

# X-NET PPI Workshop

Tue 27 June 2023



## “Creating And Nurturing Diverse Teams For Effective Biomedical Science”



## REPORT ON THE X-NET PPI WORKSHOP

TUESDAY 27 JUNE 2023, ONLINE

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This report was prepared by [Sarah McLusky](#), based on information provided by Cristina Martin and participant contributions to the workshop Padlet. (July 2023)

## SUMMARY

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### Participants

- 14 participants attended, 10 were able to stay for the entire session.
- The participants were equally split by gender and drawn from across the UK. All participants were aged 45+ with a mixture of working and retired, from a range of employment backgrounds. The selection of older participants was deliberate, so they had life experience to draw on.

### Suggestions for overcoming structural and cultural barriers.

- Communicate thoughtfully in ways that are tailored, accessible and understandable.
- Promote diversity and inclusion in all aspects of the research process, from the design to dissemination and including both researchers and participants.
- Be mindful of cultural differences in how people perceive and experience health, and reach out to seldom-heard groups.
- Find ways to integrate health and social care research, working together to identify common priorities, share resources, and collaborate on research projects.

### Suggestions for overcoming interpersonal barriers.

- Treat everyone with equal respect, regardless of their role.
- Be a critical friend, not a critical enemy.
- Leave your ego at the door.
- Avoid dictatorial leadership styles.
- Take the time to build positive interpersonal relationships.

### Suggestions for overcoming personal barriers.

- Pay or otherwise compensate everyone for their time and expenses.
- Provide and promote training that meets the needs of different collaborators depending on their existing knowledge and confidence.
- Use facilitators and provide other kinds of practical support.

### What is at stake? Why is interdisciplinary collaboration important?

- No one department or institution can tackle complex problems.
- Better collaboration means more efficient use of limited resources.
- Keeping patients involved makes research better.

## ABOUT THE WORKSHOP

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The workshop was hosted online via Zoom on Tuesday 27 June 2023, from 1-3pm. It was planned and delivered by freelance facilitator [Sarah McLusky](#) with guidance and contributions from X-Net project manager Cristina Martin.

### Aims of the workshop

- To explore public perceptions of research and how it is done.
- To gather ideas about how interdisciplinary research could be done more effectively.
- To get alternative perspectives on how to overcome barriers to interdisciplinary research.

The workshop was designed to be interactive to encourage discussion and contributions. The bulk of time was spent in breakout groups and contributing to online noticeboard Padlet.

- **Welcome and getting to know each other:** The session began with everyone being invited to introduce themselves. This helped ensure everyone's camera and mic was working but also made it clear that we wanted to hear from all the participants. A quick game of 'Blankety Blank' helped everyone feel more relaxed. Then we agreed some ground rules for working together in the workshop which included: only sharing what's written on the Padlet, listen to each other, respect different views, take turns to speak, leave your ego at the door and be kind.
- **X-Net Project introduction:** Cristina gave a very short overview of the X-Net project to put the session in context.
- **Experiences of collaborative working:** To help people identify relevant life or work experiences they were first invited to think about times when they have been involved in complex projects. They were given some time to think alone and were then randomly paired with one other participant in a breakout group. This section was not captured in any way.
- **Overcoming structural/cultural barriers:** the first discussion session invited participants to consider ways of overcoming structural and cultural barriers such as different ways of working. Participants were put into 3 random breakout groups of around 4 people and stayed in these groups for the rest of the session. At least one person in each group was tasked with capturing their discussion on Padlet.
- **Overcoming interpersonal barriers:** the second discussion session invited participants to consider ways of overcoming interpersonal barriers such as power dynamics, trust, and leadership.
- **Overcoming personal barriers:** the final discussion focused on overcoming personal barriers like confidence and skills gaps.
- **What happens next:** The session closed with a quick recap and then an explanation of how their contributions would be used for reports and recommendations. Cristina also gave details of how participants could claim their fee.

