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PANDA: A case-study examining a successful Audiology and Otology Patient and Public Involvement and Engagement research group

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PANDA: A case-study examining a successful Audiology and Otolaryngology Patient and Public Involvement and Engagement research group

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Abstract

There has been increasing involvement of patients and members of the public in research; however, case studies describing patient research groups with hearing loss are non-existent. Such case studies will be valuable, enabling evidence-based dialogue and promoting best practice in the engagement of patients, the public and researchers. This paper aims to discuss this practice. The absence of such dialogue may hinder initial efforts by researchers to realise the potential of Patient and Public Involvement. The objective of this study was to set up and run a patient and public involvement and engagement group in audiology research, use the lessons learnt to provide a guide to others in a similar situation, and prompt the dialogue referred to above. A successful group with over 70 members has been set up, with an average attendance for meetings of between 15 and 20 participants. Feedback from the group indicates that members are happy with, and benefit from, their involvement and particularly appreciate the concern of those managing the group better to accommodate sensory impairments. Additionally, the group has improved research output for specific grant applications. We conclude that although this case study contains elements unique to the setting (a large NHS Trust in the Midlands), it also provides transferable observations and resources that can be adapted and utilised by researchers working with patients and the public with hearing loss.

Keywords

Audiology, otology, research, PPIE, patient engagement, case study

Introduction

Increasingly in the UK there has been a paradigm shift away from the paternalistic doctor-patient relationship and a move towards a patient-centered model of care which emphasises patient choice.¹ Alongside this shift, the role of the patient and members of the public in research has also gained prominence, and there is now a wide body of work, case studies and articles dedicated to promoting the benefits of involving members of the public and patients in co-producing research and services.^{2, 3, 4, 5} Additionally, funders such as the National Institute of Health Research (NIHR) have promoted patient and public involvement and engagement in research (PPIE) through policies, reviews and a dedicated web resource "INVOLVE"⁶ in a drive to increase the use of PPIE.⁷

However, with regards to audiology-specific PPIE in research, there is a very limited set of resources to utilise; a literature search did not produce any relevant articles. This does not necessarily indicate that there is no PPIE in audiology research. Like the majority of PPIE in research, it is probably under-reported and goes unrecognized.⁸

Our case study intends to document the general Audiology and Otolaryngology Research PPIE group that our team implemented, and a study-specific Audiology and Otolaryngology Research PPIE sub-group that developed from this. The aim of this literature is to address the scarcity of information available by offering advice and guidance for researchers with similar intentions of setting up and running an audiology specific PPIE group.

Background

The Audiology and ENT Departments at the Trust
The service catchment area for the Audiology Department encompasses the entirety of Birmingham and its population of 1.14 million.⁹ More specialised aspects of the Audiology service, such as the Cochlear Implants (CI) and Bone Anchored Hearing Systems (BAHS) programmes, see patients from further afield.

The Audiology and ENT departments have a growing research portfolio; one of the recently concluded projects examined the feasibility of a Middle Ear Microphone (MEM) using both cadaver work and a clinical trial to determine the best placement and the capabilities of the

microphone in-situ. The department's CI patients took part in the trial, which had a PPIE element.¹⁰ The research team now successfully oversees and runs a number of commercial and academic trials. This research growth has helped the department win an award in 2019 for most improved specialty from the West Midlands Clinical Research Network due to the teams' contribution towards increasing patient research recruitment in the area. Despite the Audiology and ENT departments' increase in quality and quantity of research output and its large population of patients, there has not previously been an attempt to create an Audiology and Otology research specific PPIE group at the Trust. The Department was encouraged to create such a group by the policy framework described above, by the large number of existing patients who it hoped to engage, and also by the existence of the Birmingham-based 1000 Elders, a flourishing group dedicated to bringing researchers and older adults together to carry out research into how we can age more healthily.¹¹

Objectives/Aims of the Audiology and Otology PPIE Group

In preliminary discussions within the research team, the benefits of developing the Audiology and Otology specific PPIE group were expected to be twofold. Firstly, when the research team proposed a PPIE group, they anticipated gaining the following advantages:

- Develop research proposals and creating a list of research priorities
- Choose between alternative directions for research.
- Identify otherwise unanticipated problems as well as solutions to overcome them.
- Confirm the right decisions have been made, thus instilling confidence in those decisions.
- Understand what matters most to patients/carers and the public, providing a rationale for a project as well as personal motivation.⁵

In addition, we expected that we would:

- Improve the quality and accessibility of study related patient information leaflets, infographics and the plain English summary.
- Engage the wider audiology and otology teams with PPIE work and increasing their understanding of its usefulness and importance.
- Develop the Trust's research reputation by utilising the PPIE group to improve the research we are facilitating and increasing the likelihood of its success.

