The Research Agenda for ENT, Hearing and Balance Care
A UK Partnership of Patients, Professionals and the Public

GENERATE

Patients, Professionals, and the
Public in Partnership

Citation

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This document and the full report on GENERATE will be available online at www.entuk.org in 2016.

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ENTUK

British Society of Audiology
KNOWLEDGE | LEARNING | PRACTICE | IMPACT

BAA
BRITISH ACADEMY OF AUDIOLOGY

evidENT
evidence-based ENT

Hearing Link

The Ear Foundation
Hearing & Communicating in a Technological Era

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

AOT
Association of Otolaryngologists in Training

ACTION ON HEARING ~~LOSS~~

BAAP
British Association of Audiovestibular Physicians

Fifth Sense
Smell, Taste, Life.

Contents

Foreword

We are delighted to present the national research agenda for ENT, Hearing and Balance care in the UK. This document summarises the results of three years of planning and working with patients, the public and our professional colleagues from across the UK to decide which questions around the care of people with ENT, Hearing and Balance problems are most in need of research. We would like to thank all the participants who have contributed their ideas and shared their time, many of whom travelled long distances to take part in the discussions. We hope that you can hear your own voices clearly in this research agenda. This agenda is only the start of the journey to develop the evidence base for ENT, Hearing and Balance care. The partnerships built through this initiative will be carried forward in order to deliver this agenda and develop high value research and care for the benefit of our patients and their families.

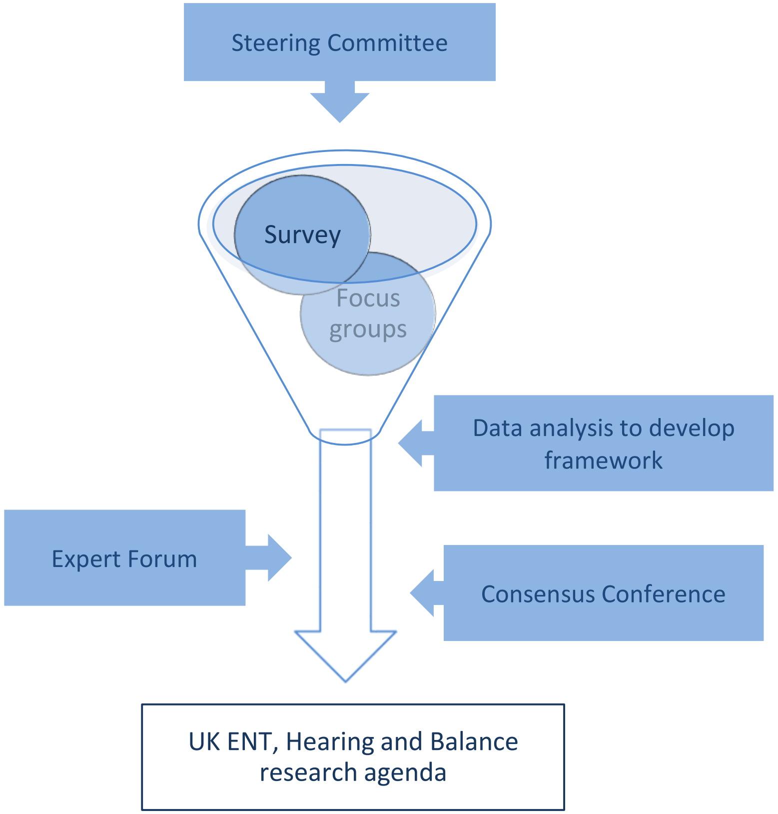
Professor Anne Schilder
Professor Valerie Lund CBE
Ms Natalie Bohm

Introduction

We strive to deliver the best care for patients with ENT, Hearing and Balance conditions. To do this, it is key that high value research is developed and conducted to inform us about what treatments work best and how we can most effectively deliver care. Recognising that competition for research resources is strong, and that ENT, Hearing and Balance professionals need to build capacity and expertise to deliver the research needed, ENT-UK took the initiative to develop a strategic research agenda. With the support of the British Society of Audiology and the British Academy of Audiology, ENT-UK commissioned the evidENT team at University College London (UCL) to conduct a research priority setting exercise aimed at identifying research priorities in ENT, Hearing and Balance. This initiative was named GENERATE, and the research agenda presented in this booklet is the result of this collaborative work.

