CFHealthHub Digital Learning Health System

Empowering Clinicians to Transform Patients' Lives

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 (LHS)**. Despite a challenging few months during the COVID-19 pandemic, we are delighted to showcase some of the fantastic work taking place across the UK. We **welcome any feedback** on this newsletter, as well as **suggestions for future content** - please email India at i.davids@sheffield.ac.uk.

Key changes

This month, we said a temporary farewell to **Carla Girling**, CFHealthHub Study Manager, who has gone on **maternity leave**. We thank her for all her hard work over the past few years and wish her all the very best for the next nine months!

We are pleased to be joined by **Alex Scott** who has taken over from Carla as **CFHealthHub Study Manager**.

Alex joined the Clinical Trials Research Unit (CTRU) in June 2016 as Trial Manager on the Alleviating Specific Phobias Experienced by Children Trial (ASPECT). He has subsequently worked on several NIHR funded studies, including the CFHealthHub randomised-controlled trial (RCT).

Welcome Alex! He can be contacted on: alex.scott@sheffield.ac.uk

NICE Quality Indicators

CF teams are dedicated to providing the best possible care that they can. However, it is not always easy to understand what we should measure to understand if we are getting better. Over the past five years, we have worked with the National Indicator service to rigorously develop two **NICE-approved indicators**. The aim being to facilitate centres to understand **what proportion of people with CF in their centre are being supported by CFHealthHub** and **what impact this is having on their adherence rates**. Sharing an indicator within a LHS can allow centres to facilitate collaborative learning, driving improvement.

The CFHealthHub indicators are the **first NICE approved indicators in CF**. Links below:

- **Adherence to nebulised therapy in CF:** https://bit.ly/2BcnWgh

- **Normative adherence to nebulised therapy in CF for patients with chronic pseudomonas acquisition:** https://bit.ly/3g1KoaO

1206 adults with CF now on CFHealthHub

Open Innovation during COVID-19

There has never been such an urgent need for the NHS to undertake mass service redesign like has been required during COVID-19. With CF patients identified by the Government as amongst those most vulnerable, CF centres across the UK have had to rapidly adapt their services to deliver care in a new 'virtual' world.

As a digital learning health and self-care platform, CFHealthHub has enabled clinicians to have access to the **key objective markers** required to perform a **clinical assessment virtually**. Patients are able to **self-record** their **weight** and **lung function** at home, and can choose to automatically share this information, along with their adherence data, with their CF team via CFHealthHub.

With CFHealthHub at the heart of clinic activity, CF teams have **redesigned clinic processes**. They have shared with one another their experiences, both the successes and the challenges, creating a community of shared learning via open innovation. Teams continue to look for ways in which the service they offer may be improved, during COVID-19 and beyond, using the **microsystems approach** to quality improvement.

Activities include:
- Gaining information from the 'coal face' through **'love and nuts'** staff and patient surveys.
- **Process mapping** new ways of working.
- Using **silent brainstorming**, **multi-voting** and other techniques to explore possible service improvements.
- Using **Plan-Do-Study-Act (PDSA) cycles** to record changes and outcomes.

The support for one another and the strength of the collaborative spirit during the pandemic has been truly inspiring!

Virtual Meetings

We've had some great discussions on our weekly **CFHealthHub Collaborative calls** (**Tuesdays, 9-10am**) during the last few months. They have continued to be really well attended throughout COVID-19, and the switch to **video calls via MS-teams** has been a great success, enabling people to feel connected and part of a team at a time when many have been shielding or working from home.

We've continued to share ideas across the LHS, and have experimented with new software such as Jamboard and Draw.io. Anyone involved in the implementation of CFHealthHub within your CF Centre is **more than welcome to attend** - please ask your Local CFHealthHub Lead/ Interventionist for the details.

