



Cystic Fibrosis Research News

Title:

Environmental Scan of Cystic Fibrosis Research Worldwide

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What was your research question?

Cystic fibrosis (CF) charitable organizations exist in over 40 countries, with 15 of these known to fund CF research. This study sought to understand the research funding practices of CF charitable organizations around the world.

Why is this important?

Learning about how each organization invests in research, and what they fund, will help the global community to work together to find a cure or effective control for CF. It will help to identify possible areas of collaboration and gaps in the research. In addition, CF organizations may be able to learn from the practices of sister organizations. For example, learning about how other organizations are incorporating factors such as patient engagement into the research funding process could prompt them to reflect on their own practices.

What did you do?

Cystic Fibrosis Canada contacted 24 CF charitable organizations around the world, identified through Cystic Fibrosis Worldwide's website (cfww.org). Each organization was sent a set of questions about their research goals and funding process. The purpose of the environmental scan was to focus on research; therefore, countries with CF organizations that are known not to fund research were excluded from the scan. A total of 14 responses were received:

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12 from organizations that fund research, and 2 from organizations that do not fund research.

What did you find?

Common themes across organizations included: (1) Open call: 10 CF organizations practice an open call for research projects; 2 practice a mix of open call and targeted research; (2) Peer review: 12 CF organizations use a peer review process to evaluate potential research projects; (3) Patient engagement: 10 CF organizations include at least one patient representative on the group(s) making funding decisions.

Innovative approaches that stood out included: funding one larger project, rather than 3-4 smaller projects; funding one larger project with a series of sub-projects focused on a common theme; partially funding a research project; and, indefinitely funding a researcher's salary.

What does this mean and reasons for caution?

The environmental scan identified 15 countries with CF charitable organizations that fund research. The scan increased understanding of this research, which is necessary to ensure that all areas of potential investigation are covered and that charitable organizations in different parts of the world are able to learn from each other. It was out of scope of the current project to examine the impact of CF charitable research per dollar (i.e., it is difficult to measure the success of various funding practices). Despite this limitation, the scan does provide insight into CF charitable research, with implications for knowledge sharing across organizations.

What's next?

Future work could include taking into consideration the impact of various funding practices by examining the impact of CF research per dollar.

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