Methodology

In January 2014, an independent Steering Committee was established to oversee GENERATE. This Committee included representatives of the groups that develop, use or benefit from research in ENT, Hearing and Balance. evidENT, a multidisciplinary clinical research team based at the Ear Institute at UCL and supported by the National Institute of Health Research, worked with academics from UCL's Department of Applied Health Research and Improvement Science London to design the research priority setting exercise. The approach used was based on a systematic review of the literature on research priority setting in healthcare. Research ideas were gathered through an online survey posted through patient and professional groups. Respondents to the survey were asked to indicate, based on their experience, the most important topics, questions or issues in ENT, Hearing and Balance care that should be answered by research, and why they felt these were important. In addition, five focus groups involving patients, healthcare professionals from various disciplines and settings, service managers and commissioners, researchers and representatives from industry, met to discuss these questions in more depth. These discussions were audio recorded and transcribed to ensure that all information was captured. Many of the issues and research ideas raised in the survey and focus groups were not traditional research questions, yet these were the issues that our respondents felt were important. Therefore a



framework analysis[1] was used, allowing all those ideas to be incorporated into the agenda. Using this method the academic team analysed the data and identified a number of research themes and topics into which all the ideas could be categorised (these form the framework and are described in detail below). Initial analysis produced a long list of research ideas across this framework. An Expert Forum of 21 participants, chosen based on the framework themes and topics, and including patient participants, was held in June 2015 to put the research ideas into the context of current evidence and developments. This led to a shorter list of research ideas that were prioritised in a Consensus Conference held in September 2015. This Conference had 48 participants including patients, members of the public, healthcare professionals from different specialties and disciplines, research funders and policy makers. They discussed and prioritised the research ideas in facilitated small groups. This was followed by a plenary session where these priorities were reviewed by all participants and final consensus was reached.

Results

There were 685 responses to the survey. Other than the six key healthcare professional groups (audiologists, audiovestibular physicians, ENT surgeons, GPs, nurses and speech and language therapists), there were respondents from 21 professional groups including paediatricians, geriatricians, physiotherapists, clinical psychologists, pharmacists and teachers of the deaf. Non-healthcare professional respondents identified themselves as patients, patient carers, parents, members of the public, voluntary workers and charity organisations. The five focus groups involved 43 people from various backgrounds (see above).

The survey and focus groups raised over 1500 research ideas. After removing duplicated suggestions and further analysis 670 research ideas were identified; these were reviewed in the Expert Forum. The experts advised removing questions that had already been answered or were the subject of on-going research within ENT, Hearing and Balance, or could be answered by using knowledge from other fields. They also advised combining some of the topics into broader topic areas as there was some overlap. As a result, 99 research ideas across six different topic areas were presented to participants in the Consensus Conference. Their discussion resulted in 21 priorities for the research agenda for ENT, Hearing and Balance care.

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[1] Ritchie J, Spencer L and O'Connor W. (2003). Carrying out qualitative analysis. In Ritchie J. and Lewis J., eds. *Qualitative Research Practice* London: Sage Publications Ltd. Ch. 9.

The GENERATE Framework

An overview of the framework for the research agenda in ENT, Hearing and Balance care is presented on page 10. A list of all initial research ideas structured across the framework will be available in the full online report. From the survey responses and focus group discussions, six broad research themes were identified and included in the framework. The definitions of the research themes are listed below. A seventh theme 'Creating a research culture in ENT, Hearing and Balance' contains cross-cutting ideas about what the final agenda should incorporate and strategies for implementing it, rather than research ideas. It is outlined in detail on page 20.

Analysis of the survey responses and focus group discussions revealed that they crossed six topics, based on ENT, Hearing and Balance problems and the different age groups affected by them. The research priorities in this booklet are presented under these research topics for clarity. The full online report will include an overview of the research priorities across the research themes. An explanation of the research topics are on page 9.

Research Themes

Understanding health, illness and disease: What causes ENT, Hearing and Balance problems, and what impact do they have on people, their families and society?

Prevention of ill health, maintenance of good health: How can we prevent ENT, Hearing and Balance problems and keep people healthy?

Clinical and cost-effectiveness: How effective are current and new ways of diagnosing and treating ENT, Hearing and Balance conditions?

Designing and delivering health care: How do we improve the quality and value of ENT, Hearing and Balance care, and make it sustainable and patient-centred?

Creating effective communication: How can we improve communication and interactions with patients and between healthcare professionals in order to improve health?

Promoting knowledge and learning: How can we share knowledge and learning with patients and professionals in order to improve health?

Research Topics

Inflammation, Infection and Allergy in Adults: This topic includes research ideas about allergies and infections of the ears, nose and throat in adults. Children also suffer from these infections, these ideas are captured under the topic 'Children and Young People' Participants noted that despite previous research efforts many uncertainties exist. Policy makers often quote ENT operations for these conditions as an example of practice variation.

Head, Neck and Airway Problems: This topic deals with ENT conditions that affect voice, swallowing and breathing. Clinicians recognised that these increasingly account for time taken in clinic, and many are uncertain about the best ways of managing them. Patients felt that they were receiving inconsistent advice and that there seemed to be a lack of knowledge about best management.

Balance Problems: This topic includes uncertainties raised about diagnosis and treatment of balance conditions across all ages. This area was felt to be under-researched and poorly understood, despite its significant impact on quality of life and day-to-day ability to function. As one survey respondent noted when answering why this should be a priority area: "You wouldn't ask if you had it."

