

Changing practice in cystic fibrosis: Implementing objective medication adherence data at every consultation, a learning health system and quality improvement collaborative

GIRLING, Carla, DAVIDS, India, TOTTON, Nikki, ARDEN, Madelynne <<http://orcid.org/0000-0002-6199-717X>>, HIND, Daniel and WILDMAN, Martin J.

Available from Sheffield Hallam University Research Archive (SHURA) at:

<https://shura.shu.ac.uk/34206/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

GIRLING, Carla, DAVIDS, India, TOTTON, Nikki, ARDEN, Madelynne, HIND, Daniel and WILDMAN, Martin J. (2024). Changing practice in cystic fibrosis: Implementing objective medication adherence data at every consultation, a learning health system and quality improvement collaborative. Learning Health Systems. [Article]

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

RESEARCH REPORT

Changing practice in cystic fibrosis: Implementing objective medication adherence data at every consultation, a learning health system and quality improvement collaborative

Carla Girling¹  | India Davids¹  | Nikki Totton¹ | Madelynn A. Arden² | Daniel Hind¹ | Martin J. Wildman³

¹Clinical Trials Research Unit, University of Sheffield, Sheffield, UK

²Department of Psychology, Sociology and Politics, Sheffield Hallam University, Sheffield, UK

³Sheffield Adult Cystic Fibrosis Unit Sheffield Teaching Hospitals NHS Foundation Trust, Northern General Hospital, Sheffield, UK

Correspondence

Carla Girling, Clinical Trials Research Unit, University of Sheffield, Regent Court, 30 Regent Street, Sheffield S1 4DA, UK.
Email: c.girling@sheffield.ac.uk

Funding information

NHS England Commissioning for Quality and Innovation

Abstract

Background: Medication adherence data are an important quality indicator in cystic fibrosis (CF) care, yet real-time objective data are not routinely available. An online application (CFHealthHub) has been designed to deliver these data to people with CF and their clinical team. Adoption of this innovation is the focus of an National Health Service England-funded learning health system and Quality Improvement Collaborative (QIC). This study applies the capability, opportunity, and motivation model of behavior change to assess whether the QIC had supported healthcare professionals' uptake of accessing patient adherence data.

Method: This was a mixed-method study, treating each multidisciplinary team as an individual case. Click analytic data from CFHealthHub were collected between January 1, 2018, and September 22, 2019. Thirteen healthcare practitioners participated in semi-structured interviews, before and after establishing the QIC. Qualitative data were analyzed using the behavior change model.

Results: The cases showed varied improvement trajectories. While two cases reported reduced barriers, one faced persistent challenges. Participation in the QIC led to enhanced confidence in the platform's utility. Reduced capability, opportunity, and motivation barriers correlated with increased uptake, demonstrating value in integrating behavior change theory into QICs.

Conclusion: QICs can successfully reduce barriers and enable uptake of e-health innovations such as adherence monitoring technology. However, ongoing multi-level strategies are needed to embed changes. Further research should explore sustainability mechanisms and their impact on patient outcomes.

KEYWORDS

CFHealthHub, cystic fibrosis, e-health innovation, health behavior change, implementation science, learning health system, longitudinal mixed-methods, quality improvement, theoretical domains framework

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2024 The Author(s). *Learning Health Systems* published by Wiley Periodicals LLC on behalf of University of Michigan.

1 | BACKGROUND

Cystic fibrosis (CF) is an inherited, progressive, and life-limiting condition, affecting around 10 000 people in the UK. People with CF (PwCF) have a median life expectancy of 47 years,¹ typically dying from lung damage caused by recurrent lower respiratory infections.² Consistent use of long-term preventative inhaled medications is required to preserve lung function.³ Use of preventative medications (defined as inhaled steroids and antibiotics), within clinical trials, is between 80% and 100%.⁴ However, real-world adherence is between 30% and 50%,^{5,6} meaning that PwCF are unlikely to be obtaining the optimal benefits.

Although adherence to inhaled medication is critical to health, objective real-time data have not been readily available to clinical teams. To address this gap, an National Health Service (NHS) England Commissioning for Quality and Innovation^{7,8} and National Institute for Health Research (NIHR) funded programme of research developed and trialed the learning health system “CFHealthHub”^{9–11} (ref CQUIN-PSS3, CQUIN-IM2, NIHR-RP-PG-1212-20015). Objective adherence data are a quality indicator that would enhance clinical decision making, which otherwise would be informed only by lung function and body mass index.^{9,12–14} The CFHealthHub QIC aimed to facilitate clinicians' adoption of accessing this data, a pivotal step in improving clinical care.

Quality improvement collaboratives (QICs) are increasingly used to close the gap between current and evidence-based healthcare practices.^{15–18} Multidisciplinary teams collaborate across organizations to enhance care through shared learning and skill development.^{19,20} However, QIC evaluations often lack reference to psychological theory in conceptualizing and describing mechanisms of change.¹⁶ A recent systematic review recommends specifying modifiable target behaviors, using validated frameworks for effective change in clinical practice.²¹

To inform the CFHealthHub QIC development previous work analyzed clinician barriers to adopting adherence data, using the Capabilities, Opportunity, and Motivation (COM-B) Behavior change model.²² COM-B theorizes that behavior arises as a result of interaction between the three components (Capability, Opportunity, and Motivation). The COM-B model lies at the center of the behavior change wheel, a tool for designing behavior change interventions,^{23,24} which we had previously used to link QIC functions to behavior change techniques.

