



CFHealthHub Digital Learning Health System

Empowering Clinicians to Transform Patients' Lives



April 2020 Issue 1



Welcome to the CFHealthHub Newsletter

The CFHealthHub Newsletter is a place to share updates, ideas, and stories of success across the CFHealthHub Digital Learning Health System. Given the COVID-19 pandemic, the first edition of the newsletter is designed to provide important updates, clarity over what is required over the next few months, as well as the opportunity to share moments of success during this challenging time.

COVID-19 Update

During the COVID-19 pandemic, optimum adherence to preventative inhaled therapies will reduce exacerbations and, in the event of COVID-19 infection, likely improve outcomes. Over the next few months, healthcare teams across the NHS will be under increasing pressure as they face high emergency workloads and staff sickness.

CFHealthHub provides a robust and well-supported digital platform that optimises care during COVID-19.

We anticipate that some CFHealthHub Local Leads/Interventionists will be pulled away from their CFHealthHub roles to support other areas and deliver front-line patient-care. There will inevitably be a high degree of flexibility needed in the coming months, including amendments to working schedules, upcoming plans, and priorities.

We have submitted changes to the current CFHealthHub protocol which will enable clinical teams to support preventative self-care for people with CF during the COVID-19 emergency.

A CFHealthHub ethics amendment has now been approved by the Ethics Committee. This will allow:

1. Telephone recruitment: CFHealthHub Local Lead/Interventionist will be able to carry out the consenting process with patients via the telephone (during COVID-19 pandemic only).

2. A small central team, comprising NHS-employed staff and/or Allied Health Professionals, will provide bespoke support to individual CF teams across the UK. The aim is to support CFHealthHub Local Leads/Interventionists to stay in their roles, and as people are likely to be pulled into clinical work, to maintain accurate prescriptions, provide technical support and some level of adherence support for a short time period. This is set out in the CFHealthHub COVID-19 protocol.

Key Changes

CFHealthHub Collaborative Event

The Collaborative Event that was originally scheduled for July 3rd 2020 will be postponed until further notice.

European Cystic Fibrosis Society (ECFS) Conference

The 2020 Conference scheduled in Lyon in June has been cancelled. Well done to everyone who had abstracts accepted and to our two case study winners (Lou and Jayne) at the Collaborative event in November. We had a total of 9 abstracts accepted from across the Collaborative. Thank you for all your hard work in putting these together. We hope to have as much success in 2021.

Tuesday Collaborative Support Call (9-10am)

The support calls for sites will still be taking place on Tuesday mornings. We know it may be difficult to dial-in during the next few months (so this is not compulsory), but the calls will be used as a space to check-in, share learning and connect with each other.



"Using the CFHealthHub and the support from Sophie has helped me in doing my nebulisers, from doing none at all to not missing any. Thank you Sophie for all your support. Stay safe."

Lorna - CFHealthHub Patient

Software Updates

CFHealthHub supports CF teams to conduct remote monitoring. This function will soon be enhanced by the addition of a patient-facing data entry function for spirometry readings and weight. This will allow teams to continue to access FEV1, BMI and adherence data in one system, remotely.

Behind the Scenes

So many people make up the CFHealthHub team. We would like to say a great big thank you to the software team at the University of Manchester who have been working day and night to develop the spirometry self-entry module on CFHealthHub. We applaud you for your hard work and dedication to the programme.

Systems Optimisation

We delivered Microsystems Coaching Academy (MCA) Quality Improvement training to 10 CF centres across the UK in 2019. The sessions were designed to build quality improvement capability and provided an opportunity for teams to plan how to embed adherence data from CFHealthHub into routine clinical practice, using Plan-Do-Study-Act (PDSA) cycles.

30 PDSA cycles have been started across the country which led to a system-wide increase in CF teams accessing adherence data on CFHealthHub. These include: 1) training the CF team to access and interpret adherence data on CFHealthHub; 2) opening CFHealthHub in a regular MDT meeting; 3) maintaining an accurate and up-to-date record of patient prescriptions; and 4) opening CFHealthHub in a pre-clinic meeting.

CF Centres have found these new skills invaluable when having to quickly redesign care pathways during COVID-19 (e.g. transfer to virtual clinics; development of proformas; effective meeting skills; use of pre-clinic meetings).