Adult Hearing Loss and Tinnitus: Both patients and professionals felt that more research was needed in hearing loss and tinnitus in adults. The personal and societal impact of hearing loss is vast and under-recognised. Children also suffer from hearing loss and tinnitus, and these ideas are captured under the topic 'Childern and Young People.'

Children and Young People: ENT, hearing and balance conditions are common in this age group; many concerns were raised about their impact on children and young people, who are "…yet to live their life" (Patient, survey respondent). Special mention was made of children with complex needs who often have ENT problems but have been excluded from many studies so far.

An Ageing Population: Many issues were raised around the health challenges faced by an ageing population. Loss of ENT, hearing and balance function has a significant impact on the health and wellbeing of older people, and on their families. This also incurs high health care costs to society.

Research Topics

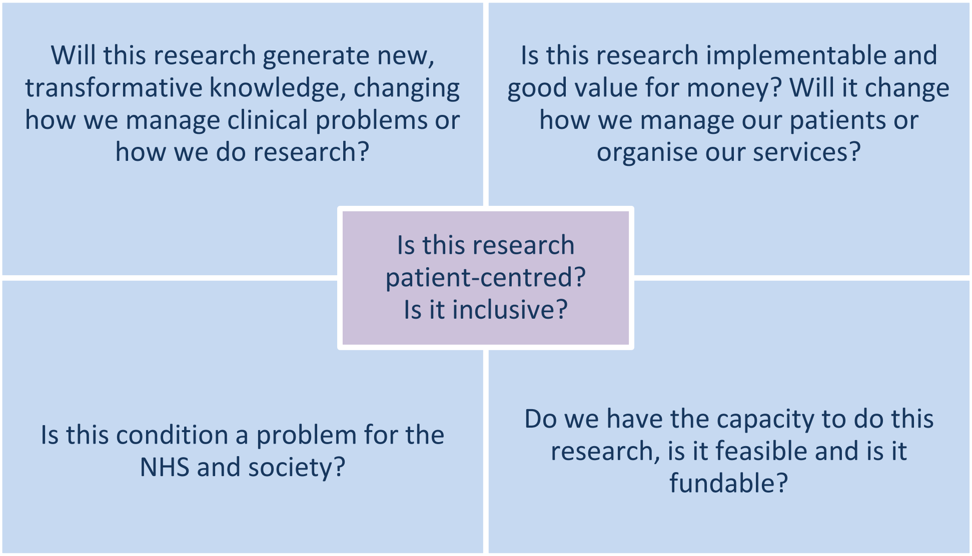
- Adult hearing loss and tinnitus
- Balance problems
- An Ageing Population
- Children and young people
- Inflammation, infection and allergy in adults
- Head, neck and airway problems

Themes

- Understanding health, illness and disease
- Prevention of ill health, maintenance of good health
- Clinical and cost-effectiveness
- Designing and delivering health care
- Creating effective communication
- Promoting knowledge and learning

Values and Criteria for Prioritisation

One of the guiding principles of GENERATE is that it is transparent, both in its process and in its decision-making. Part of this transparency involves understanding the participants’ reasons for choosing the research priorities that are summarised in this agenda. All the way through the initiative, from the initial survey and focus groups to the Consensus Conference these criteria, or values, have been explored and discussed. These are summarised in the figure below. Some of the values may seem to contradict each other: prioritise pragmatic research projects versus aspirational projects; focus on conditions that affect large numbers of people versus on those that have a major impact on fewer people; find better ways to use the knowledge we already have or develop entirely new ideas? There is no right or wrong answer in this. Importantly, these options were considered and weighed so that consensus could be reached, even if there was not always perfect agreement.



Will this research generate new, transformative knowledge, changing how we manage clinical problems or how we do research?

Is this research implementable and good value for money? Will it change how we manage our patients or organise our services?

Is this research patient-centred? Is it inclusive?

Is this condition a problem for the NHS and society?

Do we have the capacity to do this research, is it feasible and is it fundable?

"…actually are we at the stage of talking about treatments? Shouldn't we focus more on aetiology, causation…" (Researcher, focus group participant)

"…there are so many areas, not only from the technological side but also from beyond the technological side how to develop the services, how to run the services which can be looked into purely from a research point of view" (Healthcare professional, focus group participant)

"I think maybe instead you could do some human research instead of some laboratory research, it would be good…" (Patient, focus group participant)

"These are all very common conditions of childhood which have a significant impact on the child a short and long term as well as their educational attainment" (Healthcare professional, survey respondent)

"…in silence tinnitus is always there to remind you something's wrong, and in noisy environments the deafness is always there to remind you something is wrong, and that's why it's incredibly insidious" (Patient, focus group participant)

"It's not life threatening. It's not visible. However smell and taste are TWO of the senses. This has a huge effect on the quality of life on a day to day, hour by hour, minute to minute basis" (Patient, survey respondent)

Adult Hearing Loss and Tinnitus

- What are the best management strategies for tinnitus?
- Which hearing aid strategies work best for adults with hearing loss?
- What are the effects and costs of novel medical and biological treatments (such as cell-based therapies) for sensorineural hearing loss?
- What is the burden and impact of hearing loss on an individual, family and population level?

