

Cystic

Fibrosis

strength in
numbers

UK CF Registry Data Report 2014
At a glance

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Fibrosis strength in numbers

Welcome to our 'at a glance' summary of the UK CF Registry's Annual Data Report 2014, highlighting the key information from the full report, available at www.cysticfibrosis.org.uk/registry. We listened to feedback from recent reports and hope the new format is easier to get around.

There is a lot of good news to celebrate in 2015:

- There are more adults (over 16s) with CF than ever before.
- There are more people with CF with complete data on the registry.
- More people know their genotype, which is becoming increasingly important as new gene-specific medicines come on to the market.

The Registry data is growing, providing more information, to researchers to improve and find new drugs and treatments, and to clinicians to help them see and discuss with their patients the latest trends and outcomes in care. All this comes from the people and families living with CF who have given permission for their clinical data to be put on the registry.

We really are stronger together!

Our thanks go out to all the people who consent to have their data entered on to the registry – it is this valuable information and its benefits for quality improvement and research that bring people with CF and their families closer to a better future.

Dom

Mr Dominic Kavanagh
Patient Representative

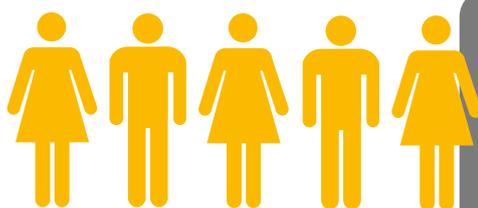
Marian

Mrs Marian Dmochowska
Parent Representative

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At a glance

cysticfibrosis.org.uk/registry



10,583

people on the UK CF Registry.



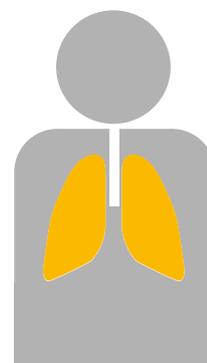
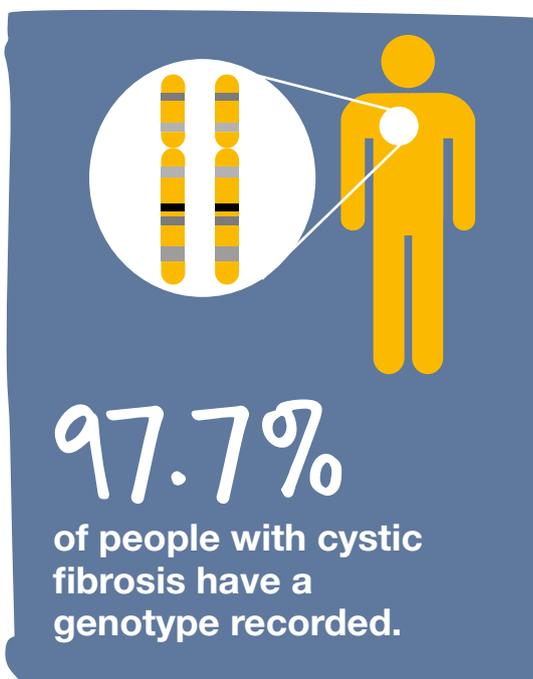
89%

of which have complete data.



59.3%

of people with cystic fibrosis are aged 16 or older.



72

transplants took place in 2014 compared to 57 last year.



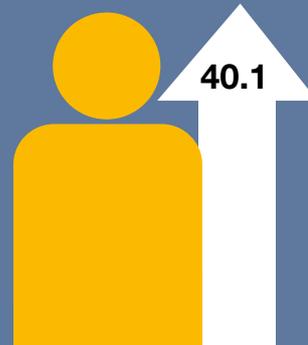
70.1%

of adults with cystic fibrosis are in employment or study.



2 months

is the median age of diagnosis.



40.1

is the median predicted age of survival.

cysticfibrosis.org.uk/registry

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