



CFHealthHub Digital Learning Health System

Empowering Clinicians to Transform Patients' Lives

@CFHH_Collab



April

2020

Issue 1

 **CFHealthHub**
www.cfhealthhub.com/

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.

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 the patient via the telephone (during COVID-19 pandemic only).

2. The central CFHealthHub team to step in and support sites when/ if all team members are pulled away from CFHealthHub into clinical duties.

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. This is set out in the CFHealthHub COVID-19 protocol.

Key tasks during this period (if you have capacity at your Centre):



Update the Sheffield Clinical Trials Research Unit (CTRU) with the names and contact details of a few key contacts at your CF Centre. This will enable us to provide appropriate cover (e.g. if the Local CFHealthHub Lead/ Interventionist is off sick or is pulled into front-line work during the next few months).



Please remember to update members of the central CFHealthHub team of any changes in your duties/role. Email prompts will be sent out every Tuesday, following the Tuesday 9-10am call.

Please use the traffic light colour system below to indicate weekly activity at your Centre during COVID-19 for the following tasks:

- Quality Improvement
- Training staff
- Recruitment
- Managing prescriptions
- Technical support
- Adherence support

Activity Status



Normal Activity



Reduced Activity



No Activity

Who to Notify ?

Marlene Hutchings - marlene.hutchings1@nhs.net

Carla Girling - c.girling@sheffield.ac.uk

Louise Turner - louise.turner@sheffield.ac.uk

India Davids - i.davids@sheffield.ac.uk

Software Updates

Patients with scales and home spirometers will soon be able to input their own weight and spirometry readings onto CFHealthHub. This will enable patients and CF teams to continue to access FEV1, BMI and adherence data on CFHealthHub during COVID-19, allowing CF teams to support patients 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.

Key Changes

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 Support Call (9-10am)

The Tuesday call will not be compulsory in the next few months, but this time will be used as a space to share learning, connect and check in with each other.

Quality Improvement Support

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 Leads - Charlotte Carolan and Sophie Dawson - are available to provide support with any ongoing projects or new ideas you may have during this time.

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 team 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!

The next step will be to work collaboratively with the MDT to implement PDSA cycles to improve the process, making it more efficient and patient focused.

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 so hearing other centres' plans and how they work in practice at the weekly teleconference is really helpful.

York/Hull - Staff/patients self-shielding at home has allowed protected time for contact with patients to provide adherence support.

Stoke - Using QI approaches to continually improve new 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!



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



Central Contacts



Tweet

Amanda Bevan
@APaedPharmacist

Starting to look at the medicines supply process for pwCF, it's a bit complicated! Can we make it better? @cftrust @CFHH_collab #cysticfibrosis



Tweet

Jayne Faulkner
@JazziJ31

More virtual Physio & CFHealthhub consultations completed today supporting treatment adherence from afar. Every patient so appreciative for the contact, but also telling me to look after myself and to stay safe #kindness #itswhywedowhatwedo #physio #cfhealthhub #NHS #staysafe



Dr Martin Wildman
Chief Investigator
0114 271 5212
Martin.wildman3@nhs.net



Carla Girling
Study Manager
0114 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
HeRC, University of Manchester
Steven.antrobus@manchester.ac.uk



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



Marlene Hutchings
Research Physiotherapist
Sheffield Teaching Hospitals NHS
Marlene.hutchings1@nhs.net



Prof. Madelynne Arden
Health Psychologist
Sheffield Hallam University
M.Arden@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

