

# The Top 10 Research Priorities in Cystic Fibrosis Developed by a Partnership Between People with CF and Healthcare Providers

Rowbotham et al. (2018)

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## For which topic were research priorities identified?

cystic fibrosis

## In which location was the research priority setting conducted?

international

## Why was it conducted at all?

Cystic fibrosis (CF) is the commonest life-limiting inherited disorder in the UK. It affects many parts of the body including the lungs and gut leading to increased infection and problems digesting food. People with CF need to undergo many treatments each day throughout their whole lives. These include tablets, inhalers and breathing exercises, which are a huge burden, taking up several hours every day. It is therefore, really important that the treatments we give are supported by good evidence, usually gathered from clinical trials. Unfortunately, we do not have good evidence for many of the CF treatments.

## What was the objective?

to find out which the cystic fibrosis community feel are the top priority research questions

## What was the outcome?

a ranking list of 10 research questions

## How long did the research prioritization take?

March 2016 - January 2017

## Which methods were used to identify research priorities?

JLA method

## How were the priorities for research identified exactly?

Step 1: setting up PSP: steering group established, stakeholders and partner organizations identified. Step 2: collecting research uncertainties: survey asking: What question on Cystic Fibrosis would you like to see answered by research?. Step 3: data processing: submissions reviewed, out-of-scope and non-questions removed, check against evidence, resulting in 127 questions, steering group undertook Delphi assessment to produce shortlist, resulting in 71 questions. Step 4: interim ranking: via survey, participants were asked to rank their top 10 questions, resulting in top 20 questions. Step 5: final prioritization: workshop: small group discussions and small group rankings, plenary discussions and ranking

## Which stakeholders took part?

People with cf and those who look after them. Survey: 482 participants: 224 laypersons (95 persons with cf, 105 parents, 25 family and friends), 211 professionals (61 doctors, 22 nurses, 49 physiotherapists, 10 non-clinical researchers and others). Ranking: 677 participants: 314 laypersons (121 persons with cf, 160 parents, 33 family and friends), 303 professionals (85 doctors, 32 nurses, 65 physiotherapists, 7 non-clinical researchers and others). Workshop: lay and professional participants.

## How were stakeholders recruited?

The survey was advertised through professional groups, clinic posters and a Twitter account.

## Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of lay members (two people with CF and two parents) and professionals (two respiratory pediatricians, respiratory physician, physiotherapist, dietitian, nurse, pharmacist, clinical psychologist and social worker), a specialist commissioner, a UK Cystic Fibrosis Trust representative, and 4 academics. The members were involved in data processing.