

Steering Group

The steering group is responsible for guiding the priority setting partnership and comprises patient, clinician, research representatives.



Dr Helen Henshaw (PSP coordinator)
Senior Research Fellow, NIHR Nottingham Hearing BRU

Helen studied at the University of Leicester, gaining her PhD in Psychology in 2011. She began her translational hearing research career at NIHR Nottingham Hearing Biomedical Research Unit in September 2009, and works alongside clinical and academic colleagues in the Habilitation for Hearing Loss team. Their research aims to evaluate novel interventions for adults with hearing loss and those with whom they communicate.



Helen initiated the James Lind Alliance Priority Setting Partnership (JLA PSP) for Mild-Moderate Hearing Loss together with colleagues at the BRU (Dr Melanie Ferguson) and the user organisation Hearing Link (Linda Sharkey) in 2013. She coordinates the PSP, which is guided by the Steering Group. The first Steering Group meeting for the mild-moderate hearing loss PSP took place in summer 2014.



Dr Melanie Ferguson (Clinical Science/Research representative)
Consultant Clinical Scientist (Audiology), NIHR Nottingham Hearing BRU

Mel Ferguson is a consultant clinical scientist (audiology) and research lead at the NIHR Nottingham Hearing Biomedical Research Unit in Hearing. The overall research aim of her research programme is to promote healthy hearing by reducing activity limitations and participation restrictions using a holistic approach to habilitation. This is based on three primary themes (i) listening and cognition, (ii) multimedia educational support, and (iii) patient-centred care, which includes evaluating interventions for people with hearing loss (e.g. auditory-cognitive training, interactive education on hearing technology and communication, and motivational engagement).



Prior to April 2009, Mel was head of the MRC Institute of Hearing Research Clinical Section in Nottingham where she carried out research on auditory development in primary school-aged children, specifically characterising the nature of auditory processing disorder. Previous research at Medical Research Council Institute of Hearing Research included early adult hearing screening and evaluation of the modernisation of hearing aid services programme. She is the lead for the British Society of Audiology Learning Events group, lead examiner for the British Academy of Audiology Higher Training Scheme Research Methods module and immediate past Chair of the British Academy of Audiology Higher Training sub-committee.



Linda Sharkey (user organisation representative)
UK Director, Hearing Link

Linda is the UK Director at Hearing Link, a UK hearing loss charity, and is the user organisation representative in the JLA PSP for mild-moderate hearing loss. Linda has spent many years in the hearing-care sector, originally working as an Audiologist in the NHS in Scotland before joining the Hearing Link charity in 2007. Her current areas of interest are hearing rehabilitation, self-management and volunteering.



Linda's UK-wide role means that she can often be spotted outside of her native Scotland in the course of her duties. In her spare time, Linda enjoys netball and writing.

The James Lind Alliance

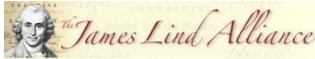
The priority setting process is overseen by a representative of the James Lind Alliance (JLA) as a neutral facilitator, ensuring transparency and equal input from patients, carers and clinicians.



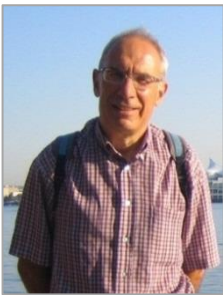
David Crowe (James Lind Alliance Advisor)

David is a James Lind Alliance Advisor (JLA) working with the mild to moderate hearing loss priority setting partnership; he is also the JLA Advisor for Bipolar and Cavernoma partnerships. David is an experienced and passionate Consultant, with a background of organisational development and change in both the private and public sector. He has worked at a senior level within different organisations for over 15 years including the NHS at national and local levels, for over 12 years as a freelance Consultant, and joined the JLA Team in 2014.

David has extensive experience of working with the complexities of diverse subcultures within large organisations, and the “growing pains” of smaller organisations. He has worked with a wide range of research organisations in project management and team development. He has a real passion for his work, looking to facilitate authentic sustainable change in work with groups and individuals that can be proven and evidenced. David is a member of the Chartered Institute of Personnel and Development, a trained Coach, and a member of the Association for Coaching.