Establishing a clear goal in mind for the PPIE group prior to its creation was seen as an essential step to ensuring that

it would be able to provide meaningful contributions to research. The Public Involvement Impact Assessment Framework¹² stresses the importance of careful planning, prioritisation and impact reporting, which can influence patient involvement and reduce barriers. This is supported by Dudley's⁴ qualitative study assessing the impact and patient involvement; quotations reproduced from trial managers and chief investigators show that when it was added to a study without preparation or consideration of the aims, PPIE tended to be tokenistic and the interviewees could not recall any benefit.⁴

Our discussions recognised that attitudes to PPIE among researchers are mixed, with some fearing that patients/public lack of specialist background means that they are unable to engage in a meaningful way with the research, and that PPIE is essentially nothing more than a box-ticking exercise.³ By demonstrating that rigorous and meaningful engagement with patients and the public can lead to improvements in research in the Audiology and ENT departments, the team aimed to establish the groundwork for further significant interactions between patients/public and researchers to overcome the resistance to utilising PPIE.

From a patient perspective, our vision is that patients will gain knowledge about NHS policies and procedures and new treatments in addition to the research process. PPIE members can develop confidence and new skills such as presentation and communication techniques and will be able to present on their work to the Trust's Audiology and Otology PPIE group and more widely as occasion requires. The research collaboration formed will help the NHS Trust's portfolio by demonstrating a focus on research projects that are important from both clinical and patient perspectives.

Creating PANDA

Having identified the need and potential value of an Audiology and Otology specific PPIE group, the team developed a number of strategies to advertise the initiative to a broad patient population as something interesting and attractive. Given the population diversity in Birmingham and surrounding areas and that hearing loss affects all, our priority was to recruit as broad a range of interests, ages and ethnicities to the group.

We were inspired to give our group an animal name by a similar PPIE group at the Trust for uveitis called PInGU (an acronym for Patient Involvement Group in Uveitis), which used a penguin as its logo. Our consideration was that a group with an animal logo/name would stand out from the usual waiting room posters of generic patients and medical images. By not using a predominantly ear-focused picture, we would not be reducing members to the status of their hearing loss. We chose the name 'Patient

Advice iNformation and Discussion in Audiology' Group to form the acronym PANDA. From this, we produced succinct and eye-catching information posters using pictures labelled for reuse, i.e., no copyright and large text to facilitate easy reading. See Figure 1 (Appendix) for an example of the PANDA poster. We placed these in public areas, both in the hospital and in local communities, and Figure 2 (Appendix) demonstrates how the PANDA poster compares to standard hospital posters.

Additional actions to disseminate information regarding PANDA included contacting the hospital's communication team to circulate an email, which was sent to over 20,000 staff members; advertising on the 'Action for Hearing Loss' monthly newsletter; and engaging in face-to-face conversations with patients and staff visiting the hospital at our stand on the Birmingham Health Partners Research Showcase day. The team explored creating other ways of publicising membership of the new group, such as Panda key-rings.

In addition to this, the research team liaised with a number of individuals and departments to advertise the group further. These included other researchers at the hospital; the organisers of the University of Birmingham 1,000 Elders Group, referred to above, so we could take advantage of their distribution list of participants willing to receive notification of studies and provide comments; and the NHS Trust's Black Asian Minority and Ethnic (BAME) chair to discuss linking their population to the patient group.

It is difficult to identify which methods had proved most successful in attracting members, as most messages to the dedicated Audiology and Otology specific research email (O&AResearch@uhb.nhs.uk) did not indicate where they had seen the group advertised. However, spikes of interest were noticeable after the information was circulated to the 1000 Elders group and also following information being posted on the 'Action for Hearing Loss' newsletter which happened as separate events.

Meeting Schedule and Times

Quarterly meetings were set up, and after feedback from the first meeting as to preferred times, the timings of these were amended to include rotating time slots in the day and evenings, to cater for the different commitments of likely participants.

