

# Cystic Fibrosis our focus

**At a glance: CF Insight Survey**  
June 2018

## About the survey

In November 2016 we launched our first CF Insight Survey. The survey was designed with people with cystic fibrosis (CF) and 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.

To form this year's survey, last autumn we invited people with CF, partners and family members to participate in online focus groups and also to talk one-to-one about what we could explore in the second survey. The subjects raised are all either featured in this year's survey or being explored in other ways – for example, in our Information and Support Team's work.

We have taken some of the most striking data from the 2018 CF Insight Survey and created an 'at a glance' report. Keep an eye out for the full Insight Survey report, which will be released in September this year.

**“Collaboration with people with CF, partners and families helped us to create a set of questions that were open and accessible to all, focusing on topics not represented in other pieces of work, such as the impact of CF on work and social life, getting older with CF and what really matters to people now, such as access to medicines.”** – Paul Rymer, Head of Principal Involvement, Cystic Fibrosis Trust

# Results

## How many people took part?

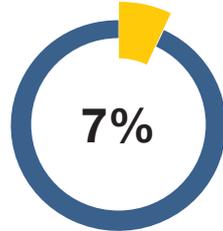
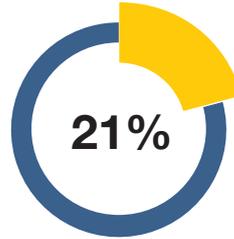
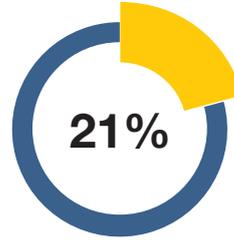
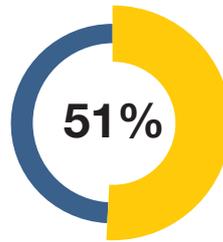


1,095

people completed 100% of the survey, while 400 more surveys were 'substantially completed'

5%

more partners completed the survey than last year



## Education

77%

of people with CF felt that their condition has had an impact on their career or education



This number increased dramatically if people were under 21 or over 45.

People under 21

82%

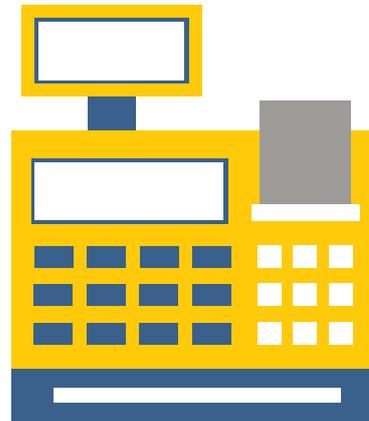
People over 45

88%

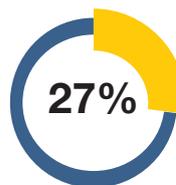
## Employment

63%

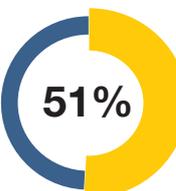
of adults with CF were in some kind of employment



This number was very different for male and female respondents.



of women with CF were in full-time employment



of men with CF were in full-time employment



## Benefits



## Financial burden



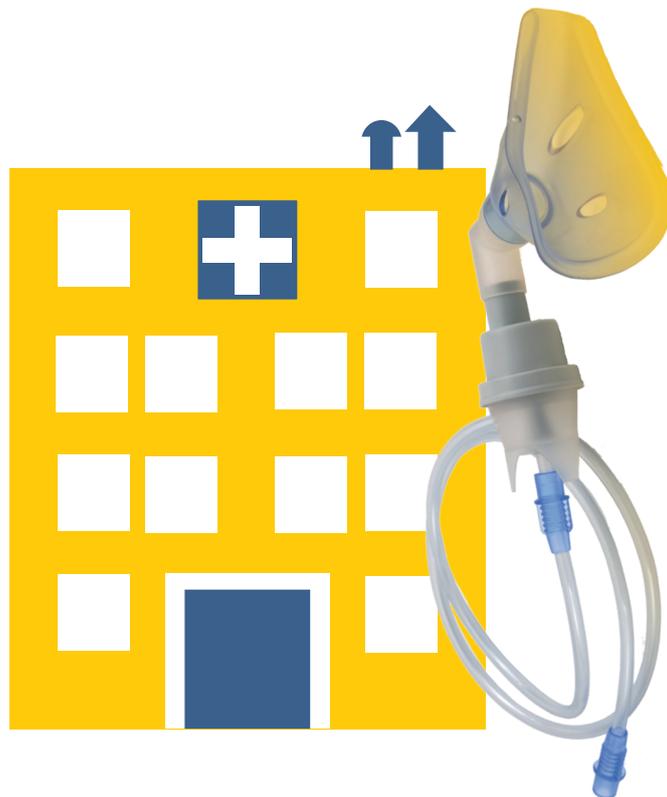
# 77%

of adults with CF experienced at least some concern about the financial burden of their condition.

