

Cystic Fibrosis strength in numbers

At a glance: UK CF Registry Survey Report
February/March 2015

Want more detail?

You can access the full report [online](#).

About this report

The UK Cystic Fibrosis (CF) Registry is a research project that has been hosted by the Cystic Fibrosis Trust since 2007. It securely collects information about people with CF in the UK who consent to this.

We want to be sure future development of the UK CF Registry meets the needs of people with CF, their families, healthcare teams, researchers and the wider NHS. This survey, open to people with CF and their parents, is part of that process for the UK CF Registry.

Results

848
responses



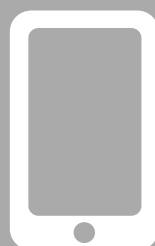
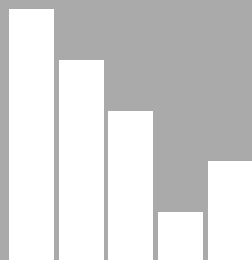
94% would like to self-report information about themselves to the UK CF Registry



81%

would like to access some or all of their own UK CF Registry data

Online PDF documents, online charts and tables, smartphone apps and printed reports were the top four ways of looking at results from the UK CF Registry



Choosing treatments, understanding CF, having a discussion with your CF team, and choosing a CF centre were the top four uses of UK CF Registry results by people with CF and their parents



84% would be happy for us to learn more by linking UK CF Registry data to other source(s)