Software Update

The last few months have seen us pivoting to focus on delivery of the **patient FEV1 data capture module**, with version 1 live and version 2 under development. We've also developed the new **Sign-up module** that will allow us to move away from Prospect and use CFHealthHub to capture more of the patient interactions in one place. Our 'super-users' have been hard at work testing and providing invaluable feedback to the team for new releases. On the horizon is the **centre-level dashboard** work, including the new **NICE indicators**. The dashboard will provide an at-a-glance view of how things are looking in your centre and will help you to more easily focus on the areas needing attention.


Sadly the UoM team is losing Oluwatoni (Toni) Olatunji to University of Salford. Toni has worked tirelessly to not only improve the security on CFHealthHub but also identify a **roadmap for future work**. We're thankful for Toni's hard work on CFHealthHub and wish him the best of luck in his next adventure.

EMBRACE

Medication possession ratio (MPR) data has all been collected and is being validated. This has been a really big piece of work. We would like to say **well done** to all involved – it's not been easy to get all of the information!

MDT teams are currently **mapping their prescribing and supply routes** to improve efficiency and use real time adherence data to inform the process at both ends – decision making and supply to patient.

Most importantly, we will soon be **asking patients for their opinions** about how they get their nebulised medicines. This will be via an **online questionnaire**. The ethics request has been submitted. We're looking forward to understanding their perspective and to build it into the process maps – watch this space!
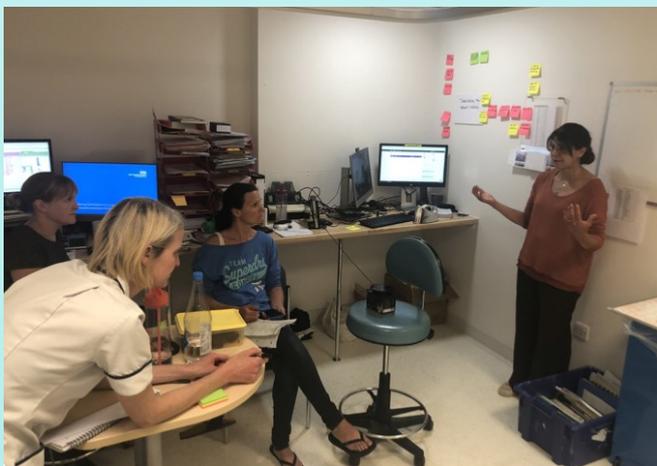
York-Hull CF team: process-mapping in action, with team members joining in person or via video call.

CFDigiCare

It is now more than five years since CFHealthHub was 'born', when we brought together the expertise of people with CF, clinicians, and the University of Manchester software team to co-produce a digital **behaviour change** platform.

As a CFHealthHub community, we are unique in having created an **innovative model of care** that has been evaluated in the **largest CF RCT** to have been carried out in the UK. With the COVID-19 emergency, CF Centres have **worked together** to enhance CFHealthHub, with additional FEV1 and BMI data capture now available. This is once again dependent on **patients** and **clinicians** from across the system **testing** and **improving** the software as it constantly adapts to what clinical teams and patients need to support the very **best outcomes**.

We are delighted that the CFHealthHub community has now formalised itself into an organisation, named the **CF Digital Self-care Behavioural Science Collaborative** (**CFDigiCare**). Bringing together people with CF and clinicians, we aim to use the experience gained by utilising CFHealthHub to support each other in **optimising care** and to **inform policy and decision making** surrounding digital models of care in CF.

A number of seats were available on the **steering committee** to ensure that CF team members across the LHS could be a part of the central decision-making and policy creation, and we are delighted that these have now been filled (more information to follow).

Patient story - Emma[*]

"Before I started the CFHealthHub, I felt a little nervous as deep down I knew I wasn't doing as many of my nebs as I should be. At the same time, I was **looking forward to seeing the data**. I was really disappointed that I was randomised into the control group so I had to wait a year before I could have access to my data. I would always feel a little down and even disappointed with myself before clinic/ check-ups as I knew that I wasn't being totally honest about the amount of nebs I do but that was down to a bit of embarrassment because I know I should do them all. I would always feel I was letting myself and my family down, especially if my lung functions weren't great, as I'd blame myself for not doing all of my meds.

