

UK Cystic Fibrosis Registry 2023 Annual Data Report

At a glance

This 'at a glance' version of the UK Cystic Fibrosis Registry Annual Data Report 2023 highlights some of the key information about people with cystic fibrosis (CF) in the UK during 2023. For more detail, see the full report at cysticfibrosis.org.uk/registry

Number of people with CF in 2023

11,318¹
registered* people



¹ different to that reported in the 2023 data highlights report, due to data cleaning

* people who have had at least one annual review recorded in the past three years

Births



116 women
with CF had
babies in 2023



31 men with CF
became fathers
in 2023



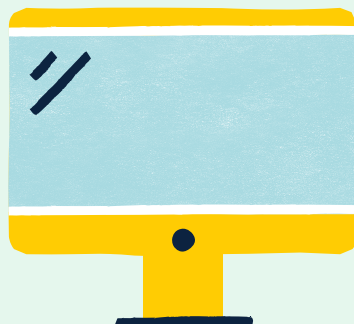
173 new diagnoses
in 2023

124 of these were identified
by new born screening

6,588

people with CF
are 16 years
or older.

Of these, **4,459**
(68%) were in
work or study
in 2023



Ethnicity

White **94.5%**

Asian **3.2%**

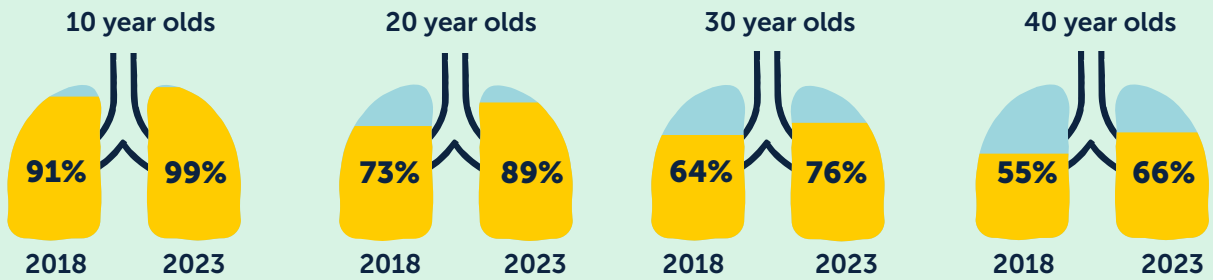
Black **0.3%**

Mixed **1.1%**

Other **0.9%**

* % of those with known ethnic group recorded

Median FEV₁% predicted at annual review*

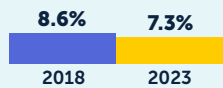


* FEV₁% is reported for people who have not had a lung transplant

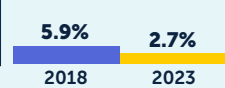
Lung infections and respiratory culture samples 2018 and 2023

Age under 16 years

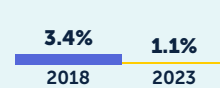
Chronic *Staphylococcus aureus*



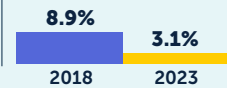
Chronic *Pseudomonas aeruginosa*



Non-tuberculous mycobacteria (NTM)

