

# **UK Cystic Fibrosis Registry**

## **2025 Annual Data Report**

October 2026

**Lifting limits**  
Changing lives



# UK Cystic Fibrosis Registry 2025 Annual Data Report

An at-a-glance version of this report can be found at  
**[cysticfibrosis.org.uk/registry](https://cysticfibrosis.org.uk/registry)**

## Report prepared by

Selin Yildizoglu, Senior Data Analyst, Cystic Fibrosis Trust  
Mary Cerkenik, Medical Statistician, Cystic Fibrosis Trust  
Ailith Ewing, Senior Statistician, Cystic Fibrosis Trust  
Susan Charman, Principal Statistician, Cystic Fibrosis Trust  
Jamie Duckers, Consultant Respiratory Physician, Cardiff and Vale University Health Board  
Gwyneth Davies, Clinical Associate Professor, UCL Great Ormond Street Institute of Child Health  
Sarah Clarke, Associate Director of Data and Quality Improvement, Cystic Fibrosis Trust

## With assistance from

Siâron Hughes, Freelance Graphic Designer, su-ma.com  
Elaine Gunn, Registry Data Manager, Cystic Fibrosis Trust  
The UK CF Registry Steering Committee

## Acknowledgements

First and foremost, the UK Cystic Fibrosis Registry team would like to thank people with cystic fibrosis and their families for their support, as well as anyone who has generously donated to Cystic Fibrosis Trust. We would also like to express our gratitude to the UK cystic fibrosis centres and clinics, for their continued dedication to obtaining consent and submitting data to the Registry.

## Contact information

For more information about this report, or the UK Cystic Fibrosis Registry, please contact us: **[registry@cysticfibrosis.org.uk](mailto:registry@cysticfibrosis.org.uk)** @CFTrust

## Suggested citation

UK Cystic Fibrosis Registry 2025 Annual Data Report (2026), Cystic Fibrosis Trust. London

## Contents

|                                                                                                                   |           |
|-------------------------------------------------------------------------------------------------------------------|-----------|
| Report prepared by                                                                                                | 3         |
| Acknowledgements                                                                                                  | 3         |
| Contact information                                                                                               | 3         |
| <b>Foreword</b>                                                                                                   | <b>8</b>  |
| <b>Executive summary</b>                                                                                          | <b>9</b>  |
| <b>Introduction</b>                                                                                               | <b>10</b> |
| Cystic fibrosis                                                                                                   | 10        |
| UK Cystic Fibrosis Registry                                                                                       | 10        |
| Governance                                                                                                        | 11        |
| Data collection                                                                                                   | 11        |
| Where can I find more information?                                                                                | 11        |
| <b>Guide to the charts</b>                                                                                        | <b>12</b> |
| Box plots                                                                                                         | 12        |
| Funnel plots                                                                                                      | 13        |
| <b>Changes in how we evaluate lung health: switching to the 2022 Global Lung Initiative (GLI) global equation</b> | <b>14</b> |
| <b>Section 1: UK-wide analysis</b>                                                                                | <b>16</b> |
| 1.1 Summary of the UK Cystic Fibrosis Registry                                                                    | 16        |
| <b>Diagnosis of cystic fibrosis</b>                                                                               | <b>17</b> |
| 1.2 Age at diagnosis                                                                                              | 17        |
| 1.3 New diagnoses of cystic fibrosis by year, 2017–2025                                                           | 18        |
| 1.4 Mode of presentation                                                                                          | 19        |
| <b>Demographics</b>                                                                                               | <b>20</b> |
| 1.5 Age distribution by sex                                                                                       | 20        |
| 1.6 Age distribution of the UK CF population in 2015 and 2025                                                     | 21        |
| 1.7 Ethnicity                                                                                                     | 21        |
| 1.8 Height percentiles of children and young people (ages 2–19)                                                   | 22        |
| 1.9 Weight percentiles of children and young people (<20 years)                                                   | 23        |

