

Cystic Fibrosis our focus

At a glance: CF Insight Survey November 2016

About the survey

In November 2016 the Cystic Fibrosis Trust launched the CF Insight Survey. The survey was designed for people with cystic fibrosis (CF), their friends and families, to help build a picture of what CF is really like for people living with the condition. The survey covered everything from participating in clinical trials, to the burden of treatment. Your answers were honest and your feedback was invaluable.

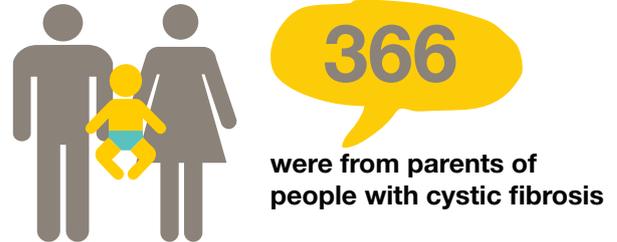
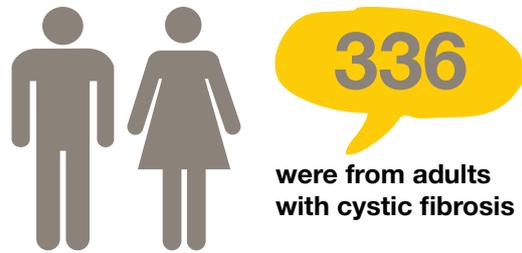
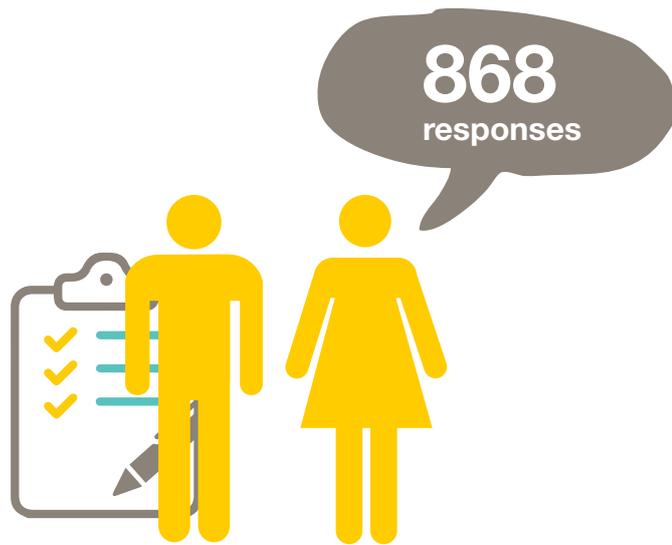
People with different experiences of CF helped to write the questions for the survey. To help ensure that the survey captured individual experiences, parents with more than one child with CF were able to complete the survey multiple times to represent the experiences of each of their children.

We have taken some of the most striking data from the CF Insight Survey and created an 'at a glance' report. In this report we have included anonymous quotes from people that completed the survey so that you can find out more about what it's like living with CF for people with the condition, their friends and families.

“Responses will help us to build on our knowledge of what people’s priorities, interests and concerns are in relation to living with CF, and help direct the work of the Trust in the future.” – Paul Rymer, Head of Principal Involvement, Cystic Fibrosis Trust

Results

How many people took part?

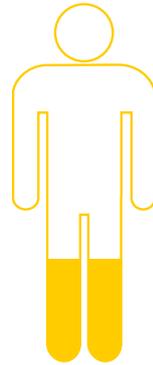


Outpatient appointments



Each appointment, including travel, takes on average:

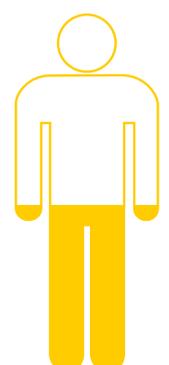
4 hours 46 minutes



28%
of people travel for more than 90 minutes (one way) to reach their centre



25%
of people travel between 60 and 90 minutes



47%
of people travel for less than one hour

The average travel time to an out-patient appointment is



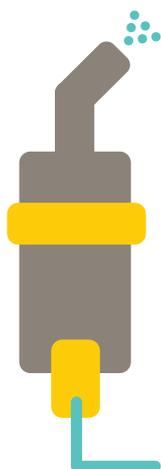
What about the financial burden of cystic fibrosis?

