

Remote working in patient and public involvement and engagement in health and social care research

Research results and good practice recommendations



These 'Good practice' recommendations for remote working in patient and public involvement and engagement (PPIE) in health and social care research have been developed based on the findings of research done in 2020-2021 during the COVID 19 pandemic. This project was funded by the National Institute of Health Research (NIHR) Applied Research Collaborative Northwest Coast (ARC NWC) and the UK Research Innovation (UKRI) Economic & Social Science Research Council (ESRC).

The aim of this overview of the research findings and good practice recommendations is to support remote working in PPIE. It provides practical guidance on how to organise and run remote meetings for public contributors so that everyone can get the most out of the meetings, be fully engaged and actively participate.



01 Introduction

Covid-19 (C19) prevention measures in March 2020 forced a shift to remote forms of working in patient and public involvement and engagement (PPIE). Due to lockdown, shielding and social distancing, the usual ways of involving the public were not possible and, even now with the removal of C19 restrictions, remote working is likely to continue.

In light of this, we undertook a research project, to understand the barriers and facilitators of remote working in PPIE, by exploring public contributors and PPIE professionals (those who are employed to facilitate and organise PPIE by organisations) experiences of working remotely. A particular focus of the project was to consider how the move to remote working in PPIE could affect the diversity of public contributors and how the 'digital divide' might negatively impact on diversity and inclusion in PPIE in health and social care research.



We will use the term remote communication technologies to cover all types of tools and platforms for non-face-to-face communication, such as telephones (land lines, mobiles, smart phones), online conferencing/meetings, social media, and apps.

02 Overview

This study used a mixed method approach comprising of an online survey with public contributors involved in health and social care research; an online survey with public involvement professionals, those who are employed by organisations; qualitative interviews with public contributors and a discrete choice experiment to examine public contributors preferences for different ways of organising remote PPIE meetings. We embedded public involvement in all stages and co-produced the study from its inception, design and subsequent analysis of the data.



We had 244 respondents to the public contributor survey and 65 for the public involvement professionals (PIPs) survey, 209 for the discrete choice experiment survey and conducted 22 qualitative interviews.

03 Results

We found that public contributors had adapted well to working remotely, and many were very positive about the experience. There were both benefits and drawbacks to working remotely.

- **Benefits included:** Learning new skills; not having to travel – which was particularly important for people with disabilities and caring responsibilities; for many their PPIE activity had increased and become more varied and it was reported that more attention had been given to public involvement leading to better involvement, with more frequent, productive and inclusive meetings.
- **The drawbacks included:** Missing informal, social interaction and hence relationship formation; communication hindered by lack of non-verbal clues and body language; and issues with working from home - poor internet, noise, lack of privacy, lack of space and family interruptions.
- **Suggestions for the future:** In terms of views on how PPIE should be organised when lockdown restrictions were removed, our participants generally favoured a mixture of face-to-face and remote meetings and working, rather than going back to only having face-to-face meetings.
- **Strengths:** A strength of the study is the number of respondents to the surveys and that we were able to follow up issues in the qualitative interviews. Further, both the surveys, with their free text response sections and the interviews gave public contributors and PIPs the opportunity to raise issues that had not been covered in the survey questions.
- **Limitations:** There were limitations with our study, due to ongoing Covid restrictions during the research project we were unable to include people who did not have access to digital tools in our research and our findings have to be interpreted in light of this.



Good practice recommendations

A number of good practice recommendations can be made on the basis of our research. To develop these we used the following process.

Development process

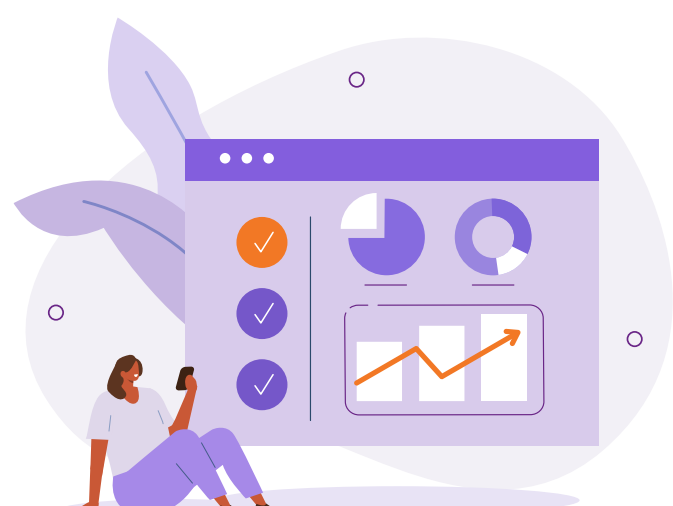
Stage 1: Analysis of data.

From the surveys, interviews, and our literature review.

Stage 2: Focus group discussion (FGD) with public contributors.

We held three FGDs with public contributors, lasting around an hour, to discuss and analyse the findings and develop the good practice recommendations.

