Cystic Fibrosis strength in numbers

UK Cystic Fibrosis Registry Annual Data Report 2019: **at a glance**

This 'at a glance' version of the UK Cystic Fibrosis Registry Annual Data Report 2019 highlights some of the stand-out statistics concerning people with cystic fibrosis (CF) in the UK during 2019. For more detail, see the full report at **cysticfibrosis.org.uk/registryreports**

Number of people with CF

10655

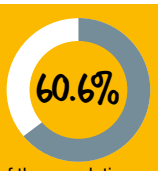
Active patients

People who are currently alive and have had an annual review recorded in the past three years.

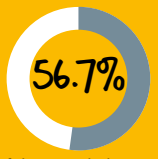
Median age

21

is the median age of the UK CF population.



of the population are aged 16 or over.

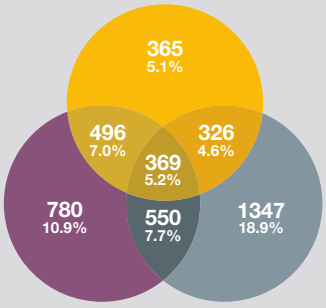


of the population are aged 18 or over.

Mode of presentation

2952

(29.3%) of people were diagnosed by newborn screening (NBS). Aside from (NBS), the three most common presentation modes were:



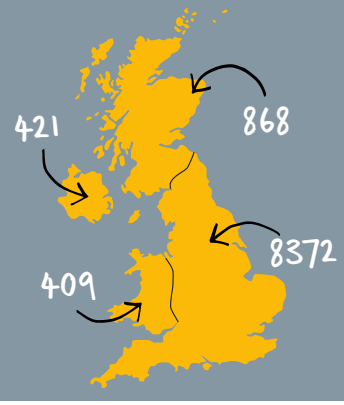
- **Abnormal stools/fatty stool (steatorrhea)/malabsorption**
- **Failure to thrive/ malnutrition**
- **Persistent or acute respiratory infection**

Diagnosis

22 days

is the median age at which people aged under 16 in 2019 were diagnosed with CF. **14.9%** of adults in the Registry were diagnosed aged 16 or over.

CF population by devolved nation



Infections

Pseudomonas aeruginosa

39.4%

of people aged 16 and over have chronic *Pseudomonas.*

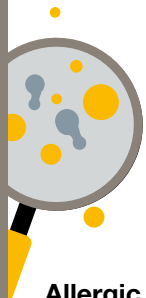
The median age of people with chronic *Pseudomonas* in 2019 was **30 years**, compared with **25 years** in 2009. In 2019 **88.7%** of people with chronic *Pseudomonas* were on inhaled antibiotic therapy, compared with **74.3%** in 2009.

Non-tuberculous *mycobacterium* (NTM)

has reduced from **7.1%** to **6.7%** in the past year.

53.7%

of people recorded as having NTM are on treatment for it, which is **4.5%** more than in 2018.



Aspergillus is reported in

15.7%

of people.

Allergic bronchopulmonary aspergillosis (ABPA), an immune response to *Aspergillus*, has reduced in prevalence from **15.1** in 2014, to **7.5%**.

Median predicted survival age

49.1 years old

Based on 2015-2019 data.

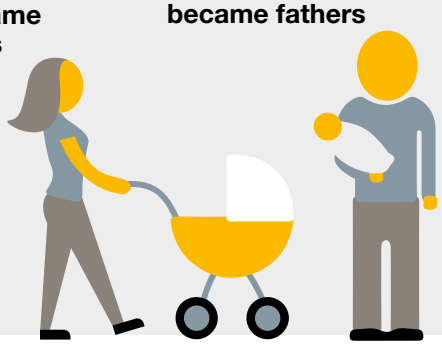
The median predicted survival age for females **(45.7)** is almost 6 years lower than males **(51.6)**.

Deaths in 2019
Of the **114** people with CF who died in 2019, the median age at death was **31** years old.

Pregnancy

58 women
women with CF became mothers

45 men
men with CF became fathers



Mucus thinners

36.8%
of people are on hypertonic saline or mannitol, compared with **6.9%** in 2009.

67.6% of people are on DNase, compared to **38.4%** in 2009.

Intravenous (IV) antibiotics

44.5%
of people had at least one course of IV antibiotics in 2019.

38.0% in hospital
23.1% at home

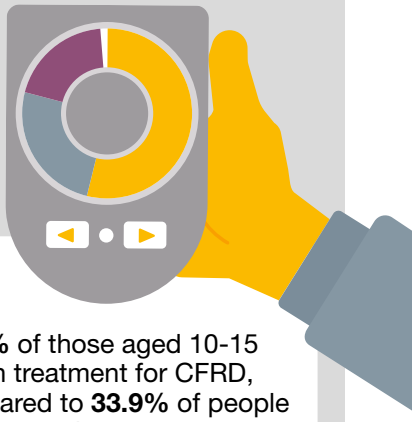
65.1%

of people with CF were in work or study

62.4% of women

67.5% of men

Cystic fibrosis-related diabetes (CFRD)

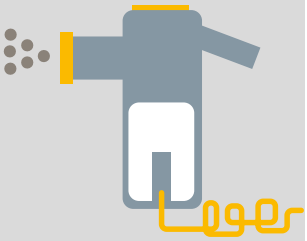


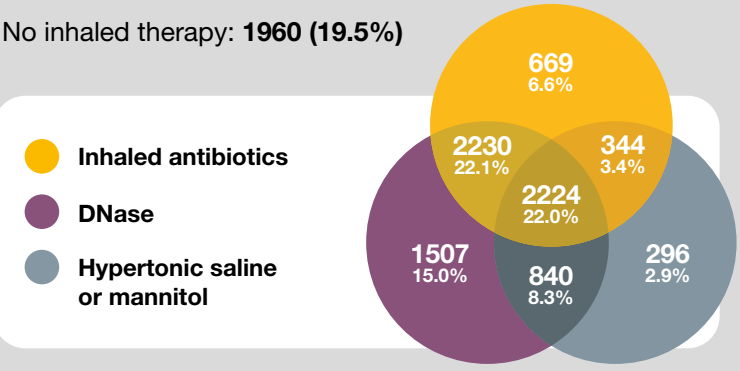
13.1% of those aged 10-15 are on treatment for CFRD, compared to **33.9%** of people aged 16 and over.

Burden of treatment

80.5%
of people with CF are on at least one form of inhaled therapy.

No inhaled therapy: **1960 (19.5%)**





People on CFTR modifiers

Ivacaftor: **646**
Lumacaftor/ivacaftor: **404**
Tezacaftor/ivacaftor: **197**
Elexacaftor/tezacaftor/ivacaftor: **13**

Transplant

	2009	2019
Evaluated:	144	241
Accepted:	79	96
Bilateral lung:	19	50