

Cystic Fibrosis advancing care with clinical trials

Trials Accelerator Impact Report 2020

Welcome to our first annual Trials Accelerator Impact Report, highlighting the achievements of the programme since its launch three years ago.

Overview of the Trials Accelerator

With more advances in cystic fibrosis (CF) care and treatment than ever before, and a host of new treatments in the pipeline, this is an exciting time for the CF community. The Trust's Trials Accelerator is a UK-wide initiative that brings together CF centres to increase the number of CF trials running in the UK and the opportunities for people living with CF to participate in clinical trials.

Since launching in 2017, we have increased the number of CF centres who can run trials, funded a national team of 20 CF Trial Coordinators and created a wealth of information about taking part in clinical trials on our Clinical Trials Hub. We also collaborate with pharmaceutical companies and researchers to showcase the UK as a desirable country in which to invest in CF clinical trials, bringing even more trials to the UK CF community than ever before.



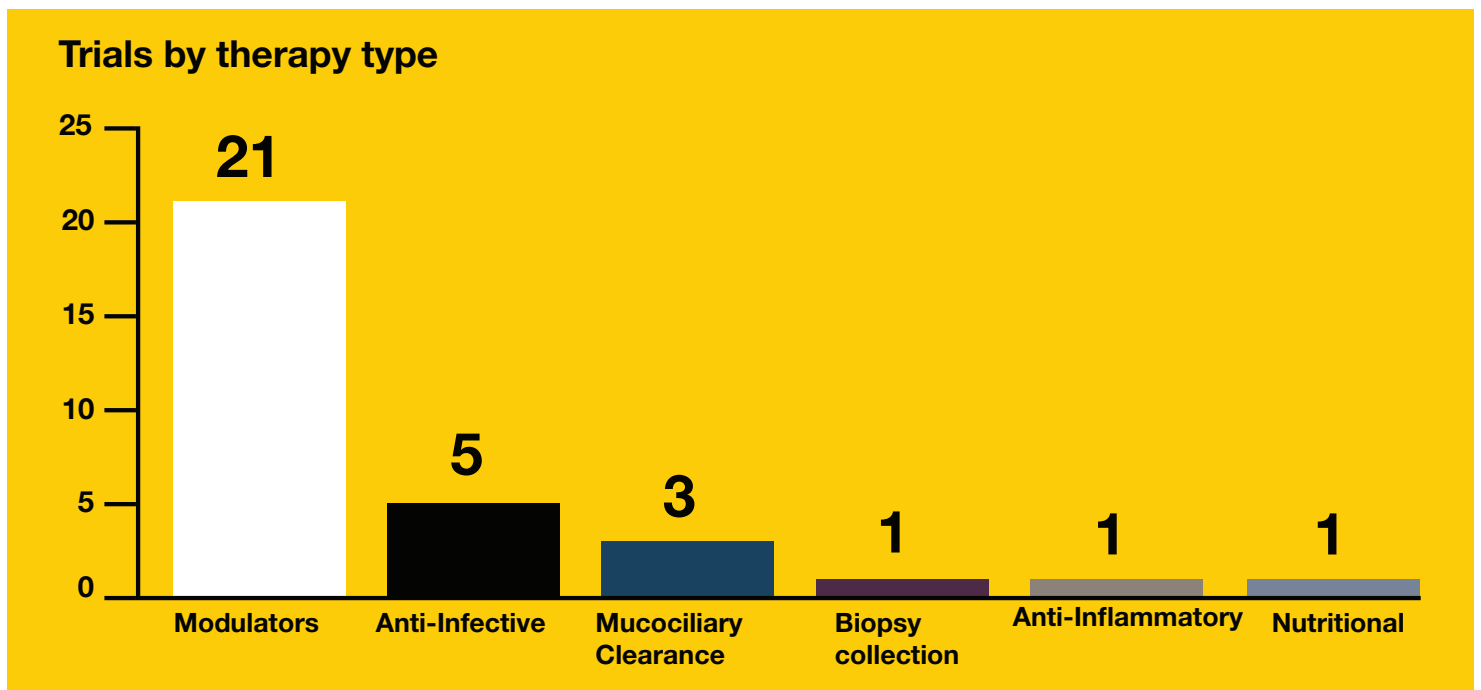
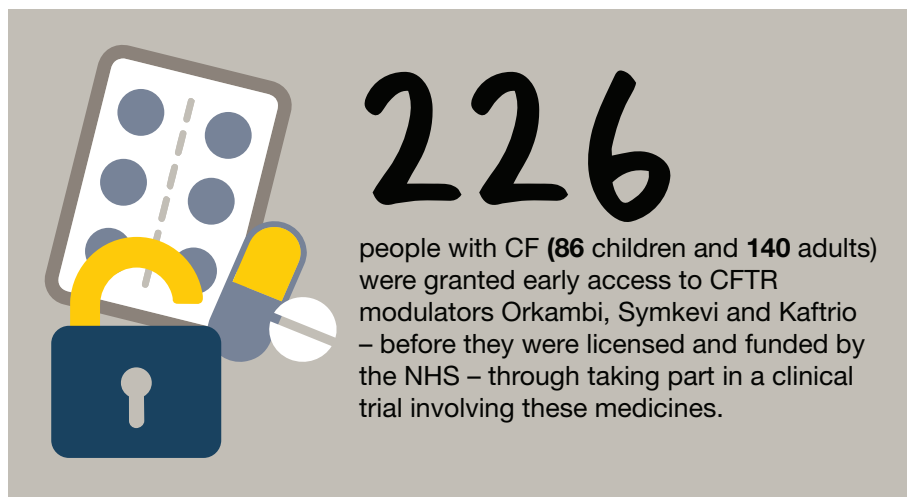
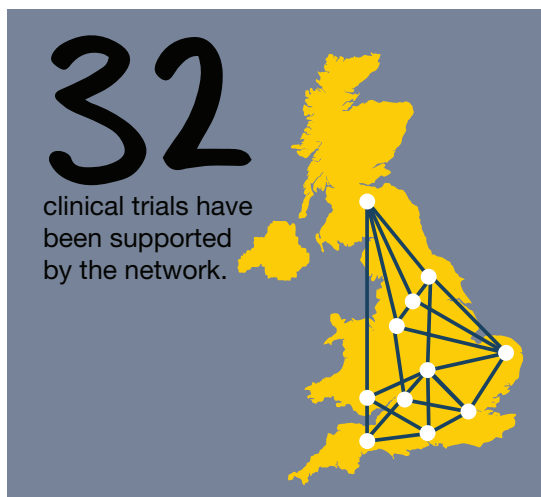
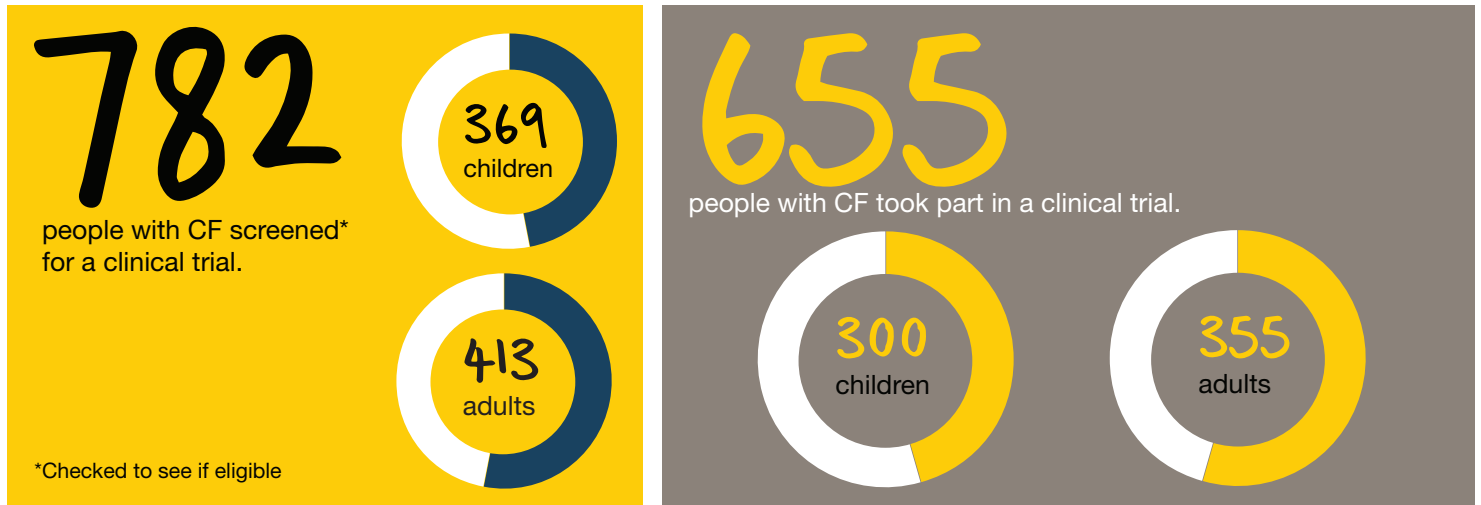
The Trials Accelerator is divided in to the following areas of activity (infographic below):