|                                                                                                                                                     |           |
|-----------------------------------------------------------------------------------------------------------------------------------------------------|-----------|
| 1.10a Body Mass Index (BMI) percentiles in children and young people (<20 years)                                                                    | 24        |
| 1.10b Body Mass Index (BMI) percentiles in children and young people (<20 years) for 2019 and 2025                                                  | 25        |
| 1.11a Body Mass Index (BMI) in adults ages 20 and older                                                                                             | 26        |
| 1.11b Body Mass Index (BMI) in adults for 2019 and 2025                                                                                             | 27        |
| 1.12 Education and employment in adults (16 years and over)                                                                                         | 28        |
| 1.13 Live births                                                                                                                                    | 28        |
| <b>Health related quality of life</b>                                                                                                               | <b>29</b> |
| 1.14 Health related quality of life (6 years and over)                                                                                              | 29        |
| <b>Lung health</b>                                                                                                                                  | <b>30</b> |
| 1.15 Annual review FEV <sub>1</sub> % predicted (GLI Global equation) in people aged 6 years and older who have not had a lung transplant           | 31        |
| 1.16 Best FEV <sub>1</sub> % predicted (GLI Global equation) in people aged 6 years and older who have not had a lung transplant                    | 32        |
| 1.17 Annual review FEV <sub>1</sub> % predicted (GLI Global equation) over time in people aged 6 years and older who have not had a lung transplant | 33        |
| <b>Lung infections</b>                                                                                                                              | <b>34</b> |
| 1.18 Lung infections in 2025                                                                                                                        | 34        |
| 1.19 Lung infections 2019–2025                                                                                                                      | 37        |
| 1.20 Respiratory culture sample type                                                                                                                | 38        |
| 1.21 Non-tuberculous mycobacteria (NTM) or atypical mycobacteria                                                                                    | 38        |
| <b>Complications</b>                                                                                                                                | <b>40</b> |
| 1.22a Complications 2019 and 2025 in young people (<16 years)                                                                                       | 40        |
| 1.23 Incidence of complications                                                                                                                     | 44        |
| 1.24 CF diabetes                                                                                                                                    | 44        |
| <b>Antibiotics</b>                                                                                                                                  | <b>45</b> |
| 1.25 Intravenous (IV) antibiotics                                                                                                                   | 45        |
| 1.26 Inhaled antibiotic use                                                                                                                         | 47        |
| 1.27 Inhaled antibiotic use among people with chronic <i>Pseudomonas aeruginosa</i>                                                                 | 47        |
| 1.28 Long-term azithromycin use                                                                                                                     | 48        |
| 1.29 Prophylactic flucloxacillin use                                                                                                                | 48        |
| <b>Bronchodilators and corticosteroids</b>                                                                                                          | <b>49</b> |
| 1.30 Inhaled bronchodilators and corticosteroids                                                                                                    | 49        |
| <b>Muco-active therapies</b>                                                                                                                        | <b>50</b> |
| 1.31 Mannitol                                                                                                                                       | 50        |
| 1.32 DNase                                                                                                                                          | 50        |
| 1.33 Hypertonic saline                                                                                                                              | 51        |
| 1.34 Inhaled therapies                                                                                                                              | 51        |

|                                                                                                                                |           |
|--------------------------------------------------------------------------------------------------------------------------------|-----------|
| <b>CFTR modulators</b>                                                                                                         | <b>52</b> |
| 1.35 CFTR modulator usage in December of 2023, 2024 and 2025 among people with a 2025 annual review (by age group)             | 53        |
| 1.36 CFTR modulator use in 2025                                                                                                | 53        |
| 1.37 Proportion of people who have never used a CFTR modulator 2021-2025                                                       | 54        |
| 1.38a CFTR modulator use in people aged 6 years and older by genotype group                                                    | 55        |
| 1.38b Demographic characteristics in people aged 6 years and older by genotype group and CFTRm use                             | 56        |
| <b>Physiotherapy</b>                                                                                                           | <b>57</b> |
| 1.39 Primary airway clearance technique                                                                                        | 57        |
| 1.40 Primary or secondary airway clearance technique                                                                           | 58        |
| 1.41 Exercise testing                                                                                                          | 58        |
| <b>Other therapies</b>                                                                                                         | <b>59</b> |
| 1.42 Oxygen and non-invasive ventilation                                                                                       | 59        |
| 1.43 Transplants                                                                                                               | 59        |
| 1.44 Feeding                                                                                                                   | 60        |
| 1.45 Pancreatic enzyme supplementation                                                                                         | 60        |
| <b>Survival</b>                                                                                                                | <b>61</b> |
| 1.46 Median predicted survival age                                                                                             | 61        |
| 1.47 Median predicted survival age based on current age                                                                        | 62        |
| 1.48 Age distribution of deaths in 2023–2025, 2017–2019, and 2013–2015                                                         | 63        |
| 1.49 Causes of death                                                                                                           | 63        |
| <b>Genotypes</b>                                                                                                               | <b>64</b> |
| 1.50 CFTR variant combinations in the UK population                                                                            | 64        |
| 1.51 CFTR variants in the UK population                                                                                        | 65        |
| 1.52 CFTR variant prevalence by devolved nation                                                                                | 65        |
| 1.53 Genotype prevalence by devolved nation                                                                                    | 66        |
| <b>Sections 2 and 3: Centre-level analysis</b>                                                                                 | <b>67</b> |
| <b>Section 2: Paediatric centre analysis</b>                                                                                   | <b>68</b> |
| 2.1 Age-adjusted FEV <sub>1</sub> % predicted at annual review, in people aged 6 and over without a history of lung transplant | 68        |
| 2.2 Age-adjusted Best FEV <sub>1</sub> % predicted, in people aged 6 and over without a history of lung transplant             | 68        |
| 2.3 Age-adjusted Body Mass Index (BMI) percentile in people aged 1–15 years                                                    | 69        |
| 2.4 Age-adjusted proportion of people with BMI < 5th percentile                                                                | 69        |
| 2.5 Age-adjusted proportion of people with BMI ≥ 95th percentile                                                               | 70        |
| 2.6 Proportion of people with chronic <i>Pseudomonas aeruginosa</i>                                                            | 70        |
| 2.7 Proportion of people receiving DNase treatment                                                                             | 71        |
| 2.8 Proportion of people on hypertonic saline or mannitol treatment                                                            | 71        |

