

# Cystic Fibrosis Research News

**Title:**

Guiding the rational design of patient-centred drug trials in Cystic Fibrosis: A Delphi study

**Lay Title:**

A study to understand which factors are important to people with Cystic Fibrosis when deciding whether to take part in clinical trials

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**What was your research question?**

We wanted to understand which factors influence the decision of people with CF and parents of children with CF to enrol in trials, and what makes it easier or more enjoyable to take part in trials.

**Why is this important?**

New drug developments in CF make this an exciting time to be involved in trials. CF is a rare disease so it can be difficult to recruit enough people into trials. This can mean that trials take longer to finish, or don't collect enough results to show if a drug works. As such, potentially beneficial treatments are slower to reach the clinic. We want to help make participation in trials easier and more enjoyable for people with CF and to understand how to support those taking part. We will seek to get findings included in future protocols.

**What did you do?**



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We did a literature search and held a focus group. We considered over 100 factors that *might* influence the decision to participate in a trial. We then designed a series of online questionnaires to ask people with CF, parents of children with CF and healthcare professionals to rate how important they think each factor is when deciding whether to take part in a trial. If more than 70% of respondents 'agreed' or 'strongly agreed' that a factor would influence their decision to take part, we regarded it as being important in influencing the decision to participate in a trial.

## **What did you find?**

We found many ways to make trials more patient-centred. Some would require major changes in the way we run trials, but others would be easy to include. We found that research teams need to focus on ensuring good communication. We also found that lack of time is a huge barrier to participating in trials. Therefore, it is important to minimise the length and frequency of hospital visits and use remote appointments where possible. One of our most striking findings was that really simple things can hugely enhance experiences of trial participation, e.g. on-site access to Wifi and cups of tea!

## **What does this mean and reasons for caution?**

We will share our results with people who design and run clinical trials to help them make trials more patient-centred. We hope this will improve recruitment to trials, mean that fewer people drop out and ensure that people enjoy participating in trials. Ultimately, we hope that this will ensure that new drugs are developed as efficiently as possible.

Access to healthcare and the way trials are delivered varies across the world. All our respondents were based in the UK. Many of the findings will be relevant to other countries but the result should be interpreted with caution by sites outside of the UK.

## **What's next?**

We identified a few controversial issues like how placebos, washout periods and location of trial visits are viewed by the CF community. We plan to explore these in more detail with people with CF later in the year.

## **Original manuscript citation in PubMed**

<https://pubmed.ncbi.nlm.nih.gov/33895096/>

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