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"It gives me confidence and value. When working as a deaf person these were constantly undermined". Evaluating All_Ears@UoS patient and public involvement and engagement (PPIE) group to capture the perspectives of the group and of the researchers - three years on.

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Abstract

Background

All_Ears@UoS is a thriving patient and public involvement and engagement (PPIE) group that was established in March 2022. The ethos of All_Ears is an enduring partnership between researchers and people with lived experience of hearing loss and deafness to shape and inform research. This paper is an evaluation of impact, engagement and value of the group from both the group members and researchers' perspective. The UK Standards for Public Involvement were used a framework.

Methods

Two mixed-methods questionnaires were co-designed with members of All_Ears and shared via an online platform to gather feedback from both group members and researchers perspective. Each questionnaire combined rating scale questions to measure satisfaction across the six standards for Public Involvement and questions with free-text response to gather feedback and demographic data. Descriptive statistics were used to describe the satisfaction and demographic data. Reflexive thematic analysis was used to analyse the free-text responses.

Results

Strengths aligning with the UK Standards for Public Involvement were identified by both groups. Group members highlighted *Communication*, *Working Together*, and *Inclusive Opportunities*, while researchers emphasised *Communication*, *Impact*, and *Inclusive Opportunities*. Thematic analysis of group member responses developed six themes, encompassing the perceived value of the group for research, opportunities for learning and raising awareness, the benefits of the group, aspects that were working well or less well, and considerations around diversity and inclusivity. From the analysis of researcher responses, four themes were developed. Three reflected strong support for PPIE within research, while one focused on strengths and challenges in how the group was organised and run.

Suggested areas for improvement from both groups were to enhance training opportunities to develop skills to support involvement and greater flexibility around meeting scheduling. Group members suggested that a faster reimbursement process is necessary while researchers highlighted a need for increased visibility of public involvement within the University.

Conclusions

This evaluation has highlighted the value and impact of All_Ears on research and at an individual and societal level. We aim to continue to the grow the reach and impact of the group and to address the areas highlighted for improvement.

Plain English Summary

Patient and public involvement and engagement (PPIE) means researchers working in partnership with people who have lived experience to shape and guide research. In March 2022, we set up a PPIE group for people with lived experience of hearing loss and deafness called All_Ears@UoS. After three years, we carried out an evaluation to understand what was working well and what areas could be improved.

We used questionnaires to gather feedback from both group members and researchers. Group members highlighted that communication (both during and between meetings), as well as the diversity and inclusivity of the group, were key strengths. Both group members and researchers reported that the group had a positive impact on themselves, the deaf community, wider society, and the research itself. One researcher said it was 'invaluable to have insights and guidance of CI users and those with hearing impairment' and another commented that a benefit was 'Access to a diverse PPIE group which is hard to find elsewhere'.

Areas for improvement highlighted by group members included the reimbursement process, making meetings more flexible, and offering more training opportunities. For researchers, increased visibility at the University, more training opportunities and changes to meeting scheduling were areas to be improved.

We will use these findings to continue developing the group and increasing its impact. We will also work together with group members to decide how best to make these improvements.

Background

Patient and public involvement and engagement (PPIE) is increasingly recognised as core to health and medical research (1). Effective PPIE should enable the public and researchers who engage with it to see that their efforts are achieving the anticipated value. Here, we evaluate the engagement, impact and value of an established PPIE group for people living with hearing loss, All_Ears@UoS, from the perspectives of both group members and researchers.

Researchers acquire professional or research knowledge within their careers. The public develop experiential knowledge(2) gleaned through care giving and or living with a condition. Public involvement is a sharing of knowledge, or partnership, between researchers and the public that supports two-way learning (3). PPIE explores not just a persons lived experience but also the impact of their lived experience on their daily life. Effective partnership working is fundamental to ensuring that research is meaningful, relevant and translates to improved practice (1, 4). It encourages meaningful participation and engagement. Key to this is ensuring that people with a diversity of knowledge and backgrounds can be found and brought together and that barriers to partnership working are uncovered, explored and worked through to enable trust and common purpose to be built. Community engagement can ensure the voice of diverse communities is at the core of public involvement activities. Both public involvement and community engagement are methods which acknowledge the impact of social and cultural differences.

People who are deaf or hard of hearing are an underserved community in research. That is they are part of a group that is not adequately represented, included in or served by research (5). In addition to this, the lived experience of hearing loss and deafness is largely underappreciated in society (6), despite around 18 million people in the UK living with at least some measureable hearing loss or tinnitus. Over half the population aged 55 or more have hearing loss (7, 8). While some people have marked hearing loss, or are deaf from birth, many live with a progressive, and often unpredictable, hearing loss. Hearing loss can be detrimental to a person's education, relationships and employment opportunities. The severity of hearing loss, age and presence of common comorbidities, along with socioeconomic status, access to services and care and support networks all affect daily living. Hearing aids, cochlear implants or learning and using Sign Language and lip reading can significantly improve daily life for people with hearing loss or deafness. Better understanding of the complexity and diversity of hearing loss and deafness through taking the time to listen is critical, not only for improving audiology research, but also for improving health research and services (9, 10).

Multiple barriers to getting involved in research exist for different communities such as a lack of awareness of opportunities through poor recruitment strategies, practical and financial constraints, physical disability, cultural differences and a lack of trust in health research are all barriers to getting involved in research. Poor deaf awareness by the very agencies tasked to make research and healthcare provision effective can make these barriers greater for deaf and hard of hearing people (9, 10). This lack of awareness can limit or preclude access to information and services. Researchers must make a deliberate and conscious effort to reduce the barriers that exist for different communities to generate the evidence needed to develop and inform healthcare improvements.

In early 2022, we set about establishing a PPIE group of people with lived experience of hearing loss and deafness (11). This was to inform and support our research into hearing loss. We aimed to build an enduring group where people with lived experience of hearing loss worked in partnership with researchers to improve outcomes for people with hearing loss. Community engagement was used an approach to build trust with the local community and over time, build a diverse group. An evaluation of the first year of All_Ears@UoS highlighted the value to group members, and the challenges of our PPIE activities. We used the findings to co-develop a two-year action plan. Group members were clear that they found personal value through the group and described feeling listened to and empowered. They felt the group was adding value to wider society through the joint working to raise awareness of hearing loss and cochlear implants. However, they also identified that the time and format of meetings prevented some members from participating. Alongside the feedback from group members, we reflected on the challenges that we faced in supporting and enabling diversity and inclusion within the group. We also considered the intersection of researchers with the group.

Regular review of PPIE activities using a robust evaluation framework can support effective PPIE and help with the sharing of best practice with researchers and public involvement professionals. Despite the increasing number of tools and frameworks available to evaluate PPIE activities, the quality of evaluation of PPIE activity is often insufficient and inconsistent (12, 13). This limits the quality of evidence used to

inform assessment of the wider impact and value of PPIE. Building on our first evaluation of the group in 2022 (11), we have used the UK Standards for Public Involvement as a framework for this evaluation (14).

The members of the public involved with All_Ears and the breadth of researchers who engage with group members has changed over time. All_Ears has become more representative of the deaf and hard of hearing community and of the community in the Hampshire and Solent region. This evaluation aimed to explore the impact of these changes over time.

Against considerable changes to the running and make-up of the group, many aspects have been constant. Our aims and ethos have remained the same. We work alongside group members; both public members and researchers, to co-run public engagement activities and exhibits at community events and science festivals. We make a deliberate effort to highlight the value in recognising social, cultural and demographic differences among group members and researchers. The format of the in-person meetings has not changed. Our meetings are a mix of small-group activities and topic-led discussions. Group members and researchers work together on activities designed to create the time and space to share personal experiences related to hearing loss and deafness. The topic-led discussions are usually led by researchers wanting to explore research ideas with All_Ears members. These discussions can spark new ideas and highlight issues that are important to public members that could be explored and developed into research projects. Researcher-led discussions have spanned early ideas for that might lead to projects through to discussions of projects under development and reporting on progress with research projects that are underway.

Three years into All_Ears we wanted to evaluate the impact, value and engagement of the group from the group members, and the researchers, perspectives to better understand what was working, that is the effectiveness, in the partnership between group members and researchers.

Aims

Evaluate the All_Ears PPIE group, using the six UK Standards for Public Involvement as a framework, to determine what is working and what can be improved for both group members and researchers.

Methods

Establishing the group

All_Ears@UoS was established in March 2022. Since its inception we have continued to co-develop and expand the reach of the group. Community engagement is an approach we used to build trust with people from diverse backgrounds, share information and knowledge and encourage people to get involved with research. Community engagement is distinct from public involvement as it aims to build long-term relationships with communities and work together on shared priorities whereas public involvement aims to work in partnership to improve the relevance and quality of the research (Fig. 1a).

We developed an effective seven step approach to community engagement which is described as ‘Meeting people where they are’ (Fig. 1b). Using this approach, we have built and maintained partnerships in the community including with underserved groups. We have raised awareness of hearing and cochlear implants and we have encouraged people to join All_Ears. Nearly half of our members have been recruited through community engagement which has increased the diversity of the group over time. We work cloesley with staff and clinicians at University of Southampton Auditory Implant Service (USAIS) and a proportion of our group members were recruited through advertising to patients at USAIS.

Our earlier evaluation (11) details how the group was established, co-developed and its effectiveness from the perspective of the public members. The findings informed our approach to the next phase of the group with a focus on growth and how to develop effective ways for researchers to contribute and be informed by the group.