Balance Problems

- What is the optimum pathway for people with balance problems?
    - What can be dealt with in primary care and the community, and what are the indications for referral?
    - How should specialist clinics be set up?
- How can patients be empowered to self-manage their balance problems?
- Develop clear diagnostic criteria for different balance disorders so that patients can be informed about prognosis and best treatment.

An Ageing Population

- What are effective interventions for hearing loss in older people?
- Is it beneficial to introduce an adult hearing screening programme and how do we best develop it?
- What is the optimum design for 'balance pathways' in older people with balance problems?
    - How and where can older people with balance problems and with multiple medical conditions and decreased mobility best be managed?
    - How can self-management strategies be built in these pathways and what is their impact on patient outcome?

Children and Young People

- What outcome measures and instruments should we use for common childhood ENT, Hearing and Balance conditions, based on our understanding of the impact of these conditions, for otherwise healthy children and for those with complex needs?
- How do we best diagnose and manage obstructive sleep apnoea (OSA) in children?
- How can we improve knowledge of childhood ENT conditions and their evidence-based management for healthcare professionals in different settings, and what is the impact of this on patient outcome?

Inflammation, Infection and Allergy in Adults

- Define the different variations of disease that make up rhinosinusitis ("endotypes and phenotypes") and develop ways of classifying them based on signs, symptoms and biochemical markers.
- What are the most clinical and cost effective treatments for chronic rhinosinusitis?
- How do we improve the implementation of guidelines on antibiotic use in ENT infections in order to reduce the antibiotic burden and its impact on antibiotic resistance in adults and children?
- What outcome measures and instruments should we use in primary and secondary care for chronic ENT infections and inflammatory conditions?

Head, Neck and Airway

- What outcome measures and instruments should we use for head, neck and airway conditions for benign and malignant disease?
- What is the optimal management for adults with OSA?
- What is the optimal management for adults with voice problems?
- What is the role for improved diagnostics in head, neck and airway conditions?

Developing a strategic research agenda

This agenda should:

- Ensure that future research in ENT, Hearing and Balance is patient centred and of high value.
- Ensure that research leads to the development of sustainable high value health care in ENT, Hearing and Balance.
- Incorporate novel, innovative therapies with the potential for benefit in the future.

In order to implement this agenda the following strategies need to be considered:

- Develop the capability and capacity for research in ENT, Hearing and Balance by growing the workforce to develop and deliver the projects.
- Develop and nurture research collaborations across both health care and academic disciplines in order to develop and deliver the high value translational research that has the potential to change practice.
- Developing data collection platforms that capture information that is both applicable to clinical care as well as research.
- Clinicians and researchers should work with patients and carers to decide which outcomes to include in future research.

Adult Hearing Loss and Tinnitus

The Priorities

- What are the best management strategies for tinnitus?
- Which hearing aid strategies work best for adults with hearing loss?
- What are the effects and costs of novel medical and biological treatments (such as cell-based therapies) for sensorineural hearing loss?
- What is the burden and impact of hearing loss on an individual, family and population level?

Hearing loss and tinnitus have been research priorities for patients and professionals through the initiative. Both hearing loss and tinnitus are recognised as common conditions that are often not obvious; symptoms may be hidden but can have an impact both on those suffering from it as well as those around them. In particular tinnitus was highlighted by patients as a condition with underestimated impact. Research in this area has been seen to be under-resourced, with a lack of evidence for current management strategies. Research into the effects and costs of existing and novel therapies for tinnitus has the potential to provide benefit to patients and to the NHS by reducing the burden of tinnitus.

As noted in other topics, hearing loss is a growing burden on society and the NHS; it may have a significant impact on people's mental and cognitive health and ability to interact in society. Hearing loss is a condition of major health, societal and financial impact. It affects people's ability to communicate and function in the workplace, and has been linked to dementia.

Although hearing aids continue to improve, their uptake is low. More research into technologies to improve their user-friendliness could provide a rapid return in terms of patient benefit and research investment. Implantable devices to improve hearing, such as cochlear implants and middle ear implants, were also considered under "hearing aids." With rapid advances made in this field, it was noted that research into who would benefit from them, and when, would be timely. Registries of patients receiving such implantable devices would facilitate such research.

Investment in research that was aspirational in terms of being potentially years away from application in clinical practice was also considered alongside research with more immediate benefit to patients. The development of novel, innovative therapies for sensorineural hearing loss was recognised as having the potential to transform care in the future, and therefore was regarded as one of the research priorities.

Better understanding of the burden and impact of hearing loss on an individual, family and at a population level is important to both patients and professionals. Although research has been done in this area it was felt that more is needed to raise the profile of the problem with policy-makers, research funders and service commissioners. This knowledge would inform future research and health services, basing it around patient experience and clinical need, as well as providing the incentive for resource allocation.