This study aimed to assess if the CFHealthHub QIC influenced the adoption of the behavior “accessing objective adherence data from CFHealthHub.” The primary objective was a cross-case analysis to understand the conditions needed for healthcare practitioners to access adherence data. If the QIC was successful, then clinical teams would report a decline in barriers over time and increased CFHealthHub activity observed through web analytics.

2 | METHODS

2.1 | Study design

This was a longitudinal, mixed-methods study, with cross-case analysis at the level of the CF center. The study integrated two units of

analysis: (1) automatically generated click data, captured from the CFHealthHub web application over a 20-month period; and (2) transcripts from semi-structured interviews conducted before and 12 months later following the QIC. The mixed-methods approach enhanced the understanding of quantitative data through triangulation with healthcare practitioner accounts. Each case represented an individual UK NHS CF center. The QIC and related quality improvement work was devised based on the intervention functions “modelling, persuasion, enablement, education and environmental restructuring.”²² Further details can be found in [Additional File 1](#). Patient and public involvement was not included in this studies design but integrated throughout the overall CFHealthHub programme. The study had ethical approval from London-Brent Research Ethics Committee (17/LO/0032).

2.2 | CFHealthHub system

CFHealthHub was developed collaboratively by healthcare practitioners and PwCF to support adherence to preventative nebulized treatments. The intervention uses eTrack® (PARI Pharma GmbH) and Bi-neb® (Philips Healthcare) dose counting nebulizers to capture objective adherence data. Data from the PwCF device were transferred automatically to CFHealthHub after every use. The CFHealthHub web application provided real-time access to adherence data for healthcare professionals and PwCF.¹⁰ CFHealthHub system automatically logged web application use through individual user “clicks.” Further development and patient facing behavior change intervention content are detailed in previous publications.^{9,25}

2.3 | Setting and participants

2.3.1 | Click analytics

Every time someone clicked on an aspect of the web application this was counted. Clicks were timestamped and logged against usernames. Aggregate click data were gathered from all healthcare practitioners with a CFHealthHub account between January 1, 2018, and September 22, 2019 (Case 1 $n = 55$, Case 2 $n = 48$, Case 3 $n = 50$). The desirable behavior, “accessing objective adherence data,” was measured by the total number of clicks into the web application. Data were extracted from all patient pages within CFHealthHub (including adherence, prescription, and patient details pages); this was combined and formed the “total clicks” analysis. To further understand the clinicians use of the real-time patient adherence graphs, a separate analysis was performed on the “how am I doing” page click data. To understand integration into the clinical team, data associated with the quality improvement lead at each center were excluded before conducting the analysis.

2.3.2 | Semi-structured interviews

Participants ($N = 13$) were healthcare professionals from three participating UK CF centers, with a combined multidisciplinary team

TABLE 1 Participants by profession and case.

Profession	Case 1	Case 2	Case 3	Total
Consultant respiratory physician	0	2	1	3
Physiotherapist	0	1	1	2
Dietician	1	0	0	1
Social worker	0	0	1	1
Nurse	1	0	1	2
Quality improvement local lead	0	1	1	2
Ward manager	1	0	0	1
Clinical coordinator	1	0	0	1
Total number of participants	4	4	5	13

numbered 110 professionals. Participants were approached using convenience sampling. Those who had participated in previous interview study²² were contacted via email, after which an open invite to the entire multidisciplinary team was made available. All interviewers were employees of the central study team at the University of Sheffield and had a background in health research, with experience of the CFHealthHub project. Contemporaneous notes on the salient points of each interview were made. Participant demographics can be found in Table 1.

2.4 | Procedure

The study team contacted potential participants by email. All participants gave informed consent prior to the interview. The interview topic guide (Additional File 2) was based upon constructs from the Theoretical Domains Framework (TDF),^{23,24} mapped to the COM-B framework and devised by investigators with expertise in behavior change (MA) and CF (MW). Interviews were conducted over the telephone and digitally audio-recorded. Interviews were transcribed verbatim with a duration between 22 and 84 min. Transcripts were checked and then coded by two interviewers, using NVivo 12 (QSR International). Based on the principle of information power, narrow aims and the application of existing theory justify small sample size.²⁶ Informational redundancy was achieved after 10 interviews with no substantially new themes identified in subsequent interviews.²⁷ Quantitative and qualitative data were analyzed separately then examined together. Qualitative data were then compared between the two time points.

2.5 | Click analytics analysis

2.5.1 | Scatterplots

An initial scatterplot was generated to illustrate the relationship between time (in weeks) and the dependent variable (total number of clicks). This helped to identify whether the rate of improvement was consistent or stepped.

2.5.2 | Statistical run charts

For cases with a stepped improvement, data were presented with statistical run charts, created using WinChart (Prism, Europe Version 4.16). Special and common-cause variation were identified, in accordance with NHS Improvement guidelines,^{28,29} special cause (i.e., a process shift) is indicated by, either:

- a point above or below a control limit, or
- eight consecutive points above or below the average.

Where variation remained within the control limits and occurred throughout the observations at random, we considered it common-cause variation—noise inherent in the implementation process.

2.5.3 | Linear regression analysis

To determine the rate of improvement over time within these behaviors, a linear regression model (SPSS 26, IBM) was used and the coefficient for time evaluated. A separate model was run for each case. R^2 values were calculated to evaluate the model quality.