Patient representatives



Robin Wickes (Patient/Public representative)

After many years as a consultant in the IT industry Robin took early retirement in 2008, largely because of an increasing hearing loss. Since then, his hearing has continued to go downhill very gradually and his level of hearing loss is now at the severe end of moderate.

For the past five years Robin has been a keen volunteer for several hearing organisations including Hearing Link and Action on Hearing Loss. His volunteering activities are varied and include providing face-to-face advice and emotional support to deaf people, manning stands at exhibitions and giving talks to all sorts of audiences – both deaf and hearing – about deaf-awareness and the support available for people with hearing loss. In these volunteering roles, Robin’s moderate hearing loss has been quite a useful, making him “in-betweeny”. On the one hand his hearing loss allows him to empathise with and relate to deaf people, while on the other he can still usually hear well enough to be able to communicate in the hearing world.



Jean Straus (Patient/Public representative)

Jean is becoming an expert at being a person who can’t hear. She lost her hearing suddenly. 12 years ago a debilitating incident of dizziness and tinnitus, left her with an accompanying permanent loss of hearing in her left ear. Jean got a hearing aid. Then, in the middle of the night, several years later, Jean awoke to discover that her good ear had more or less ceased being a hearing ear. In both instances she was subjected to a battery of medical examinations to rule out anything deemed more sinister than hearing loss. As it happened suddenly, Jean took immediate action, attending to her hearing loss. She believes this might not have been the case if the hearing loss had been gradual.

As often happens when a person is afflicted with a new condition, Jean tried to understand what was going on. In doing so she became a volunteer for Hearing Link and Action on Hearing Loss, as a reader, writer, campaigner, and speaker. When Jean lost her hearing the first time she was working as a teacher of secondary pupils with mental health problems. In retirement, Jean is able to follow what interests her giving her life structure and purpose and feels her hearing loss campaigning and research are making a difference.



**ACTION ON
HEARING
LOSS**

**Gemma Twitchen (Action on Hearing Loss representative to July 2015)
Senior Audiology Specialist, Action on Hearing Loss**

Gemma has over ten years' experience of working as an audiologist in the NHS with adults and children. She studied audiology in Nottingham and at the Royal Devon and Exeter Hospital where she continued to work as an audiologist for several years post qualification. She is currently part of Action on Hearing Loss' research and policy team supporting the organisation with specialist knowledge about audiology, hearing loss and tinnitus. She is also the key audiology spokesperson for the charity and has been interviewed by major print and broadcast media outlets.

Gemma has a passion for improving ear and hearing health in the developing world and in 2011 she volunteered in Malawi to support the country's only Ear, Nose, Throat doctor (ENT) to deliver audiology services for the entire 16.5 million population. Gemma is returning to Africa at the end of this year to volunteer as an audiologist for the charity for six months where she will be supporting and training hospital staff who are providing basic audiology care.



**ACTION ON
HEARING
LOSS**

**Louise Hart (Action on Hearing Loss representative, July 2015 onwards)
Senior Audiology Specialist, Action on Hearing Loss**

As an audiologist that works at Action On Hearing Loss and also sees NHS patients, the issues for those with mild to moderate hearing loss are only too often apparent. Each individual is affected differently by their hearing loss. Taking an overarching view of how mild to moderate loss affects the population (often perceived as a minor impact) and making gross assumptions using other health examples will not contribute to needed quality of life improvements for these individuals. Factors such as other co-morbidities, nature of their loss, lifestyle etc all affect how people interact with their auditory environment. Better research and targeted research into the effects of mild to moderate hearing loss looking both the short and long term affects will help us as audiologists to provide a more effective outcome for our mild to moderate hearing loss clients. Also targeted improvements in technology can only be a bonus to this population.



