of gut function in overall health and neurologic disease. Anchored in her work in Parkinson's

disease, Dr Marta Camacho will explore relevant factors, tools and insights on the gut-brain axis that could be integrated in research and in our daily lives.

Clinical Academic Posts – Value for Research and the NHS? <https://youtu.be/nE2tiTukmsQ>

- Professor Christi Deaton is Professor Emerita and capacity building lead for BRC. Much of the research in healthcare is led by physicians, nurses, midwives and allied professionals who are also practicing clinically. Balancing these dual clinical and academic roles can generate tension within the NHS, which is understaffed and struggling to deliver services and address long waiting lists. Professor Christi Deaton discusses the challenges and benefits of clinical academic posts and how the inherent tensions might be resolved.

Our YouTube channel link
www.youtube.com/@nihrcambridgebrc6564

If you are a researcher who would like to contribute to this series, or if you have public contributors who may wish to attend, please get in touch at cuh.ppi@nhs.net



Be a part of the CUH PPI panel and help make a difference in research

We're constantly seeking new members to join the CUH PPI panel and actively participate in the ongoing research conducted at Cambridge University Hospitals and the Cambridge Biomedical Research Centre.

Membership of the CUH PPI panel is free and open to members of the public who are aged 16+, live in the East of England and do not currently work in health research or the media. Panel members choose which research projects they would like to be involved in and we have a mix of online, digital and in-person opportunities to choose from.

Click [here](#) to read more

Watch our PPI strategy lead and panel members talk about being involved in research:
<https://youtu.be/x3ZaCdXLVJs>

Researchers' feedback to CUH PPI panel members



It's been a busy time with researchers needing your help. What difference did your involvement make to their research?

Check out the feedback they gave on the academic research projects [Click here](#)
Feedback has been shared from projects conducted in 2023 & 2024.

These files are password-protected and only available to CUH PPI panel members.



Events

CCVS **Engage!** **CAMBRIDGE CITY COUNCIL**

An event uniting voices and focusing action around community engagement in Cambridge City

summer events
planning calendar
volunteering platform
meet other organisations
collaboration
workshops
marketplace

Monday 3 June
10:00 - 15:00
Meadows Community Centre
299 Arbury Road, Cambridge CB4 2JL

Please contact us if you would like to volunteer at the event, run a workshop or have a marketplace stall
Email: suzanne.goff@cambridge.gov.uk

CCVS Engage!

Join us on Monday, 3rd June, from 10:00 to 15:00 at the Meadows Community Centre, 299 Arbury Road,
Cambridge, CB4 2JL

An event uniting voices and focusing action around community engagement in Cambridge City.
Are you a charity or community group that would love to be involved in the Engage event? We are looking for
short workshops and talks around the theme of community engagement.

If you'd like a stall in the marketplace, please get in touch too!

Email: enquiries@cambridgecvs.org.uk



Public Webinars about the East of England: Secure Data Environment

The topic is "Using NHS data from the East of England for research."

What matters to you when your NHS patient data is used for research? We want people across the East of England to understand how their patient data is used for research and to hear from them what is important to them in this process. Learn about the East of England SDE and share your thoughts at one of our four upcoming webinars on June 4th, 13th, 17th, and 27th, respectively.

Book a free ticket [here](#)

Regional Patient and Public Involvement Week Activities, 24–28 June

Monday 24 June

Understanding clinical research and how you can help shape it!

How do doctors and scientists learn more about human health and disease through research?

Join this information session to find out about the different types of clinical research and the ‘rules’ and processes researchers follow to turn an idea into a scientific discovery.

Time: 1.00–2:30

Location: Online Link to sign up: <https://bit.ly/UnCRshape>

Tuesday 25 June

Cambridge Patient and Public Involvement Showcase

Talks in the seminar room from 10am to 12pm and 1pm and 3pm, from different organisations highlighting Patient and Public Involvement in their research.

Poster stands in the Atrium over light lunch: 12.00 to 13:00.

This free event for the public and research staff will showcase and celebrate the difference public involvement has and is making today in Cambridge research.

