

**DHSC ROUNDTABLE MEETING  
RESEARCH ON ADULT HEARING LOSS & TINNITUS  
TUESDAY 15 DECEMBER 2020, 10AM – 1PM**

This event will bring together a wide range of stakeholders and partners to discuss issues relating to research on adult hearing loss and tinnitus. The aim is to discuss research priorities and how we can address major outstanding issues by growing the capacity and capability of these research sectors. The focus will be on identifying specific short, medium and long term actions for how we can all work together to improve outcomes for people who experience these conditions.

**INFORMATION ON RESEARCH FUNDERS /COMMISSIONERS**



The [NIHR](#) was established in 2006 under the government's health research strategy [Best Research for Best Health](#) to "create a health research system in which the NHS supports outstanding individuals, working in world-class facilities, conducting leading-edge research focused on the needs of patients and the public". Since that time, NIHR has transformed research in and for the NHS and helped to shape the health research landscape more broadly by commissioning and funding NHS, social care and public health research to develop the research evidence to support decision making by professionals, policy makers, patients and the public.

NIHR delivers against its mission: to improve the health and wealth of the nation through research, through five core workstreams:

**1. We fund, support and deliver high quality research**

At the core of NIHR is a commitment to fund high quality research that benefits the NHS, public health and social care. Our research funding schemes – programmes, units and schools – deliver a coherent programme of response mode and commissioned research.

**2. We engage and involve patients, carers and the public**

The NIHR engages and involves patients, carers and the public in all the processes by which research is identified, prioritised, designed, conducted, evaluated and disseminated. We do this in order to improve the reach, quality and impact of our research.

Our pioneering partnership with these communities has become one of the hallmarks of NIHR and is considered to be world-leading.

**3. We attract, train and support the best researchers**

The NIHR is the largest funder of health research training in the UK. We invest in academic career pathways for health and care researchers from all professional backgrounds, building the capacity and capabilities needed to tackle the complex health and care challenges of the future.

Our collegiate ethos extends across our health research and health research delivery workforce.

**4. We invest in world-class infrastructure and a skilled delivery workforce**

The NIHR's sustained investment in people, facilities and technology has transformed the health and care system's ability to translate discoveries into improved treatments and services. This infrastructure supports research funded by NIHR and by our partners.

Our people encompass internationally renowned investigators and a delivery workforce of doctors, nurses, midwives and other professionals.

### **5. We partner with other public funders, charities and industry**

The NIHR works with UKRI, charities and industry to maximise the value of research to patients and the economy. We do this both to achieve our aims and to improve the UK research ecosystem, thus playing our part in supporting the UK's world-leading life sciences sector. We work with a diverse range of industry sectors and provide extensive support to small and medium-sized enterprises.

### **6. We fund applied global health research and training**

In addition to our national role, the NIHR supports high-quality applied health research for the direct and primary benefit of people in low and middle-income countries using [Official Development Assistance \(ODA\)](#) funding.

### **Contact**

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### **NIHR Biomedical Research Centres (BRCs)**

The National Institute for Health Research (NIHR) funds 20 Biomedical Research Centres across the UK. They bring NHS departments and universities together to conduct translational research that is translating lab-based scientific breakthroughs into new treatments, diagnostics and medical technologies.



### **NIHR Manchester Biomedical Research Centre**

The NIHR Manchester Biomedical Research Centre (BRC; hosted by the Manchester University NHS Foundation Trust and the University of Manchester: <https://www.manchesterbrc.nih.ac.uk/>) received £28.5m, in 2017, to fund seven research themes: hearing health, musculoskeletal disease, respiratory disease, dermatology and cancer (prevention, radiotherapy and precision medicine). The overarching aim of the Manchester BRC is to drive health improvements for all by bridging the gap between new discoveries and individualised care.

The work of the Hearing Health theme spans the continuum from:

- prevention and minimising risk, assessment and diagnosis, and treatment and outcomes; and
- growing well, living well and ageing well.

The Hearing Health team include: clinicians, audiologists, hearing scientists, health psychologists, language therapists, geneticists, neuroscientists, data scientists, material scientists and engineers.

The infrastructure provided by the BRC has been a catalyst for initiatives that are transforming the Hearing Health research landscape. For example, the Manchester BRC has

established the UK's only Hearing Device Research Centre (HDRC). The HDRC drives innovations in interventions for hearing loss and accelerates the translation of new hearing technology into the NHS. The HDRC also supports the evaluation of hearing devices available on the NHS, the largest purchaser of hearing devices in the world (1.2m p.a.). In addition, our bespoke hearing research van makes research accessible to people who would otherwise not be able to participate.