## ABOUT THE PARTICIPANTS

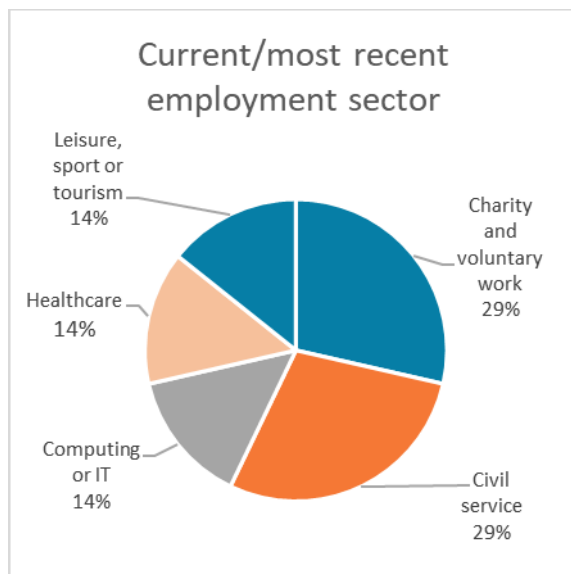
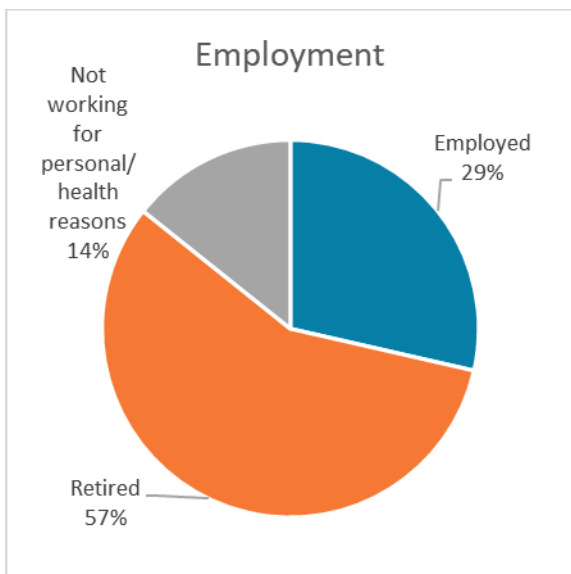
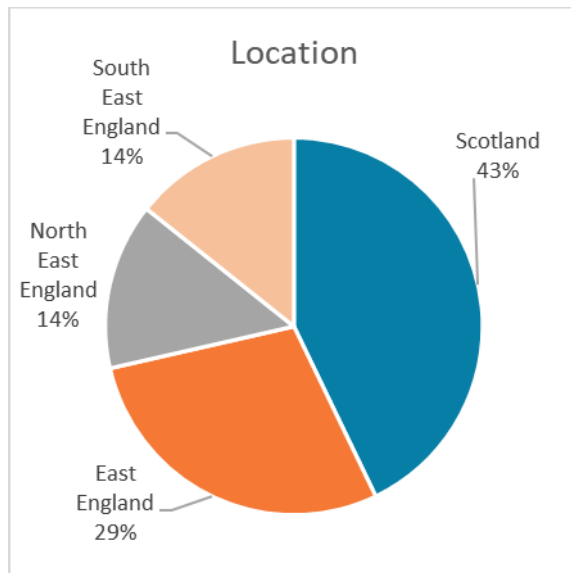
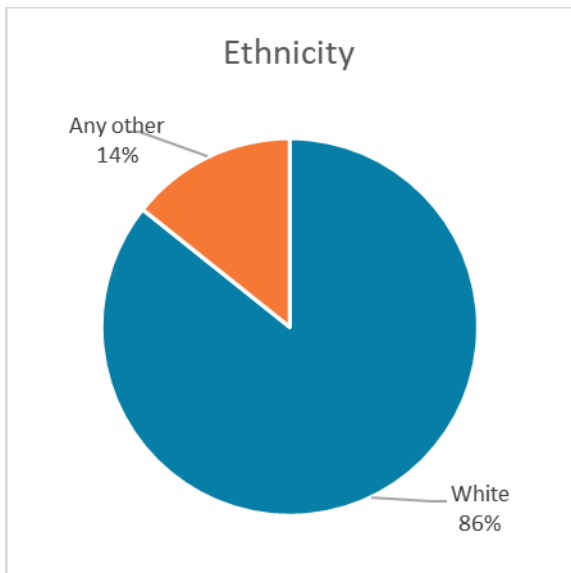
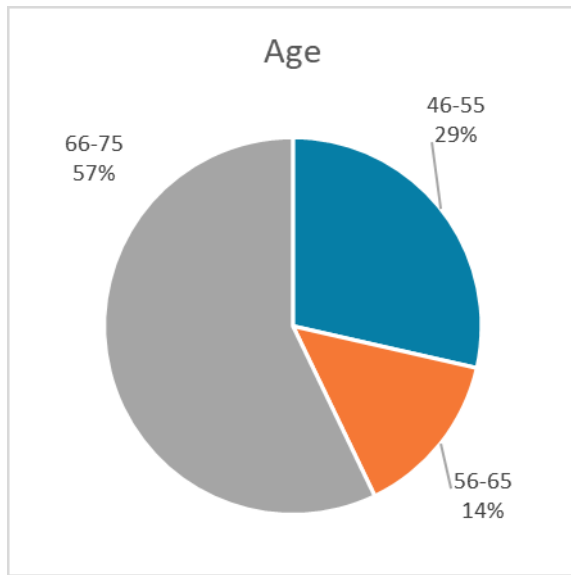
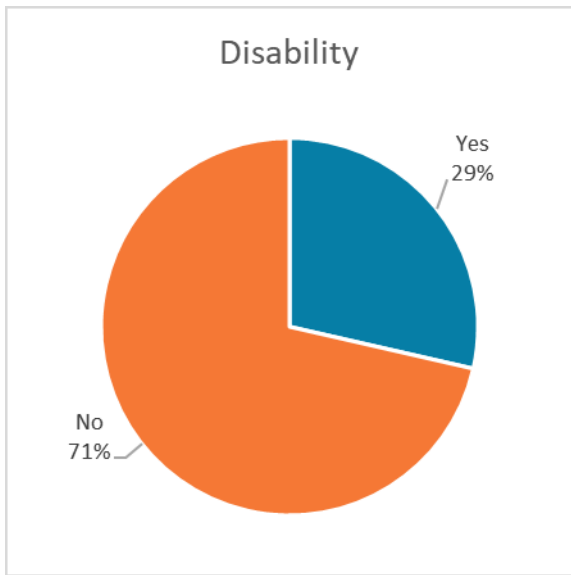
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Participants were recruited by X-Net project manager Cristina Martin. They were recruited via existing PPI groups including the [Tayside Medical Science Centre PPI group](#) at the University of Dundee, and the [Asthma UK Centre for Applied Research](#), University of Edinburgh. Participants were offered payment for attending and contributing in line with the [latest NIHR guidance](#).

