

The iterative co-production of a data feedback platform providing patient level adherence data to multi-disciplinary teams to optimise individual care and centre level adherence data to centre directors allowing benchmarking to enable centre level quality improvement cycles in a 3 centre improvement collaborative.

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Background: Crises requiring rescue absorb much clinical time. Making self-care metrics salient can help clinical teams direct an appropriate level of attention and resources to support prevention. CFHealthHub collects and feeds back patient and centre level adherence data on inhaled therapies.

Methods: An iterative, user-driven co-development process identified key data and desired functionality to support patient adherence. A Clinical Microsystems Quality Improvement (QI) curriculum (Nelson, Bataldan and Godfrey 2007) will deliver a QI collaborative to transform care from hospital based rescue to community based prevention.

First name	Last name	Age	Adherence (%)	Prescription changed	Meeting View
Patient 1		21	26	<input checked="" type="checkbox"/>	Select
Patient 2		34	23	<input checked="" type="checkbox"/>	Select
Patient 3		18	34	<input type="checkbox"/>	Select
Patient 4		22	30	<input type="checkbox"/>	Select
Patient 5		29	52	<input type="checkbox"/>	Select
Patient 6		43	17	<input checked="" type="checkbox"/>	Select

Figure 1: Example of CFHealthHub patient adherence list

Results: Adherence data and clinical indicators (IV days, FEV1, BMI) allowed targeted adherence support. Functionality to sort and search for patients supported targeted discussions in clinic meetings (fig.1). Patients can opt to withhold sharing their identifiable data with the clinical team; an important measure of patient/professional relationship.

QI has delivered intensive adherence support with 7 MDT members (fig 2). Using CFHealthHub in weekly meetings increased the proportion of clinical encounters accompanied by adherence data, and continues to inform the development of CFHealthHub functionality.



Figure 2: PDSA process map to deliver intensive adherence support to CF patients

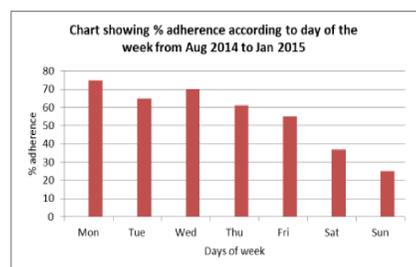
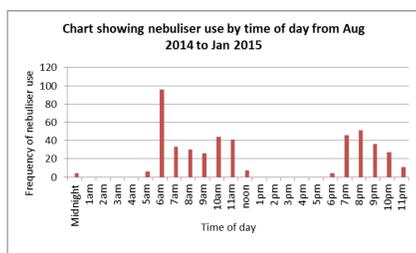
Conclusion: CFHealthHub has the potential to better target individual patient self-management whilst enabling centre level data sharing to support benchmarking and QI across networks. Future work will explore the impact of the platform on system wide adherence levels.

Understanding the potential acceptability and utility of objective nebuliser adherence graphs to support behaviour change in adults with Cystic Fibrosis.

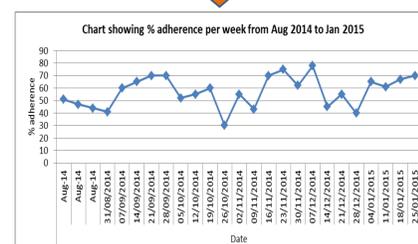
Dr Sarah Drabble, Prof Alicia O’Cathain A, School of Health and Related Research, University of Sheffield, UK, Prof Madelynne Arden, Sheffield Hallam University, Sheffield, UK, Marlene Hutchings and Dr M. Wildman Sheffield Teaching Hospitals, UK, on behalf of the CFHealthHub research team

Methods: Semi-structured interviews with 18 adults with CF, with adherence levels from 0% to 98.5%. Patients were presented with 3 different adherence graphs to generate discussion of adherence behaviour and the acceptability of graphical feedback on nebuliser use.

