

# Cystic Fibrosis Research News

**Title:**

Factors Influencing Clinical Trial Participation for Adult and Pediatric Patients with Cystic Fibrosis

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**What was your research question?**

What are the research interests and barriers/facilitators for people living with CF to participate in a research study or clinical trial? Are there any differences in these factors between adult patients and parents of child patients?

**Why is this important?**

Despite the important role that research plays in advancing care in CF, we do not fully understand the factors which influence participation in research studies and clinical trials for people living with CF. Without taking CF patient and parent perspectives into consideration, research studies and clinical trials may have difficulty recruiting patients, which could delay the development of promising CF therapies.

**What did you do?**

We conducted a survey which involved patients/parents from two large adult and child CF clinics in Vancouver, Canada to characterize their research interests, preferences, and



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perceived barriers/facilitators to participating in a clinical trial or research study. We also compared the responses between adult and parents of child patients.

## **What did you find?**

Respondents are most interested in CF clinical trials that target the underlying genetic defect, inflammation, and infection. Respondents were motivated to participate in research because it would benefit themselves or their child in the future. For barriers to participating, the requirement to stay overnight was a larger barrier for adults, and blood sampling was a larger barrier for parents of children with CF. The top attraction to participating in research trials was ongoing access to the study drug free of charge after the completion of the trial. Based on the typical requirements of a Phase 1 clinical trial, less than 10% of respondents would be able/willing to participate.

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

Using the results from this study, we can tailor the design of research studies and clinical trials to meet the preferences of people living with CF which will hopefully enhance study participation. A few limitations of this study are that the results may not apply to people living with CF outside of Canada. There is also the potential for bias in our study as individuals who are more likely to participate in research studies and clinical trials were also more likely to complete our survey.

## **What's next?**

Our survey provides novel insights into the factors influencing clinical trial participation for people living with CF. For future studies, it will be important to understand the opinions and attitudes of children towards research participation more directly, and to more proactively involve patients during the study design stage of clinical trials.

## **Original manuscript citation in PubMed**

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