Reasons for these choices

Tinnitus is a common, often hidden condition with underestimated impact; research has been under-resourced and there is a lack of evidence for best management.

Hearing loss is a common, growing problem affecting large numbers of people.

The uptake of hearing aids is low and many people are unhappy with the benefit they offer; research into new devices and technologies would help us better meet population needs and could provide rapid benefits.

Long-term aspirational priorities, such as research into novel hearing treatments should balance shorter-term research gains.

The better the understanding of burden and impact of hearing loss, the more value research and services based on this understanding will have, as it will be informed by patient experience and clinical need.

Balance Problems

The Priorities

- What is the optimum pathway for people with balance problems?
    - What can be dealt with in primary care and the community, and what are the indications for referral?
    - How should specialist clinics be set up?
- How can patients be empowered to self-manage their balance problems and how does this impact on their outcomes?
- Develop clear diagnostic criteria for different balance disorders so that patients can be informed about prognosis and best treatment.

There has been clear recognition throughout the initiative that access to services is a concern for people with balance problems: access to the right care by the right specialists, access to support and access to knowledge about management options. Balance problems are known to be common and may have a significant impact on the lives of people of all ages, yet survey respondents and focus group participants expressed concerns about poor management with long delays in diagnosis and treatment. This delay causes significant stress to sufferers, with patients moving from clinic to clinic until they get a diagnosis. Service organisation was raised as key to alleviating this. The research priorities reflect this need, calling for research into the optimum pathway for people with balance problems. Some of these problems may be managed in the community or primary care. However, balance problems can be complex, involving multiple clinical specialties, and so careful consideration needs to be given to the cost-effectiveness of these pathways and the best utilisation of resources. Survey respondents and focus group participants suggested that models of care to be considered should focus on the symptoms of the patient, not on single body systems or clinical specialties, with the role of multidisciplinary clinics being considered. An added complication is that little is taught on ENT and balance problems at medical school, with the result that directing patients to the right pathway from initial presentation may be challenging. The indications for referral to specialist and sub-specialist management need to be clarified and strategies for sharing this knowledge effectively need to be determined, in order to ensure that patients benefit.

This is related to the research priority in this topic where clear diagnostic criteria for different balance disorders need to be determined. These also require research to improve knowledge about the individual causes of dizziness. Diagnostic criteria based on this understanding has a clear benefit for patients: it lets them know what is wrong with them, what to do about it and gives them an idea of what to expect from their condition in the future. Moving forward there needs to be consideration of developing data collection platforms to collect the information needed for this research.

Patients noted that the impact of balance conditions on their lives was often unappreciated and its causes misunderstood. They felt that in future research a patient-centred approach that recognised the lived experience of these conditions was vital, and that the role of self-management and patient support needed to be investigated to determine what strategies had the greatest impact on their quality of life and disease outcomes. Healthy physical and social environments, including designs of buildings and communities and educating policy-makers and the public about their importance, were ideas considered by our patient respondents, so that people with balance problems are not limited in their ability to interact with society.

Reasons for these choices

Management and care need to be centred around patients with a focus on the problems of the patient, not on clinical specialties or a single body system.

Lack of access to services and delay in diagnosis causes distress to patients and lengthens their experience of illness.

Improving the ability for patients to self-manage, including online and peer support, since balance problems are often chronic.

Balance conditions are difficult to diagnose, and more research is needed to understand individual causes and patterns of balance problems to inform diagnostic criteria. Diagnosis is important both for patient benefit and developing future research of existing and novel therapies.

An Ageing Population

The Priorities

- What are effective interventions for hearing loss in older people?
- Is it beneficial to introduce an adult hearing screening programme and how do we best develop it?
- What is the optimum design for “balance pathways” in older people with balance problems?
    - How and where can older people with balance problems and with multiple medical conditions and decreased mobility best be managed?
    - How can self-management strategies be built in these pathways and what is their impact on patient outcome?

The importance of effectively managing ENT, Hearing and Balance conditions in an ageing population was mentioned by many survey respondents and in the focus groups. Consideration needs to be given as to what is meant by an ageing population; there can be a marked difference between biological age and chronological age. When considering ageing and the older patient this difference gives rise to different considerations: the management of older people with multiple medical problems as opposed to the expectations and quality of life of the ageing but fit population. The expectation of either of these groups is that if you live long enough you will develop some degree of hearing loss or balance problems, and these have driven the chosen priorities.

Research into effective interventions for hearing loss have the potential to impact on large groups of people, making this idea one of the top research priorities in this topic area. It was recognised that there needs to be better understanding of why age-related hearing loss develops, as this could lead to interventions to reverse or stop it without resorting to hearing aids. Although the design of hearing aids has improved, older people in particular can find them especially difficult to use if they have poor hand function or struggle with new technologies, and there is concern that there is a stigma attached to their use. Respondents also considered that research on how to improve access to hearing services for older people would be useful. However, in the Consensus Conference it was felt that better devices and treatments for hearing loss, as well as healthy environment interventions, such as acoustically friendly buildings, would have an impact both on individual quality of life (“a real impact at the point of intervention”) and on population health. It was recognised that intervention for hearing loss in older people should also involve family and carers.