Time: 10:00–15:00

Location: Atrium & Seminar Room, Jeffrey Cheah Biomedical Centre, University of Cambridge Campus, Puddicombe Way, Cambridge CB2 0AW

Booking link for the morning session: <https://bit.ly/CambPPIweek-AM>

Booking link for the afternoon session: <https://bit.ly/CambPPIweek-PM>

Wednesday 26 June

ARU's answer to Patient and Public Involvement and Engagement (PPIE): 'Let's Shape Research Together'

The event will bring together experts leading in the field from across the East of England and provide a forum for networking, learning, and exchanging best practices.

Time: 12.00 - 16:00

Location: Anglia Ruskin University, Sci 105, Science Building, East Road, Cambridge, CB1 1PT

Link: <https://bit.ly/UnCRshape>

Thursday 27 June

Getting involved in Cambridge - Come meet our public involvement teams!

Meet friendly health, community and research organisations who are looking for volunteers (members of the public) to get involved in their work in the city of Cambridge and across the region. No experience is required!

Find out more about involvement opportunities and how your experience can help our researchers improve their research.

If you're a researcher, find out how PPI panels can help your research.

Time: 11:00 - 14:00

Location: David Dunn Suite (walk through Addenbrooke's main entrance, turn left and first door on right) Addenbrooke's Hospital, Hills Road, Cambridge, CB2 0QQ

Link to help us manage capacity link: <https://bit.ly/MeetPPIteams> or just drop in!

Friday 28 June

Showcase of initiatives through online campaigns.

Follow the hashtag #EoE-PPIWeek on social media and find out about PPI best practice case studies from Anglia Ruskin University, Cambridge Biomedical Research Centre and others.

Social media links:

[@CambridgeBRC](#)

[@ARUresearch](#)

LinkedIn: [ARU Enterprise and Innovation](#)

Survey

NHS Patient Data for Research: What Matters to You?



The NHS in the East of England is creating a Secure Data Environment (SDE) to allow researchers to access de-personalised NHS patient data for research, without the data leaving the NHS environment. The data that will be used for the research in the SDE will come from people living in, or receiving healthcare in the East of England. We want to know what is important to people when their NHS data is used for research, and hear from them what health problems they would like to see health researchers tackle using the data.

In addition to other public involvement events, we are inviting members of the public from across the East of England to share their thoughts via a survey - <https://forms.office.com/e/Z78PiacwQ7>. We need responses from as many people across the Eastern region as possible - please share with your friends, neighbours and community groups.

Articles



How our brains compensate for age-related cognitive decline

Scientists have found the strongest evidence yet that our brains can compensate for age-related deterioration by recruiting other areas to help with brain function and maintain cognitive performance.

“Now that we’ve seen this compensation happening, we can start to ask questions about why it happens for some older people but not others—is there something special about these people?”

-Ethan Knights

As we age, our brain gradually atrophies, losing nerve cells and connections, and this can lead to a decline in brain function. It’s not fully understood why some people appear to maintain better brain function than others, and how we can protect ourselves from cognitive decline.

A widely accepted notion is that some people's brains are able to compensate for the deterioration in brain tissue by recruiting other areas of the brain to help perform tasks. While brain imaging studies have shown that the brain does recruit other areas, until now it has not been clear whether this makes any difference to performance on a task, or whether it provides any additional information about how to perform that task.

In a study published in the journal *eLife*, a team led by scientists at the University of Cambridge in collaboration with the University of Sussex have shown that when the brain recruits other areas, it improves performance, specifically in the brains of older people.

Study lead Dr Kamen Tsvetanov, an Alzheimer's Society Dementia Research Leader Fellow in the Department of Clinical Neurosciences, University of Cambridge, said: "Our ability to solve abstract problems is a sign of so-called 'fluid intelligence', but as we get older, this ability begins to show significant decline. Some people manage to maintain this ability better than others. We wanted to ask why that was the case – are they able to recruit other areas of the brain to overcome changes in the brain that would otherwise be detrimental?"

Brain imaging studies have shown that fluid intelligence tasks engage the 'multiple demand network' (MDN), a brain network involving regions both at the front and rear of the brain, but its activity decreases with age. To see whether the brain compensated for this decrease in activity, the Cambridge team looked at imaging data from 223 adults between 19 and 87 years of age who had been recruited by the Cambridge Centre for Ageing & Neuroscience (Cam-CAN).