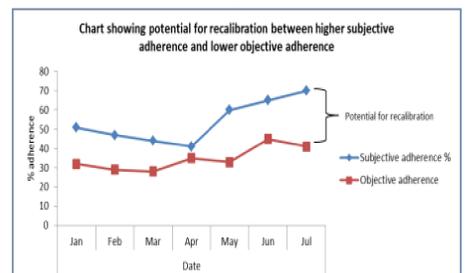
Discussion of the different graphs with patients enabled:
 1. Identification and discussion of patterns of behaviour and routines e.g. discrepancies between different days of the week and different times of the day.
 2. Reflection on some challenges of managing adherence in daily life.
 3. Potential to improve adherence behaviour by establishing routines / habits.



Potential issues identified by patients:
 1. Accuracy and trustworthiness of the data.
 2. Potential negative feelings about poor adherence.
 3. How good and bad adherence is defined by the self and others.



Identification of differences between objective and perceived (self-report) adherence can allow potential recalibration - bringing objective and perceived adherence closer together.



CFHealthHub: Understanding adherence to nebuliser treatment in adults with cystic fibrosis using the comprehensive multiple randomised controlled trial (cmRCT) design.

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CFHealthHub Data Observatory is a cohort multiple randomised controlled trial (cmRCT) design. **Eligibility criteria:** aged 16+, on the CF Registry, currently/willing to use inhaled mucolytics or antibiotics via a chipped nebuliser. **Data collection:** CF Registry data, medical notes and CFHealthHub data. **Design:** The cmRCT uses a two-stage consent process (fig.1) which provides a low-cost, ethical and scientifically robust platform for the testing adherence and behaviour change intervention (fig 2).

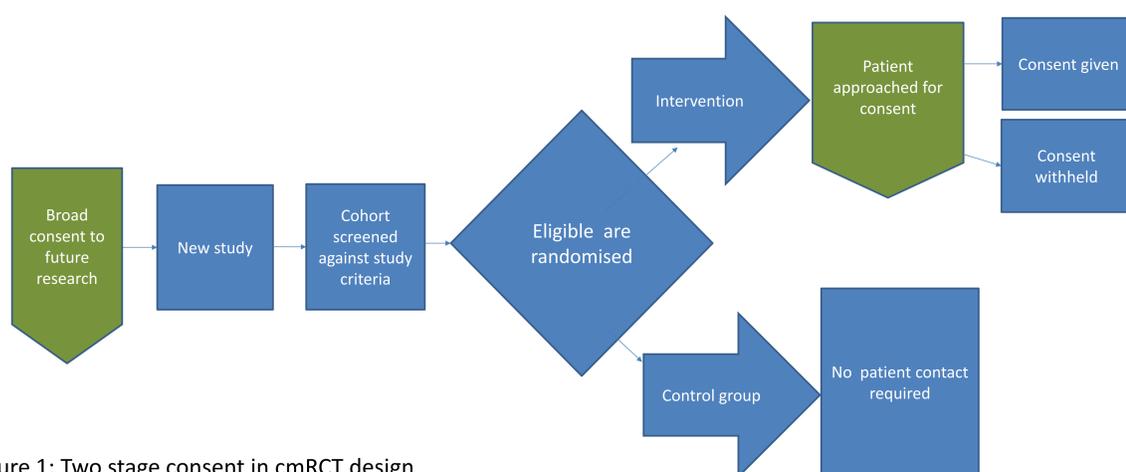


Figure 1: Two stage consent in cmRCT design

Pro's	Con's
Patient autonomy is still respected	Patients can decline undesirable interventions
Informed consent is 'patient centred'	Not suitable for groups with high attrition, unstable populations, or short term conditions
Patients understand this consent as well as typical consent procedures	
Randomisation is maintained	
No observer effect in the control group	
Patient disappointment at Randomisation avoided	
Patient cohort is not disbanded so can support future research	

Figure 2: Pro's and con's of the cmRCT design