2.6 | Interview analysis

Semi-structured interviews supplemented quantitative data, exploring the differences seen in the click analytic data. Transcripts underwent framework analysis, based on elements of the TDF and then combined into the COM-B.²³ Two researchers coded each interview. Italicized sections of quotes indicate researcher emphasis on behavioral determinants (TDF domains).

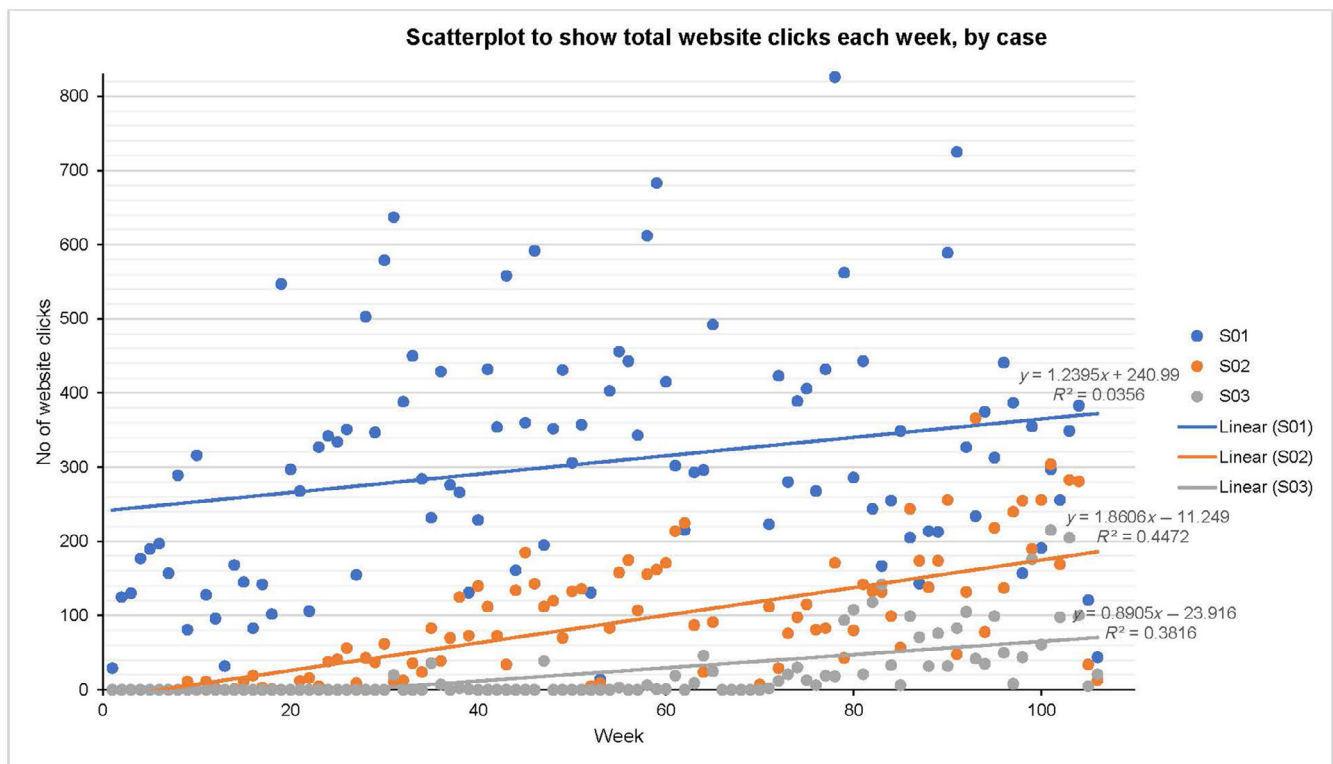
2.7 | Integration

To explore divergence in implementation outcomes, we used cross-case comparison joint displays to map quantitative indicators of the desirable behaviors (adherence page clicks; patient landing page clicks) to clinician-reported determinants of uptake, presented within the COM-B framework.

3 | RESULTS

3.1 | Click analytics scatterplots

On visual assessment of scatterplots, all cases showed a consistent change over time for the “total number of clicks” in the CFHealthHub web application (Figure 1). To investigate healthcare practitioners' access to adherence data, click data pertaining to the “how am I doing?” page, which displayed the real-time adherence data were analyzed. Cases 1 and 2 showed a steady increase in clicks over time.



S01, week 70, outlier with value ~1400 is not visible on the graph.

FIGURE 1 Scatterplot of the number of total website clicks by week.

Case 3 demonstrated an increase, with a stepped change at week 72, prompting further analysis via statistical run chart (Figure 2).

72 due to special cause variation (a point above the control limit). Week 72 coincided with the start of the first QIC meeting.

3.2 | Regression analysis

Between the baseline and follow-up periods, the total number of clicks per week increased for Case 1 (1.86 clicks per week) and Case 3 (0.89 clicks per week) (Table 2), and this was statistically significant ($p < 0.001$ for both). Case 1 showed an increase in activity of 1.2 clicks a week, which was not statistically significant. While the R^2 value for Case 1 was poor ($R^2 = 0.04$), indicating that time did not account for a substantial amount of the variance in the dependent variable (total number of clicks), the R^2 for Case 2 and 3 was acceptable ($R^2 = 0.44$ and 0.38 , respectively) when considering the amount of factors that influence human behavior.³⁰

A further regression analysis was performed on the adherence data page (“how am I doing?” page), indicating whether adherence data were being accessed by the clinical team. Case 2 and 3 showed a significant change over time.