85% of adults with CF experience at least some concern about the financial burden of the condition.



92% of adults aged 25 and under report at least some concern about financial burden.

The top five tech and apps that people find useful for CF care are:



1. Nebulisers



2. Fitness trackers and smart watches



3. Smartphones with built-in fitness/health monitoring apps



4. Calorie counting /nutrition apps

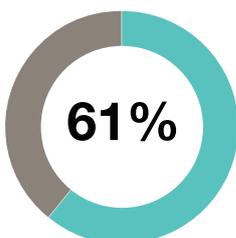


5. Fitness apps

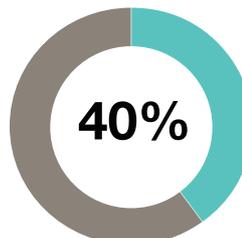


"Having reminders is a real help for someone who is forgetful or might remember but get distracted. So having the little notification on my phone to make me go 'Oh! I need to do that now' is great."

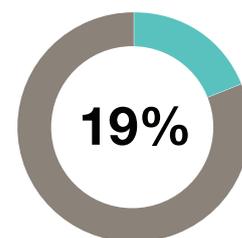
What about clinical trials?



61% of adults have been invited to take part in a clinical trial

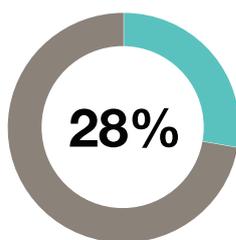


40% of adults have participated in at least one trial

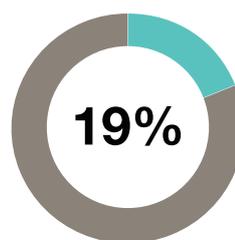


19% of adults have participated in more than one trial

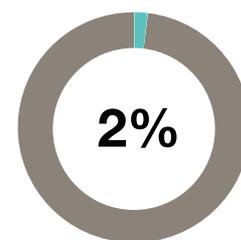
When it comes to parents of children with CF, things are a little different...



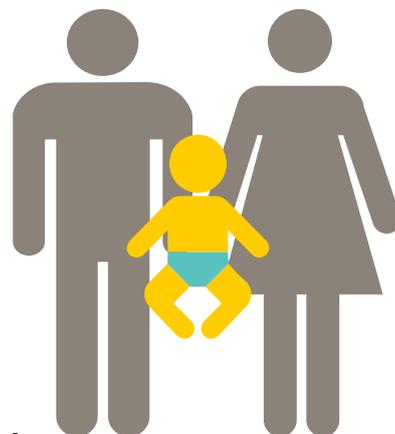
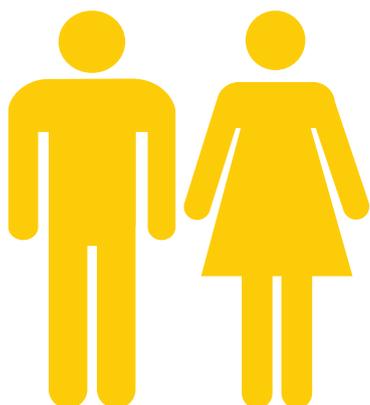
of parents say their children have been invited to participate in a trial



of parents say their children have participated in at least one trial



of parents say their children have participated in more than one trial



73% of adults with CF reported a largely positive experience of trials.

51% of parents reported a largely positive experience of trials.

However, **23%** of adults with CF and **31%** of parents did not have a positive experience taking part in clinical trials. Both groups cited poor communication as the reason.

"A far as I'm aware the trial is still ongoing. We've been getting no feedback."



"The trials have both been fine, but there was no feedback at the end so as a patient I'm none the wiser for my efforts."

We have launched the Clinical Trials Accelerator Platform, a UK-wide initiative to bring together existing CF centres to improve access, participation and delivery of clinical trials. The importance of communication before, during and after a trial is a primary focus we are addressing. We want **you** to be involved in clinical trials from start to finish.

By holding the survey annually, we hope to build a picture of how life with CF is changing as the years go by. Thank you for taking part!