

# Cystic Fibrosis Research News

**Title:**

Do current clinical trials in cystic fibrosis match the priorities of patients and clinicians? A systematic review.

**Authors:**

Izabella S Kalaitzis, Nicola J Rowbotham, Sherie J Smith, Alan R Smyth

**Affiliations:**

Evidence Based Child Health Group, University of Nottingham, UK

**What was your research question?**

Do current cystic fibrosis (CF) clinical trials reflect the research priorities set by the larger CF community?

**Why is this important?**

Recently, the first James Lind Alliance Priority Setting Partnership in CF (or @questionCF as it was known on Twitter!) was completed, bringing together people with CF, their family, their friends, and health care professionals, to identify the Top 10 priorities for CF research.

These top 10 priorities were

1. What are the effective ways of simplifying the treatment burden of people with CF?
2. How can we relieve gastro-intestinal symptoms, such as stomach pain, bloating and nausea?
3. What is the best treatment for non-tuberculous mycobacterium (including when to start and what medication)?
4. Which therapies are effective in delaying or preventing progression of lung disease in early life?
5. Is there a way of preventing CF related diabetes?
6. What effective ways of motivation, support and technologies help people with CF improve and sustain adherence to treatment?
7. Can exercise replace chest physiotherapy?
8. Which antibiotic combinations and dosing plans should be used for CF exacerbations and should antibiotic combinations be rotated?
9. Is there a way of reducing the negative effects of antibiotics e.g. resistance risk and adverse symptoms in people with CF?
10. What is the best way of eradicating *Pseudomonas aeruginosa*?



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We wanted to see how well what was going on in clinical trials around this time matched with what the CF community wanted. We hope that by increasing awareness of the Top 10 priorities, it will fuel future research into areas that are important to the CF community.

## **What did you do?**

We searched all the trial databases and online medical publication databases that we could, to look for active trials in CF. We included all trials that were looking at an intervention in CF care and were registered or published between 1<sup>st</sup> January 2016 to 11<sup>th</sup> September 2017. We then checked to see if these active trials could be matched against one or more of the top 10 research priorities.

## **What did you find?**

We found 259 trials, with 193 of these fitting the inclusion criteria described above. Only 63 (33%) of the trials that we found matched one or more of the 10 research priority areas.

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

This shows that current clinical trials poorly reflect the Top 10 research priorities selected by the CF community. This study covers the time period when the PSP was being carried out so it is not saying that the priorities of CF community have been ignored, just that there was a mismatch at that time.

## **What's next?**

We hope that by increasing awareness around the Top 10 research priorities, that this will fuel future research in areas important to the CF community. We hope to get a much greater percentage of matches when we repeat this exercise in five years time.

## **Original manuscript citation in PubMed**

<https://www.ncbi.nlm.nih.gov/pubmed/?term=Do+current+clinical+trials+in+cystic+fibrosis+match+the+priorities+of+patients+and+clinicians%3F+A+systematic+review.>

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[cfresearchnews@gmail.com](mailto:cfresearchnews@gmail.com)