Evaluation of the group using anonymous questionnaires

Two co-designed questionnaires to evaluate impact, engagement and value of the group were developed. The group member’s questionnaire was to gather the perspective of All_Ears group members. The second, the researcher’s questionnaire, was designed to gather the perspective of researchers who have worked with All_Ears.

We established an evaluation steering group of three self-selected members of All_Ears, and the research team. The steering group developed a way of working, discussed the process and content of the evaluation and designed and refined the questionnaires. The first evaluation of the group in 2023(11) was used as a template. A development in this evaluation was a discussion about the need, value and sensitivities of collecting and reporting the demographic information of respondents. A discussion with with the wider All_Ears membership about the format and content of the questionnaire, and whether or not demographic information should be collected, was held at a PPIE meeting. There was near consensus that suggested demographic data should be collected. Feedback from the wider group was used to refine the questionnaires which were then reviewed by the evaluation steering group. The feedback and points raised through the review were addressed and the documents were submitted for independent ethical review and approval through the University ethics committee.

Questionnaire structure

Both group member and researcher questionnaires included a combination of i) Questions using a rating scale (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree or rate 0–5), ii) Short and longer free text answers and iii) Demographic self-identification using a check box list.

The UK Standards for Public involvement was used as a framework for the rating scale questions and free-text questions (14). We asked participants to indicate their agreement with a series of statements which aligned with each of the six standards. Free text response questions were included to give

participants the opportunity to share their wider perspectives to enable us to gather more detailed, qualitative data. See additional file 1 for the questionnaire drafts (group members 1a, researchers 1b). The questions, written in plain English, were: (1) What has worked well? (2) What areas would you like to see improvements in? (3) What do you see as the impact of being involved within this group? (4) Describe any benefits of being part of All_Ears.

Respondents were asked their i) age, ii) ethnicity, iii) gender, iv) current employment status, v) sector of employment, vi) first part of postcode. In the researcher's questionnaire – we also asked researcher to identify the institution they were based at and their current research role e.g., doctoral researcher, clinical researcher, principal investigator etc.

Any group members who were in the group for the first evaluation in May 2023 were asked to reflect on their experiences since that evaluation. This was our first evaluation of the researcher's perspective, and the questionnaire asked them to consider their experiences since their first involvement with the group.

Ethics

Ethical approval for the evaluation was granted by University of Southampton Ethics Committee, reference number **ERGO/103288.**

Consent

Group members and researchers were asked to read the combined participant information sheet and consent form (https://acrobat.adobe.com/id/urn:aaid:sc:EU:6132de42-58b5-4009-91c8-65908f67e2ff) before completing the questionnaire. Participants were asked to confirm that they were over 18 and that they agreed to participate in the evaluation by completing the survey. They were asked to give their consent for the use of the fully anonymised data in peer-reviewed and grey publications, and for sharing of the findings with other clinical centres and through internal university channels.

Survey administration

The survey was made available to the group using Microsoft Forms and both questionnaires were live for four weeks in June 2025.

Analysis of data

Researcher (KH) completed an initial review of the data before sharing with the evaluation steering group members for their initial comments and interpretation. Descriptive statistics were used to analyse the demographic data and rating scale questions. The answers to free text responses on the questionnaire were analysed using Braun and Clarke's six step process of thematic analysis(15–17) by researcher

(KH). The same approach was taken for the thematic analysis as described in our first evaluation (11). The analysis was managed using the standard software NVIVO. As stated in our previous paper, KH is a researcher and has been a co-lead of All_Ears from the beginning. KH is invested in the success of the group and has built relationships with group members. This likely influenced how the data were interpreted during thematic analysis. The survey findings were discussed with group members in a meeting in October 2025. In the meeting, group members were asked to discuss, comment on and provide actions against the areas that were described in the survey as working well and areas identified as needing improvement.

Guidance for Reporting Involvement of Patients and the Public (GRIPP2) (18) long form has been used to format the reporting of these findings (additional file 2).

Results

Findings from ongoing monitoring of PPIE activities

A summary of the various involvement and engagement activities to date is shown in Table 1. Group members have supported research in a variety of ways, from contributing to meetings, reviewing project documents and grant applications and supporting presentations and public engagement events. Additional file 3 shows the breakdown of number of attendees for each meeting, including whether the attendees were new and where the attendees were recruited from.

Table 1
Summary of involvement and engagement activities that the group have been involved with.

Involvement and engagement activities	Number
In-person meetings	19
Online meetings	2
Review project/study documents	16
Involvement in grant applications	7
Ethics application panel	3
Public engagement events	11
Co-produced presentations	2

Findings from group member's survey

Demographic of survey respondents

The response rate of the group member's survey was 40% (18/44). All respondents were over 30 years old, and the majority (44%, 8/18) were aged between 50 and 69 years old. The data showing age, gender

and ethnicity of the respondents [Table 2] enables comparison with the the demographic of respondents in our evaluation in 2023. A high proportion (94%, 17/18) of the 2025 group member respondents were female, in contrast to 64% (7/11) in the 2023 evaluation. This reflects that at the time of the the 2025 survey, 75% of the public membership identified as female (data not shown). The ethnic diversity of the survey respondents was greater in 2025 compared to the 2023 with 61% (11/18) White British, 6% Asian or Asian British (1/18) and 33% Black, Black British, Caribbean or African (6/18). The employment status of the group members, [Table 3] shows the majority described themselves as ‘Retired - with several community commitments’, with 22% (4/18) of members describing themselves as being employed either full or part time.

Table 2
Comparing demographic of respondents (group members) from this, 2025, and the previous, 2023, evaluation.

Age	All_Ears survey respondents (2025)	Percentage of All_Ears survey respondents (2025)	All_Ears survey respondents (2023)	Percentage of All_Ears survey respondents (2023)
	Number	% (n = 18)	Number	% (n = 11)
17 or younger	0	0	0	0
18–29	0	0	0	0
30–49	3	17	1	9
50–69	8	44	4	36
70–79	5	28	4	36
80 and above	2	11	2	18
Gender				
Female	17	94	7	64
Male	1	6	4	36
Ethnicity				
White British	11	61	10	91
Asian or Asian British	1	6	0	0
Black, Black British, Caribbean or African	6	33	1	9
Mixed or multiple ethnic groups	0	0	0	0
Other ethnic group	0	0	0	0

Table 3
Employment status of group member survey respondents.

Employment	
Employed, full time	2
Employed, part-time	2
Full time carer	1
Not employed, looking for work	0
Not employed, NOT looking for work	0
Retired – with several community commitments e.g. All_Ears, member of school or other community board	12
Retired – community commitment All_Ears	2
Disabled, not able to work	0

Note. Respondents could select more than one response if appropriate.

Outward postcodes were collected to determine the area that members were living in. All postcodes in the dataset related to specific geographical locations, with no non-geographic codes returned. The majority 56% (10/18) of respondents have a Southampton (SO) postcode, covering 8/23 different SO districts. Those living in Southampton live within a 15-mile radius of the Highfield campus of the University. The remaining group members live in areas across Hampshire, Portsmouth, Basingstoke and Dorset. Some members travel up to 40 miles each way to attend meetings and events. A map [additional file 4] identifies the location of the in-person meetings, which are held at the Highfield campus of the University of Southampton, and the distance in miles to surrounding regions where group members travel from.

The survey data demonstrates All_Ears is engaging with a broad demographic. Deprivation at a neighbourhood level – the index of Multiple of Deprivation (IMD) – can be determined from though the Lower Layer Super Output Areas (LSOAs) each of which comprises a population of approximately 1,500 people. Of 317 local authorities in England, Southampton is ranked 55th most deprived based on the average rank of LSOAs. As Southampton districts include multiple LSOAs, it is not possible to determine IMD using just the outward postcode however a typical IMD decile range for each Southampton district could be determined. Across the eight Southampton (SO) districts participants reported, there is a spread across affluent (IMD 7–9) and more deprived (IMD 1–3) areas.

Rating scale questions

Summary of rating scale questions

The group member survey asked participants to rate 30 statements. The statements were descriptions of effective public involvement activities or ethos. A higher proportion of positive responses (strongly agree/agree) would suggest respondents felt the group's PPIE activities aligned closely with the six UK standards for public involvement. The summary of the ratings (%) of the statements (y-axis) for each of the UK standards for public involvement is in Fig. 2. Additional files 5a and 5b show the detailed scores alongside each of the statements (the number beside the statement links to the numbers seen in Fig. 2).

The responses were positive for 5 out of 26 statements against the standards and either positive with some ambivalence (neither agree nor disagree) for the majority of statements (22/30). Aspects of communications, working together and inclusivity were identified as strengths. For 24 out of 30 statements, at least one group member selected at midpoint (neither agree nor disagree) suggesting some ambivalence.

Respondents disagreed with three statements across Communications, Impact and Inclusive opportunities. These were: 'The methods for communicating in meetings and via emails are inclusive for the whole group [Communications]'. 'Time and activities such as meetings are allocated to reflect and evaluate the patient and public involvement [Impact]'. 'The group is a true representation of the Deaf or hard of hearing community [Inclusive opportunities]'. These topics will be discussed in group meetings to determine how we can make improvements. No group respondent selected strongly disagree for any of the statements. Similarly, 23/26 statements had between 5% and 25% of respondents stating they neither agree not disagreed.

Evaluating changes in attitudes over time (between first and second evaluation)

15 of the statements were rated in both the 2023 (11) and this evaluation. We evaluated how attitudes of the group members have changed since the evaluation in 2023.