3.3 | Case 3 statistical run charts

A run chart was created to investigate Case (Figure 2). The run chart showed a split, representing a significant change in activity at week

3.4 | Interview results

In interviews, Cases 2 and 3 reported a significant attitudinal change in the team, over the year, with more openness to understand and use adherence data:

“As a team we’re all, I think we’re all now more on to the adherence thing...”

S02-F06 (Clinical Coordinator)

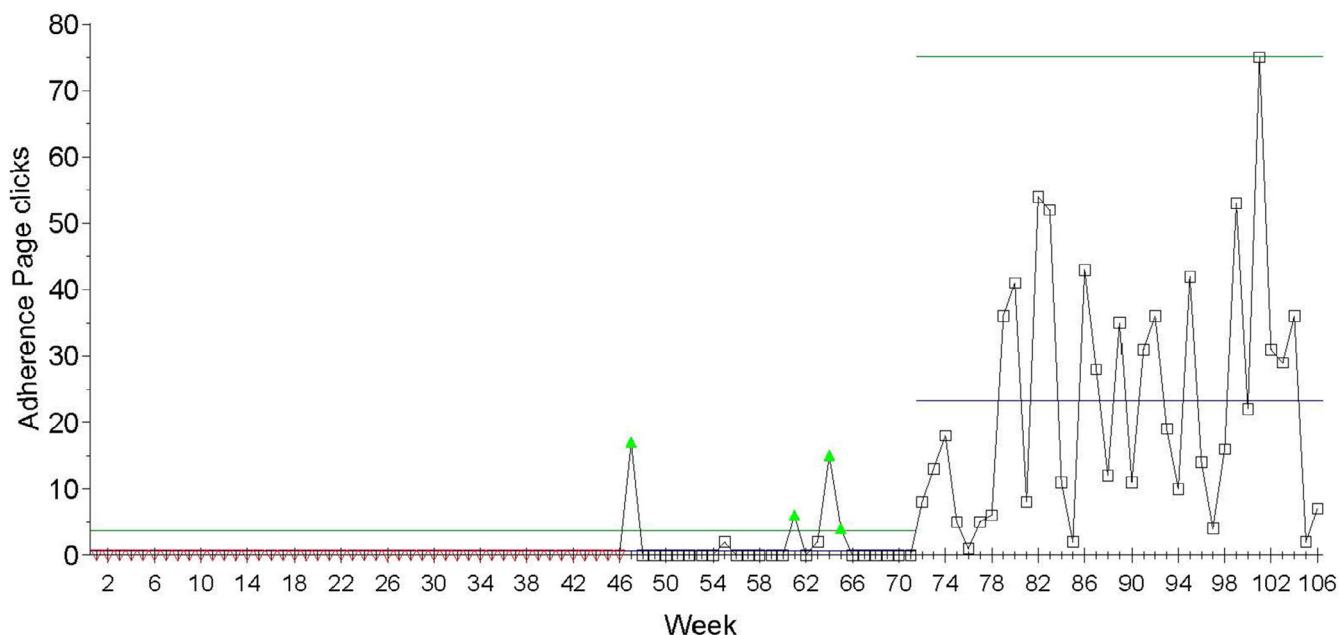
“it’s been embedded into the team and certainly my practice now”

S03-F05 (CF Specialist Nurse)

Case 1 did not report this change and that is reflected in relatively high level of activity but slower additional progress. Contextual information suggests that this case is further along in their implementation journey, perhaps leaving less room for improvement in 18 months:

“we’ve been on such a long journey as service improvement, it was probably a lot easier for us to

Statistical process chart for Case 3, adherence page clicks over time



Split Start 1 72
 U.C.L. =3.7 75.2
 Mean =0.6 23.3
 L.C.L. =n/a n/a

FIGURE 2 Statistical process chart.

TABLE 2 Regression analysis summary for total clicks on all relevant pages and specific adherence “how am I doing?” page clicks, across cases.

Case	Clicks across all pages of CFHealthHub			“How am I doing?” Adherence page clicks only		
	R ²	Coefficient for time (weeks) (95% confidence interval)	p	R ²	Coefficient for time (weeks) (95% confidence interval)	p
Case 1 (n = 55)	0.04	1.24 (0.02, 2.49)	0.053	0.01	0.15 (0.16, 0.43)	0.36
Case 2 (n = 48)	0.44	1.86 (1.46, 2.26)	<0.001	0.21	0.33 (0.2, 0.46)	<0.001
Case 3 (n = 50)	0.38	0.89 (0.67, 1.11)	<0.001	0.39	0.31 (0.23, 0.38)	<0.001

implement than...other centres that are possibly just starting their journey”

S01-F06 (Clinical Coordinator)

“it’s a way for us to be aware of somebody’s adherence”

S03-F04 (Senior Physiotherapist)

Table 3 displays rate of change and corresponding example quotes. Table 4 demonstrates the participants reported change between T1 and T2.

3.4.1 | Capability

Participants from all cases reported having a more detailed knowledge of the problem of adherence, and the skills to access adherence data, following training:

Click analytics show that accessing adherence data on CFHealthHub increased, but qualitative data suggested that the observed increase in the use of the “landing page” was generally concentrated around multidisciplinary team meetings, rather than in consultations with patients. Participants discussed memory, attention, and decision processes that affected their use of the platform on the ward:

“the truth of the matter is, because I don’t have a good habit for that, I suspect I forget more often than I remember”

S02-F03 (Respiratory Consultant)

TABLE 3 Barriers at time two, by case.