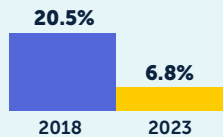


Aspergillus

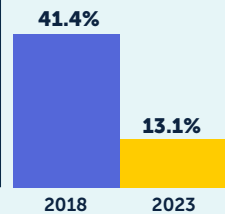


Age 16+ years

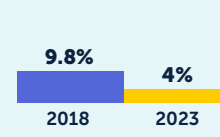
Chronic *Staphylococcus aureus*



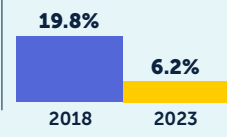
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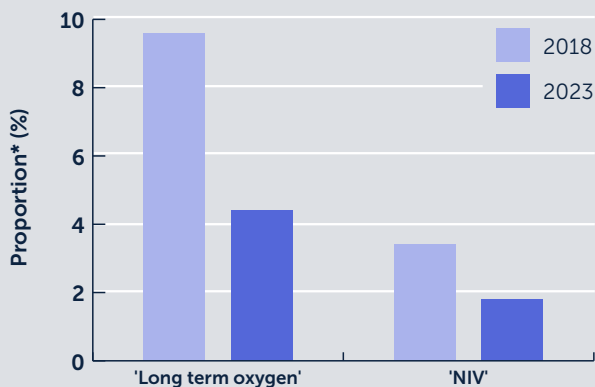
Non-tuberculous mycobacteria (NTM)



Aspergillus

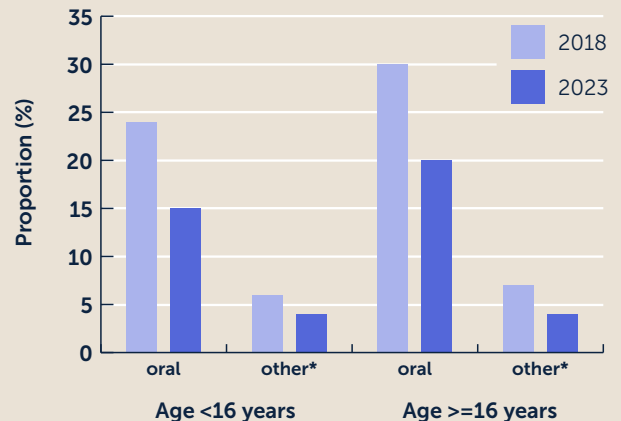


Respiratory support



* age 18+ years

Supplemental feeding



* enteral and parenteral feeding

CF diabetes*

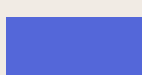
Age 10** to 15 years

11.4%



2018

8.1%



2023

Age 16+ years

33.8%



2018

33.7%

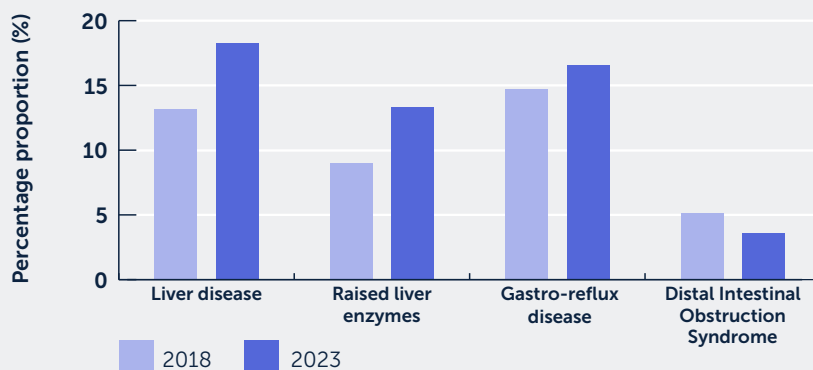


2023

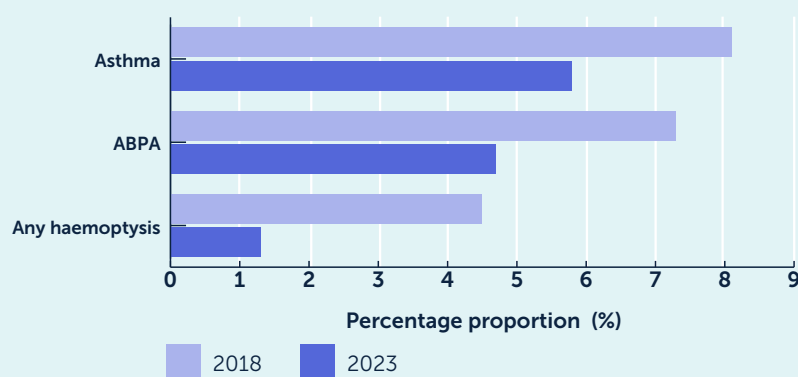
* on treatment for CF diabetes

** in both 2018 and 2023, 1% of people under 10 years had CF diabetes

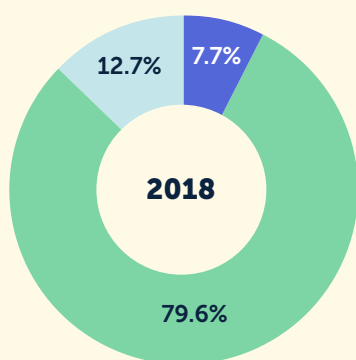
Liver and gastrointestinal complications