For 14 of the 15 statements related to Communications, Governance, Impact, Working together and Inclusive opportunities, the percentage of group respondents that selected 'Strongly agree' increased in the second evaluation (see Figs. 3 and 4 by comparing the green bars). This shows a substantial positive change in attitudes where a higher percentage of group members more strongly agreed that our group and activities align with the key areas of public involvement.

There was a decrease in the percentage of group respondants that 'Strongly agreed' in the second evaluation to one statement which was 'There are opportunities to improve one's skill set to enable more involvement'. This aligned with the standard Support and learning (Fig. 4). These findings suggest an overall improvement across areas which relate to Communications, Governance, Impact, Working together and Inclusive opportunities. An area for improvement is to ensure group members feel there are opportunities for them to improve their skill set to enable more involvement.

Thematic analysis of open-text questions / free-text responses

Six themes aligning with at least one of the six standards, summarised in Table 4, emerged from the reflexive thematic analysis of the group members responses to the free-text questions. The standard for public involvement which most aligns with each subtheme is shown in Table 4. Impact and Inclusive opportunities were the two standards with the most prominent subthemes. Additional file 6 outlines the full quotations from the free text responses which align with the themes and subthemes.

Table 4
Themes and subthemes developed from the group member's survey (G = group members).

Theme	Subtheme	UK Standard for Public Involvement that the subtheme most aligns with
G1. Supporting research		Impact
G2. Learning opportunities and knowledge exchange	G2.1 Knowledge exchange (onward facing)	Support and learning
	G2.2 Personal learning (inward facing)	Support and learning
G3. Raising awareness	G3.1 Raising awareness within deaf and hard of hearing community	Impact
	G3.2 Raising awareness and sharing knowledge with the wider community	Impact
	G3.3 Using public engagement activities to raise awareness	Impact
G4. Impact, benefits and opportunities the group brings	G4.1 Impact of the group	Impact
	G4.2 Personal benefit of being involved	Impact
	G4.3 Opportunities the group brings	Impact
G5. Diversity and inclusivity within the group	G5.1 Involvement with diverse communities	Inclusive opportunities
	G5.2 The group is inclusive	Inclusive opportunities
	G5.3 Lack of involvement from some communities	Inclusive opportunities
G6. Running the group	G6.1 Leadership of the group	Communications
	G6.2 Areas that are working well	Working together
	G6.3 Areas that need improvement	Governance
	G6.4 Suggestions to improve meetings	Inclusive opportunities

Group members reflected on the breadth of ways they have supported research that they feel aims to improve outcomes and reduce the daily challenges experienced by people who are deaf or hard of hearing [Theme G1]. This included contributing to articles, providing feedback on written material and ethics applications and contributing to group discussions. Group members gave examples of their involvement which highlighted how they support research. Examples (verbatim in quotation marks) included 'feedback on some proposed projects [G3]', they 'responded to a proposed ethics document re a piece of research [G5]', they were involved with 'writing materials, taking part in research [G8]' and two members commented that they had contributed to 'articles – BMJ, CIICA and All Ears website [G15]'. The opportunity to contribute to research through public engagement activities such as 'Helping out at open days and New Forest Shows [G11]', was described as a benefit. Some group members described how they felt that their involvement in the group and contribution to research was impactful, valued and used to improve the lives of those who are deaf or hard of hearing.

The positive benefits and impact of sharing and receiving knowledge between researchers, group members and members of the deaf and hard of hearing community as well as the wider community were discussed [Theme G2]. This encompassed the personal experiences of learning new skills and knowledge as well as using lived experience to share knowledge and educate others. This theme was split into subthemes depending on whether the learning was onward facing through knowledge exchange between researchers, group members and community members or the personal learning that group member's described from their involvement with the group.

Several group members described the knowledge exchange and learning that takes place from each other, 'The All_Ears group have learnt much from each other [G1]', whether it be through 'spreading tips about how to make life easier, e.g. Speech to Test apps [G11]' or through listening [Subtheme G2.1]. The personal benefit of learning from each other, researchers or by attending group meetings was highlighted.

The group members also reflected on the personal learning opportunities. The opportunities to learn new skills and to learn about the research process [Subtheme G2.2]. Support and learning are one of the UK standards for public involvement which states that we should offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

The group members shared how they felt that their involvement with the group has lead to greater awareness of hearing health in the deaf and hard of hearing community and in their local communities [Theme G3]. The opportunity to raise awareness with the aim to make a difference was valued by the group. The group appreciate being able to share information with each other and raise awareness within the deaf and hard of hearing community [Subtheme G3.1]. Additionally, raising awareness in the wider community including the group member's local communities is important for them- 'The most important thing is the awareness as a group we are able to share with particularly the grassroot community [G9]' [Subtheme G3.2]. Some members come along to our meetings with the intention of receiving

information which they can use for ‘educating the community [G16]’ or to ‘share experiences with the community [G13]’.

An important and ongoing aim of All_Ears has been to raise awareness of hearing health and cochlear implants in our local community and to encourage people from diverse backgrounds to get involved with research. Cochlear implants can be a life changing intervention for people with severe to profound hearing loss. Unfortunately, only a small percentage of those who could benefit from an implant actually has one (19, 20). While this may refect a personal choice not to have a device, people from underserved communities including those living in more deprived areas and those from ethnic minorities are less likely to be referred for cochlear implantation (12). Through our consistent efforts to engage with local communities, we have not only increased the diversity of our group, but our group members are equally motivated to raise awareness and share knowledge within their communities – creating a ripple effect. One member highlighted the need for further engagement to raise awareness with different communities such as schools and healthcare facilities.

Public engagement activities were highlighted as way of raising awareness [Subtheme G3.3]. Group members described taking part in ‘open days [G7]’ and public engagement ‘activities to raise awareness of the effects of deafness to general public [G13]’. All_Ears group members have now taken part in 11 public engagement activities and are always willing to get involved. At the events, when we talk to members of the public about cochlear implants and how they work, having people with lived experience of cochlear implants there to show and tell – brings our exhibits to life.

Suggestions were made about how to improve public engagement activities. At events, one member described it being important to have ‘listening breaks for all on the stand at Open Days as prolonged exposure to noise is harmful [G8]’. A further suggestion was that ‘at public events such as the Science and Engineering Festival more spots to record interactions would be helpful as neither ‘staff’ or those who participate in activities can always reach the relevant spot. A book for the public to raise issues would be helpful [G8]’. This comment refers to the pot of counters used to record the number of people engaged with throughout the day. On a busy exhibit, it is not always possible to reach the pot of counters to record this.

The impact of the group to the individual, community and people’s lives were discussed [Theme G4]. A need for further work to measure and demonstrate the impact of the group was highlighted. The UK standards for public involvement for Impact states it is important to: Seek improvement by identifying and sharing the difference that public involvement makes to research. The word impact is used a lot in public involvement and research. Before the evaluation survey went live, a group meeting was dedicated to a discussion of what was meant by ‘impact in public involvement’. The definition of impact as ‘Impact refers to the difference or change that happens because of something we do. Impact means the positive changes or benefits that come from your involvment’ was used. The definition and examples of actions that could lead to impact in PPIE were discussed. Group members were asked to think about the

impacts of their involvement in the group between March 2023–2025 using the ripple effects mapping exercise (21).

Impacts of being involved have been described as ‘better awareness of deaf challenges [G16]’ and ‘greater awareness of the impact of deafness on the individual which means I now communicate differently. I'm more aware of how deafness can affect the lives of all involved not just the person who is hard of hearing [G14]’. Two group members described the impact of their contributions as being clear. Whereas, one member felt unsure if the investment in the group had led to impact. One group member indicated that they are interested to see ‘how All_Ears and our participation impacts hearing loss and cochlear implants across the Nation/local environment [G1]’ [Subtheme G4.1].

Personal benefits of being involved with the group such as increased confidence were reflected upon [Subtheme G4.2]. For public involvement to be effective and enduring, it is essential that PPIE co-leads and researchers take the time to listen, get to know members and to always provide feedback on contributions they have received from group members. Five group members highlighted feeling valued as a benefit of being involved with the group. Meeting new people, ‘getting to know each other [G17]’ and having the opportunity to keep informed about latest research and information were described as personal benefits.

Being part of the group provides different opportunities for group members to get involved, such as ‘a diverse range of projects [G15]’, opportunities to ‘give(ing) something back [G18]’ and ‘a chance to eventually have an impact on the lives of people like me [G5]’ [Subtheme G4.3]. One benefit of being part of All_Ears was the opportunity to benefit the deaf and hard of hearing community. This is a strong value of the group, as described in theme G3- Raising awareness.

Positive experiences of diversity and inclusivity within the group were reflected upon [Theme G5]. Group members commented on the accessibility of meetings and the involvement of people from diverse communities. Areas highlighted for improvement included increasing the involvement of young people and those from the Deaf community.

We are committed to involving people from a breadth of communuties in All_Ears PPIE activities. This has been reflected in responses by group members when asked to discuss what has worked well – ‘the group is diverse [G2]’ and that we are ‘engaging everyone from various backgrounds [G3]’. There is ‘encouragement of a wide range of participants with lived experience of varying degrees of hearing loss [G6]’ and ‘integration and inclusion of the multicultural diverse community [G9]’ [Subtheme G5.1]. When given the opportunity to clarify their answers for rating scale questions related to ‘*Inclusive opportunities’*, one group member commented ‘On the grounds that there is always room for improvement there could be more diversity but any lack is due more to people not coming forward rather than lack of opportunity to do so. The All_Ears organisers try hard and in inventive ways to approach as wide a range of age, ethnicity, gender, and type of hearing loss as possible [G8]’.