The volunteers were asked to identify the odd-one-out in a series of puzzles of varying difficulty while lying in a functional magnetic resonance imaging (fMRI) scanner, so that the researchers could look at patterns of brain activity by measuring changes in blood flow.

As anticipated, in general the ability to solve the problems decreased with age. The MDN was particularly active, as were regions of the brain involved in processing visual information.

When the team analysed the images further using machine-learning, they found two areas of the brain that showed greater activity in the brains of older people, and also correlated with better performance on the task. These areas were the cuneus, at the rear of the brain, and a region in the frontal cortex. But of the two, only activity in the cuneus region was related to performance of the task more strongly in the older than younger volunteers, and contained extra information about the task beyond the MDN.

Although it is not clear exactly why the cuneus should be recruited for this task, the researchers point out that this brain region is usually good at helping us stay focused on what we see. Older adults often have a harder

time briefly remembering information that they have just seen, like the complex puzzle pieces used in the task. The increased activity in the cuneus might reflect a change in how often older adults look at these pieces, as a strategy to make up for their poorer visual memory.

Dr Ethan Knights from the Medical Research Council Cognition and Brain Sciences Unit at Cambridge said: “Now that we’ve seen this compensation happening, we can start to ask questions about why it happens for some older people, but not others, and in some tasks, but not others. Is there something special about these people – their education or lifestyle, for example – and if so, is there a way we can intervene to help others see similar benefits?”

Dr Alexa Morcom from the University of Sussex’s School of Psychology and Sussex Neuroscience research centre said: “This new finding also hints that compensation in later life does not rely on the multiple demand network as previously assumed, but recruits areas whose function is preserved in ageing.”

The research was supported by the Medical Research Council, the Biotechnology and Biological Sciences Research Council, the European Union’s Horizon 2020 research and innovation programme, the Guarantors of Brain, and the Alzheimer’s Society

Over 20,000 people join search for new dementia treatments

We’ve created a resource that is unmatched anywhere else in the world, recruiting people who are not showing any signs of dementia rather than people already having symptoms.

- Patrick Chinnery

More than 20,000 volunteers have been recruited to a resource aimed at speeding up the development of much-needed dementia drugs. The cohort will enable scientists in universities and industry to involve healthy individuals who may be at increased risk of dementia in clinical trials to test whether new drugs can slow the decline in various brain functions including memory and delay the onset of dementia.

Using the resource, scientists have already been able to show for the first time that two important bodily mechanisms – inflammation and metabolism – play a role in the decline in brain function as we age.

By 2050, approximately 139 million people are expected to be living with dementia worldwide. In the UK, in 2022, UK Prime Minister launched the Dame Barbara Windsor Dementia Mission, part of the government's commitment to double increase research funding for dementia.

Although there has been recent progress developing drugs that slow down progression of the disease, the two leading treatments only have a small effect, and the vast majority of new approaches that work in animal studies fail when it comes to patient clinical trials.

One explanation for these failures is that the drugs are tested in people who already have memory loss – and by this point, it may be too late to stop or reverse the disease. Hence, there is an urgent need to understand what is going on before people develop symptoms at the very early stages of disease, and to test new treatments before people come to their doctor with cognitive problems. This approach requires a large cohort of participants willing to be recalled for clinical and experimental studies of cognitive decline.

Today, writing in the journal *Nature Medicine*, scientists led by the University of Cambridge in partnership with the Alzheimer's Society report how they have recruited 21,000 people aged 17-85 to the Genes and Cognition Cohort within the National Institute for Health and Care Research (NIHR) BioResource.

The NIHR BioResource was established in 2007 to recruit volunteers keen to engage in experimental medicine and clinical trials across the whole of medicine. Approximately half of its participants are recruited to disease specific cohorts, but the other half are from the general public, and detailed information about their genetics and their physical makeup has been collected. They have all given their consent to be contacted about future research studies.

For the Genes and Cognition Cohort, researchers used a combination of cognitive tests and genetic data, combined with other health data and demographic information, to enable the first at-scale study of cognitive changes. This will allow the team to recruit participants for studies of cognitive decline and new treatments for this.