Guidelines

Prior to the meeting, INVOLVE (2020) guides were e-mailed to everyone who had an interest in being part of the group; they comprised of the following:

- PIP1 A Quick Guide
- PIP1 What it is all about
- PIP3 How to get actively involved
- PIP4 Jargon Buster

The response to our initial PANDA meeting was better than the team anticipated; our first meeting had 35 members of the public in attendance; we had originally expected 10 attendees. The second and third meetings also held a high attendance rate which was encouraging given the technical problems at the first meeting (see below).

Outcomes for PANDA

Throughout the process of interacting and holding the group meetings, all participants are provided with feedback forms which are continually monitored and used to improve the service. The feedback from the initial meeting suggested that participants had found the first PANDA meeting overall a positive experience with the following comments being captured:

- 'very informative, both of present and future plans'
- 'any involvement to help advance research is worthwhile'
- 'it wasn't death by power-point, information was concise and clear and relevant'
- 'I actually feel involved in positive research'
- 'feel that the potential of studies would be very beneficial to healthcare'
- 'friendly and approachable, informative group'

The main issue that was highlighted repeatedly in participants' feedback was regarding the loop system, currently used by the Audiology department. Most of this feedback was negative. This prompted a wider discussion with participants saying that nearly everywhere they went the loop system did not work well, making it exceptionally hard to participate in conversations in group situations. The Audiology department has followed up on this, first by moving to what is an over-size room which has a built-in loop, but just as importantly, taking up the issue with the NHS Trust which has identified that there is insufficient support for hearing aid and loop system users on-site. This issue is particularly important in outpatient areas. The PANDA Group has thus potentially achieved an immediate quick win in the NHS Trust.

A second important issue highlighted was that despite many of the speakers having an audiology or otology background and being accustomed to speaking to people with hearing loss, basic errors such as covering the mouth or turning away from the audience while speaking were made during presentations. To address this, all speakers are now sent the Hearing Access Protocol (2020) created by the social enterprise 'Ideas for Ears,' run by people

with hearing loss.¹³ Ideas for Ears also have a comprehensive evaluation form that we used at the second meeting to measure how well we had addressed concerns over participants' inability to hear; this was returned with a 100% positive response rate which was reflected in the feedback forms that were provided in the session.

Further issues and their outcomes arising from discussions with PANDA PPIE members are highlighted in Table 1 (Appendix), including requests to hear about specific types of research and improvements to patient services.

Creating the Study Specific Rapid Ear PPIE Sub-Group

Prior to the development of the PANDA initiative, the research team had considered ways of including an independent 'patient' and 'public' perspective in the research, for example by drawing in retired clinicians, but had not found a satisfactory method. PANDA provided obvious advantages and ways forward to provide. After the presentation at the main PANDA PPIE group referred to above, a study specific PPIE Group was established to evaluate and contribute to a specific grant application "RAPID EAR" as it progresses from start-up to completion. The team made the decision to adopt a quite formal application process to recruit to a RAPID EAR PPIE group. After presenting the novel research at the main PANDA meeting, the researchers asked:

- Does this sound reasonable to you?
- Do you think people would want to join the study?
- Are we interested in things that matter to you, e.g., length of time waiting to be seen?

Responses at the meeting suggested the research was very valuable. After the meeting, an e-mail was then circulated with a plain English summary and a basic application form inviting those who were interested in applying to be a Rapid Ear PPIE member to complete a simple application form setting out their interests and experience. We received six applications, all of which were successful. The group thus comprises six people, five PPIE members, and one PPIE representative, who will take a more public role in speaking, attending research meetings and disseminating information.

Outcomes for the RAPID EAR PPI Group

The group has had a number of successful discussions in June and August 2019 in face to face meetings and via email on the following issues:

- The title of the study (the original title 'RED EAR' was not considered patient friendly).

- The way members' skills and experience (photography, drafting of research proposals, marketing and design) could be useful for the Rapid Ear application.
- Advising and redrafting the Plain English summary and the study pathway infographic.
- Interrogation of the clinical team's study design (e.g., the use of Patient Reported Outcome Measures as a primary endpoint, the Trusts that would be approached to participate).

The issues arising, actions taken and outcomes are listed in further detail in Table 2 (Appendix)..

Commentary on the RAPID EAR PPIE Group

Using a PPIE group to look specifically at certain Research Projects has been very successful in helping to create new ideas and a better research design. Clinical researchers and PPIE members agree that there has been a real engagement by all in the development of the project, and the outcomes to date have all been positive, leading to improvements in the RAPID EAR study design and application. The RAPID EAR application was submitted on January 14, 2020, with the PPIE representative being a co-applicant. The group will further help by reviewing the study methodology and will be required to analyse each step of the project as it progresses. The group will also include looking at a clinical trial, the design and production of information leaflets for GP surgeries and the design and resources of training packages for the technology being used.