<p>1. Network of trials centres</p>  <ul style="list-style-type: none"> ■ 27 CF centres form the Trials Accelerator network ■ 83% of people with CF (~8,700) have access to trials where they receive their clinical care ■ 20 CF Trial Coordinators are funded by the programme 	<p>2. Supporting sponsors</p>  <ul style="list-style-type: none"> ■ We encourage sponsors (pharmaceutical companies) to consider the UK as a country to run CF clinical trials ■ We support sponsors with trials design and planning ■ We assist sponsors with identifying suitable CF centres to run a trial in the UK 	<p>3. Community Involvement</p>  <ul style="list-style-type: none"> ■ 50+ people with CF and parents of people with CF form the CF Ambassadors Network ■ Members of the network collaborate with pharmaceutical companies and researchers to support the design of CF trials 	<p>4. Clinical Trials Digital Hub</p>  <p>This includes:</p> <ul style="list-style-type: none"> ■ Introduction to clinical trials ■ Trials Tracker database ■ Stories of trial participation ■ Downloadable resources for adults and children ■ Contact information for clinical trials teams ■ FAQs
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Impact of the Trials Accelerator so far

The below data is from the Trials Accelerator launch (September 2017) to the present.

Taking part in clinical trials



51

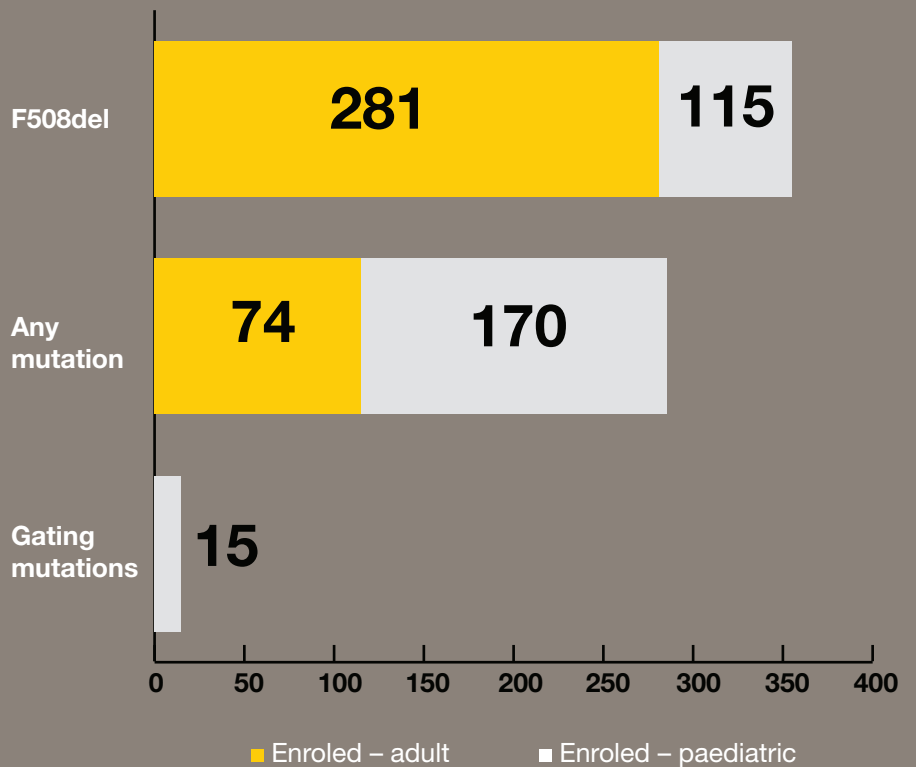
biopsies were collected from people with rare CF mutations in the UK, to help develop new modulator treatments as part of the HIT-CF study.

65%

of people enrolled onto a trial had either one or two copies of the F508del mutation.



Trial enrolment by CF mutation type



Highlights from the national 2019 annual clinical trials survey

The annual clinical trials survey is completed by members of the CF community and provides valuable feedback on the access and opportunities to take part in CF clinical trials.