For example, a pharmaceutical company with a promising new drug candidate to slow the cognitive decline could recruit people through the BioResource based on their profile and invite them to join in the clinical trial. Having a baseline measurement for their cognitive performance will allow scientists to observe whether the drug slows their expected cognitive decline.

Professor Patrick Chinnery from the Department of Clinical Neurosciences at the University of Cambridge and co-chair of the NIHR BioResource, who has led the project, said: “We’ve created a resource that is unmatched anywhere else in the world, recruiting people who are not showing any signs of dementia rather than people already having symptoms. It will allow us to match individuals to particular studies and speed up the development of much-needed new drugs to treat dementia.

“We know that over time our cognitive function decreases, so we’ve plotted out the expected trajectory of various different cognitive functions over our volunteers’ life course according to their genetic risk. We’ve also asked the question, ‘What are the genetic mechanisms that predispose you to slow or fast cognitive decline as you age?’.”

Using the research, the team have identified two mechanisms that appear to affect cognition as we age and could serve as potential targets to slow down cognitive decline and thereby delay the onset of dementia. The first of these is inflammation, with immune cells specific to the brain and central nervous system – known as microglia – causing gradual deterioration of the brain and hence its ability to perform key cognitive functions. The second mechanism relates to metabolism – in particular, how carbohydrates are broken down in the brain to release energy.

Professor Chinnery added: “Cognitive decline is a natural process, but when it drops below a particular threshold, that’s when there’s a problem – that is when we would diagnose dementia. Anything that slows that decline will delay when we drop below that threshold. If you could put off the onset of dementia from 65 to 75 or even 85, it would make a huge difference at an individual and at a population level.”

Dr Richard Oakley, Associate Director of Research and Innovation at Alzheimer’s Society, said: “This exciting study, funded by Alzheimer’s Society, is an important step in helping us to better understand how the diseases that cause dementia begin and will aid in the development of new treatments that target the early stages of these diseases.

“The data, from over 20,000 volunteers, helps us to better understand the connection between participants’ genes and cognitive decline and allows for further ground-breaking analysis in the future.

“One in three people born in the UK today will go on to develop dementia in their lifetime, but research will beat dementia. We need to make it a reality sooner through more funding, partnership working and people taking part in dementia research.”

For further information about how you can join the BioResource and contribute to studies like this one and many others, please visit bioresource.nihr.ac.uk.

Exploring women's health research

Cambridge researchers have used artificial intelligence to predict the healthiness of café, takeaway and restaurant menus at outlets across Britain. The findings highlight the double burden faced by people living in the most deprived areas, where there tend to be more food outlets per capita, and these outlets tend to be less healthy.

Research is vital to improving health and care. The more we understand about a condition, the better we can treat, manage, diagnose and prevent it.

Look at breast cancer, for example. Survival has doubled in the last 50 years. 8 in 10 women now survive beyond 10 years of their diagnosis, compared to 4 in 10 in the 1970s. This is due to research like the [HERA trial](#).

But the same focus has not been given to other women's health issues, such as the menopause, endometriosis, and miscarriage. These conditions have been largely under-researched. This has left some women with little support and clinicians without the right information to provide the best care. It's also created an environment where women often feel unheard.

The recent Women's Health Strategy for England found that 4 in 5 women felt their healthcare professionals weren't listening to them. A recent [NIHR Evidence Collection](#) makes suggestions on how to improve conversations between women and healthcare professionals.

A researcher in Wales is hoping that [more effective communication could help speed up diagnosis of endometriosis](#) in particular. Often referred to as the 'missed disease', endometriosis is a long-term condition where tissue similar to the lining of the womb grows in other places. It can cause chronic pain, fatigue, problems conceiving and more. Despite 1 in 10 women living with endometriosis, it takes an average of 8 years to be diagnosed.

There are also few treatment options for endometriosis. Researchers in England and Scotland hope to change that. Two new studies are currently testing non-hormonal drugs - [REGAL](#) and [AMY109EU](#). If effective, they will become the first new treatments in 40 years.