Now that I can see my data, I feel like I do more nebs than I was before. If I have a bad week where I don't hit my target, it **gives me a push** to try harder the following week. Going to see the team knowing they can see my data does make me feel a little uneasy at times as I know I have to be honest now, although **I wouldn't change it**! The **help and advice** I've had so far from the team is great."

*Name changed to maintain anonymity - consent provided.

Virtual Training

In response to the dramatic shift in clinical practice that we have seen during COVID-19, we have evaluated our CFHealthHub training package. Originally designed to be delivered within centres by their experienced interventionists, we understand the added strain this would put on already stretched teams. As we also have new CF Centres joining the LHS, we have developed a **virtual training package** that will be delivered by **Professor Maddy Arden** and **Marlene Hutchings**. They have led training from the pilot and through the RCT and will continue to support new team members as they embark on their journey with CFHealthHub! The first wave of training has already begun. Look out for more details coming your way - we look forward to working with you all!

<u>Reminder:</u> **Online training resources** can be accessed at the Sheffield Microsystems Coaching Academy (MCA) website: <u>www.sheffieldmca.org.uk</u>

What's going on?

Virtual CFHealthHub Collaborative Event Coming Soon!

Due to the cancellation of our fifth Collaborative event this month, we are planning to hold a **virtual CFHealthHub Collaborative event** in the Autumn as an alternative and safer way to connect during COVID-19. Date to be confirmed, so please keep your eyes peeled for more details coming soon!

Jayne Faulkner
@JaziJ3f

Excellent body of work; great achievement for OACFC to be included.Objective data gained through #CFHealthHub improving our understanding of and discussion around CF nebuliser adherence. Key to personalised care and optimising outcome for our patients. #adherence #cysticfibrosis

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NNUH Physiotherapy Team
@NNUHphysio

It's wonderful being part of this brilliant project!

Charlotte Carolan
@Physiocharlie

Shame we can't be #MCAExpo2020 this week sharing our story of national collaboration to build the #cfhealthhub community. In the meantime our national centres continue to learn together as we use @SheffieldMCA skills to redesign our CF services in view of covid-19. @cfhealthhub

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Louisa Robinson
@LouisaRobinson_

A great experience working with this amazing team doing great things in CF! And so pleased to be continuing the work with #CFHealthHub as a PhD student, to further understand behaviour and habit in adherence #PhD #healthpsychology

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Twitter 🐦

We **love** seeing your updates! Please continue to **tag us** using our new **Twitter** handle:

@CFHealthHub

Pete Moran
@petemoran_6

A huge achievement from a super project. Great to collaborate with everyone involved. And mostly- a massive thanks and well done to the pwCF who have joined it. Sharing data and learning together to help us support you with neb adherence

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CFAdultNewcastle
@cf_newcastle

We are part of the @cfhealthhub- a health system that helps habit formation for those who nebulise medications. We can use this system to support virtual clinics and the goal of #balancingCF

York Hull Adult CF Centre
@yorkhullcf

It's #CFWeek! We think research is really important to your CF care. Today we met @YorkTeachingNHS R&D team to catch up about research we're doing including @cfhealthhub which has been important in our response to Covid.

Elizabeth Shepherd
@Elizabeth871712

We managed to have our own Virtual CF conference yesterday, sharing the presentations we would have taken to Lyon with the team @Wessex_adult_CF and Paeds CF team including one about our @cfhealthhub QI work in Southampton.

Jocelyn Choyce
@jhchoyce

Productive QI meeting with the wonderful CF MDT today, discussing our new virtual clinics @cfhealthhub @CF_physios @CF_dietitians

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Jayne Faulkner
@JaziJ3f

Wow, what an achievement! So proud to be part of this project. CFHealthhub is proving to be invaluable during these challenging times, supporting a proactive approach to virtual consultations at OACFC 👏👏