## Concerns

We asked people with CF what their concerns relating to care were for the next 12 months. They said:

1. Access to new treatments and medicines
2. Cross-infection
3. Getting a hospital bed when they need one
4. The additional costs of care like travel and prescriptions
5. Access to current medicines

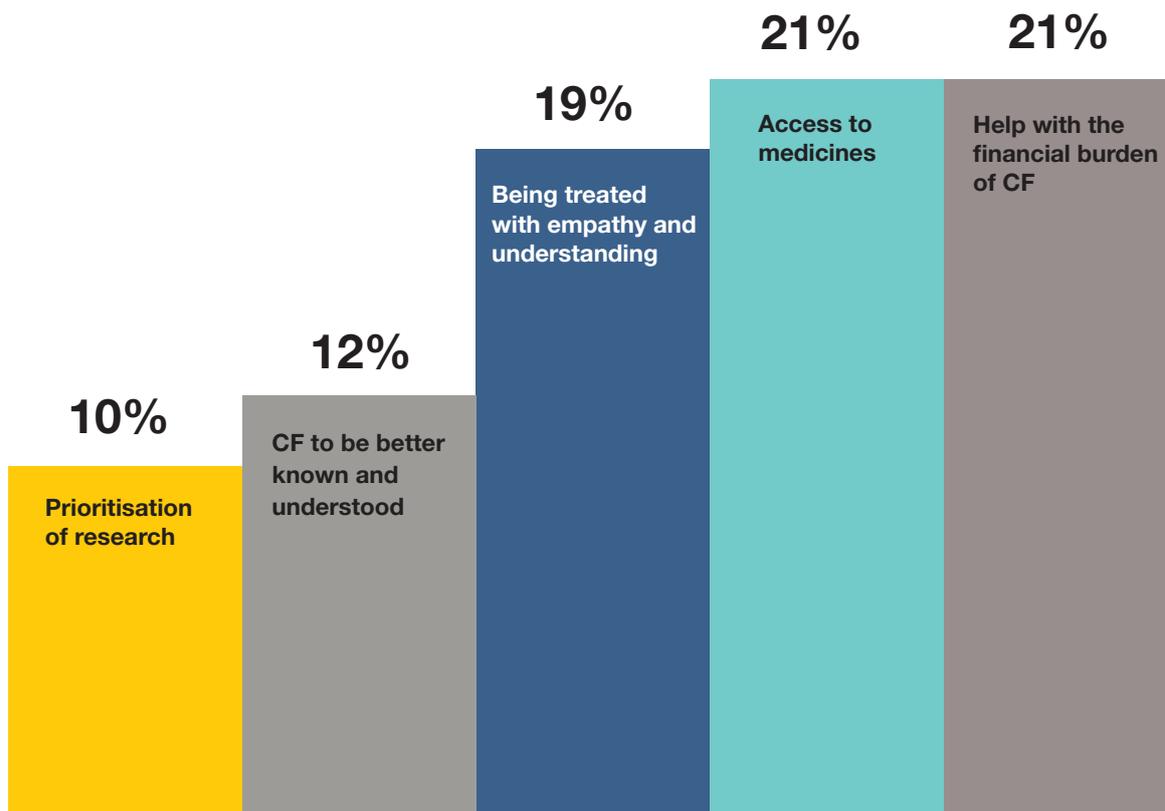


You said...

*"It is hard to plan your future when you can't assume that you will be healthy enough to work/live independently but you have no idea of how long you will be able to do those things"*

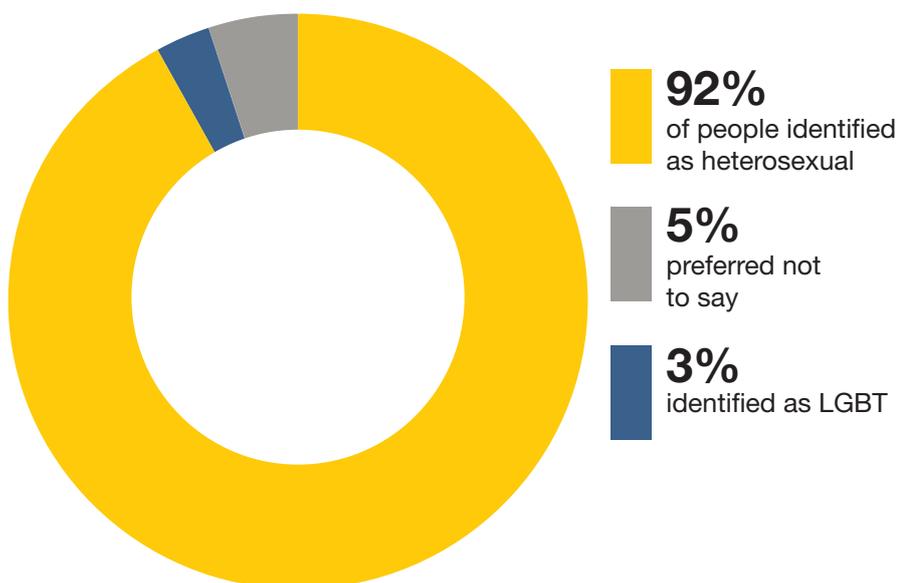
## If you could change one thing...

When people with CF were asked what the one thing was that would improve their lives, they said:



When asked the same question, partners were the highest percentage of respondents that felt CF being better understood would improve their lives, while parents of under 16s with CF felt most strongly out of all groups that access to medicines would improve the lives of their children.

## Gender and sexuality



The amount of people who identified as LGBT is 1% higher than the national average in 2016.