Menopause research has received more attention in recent years, contributed to by the work of the campaigning of TV presenter Davina McCall. Our latest [Be Part of Research](#) blog takes a look at research into hormone replacement therapy, diet, and premature ovarian insufficiency (POI). POI is when menopause happens before the age of 40.

Meanwhile, innovative research in Scotland could transform pregnancy care. Researchers have created a [3D model of the placenta](#), the organ that passes nutrients from mother to foetus. Little is known about the placenta. But failure of the organ can cause life-threatening complications. The 3D models will help further our understanding and improve treatment of these conditions.

[Another common condition seldom talked about is pelvic prolapse](#). This is when one or more organs in the pelvis, for example, the womb or the bowel, slip down and bulge into the vagina. It can cause pain and discomfort. Vaginal pessaries are often used to help keep the prolapsed organs back in place. Currently, women using a pessary have a check-up every 6 months. [But a recent study showed that self-management was safe](#) and actually led to fewer complications. It may take time to be rolled out, but self-management could help improve the lives of thousands of women.

Research is also seeking to find better treatments for recurrent urinary tract infections (UTIs). 1 in 2 women will get a UTI in their lifetime. And about 1 in 4 of those women will go on to have them frequently. Women with recurrent UTIs are usually treated with daily, low-dose antibiotics. But bacteria can become resistant to these drugs over time. A study in Wales is [comparing the effectiveness of treatments like cranberry juice and a drug called methenamine](#) to antibiotics. Meanwhile, researchers in England are also studying the use of [different types of antibiotics](#).

Researchers in Northern Ireland are looking at [whether cow's milk could help improve iodine levels in early pregnancy](#). Iodine is vital for normal brain development in the foetus. Low levels of iodine can also cause hypothyroidism in pregnant women.

Many other studies into reproductive and maternal health have taken place over the past year, including research into:

- a [new twice-a-year contraceptive jab](#)
- a [new smartphone app to manage type 1 diabetes during pregnancy](#)

- the [link between mental health and premature births](#)
- [how individuals living with inflammatory arthritis experience family planning care](#)
- [how maternity services can be improved](#)
- the [causes of postpartum psychosis](#)

In England, the [NIHR's research inclusion strategy](#) is aiming to address inequalities in access to health research and in the conditions that are researched.

You can take part in a broad range of research using the [Be Part of Research](#) website. Either search our study listing or sign up to be contacted about studies that match your interests.

Public and Patient Experience of the NHS App

This report comes from the Patient Coalition for AI, Data and Digital Tech in Health, a group of organisations aiming to champion the patient perspective in digital health. They surveyed 637 people to ask about awareness and use of the NHS App.

Just over three quarters (78%) of respondents were actually using the App and most of those (81%) found it easy to use. The most common uses were ordering a repeat prescription, reviewing personal health records and checking test results.

A quarter of respondents (23%) who were not using the App cited a number of barriers. 10% did not have a smartphone; others had problems with downloading the App, registering and logging in. Many were not aware that it could be accessed via a tablet or laptop, and some were completely unaware of the App.

The report states that "*there is a lot of frustration among people who can't access the services that are listed on the NHS App*". More than a third (39%) of respondents wanted to see their test results but couldn't and 36% wanted access to their personal health records. "*These responses,*" say the authors, "*highlight how many people still don't have access to these services*".

They go on to say that, "*While GPs restricting access to information via the App may call this 'stewardship', many people in the survey perceive this as GPs acting as gatekeepers, disempowering*

patients". There is a sense that "GPs shouldn't be able to control the flow of information, as this results in a lack of consistency and leads to disadvantage".

The report covers other issues, such as the needs of carers who are helping others to use the App. And it touches on issues of data security, noting that some respondents said their use of the App was limited by their concerns about what will happen to their health data.

A series of recommendations concludes with the statement that *"some human issues will never be addressed by improvements to the App, and it is, therefore, always important to retain alternative methods of accessing healthcare".* In particular, *"Healthcare providers need to ensure healthcare services will still be available for use via traditional face-to-face or telephone appointments and make it clearer to people that using digital services is a choice".*

Baby born deaf can hear after breakthrough gene therapy



A baby girl born deaf can hear unaided for the first time, after receiving ground-breaking gene therapy when she was eleven months old at Addenbrooke's Hospital in Cambridge.

