Imperial College London

What does research impact mean to participants?

Interview study to explore participants' views of on the impacts of healthcare research

Participant Information Sheet

1. What is the purpose of this study?

We are interested in speaking to people who are (or have previously) taken part in healthcare research to find out their views of what makes 'good' research. This will help us understand the important positive and negative impacts of healthcare research from the perspective of research participants and patient advisors. The study results will be used to design future research and to develop ways of recording these important impacts.

We are specifically interested in research led by non-medical healthcare professionals (e.g. nurses, midwives, physiotherapists, dietitians, occupational therapists, other allied health professionals, pharmacists, healthcare scientists and clinical psychologists). A list of all 14 allied health professionals can be found here: https://www.england.nhs.uk/ahp/role/.

This is a research study and before you decide whether or not you want to take part, is it important for you to understand why the research is being carried out and what it will involve. Please read this information sheet carefully and discuss with others if you wish. We are happy to answer any questions. Contact details are provided at the end of this leaflet.

2. Why have I been invited?

You have been invited to take part because you are a current (or previous) participant/advisor in a research study led by one of the professions listed above, and agreed to be contacted about future research. We are looking for adults (aged over 18 years) who participated in research or a research advisory group within the past 3 years. We hope to interview 15-25 individuals who have been involved in different types of research and at different locations in the UK.

3. Do I have to take part?

Participation is voluntary and you are under no obligation to take part. If you do decide to take part, you will be asked to sign a consent form and will be given a copy of this to keep. You are still free to withdraw from this study at any time and without giving a reason.

4. What will happen to me if I take part?

You will be invited to take part in in a one-off telephone call or video interview (using Zoom, Teams, Skype etc.). This will be at a date and time that is convenient for you. The interview will be with a healthcare researcher who will ask about your experience of being a research participant, including any benefits or challenges. They will also ask for your views of what makes 'good' healthcare research. Interviews will be carried out in English language. Please discuss with the research team if you feel you may need an interpreter.

Before the interview, you will be asked to provide some background demographic information using an electronic form (Qualtrics, hosted by Imperial College London). This will help us make sure that a range of views are represented. You will also be asked to sign a consent form.

The interview is expected to take between 35-45 minutes and will be audio recorded using the inbuilt recorder within the video platform and/or an external audio recording device. After the interview, a written transcript will be made from the audio recording and the audio file will be destroyed. The transcript will be anonymised by removing names, places and other potentially identifiable details. You will be asked if you would like a copy of your transcript as part of the study consent form.

Your anonymous transcript will be analysed together with those from the other interviews. Key themes and ideas will be identified by the research team and compared across all participants. Anonymised quotes will be used as part of the study reports, but it will not be possible to identify anyone from these quotes.

5. What do I have to do?

Taking part in this study involves a one-off interview. There are no other requirements. Participation will not affect your daily activities, medical care or involvement in other research.

6. What are the possible disadvantages and risks of taking part?

There are no expected risks associated with taking part in this research. We are unable to offer any reimbursement for your time.

7. What are the possible benefits of taking part?

There are no specific benefits to you from taking part in this interview study. The information you provide will be used in the design of future research, with the aim of ensuring positive impacts for research participants.

8. Will my participation be confidential?

Imperial College London is the sponsor for this study and will act as the data controller. We are responsible for looking after your information and using it properly in accordance with the UK Data Protection Act (2018). Imperial College London will keep your personal data for 10 years after the study is complete. This includes study consent forms and anonymised interview transcripts. Your data will be treated as confidential.

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in this research study, we will use your data in the ways needed to conduct and analyse the research, as outlined in this leaflet.

The information we need for this research project includes your name, contact details, age and ethnicity. People who do not need to know who you are will not be able to see these details. Your data

will have a study ID code instead. We will keep all information about you safe and secure. We will write our reports in a way that no one can work out that you took part in the study. If you would like more information about how we use your information, please contact the chief investigator (details at the end of this leaflet).

To support this research study, we will need to share your data with certain third parties. An external transcription company will be used (PageSix), and a small number of university/NHS employees may assist with the analysis and with sharing the study findings with you by email/post. Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

9. What will happened to the results of this study?

We aim to publish our findings in a healthcare journal and present the study at relevant healthcare conferences. You will be invited to opt in or out of receiving notification of the study findings as part of the study consent form.

We will also use the results to develop a framework to record research impact. The consent form asks you to indicate whether or not you wish to be contacted about this next stage of the project. You do not have to take part in the next stage.

10. Who is organising and funding this study?

This study is funded by NIHR Imperial Biomedical Research Centre and Imperial Health Charity. The study team are clinicians and researchers at Imperial College London and Imperial Healthcare NHS Trust: Dr Lisa Newington (physio), Dr Caroline Alexander (physio) and Prof Mary Wells (nurse).

11. Who has reviewed this study?

This study has been reviewed by the funders (Imperial Health Charity), Imperial College London Research Governance Integrity Team (ref: 21CX6867) and the NHS Research Ethics Committee and Health Research Authority (ref: 21/WA/0229).

12. What if I no longer wish to be involved?

Before your interview, you can stop being involved in this study at any time, without giving a reason. We will keep the information you have already provided. After the interview, you can request for your interview to be removed from this project for 14 days after the interview and the audio file and transcript will be permanently deleted. Please contact the chief investigator (details at the end of this leaflet) if you wish to make this request. After this time, the anonymous transcripts will have been incorporated into the analysis and it will not be possible to remove individual components. You can still opt out of future contact at any time by contacting the chief investigator.

13. What if I have a concern or complaint, or something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action. Regardless of this, if you wish to complain or have any concerns about the way you have been treated during the course of this study, then you should immediately inform the chief investigator (Lisa Newington) using the contact details below. If you are not satisfied with the response, you can contact Imperial College London Research Governance team: rgitcoordinator@imperial.ac.uk. If you wish to raise a complaint about how we have handled your personal data, please contact Imperial College London's Data Protection Officer: dpo@imperial.ac.uk or 0207 594 3502. The normal NHS complaints mechanisms are also available to you.

Thank you for your interest in our research!

If you are happy to take part in an interview, or would like any additional information about this study, please contact Lisa Newington on l.newington@imperial.ac.uk or 07866 997732

The research team

Lisa Newington

Caroline Alexander

Mary Wells