Case	Per week improvement total page clicks	Per week improvement adherence page clicks	Capability	Opportunity	Motivation
Case 1	1.24	0.14	<ul style="list-style-type: none"> Reference to specific adherence data (CFHealthHub specific) training Greater understanding of the issue of adherence, with reference to center-level adherence Discussion of adherence largely embedded in pre-clinic/MDT meetings Structure to discuss adherence with patient variable due to patient-led approach 	<ul style="list-style-type: none"> Becoming more widely used by the team in working day CFHealthHub less driven by specific champion Multiple influential figures reported including consultants and other allied health professionals Resolved most of the resource/barriers, with exception of time to open CFHealthHub and discuss adherence still considered as a barrier 	<ul style="list-style-type: none"> Greater confidence in interpreting adherence graphs by wider team Confidence in discussing adherence still varies between professional roles
Case 2	1.86	0.33	<ul style="list-style-type: none"> Reference to specific CFHealthHub and QI training Varied understanding of center-level adherence Structure for opening CFHealthHub in MDT meetings, identification of physical prompts (e.g., whiteboard) Increased reporting of opening as part of their usual working day. References to habit, but no mechanism for this development 	<ul style="list-style-type: none"> Increased support from higher management and senior colleagues Team attitude reported as positive towards CFHealthHub. A general culture of change amongst the team Some resolution of resource barriers; however, barrier of time in pre-clinic and rotational staffing remain 	<ul style="list-style-type: none"> Greater confidence in interpreting adherence charts by wider team Confidence in discussing adherence still varies between professional roles Goals for CF care to be less intrusive and inconvenient, fitting with CFHealthHub value of reducing burden
Case 3	0.89	0.31	<ul style="list-style-type: none"> Reference to specific CFHealthHub training Varied understanding of center-level adherence Discussion of adherence largely embedded in pre-clinic/MDT meetings 	<ul style="list-style-type: none"> Team culture changing from negative stance towards adherence in the past. Culture improving but ongoing Resource barriers ongoing, including time, access to computers, and use of multiple IT systems CFHealthHub still being driven by the quality improvement lead role. Limited other influential figures 	<ul style="list-style-type: none"> Consensus that CFHealthHub is useful tool for the CF team and greater intentions to use it Adherence perceived as fitting into some job roles more than others (e.g., Physios and Doctors), therefore leading to avoiding adherence discussions to prevent overwhelming patient Not all team members confident at discussing adherence

Abbreviations: CF, cystic fibrosis; MDT, multidisciplinary team.

TABLE 4 Interview data summarized by time point.

Time point	Capability	Opportunity	Motivation
T1	<ul style="list-style-type: none"> Limited direct training on accessing adherence data Limited ongoing skills support, including varied abilities for interpreting the adherence data Varied understanding of patient's overall adherence in the center Not much understanding of what features are on CFHealthHub Only remembering when prompted by discussion with patient or clinician. No feedback for use of system, no routine reported 	<ul style="list-style-type: none"> Some troubles accessing a laptop or computer, difficulty accessing Wi-Fi No regular meetings to open and share adherence data Lack of support from senior management Lack of support from other team members CFHealthHub champion (local improvement lead) an important influence 	<ul style="list-style-type: none"> Deferred responsibility for understanding patient adherence "it isn't part of my role" Not confident in how to interpret adherence charts Belief that opening adherence data at every encounter is not achievable Belief that adherence data will be used to "tell patients off" Belief that embedding will require staff energy Adherence data showed threatening information, causing cognitive dissonance Stress caused by overall workload
T2	<ul style="list-style-type: none"> Some direct training Detailed knowledge of adherence problem. Good procedural knowledge of the system Varied reports of a "habit" to open CFHealthHub Physical prompts identified Feedback on behavior provided Reported routines for using CFHealthHub around team meetings 	<ul style="list-style-type: none"> Overcome technological barriers Support from senior management identified (specifically consultants) Regular meetings established to use CFHealthHub Lack of time to use it with patients still reported General change in attitude towards adherence and quality improvement by team members 	<ul style="list-style-type: none"> Increased confidence in interpreting data but lacking in confidence at delivering support Reporting intention to use adherence data, but decision to discuss adherence is ultimately made based on perceptions of patient willingness Awareness of difficulty in delivering adherence support when adherence data are inconsistent with patient reports General goals for CF care aligning with aim of CFHealthHub QIC goals

Abbreviations: CF, cystic fibrosis; QIC, Quality Improvement Collaborative.

Participants identified that, since time point 1 interviews, they had introduced specific prompts for the behavior (accessing objective adherence data) in multidisciplinary team meetings:

"an example of that would be if we talk about HealthHub data on a pre-clinic meeting and we actually write it on our clinic board so that *we can all see it throughout the clinic*"
 S03-F03 (Respiratory Consultant)

doctors are... bringing it more into everyday practice now, yeah."
 S03-F05 (CF Specialist Nurse)

Key environmental barriers, such as equipment issues, had been addressed in multidisciplinary team meetings. In Case three, continued equipment barriers in clinic rooms may explain why team members reported not using adherence data at clinical encounters:

3.4.2 | Opportunity

The click analytic data showed increases in activity after collaborative events, where influential figures endorsed CFHealthHub and peer support provided. Follow-up interview data corroborates the importance of social influence, of local clinical leads endorsing and modeling the access of adherence data:

"as clinical lead...I'm committed to CFHealthHub."
 S02-F01 (Respiratory Consultant)

