

Interview Schedule

Study: What does research impact mean to participants? Interview study to explore participants views on the impacts of healthcare research

Design: Semi-structured 1:1 interviews

Question development: Interview questions were developed in collaboration with two patient and public advisors. Questions will be further refined to accommodate any additional topics that arise during the initial interviews.

1. Can you tell me a bit about the research study you were involved in?

Prompts:

What were you required to do for the study? – was this alongside or separate from clinical care?

If new treatment/intervention involved – how did you feel about being offered/not offered that?

How long was the study involvement?

Was there any financial incentive/reimbursement?

How do you feel about this experience?

2. Do you feel there were any benefits to you of being involved in the study?

If yes: can you tell me a bit about the benefits?

If no/neutral: were there any impacts to you more broadly? Can you tell me a bit more about this?

Prompts (only once interviewee has explored their initial thoughts):

Access to healthcare/additional appointments

Improvement in symptoms/health status

Relationship with clinical team

Finding out more about their condition – health awareness

Finding out more about health research – research awareness

Financial incentive

3. Do you feel there were any challenges for you during your involvement in the study?

If yes: can you tell me a bit about these challenges?

Prompts (only once interviewee has explored their initial thoughts):

Time

Need to complete questionnaires/study documents

Travel (? Any reimbursement for these costs)

Impacts to family/friends

Medical/research jargon

Relationship with clinical/research team

What might the researchers/healthcare professionals have done differently to improve this?

4. Do you think your view of healthcare has changed at all as a result of being involved in the study? If so how?

Prompts:

Knowledge of own health/health condition

Knowledge of healthcare organisation

Knowledge of healthcare research processes

View of healthcare professionals

Were you ever asked something that you didn't think was relevant to your condition?

5. Do you think you would take part in another clinical research study, if you were asked?

If not, why might be this be?

If yes, would there be any type of research that you wouldn't want to be involved in?

Prompts:

Randomised controlled trials

New interventions

Interview studies

Questionnaire based studies

Longitudinal studies – with follow-up over many years

6. What do you think makes a good healthcare research study, from your perspective?

Prompts:

Participant information

Participant experience

Research team

Feedback – do you want to know the overall results?

Research question/ potential research benefits

Ability to change care for patients

Reimbursement for participants' time

Low level of risk to participants

Do you think this is different to how research teams or the NHS view 'good' research?

If yes: in what way?

7. Within the NHS, we need to make sure we can record the important impacts of each healthcare research study. What type of things do you think we should be looking for?

Prompts:

Positive and negative impacts to participants/healthcare teams

Things that are important for patients/participants

What do you think is important for researchers/funders

Cost-effectiveness

Population level and individual patient/participant level

How might we collect this information?

8. Is there anything else you would like to add about your experience of being a research participant?

9. Is there anything else you would like to about the general impacts (or positives and negatives) associated with healthcare research?

10. Finally, the term allied health professionals is used to describe a particular group of healthcare professionals within the NHS – what does this term mean to you?

Prompts:

Ideas for other terms / categories of healthcare professionals

Role of uniforms in identifying healthcare professionals

Is professional discipline important for the delivery of patient care / research