The group was described as inclusive and a space where group members felt that they were ‘all treated equally [G2]’ and that meetings are ‘very inclusive and accessible’ and ‘I never feel out of place [G2]’ [Subtheme G5.1]. Nine comments were coded for this subtheme highlighting that multiple group members shared this view. The accessibility of group meetings were raised. There is ‘attention to accessibility in the group meeting [G5]’. One group member commented on the fact we only hold in-person meetings and questioned how inclusive this was. Until Decemeber 2025, it had been a conscious decision to hold our meetings in-person. We wanted to build meaningful and long-standing relationships with group members and felt in-person meetings would more easily facilitate this. When we started we discussed with the membership at the time how they would like to work with us, such as when our meetings should be, whether online or in-person. It was decided that we would hold in-person meetings, in the morning. Over time the group has gained new members with new ideas and following feedback, we have changed the times of the meetings and days across the week to give different people the opportunity to come along. Some of our members primarily contribute via email, rather than attending in-person. The group is gaining reach and we are now recruiting more members who live outside of Hampshire. In response to the changes in group membership, and feedback from the evaluation, we held our first online meeting in December 2025. Going forwards, we aim to run a combination of in-person and online meetings to give the opportunity for different members to get involved.

A lack of involvement from the Deaf community and young people [Subtheme G5.3] was highlighted. One group member described ‘being optimistic about the commitment of the group for teens [G17]’. Regarding reaching young people in their 20s, through raising awareness of All_Ears during Audiology teaching sessions led by a group co-lead (KH), two university students have recently joined the group. Holding some of our group meetings online in the evening, will allow those who are studying and/or working to get involved.

The final theme describes attitudes towards the running and organisation of the group [Theme G6]. Effective leadership and the friendly and welcoming environment were identified as working well. The slow reimbursement process and the reduced engagement from some members of the group were noted as needing improvement. The effective leadership of the group was described as being beneficial for the successful running of the group [Subtheme G6.1 and the enthusiasm of the research team was highlighted ‘The university team is very enthusiastic in what they do, and this really captures our attention [G2]’. Meaningful involvement from the researchers was identified and described in ‘directive from senior academics for meaningful PPI and a dedicated researcher working with the representatives [G12]’. One response suggested a need to diversify the PPIE co-lead in case the person becomes unavailable. This is a useful point. From the start of All_Ears, the PPIE team felt it was important to have one key contact for group members to communicate with between and during meetings and to build trust and a rapport with over time. This has worked well, however going forwards, as the group builds we need to build capacity and develop a strategy to involve other researchers in running the group.

Effective, regular communication between the PPIE co-leads and the group was described in multiple responses that described what is working well. This aligns with the UK standard for public involvement -

Communications, which states '*Use plain language for well-timed and relevant communications, as part of involvement plans and activities'*. There is 'regular written communication, before, during and after every meeting which is clear to all [G6]' and 'we are well informed in advance of the coming meetings and events' [G2]'. Some members mentioned that 'email communication for purposes of sharing info, arrangements [G5]' were working well and that 'email updates were very helpful [16]'. Whereas, two members commented that not having access to email could be a barrier to involvement, but that communication in the group is still effective.

Multiple responses referred to a friendly and welcoming environment, where there is 'mutual support [G11]' [Subtheme G6.2]. Our intention has been to create a welcoming environment where people feel comfortable to share their experiences and ideas and work together. One group member shared that 'Being part of a friendly, like-minded group of people with shared lived experiences [G18]' was a benefit of being part of the group and another commented on the 'friendly, helpful group [G4]'. Two responses highlighted the website as being 'great [G18]' and a 'repository of useful information [G11]'. When asked to comment on areas that could be improved, three group members stated that everything was 'working really well [G12]'. The opportunity to interact with each other in-person, in a 'relaxed setting where people can interact both sat round table formally and less formal too in coffee break too [G7]' was described as something that is working well.

The reimbursement process was highlighted as an area for improvement as the unpredictable, and sometimes slow, expense process resulted in group members feeling PPIE is undervalued by the university [Subtheme G6.3]. Institutional processes resulting in delayed compensation has been described in the literature (22). When discussed in a recent meeting, group members commented that four weeks would be a reasonable amount of time to be reimbursed. Whereas currently, they thought the average time was eight weeks. Another area for improvement was related to technology, specifically access to email, which could be a barrier to involvement.

Suggestions to improve meetings included one member highlighting that 'more flexibility in the times of meetings' would be an improvement as 'if employed and working the time of the meetings make it difficult to participate as much as one would like [G3]'. Another member suggested that 'maybe online meetings..' would be beneficial for 'wider reach [G18]'. One member suggested that having more discussion time in meetings would improve meetings [Subtheme G6.4].

Findings from researcher's survey

Demographic of survey respondents

A summary of the demographics and roles of the eight researcher respondents [data in Additional file 7] shows the majority of the respondents were female (88%, 7/8) and mostly affiliated with the University of Southampton (7/8, 88%), one respondent was affiliated with the University of Cambridge. The respondents cut across disciplinary backgrounds with representation from Social Sciences (1/8, 12.5%), Engineering (1/8, 12.5%), Life Sciences (1/8, 12.5%), Medicine (2/8, 25%), Clinical Neurosciences (2/8,

25%) and the Auditory Implant Service (1/8, 12.5%). The researcher respondents held a mix of positions which included academic (1/8, 12.5%), clinician (2/8, 25%), academic and clinician (3/8, 37.5%), undergraduate (1/8, 12.5%) and project manager (1/8, 12.5%).

The majority of researchers (Fig. 5) have been involved with the group more than once (5/8, 62.5%) and their involvement is either ongoing (4/8, 50%) or may continue in the future (3/8, 37.5%). Most researcher respondents found out about the group through colleagues and other researchers (Fig. 5c). This highlights the importance and value of the All_Ears team in engaging with the research community to raise awareness of the group. Figure 5d demonstrates the variety of ways the researcher respondents have been involved with the group. The majority of respondents discussed early ideas for research projects and shared information about projects through emails and by attending in-person meetings.

1. How many times have you been involved with the group?
2. Is your involvement with the group ongoing?
3. How did you find out about the group?
4. What type of involvement did you have with the group?

Rating scale questions

Researchers strongly agreed there was value to working with All_Ears and that this had been beneficial for their research. Figure 6 summarises the scores (%) from the rating scale questions for the statements (y-axis) for each of the UK standards for public involvement. See additional file 5c and 5d to visualise the scores alongside each of the statements. There were positive responses to the majority of the statements (76%, 22/29). ‘Working together’, was identified as a strength, all researchers either strongly agreed or agreed with this statement. This shows that the researchers acknowledge there is a collaborative approach between group members and researchers, that decisions are shared between group members, co-leads and researchers working with the group. ‘Communications’, ‘Impact’ and ’Inclusive opportunities’ received positive responses. For 22 out of 29 statements, at least one researcher selected at midpoint (neither agree nor disagree).

Areas identified as needing improvement were the need for increased visibility of public involvement at the University and the need for better resources and support and learning for the group. One respondent disagreed with the statement ‘Throughout the University of Southampton, there is visible and accountable responsibility for public involvement’. Another respondent disagreed with the statement ‘Resources have been designated by All_Ears@UoS, through external funding, to support learning and development opportunities for both researchers, contributors, and staff’. Support and learning were identified as an area for improvement from both the group member’s and researcher’s perspective. The standard states that we should ’offer and promote support and learning opportunities that build confidence and skills for public involvement in research’. We need to invest time and designate resources through funding to develop and provide training opportunities for group members and researchers to develop their skillset to enable more involvement in research.

Thematic analysis of open-text questions / free-text responses

Key themes developed from the reflexive thematic analysis of the responses from the free-text questions in the researcher's questionnaire were; benefits of working with the group for researchers (R1); positive impact on research and society (R2); value of group members (R3); and organisation and running of the group (R4). Each theme is comprised of subthemes (see Table 5). Additional file 6 outlines the full quotes from the free text responses which align with the themes and subthemes.

Table 5
Themes and subthemes developed from the researcher's survey responses. (R = researchers)

Theme	Subtheme	The UK Standard for Public Involvement that most aligns with each subtheme
R1. Benefits of working with the group for researchers	R1.1. Increased knowledge, awareness and skills	Impact
	R1.2 Value of working with the group members	Impact
	R1.3 Increased positive feeling from working with the group	Impact
R2. Positive impact on research and society	R2.1 Public involvement is an invaluable part of research	Impact
	R2.2 Improved study design, increased relevance and real-world applicability of research	Impact
	R2.3 Societal impact	Impact
R3. Value of group members	R3.1 Valuable contributions from group members	Impact
	R3.2 Positive attributes of group members	Support and learning, Inclusive opportunities
R4. Organisation and running of the group	R4.1 Areas that are working well	Inclusive opportunities, Working together
	R4.2 Areas for improvement	Working together

The researchers described a range of benefits of working with the group such as gaining new, and improving existing, skills such as effective communication and acquiring new knowledge of PPIE [Theme R1]. They recognised that they learnt from group members who shared their lived experience and that they felt more positive and motivated as researchers with greater confidence and an increased sense of purpose. These findings highlight the benefit to researchers of working with a diverse group of people.

