

**Cystic**

**Fibrosis**

a fight we  
must win

**SmartCareCF**

A bold vision to improve the health  
and wellbeing of people living with  
cystic fibrosis

# What is SmartCareCF?



The SmartCareCF programme has been initiated by the Cystic Fibrosis Trust. Working alongside specialist cystic fibrosis (CF) clinical professionals, industry and academic experts, and - most importantly of all - with people living with cystic fibrosis, the purpose is to investigate and realise the potential for innovations in areas such as:

- **communications technologies**
- **virtual clinics**
- **home monitoring and diagnostics**
- **wearable devices and biosensors**
- **bioinformatics**
- **smartphone apps**

The aim is to improve the health and wellbeing of people living with cystic fibrosis and to make life easier for them and all those involved in their care.

Collaboration with the clinical community, NHS, academia, ICT industries, pharma, device manufacturers and people living with cystic fibrosis is central to the success of this project. This will include using an open collaboration platform, 'Hack It Up!', to draw on the experience of the CF community to define the areas where there is the greatest potential for innovation and to enable the community to participate fully in the design, development and testing of potential solutions.

The Cystic Fibrosis Trust is also funding a multi-centre study, which is being led by Professor Andres Floto, Research Director and Honorary Consultant at the Cambridge Centre for Lung Infection. The study will investigate the feasibility and acceptability of remote-monitoring, and is one of the many aspects which will need to be considered in helping to inform the way forward for the programme.

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# What is the motivation behind SmartCareCF?

## 1. Quality of life and cross-infection risk

The last 50 years have seen major advances in care, with median predicted survival increasing from less than five years of age to around 40. These advances have been driven by the development of a specialist model of care, earlier diagnosis/new born screening; and new therapies. With improved survival, quality of life is an increasing priority for people with cystic fibrosis. Each new therapy has added to the daily routine for people with CF who now face a heavy burden of treatment even when well.

**“At the moment, people with cystic fibrosis have to go to clinic every two or three months, irrespective of how they are feeling and for the 70 per cent of adult patients that have jobs or are in full-time education, that can mean they have to take a whole day off just to be told everything is OK,” said Professor Floto.**

Some CF teams have started exploring the potential of Skype-style virtual clinics informed by some element of remote-monitoring as a pragmatic way to make some aspects of care more convenient and minimise exposure to cross-infection risks.

## 2. Understanding “my CF”

Many individuals with cystic fibrosis have a natural desire to understand their own particular ‘version’ of CF, learn how specific treatments impact on their health and find out what they can do to feel better and minimise the disruption CF causes in their life. Currently, clinical practice relies on snapshots of data and patients remembering how they felt in between. New technologies may fill in some of the gaps, provide a more complete picture of wellness/sickness, identify early warning signs, show how things change over time and shed light on the effects of specific treatments on individuals. This could usefully add to the information available to CF teams and people with CF when they make treatment decisions and help them achieve their goals.

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## So what's next?



We are seeking to bring together experience and learnings from Hack It Up!, research currently underway in the UK and internationally, specialist clinical experience, academic insights, industrial expertise, and, above all, the insights and ingenuity of those living with cystic fibrosis. By working together we will be able to harness new technologies to improve the health and well-being of people with cystic fibrosis.

**[cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)**

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