- FGD 1 - 1st step of reviewing research findings – 14th June 2021.
- FGD 2 - 2nd step - review and funnel data from FGD1 – 9th July 2021.
- FGD 3 - 3rd step - review data from FGD 2 and decide main details of the good practice recommendations – 26th July 2021.



Good practice recommendations

- ✓ **Length and timing of meeting - Do not have long meetings.**
We found that people would prefer shorter meetings, i.e., less than 2 ½ hours and were prepared to forgo a social activity if this meant the meetings could be shorter. People also preferred meetings to take place during 'working' hours.
- ✓ **Allow people flexibility during the meeting.**
We found that people liked to be able to have their cameras off at points during the meeting and be able to feel that they could step away and leave the meeting briefly if they needed to, i.e., to attend to family members, take a comfort break or stretch to ease physical issues caused by sitting.
- ✓ **A good meeting chair and good moderation are very important.**
A good meeting chair can ensure everyone participates, the discussion is well managed and make sure that the discussion is well-balanced, and everyone's contribution is heard.
- ✓ **Meeting etiquette - Ensure everyone knows how to raise points and contribute.**
It is important to set out clear meeting ground rules at the beginning of meetings. For example, make it clear how people are expected to contribute, do they raise a virtual hand, just speak / unmute to speak, or raise their hand on camera?
- ✓ **Good feedback - Provide public contributors with feedback on their contribution.**
Although this is not unique to remote PPIE meetings, public contributors valued having feedback on how their contribution had made a difference. We found that group feedback was just as valued as individualised feedback.
- ✓ **Payment and expenses - Make sure people are not out of pocket when contributing remotely.**
A small expenses type payment to cover phone, data or electricity charges was valued by public contributors.
- ✓ **Recognise individual needs - Be mindful of individual public contributors' needs when working remotely.**
Public contributors had a variety of different needs to ensure that remote meetings worked well for them. Some found it hard to hear in meetings, others to see everybody, some had issues with sitting for a long-time, and others had home circumstances that made participation difficult.
Sometimes public contributors found the chat function useful, others felt that there was too much going on in the meeting to follow the chat. Meeting organisers should also remember that when sharing the screen people can often not see the presenter and this makes it difficult if people are relying on facial clues and lip reading. Captions could be used to help all follow what is going on.
- ✓ **Maintain good level of support for public contributors.**
One positive element mentioned by public contributors was that during lockdown they received a better level of individual support (i.e., one to one phone calls) and more regular meetings. Remote working has facilitated more informal and regular meetings, and this is something that could be continued, even when we go back to working in person and face-to-face meetings become more common.
- ✓ **Hybrid meetings.**
Our research did not consider hybrid meetings, but our experience with this since the easing of lockdown, prompts some reflections. Hybrid meetings can be viewed as a distinctive type of meeting, not a face-to-face meeting with video conferencing in the corner. Often people on the video call cannot see or hear people in the face-to-face room, and vice versa. It is good practice to have facilitators and moderators for both the video call and in the room and invest in technical solutions that ensure that people on the video call can hear those in the room. Care needs to be taken to ensure that all can participate fully and those participating online are not marginalised.

04 Remote meetings checklists

This checklist is designed to help people organise and plan a remote PPIE meeting. They are designed to encourage and enhance public contributors' ability to contribute and ensure the smooth running and inclusivity of the meetings.

Before the meeting

- ✓ **Advise the PPIE opportunities appropriately and ensure relevant groups can be reached in a timely way**
- ✓ **Practice and preparation**
Send out:
• Agenda and meeting papers (Make sure everyone can access the papers, some may need hard copies, some are ok with attachments)
• Clear aims & objectives of the meeting
• Clear joining instructions
• Meeting details, meeting sizes, lengths, and breaks
- ✓ **Consider and address any accessibility issues participants may have**
• Microphone / sound, how to mute
• Virtual background recommendations
• Camera position tips

During the meeting

- ✓ **The organisers should join early so that any technical issues can be sorted out before everyone else joins**
- ✓ **Meeting Etiquette Rules**
• Meeting PPI members / introductions
• Mute microphones
• How to contribute - raise hand etc.
- ✓ **Meeting lengths**
• Make sure the meeting does not run over and all items are covered on the agenda.
- ✓ **Meeting breaks**
• Make sure there are short breaks offered, especially if the meeting lasts longer than an hour
- ✓ **Organisers' roles**
• Be clear on everyone's role and how tasks will be divided up between the organising team. i.e. what the chair / moderator, host, presenter, technical help and co-facilitator will be doing
- ✓ **Security and privacy**
• Explain any relevant issues (such as if topics are confidential, documents shared should be kept confidential etc.)
- ✓ **Expect the unexpected**
• Back up plans if people cannot join the meeting



After the meeting

- ✓ **Give public contributors the opportunity to share anything they may not have had the opportunity to share during the meeting**
- ✓ **Remember to thank attendees**
- ✓ **Circulate meeting notes and details of how their contribution changed / affected the plans etc.**
- ✓ **Ask for feedback on how to improve future meetings**
- ✓ **Networking and Socializing – explore if public contributors would like time scheduled for this, i.e. a virtual coffee chat**

05 The team

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06 Partners