The development of an adult hearing screening programme as a research priority is related to the development of effective devices, treatments and environmental interventions, as people could then benefit from early identification. The ability to screen for hearing loss and stop progression or restore hearing would “be a game changer.” It would transform expectations of quality of life, and could play a huge role in vulnerable populations, such as those suffering from dementia, as well as maintaining cognitive health in older people. How best to screen for hearing loss and which tests to use for a screening programme needs further research. There are also questions around whether earlier diagnosis of hearing loss has an impact on patient experience and outcome, who should be screened, and the cost-effectiveness of screening. Screening was also seen as a good research tool to gather population data that can increase the understanding of hearing loss.

Reasons for these choices

Effective interventions for age-related hearing loss would impact on a large group of people, improving individual quality of life and population health. These interventions for age-related hearing loss combined with the public health intervention of an adult hearing screening programme could transform expectations of quality of life and have a significant impact on vulnerable populations.
Balance pathways in older people can have an impact on quality of life and on the health burden of falls, and need to consider the potential for multiple medical problems.

Research to identify the best pathways to manage balance problems both in fit older people, as well as in the vulnerable who may have decreased mobility, be house bound or in residential care, is also a key research priority. This has an impact on maintaining ongoing quality of life and reducing the health burden associated with falls. This is similar to one of the priorities in the Balance topic, but emphasis here was placed on the need to take a holistic approach to older people in consideration of their potential for multiple medical problems and the possibility they may be in residential care, and to include research into effective self-management strategies and their role in pathways.

Children and Young People

The Priorities

- What outcome measures and instruments should we use for common childhood ENT, Hearing and Balance conditions, based on our understanding of the impact of these conditions, for otherwise healthy children and for those with complex needs?
- How do we best diagnose and manage obstructive sleep apnoea (OSA) in children?
- How can we improve knowledge of childhood ENT conditions and their evidence-based management for healthcare professionals in different settings, and what is the impact of this on patient outcome?

From both the survey and discussions throughout the initiative it was felt that more research was needed about the impact of ENT, Hearing and Balance conditions on children, their families and society. There was a need to develop agreed outcome measures for future research of the management of these conditions that captures this impact. Current research measures outcomes that are too focused on numbers and the results of medical tests; more meaningful outcomes - in terms of patient and family experience and quality of life - need to be agreed by patients, clinicians from different disciplines and researchers. Many different people and professionals are involved in the care of children, and any research done should involve children and parents, and include multidisciplinary research teams.

Children with complex needs are often excluded from research into the effects of treatment of ENT, Hearing and Balance conditions, although the impact in this vulnerable group may be the greatest. Hence the importance in future research of considering *both* otherwise healthy children *and* those with complex needs was emphasised. The potential for inequality in accessing services for these patients, and for those from different ethnic and socioeconomic backgrounds, is recognised and needs to be considered in research that develops pathways for their care.

The following ENT, Hearing and Balance conditions were identified as either common, have a significant impact on children, or both: glue ear; recurrent ear infections; sore throats; coughs and colds; nasal obstruction and allergies; snoring and OSA. Congenital and acquired inner ear (sensorineural) hearing loss was also recognised as a condition requiring further research into the choice of best outcome measures and evidence-based management. Obstructive sleep apnoea (OSA) was singled out due to the level of concern about this condition from parents in terms of its impact on their child's development and school performance. It was felt that there is variation and uncertainty amongst clinicians in various settings about how to diagnose and treat it, and that research in this area has been under-resourced. The prioritised question about OSA specifically involved pathways of care and standardising diagnostic criteria.

Improving knowledge and education of ENT, Hearing and Balance conditions in children in different settings, such as the community, primary and secondary care, and amongst different healthcare workers was important to patients and professionals. Future research should be developed in collaboration with parents and carers and include better recognition and self-management of these problems leading to improved outcomes for children, which links to the first priority in this topic.

Reasons for these choices

ENT, Hearing and Balance conditions are very common in children.
To improve the value of future research the impact of conditions on children and families needs to be better understood. Research outcomes need to be agreed upon by researchers, clinicians and parents so that research is patient-centred and results can be compared across studies.
OSA is of great concern to parents and can have a significant impact on children and their development and school achievement; there is uncertainty and variation in how it is best managed.
Knowledge of ENT, Hearing and Balance conditions is variable in different health care settings, despite the large burden of disease of these conditions.