"the [Doctor], she's... good at it now she says 'right, we must look at HealthHub, let's get it up'... I think all the

"we don't have computers in our clinic rooms, so we don't take HealthHub in with us"
 S03-F03 (Respiratory Consultant)

3.4.3 | Motivation

Compared with one year previously, staff were motivated to use the platform perhaps due to a shift in beliefs about the consequences of accessing objective adherence data. This is represented by a language change between time point one, where participants had expressed more uncertainty when asked whether they believed using the platform could change adherence:

“I think...that's the *possibility*... the probability that most people adherence will *lift a bit*, I don't how far, I don't know how much”

S02-F01 (Respiratory Consultant)

And time point two, where participants use more assuring language, expressing confidence in the consequences of the platform:

“I think it is very helpful, *I'm confident that it's helpful* in the quality of the care that they receive”

S02-F01 (Respiratory Consultant)

Where health care professionals perceived there to be negative consequences, adherence data were not discussed with the patient, as it was feared this would damage the relationship:

“it feels difficult to have those conversations without it, without *it starting to sound a bit judgey*”

S02-F03 (Respiratory Consultant)

Representatives of all specialties claimed to have developed greater confidence in using the system, but motivation to use the platform was more obvious amongst physiotherapists and respiratory consultants:

“I would suggest that it is helpful for... the Doctors, the Nurses, the Pharmacists, and the Physiotherapists (mm) but *I would probably underline the Physiotherapists (yeah) and the Doctors as being the people who it is most important.*”

S02-F01 (Respiratory Consultant)

While participant reports suggested CFHealthHub was used as a behavioral diagnostic tool, providing visibility prior to patient consultations, participant's beliefs about capabilities in discussing adherence with patients appeared to be a hindering factor in motivation to open an adherence discussion:

“I feel a lot more confident now than I did right at the beginning ...*I think...there's still times where it can be very very challenging*”

S02-F02 (Quality improvement local lead)

In general, motivation barriers for opening adherence data on CFHealthHub had been overcome and there was positive intention to access the data. Participants also reported goals for CF care that aligned closely with the aim of CFHealthHub:

“I would hope that...CF care will still become...more acceptable and less intrusive... and less inconvenient... there will be better ways of monitoring patients remotely”

S02-F01 (Respiratory Consultant)

4 | DISCUSSION

In this study, we examined the impact of an NHS England-funded QIC on healthcare professionals' access to objective adherence data. Click analytic data revealed varying uptake trajectories with case one maintaining the behavior, and cases two and three demonstrating uptake. Qualitative findings suggested that the QIC had led to reduced barrier to accessing objective adherence data. Despite increased access, health professionals continued to identify barriers and a further strategy was likely necessary to ensure sustained change.

A frequent criticism of QICs is that they often lack an explanatory framework.²¹ This paper provides an example of how QICs can be linked to theory and frameworks to understand mechanisms of change. Literature suggests QICs increase peer reflection and lesson sharing (opportunity) and improved knowledge and problem-solving skills (capability).^{21,31,32} Interviews with healthcare professionals reflected this, highlighting the QIC role in reducing potential barriers. The CFHealthHub QIC created a “community of practice” enabling social comparison and normative pressure towards the desired behavior.²¹ Additionally, regular collaborative review of click analytic data encouraged friendly competition and a space to disseminate motivating success stories and practical steps for improvement.²¹ By applying psychological theory (COM-B) to understand QICs, we are able to better understand the process of real-world implementation.^{23,33-35}

Individual champions were important to driving the desired behavior. However, reliance on an individual is not a sustainable way to spread or maintain change.³⁶ Barriers to healthcare professionals behavior operate at the individual, team, and organizational level.³⁷ The QIC approach emphasizes relationship-building, valuing frontline staff, and creating a collaborative network of support. Changes at the healthcare system and organization level can legitimize QIC activities via senior consultants,³⁵ and this was reflected in qualitative accounts of change. Cultural shifts in attitudes towards adherence data were evident in late adopter cases, facilitated by shared responsibility and bottom-up discussions.²¹ The COM-B and corresponding behavior change theory also encourages intervention at the policy and organizational levels. Organizational incentives, such as UK government pay-for-performance schemes (fiscal measures), promoted CFHealthHub use. This encouraged innovative service delivery and patient-level outcome data collection.³⁸

4.1 | Strengths and limitations

Diffusion of e-health interventions is a difficult process,³⁹ and evaluation often relies on bias-prone cross-sectional self-report data. This mixed-methods study provides a robust approach,^{40,41} combining objective data with longitudinal qualitative research explaining different trajectories in quantitative data.

While the time-series design, using SPC charts, is useful in estimating common-cause variation,^{29,42} historical control groups are vulnerable to mistaking secular trends for an intended effect of system changes. However, time-series designs offer rich real-world insights.⁴²

Qualitative findings suggest click analytic data may underestimate “accessing adherence data” behavior, particularly in multidisciplinary meetings where multiple team members view patient adherence on a single screen. Click data infer healthcare professionals' access to adherence data but lacks context on its impact on patient care. The impact of CFHealthHub on PwCF adherence to inhaled medication was established as part of a wider randomized controlled trial.^{11,43} However, future research should explore whether the effect on adherence is further sustained after randomized controlled trials and with the support of a QIC.