Two of the applicants were also completely new to the role of PPIE in research. By engaging with them and providing them with the experience and training to become a valuable member of the team, we hope that even after the project has ended, they will have the ability and confidence to go on and do further PPIE work. Involving participants from a number of different backgrounds allowed the team to discover a number of skills and attributes within the PPIE group that contributed in areas that the research team is less experienced in, such as marketing and photography skills. This again demonstrates the benefit of including perspective beyond the academic when reviewing and working on research.

Using PPIE members to help evolve and devise new research ideas and support, through either the PPIE members' ideas or working on the clinicians' proposals, is clearly a needed collaboration. Due to the success of this, the research team continues to work together with PPIE members to develop further research ideas.

Funding

A key element in being able to carry out the PPIE groups is funding. The need for funding was first highlighted when the research team began to explore options and identified that there were financial requirements for some services they wished to provide. This is something that many teams struggle with. A recent paper identified that one of the most challenging aspects for researchers is a lack of funding and time.¹⁴ Realistically budgeting for PPIE is therefore key to optimising any funding that is available. In our case, the team was successful in applying for support from the Patient Involvement Funding stream from Research Design Service West Midlands (RDS WM) to provide initial funding and support to set up a PPIE group. We have been able to provide support for one large PPIE and a second smaller PPIE sub-group throughout 2019.

To continue the work of the PANDA PPIE group into 2020, the research team has looked at a number of funding streams. This has included approaching the Trust's charity for a small fund to continue the PPIE group, with feedback from the group through 2019 used to demonstrate the benefits to the Trust's patients. The team also approached the department's Audiology and Otology Research Group to ask for a small fund from its budget to continue work; positive interactions between clinicians that sit on the group and their experience of PPIE have made it more likely that this funding will be agreed. Funding for the RAPID EAR PPIE group will be costed into the grant application using the INVOLVE "Involvement Cost Calculator" Tool.¹⁵

Impact of PANDA

Why is impact important?

Without demonstrating that a group has impact, the PPIE can appear both a box-ticking exercise or a response to political correctness⁴ and tokenistic¹⁶ both to patients and researchers. As stated by Dudley, "objective techniques for evaluating impact [of PPIE] and its influences remains elusive in a process that is inherently relational, subjective and socially constructed."⁴ However, researchers are responding to this challenge; in 2017 a rigorous toolkit designed to demonstrate the impact of PPIE on research, GRIPP2, has been developed.¹⁷ As an alternative method, Dudley also notes the importance of nuanced assessments to judge the goals of PPIE use in research rather than a 'one size fits all approach.'⁴ Consciously structuring the way PPIE is involved in the project, reliably recording the detail of the engagement and particularly the impact of PPIE and feeding this back to the research project as a whole is important both to the PPIE group and to researchers to demonstrate the benefits of PPIE and the validity of its involvement in research.

Has PANDA had an impact?

The Audiology and Otology research team and the PPIE group are based in Birmingham at University Hospitals Birmingham; however, people got in contact from places as far afield as Exeter, Manchester and High Wycombe all asking to be part of the mailing list. This was so they could hear about the research and provide feedback even if they could not attend the meeting. A number of PPIE members spoke about research that the team had not previously heard of, and the team has started to make links with a number of academics/universities via the PPIE group members. It is clear that there is a demand for PPIE in Audiology and ENT, and that the existence of a PPIE group can not only bring together patients and public, but also draw together information and research that they have looked into themselves and enable it to be disseminated among a wider audience.

Speaking directly to patients about their experiences gave a much deeper insight into their everyday challenges, their wants and needs, and focuses that they felt were an issue, which are not always reflected in conversations with clinicians. The group has enlightened the Audiology team in a number of respects and has enabled the team to build invaluable relationships and source material for PPIE members. The team identified a number of areas in which the PANDA PPIE members improved the quality of engagement with research as previously outlined in the Study Results: Outcomes Section, and Table 1 (Appendix).

