

Cystic Fibrosis strength in numbers

UK CF Registry Annual Data Report 2018 - at-a-glance

Our at-a-glance version of the UK CF Registry Annual Data Report 2018 highlights the key information from the full report, available at cysticfibrosis.org.uk/registryreports

Active patients

10,509

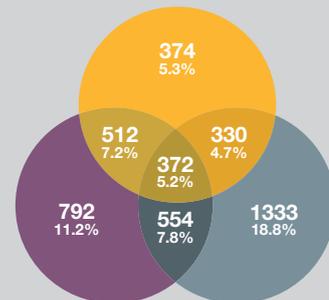
Active patients are people who are currently alive and have had an annual review recorded in the last three years.



Mode of presentation

2,751

(27.9%) people were diagnosed by newborn screening. Aside from newborn screening, the most common three presentations were:



- Abnormal stools/fatty stool (steatorrhea)/malabsorption
- Failure to thrive/malnutrition
- Persistent or acute respiratory infection

Diagnosis

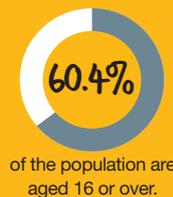
23 days

is the median age that people aged under 16 in 2018 were diagnosed with cystic fibrosis. 8.5% of people in the Registry were diagnosed at age 16 or over.

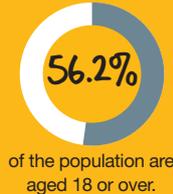
Median age

20

is the median age of people with cystic fibrosis in the UK.

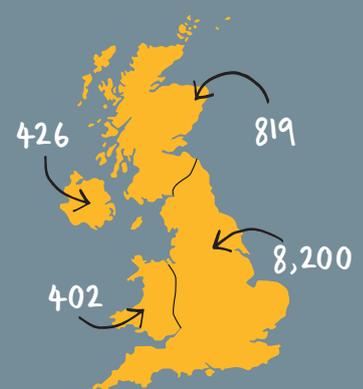


60.4% of the population are aged 16 or over.



56.2% of the population are aged 18 or over.

CF population by devolved nation



Infections

Pseudomonas aeruginosa

41.4%

of people aged 16 and over have chronic Pseudomonas.

The median age of people with chronic Pseudomonas was 24 years in 2008, compared to 29 in 2018. 88.9% of people with chronic Pseudomonas were on inhaled antibiotic therapy in 2018, compared to 76.1% in 2008.



Non-tuberculous mycobacterium (NTM)

has increased from 6% to 7% in the past year.

49%

of people recorded as having NTM were being treated, which is 10% less than in 2017.

Aspergillus is reported in

8.9% of people.



Allergic bronchopulmonary aspergillosis (ABPA), an immune response to Aspergillus infection, has reduced in prevalence from 10.5% since 2013, to 7.2%.

Median predicted survival age

for people born today, using "2014-2018" data, is

47.3 years old

The median predicted survival age for females (44.1) is 7 years lower than males (51.0).



Deaths in 2018

Of the 137 people with CF who died in 2018, the median age of death was 32 years old.

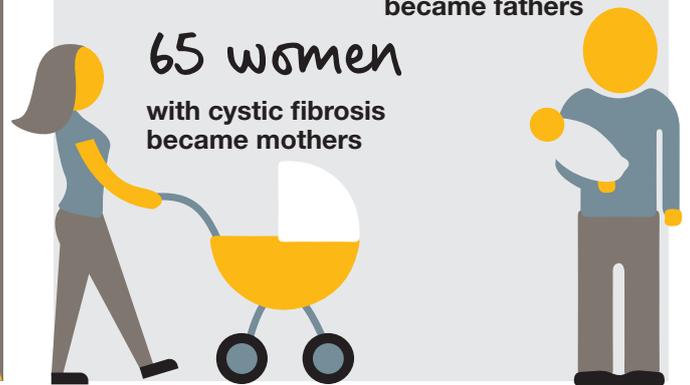
Pregnancy

45 men

with cystic fibrosis became fathers

65 women

with cystic fibrosis became mothers



Mucus thinners

32.9%

of people were on hypertonic saline in 2018, compared to 5% in 2008.

65% of people were on DNase in 2018, compared to 37% in 2008.



Cystic fibrosis-related diabetes (CFRD)

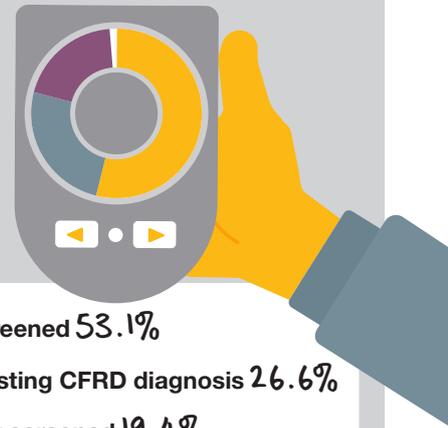
On CFRD treatment:

33.8%

11.4%

Children 10-15

Adults 16 and over



IV antibiotics

44.7%

of people had at least one course of IV antibiotics in 2018.

37.7%

24%

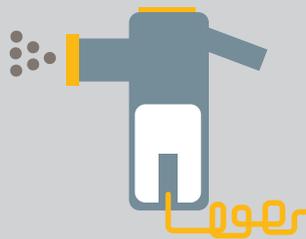


Burden of treatment

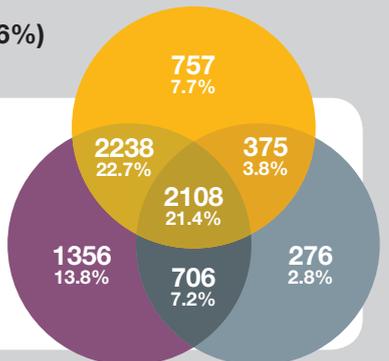
79.4%

of people with CF were on at least one form of inhaled therapy.

No inhaled therapy: 2031 (20.6%)



- Inhaled antibiotics
- DNase
- Hypertonic saline or mannitol



People on CFTR modifiers

Ivacaftor: 612

Lumacaftor/ivacaftor: 372

Tezacaftor/ivacaftor: 30



Transplant

	2008	2018
Evaluated:	126	247
Accepted:	55	104
Double lung Transplant:	16	58