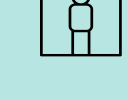


Snapshots of Success

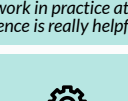
Site snapshots



Oxford - The CFHH collaborative has provided an invaluable opportunity to learn quickly from how other centres are managing the situation for their patients. Lots of planning and decision making is being done in a short space of time. Hearing other centres' plans and how they work in practice at the weekly teleconference is really helpful.



York/Hull - "Patients are losing their routines along with their jobs. The patients are recognising it and CFHealthHub helps them to find a new habit."



Stoke - Using QI approaches to optimise virtual clinics - this has enabled the team to work more efficiently, helping people to get their points across in a timely manner.



Sheffield - Contacted an unwell patient. Looking at CFHH, no nebulised treatments were taken over the past two weeks. We worked through strategies on the phone together. They have now gone from taking 0% to 100% of their treatments.

Collaborative Success!

EMBRACE

The EMBRACE (Easy Medicines for Burden Reduction And Care Enhancement) programme aims:

- To assess the gap between medicines supply and actual adherence as measured by CFHealthHub.
- To improve the medicines supply process, reduce the burden of prescription management for patients and reduce waste in the system.
- To design in each centre a protocol that routinely takes adherence into account when making prescribing decisions.

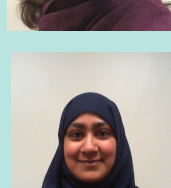
There are currently approximately 400 adults included in the project, of which just over 50 are only on one nebulised drug. We have collected medicines supply data for patients who consented to the Data Observatory for one year and compared it to their actual adherence over the same time period.

The individual centre teams are in the process of mapping their local prescribing and medicines supply process, although this has been made more difficult since MDT meetings have gone virtual! This will allow theoretical savings, targeted by the first work stream, to be realised by the system.

The next step will be to work collaboratively with the MDT in each centre to implement improvement cycles, optimising the local prescribing system, for patients and the NHS.



Dr Amanda Bevan
National Pharmacy Lead CF self-care CQUIN
Southampton University Hospitals NHS
Amanda.bevan@uhs.nhs.uk



Misbah Tahir
National EMBRACE Pharmacist
Sheffield Teaching Hospitals NHS
Misbah.tahir@nhs.net



Collaborative Events

We were delighted to hold our 4th CFHealthHub Collaborative event in Sheffield on 27th November, 2019. This was an all-day event providing a platform for CF multidisciplinary teams across the UK to come together to share learning, successes and plan improvement ideas. These events offer an opportunity for CF centres to address some of the common barriers to implementing adherence data into routine practice. Highlights included PDSA cycle planning workshops; reflections from Nottingham and Southampton CF centres on the 'Improvement Collaborative Journey' so far; and the 'Patient Case Study Competition' where CF centres had the opportunity to share examples which powerfully illustrated the impact that having access to objective adherence data on CFHealthHub had on patient-care.



85

MDT members from 17 CF Centres attended the last Collaborative event

1010

Adults with CF on CFHealthHub

What went well?



Good to meet teams from other centres and share learning

What could be improved?



As always, more time doing this (sharing practices)

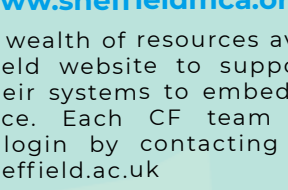
Support and Resources



Where can I find Systems Optimisation resources?

www.sheffieldmca.org.uk

There are a wealth of resources available on the MCA Sheffield website to support centres to optimise their systems to embed CFHealthHub into practice. Each CF team member can request a login by contacting India Davids: i.davids@sheffield.ac.uk



Quality, Innovation, Improvement



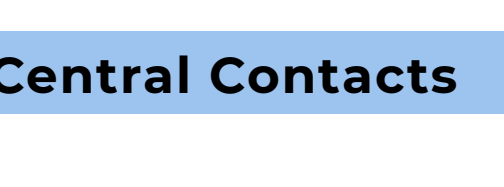
What training resources are available?

- CFHealthHub training screencasts
- PDSA cycle examples and recording templates
- Slides resources (e.g. videos, one-page booklets)
- Slides from previous Collaborative events

Here to Help

Although it is expected that most Systems Optimisation work will be on hold for the next few months, please be reminded that the National Quality Improvement - Charlotte Carolan and Sophie Dawson - are available to provide support with any ongoing projects or new ideas you may have during this time.

