

Summary Results: Patient Research Experience Survey 2016/17

These are summary results of a patient survey about experience of participating in clinical research. The survey was carried out by Local Clinical Research Networks across England and the results were collated and analysed nationally. The local surveys included the same or very similar core questions and a free text box. The survey followed a pilot in 2015/16.

The number of respondents to the survey (3,320) was much higher than the original pilot (597) which means the data is very reliable and confirms the findings from the pilot. The feedback showed that:



90%

of patients had a good experience of participating in clinical research



86%

of patients would be happy to take part in another research study

Relationships with research staff

We looked carefully at what people said to us in their free text responses to the survey. Some common themes emerged about what people found most important in their experience of research. We also noted the number of mentions belonging in each theme:

Motivation from participation

Clear information

Respect for people's time

Easy access to local research

What the themes mean in order of emphasis

Research staff



The feedback from research participants emphasised the friendliness, professionalism, knowledge, approachability, helpfulness, and respectfulness of staff being most important. This strong appreciation of staff was also expressed frequently in comments of those who had indicated that they were unlikely to take part in another research study.

Learning: Good working relations with staff are clearly key to good patient experience of a research study.

Motivation



Responses revealed much about the importance of motivation to patients for participating in research. In particular:

- altruism and improving medical knowledge
- possibility of improving own health condition
- better medical monitoring
- learning about a medical condition

Learning: It is important to acknowledge and appreciate the patient's motivation for participating in a research study.

Information



Feedback showed that good and timely information is very important to the patient's journey through a research study. This included information about the:

- research study itself
- practical arrangement for participating such as reminders etc for visits
- progress of the research study (particularly a long one) and any interim findings
- results at the end of the research study

Learning: Having the right information at the right time is important to feeling fully engaged.

Time



This was mentioned in a good number of comments in the feedback, particularly about timing of research appointments and waiting time whilst on a visit.

Learning: It is important to respect the patient's time given to participate in a research study.

Access



There were also a range of comments generally about access and these tended to be about:

- flexibility of timing
- location
- travel
- parking
- disability access

Learning: There are a number of practical factors that can affect experience in attending a research study and can significantly contribute to the burden of doing so.

Find out more

For more details about the background, the questions and full results of the Patient Research Experience Survey please read the full report which is available at: <https://www.nihr.ac.uk/why-research-matters>

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