 **Cochrane
UK**

**Sarah Chapman (Cochrane UK/Patient representative)
Knowledge Broker, (Cochrane UK)**

Sarah's work at the Cochrane UK focuses on sharing Cochrane reviews and other high quality health evidence in ways that help as many people as possible to use it to inform their decisions about health. She is the editor and main blogger for their weekly blog, Evidently Cochrane (www.evidentlycochrane.net), and tweets for @UKCochraneCentr. Sarah also runs workshops on using social media to encourage engagement with evidence.

As well as exploring ways to share health evidence widely and encourage engagement with it, Sarah has a keen interest in ensuring that research is shaped by the questions patients want answered. She has a personal interest in hearing research, as she has had hearing loss, for which she wears hearing aids, since early adulthood. Before joining the UKCC in 2007, Sarah worked for a number of UK-based institutions, including the University of Oxford and the Royal College of Nursing Institute, conducting systematic reviews in many areas of health. She is also a qualified nurse and has a degree in History from the University of Oxford and in the history of women's health and illness in early modern England (MPhil, University of Reading).

Clinician representatives



Natalie Bohm (ENT representative)
Clinical Lecturer, University College London

Natalie is an Academic Clinical Lecturer in ENT Surgery at UCL/UCLH. In 2011 she was awarded the Darzi Fellowship in Clinical Leadership and Quality Improvement where she worked with London Commissioners to develop evidence-based care pathways for ENT patients. She subsequently collaborated on developing a NICE accredited process to design national Commissioning Guidance for surgery. Natalie implemented this process with ENT UK to develop nationally agreed guidance for the commissioning of services in high volume areas of ENT. Natalie has an interest in patient and public involvement in the development of evidence and service provision and has worked with patient and public groups to understand their views and needs in the development of electronic health records. Her recent work is in the use of group processes to align the strategic development of research and its implementation in ENT and associated specialties. Natalie is currently working with ENT UK, the British Academy of Audiology and the British Society of Audiology on GENERATE, an initiative to develop a national research agenda for ENT, Hearing and Balance care.



Barry Downes (British Society of Hearing Aid Audiologists representative)
British Society of Hearing Aid Audiologists

Barry has been involved in independent sector adult hearing care in a variety of capacities since 1977. In addition to being the current President of the British Society of Hearing Aid Audiologists (BSHAA), he is a long serving member of the BSHAA Council and is currently Chair of the BSHAA Professional Development Committee. He is a Panel Member and Registration Assessor for the Health and Care Professions Council (HCPC). He is also a member of the British Society of Audiology Professional Practice Committee. His current occupation is Professional Services Manager for Amplifon UK.



Barry lives in Cheshire and is married with two daughters and four grandchildren. He has lived with hearing loss and tinnitus for more than 30 years.



Dr Helen Pryce (British Society of Audiology representative)
Specialist Hearing Therapist and Senior Lecturer, Aston University

Helen has worked in adult rehabilitation for over 20 years and has clinical interests in adaptation to hearing changes, tinnitus perceptions and medically unexplained hearing difficulties. Her research stems from these clinical interests and centres on the patient experience, patient preferences and coping with all levels of hearing loss. Her most important contributions have been to describe the complexity and range of interventions required to address communication problems in residential care settings.



Helen develops and teaches new programmes in Healthcare Sciences and Hearing Therapy with the University of Manchester, UCL and Aston. Helen is a Trustee of the British Society of Audiology (BSA) and represents BSA at the Alliance of Hearing loss and Deafness and the Academy of Healthcare Sciences.



Sue Falkingham (British Academy of Audiology representative)
Audiologist in Education and Training at Starkey Hearing Technologies

Sue has been a member of the Training and Education department at Starkey since 2010. After qualifying as an audiologist at Bradford Royal Infirmary in 1992 Sue continued to study for a BHSc Hons in Audiology Studies and then completed a Diploma in Hearing Therapy in 2000. During her career, Sue has worked at a number of high profile companies within audiology and most recently HIMSA working on the development team for Noah 4 software in Denmark. Sue has been committed to Professional Development within Audiology for many years and is currently a Board Director of BAA.



Working for Starkey Hearing technologies Sue has a clear understanding of both public and private sector hearing aid provision and is interested in cutting edge hearing aid technology and the benefits that can provide to hearing aid users.