The last eight months have been unlike anything any of us have experienced. But as a direct result of the BRC infrastructure, the Manchester BRC Hearing Health theme has:

- Contributed to national remote working guidance for hearing health professionals.
- Established a monthly online journal club and podcast series.
- Accelerated telehealth research studies.
- Published peer-review COVID-19 related articles on: (i) SARS-CoV-2 and hearing loss, (ii) impact of face masks on communication and hearing, and (iii) hearing care professionals views on remote care.
- Secured funding for COVID-19 research including: (i) persistent audiological consequences of COVID-19 [supported by the RNID and the Eleanor Peele Trust] and (ii) design of 'communication-aware' face masks.
- Develop software to allow listening lab research to go global.
- Assisted with vaccine trials.

As Seamus Heaney, Irish poet, playwright and translator said, "*If we can winter this one out, we can summer anywhere*".

## Contact

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## NIHR Manchester Biomedical Research Centre

The Nottingham Biomedical Research Centre represents a partnership between Nottingham University Hospitals NHS Trust and the University of Nottingham.

Nottingham has historically taken a leading national and international role in hearing research, which continues today. Hearing is one of five health research themes in the Nottingham Biomedical Research Centre, complemented by an imaging cross-cutting theme which works across all the others, in the city where magnetic resonance imaging (MRI) was first developed. Our vision is to make sure that the NHS provides the most effective and cost-effective hearing healthcare for people of all ages (from babies to the elderly). Our priorities are aimed towards improving and evaluating medical technologies and management strategies for hearing loss and tinnitus, reducing research waste by prioritising research questions in partnership with patients and clinicians, improving the design of clinical trials including outcome selection and measurement, and developing tools to inform the targeted delivery of effective care.

Our projects include close collaboration with hearing scientists at the University of Nottingham, the ENT department at Nottingham University Hospitals NHS Trust, Nottingham Audiology Services and the Nottingham Auditory Implant Programme. We have a long-established critical mass of staff working in fundamental hearing research, translational hearing research, ENT and Audiology, with one of the UK's largest programmes in cochlear implantation.

We offer some of the best infrastructure in the UK for supporting early-phase translational research in the hearing sciences, which form part of the NIHR Nottingham Clinical Research Facility, by placing state-of-the-art research facilities next to clinical services. Our commitment is to pursue research, through collaboration and in partnership with patients and the public, which can be translated into real world benefits for patients. A few examples of our research highlights are:

- We have initiated and co-led three James Lind Alliance Priority Setting Partnerships in tinnitus, mild to moderate hearing loss and hyperacusis to identify the questions that patients and the public want answering so that future research is focussed on their needs.
- We work in close collaboration with the Cochrane ENT group to prioritise and conduct reviews of existing research evidence to inform future research priorities and NHS commissioning. Our Cochrane Review on 'Hearing Aids for Mild to Moderate Hearing Loss in Adults' addressed the clinical question on the effectiveness of hearing aids. It provided the evidence needed by NICE to recommend hearing aids for adults with mild to moderate hearing loss.
- Our C2Hear online multimedia resource developed to support first time hearing aid users exceeded 200,000 views from over 50 countries and is specifically highlighted by NICE in the information for patients that accompanies its guidelines for Hearing Loss in Adults (NG98).
- Our tinnitus researchers have leading roles within large EU-consortiums (TINNET, ESIT, TIGER, UNITI), involving both academic and industry partners, which aim to facilitate the transfer of knowledge towards the bedside. For example, the UNITI collaboration (Unification of Treatments and Interventions for Tinnitus Patients) is currently conducting 4 randomised controlled trials with 4 different treatment interventions.
- In partnership with patients and clinicians from over 30 countries around the world, we have identified which outcomes are most important to measure when testing treatments for tinnitus and single-sided deafness. These Core Outcome Sets will inform the design of future clinical trials evaluating interventions for these conditions, and in doing so guide future clinical research worldwide to accelerate progress.
- We are part of the Global Burden of Disease study and lead the EARGEN consortia conducting the largest genome-wide association studies ever performed in the hearing field to improve the targeting of future therapies.

## Contact

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## NIHR Manchester Biomedical Research Centre

The BRC at University College London Hospitals (UCLH) was established in 2007 and is one of the largest with a five-year budget of £111.5 million. It covers nine research themes, one of which is Deafness and Hearing Problems.

In this theme, researchers and clinicians at the UCLH Royal National ENT Hospital and University College London (UCL) Ear Institute work together with experts from across UCL/H and patients to develop precision medicine for hearing loss, that is developing transformational treatments tailored to the individual patients' need.