Due to the popularity of the initial PANDA PPIE meeting, we were able to engage with a variety of people that would otherwise not have heard about our RAPID EAR project. We were, therefore, able to recruit PPIE members to RAPID EAR from a very broad range of areas. Going forward, the PANDA group can act as a conduit for recruiting people into study-specific PPIE groups of a more specialised nature within Audiology. There is evidence that PPI can have a favourable impact on all stages of the research life-cycle.⁴ Thus, including the patient perspective throughout research from the start in trial design to the completion is essential. A team that does not introduce patient advocacy at the beginning of a project may not be able to utilise the useful support and adjustments that could have been added and made throughout the project to make a more robust application from the start. The changes made to the RAPID EAR research application on the basis of PPIE work (summarised in Table 2 (Appendix) were circulated to the Audiology and ENT staff members at a recent joint team meeting between two NHS Trusts. This prompted a very positive reaction from the meeting and we were later approached by an audiologist who had not previously used PPIE to utilise the PANDA group for a proposal regarding cochlear implants and groupwork.

Unexpected impacts also arise from the public presence in a Trust of well-structured PPIE groups. The work of the PANDA group circulated among researchers at the NHS Trust informally but was also recognised for its quality at research events in the NHS Trust and at regional level (see below). The main group focus is on research, as the group is based at a large NHS Trust and run by NHS staff, but there are opportunities to influence the quality of patient care with staff interactions, waiting rooms and clinics. As highlighted in Table 1, the Head of Patient Services sought advice from the group regarding improving waiting rooms areas for those with sensory impairments. Although this was not directly linked to improving research, it was an unpredicted outcome. Utilising the research group can also help to improve patient experiences in hospital. A benefit of the group is its ability to adapt and have different functions, all aligning to fundamentally benefitting patients and their care pathway within the hospital setting and beyond. As many patients are approached regarding research in clinic, or after clinic appointments, the quality of their care experience may indirectly influence their decision to participate in a trial or not; PANDA work can have a broader impact. In addition, a PANDA member had indicated their interest in purchasing listening aids for patients at the Trust. Such communication devices can be used by the audiology department and other departments that may have patient populations with hearing loss, including those associated with cancer (due to ototoxic side-effects of many cancer drugs) or head/neck surgery (where temporary hearing loss caused by middle ear congestion can occur after surgery).

Reflections and Key Learning

Throughout this paper, we have highlighted points to be considered for anyone running a service that involves patients with hearing loss. To summarise, these are:

- **Obtain a source of funding for the group.** For our PANDA group, although costs were kept low by using free rooms for hire within the Trust/organisation, not paying for travel expenses for members and providing minimal refreshments, i.e., tea and coffee rather than a meal, we still incurred some expenses such as paying for members to attend training and providing reimbursement for travel costs for speakers. It is important to note that initial funding does not need to be a large sum of money; with effective budgeting a small amount can go far.
- **Using a variety of means to circulate information about the group to maximise the number of relevant people who hear about it.** For PANDA, we have used online newsletters for external and internal websites, internal paper newsletters, emails, face-to-face at conference and research stands, and word of mouth via both colleagues and other PANDA

members. We are currently discussing writing a blog post for a hearing loss related website and looking at further community work.

- **A suitable room that is set up with a hearing loop and accessible equipment that can be used with the hearing loop.** This should ideally be tested before the first meeting by members of the PPIE group, or at least someone with a hearing aid, to ensure that it works and that the team is able to correctly set it up. Those with hearing loss are often adept at developing coping strategies to lessen the impact of their condition, but an Audiology PPIE group should be the last place where these are accepted.
- **Ensure that speakers are prepared and understand how to interact with a group with hearing loss who may be using either a hearing loop, lip reading, or a mixture of the two.** This can include providing handouts that summarise presentations or asking the speaker to summarise key points as they go.
- **Adjusting timings for the group, as necessary.** The Audiology and ENT department staff have been very flexible in staying twice a year past working hours (5pm - 7pm) to provide support for holding the PANDA meeting in the evening. This has enabled us to attract members of working age who would not otherwise be able to attend the meeting.
- **Fostering good relations with PPIE members** by being responsive to e-mails in-between meetings and remaining open to suggestions and feedback and following up on venues of interest that they suggest.

To date, the Audiology and Otolaryngology Research Department has won one award from Birmingham Health Partners at the Research Showcase for Best Patient and Public Involvement in Research (awarded by a group of PPIE members from different PPIE groups) and received a highly commended from the Clinical Research Network West Midlands for Patient and Public Involvement and Engagement. Although this recognises that PANDA has had positive results to date, we as a department are aware that there is still a need for improvement.

