Cystic Fibrosis Trust

UK Cystic Fibrosis Registry
2024 Annual Data Report
At a glance

This 'at a glance' version of the UK Cystic Fibrosis Registry Annual Data Report 2024 highlights some key information about people with cystic fibrosis (CF) in the UK who had an annual review in 2024. For more detail, see the full report at **cysticfibrosis.org.uk/registry**

Number of people with CF in 2024

11,381

registered* people

* People who have had at least one encounter or annual review recorded in the current year or the past two years and people newly consented to the Registry.

Births

111 women with CF had babies in 2024

35 men with CF became fathers in 2024

164 new diagnoses in 2024

123 of these were identified by new born screening

6,736

people with CF are 16 years or older.

Of these, **4,588 (68%)** were in work or study in 2024.

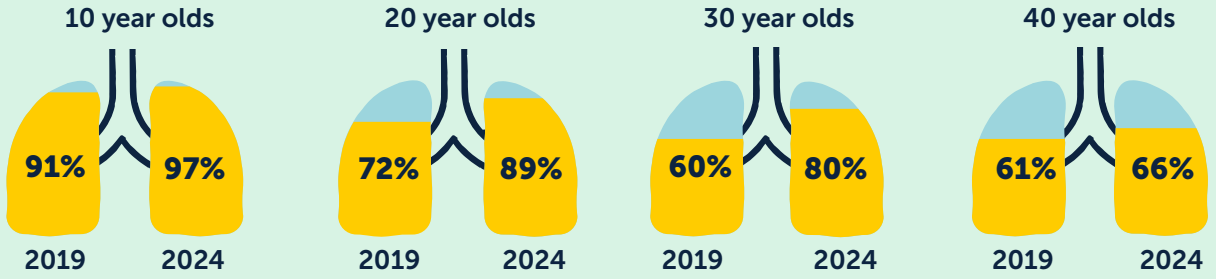
Ethnicity

White	**94.6%**
Asian	**3.4%**
Black	**0.3%**
Mixed	**1.2%**
Other	**0.6%**

* % of those with known ethnic group recorded

Lung health outcomes in 2019 and 2024

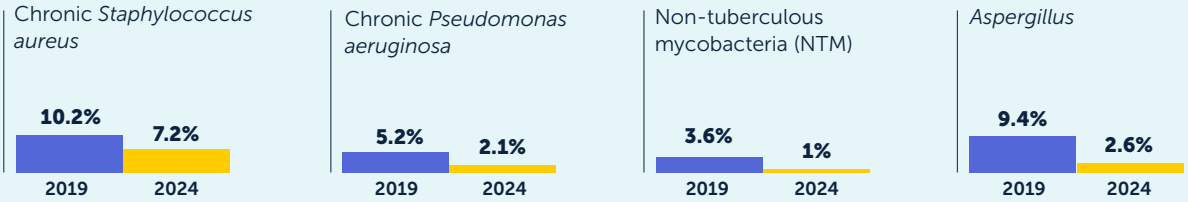
Median FEV_1% predicted at annual review



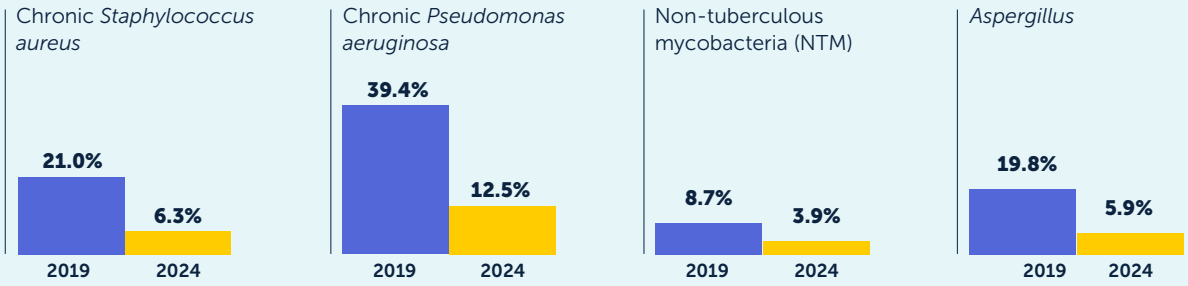
FEV_1% is reported for people who have not had a lung transplant