The breadth of the Hearing theme's research is unique; our cell biologists, geneticists, neuroscientists and data scientists have made us better understand hearing loss and identify potential new diagnostics and therapeutic approaches. Our ENT surgeons, audiovestibular physicians and audiologists have taken these discoveries into the clinic by developing and delivering clinical trials.

Our implementation scientist and health economists model how these new diagnostics and treatments can best be adopted in NHS clinics. Some of our research successes are:

#### **REGAIN - Regeneration of inner ear hair cells with gamma-secretase inhibitors**

- A big question in hearing research is whether hearing can be restored once it is lost. Damage to the sensory hair cells in the cochlea (known as sensorineural hearing loss) is a major cause of hearing loss acquired in later life. Supported by a €5.8million EU Horizon 2020 grant, the REGAIN research team at UCL/H established a consortium with partners in Greece, Germany and the US company Audion Therapeutics to take the discovery of a new drug aimed at regenerating the inner ear hair cells to the clinic. In a phase I/IIa trial 60 people with mild to moderate sensorineural hearing loss received three injections of this drug into their ear. We established that this approach is safe and are analysing the results to establish if it improves hearing.

#### **EVOTION - Big data to support hearing health policies**

- Many hearing aid users tell us that testing their hearing aids in a lab or clinic gives no indication of how they perform in the real, noisy world. EVOTION is an EU Horizon 2020 funded project collecting real life data about how hearing aids are used through the day in different environments. More than 1,000 new hearing aid users were recruited from the UK, Greece and Denmark. Working with the company Oticon, participants were offered smart hearing aids and a smartphone with a mobile application to record hearing aid and vital health data. These data will allow us to identify patterns in hearing aid use and personal and environmental factors that impact on that. This will inform how hearing aids are best programmed to improve patient benefit and also will inform public health policies. Analysis of the more than 33 million real-time data points provided by participants is underway.

#### **Discovery of new genes related to deafness**

- Researchers of the UCLH BRC and collaborators from King's College London have analysed the genetic data from over 250,000 participants of the UK Biobank, a large study that followed 500,000 volunteers in the UK, aged 40-69 years. They used these data to see which genes were associated with people who had reported having or not having hearing problems. The team identified 44 genes associated with hearing loss, 33 of which had not been identified previously. These results giving a much clearer understanding of how hearing loss develops and are an important step along the road to being able to identify who is at risk of hearing loss and eventually being able to develop tailored treatments.

#### **Contact**

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## **British Tinnitus Association**

The **British Tinnitus Association** is an independent charity that supports over one million people living with tinnitus each year, and advises medical professionals around the world. We are the primary source of support and information for people with tinnitus in the UK, facilitating an improved quality of life. Through our medical research programme, we want to find better ways to manage tinnitus and, ultimately, to help find a cure. Our vision is 'a world where no one suffers from tinnitus'.

### **Our research commitment**

Current treatment options, whilst effective at improving quality of life and reducing tinnitus-associated psychological distress, leave many of those living with tinnitus dissatisfied. “We need a cure” is a comment we hear often. People with tinnitus want their tinnitus loudness reduced and many would prefer a drug-based solution over other options.

Our research priorities are to:

- Continue our work with researchers across the world to map out current tinnitus research
- Develop the concept of a Tinnitus Biobank (a database of health information) for a long-term study into genetic and environmental factors associated with tinnitus
- Develop further research using biobank data to analyse correlations between these factors

### **Why tinnitus research is important**

- Tinnitus affects 7.1m people in the UK ([Tinnitus prevalence in the UK, 2019](#)) and research shows that it has a huge impact on mental health and quality of life – up to one in seven have had suicidal thoughts ([The Tinnitus Manifesto, 2020](#))
- 83% of tinnitus patients are unhappy with the treatment options available ([Frontiers In Neuroscience, 2019](#)) and this causes a revolving door of returning patients, costing the NHS £750 million per year ([BMC Health Services Research, 2017](#))
- Tinnitus research receives 40 times less funding than comparable conditions like depression, anxiety and hearing loss ([BMC Health Services Research, 2017](#))
- This year, more than 120,000 people signed a petition calling for more funding for tinnitus research ([Change.org petition, 2020](#)) – leading to Matt Hancock suggesting a funding review ([House of Commons Health & Social Care Debate, 2020](#))

### **Our Tinnitus Manifesto**

In January 2020, we hosted a Tinnitus Roundtable event at the House of Commons, sponsored by Sir John Hayes MP, who has tinnitus himself. The event brought together leading academics, politicians, research-funders, patient support groups, clinicians and people with tinnitus. The group helped to map out a way forward for tinnitus research, leading to three clear calls for Government, which would enable us

to seize the opportunity to grow the field and make the huge leaps forward that are so close and so important to people with tinnitus. **The calls to action:**