5 | CONCLUSION

This longitudinal mixed-methods study provides practical insights into the process of implementing adherence monitoring technology into care. QICs can successfully reduce barriers to the initial uptake of innovations. Embedding new behaviors requires ongoing, multi-level strategies tailored to the unique context of each organization. Uptake maps to reduced barriers across the three conditions of capability, opportunity, and motivation, evidencing the utility of integrating behavior change models into QICs. Further research is needed to connect clinician access to patient outcomes, evaluate, and further examine the roles of different healthcare professionals, in longer-term sustainability and spread.

AUTHOR CONTRIBUTIONS

Carla Girling (Study Manager) drafted the report with input from Martin Wildman (Consultant Respiratory Physician), Madelynne A. Arden (Professor of Health Psychology), and Daniel Hind (Professor of Complex Interventions). Carla Girling, Daniel Hind, Madelynne A. Arden, and Martin Wildman designed the research. Carla Girling and India Davids (research assistant) were involved in the acquisition of data. Carla Girling, India Davids, Madelynne A. Arden, Daniel Hind, and Martin Wildman were involved in the analysis and interpretation of the data. All authors were involved in the final approval of the version to be published.

ACKNOWLEDGMENTS

We would like to thank all patients and healthcare professionals who have been involved in the development of CFHealthHub and without whom CFHealthHub would not be possible. We would also like to thank Steve Harrison at the Sheffield Microsystems Coaching Academy, for his expertise and support in delivering the CFHealthHub Quality Improvement Collaborative.

FUNDING INFORMATION

CFHealthHub is funded by NHS England Commissioning for Quality and Innovation. The funding body did not have input in the design, conduct, or decision to publish this study.

CONFLICT OF INTEREST STATEMENT

The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health. The authors declare that they have no competing interests.

DATA AVAILABILITY STATEMENT

The qualitative is not publicly available to respect participants anonymity; however, the quantitative data which contains no identifiable information may be obtained by contacting the authors.

ETHICS STATEMENT

The study received ethical approval from the London-Brent Research Ethics Committee ref 17/LO/0032.

CONSENT STATEMENT

Written informed consent was obtained prior to participation.

ORCID

Carla Girling  <https://orcid.org/0000-0003-4216-214X>

India Davids  <https://orcid.org/0000-0003-4900-7695>

REFERENCES

- Charman S, McClenaghan E, Cosgriff R, Lee A, Carr S. UK Cystic Fibrosis Registry Annual data report 2018. 2019. Accessed May 11, 2021. <https://www.cysticfibrosis.org.uk/sites/default/files/2020-12/2018>
- Elborn JS. Cystic fibrosis. *Lancet*. 2016;388:2519-2531.
- Yang C, Chilvers M, Montgomery M, Nolan SJ, Cochrane Cystic Fibrosis and Genetic Disorders Group. Dornase alfa for cystic fibrosis. *Cochrane Database Syst Rev*. 2016;4:CD001127.
- Pugatsch T, Shoseyov D, Cohen-Cymerknoh M, et al. Adherence pattern to study drugs in clinical trials by patients with cystic fibrosis. *Pediatr Pulmonol*. 2016;51:143-146.
- Daniels T, Goodacre L, Sutton C, Pollard K, Conway S, Peckham D. Accurate assessment of adherence. *Chest*. 2011;140:425-432.
- Narayanan S, Mainz JG, Gala S, Tabori H, Grosseohme D. Adherence to therapies in cystic fibrosis: a targeted literature review. *Expert Rev Respir Med*. 2017;11:129-145.
- PSS3 cystic fibrosis supporting self-care PSS CQUIN. *NHS England* 2019. Accessed May 25, 2021. <https://www.england.nhs.uk/publication/pss3-cystic-fibrosis-self-care-pss-cquin-indicator/>
- IM2 cystic fibrosis patient adherence (adult). *NHS England* 2016. Accessed May 25, 2021. <https://www.england.nhs.uk/publication/prescribed-services-cquin-scheme-im2-cystic-fibrosis-patient-adherence/>
- Hind D, Drabble SJ, Arden MA, et al. Supporting medication adherence for adults with cystic fibrosis: a randomised feasibility study. *BMC Pulm Med*. 2019;19:77. doi:10.1186/s12890-019-0834-6
- Arden MA, Hutchings M, Whelan P, et al. Development of an intervention to increase adherence to nebuliser treatment in adults with cystic fibrosis: CFHealthHub. *Pilot Feasibility Stud*. 2021;7:1. doi:10.1186/s40814-020-00739-2
- Wildman MJ, O'Cathain A, Hind D, et al. An intervention to support adherence to inhaled medication in adults with cystic fibrosis: the ACTiF research programme including RCT. *Programme Grants Appl Res*. 2021;9:1-146.
- Robinson L, Maguire C, Hoo ZH, Wildman MJ. Making the invisible visible: the availability and desirability of adherence data in routine CF care—findings from a national questionnaire survey. *F1000Res*. 2020;8:1904.
- Wildman MJ. Adherence to nebulised therapy in cystic fibrosis IAP00610 supporting guidance. 2020. Accessed May 20, 2021. <https://www.nice.org.uk/standards-and-indicators/nindicators/adherence-to-nebulised-therapy-in-cystic-fibrosis>
- Bevan A, Hoo ZH, Totton N, et al. Using a learning health system to understand the mismatch between medicines supply and actual medicines use among adults with cystic fibrosis. *J Cyst Fibros*. 2022;21:323-331.

