

Cystic Fibrosis Research News

Title:

Telehealth in Cystic Fibrosis. A systematic review incorporating a novel scoring system and expert weighting to identify a 'top 10 manuscripts' to inform future best practices implementation

Lay Title:

Telehealth in CF: what are the top 10 research papers that can help inform best practices?

Authors:

Tamara Vagg^{1,2,3}, Shivanthan Shanthikumar^{4,5,6}, Hisham Ibrahim^{1,2,3}, Paul O'Regan⁷, Wendy W. Chapman⁸, Laura Kirwan⁷, Sarath C. Ranganathan^{4,5,6}, Barry J. Plant^{1,2,3}

Affiliations:

1. Cork Centre for Cystic Fibrosis (3CF), Cork University Hospital, Cork, Ireland
2. HRB Clinical Research Facility Cork, University College Cork, Cork, Ireland
3. Department of Medicine, University College Cork, Cork, Ireland
4. Respiratory and Sleep Medicine Department, Royal Children's Hospital, Melbourne, Australia
5. Respiratory Diseases Research, Murdoch Children's Research Institute, Melbourne, Australia
6. Department of Paediatrics, The University of Melbourne, Melbourne, Australia
7. Cystic Fibrosis Registry of Ireland, University College Dublin Belfield, Belfield, Ireland
8. The Centre for Digital Transformation of Health, University of Melbourne, Melbourne, Victoria, Australia

What was your research question?

Can we look at the available research papers for cystic fibrosis(CF) and telehealth, and rank them based on experts opinions to find a top 10? And then use these top 10 to inform CF telehealth care practices?

Why is this important?

During the COVID-19 pandemic, many CF centres were forced to try find ways of caring for people with CF safely. For many centres, telehealth was used to do this. But as the pandemic restrictions began to ease, so did the use of telehealth. Adding to this, many centres/institutions do not have telehealth integrated into their CF care model and there is overall a lack of guidance on how to use telehealth for CF care. This work is important because

Cystic Fibrosis Research News

it is the first step in informing these guidelines and learning how telehealth can improve care for people with CF, families and medical teams.

What did you do?

We did two things.

1. First, we searched through scientific databases with a list of rules to help us find research papers on CF telehealth.
2. Next, we scored the papers based on their scientific work. A paper scored higher with each scientific element it included. For example, the type of testing they used, and how many people they tested their telehealth system with. Following this, we asked 6 experts in CF care, 2 telehealth experts, 1 person with CF, and 1 parent how they would score the science. From these scores we were able to rank the CF telehealth papers we found according to their expert opinion.

What did you find?

Telehealth is used by a lot of CF centres for different reasons and the research shows that it is acceptable amongst the CF community. But, for CF centres new to telehealth, it is still unclear when/where/how to use it. There is also a lack of “large” studies (tests telehealth in more than one CF centre), and there is a need for researchers to follow a standard for reporting their findings. The “Digital Divide” is also very important to CF telehealth, this is where CF centres work towards “including” all the people under their care in telehealth, for example providing any equipment or training.

What does this mean and reasons for caution?

All 39 research papers we found, including the top 10, are examples of where CF telehealth can be and has been used well within CF care. Proving that there is a place for telehealth within CF care. There are still missing factors. Which means, for now, we cannot create a list of guidelines for CF telehealth and instead suggest that new centres looking to use telehealth refer to the top 10 manuscripts as a starting point.

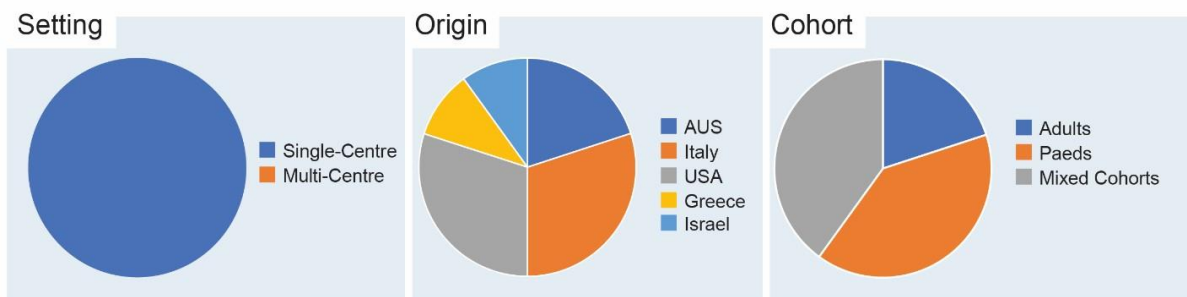
What's next?

We hope to create a “Working Group” (a group of international experts), to further investigate guidelines for CF telehealth, and to include patient groups so that they can also shape these guidelines.

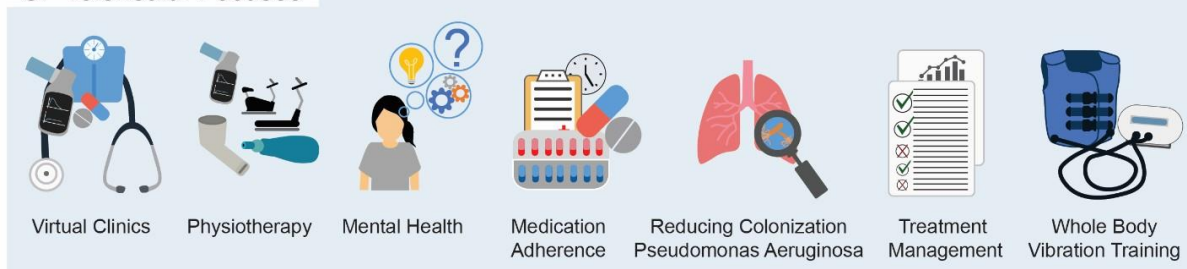
Cystic Fibrosis Research News

Original manuscript citation in PubMed

<https://pubmed.ncbi.nlm.nih.gov/37230808/>



CF Telehealth Focuses



Outcomes Measured