Infection, Inflammation and Allergy in Adults

The Priorities

- Define the different variations of disease that make up rhinosinusitis ("endotypes and phenotypes") and develop ways of classifying them based on signs, symptoms and biochemical markers.
- What are the most clinical and cost effective treatments for chronic rhinosinusitis?
- How do we improve the implementation of guidelines on antibiotic use in ENT infections in order to reduce the antibiotic burden and its impact on antibiotic resistance in adults and children?
- What outcome measures and instruments should we use in primary and secondary care for chronic ENT infections and inflammatory conditions?

Rhinosinusitis is common and survey respondents noted that many uncertainties exist around its treatment for various subtypes of the condition. Thus broad questions were developed in order to include a range of specific research questions, with the focus removed from a single disease subtype. After discussion it was suggested that strategies should not only include treatments but also prevention, so that lifestyle or environmental strategies to prevent development of chronic ENT infections or inflammatory conditions were included.

The research priority 'define different variations of disease,' was felt important as it provided knowledge for improved diagnosis, allowing for 'personalised medicine' with treatments based on these specific diagnoses, risk factors and individual disease markers. This would speed up diagnosis of rhinosinusitis as both patients and healthcare professionals noted this may come too late, exacerbating conditions and causing distress to patients. They felt that this was due to a lack of basic understanding of conditions, inadequate sharing of the knowledge that we do have, and failure to appreciate the significant impact of the condition on quality of life. Thus the basic understanding of conditions was important. It was also recognised that agreed outcome measures relevant to patients and professionals were needed to inform future research, to ensure that it was of value and would have an impact on clinical practice. The combination of the ideas about defining disease, treatments and outcome measures was felt to be a good basis for a research agenda.

There was firm agreement that antibiotic misuse and its impact on antibiotic resistance is a major issue. It was noted that there are guidelines on management of ENT infections in primary and secondary care; these may need to be updated and more strategies to improve their implementation need to be developed.

Loss of smell and taste, and the importance of improving knowledge of its causes and measurements of function, were raised by patient survey respondents. Anosmia has a significant impact on quality of life, and this should be reflected in outcome measures of future research. A loss of sense of taste and smell were recognised as potential indicators of neurodegenerative disease, such as Alzheimer's and Parkinson's disease, and these associations would benefit from further investigation.

It was felt that there were two missing questions:

- Cell-based therapies for sensory ENT disorders; this was raised across all areas and will be incorporated in this topic too.
- Patient representatives were particularly interested in what patients can do to improve their own care and that developing information on this would be of benefit.

There were many questions raised in the survey about allergies such as seasonal and perennial allergic rhinitis, and in particular the role of immunotherapy. These have not been specifically included in the final agenda as colleagues in immunology and other allied medical specialists in collaboration with ENT and primary care have active research programmes already addressing these areas.

Reasons for these choices

A robust research agenda should balance basic science and clinical research.

Research aims and outcomes need to be agreed to develop high value research.

Broad ideas were developed in order to include a range of more specific research questions, with the focus removed from a single disease subtype.

These conditions are common in primary and secondary care.

There is a large variation in management of these conditions and inconsistent advice for patients.

Head, Neck and Airway Problems

The Priorities

- What outcome measures and instruments should we use for research into head, neck and airway disease, both benign and malignant?
- What is the optimal management for adults with OSA?
- What is the optimal management for adults with voice problems?
- What is the role for improved diagnostics in head, neck and airway conditions?

Developing agreed outcome measures that are relevant for patients and clinicians was an important issue raised across the topic areas. The importance of understanding the impact of head, neck and airway problems on patients and determining what is meant by optimal management was highlighted. This discussion originally focused on benign head and neck conditions, but it was felt that this was relevant and important for head and neck cancer too. Agreeing on outcomes for future research increases its value as it allows study results to be compared and combined.

Obstructive sleep apnoea (OSA) in adults was highlighted as an important area for research. This affects a large proportion of the population and has a significant impact on health, quality of life and safety of individuals. It was felt that optimal management of OSA should include self-management and patient education, as this could have the added benefit of reducing the burden on secondary care, making the patient pathway more efficient and cost-effective. It was recognised that although treatments such as CPAP are available for OSA, these are of variable benefit for patients and that there is scope for improvement in the management of this condition. In recognition that patients with OSA often have comorbidities, it was felt that there has to be better communication and collaboration between disciplines both in the management of patients and in research about this condition, and to consider the patient as a whole.

Reasons for these choices

Agreed outcome measures will improve the value of research investment and ensure that the results are relevant to patients.
OSA was highlighted due to the large clinical burden of disease, and the potential to develop appropriate pathways that avoided inappropriate referral to secondary care.
Voice problems are a substantial area of unmet need for patients.
Improving diagnostics will have an impact on patient care, outcomes and quality of life.

The management of voice conditions was felt to be a significant area of unmet need, with patients uncertain as to what treatments were available to them and how to access them, and with variation in management and access to services across the country. Current management has been largely based on “received wisdom” and the evidence base needs to become more robust. Although this does not affect the same numbers as OSA, patients felt that the impact on individuals was significant. The voice was felt to be important to personal identity; conditions affecting the voice had a potential impact on employment, social interaction, and wellbeing.

