**Participant information sheet**

**Version number & date:** 1.5. 15th December 2020

**Research ethics application number:** 7363

**Title of the research project:** Exploring remote working practices for patient public involvement and engagement (PPIE) in health and social care research – Responding to Covid-19

**Name of researcher(s):** Frith, Gabbay, Cloke, Abba, Downing

1. **Invitation**

You are being invited to participate in this research project. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your colleagues, friends or relatives if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

*Thank you for reading this.*

1. **Why are we doing this study?**

This project is part of the NIHR Applied Research Collaboration North West Coast portfolio of research.

The aim of the project is to explore how we can facilitate and improve doing patient public involvement and engagement (PPIE) remotely, working with people without face-to-face contact, in health and social care research.

This project has been prompted by the necessary changes in our working practices due to the Covid-19 pandemic. But, once the social distancing measures have passed there is still merit in exploring how we can use communication technologies (land lines, smart phones, online conferencing, social media etc.) to facilitate remote PPIE working more effectively to include and engage a wider range of people in our work.

This project will involve both data gathering to understand public advisors’ ways of using communication technology, their needs and views on remote working and will also involve doing some user testing on different communication technologies, to see how well they work and easy people find them to use.

This study will use several different types of research method and will have two phases. The first phase, during the social distancing measures introduced due to Covid-19, will be made up of an online survey, remote qualitative interviews and remote user-testing of communication technologies. The second phase, once social distancing is over, will be made up of a paper version of the survey, face-to-face interviews and user-testing, so we can reach people who do not have the means or find it difficult to participate remotely.

1. **Why have I been chosen to take part?**

You have been chosen to take part because you have an affiliation or an association with an organisation that organises, carries out or is involved with health and social care research, either professionally or as a public advisor.[[1]](#footnote-1)

1. **Do I have to take part?**

No. You do not have to take part, participating is entirely voluntary.

1. **What will happen if I take part?[[2]](#footnote-2)**

**For public advisors**

*Online phase*

You will be invited to participate in (one of the following):

A survey. During the Covid-19 measures this will be online, you will be emailed an invitation with a link to the survey. This survey will be made up of about 40 questions to see what types of communication technologies you use (i.e. land lines, smart phones, online conferencing, social media etc.) and how you feel about using them. The survey should only take about 20 minutes to complete.

An interview – this will be done online or over the telephone and recorded with your permission. The interviews will pick up on issues that have been raised in the survey in more detail, to get a more in-depth understanding of the issues. The interviews will take approximately 30 minutes.

User-testing – we will run workshops online to do a form of user testing of certain communication tools, i.e. Zoom, Microsoft teams, teleconferences, to document experiences and issues with using these tools. These will last no more than an hour. The workshops will be audio recorded, with your permission, and notes taken by the research team.

Online survey two – you will be asked to participate in a discrete choice survey. This is a method used in economics to determine how you value different options. The survey will ask you about how you rate and rank different types of remote communication technologies. This survey will take about 25-minues to complete.

*Face to face phase*

Events and data collection will only be held face to face if lockdown and social distancing measures have been removed.

User-testing – we will run the user testing workshops face-to-face, in the computer training labs at the University of Liverpool library, and do a form of user testing of certain communication tools, i.e. zoom, Microsoft teams, teleconferences, to document experiences and issues with using these tools. These sessions will take no longer than an hour and be facilitated by members of the research team, notes will be taken during the meetings.

Survey two – you will be asked to participate in a discrete choice survey. This is a method used in economics to determine how you value different options. You will be emailed or given an invitation and asked to notify the research team of your interest in participating. A survey will be sent to you in the post. The survey will ask you about how you rate and rank different types of remote communication. This survey will take about 25-minues to complete and you will be given a stamped addressed envelope to post the survey back.

**For professionals**

You are asked to complete an online survey. This will explore how you are seeking to involve public advisors during this time of social distancing due to Covid-19. You will be asked about what methods you have used, how effective you have found them; what you see as the barriers and facilitators to this kind of remote working in PPIE and what training you have instituted or would like to have in place to support your public advisors working in this way. The survey should only take about 20 minutes to complete.

1. **How will my data be used?**

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of ‘public task’, and in accordance with the University’s purpose of “advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University’s research. The Principal Investigator acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Lucy Frith.

