

Cystic Fibrosis Research News

Title:

THE FEASIBILITY OF HOME MONITORING OF YOUNG PEOPLE WITH CYSTIC FIBROSIS: RESULTS FROM CLIMB-CF

Lay Title:

Is it possible to monitor young people with cystic fibrosis at home? Results of the CLIMB-CF study

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What was your research question?

CLIMB-CF explored whether it was possible to monitor young people with CF at home, asking them to upload readings to our app. People with CF do a lot at home already and we wanted to see whether asking them to do would affect their wellbeing.

Why is this important?

Young people with CF spend a lot of time coming to hospital and if they can carry out similar measures at home it may be possible to have fewer visits to hospital and more 'remote' care. In order to do this, we needed to check if it was possible to collect the readings at home. People with CF also have periods of time when they have more chest symptoms (exacerbations). It is possible that monitoring people at home may identify these periods and allow for early treatment.

What did you do?

We designed a mobile phone app which asked questions about how the young person was feeling and connected to pieces of equipment that took readings of things like the young person's activity levels, oxygen levels, weight and lung function. 144 people in 2 countries were asked to complete most readings every day and their weight and lung function (if old enough) twice a week. They were also asked to complete questionnaires about their mood. We then looked at how many readings were completed over a 6-month period and the effect on mood.

What did you find?

We found taking readings at home is possible and **did not affect young people or parents' mood**, but overall, people only completed 40% of the readings they were asked for and this varied a lot between people. We also found as the 6 months went on people completed fewer readings. Teenagers filled in less than other age groups. We did find that the 2 readings we only asked for twice a week were completed the most. When asked young people and their parents said they would like to collect readings once a week.

What does this mean and reasons for caution?

Our study showed collecting measures at home is possible but maybe not for everyone. The readings which were requested twice a week were completed more often, while people would like to do readings once a week. However, we currently do not know how often readings would be needed to be able to recognise times when someone is becoming more



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unwell and may need treatment. We also need to make sure everyone would be able to get the equipment and internet required for home readings.

What's next?

Moving forward, we need to find out how often readings taken at home would be needed to ensure safety and to guide treatment changes. We also need to make sure all people who would like to do readings at home have access to the equipment and support required.

Original manuscript citation in PubMed

<https://pubmed.ncbi.nlm.nih.gov/34635459/>

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