15. T Schouten LM, J L Hulscher ME, E van Everdingen JJ, et al. Evidence for the impact of quality improvement collaboratives: systematic review. *BMJ*. 2008;336:1491-1494.
16. Wells S, Tamir O, Gray J, Naidoo D, Bekhit M, Goldmann D. Are quality improvement collaboratives effective? A systematic review. *BMJ Qual Saf*. 2018;27:226-240.
17. Shojania K, Grimshaw J. Evidence-based quality improvement: the state of the science. *Health Aff*. 2005;24:138-150.
18. Øvretveit J, Bate P, Cleary P, et al. Quality collaboratives: lessons from research. *Qual Saf Health Care*. 2002;11:345-352.
19. Kilo CM. Improving care through collaboration. *Pediatrics*. 1999;103:384-393.
20. Nembhard IM. All teach, all learn, all improve?: the role of interorganizational learning in quality improvement collaboratives. *Health Care Manage Rev*. 2012;37:154-164.
21. Zamboni K, Baker U, Tyagi M, et al. How and under what circumstances do quality improvement collaboratives lead to better outcomes? A systematic review. *Implement Sci*. 2020;15:27. doi:10.1186/s13012-020-0978-z
22. Girling C, Packham A, Robinson L, et al. Implementing the use of objective medication adherence data in routine clinical practice via the digital CFHealthHub platform: situation analysis and strategy development using the theoretical domains framework. *Implement Sci Commun*. 2022;3:1-16.
23. Michie S, Atkins L, West R. *The Behaviour Change Wheel: A Guide to Designing Interventions*. Silverback Publishing; 2014.
24. Atkins L, Francis JJ, Islam R, et al. A guide to using the theoretical domains framework of behaviour change to investigate implementation problems. *Implement Science*. 2017;12:107-112.
25. Hind D, Drabble SJ, Arden MA, et al. Feasibility study for supporting medication adherence for adults with cystic fibrosis: mixed-methods process evaluation. *BMJ Open*. 2020;10:e039089. doi:10.1136/bmjopen-2020-039089
26. Sandelowski M. Sample size in qualitative research. *Res Nurs Health*. 1995;18:179-183.
27. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*. 2015;13:1-8.
28. Mohammed MA, Worthington P, Woodall WH. Plotting basic control charts: tutorial notes for healthcare practitioners. *Qual Saf Health Care*. 2008;17:137-145.
29. Benneyan JC, Lloyd RC, Plsek PE. Statistical process control as a tool for research and healthcare improvement. *Qual Saf Health Care*. 2003;12:458-464.
30. Editor MB. *The Minitab Blog*. 2013. <https://blog.minitab.com/blog/adventures-in-statistics-2/regression-analysis-how-do-i-interpret-r-squared-and-assess-the-goodness-of-fit>. Accessed 17 Jan 2024.
31. McInnes DK, Landon BE, Wilson IB, et al. The impact of a quality improvement program on systems, processes, and structures in medical clinics. *Med Care*. 2007;45:463-471.
32. Ament SM, Gillissen F, Moser A, et al. Identification of promising strategies to sustain improvements in hospital practice: a qualitative case study. 2014;14:641. doi:10.1186/s12913-014-0641-y
33. West R, Michie S. Applying the Behaviour Change Wheel A Very Brief Guide. Accessed November 10, 2017. <https://www.ucl.ac.uk/behaviour-change/files/bcw-summary.pdf>
34. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implement Sci*. 2011;6:42.
35. Bunger AC, Powell BJ, Robertson HA, MacDowell H, Birken SA, Shea C. Tracking implementation strategies: a description of a practical approach and early findings. *Health Res Policy Syst*. 2017;15:15.
36. Greenhalgh T, Wherton J, Papoutsi C, et al. Beyond adoption: a new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. *J Med Internet Res*. 2017;19:e367.
37. Wensing M, Bosch M, Grol R. Developing and selecting interventions for translating knowledge to action. *CMAJ*. 2010;182:1-4.
38. Kristensen SR, McDonald R, Sutton M. Should pay-for-performance schemes be locally designed? Evidence from the commissioning for quality and innovation (CQUIN) framework. *J Health Serv Res Policy*. 2013;18:38-49.
39. Ross J, Stevenson F, Dack C, et al. Developing an implementation strategy for a digital health intervention: an example in routine healthcare. *BMC Health Serv Res*. 2018;18:794. doi:10.1186/s12913-018-3615-7
40. Tashakkori A, Creswell JW. Exploring the nature of research questions in mixed methods research. *J Mixed Methods Res*. 2007;1:207-211.
41. Calman L, Brunton L, Molassiotis A. Developing longitudinal qualitative designs: lessons learned and recommendations for health services research. *BMC Med Res Methodol*. 2013;13:14. doi:10.1186/1471-2288-13-14
42. Kontopantelis E, Doran T, Springate DA, Buchan I, Reeves D. Regression based quasi-experimental approach when randomisation is not an option: interrupted time series analysis. *BMJ*. 2015;350:1-4.
43. Wildman MJ, O'Cathain A, Maguire C, et al. Self-management intervention to reduce pulmonary exacerbations by supporting treatment adherence in adults with cystic fibrosis: a randomised controlled trial. *Thorax*. 2022;77:461-469.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Girling C, Davids I, Totton N, Arden MA, Hind D, Wildman MJ. Changing practice in cystic fibrosis: Implementing objective medication adherence data at every consultation, a learning health system and quality improvement collaborative. *Learn Health Sys*. 2024;e10453. doi:10.1002/lrh2.10453