The researchers highlighted the importance and value of learning from those with lived experience to gain deeper insights into hearing loss [Subtheme R1.1]. One researcher commented that it has helped them 'develop their (my) knowledge and insight into PPIE and why it is important [R4]' and another commented that this insight can 'increase appropriate provision of clinical support [R3]'. The value of working with the group members included working with a diverse PPIE group and an 'interested and valuable population [R5]' [Subtheme R1.2]. Further benefits for the researchers of working with the group included that it 'boosted (their) motivation and sense of purpose in their (my) research [R1]' and that working with the group 'increased (their) confidence in engaging the public meaningfully [R1]' [Subtheme R1.3].

The researchers reflected on the value and positive impact of the group on research and wider society [Theme R2]. The perceived value of public involvement as part of the research process was highlighted [Subtheme R2.1] and researchers described public involvement as a 'valuable part of the research process [R1]' or 'an invaluable part of research [R4]' and one researcher felt 'the group has had invaluable contributions to their (my) research including allowing them (me) to gain more of an insight into hearing loss and helping to design studies that is most likely to benefit the people who it most affects [R4]'. Multiple benefits of incorporating public involvement at all stages of the research cycle were described such as improved study design, increased relevance and real-world applicability of research [Subtheme R2.2]. One researcher stated that All_Ears 'contributes to research at all stages [R4]' and another researcher indicated that they worked with the group during the early stages of the research process. Four researchers identified that an impact of working with the group was increased relevance and therefore 'Better-designed studies with real-world applicability [R1]'. One researcher explained that public involvement 'means that research becomes relevant and focused on the users of cochlear implants and hearing technology [R2]' and that 'this has impact on national research and also society [R2]'.

Societal impact was highlighted;'opportunity(ies) to influence real-world change [R1]' and to 'impact (on) national research and also society [R2]' [Subtheme R2.3]. A key driver of All_Ears is to raise awareness of hearing and cochlear implants in the community. An increase in reach into the community was highlighted by one researcher. Researchers described the value of 'constructive feedback [R1]' [Subtheme R3.1] and that group members were engaged, exceptional and skilled [Subtheme R3.2].

The diversity within the group, 'inclusive atmosphere where all voices are heard and lived experiences are valued [R1]', and good collaboration between group members and researchers which is facilitated by 'clear communication and coordination from the group facilitators [R1]' shows positivity from researchers about the organsiation of the group [Theme 4]. Good communication between researchers and (the) group [R5]' and 'continuation of contact [R3]' are reported as strengths which support the running of the group. One researcher commented on the importance of having an approachable co-lead [Subtheme R4.1].

The scheduling of meetings was identified as an area for improvement. One researcher suggested that 'more frequent meetings [R2]' would be helpful and another suggested that fixed scheduling of meetings

may improve how researchers work with the group. One researcher commented that 'time and funding are always the issues [R8]', that 'this is such an amazing group to work with but sometimes it would be great to have longer with them [R8]' [Subtheme R4.2]. Our group meetings are held every 2–3 months in-person and we aim to book meetings at least a month in advance. Organising the meetings can be challenging as the rooms we use, which meet our accessibility requirements, are used for teaching. We need to ensure our notetaker is available as well as the co-leads running the meeting. We advise researchers who would like to work with the group, to contact the group co-leads at the earliest stage to discuss what type of involvement they are looking for and to outline the expectations of working with the group. We advise researchers when our upcoming meetings are so they can put in a request for time within a meeting to come to speak to the group and to share any project documents or thoughts ahead of the meeting.

One researcher commented that 'more structured follow-up to show how public feedback has influenced research [R1]' would improve how researchers work with the group. Completing the feedback cycle in public involvement is important as it ensures group members understand the impact of their involvement and know their feedback/input has been acknowledged and taken on board (23, 24). When we start working with a new researcher, we highlight expectations around feedback and share our framework (see additional file 4 in (11)). When group members provide feedback on project documents or ideas, the researcher must provide feedback to the group members within two weeks. If the feedback cycle is not complete, there is a risk that group members could feel their involvement was tokenistic and not genuine.

Discussion

This evaluation of the All_Ears PPIE group, using the UK standards for public involvement, has identified the strengths and areas for improvement from the perspective of group members and researchers three years into the life of the group. Group members identified strengths in the effective communication during and between meetings, the friendly, supportive environment and shared passion to raise awareness and make a difference and also the inclusivity within the group. Areas for improvement were the opportunities to improve one's skill to enable more involvement, the reimbursement process and the flexibility of meeting times and format. Researchers reported the value of working with the group on them and their research, the impact on them and society and the diversity and skill of the group members as strengths. Increased visibility of public involvement at the University, investment of more resources to support training and learning and changes to the scheduling of meetings were suggested areas for improvement.

When evaluating PPIE, it is important to tease apart the meaning of value and impact. The value of PPIE are the benefits of researchers and the public working in partnership in research. The impact of PPIE refers to the difference or changes that happen because of this partnership. These changes can be to the research, to the people involved, to the PPIE processes, to healthcare and to society. A key benefit of PPI on both group members and researchers is being valued. This was highlighted in our findings and in

a recent scoping review of the value of PPIE on health research (22). Researchers reported that sharing their ideas with group members increased their sense of purpose and made them feel like their research was valued. For the group members, feeling valued and feeling like their experiences and expertise were valued was important to them particularly for those who felt like their deafness often left them feeling undervalued. Without a secure and trusting relationship, neither group members nor researchers are likely to feel valued for their role. Public involvement is valuable for research. All researcher respondents felt strongly that working with All_Ears was beneficial for their research. By group members' sharing their lived experience, the researchers gained valuable insight and guidance which informed their research.

Increased confidence, knowledge and skills are impacts of public involvement (12, 22). Group members and researchers described the impact on the deaf community and on society, of raising awareness of deafness and the challenges that deaf and hard of hearing people face. The impacts of PPIE on the research process and outputs are widely reported (4, 25, 26). Despite this, All_Ears group members were less clear about the impact of the work on research. This may be because members do not have enough ongoing feedback from researchers and that the timeline of taking a piece of research from idea to change in practice is typically many years. Better translation of the impact group members make on research is required. Sharing the findings from the researchers' survey with group members may support this.

The variety in PPIE activities and lack of reporting of impact is an issue in public involvement (13). In a narrative review of reviews, the impacts that were reported were classified into four broad types 1) People (PPIE contributors, researchers, healthcare staff and policy makers), 2) Different phases of the research process, 3) Services and systems and 4) On the PPIE processes (13). Similar to our findings, commonly documented impacts of PPIE related to the impacts on group members such as learning new skills and feeling empowered, while researchers reported improved understanding of, and collaboration with, the public. Researchers also described the impact of working with the public on the earlier phases of the research process (13). Related to services and systems, one study described the positive impact at a community level through increased health literacy and better access to care and social support was described, which resonated with our work (27).

Several studies (28–30) have described the emotional effort and difficulty that group members experience from sharing their personal and sometimes painful experiences (22, 31) as running in parallel with the benefits. A negative impact on group member's physical and mental health as a result of their involvement and the demand of the roles has been described. This was not highlighted by group members in our survey however a couple of members have had to leave the group due to increased caring and other responsibilities highlighting that a level of commitment is required. Many public contributors carry out their roles alongside employment, caring responsibilities and other community roles/responsibilities as well as living with health conditions. Possible physical, emotional and intellectual burden of public involvement for group members should be considered (32) and should be part of the expectation setting with researchers as they work to incorporate PPIE into their research.

The burdens of emotional labour for researchers such as feeling a responsibility to take care of, and support, the group members whilst dealing with their own emotions related to involvement has been described (31, 33). Some researchers have described a challenge of having to be polite when they felt they wanted to be otherwise and suppressing their own opinions in front of public contributors (34). This issue was not highlighted in our findings. If relationships are built where both parties feel they are on a level playing field, and a space is created for open and honest discussion, researchers should not feel like they have to watch what they say. Sometimes hard, confronting conversations are needed between researchers and group members for progress to be made. We have found that emotive topics can lead to heated discussions but with trust and careful facilitation, both researchers and group members can feel heard, listened to and satisfied with the outcome of the discussion (3). Emotional labour for those involved in public involvement is inevitable as it involves people being vulnerable and sharing their personal experiences. It is important that this is acknowledged and that people are supported if needed.

The need for additional training is a recurring issue in public involvement (12, 35, 36). The public and researchers have described feeling insufficiently equipped for collaboration and that they would like further training to support their involvement (12, 37). This aligns with our findings. Different approaches to public involvement training, from group and peer-to-peer support(38) to more structured training for public contributors(39) have been described. One group trialled a group and peer-to-peer support programme where the goal was to learn from each other whilst collaborating on research projects (38). Training tailored to public partners should teach about the research cycle and timelines to change in practice alongside highlighting what public involvement truly means and how public partners can meaningfully contribute to each stage of the research cycle. For researchers, embedding formal and experiential PPI training early on is beneficial for the researcher's skillset and development and has been shown to shift the focus of doctoral research projects resulting in more translatable research (40, 41). Guidance materials have been developed which aim to support researchers who are engaging with the public in PPI (42, 43). We will discuss training with group members and researchers to better understand what they feel could better support them.

