



Cystic Fibrosis Research News

Title:

Using a learning health system to understand the mismatch between medicines supply and actual medicines use among adults with cystic fibrosis

Lay Title:

Using a digital system, CFHealthHub, to automatically record the use of preventative inhaled treatments as to compare the amount of medicines collected from pharmacy to the amount actually used.

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What was your research question?

How does the amount of inhaled treatments that people with Cystic Fibrosis have at home compare to the amount that they actually use?

Why is this important?

The James Lind Alliance has worked to understand the issues that matter to people with CF. The burden associated with managing medicine supply was identified as important. The Easy Medicines for Burden Reduction and Care Enhancement (EMBRACE) programme was set up to use CFHealthHub in order to automatically measure how much medicine people have at home compared to how much they need. This research is an important stepping stone to allow the EMBRACE programme to realise the potential of using real-time data on the actual use of medicines so as to supply medicines when required, and possibly reducing a person's burden of managing their medicine supply.

What did you do?

We studied data from 275 people with CF who had used CFHealthHub across 12 UK adult centres over a period of 12 months. In particular we studied data from nebulisers with an

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automatic dose-counting feature recorded via CFHealthHub. We measured how many doses of medicines had been collected from pharmacy and compared this with the number of doses taken by the nebuliser. We then worked out how many extra doses had been collected from the pharmacy and calculated the cost of the medicines collected but not used. The method of calculating extra doses is very conservative, to avoid over-estimating the cost of excess medicines collected.

What did you find?

We captured data electronically to compare the amount of treatment actually used against the agreed prescription for the 12-month period and found that the average adherence to treatment was 57% and the average amount of medicine collected was 74%. Discounting 20% of medicines as a back-up supply we found that the average potential cost of excess medicines collected was £1124 every year. The cost of excess medication depended on adherence and was lowest in those with adherence of at least 80% (£183 per year) and highest in those with adherence of up to 50% (£2017 per year).

What does this mean and reasons for caution?

CFHealthHub can capture data electronically to identify a gap between how much medicine is collected from pharmacy and how much is used. Closing this gap may save money. By showing this gap we have highlighted the potential of automating the supply of medicines to match actual use. The savings from preventing excess supply could finance the implementation of the system. Caution is required, since using CFHealthHub to prevent waste is likely more challenging than documenting that waste has occurred.

What's next?

Work is already underway to use data from CFHealthHub to deliver the EMBRACE enhancement in a programme where physiotherapists are working with people with CF to use CFHealthHub data to match medicine supply to actual use of medicine.

A lay summary video can be found at

https://youtu.be/PEpbC-tU_Ro

Original manuscript citation in PubMed

<https://pubmed.ncbi.nlm.nih.gov/34565705/>