Polly Kerr
Patient and Public Involvement Manager
Polly.kerr@phc.ox.ac.uk
01865 617765

Mark Taylor, Head of Strategic Partnerships, NIHR
Mark.taylor@nihr.ac.uk
01865 986202

6th May 2022; v1.1

Patient and public involvement in National Institute for Health and Care Research (NIHR) research 2006-2021: intentions, progress and themes from the patient and public perspective

PARTICIPANT INFORMATION SHEET – SURVEY QUESTIONNAIRE

Central University Research Ethics Committee (CUREC) Approval Reference: R67449/RE001

1. *Why is this research being conducted?*

We are a research team at the University of Oxford, Sheffield Hallam University and the National Institute for Health and Care Research (NIHR) working with a group of independent patients and carers to conduct a study to understand more about the experiences of public, patient, carer and people who use social care services' involvement (PPI) in health, social care and related research as funded by NIHR over the previous decade or so. NIHR, since its inception, has made PPI with research a key priority and policy.

NIHR will wish to investigate the impact of its PPI policy, and in order to assess impact we need to understand both the original policy intentions and what changes may have occurred from the point of view or experience of the public, patients, carers and people who use social care services. We wish to investigate whether those involved in research have seen any significant changes in how PPI is structured / organised / delivered in health, social care and related research since 2006. By default, we hope to also note changes in how people have engaged with / experienced PPI over the period.

We would like to invite you to participate in this research, to contribute your experiences and views through an online questionnaire.

2. *Why have I been invited to take part?*

We have worked with a range of groups known to NIHR to identify people who have had a long-standing relationship with research and researchers, and who are aged over 18 years. You have been contacted due to your connections with one or more of these groups and we are now inviting you to participate by completing the questionnaire.

3. *Do I have to take part?*

No. You can ask questions about the research before deciding whether or not to take part. If you do agree to take part, you may withdraw yourself from the study at any time while completing the questionnaire, without giving a reason.

After completing the questionnaire it may not be possible to remove your data from the study as it will be anonymous and will have been combined with other data in the study.

4. *What will happen to me if I take part in the research?*

If you decide to participate, you can access the online questionnaire through the link provided, and proceed to answer the questions. These questions will ask you to share your experience of PPI in health, social care and related research funded and supported by NIHR, and whether you have noted any changes in how it has been undertaken since you were first involved. The questionnaire will also ask some questions about you and your identity. The questionnaire will take around 10 minutes to complete.

At the end of the questionnaire, you will be asked to indicate if you are happy to be contacted by the research team at a later date to be invited to participate in a follow-up interview or workshop; this is optional.

5. *Are there any potential risks in taking part?*

There are no major risks to participating, and the main disadvantage to you will be the time taken to complete the questionnaire.

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

There are no direct benefits of taking part, beyond contributing to our understanding of experiences of PPI, and how to support this role in future research.

7. *What happens to the data provided?*

The information you provide during the study is the **research data**. Any research data from which you can be identified, e.g. name, age, involvement in NIHR research studies etc.) is known as **personal data**.

Personal / sensitive data will be stored on the NIHR secure servers. NIHR use leading technologies and encryption software to safeguard your data and maintain strict security standards to prevent any unauthorised access to it. We make every effort to reduce the risks associated with data in transit over the internet by using appropriate technology, including (but not limited to) SSL for any of our websites or applications which collect data from you. SSL is a digital certificate that authenticates a website's identity and enables an encrypted connection. SSL stands for Secure Sockets Layer, a security protocol that creates an encrypted link between a web server and a web browser. Any data will be stored for up to 5 years after the study concludes.

Other research data (including consent forms) will be stored for 5 years after publication or public release of the work of the research.

The researcher and research team will have access to the research data from the questionnaire. The data will be stored securely on the NIHR password-protected computer system. Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the research.

Only anonymised data will be presented in study reports and other outputs.

Raw data (i.e your individual questionnaire responses) from the research will be destroyed two years after the end of the study. The processed data (i.e. aggregated responses from questionnaire participants) will be added to the NIHR research data archive for secure storage. With your permission, anonymised data will be included and made available for other researchers to access with our permission in the future, for appropriate research only. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

Your personal data may be transferred to, and stored at, a destination outside the European Economic Area. Identifiable data will be removed whenever possible and any data transfer will be done securely and with a similar level of data protection as required under UK law.

8. Will the research be published?

We plan to write up the results from this research in papers to be published in academic journals, and in other formats for public and practitioner audiences, including a report, briefing and / or blog posts. We will also present results at relevant conferences and meetings.

9. Who is funding the research?

This research is being underwritten by NIHR.

10. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, a subcommittee of the University of Oxford Central University Research Ethics Committee (Reference number: R67449/RE001).

11. *Who do I contact if I have a concern about the study or I wish to complain?*

If you have a concern about any aspect of this study, please contact Polly Kerr (polly.kerr@phc.ox.ac.uk) and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Chair, **Medical Sciences Interdivisional Research Ethics Committee**; Email: ethics@medsci.ox.ac.uk;
Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, OX3 7GB.

12. Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study.
The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest.

Further information about your rights with respect to your personal data is available from http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/.

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Polly Kerr
Nuffield Department of Primary Care Health Sciences
Radcliffe Primary Care, Woodstock Road, Oxford, OX2 6GG
University tel: 01865 617765
University email: polly.kerr@phc.ox.ac.uk

Dr Mark Taylor
National Institute for Health and Care Research
Grange House, 15 Church St, Twickenham TW1 3NL
Email: mark.taylor@nihr.ac.uk
Telephone: 01865 986202