Many studies have only evaluated the value, impact and benefits from the public contributors' perspective (12) and the experience of PPIE for researchers has been overlooked (34). For non-tokenistic public involvement to be embedded within research and widespread, it is important that researchers appreciate the value for them and their research. Therefore, better evidence from evaluating researchers to understand the value and challenges for them is necessary (34, 44). Our findings highlight the benefits to researchers of working with the group, the impact on research and society, and add to the evidence base. Evaluating both researchers and group members allows us to understand how collaborative and meaningful the partnership is (45).

A priority for us it that All_Ears is diverse, inclusive and accepting. By increasing the accessibility of our PPIE activities and reducing barriers to involvement, we aimed to support involvement from a wide range of people with diverse backgrounds and experiences (46). Findings from the initial evaluation highlighted a need to improve the diversity of the group and to increase how inclusive and accessible the meetings

and communications are. A consistent effort has been invested in both areas over the past two years and the findings from this evaluation reflect the progress we have made. Group members acknowledged the diversity of the group and highlighted the efforts the team have gone to engage with a diverse people in terms of age, ethnicity, gender and type of hearing loss. Several researchers commented that the diversity of the group was a strength. Despite this, there are still communities that are currently not represented in the group such as members of the Deaf community who communicate predominantly using sign language. We commit to investing time and efforts to build trust with this community. It is important that we do not get complacent and that we continue to use our seven-step community engagement approach to maintain and build trust with communities (Fig. 1b). Diversity in the way group members think is important too, as we want group members to feel they can share their experiences and challenge views freely.

Another group currently not well represented in All_Ears is young people. Despite the examples of excellent initiatives where researchers have co-developed their activities and modes of working with young people (47–49), young people are a highly underrepresented group within public involvement (50). Additional barriers that exist when working with young people such as lack of transport, limited availability due to education and digital exclusion (51, 52) often reduce or limit involvement of young people in research. To integrate the voice of young people in All_Ears, we established All_Ears@UoS Young People's Advisory Group (YPAG) in March 2025, and we held our first meeting in August. Our aim is to build a group for young people aged 14–16 years old with lived experience of deafness. We plan to run (mostly) online meetings to increase the reach of the group and remove potential barriers to involvement such as location and travel. Recruitment has been a challenge, and we are still actively recruiting members (https://generic.wordpress.soton.ac.uk/all-ears/2025/03/07/join-our-new-young-peoples-advisory-group-ypag/). More targeted engagement with parents of young people with cochlear implants may help with recruitment. This group is in its early stages, and we look forward to building and growing a partnership with members of the YPAG.

Key strengths of this work are the co-developed evaluation questionnaires, and that we have evaluated both sides of the PPI partnership by gathering the perspectives of researchers and group members. The UK Standards for Public Involvement (53–55), were used as a framework for the survey (14). To measure changes in attitudes over time, we replicated the format of our initial evaluation and compared the data from the first and second evaluation. A mixed-methods approach gathered both quantitative data and qualitative data. We acheieved a high response rate for the researcher's survey (73%, 8/11). Targeted emails were sent out to each researcher who has worked with All_Ears inviting them to complete the questionnaire. The response rate for the group member's survey was 40% (18/44). Typically, low response rates in researcher's evaluations have been reported (12) and often public contributors show higher response rates.

A limitation of this work is that a high proportion of respondents selected neither agree nor disagree for the rating scale questions, making aspects of the data interpretation difficult. Survey fatigue, feeling less informed or connected to topics, and being newer to the group may have affected the responses (56).

Equally, despite the survey being co-developed it may be that the questions lacked nuance or how easily they could be interpreted. To reduce the likelihood of this issue in future evaluations, it will be important to ask group members a question to determine their level of involvement i.e. how many online and in-person meetings they have attended and whether they regularly read meeting notes).

Conclusion

This evaluation has highlighted the value and impact of the group on the individuals involved, on the deaf and local community, on society and on the research process from both the group members and researchers perspective. Increased knowledge, awareness and confidence, meeting new people and contributing to important research are some of the described benefits by group members. Researchers felt there is a clear value to working with All_Ears and that is beneficial for their knowledge, skillset, motivation and for their research. Working with All_Ears improved the study design, increased relevance and real-world applicability of their research. Our findings show we are effective when evaluated against the six UK Standards for Public Involvement and that there are clear areas where further focus is needed such as Support and Learning and Governance. Diversity and inclusivity have been described as a real strength within the group. Both group members and researchers recognised the value of the diverse and inclusive group for the group itself, for more inclusive research and public involvement and for better awareness of deafness across society. We acknowledge that while there are still communities who are not represented within the group we still have work to do. A strength of this evaluation is that we gathered valuable insight from researchers who have worked with the group and have a better understanding of what is useful for their research and what changes we can make to better facilitate their engagement with the group. Findings from this evaluation will be discussed the group to develop an action plan for the future. As All_Ears membership and reach continues to grow and evolve over time, we look forward to experiencing the value and impact of the group on the members and researchers, on research and on society as a whole.

Abbreviations

BSL British Sign Language

BMJ British Medical Journal

CIICA Cochlear implant international community of action

GRIPP2 Guidance for Reporting Involvement of Patients and the Public

IMD Index of Multiple of Deprivation

SO Southampton

LSOAs Lower Layer Super Output Areas

PPI Patient and public involvement

PPIE Patient and public involvement and engagement

UK United Kingdom

USAIS University of Southampton Auditory Implant Service

YPAG Young People's Advisory Group

Declarations

Ethics approval and consent to participate.

Ethical approval for the questionnaire was granted by the University of Southampton Ethics Committee, reference number **ERGO/103288.**

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and analysed during the current study are available in the University of Southampton PURE repository, [https://doi.org/10.5258/SOTON/D3955].

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

The group was initiated by TN and then developed and lead by TN and KH, who together, devised the plan for the evaluation and development the first full draft of the manuscript. KH did the initial analysis of the findings. SS, MH, RB, are all PPIE group members who volunteered to be part of the evaluation steering group. SS, MH, RB contributed to the design and planning of the evaluation and analysis/interpretation of the data. All authors reviewed and approved the final manuscript.

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KH is a post-doctoral research fellow in Faculty of Medicine and PPIE group co-lead for All_Ears.

SS, MH, RB are members of All_Ears and were involved in the design stages of the evaluation.

TN is a Professor in Neuroimmunology and Director of the University of Southampton Doctoral College.

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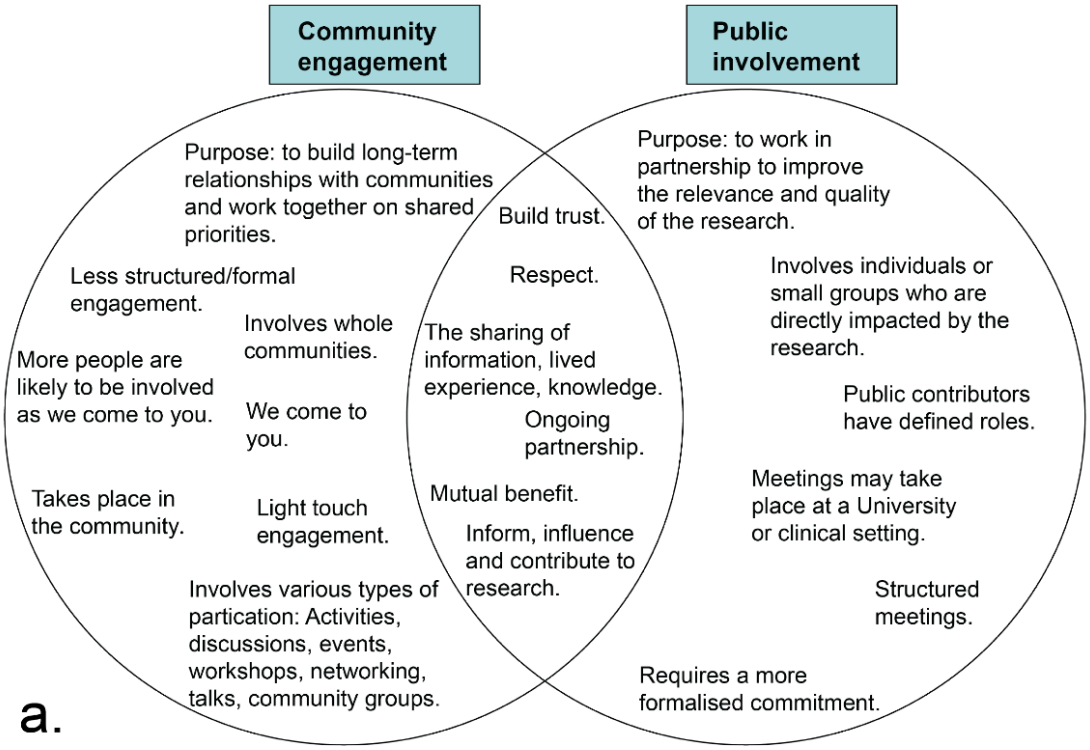
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Figures