Central Contacts



Dr Martin Wildman
Senior Technical Project Manager
H&RC, University of Manchester
014 271 5212
Martin.wildman@nhs.net



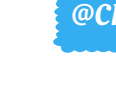
Carla Girling
National Learning Health System and
Data Observatory study manager
014 222 4027
C.girling@sheffield.ac.uk



Charlotte Carolan
National Quality Improvement
Programme Manager
Charlotte.carolan@nhs.net



Sophie Dawson
National Quality Improvement
Programme Manager
07864 953730
Sophie.Dawson@nuh.nhs.uk



Steven Antrobus
Senior Technical Project Manager
H&RC, University of Manchester
Steven.antrobus@manchester.ac.uk



Dr Pauline Whelan
Digital Health Lead
H&RC, University of Manchester
Pauline.whelan@manchester.ac.uk



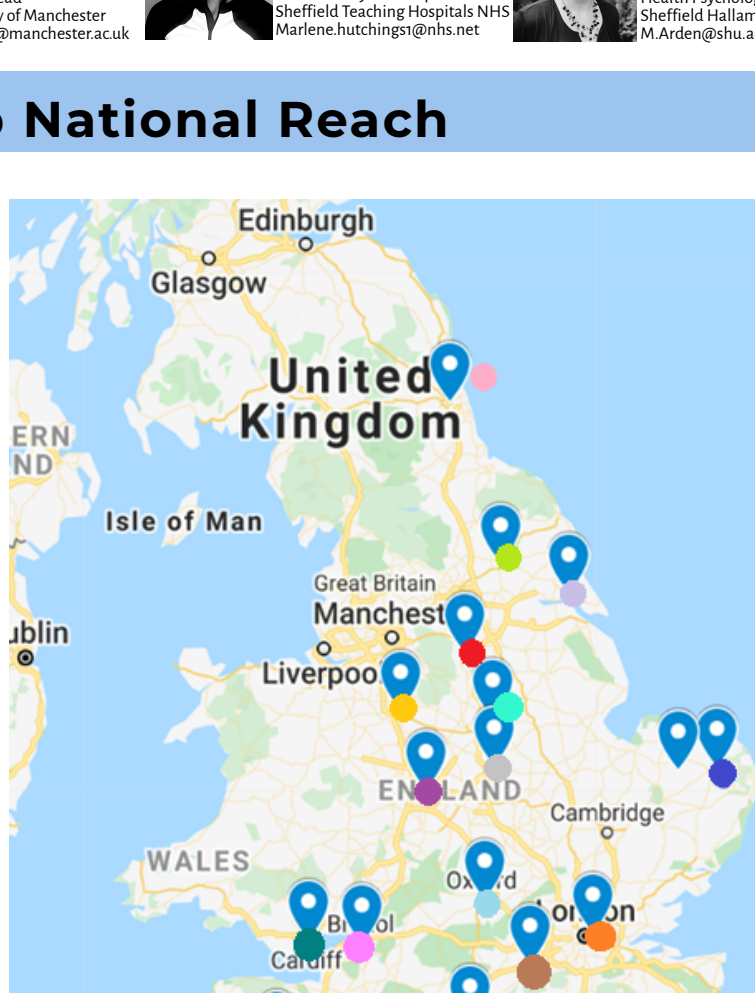
Marlene Hutchings
Research Physiotherapist
Sheffield Teaching Hospitals NHS
Marlene.hutchings@nhs.net



Prof. Madelynne Arden
National Quality Improvement
Health Psychologist
Sheffield Hallam University
M.Ardens@shu.ac.uk

CFHealthHub National Reach

- Newcastle Royal Victoria Infirmary
- York Hospital
- Hull University Teaching Hospitals
- Sheffield Teaching Hospitals
- Royal Stoke University Hospitals
- Nottingham University Hospitals
- Norfolk and Norwich University Hospitals
- Glenfield Leicester Hospital
- Bristol Royal Infirmary
- All Wales Cystic Fibrosis Centre
- University Plymouth Hospitals
- St. Bartholomews Hospital
- Frimley Park Hospital
- Southampton University Hospitals
- Royal Devon and Exeter NHS Foundation Trust
- Royal Cornwall Hospital
- Birmingham Heartlands Hospital
- Oxford Adults Cystic Fibrosis Centre



The CFHealthHub Data Observatory is funded by NHS England Commissioning for Quality and Innovation (CQUIN)