Before the workshop 16 participants had signed up. On the day, 14 of these attended for at least part of the session. Due to technical problems and other commitments, 4 of these people missed substantial parts of the workshop but were offered the chance to contribute to the Padlet independently. Four members of the X-Net team attended but they did not participate in the breakout groups and discussions.

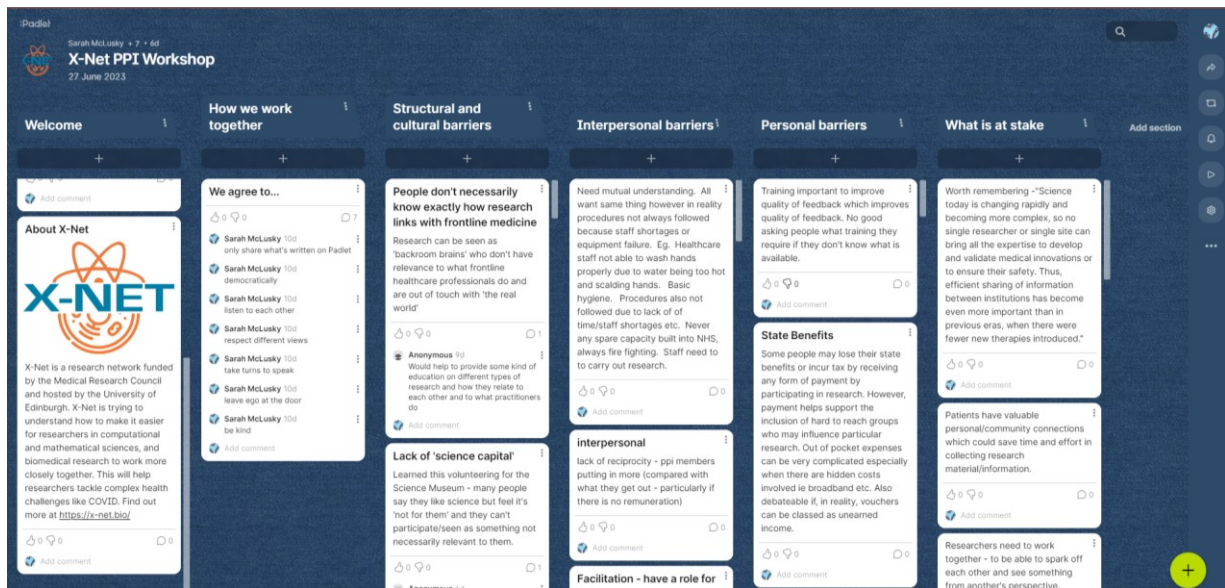
### Participant demographics

The participants were equally split by gender with 50% male and 50% female. Following the workshop participants were invited to complete an anonymous form collecting personal information. Only 50% of the participants (n=7) completed this form so the data is incomplete but is presented as general indicators of the audience breadth.



## CONTRIBUTIONS

Participant contributions were collected on an online noticeboard called Padlet and grouped under headings for each topic/barrier.



Although the questions were framed with respect to the challenges facing researchers, perhaps understandably, participants have answered them primarily from their own perspective. They have focused overwhelmingly on the barriers faced by patients and public collaborators who take part in research. Their responses emphasised the need to overcome barriers to ensure inclusivity and maximize participation in research.

### Overcoming structural and cultural barriers

#### *Communication and understanding*

Effective communication is essential for ensuring that research findings are translated into practice and that the public is informed about the latest developments in healthcare. However, there are several barriers to effective communication between researchers, frontline healthcare professionals, and the public. Current barriers include different ways of communicating and understanding scientific concepts, lack of connections between research and frontline medicine, trust and confidence issues, and cultural differences in how time is perceived and how work is done.

#### *Diversity and inclusion*

Diversity and inclusion need to be prioritised in both research and frontline medicine. This includes reaching out to people who are seldom heard and addressing discrimination and exclusion. Issues include a lack of funding for research that focuses on under-represented groups, discrimination and exclusion in the research community, and cultural differences in how people perceive and experience health.

#### *Integration of medicine and social care*

There is a need to integrate healthcare and social care research and practice as fundamentally both sectors are essential for improving the health and well-being of people. Currently there are different

funding streams and priorities for healthcare and social care as well as diverse cultures and practices, and a lack of communication and collaboration between professionals.

### *Cultural awareness*

Culture plays an important role in how people perceive and experience health. However, there are assumptions about the homogeneity of cultures and a lack of funding for research on cultural aspects of health. Cultural awareness is essential for ensuring that research is relevant and meaningful to people from all backgrounds. Training in cultural competency could be helpful as well as being open to different ways of working and communicating.

### *Suggested solutions*

- Communicate thoughtfully in ways that are tailored, accessible and understandable.
- Promote diversity and inclusion in all aspects of the research process, from the design to dissemination and including both researchers and participants.
- Be mindful of cultural differences in how people perceive and experience health, and reach out to seldom-heard groups.
- Find ways to integrate health and social care research, working together to identify common priorities, share resources, and collaborate on research projects.

## **Overcoming interpersonal barriers**

### *Need for mutual understanding.*

Everyone wants the same thing – better healthcare – but everyone has their own procedures, priorities, stresses, and limitations. Acknowledging this, treating others with respect, and taking the time to get to know each other (while remaining professional) can make a big difference. So-called ‘soft skills’ like communication and collaboration are key.

### *Hierarchies and power dynamics*

Healthcare and academia have very entrenched, if unspoken, hierarchies. For examples doctors, professors and medicine are seen as higher status than nurses, students, patients, and social sciences. It is important to acknowledge and actively address these power dynamics to ensure that everyone has a chance to contribute.