Lung infections and respiratory culture samples 2019 and 2024

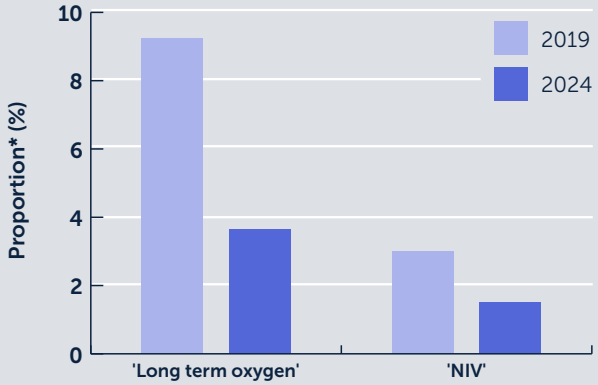
Age under 16 years



Age 16+ years

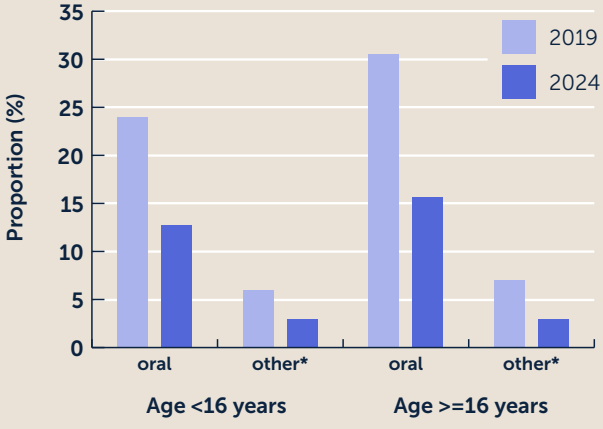


Respiratory support



* age 18+ years

Supplemental feeding

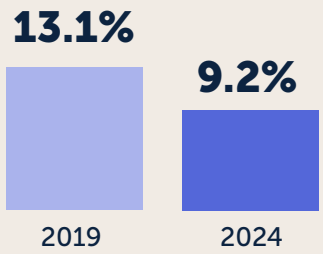


* enteral and parenteral feeding

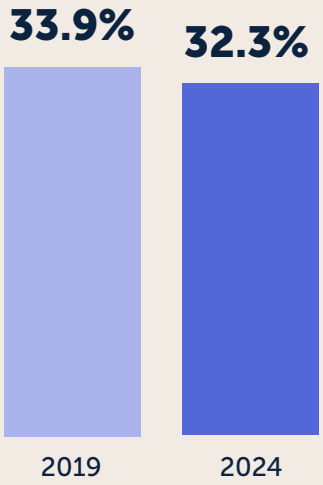
Complications in 2019 and 2024

CF diabetes*

Age 10** to 15 years



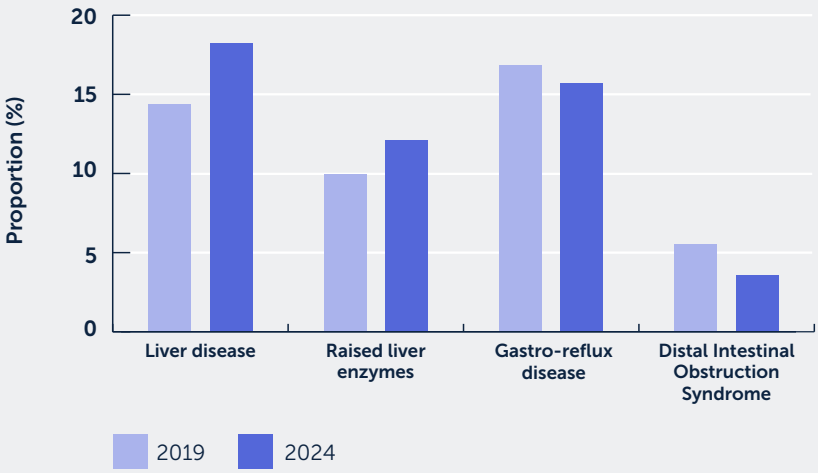
Age 16+ years



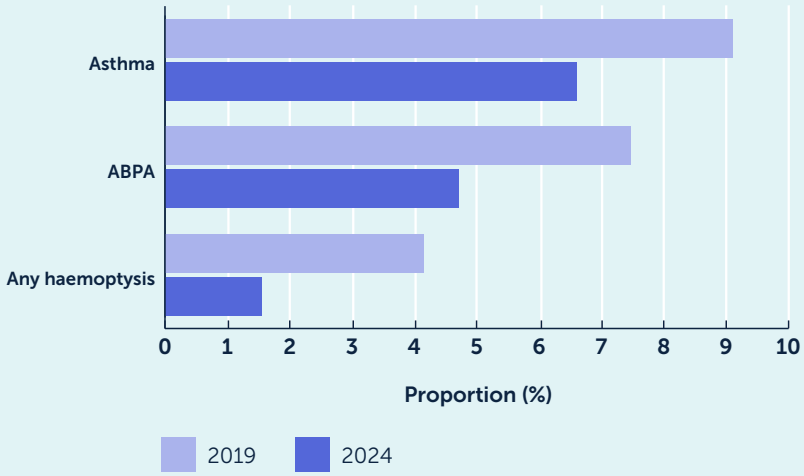
* on treatment for CF diabetes

** in both 2019 and 2024, 1% of people under 10 years had CF diabetes

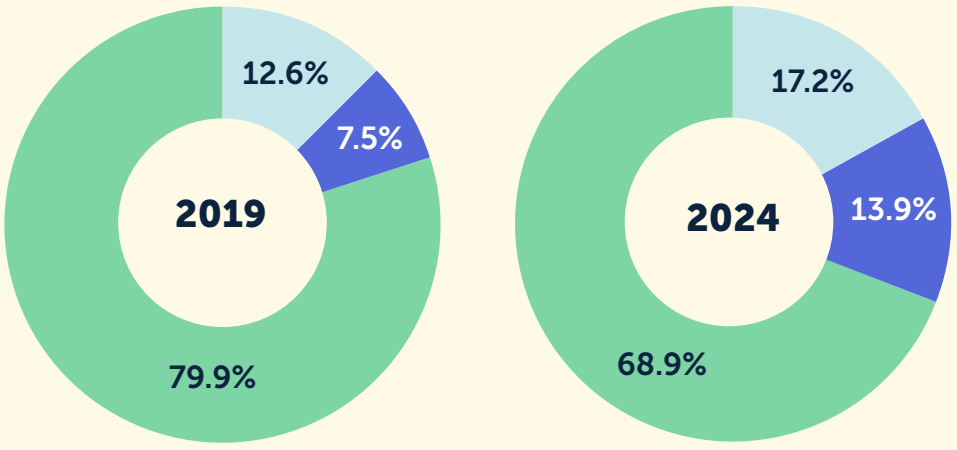
Liver and gastrointestinal complications



Respiratory related complications



Primary airway clearance



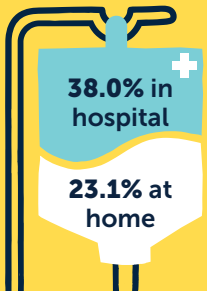
* includes all varieties of ACT inc. breathing ex, manual techniques and devices

Medications and other treatments

Intravenous antibiotics (IV) in 2019 and 2024

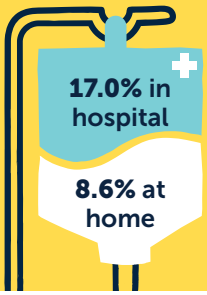
44.5%

of people had at least one course of IV antibiotics (at home or in hospital) in **2019**



