**Participant information sheet**

**Version number & date:** 1.3. 15th April 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, Hassan, Wheeler, Ring, Goodall, Gabbay, Cloke, Abba, Downing, Porroche-Escudero

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.

This is an invitation to take part in an online survey.

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

You can take part in this survey if you have an affiliation or an association with an organisation that organises, carries out or is involved with health and social care research, as a public advisor. Or if you have acted as a public advisor/contributor on health research, implementation or related projects.

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?**

You are asked to complete this online 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 20-30 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? | Survey |
| 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 online survey responses, will be stored securely in accordance with University data storage procedures.  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. |
| 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 and anonymised findings archived. |
| 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. |

1. **Expenses and / or payments**

There will be no payment for taking part in the study.

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

We do not think that there are any risks to taking part. The survey is online. If any of the issues covered are distressing, you are free to close the survey. You do not have to answer any questions 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 the survey you cannot withdraw your data as the survey answers are anonymised.

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?**

Please email [arcnwc@liverpool.ac.uk](mailto:arcnwc@liverpool.ac.uk) and they will put you in touch with a member of the research team.