Further information on how your data will be used can be found in the table below.

|  |  |
| --- | --- |
| How will my data be collected? | Surveys, interviews, workshops. |
| How will my data be stored? | All data will be stored on the password protected University server.  All hard copies of documents will be stored in a locked filing cabinet on University premises. |
| How long will my data be stored for? | 10 years |
| What measures are in place to protect the security and confidentiality of my data? | The audio files, online survey responses, notes on user testing workshops will be stored securely in accordance with University data storage procedures. The consent forms, paper survey responses and hard copies of workshop notes will be stored in a locked filing cabinet.  All research results will be fully anonymised, all data shared in the research team will be anonymised. Data will be prepared and fully anonymised data deposited for sharing on the UK Data Service (UKDS) ReShare.  The audio recordings of data (from the interviews and user-testing workshops) maybe transcribed by professional transcribers. If this is the case we will use a professional transcription services regularly used by the University, audio and word files will be sent in an encrypted format, and the transcribers will sign a confidentiality agreement. Audio data will not be shared as it is not possible to ensure confidentiality and anonymity. |
| Will my data be anonymised? | Yes |
| How will my data be used? | We will use the data to improve practice in remote working in PPIE. We will produce guidelines, reports and academic journal articles. Reports and guidance will be open access and hosted on the ARC’s website. |
| Who will have access to my data? | Only the research team |
| Will my data be archived for use in other research projects in the future? | No |
| How will my data be destroyed? | Deleted from the University server and hard copies of any documentation such as consent forms and paper based survey responses shredded. |

1. **Expenses and / or payments**

There will be no payment for taking part in the survey part of the study. For the qualitative interviews we will give participants a thank you shopping voucher (of no more than £20), this is to enable people to pay for data, internet etc. to ensure a wide range of people can participate. For designated tasks, such as the user testing of communication technologies or specific workshops public advisors will be paid for their time and, if relevant, travel expenses. The payments will be line with the ARC public advisor policies.

1. **Are there any risks in taking part?**

We do not think that there are any risks to taking part. The surveys, interviews and workshops will be held virtually and, if relevant face-to-face in familiar environments and facilitated by experienced researchers. If any of the issues discussed are distressing, you are free to leave the workshop, discontinue the interview or close the survey. You do not have to answer any questions or participate in any online or face-to-face activities that you feel uncomfortable with.

1. **Are there any benefits in taking part?**

There are no direct benefits to you as an individual participating in this project, but this project will hopefully improve the conduct of remote working in PPIE and help make PPIE activities more accessible.

1. **What will happen to the results of the study?**

We will use the data to improve practice in remote working in PPIE. We will produce guidelines, reports, academic journal articles and present our findings at events and conferences. Reports and guidance will be open access and hosted on the ARC’s website where you can access them if you are interested <https://arc-nwc.nihr.ac.uk/>.

We will also make available hard copies of our reports and guidance. Please contact or tell the researcher that you are interested in receiving these and we will take your contact details – and these will be held separately and not linked to your research data.

1. **What will happen if I want to stop taking part?**

You can stop taking part in the survey at any time and not submit the survey. Once you have submitted or posted the survey you cannot withdraw your data as the survey answers are anonymised.

You can stop taking part at any time and can leave the workshop. The data from the workshops and activities will be anonymised so individual contributions to workshops cannot be withdrawn once the workshop begins.

You can discontinue the interview at any point without giving a reason and the data can be withdrawn from the study up to two weeks after the interview, then the data will be anonymised and you can no longer withdraw your data.

1. **What if I am unhappy or if there is a problem?**

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Lucy Frith, [frith@liverpool.ac.uk](mailto:frith@liverpool.ac.uk) 0151-795-5333, and we will try to help.

If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at [ethics@liv.ac.uk](mailto:ethics@liv.ac.uk). When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), and the researcher(s) involved, and the details of the complaint you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

1. **Who can I contact if I have further questions?**

Lucy Frith

0151-795-5333

frith@liverpool.ac.uk

1. We will delete one of these categories as appropriate. [↑](#footnote-ref-1)
2. We will delete these options as appropriate to the phase of the study and part the participants are being recruited to. [↑](#footnote-ref-2)