20.0%

of people had at least one course of IV antibiotics (at home or in hospital) in **2024**

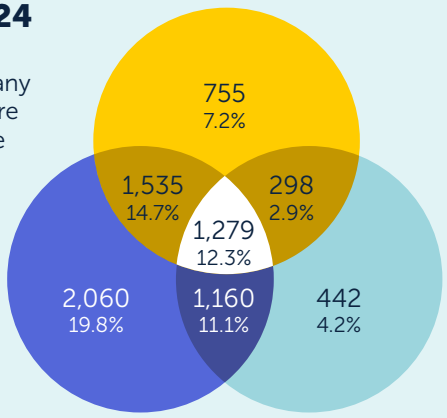


The proportion of people taking all 3 types of inhaled medication has fallen from 22% in 2019 to 12.3% in 2024.

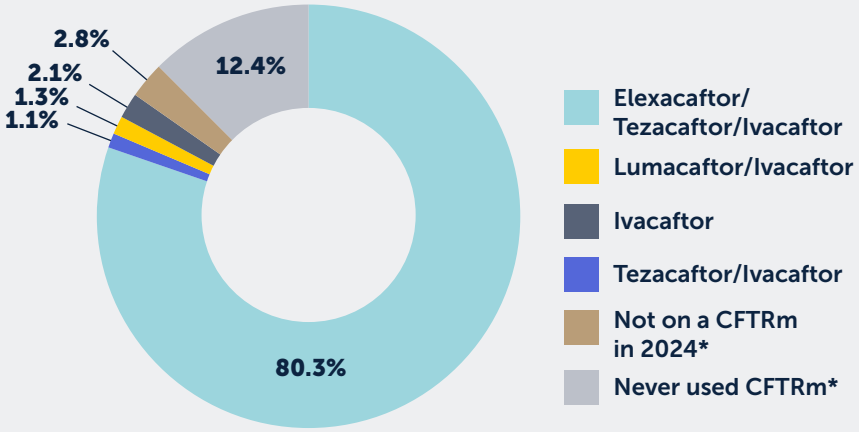
Inhaled therapies in 2024

The Venn diagram shows how many people with CF are on one or more of some inhaled therapies and the combinations they take.

None of these inhaled medications: 2,895 (27.8%)



CFTR modulators (CFTRm) use in 2024



8,830 people had a CFTRm record in 2024

* An individual was categorized as 'Not on a CFTRm in 2024' if they had a previous record of CFTRm use but no record of CFTRm use in 2024. Individuals categorized as 'Never used CFTRm' had no records of CFTRms prior to or in 2024.

For more information about the UK Cystic Fibrosis Registry please visit our website **cysticfibrosis.org.uk/registry**

To read the full Registry Annual report data please scan the QR code.

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