One key aspect that the team aims to improve on is the diversity of the patient and public involvement group. Diversity of members especially in the Audiology discipline can sometimes be difficult to initially attain. This was again highlighted when the research team was establishing the PPIE group. This is due to a multitude of reasons including items like participants being at work or without access to certain advertising platforms. The group has proven to be successful and helpful, both to individuals involved but also to the staff carrying out the research. However, there is still significant room for

improvement for introducing different patient populations to the group, especially individuals who are younger or infrequently represented in PPIE. Additional recruitment to the group from different populations should be considered through community engagement and collaboration with other partners, such as the BAME network. Providing an open forum in the hospital setting initially reaches the largest potential group of members and has advantages, as the technology required is more within our control but also comes with the practical limitations that can come from any hospital attendance (travel time, finding your way around a complex site, etc.).

Conclusion

Setting up a patient research involvement group can increase the success of research. This has been identified and shown in many projects.^{18, 19, 20} This case-study exhibits some of the ways in which involvement can be increased and improved in an Audiology and Otolaryngology arena, an area in PPIE that is currently lacking an evidence base despite the fact that hearing loss affects so many people. Increasing this knowledge and presence will only make the research better, which is something the team has evidenced above. It is understood that working in a NHS/hospital environment comes with a number of pressures and time constraints however knowledge of the right teams and support structures can aid in facilitating relationships and discussions more effectively.

We hope this inspires and increases PPIE representative groups nationally for the Audiology and Otolaryngology patient population, but also assists in offering suggestions on how to recruit and facilitate the introduction of such groups in Audiology, ENT and other medical disciplines in a hospital setting. The research team will continue the patient collaboration hoping to grow further and create more innovative and patient supported research.

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Appendix

Figure 1. Panda Information Poster



PANDA: Patient Advice
iNformation & Discussion
Audiology Group

**ARE YOU INTERESTED IN JOINING
AN AUDIOLOGY GROUP THAT:**

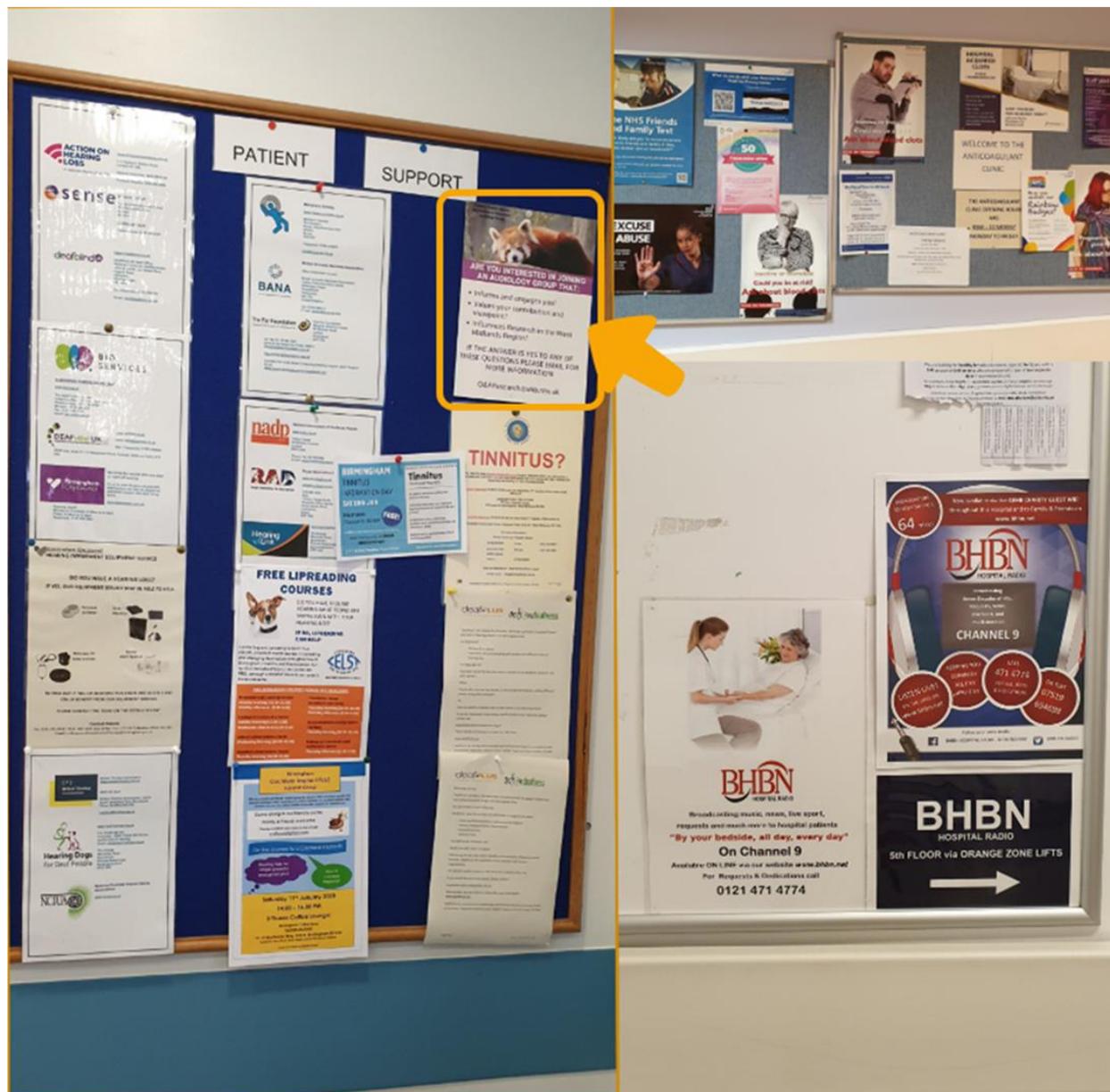
- Informs and engages you?
- Values your contribution and viewpoint?
- Influences Research in the West Midlands Region?

