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Cystic Fibrosis Research News

Title:

A discrete choice experiment to quantify the influence of trial features on the decision to participate in cystic fibrosis clinical trials

Lay Title:

How important are different trials features when people decide whether to take part in cystic fibrosis clinical trials?

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What was your research question?

How important are different, predefined, trial features when people decide whether to take part in cystic fibrosis (CF) clinical trials? Which predefined features have the biggest influence on whether people with CF choose to take part in trials.

Why is this important?

It is important to understand the preferences of people with CF for trial design to, firstly, recruit enough people to trials, and secondly, to ensure that participants have a good experience of taking part. We hoped to understand which features are most important to people with CF so that we could advise those designing and delivering trials what they need to do to develop trials that are preferred by people with CF.

What did you do?

We designed a survey called a discrete choice experiment. This used a special type of design to help us quantify how important different features are to people with CF when deciding whether to take part in trials. These features included type of medicine, trial location, stipend (payment) provision, washout (the need to stop a usual medicine), access to medicine when the trial finishes and trial design. People with CF tested our survey to ensure it was clear and relevant. We recruited people with CF, aged 16+ though clinic and social media. We had 207 responses to the survey.

What did you find?

The most important predefined feature people with CF considered when deciding whether to take part was the location of the trial. People prefer taking part at their usual clinical centre. Greater travel distances made people less willing to take part. The next most important feature was whether people could access the medicine after the trial. People would rather take part in trials of modulators, but were still prepared to take part in trials of other medicines. People prefer not to stop their usual medicines, but were more prepared to stop non-modulators than modulators. Stipend (payment) provision was not especially important. People were prepared to take part in trials with placebos.

What does this mean and reasons for caution?

The results of our survey gave us an insight into what features are most important to people with CF when they decide whether to take part in trials.

Answers to surveys can sometimes give a false picture, as people may give what they think is the right answer, rather than their actual opinion. People may also say they would take part in a trial in theory, but it can be much more difficult to take part in trials in the real world, and this could influence the results.

What's next?

The major trials networks in Europe and the UK have agreed to incorporate our findings into their review process to make trials more participant centred. We will work with them to guide the design of trials that are designed to meet the preferences of people with CF.

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https://pubmed.ncbi.nlm.nih.gov/33653764/