Cystic Fibrosis strength in numbers

UK Cystic Fibrosis Registry Annual Data Report 2020: **at a glance**

This 'at a glance' version of the UK Cystic Fibrosis Registry Annual Data Report 2020 highlights some of the stand out statistics concerning people with cystic fibrosis (CF) in the UK during 2020. For more detail, see the full report at **cysticfibrosis.org.uk/registryreports**

Number of people with CF

10837

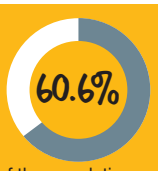
active patients

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.



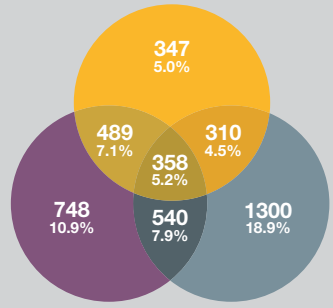
of the population are aged 16 or over.

of the population are aged 18 or over.

Mode of presentation

3011

people **(30%)** 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 2020 were diagnosed with CF. **14.7%** of adults in the Registry were diagnosed aged 16 or over.

Active CF population by devolved nation

Infections

Changes in infection rates may be driven by reduced availability of samples due to COVID-19 clinic disruption and modulator uptake.

Pseudomonas aeruginosa

31.9%

of people aged 16 and over have chronic *P. aeruginosa.*

The median age of people with chronic *P. aeruginosa* in 2020 was **31 years**, compared with **25 years** in 2010. In 2020 **91.4%** of adults with chronic *P. aeruginosa* were on inhaled antibiotic therapy, compared with **78.8%** in 2010.

Non-tuberculous *mycobacterium* (NTM)

prevalence remains stable at **6.9%.**

52.6%

of people recorded as having NTM are on treatment for it, which is similar to 2019.

Aspergillus is reported in

13.7%

of people.

Allergic bronchopulmonary aspergillosis (ABPA), an immune response to *Aspergillus*, has reduced in prevalence from **10.6%** in 2015, to **7.1%**.

Median predicted survival age

50.6 years

based on 2016-2020 data

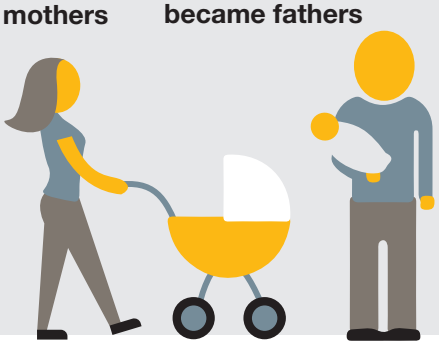
The median predicted survival age for females **(47.0)** is 6 years lower than males **(53.1)**.

Deaths in 2020
Of the **97** people with CF who died in 2020, the median age at death was **36** years old.

Pregnancy

56 women with CF became mothers

44 men with CF became fathers



Mucus thinners

40.3%
of people are on hypertonic saline or mannitol, compared with **11.3%** in 2010.

69.6% of people are on DNase, compared to **42.7%** in 2010.

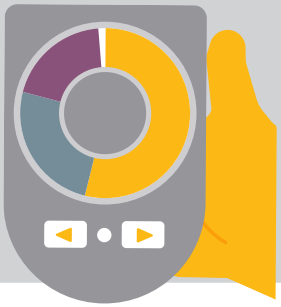
62.3%

of people with CF were in work or study.

62.4% of women

67.5% of men

Cystic fibrosis-related diabetes (CFRD)



10.4% of those aged 10-15 are on treatment for CFRD, compared to **35.3%** of people aged 16 and over.

Intravenous (IV) antibiotics

39.2%
of people had at least one course of IV antibiotics in 2020.

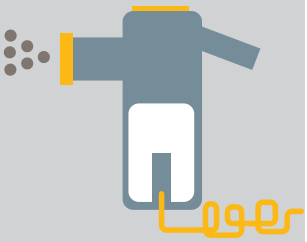
32.1% in hospital

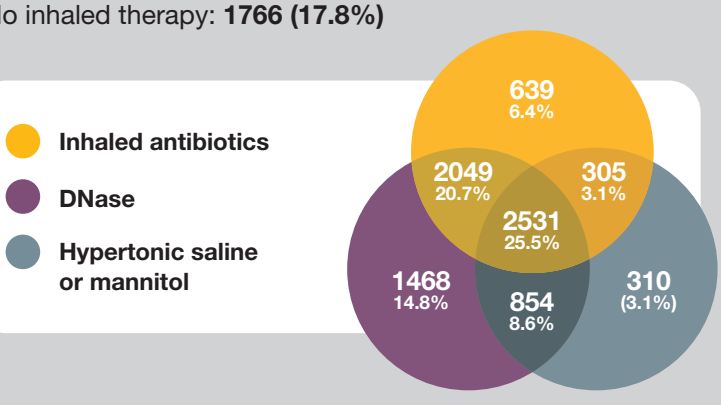
21.7% at home

Burden of treatment

82.2%
of people with CF are on at least one form of inhaled therapy.

No inhaled therapy: **1766 (17.8%)**





People on CFTR modifiers as of December 2020

Ivacaftor: 871

Lumacaftor/ivacaftor: 1194

Tezacaftor/ivacaftor: 1358

Elexacaftor/tezacaftor/ivacaftor: 2700

COVID-19 cases and hospitalisations in 2020.