Cystic Fibrosis strength in numbers

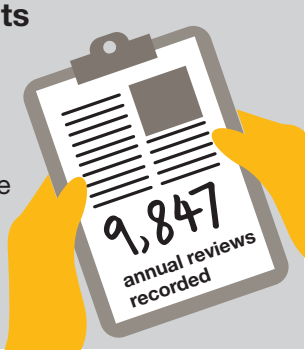
UK CF Registry Annual Data Report 2018 - **at-a-glance**

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

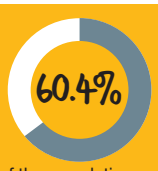
Active patients are people who are currently alive and have had an annual review recorded in the last three years.



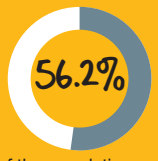
Median age

20

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



of the population are aged 16 or over.

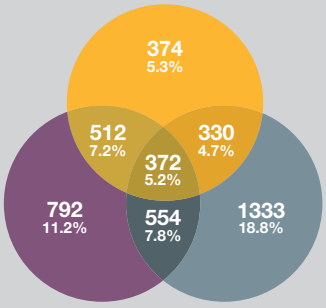


of the population are aged 18 or over.

Mode of presentation

2,751

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



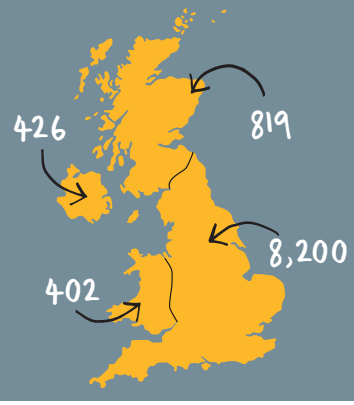
- **Abnormal stools/fatty stool (steatorrhea)/malabsorption**
- **Failure to thrive/ malnutrition**
- **Persistent or acute respiratory infection**

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.

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 by **10.5%** since 2003, to **7.2%**.

Median predicted survival age

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

47.3 years old

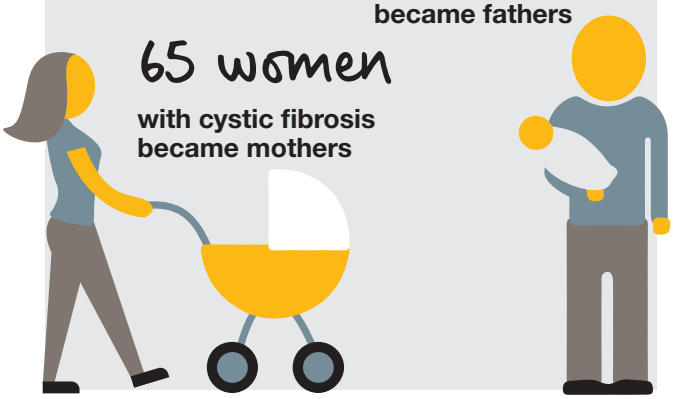
The median predicted survival age for females **(44.1)** is 7 years lower than males **(51.0)**.

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.

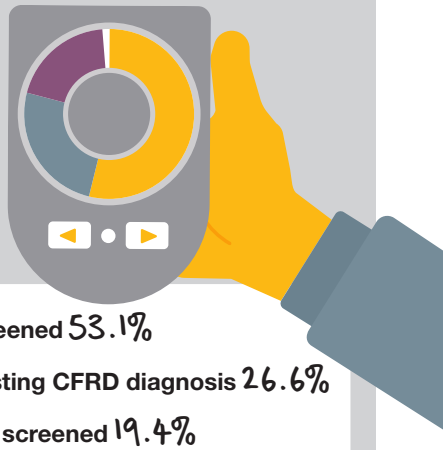
65% of people were on DNase in 2018, compared to **37%** in 2008.

IV antibiotics

44.7%
of people had at least one course of IV antibiotics in 2018.

Cystic fibrosis-related diabetes (CFRD)

On CFRD treatment:

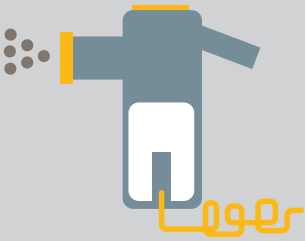


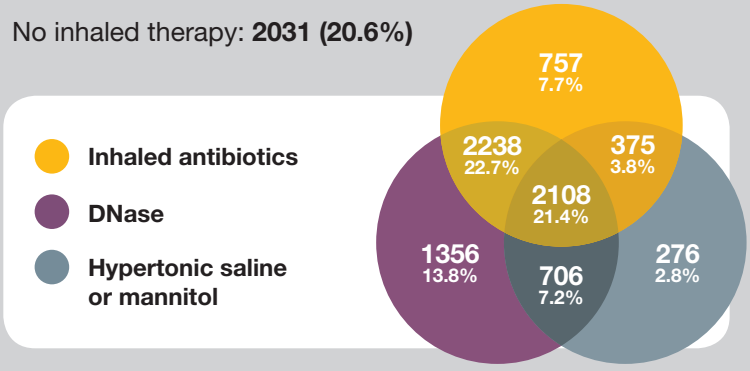
- Screened 53.1%
- Existing CFRD diagnosis 26.6%
- Not screened 19.4%
- Unknown 0.9%

Burden of treatment

79.4%
of people with CF were on at least one form of inhaled therapy.

No inhaled therapy: **2031 (20.6%)**





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