

USING A 1500-PATIENT LEARNING HEALTH SYSTEM (LHS) TO SUPPORT VIRTUAL CLINICS AND MEDICINES OPTIMISATION: A UK SEVEN-CENTRE PATIENT AND PUBLIC INVOLVEMENT (PPI) PROJECT TO UNDERSTAND USER EXPERIENCE

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1. INTRODUCTION

- **CFHealthHub** is being used by over **1500 people with CF** across **17 UK adult CF centres** who form the **CFDigiCare** (CF Digital Self-care Behavioural Science Collaborative) learning health system.
- CFHealthHub allows people with CF to share **real-time FEV1, weight/ BMI** and **nebuliser-usage data** with their CF team.

2. AIMS

- We aimed to understand CFHealthHub user views on:
 1. **Virtual clinics** supported by real-time adherence, FEV1 and weight/BMI data; and
 2. CFHealthHub being used to deliver **‘just in time’ medicines delivery** (EMBRACE: Easy Medicines for Burden Reduction and Care Enhancement).

3. METHOD



- We conducted a **Patient and Public Involvement (PPI) project** at **seven UK adult CF centres** (Nottingham, Sheffield, York-Hull, Newcastle, Birmingham, Plymouth, Oxford).
- **21 people with CF** shared their views by taking part in a **semi-structured interview** between **Oct-Nov 2020**.
- Interviews were conducted by the **Local CFHealthHub Lead/ Interventionist** in each Centre.

4. RESULTS

Using CFHealthHub to enhance delivery of virtual clinics

- People with CF said it was **helpful** that CFHealthHub now displays FEV1 and weight/ BMI data alongside adherence data, enabling the delivery of virtual clinics.
- Key benefits identified by people with CF included:
 1. having all **information** in **one place**;
 2. enhanced **monitoring** and **support** by CF team; and
 3. enabling people with CF to **self-monitor** and **track trends and patterns** in their data.

Person with CF: “Having somewhere to put all this information really helps me keep track of my treatment as well as seeing my weight and how the treatment is helping me keep my lung function to the best it can be.”

Using CFHealthHub to improve the medicines supply process

- All people with CF were in favour of their nebuliser-usage data on CFHealthHub being used to support ‘just in time’ medicines delivery.
- People with CF highlighted the **pitfalls** of **current medicines supply processes** (e.g. having excess stock taking up storage space; frequent calls with delivery companies/ other agencies).
- People with CF said ‘just in time’ delivery would be helpful to **reduce waste and stockpiling**, providing they had some surplus (a buffer) to allow for human error/ late deliveries (“*You want a decent amount of stock rather than an excessive amount*”).

Person with CF: “If this could be done through some other means and this could be taken off me, that would definitely make things easier.”

5. CONCLUSIONS

- CFHealthHub can **support virtual care delivery** by enabling people with CF to access and share real-time FEV1, weight/ BMI and adherence data all in one place.
- CFHealthHub offers a unique opportunity to **improve the medicines supply process** by ensuring that people with CF get the right amount of medication when they need it.
- This has the potential to **reduce waste, save costs, reduce burden** for people with CF, and **improve patient care**.

6. ACKNOWLEDGEMENTS

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7. CONTACT INFORMATION

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