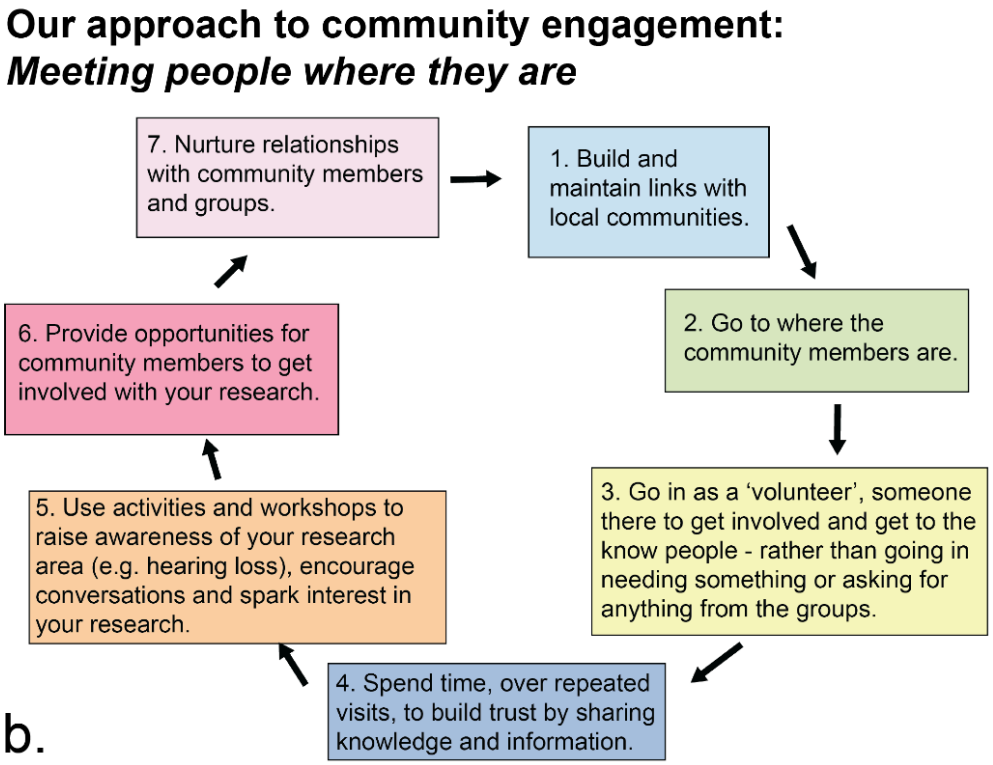


Figure 1

The intersection between community engagement and public involvement.

a. Schematic outlining the similarities and differences of community engagement and public involvement.

b. The seven steps to our community engagement approach which we summarise as ‘Meeting people where they are’.

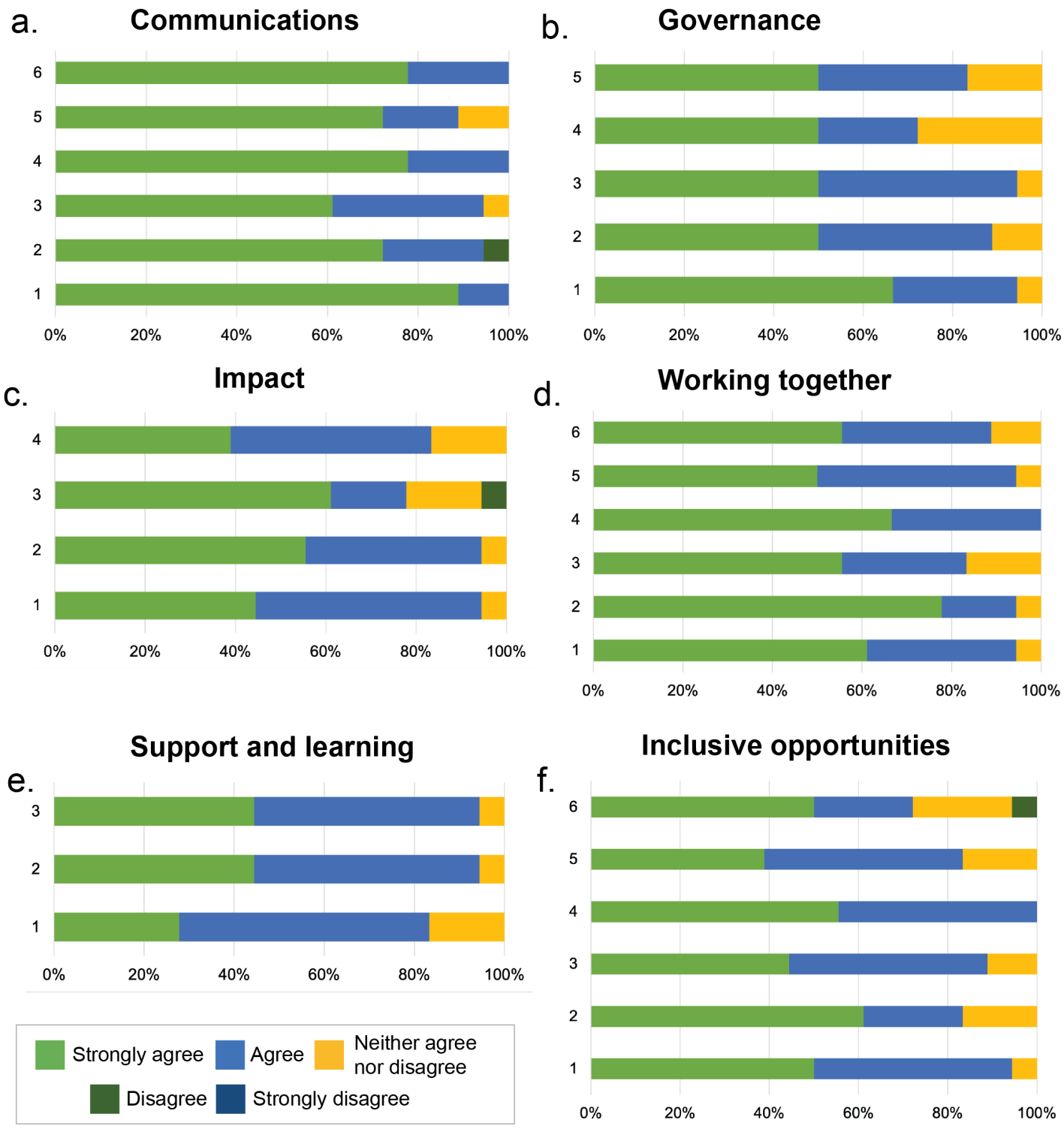


Figure 2

Stacked bar charts showing the scores (%) from the rating scale questions. Statements (y-axis) which aligned with each of the six UK standards for public involvement were included (30 statements in total).

The numbers beside the bar summarise each statement within the standard and match the numbers listed next to the statements written in full in additional file 5a and 5b.

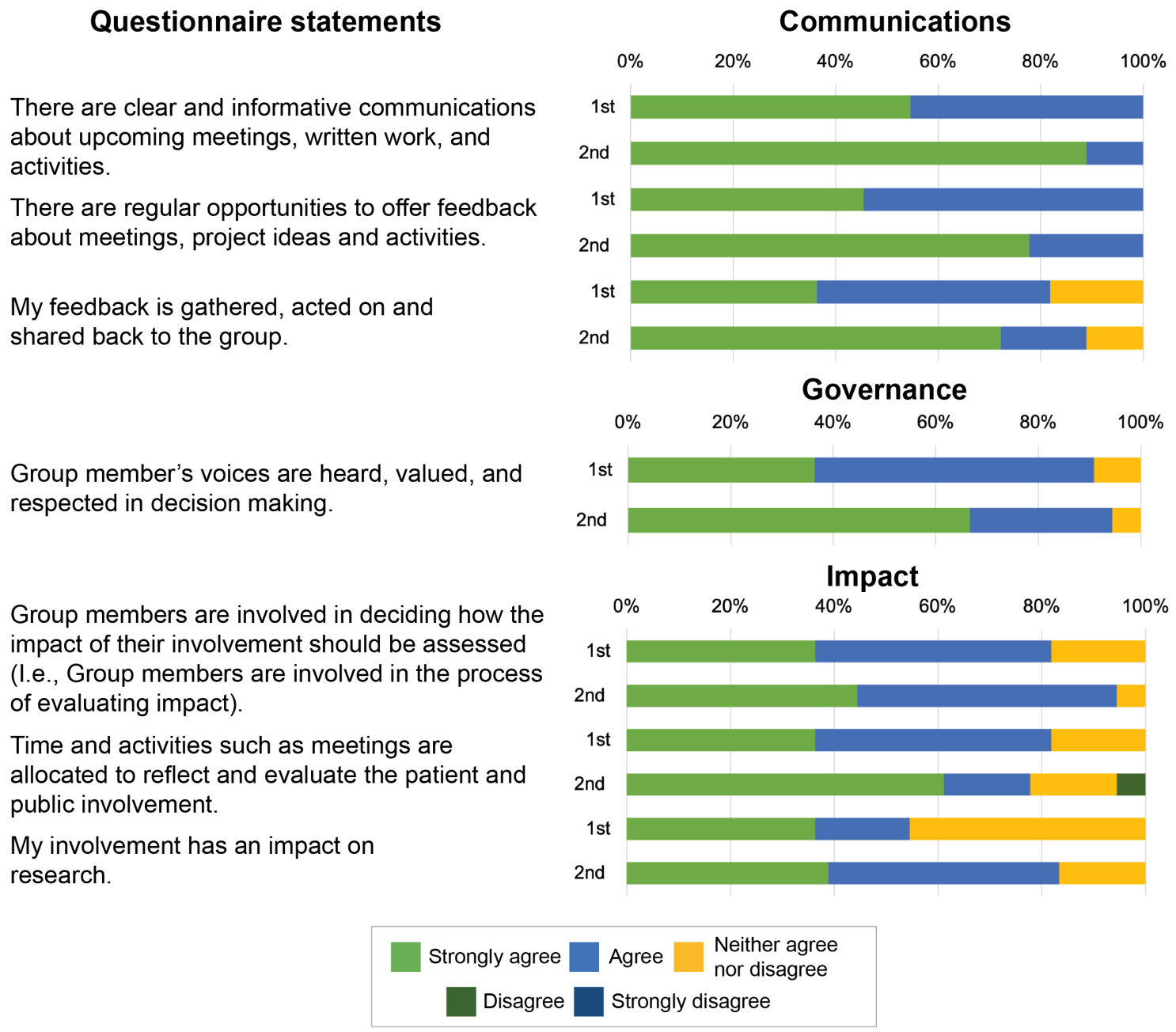


Figure 3

A comparison of rating scale question responses from the 2023 evaluation to this evaluation. Stacked bar charts comparing the scores (%) from the rating scale questions for the statements from the 2023 evaluation [1st] and this [2nd] evaluation. The statements related to Communications, Governance and Impact.