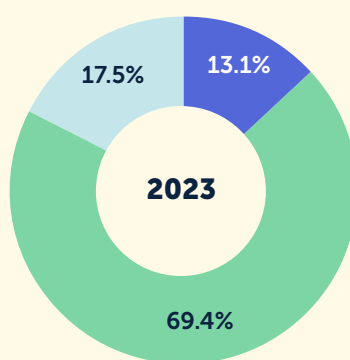
Respiratory related complications



Primary airway clearance



2018



2023

- Exercise
- Any airway clearance*
- None

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

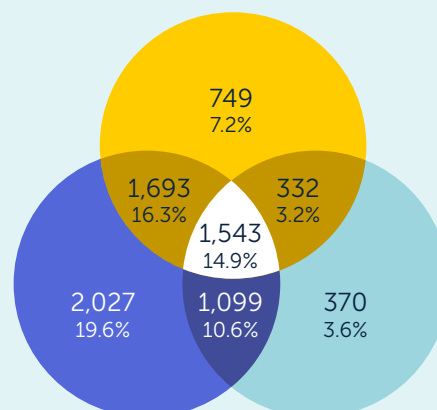
Inhaled medications therapy in 2023

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

The proportion of people taking all 3 types of inhaled medication has fallen from 21.4% in 2018 to 14.9% in 2023.

None of these inhaled medications: 2,541 (24.6%)

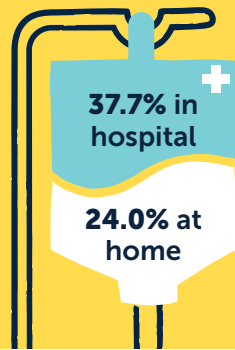
- Inhaled antibiotics
- DNase
- Hypertonic saline or mannitol



Intravenous antibiotics (IV) in 2018 and 2023

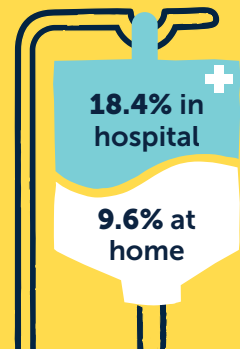
44.7%

of people had at least one course of IV antibiotics (at home or in hospital) in **2018**

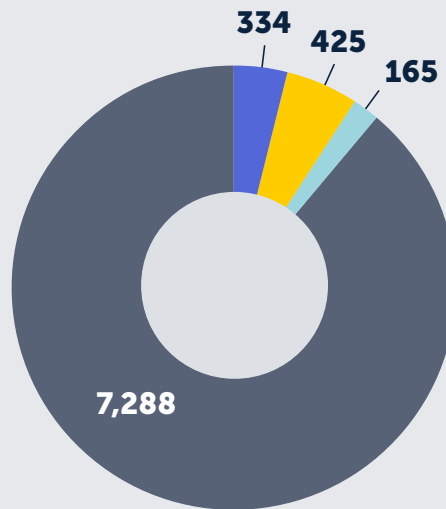


22.0%

of people had at least one course of IV antibiotics (at home or in hospital) in **2023**



In December 2023 a total of 8,212 people with CF were taking a CFTR modulator



- Elexacaftor/Tezacaftor/Ivacaftor
- Ivacaftor
- Lumacaftor/Ivacaftor
- Tezacaftor/Ivacaftor



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

To read the full Registry Annual report using 2023 data please scan the QR code.