Evidence of increasing awareness and access to trials

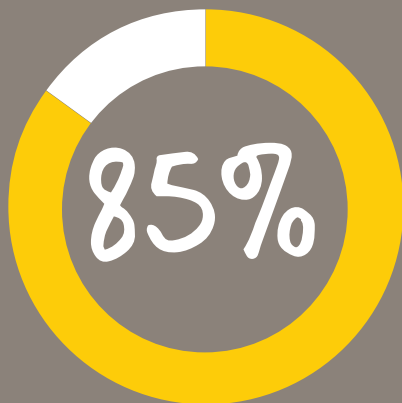
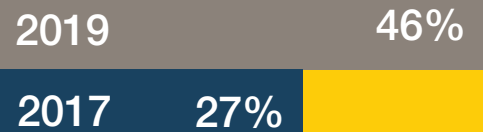
71%

of patients have spoken to their CF team about clinical trials in general.



46%

said they have had the opportunity to consider a clinical trial.



felt the opportunity to take part in clinical trials was positive.

70%

rated the opportunity overwhelmingly positive

(an increase of 10% from previous year).



Supporting sponsors (pharmaceutical companies and researchers)

The below data is from the Trials Accelerator launch (September 2017) to the present.

CF Ambassadors

Members of the CF Ambassadors Network have been involved in

48 separate projects

with sponsors, helping to shape the design of clinical trials and ensure they meet the specific requirements of people with cystic fibrosis.



17 different sponsors

have collaborated with the Trials Accelerator (this includes opening a CF trial at a network centre or engaging with our network of CF Ambassadors).

Supporting new research priorities

In 2015, members of the CF community identified the top 10 questions they would like to see addressed by CF research. Four of these key questions are currently being taken forward to apply for funding from the National Institute for Health Research (NIHR), to help turn these questions into clinical trials. To support the funding application process, people with CF and their families recently joined a series of focus groups to discuss how the answers to these research questions could improve their future. Their valuable insight and input will form an important component of the forthcoming funding applications.



Successful Network of CF Trial Coordinators

The Trials Accelerator funds 20 CF Trial Coordinators at CF centres across the UK. They form an integral part of the local clinical and research team and are involved in all aspects of trial delivery, helping ensure as many people with CF as possible can gain faster access to better treatments through clinical trials.



Top row L-R: Kevin Galono, Suzanne Sketchley, Diane Murray, Jessica Longmate, Helen Chadwick
Bottom row L-R; Sophie Whiteley, Juneka Begum, Sally Coplowe, Danielle Brown, Ryan Leslie

“The Trials Accelerator has changed the entire landscape for CF clinical trials at our site. Since joining the programme our portfolio has grown from strength to strength and there are many more trials for our patients to participate in. They also now have another familiar face: their own CF researcher, who they know is their point of contact for trial information. Patients are so much more aware of what is on offer for them with my role and there is so much more on offer since our site became a CTAP centre.” – Jessica Longmate, Trial Coordinator, Nottingham University Hospital

Clinical Trials Hub



10,000+ visits to the online Clinical Trials Hub since launch in September 2017.

The Clinical Trials Hub provides a wealth of information about what clinical trials are and what they entail, as well as stories from those that have taken part.

17,000+ visits to the online Clinical Trials Tracker since launch in September 2017.

The [Trials Tracker](#) details all CF clinical trials that are open in the UK.



Looking ahead

As well as the impact and achievements of the Trials Accelerator so far, we still have a lot more work to do in supporting the development of new treatments for all people with cystic fibrosis. Here are some of the projects we are planning for the next year:

- Create a small, specialist network of CF centres and Trial Coordinators to run **early phase CF clinical trials** (studies that trial a new medication for the first time in a person with cystic fibrosis). These studies are a vital first step in the clinical trials process and require specialist facilities and staff. Over the next year, we will bring together six Trial Accelerator centres from around the UK to lead on the delivery of these trials.
- Collaborate with pharmaceutical companies to support an emerging type of study called a **‘Real-World Evidence’** (RWE) trial. These studies are observational and collect data from people with CF taking newly licensed medications to help assess the long-term impact on their quality of life.
- Roll out a **Clinical Trials Champions** scheme, where CF Trial Coordinators will visit CF centres across the UK to let them know what clinical trials are running and how they can offer their patients opportunities to take part. This will help us ensure **everyone with CF** can have access to emerging CF treatments through clinical trials, no matter where they live or which CF centre they attend.

A big thank you

We would like to thank those members of the CF community in addition to the CF professionals who have supported the creation and ongoing development of the Trials Accelerator programme. By providing your feedback, engaging with our workshops and completing our surveys, your opinions have helped ensure that the Trials Accelerator is meeting the clinical trial needs and priorities of the CF community and is at the forefront of global efforts to develop life-changing new therapies for people with cystic fibrosis.

For more information on Clinical Trials please visit the Clinical Trials Digital Hub cysticfibrosis.org.uk/get-involved/clinical-trials