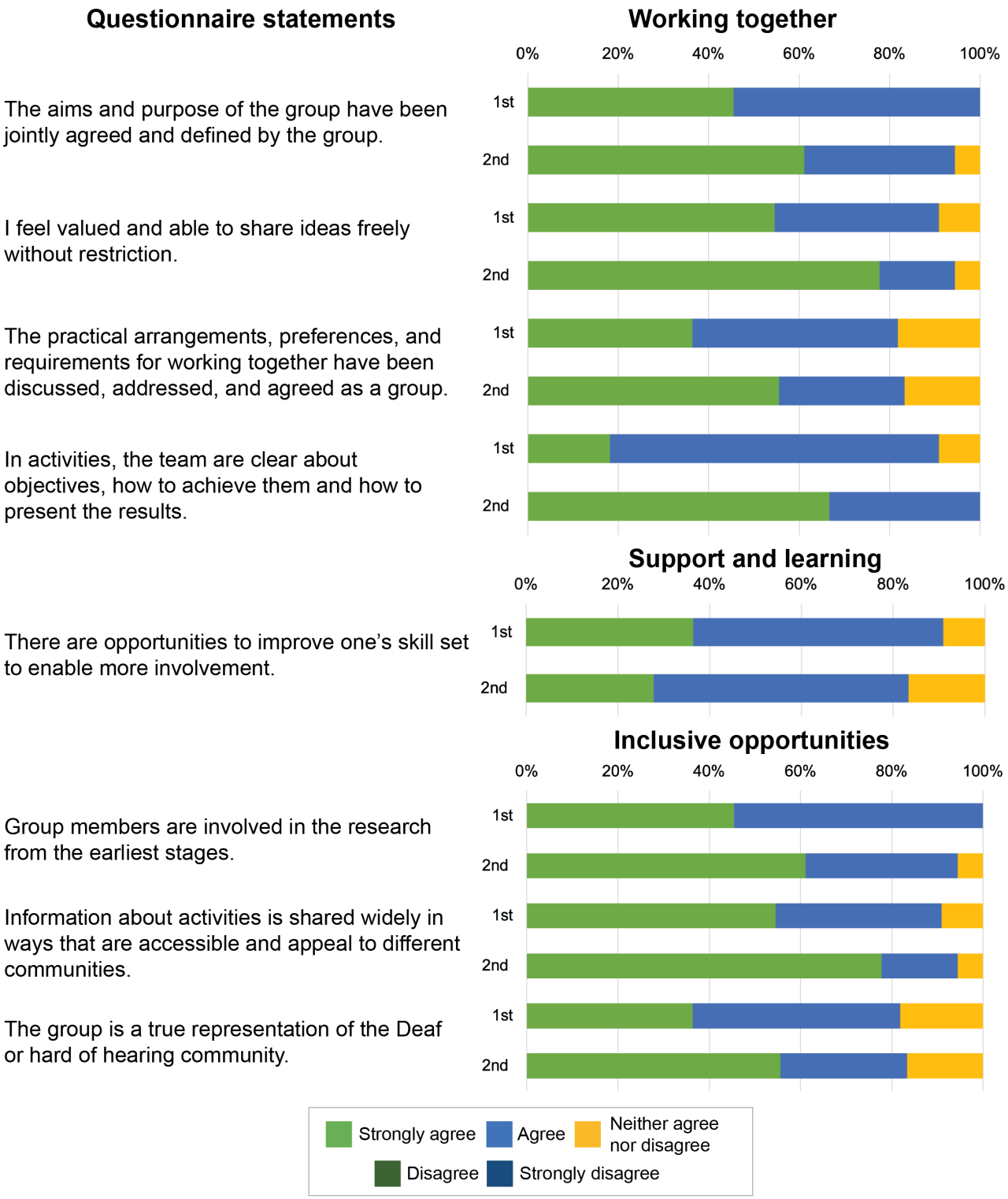


Figure 4

A comparison of rating scale question responses from the 2023 evaluation to this evaluation. Stacked bar charts comparing the scores (%) from the rating scale questions for the statements from the 2023 evaluation [1st] and this [2nd] evaluation. The statements related to Working together, Support and learning, and Inclusive opportunities.

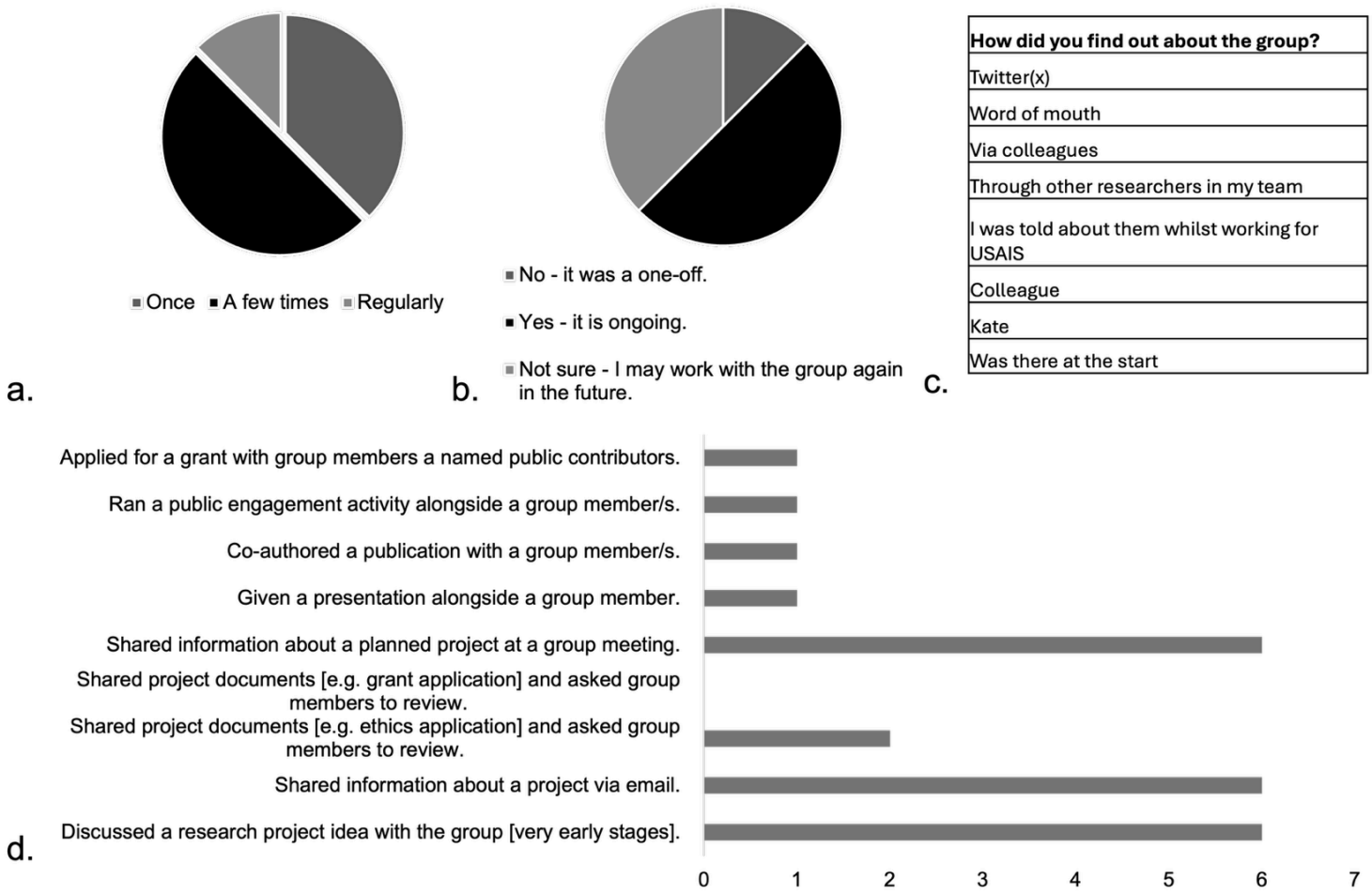


Figure 5

Summary of data regarding types of involvement from researchers with the group. The questions were:

a) How many times have you been involved with the group?

b) Is your involvement with the group ongoing?

c) How did you find out about the group?

d) What type of involvement did you have with the group?



Figure 6

Stacked bar charts showing the scores (%) from the rating scale questions. Statements (y-axis) which aligned with each of the six UK standards for public involvement were included. The numbers beside the bar summarise each statement within the standard and match the numbers listed next to the statements written in full in Additional file 5c and 5d.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Additionalfile1.docx
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