1. Commit 1% of the health service cost of treating tinnitus towards research to find cures - a total of £7.5m per year to be dedicated to research
2. Build a long-term infrastructure to ensure that there is the capacity to deliver the quality and volume of research needed to make real progress, building on the work of the committed research community
3. Prioritise studies that will help establish the key foundational knowledge for tinnitus research, and enable the community to move forward to find cures, including:
  - a. Identifying tinnitus biomarkers
  - b. Developing reliable objective measures of tinnitus
  - c. Identifying tinnitus subtypes

**Contact**

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The Royal National Institute for Deaf People (RNID): we are the charity making life fully inclusive for deaf people and those with hearing loss or tinnitus. There are three areas to our work:

- **Campaigning** – We won't stop until we see a world where deaf people and those with hearing loss or tinnitus are fully included in society
- **Information and Support** – We provide trusted independent information and support for deaf people and those living with hearing loss or tinnitus
- **Research** – We work towards preventing hearing loss, restoring the hearing of those who have lost it and silencing tinnitus.

### **Our Research**

We fund research and help to connect the research community to bring about better medical treatments for hearing loss and tinnitus. **We focus our research on:**

#### **Preventing hearing loss**

We fund research to:

- better understand the cellular and molecular mechanisms that underlie hearing difficulties
- advance the development and testing of treatments to prevent any type of hearing disorder.

#### **Restoring hearing**

We fund research that will:

- lead to transformative improvements to the quality of hearing gained from medical devices
- advance the discovery, development and testing of drug, gene or cell-based therapies to repair damage to any part of the auditory system to improve hearing.

#### **Silencing tinnitus**

We will fund research to:

- improve our understanding of the biological mechanisms involved in tinnitus
- develop and test new approaches to reduce the perception of tinnitus.

### **Our approach**

We accelerate the discovery and development of new treatments, and build future research capacity through a range of [funding schemes](#) and [the Hearing Medicines Discovery Syndicate](#) .

Find out more by reading our [Research Strategy 2020](#)

### **Why research into better treatments is important:**

- Hearing loss **affects 12 million people** in the UK, 1 in 8 have tinnitus.

- Hearing loss can have a **devastating impact** on relationships, education, job prospects, and can lead to loneliness and isolation. It is a risk factor for dementia.
- People tell us that **being able to hear well would make the biggest difference** to their lives
- There is **high unmet clinical need**. Today's treatments are largely limited to medical devices. People still struggle to hear when there are high levels of background noise, they do not slow or prevent the loss of hearing and they do not restore natural hearing.
- **Hearing research is under-funded** relative to its impact. In 2018, only 83p per person with hearing loss was spent on 'ear-related' research by the UK's main public funders. This compared to £193 per person living with cancer, £21 per person living with cardiovascular disease and £16 per person living with sight loss (*UK Health Research Analysis 2018*)

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The [Medical Research Council](#) (MRC) is part of UK Research and Innovation (UKRI). UKRI is a non-departmental public body sponsored by the Department for Business, Energy and Industrial Strategy (BEIS). UKRI brings together the seven disciplinary research councils, Research England, which is responsible for supporting research and knowledge exchange at higher education institutions in England, and the UK's innovation agency, Innovate UK. The nine councils work together in innovative ways to deliver an ambitious agenda.

The MRC's mission is to improve human health through world-class medical research, from fundamental science to early clinical trials and preventive medicine. For the good of society, we strive to find better ways to treat and prevent disease and to advance people's health worldwide. Working in partnership with other UKRI councils, the National Institute for Health Research (NIHR) and devolved administrations, the NHS, charities and industry, we are a dynamic organisation continually evolving and embracing new opportunities to achieve a mission first framed over a century ago. MRC published its delivery plan in 2019 which forms part of a [full set](#) covering UKRI's nine councils, in addition to a plan covering cross-UKRI areas.

Our work ranges from laboratory research, for example on genes and molecules, right through to research with people, such as clinical trials and population studies. Our science is split into six broad areas of research: infections and immunity, molecular and cellular medicine, neurosciences and mental health, population and systems medicine, global health and translational research. All funding opportunities can be found on the UKRI website through the [Funding Finder](#). Our research is carried out in universities, hospitals and a network of dedicated establishments across the UK and Africa.

For further information about funding opportunities within the MRC please contact: Maya Bronfield: [NMHB@mrc.ukri.org](mailto:NMHB@mrc.ukri.org).