### *Fair division of labour*

Often there can be a perception that not everyone is pulling their weight, especially if some parties are either not paid or are paid much less than others. It is important to build trust by agreeing on plans and actions then following through on what has been promised.

### *Suggested solutions*

- Treat everyone with equal respect, regardless of their role.
- Be a critical friend, not a critical enemy.
- Leave your ego at the door.
- Avoid dictatorial leadership styles.
- Take the time to build positive interpersonal relationships.

## Overcoming personal barriers

### *Financial barriers*

Paying everyone for their participation in research can be helpful to include seldom-heard groups and gather a diverse range of perspectives. This might need to go beyond paying people for their time and extend to other out-of-pocket expenses such as travel, technology and broadband. However, it is important to be aware of how paying public participants can have implications for tax and eligibility for benefits.

### *Practical barriers*

Financial incentives can go some way to motivating and valuing participants, but awareness of other possible barriers could help engage a wider range of people. Additional barriers highlighted included access to resources (including technology), IT or other skills, ageism, and other kinds of discrimination/bias. Time is often the biggest challenge.

### *Knowledge barriers*

Participants mentioned that a lack of specialist knowledge could be a barrier, compounded by the fear of asking for help due to stigma. There were also concerns that lived experience is sometimes dismissed or not as highly valued as scientific knowledge. Both training and facilitation can help tackle this barrier. Facilitators were highlighted as being key to building trust and promoting inclusivity for individuals with disabilities.

### *Suggested solutions*

- Pay or otherwise compensate everyone for their time and expenses with a flexible approach to accommodate people in different circumstances.
- Provide and promote training that meets the needs of different collaborators depending on their existing knowledge and confidence – for public participants this might be subject knowledge, whereas researchers might need training on participatory approaches.
- Use facilitators and provide other kinds of support, e.g., offer translators or different modes of engaging, to ensure that everyone has an opportunity to contribute.

## What is at stake? Why is interdisciplinary collaboration important?

Finally, we asked the participants what message they would like to give researchers about *why* it is important to collaborate more effectively. Their responses can be summarised under three main sentiments.

### *No one department or institution can tackle complex problems.*

Given the rapidly changing and complex nature of science, no single researcher or institution can have all the expertise required to develop and validate medical innovations. Therefore, sharing information between institutions has become crucial. Collaboration can also spark new ideas and enable researchers to learn from different perspectives. Furthermore, failure to work together cooperatively can result in reputational damage and mistrust.

### *Better collaboration means more efficient use of limited resources.*

Effective collaboration reduces duplication of efforts, makes more efficient use of time, money, and resources, and enhances the progress of research, leading to greater benefits for future generations.



*Keeping patients involved makes research better.*

Patients, who have personal and community connections, hold valuable knowledge that can help with research if they are embedded in research projects. It is essential to keep patients and other contributors engaged and informed as, if they don't feel valued, they will lose interest and won't participate in future projects.

## REFLECTIONS ON THE WORKSHOP

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Asking public participants to make suggestions on how to do interdisciplinary research better was a big stretch. They can only draw on their own experiences and so, not unreasonably, they have responded to the questions from a public/patient involvement perspective. Their suggestions are thoughtful and valuable. Many ideas on how to communicate and collaborate more effectively can be extrapolated to apply to other participants from outside of the academia such as health professionals, charities, businesses.

When it came to running the session there were some technical challenges. Despite having been asked in advance to join from a laptop or desktop, many participants were joining from phones or tablets. This meant that access to the chat was difficult and contributing to Padlet was impossible. To some extent this was mitigated by working in groups where at least one person was able to access Padlet. Some also had problems with their cameras, microphones, or internet connections.

Other participants arrived late or left early. This made it tricky to allocate and re arrange groups, and to brief people arriving late, but ultimately it didn't have a significant impact. Some of these people made valuable contributions when they were present or contributed to the Padlet later.

These challenges directly relate to comments made in the 'personal barriers' section. Running sessions online has advantages and disadvantages. Some people won't have access to resources like laptops or high-speed broadband or will struggle with IT skills. The alternative would be to run the session in person. However, this would involve a greater time commitment, higher costs, and potentially fewer attendees. It is a difficult call and a decision that must always be taken with the target audience in mind.