

Beyond the Expected: Identifying Broad Research Priorities of Researchers and the Cystic Fibrosis Community

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For which topic were research priorities identified?

cystic fibrosis

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Clinical research efforts for cystic fibrosis (CF) must be prioritized. The CF Foundation (CFF) supports clinical research activities that have formed the building blocks to support a highly successful drug development pipeline. However, in recent years funding organizations in the United Kingdom and the United States have highlighted the voice of the community as another necessary building block to facilitate research. Following their principles of aligning research priorities with issues that matter to patients and families, the CFF recognized the importance of ensuring that its research activities meet the needs of the community it serves.

What was the objective?

to identify a broad range of research priorities that are perceived to receive less attention, compare priorities between researchers and community members, and determine overlap with currently funded research

What was the outcome?

a ranking list of 12 research topic

How long did the research prioritization take?

January 2018

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: survey 1: soliciting thoughts and opinions about research topics that deserved additional time and resources, more than 400 unique questions submitted, 12 research topics identified. Step 2: survey 2: participants were asked to rate sub-topics

Which stakeholders took part?

Clinical researchers, adults with CF, and family members. 154 participants: 19 researchers and 135 patients and family members.

How were stakeholders recruited?

The researcher sample was drawn from Clinical Research Advisory Board (CRAB) members and the community sample was drawn from Community Voice, a CFF supported group of adults with CF and adult family members across the United States.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.