**IF THE ANSWER IS YES TO ANY OF
THESE QUESTIONS PLEASE EMAIL FOR
MORE INFORMATION:**

O&AResearch@uhb.nhs.uk

Appendix (continued)

Figure 2. Panda Poster in SITU



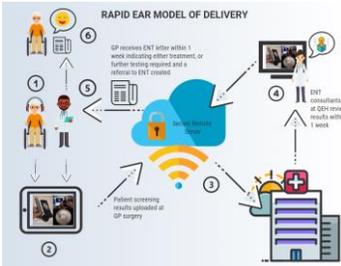
Appendix (continued)

Table 1. PANDA PPIE Meeting Outcomes

| Items Arising | Actions Taken | Outcome |
|---|--|--|
| Portable t-loop system used at the first PANDA meeting was not sufficient for those using a t-loop | University Hospitals Birmingham has one dedicated meeting room with a loop system, Lecture Theatre 3. This room holds approx. 250 people and the education department do not 'underbook' it. i.e. they would not originally offer the meeting room to our group of 40 people. However, after feeding back the negative comments we were allowed to book the Lecture Theatre 3 for all future meetings. | A Hearing Access Evaluation Form was circulated at the second meeting taking place in Lecture Theatre 3. There were nine responses to the question 'how well could you hear and follow the main speakers at this event meeting?'. Five responders indicated they could hear 'very well' and four responders indicated they could hear 'quite easily'. There were no responses under 'neutral' 'quite poorly' and 'very poorly'. |
| A number of comments were made about the difficulty in hearing speakers due to microphone use and inability to lip read due to speakers turning away at the first PANDA meeting. | One of the PANDA Group members forwarded a link to the Ideas for Ears website and their Hearing Access Protocol. This Protocol was circulated to speakers prior to the second meeting and will be circulated to speakers for all future meetings. | See above – no issues were reported with being able to hear. |
| PANDA Members had issues with the timing of 17:00 – 19:00 for the meeting due to the clash with rush-hour traffic and also dinner time for some members | Some members had indicated that due to work they were only able to attending meetings after 17:00. Therefore, it was decided to alternate meetings between evenings and afternoons to provide an opportunity for all members to attend. | The first meeting held at 17:00 had 40 attendees. The second meeting held at 15:00 had 20 attendees, most of whom had attended the previous meeting. It is difficult to determine if this is a natural drop off in interest after the first meeting, or whether the timings had affected attendance. This will be monitored and possibly re-evaluated going forward. |
| Members of the PANDA PPI group indicated interest in areas of research including Alinka Greasley's work with music and hearing aids the work of Aston University's PPI group | Alinka Greasley [University of Leeds] and Claire Wilkes [University of Aston] were asked to come to the PANDA meeting and talk about their work. | Alinka Greasley gave a talk on music and hearing aids which was well received by the audience. Patients/public were able to ask questions about their hearing aids and listening experience, and audiologists were able to ask questions and receive information about how to optimise hearing aids for music listening experiences. The Head of Audiology circulated the music and hearing aid information booklets for audiologist around the department and there was an increased awareness by audiologists of adjustments they could offer to optimise patient's hearing aids. Claire Wilkes gave a talk on the value of PPIE in training audiologists of the future. The talk was well received and Claire invited PANDA members to attend a PPIE day at Aston University of 18 th November. To date, eight of the PANDA members present, and one further member, have taken up this offer |
| Mandy Green, Head of Patient Services, wanted feedback and information on improving waiting room areas for people with sensory impairment. | Mandy Green came to speak to the PANDA PPIE group. Most of those present provided their own experiences and opinions on waiting room areas. This included: staff education; more loop systems; more visual cues; improved patient records. | Mandy Green took feedback collated from meeting to the steering group working on improving waiting areas. She is planning to report back to the group on changes made once these have been implemented. |
| The research team had an immediate need, namely to achieve PPIE in a new research project designed to test ways of more rapidly assessing those identified with hearing loss and perhaps other problems. The team were concerned how to recruit to a study-specific PPIE group "RAPID EAR". | The research team presented RAPID EAR to the PANDA PPIE group and took questions from the audience. | The further action relating to his project is described in the next paragraphs. |