Accurate diagnosis of head, neck and airway problems is the first step leading to appropriate management, which compliments the priorities that focus on appropriate management. Improved and more rapid diagnosis relieves the stress on patients and reduces the added health problems due to delay.

Further head and neck cancer questions were raised by survey respondents, but many of these were already the subject of research in progress by cancer researchers and therefore were not included in the final agenda.

Creating a Research Culture in ENT, Hearing and Balance: Towards a Strategic Research Agenda

Throughout the development of the research agenda, from the initial data gathering by survey and focus groups, to the in depth discussions from the Expert Forum and Consensus Conference, key ideas about what the final agenda should incorporate and strategies for implementing it emerged. Together they form the seventh theme of the framework, ‘Developing a Research Culture in ENT, Hearing and Balance’ and will inform the next steps after the launch of this agenda.

Patients and professionals wanted this agenda to contain:

Patient-Centred Research and Self-Management: Putting patients at the centre of research was seen as key to this agenda. Patients and carers have been central to developing this agenda; they have been involved in every step of the process. Ongoing collaboration with patients and carers to deliver the agenda and develop the research projects will ensure that future research in ENT, Hearing and Balance is patient centred. Patients voiced the importance of better communication and sharing knowledge between healthcare professionals and with patients in developing patient pathways for common ENT, Hearing and Balance conditions. Patients particularly wanted research that would include self-management and peer-support as part of management strategies.

Research Leading to Sustainable Health Care: Ensuring that research leads to the development of sustainable high value health care in ENT, Hearing and Balance in a system that is recognised as stretched, with growing demand placed on it, was seen as an important goal throughout this initiative. Sustainable health care depends on improving the overall health and wellbeing of the population, and encouraging people to take responsibility for and manage their own health as well as developing efficient, cost-effective and high value services.

Novel Therapies: The development of cell-based and molecular therapies across ENT, Hearing and Balance conditions was seen as a long term but important research priority by both patients and professionals. It was recognised that it would take time for these novel therapies to find their way into clinical practice and provide benefit for patients; these long term strategies were considered an important balance to some of the shorter term research priorities.

In order to implement this agenda, consideration needs to be given to the following:

Capability and Capacity: To implement this research agenda and grow the workforce to develop and deliver the projects, there needs to be understanding of current capability and capacity for research in ENT, Hearing and Balance. Mapping current research activity across the translational pathway - who is doing what research and with whom do they collaborate - is necessary to see where further growth and development is needed. Close collaboration with the NIHR Clinical Research Network and its ENT group will be key to the planning of research carried out in the NHS. Importantly, the resources needed to support the advancement of clinical academics in ENT, Hearing and Balance needs to be mapped against what is currently available in order to identify them and the areas needing further development. Future researchers will need guidance and mentoring; the regional ENT trainee research collaboratives and Interact, their recently established national working group supported by ENT-UK, can play an important role in this process.

Collaboration: Patients with ENT, Hearing and Balance problems present to multiple health care disciplines and across a variety of health care settings. In order to develop and deliver the high value translational research that has the potential to change practice, research collaborations need to be formed across both health care and academic disciplines. Key clinical collaborations considered were across community, primary and secondary care through a variety of specialties including GPs, Physiotherapists, Paediatricians and those caring for the elderly. Key academic collaborations discussed were with Health Informatics, Innovation and Implementation Science and Health Services research. The need for expert qualitative input into the traditionally quantitative field of ENT, Hearing and Balance research was felt to be important. So was seeking collaborations to help span the gaps along the research pathway, improving translation of research from bench to bedside. This approach will facilitate the breakdown of the traditional silos of research and clinical care to develop knowledge and services that are sustainable in modern health care.

Developing Data Collection Platforms: Embedding research in day-to-day clinical practice and collecting and using "real world health data" to develop knowledge that is relevant to patients and professionals was raised throughout the initiative. This was described as developing electronic health records that capture information that is both applicable to clinical care as well as to research, and as developing databases or registries of specific ENT, Hearing and Balance conditions and interventions; this is the concept of developing data collection platforms. These will require significant resources and collaboration with the operational side of the NHS to integrate them into existing and future IT systems.

Outcome Measures: The need to gain a better understanding of the impact of ENT, Hearing and Balance conditions on patients and their families was raised across the whole spectrum of the research themes and topics. It was felt important that clinicians and researchers should work with patients and carers to decide which outcomes to include in future research. The development of so-called 'core outcome sets' across a range of conditions and interventions requires a strategic approach with patient and professional organisations deciding which conditions to prioritise and how to ensure that they are kept up to date. Careful thought needs to be given as to how best to secure and effectively use the financial and human resources to do this. One of the benefits of this being a strategic priority is that it can give rapid return on investment as these 'core outcome sets' can be developed in a relatively short time frame and have wide applicability.

The Team

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