

Cystic Fibrosis Research News

Title:

Remote endpoints for clinical trials in cystic fibrosis: Report from the U.S. CF foundation remote endpoints task force

Lay Title:

Remote endpoints for research in cystic fibrosis

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What was your research question?

We aimed to understand what remote (at home) tools are currently being used in cystic fibrosis (CF) research, how feasible it is to use them, and the unanswered questions about their performance. Additionally, we discussed the next steps needed to ensure these tools could be used in CF research studies.

Why is this important?

The use of remote (home) testing could allow for a wider representation of CF patients to participate in research. Testing at home could decrease the amount of missed work and school and avoid the need to travel to CF centers for research. However, before a research tool can be used at home, it is important to make sure that it can successfully be done at home. We also need to make sure that the results obtained at home are accurate and similar to results that we would get during a research visit done at the CF center.

What did you do?

CF research experts and community members were invited to participate in a task force organized by the CF Foundation. We reviewed many different research tools that evaluate a range of CF symptoms. We assessed how they currently being used in remote research studies. These included but were not limited to home spirometry, home respiratory sample collection, gastrointestinal and nutritional measurements, endocrine measurements, and remote patient questionnaires. We also determined the key questions that must be answered before researchers can confidently use them in remote research studies. For example, can it easily be done at home and are the results accurate?

What did you find?

There is variability among different CF research tools. Some have been used in many studies remotely while others are just starting to be evaluated in the home setting. The use of remote research tools hold promise for the ability to do either fully remote or hybrid (part remote/part in-clinic) studies. There are potential benefits to people with CF to be able to complete research studies remotely due to challenges in coming for in-person visits. Remote

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studies may also allow researchers to get more frequent measurements and data from a more “real world” setting.

What does this mean and reasons for caution?

While it is exciting to think about the opportunity for research studies to be done remotely, it is important that the tools are studied extensively first to ensure they are accurate. Most of the endpoints that we reviewed still need further study to be valid for remote research. As the number of research studies are being done either fully or partially remotely, it is also important to consider the effect of a digital divide. Researchers must also ensure that the recruitment, retention, and completion of study procedures is similar in remote studies as in-person studies.

What's next?

Further study of remote research tools is needed before wide use in CF research studies. The addition of home assessments into in-person research studies may help to increase our knowledge of these research tools. Close assessment of study participation to prevent disparities in remote research will also be needed.

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