Opal Sandy from Oxfordshire is the first patient treated in a global gene therapy trial, which shows "mind-blowing" results. She is the first British patient in the world and the youngest child to receive this type of treatment.

Opal was born completely deaf because of a rare genetic condition, auditory neuropathy, caused by the disruption of nerve impulses travelling from the inner ear to the brain. Within four weeks of having the gene

therapy infusion to her right ear, Opal responded to sound, even with the cochlear implant in her left ear switched off.

Clinicians noticed continuous improvement in Opal's hearing in the weeks afterwards, and at 24 weeks confirmed close to normal hearing levels for soft sounds, such as whispering, in her treated ear. Now 18 months old, Opal can respond to her parents' voices and can communicate words such as "Dada" and "bye-bye."

Auditory neuropathy can be due to a variation in a single gene, known as the OTOF gene. The gene produces a protein called otoferlin, needed to allow the inner hair cells in the ear to communicate with the hearing nerve. Approximately 20,000 people across the UK, Germany, France, Spain, Italy are deaf due to a mutation in the OTOF gene.

The CHORD trial, which started in May 2023, aims to show whether gene therapy can provide hearing for children born with auditory neuropathy.

Children with a variation in the OTOF gene often pass the new-born screening, as the hair cells are working but they are not talking to the nerve. It means this hearing loss is not commonly detected until children are 2 or 3 years of age, when a delay in speech is likely to be noticed.

Professor Bance added, "We have a short time frame to intervene because of the rapid pace of brain development at this age. Delays in the diagnosis can also cause confusion for families, as the many reasons for delayed speech and late intervention can impact children's development."

"More than sixty years after the cochlear implant was first invented – the standard of care treatment for patients with OTOF-related hearing loss – this trial shows gene therapy could provide a future alternative. It marks a new era in the treatment for deafness. It also supports the development of other gene therapies that may prove to make a difference in other genetic related hearing conditions, many of which are more common than auditory neuropathy."

Mutations in the OTOF gene can be identified by standard NHS genetic testing. Opal was identified as being at risk as her older sister has the condition; this was confirmed by a genetic test result when she was 3 weeks old.

Opal was given an infusion containing a harmless virus (AAV1). It delivers a working copy of the OTOF gene and is delivered via an injection in the cochlea during surgery under general anaesthesia. During surgery, while Opal was given the gene therapy in right ear, a cochlear implant was fitted in her left ear.

Dr Brown added: "It is likely that in the long run, such treatments require less follow-up so may prove to be an attractive option, including within the developing world. Follow-up appointments have shown effective results so far with no adverse reactions and it is exciting to see the results to date."

"Within the new planned Cambridge Children's Hospital, we look forward to having a genomic centre of excellence which will support patients from across the region to access the testing they need and the best treatment at the right time."

He added: "We would like to emphasise that, with the right support from the start, deafness should never be a barrier to happiness or fulfilment. As a charity, we support families to make informed choices about medical technologies so that they can give their deaf child the best possible start in life."

The CHORD trial is sponsored by Regeneron. Patients are being enrolled in the study in the US, UK and Spain. It is one of several ongoing gene therapy studies across the world using the OTOF gene, though the surgical and delivery methods are unique.

Patients in the first phase of the study receive a low dose to one ear. The second phase are expected to use a higher dose of gene therapy in one ear only, following proven safety of the starting dose. The third phase will look at gene therapy in both ears, with the dose selected after ensuring the safety and effectiveness in parts 1 and 2. Follow-up appointments will continue for five years for enrolled patients, which will show how patients adapt to understand speech in the longer term.

In Cambridge, the trial is supported by [NIHR Cambridge Clinical Research Facility \(opens in a new tab\)](#) and [NIHR Cambridge Biomedical Research Centre \(opens in a new tab\)](#).



Use MyChart?

Did you know you can set your research preferences?

Patients at Cambridge University Hospitals can now use the patient portal MyChart to set their preferences about hearing about research opportunities. Patients who give their consent for contact can be contacted by research teams at CUH about research opportunities that may be relevant for them.

MyChart is free to [sign up](#) to and available to all CUH patients. You can change your preferences about research contact at any time in MyChart.



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