Appendix (continued)

Table 2. RAPID EAR PPIE Meeting Outcomes

| Items Arising | Actions Taken | Outcomes |
|--|--|--|
| <p>It was noted that members of the group came from diverse backgrounds and might have a range of useful skills.</p> | <p>Member of the group were asked if they had any transferable skills, or skills they thought might be useful</p> | <p>The team outlined their skillsets. Member A is an amateur photographer and good with photoshop. Member B has been to be a marketing manager. Members C and D both have training experience. Member C has a lot of experience in writing and editing and sits on panels for various funders. Member D is a Professor of English and has experience in drafting academic research proposals. The team have utilised some of these skills already as noted within this table.</p> |
| <p>Members of the group discussed the project's original name "RED EAR"..</p> | <p>Members thought the title sounded scary and unsuitable for what the project entailed It was decided to rename the project based on the PPI feedback.</p> | <p>A number of suggestions were made by the PPI team including "HEARoes" which the clinical team really liked, but didn't think was reflective of the project either. The clinical team came up with Rapid Ear. Therefore the RED EAR project is now the RAPID EAR project.</p> |
| <p>Members of the RAPID EAR PPI group thought the original infographic was confusing.</p>  | <p>Via email exchanges the group discussed ways of improving the infographic. RAPID EAR. At the 29.08.2019 meeting the group discussed further edits.</p> | <p>PPI member PM, whose hobby is photography and photoshop, created new versions of the diagram based on this feedback. This radically revised version of the infographic will be used (minor edits still ongoing):</p>  |
| <p>One of the members of the RAPID EAR PPI group with experience of editing and writing plain English summaries identified that the current plain English summary for the grant application was still too complex.</p> | <p>Members agreed to collaborate in the revision of the plain English summary.</p> | <p>One member took the lead, editing the plain English summary from 457 words requiring a KS4 reading ability to 279 words with a reading ability of KS2. This included simplifying sentences and words used, using shorter sentences, and using bullet points. The clinician who had originally written the plain English summary reflected on the improvement and noted that 'there is a lot of added value in making [the plain English summary] more accessible'. Some further editing may be necessary to reflect changes as the project progresses to submission for funding but the final version will be based on the version agreed by the Group.</p> |
| <p>Rapid Ear members felt that the outcome measures originally chosen by the clinical team did not reflect what was important to them.</p> | <p>A selection of Patient Report Outcome Measures chosen as a primary endpoint.</p> | <p>All participants on the Rapid Ear study will now be asked to complete two questionnaires at baseline, 3, 6, 9 and 12 months after participating in the study. These questionnaires are the Hearing Handicap Inventory for Adults (HHIA) and the Euro Quality of Life Questionnaire (ED-EQ-5L)</p> |
| <p>Rapid Ear members discussed barriers to patients wishing to participate in the study and to outside bodies and funders supporting the study</p> | <p>The Clinical team agreed to approach a Trust in a rural area, such as Herefordshire, to be part of Rapid Ear, as well as one of the already suggested urban trusts.</p> | <p>To be confirmed, but likely that there will now be a mix of urban and rural sites chosen for Secondary sites, rather than exclusively as previously decided.</p> |