|                                                                                                               |            |
|---------------------------------------------------------------------------------------------------------------|------------|
| 2.9 Proportion of people receiving DNase/hypertonic saline/ mannitol treatment                                | 72         |
| 2.10 Intravenous (IV) antibiotic use                                                                          | 72         |
| 2.11 Inhaled antibiotic use for people with chronic <i>Pseudomonas aeruginosa</i>                             | 73         |
| 2.12 Data completeness                                                                                        | 73         |
| <b>Section 3: Adult centre analysis</b>                                                                       | <b>74</b>  |
| 3.1 Age distribution                                                                                          | 74         |
| 3.2 Age adjusted FEV <sub>1</sub> % predicted at annual review in people without a history of lung transplant | 75         |
| 3.3 Age adjusted Best FEV <sub>1</sub> % predicted in people without a history of lung transplant             | 75         |
| 3.4 Age-adjusted Body Mass Index (BMI) among people aged 16 years and older                                   | 76         |
| 3.5 Age-adjusted proportion of people aged 16 years and older with BMI < 18.5                                 | 76         |
| 3.6 Age-adjusted proportion of people aged 16 years and older with BMI ≥ 30                                   | 77         |
| 3.7 Proportion of people with chronic <i>Pseudomonas aeruginosa</i>                                           | 77         |
| 3.8 Proportion of people receiving DNase treatment                                                            | 78         |
| 3.9 Proportion of people receiving hypertonic saline or mannitol                                              | 78         |
| 3.10 Proportion of people receiving DNase/hypertonic saline/mannitol treatment                                | 79         |
| 3.11 Intravenous (IV) antibiotic use                                                                          | 79         |
| 3.12 Inhaled antibiotic use for people with chronic <i>Pseudomonas aeruginosa</i>                             | 80         |
| 3.13 Data completeness                                                                                        | 80         |
| <b>Appendix 1: UK CF Registry Committee structure</b>                                                         | <b>81</b>  |
| UK CF Registry Steering Committee                                                                             | 81         |
| <b>Appendix 2: Centre-level data tables</b>                                                                   | <b>82</b>  |
| Paediatric centres/clinics providing data in 2025 – ordered alphabetically by country/city                    | 82         |
| Adult centres/clinics providing data in 2025 – ordered alphabetically by country/city                         | 88         |
| <b>Appendix 3: Full list of CFTR variants in the UK CF population</b>                                         | <b>94</b>  |
| <b>Appendix 4: Additional tables</b>                                                                          | <b>105</b> |
| CF population by devolved nation                                                                              | 105        |
| <b>Glossary</b>                                                                                               | <b>106</b> |

# Foreword



Welcome to the UK Cystic Fibrosis Registry 2025 Annual Data Report. As Cystic Fibrosis Trust approaches its 20th year of hosting the UK CF Registry, I would like to begin by thanking the individuals and families who generously consent to sharing their data. Around 98% of people with CF and their families continue to entrust us with their health information, enabling the Registry to generate real-world insights into changing health needs and outcomes. These insights help inform and shape our goals and mission: that all people with cystic fibrosis can live a full life, without limits.

In an era of profound transformation, the UK CF Registry Annual Data Report shows that living with CF remains hard. More than 27% of our community manage CF diabetes, and nearly a quarter of adults (23%) live with liver disease. Nutritional profiles are also changing, with rising rates of adults overweight and obese ( $\text{BMI} \geq 25$ ).

Together, these patterns underline the need for health systems to anticipate and respond to the complex complications of an ageing CF population. The Registry provides Cystic Fibrosis Trust with the evidence needed to advocate for tailored, high-quality care for everyone living with cystic fibrosis.

Our new 2025 data report shows us an increasing proportion of people living with CF are adults. Two-thirds of people on the Registry (66.5%) are now aged 16 or older, and the median age is 23 years. For the first time, we report that the median predicted survival for babies born today is over 70 years. Importantly, this report also presents median predicted survival by current age, showing that people who have already reached a given age are also predicted to live into their 70s and beyond. While this is an extraordinary marker of progress, it also carries an urgent reminder: half of people are not predicted to reach this age, and many continue to lose their lives decades too early.

These survival predictions should also be understood with care. They describe population-level trends and do not account for every individual circumstance, including the care a person receives or whether they have used CFTR modulator therapies. Following the approval of a new triple modulator therapy in late 2025 and the expansion of eligibility criteria, only 2.3% of people living with CF in 2025 are recorded as ineligible for CFTR modulator therapies. However, more than 11% of people with CF had never used a CFTR modulator. The reasons for this are likely to be varied, including genotype or age ineligibility, living with a transplant, or a decision made between an individual and their care team, and we can't always determine this from the Registry data. What we do know is that modulators do not work for everyone. We remain focused on ensuring that no one is left behind: those who cannot benefit from CFTR modulators, those living with a transplant, and everyone living with CF, whatever their personal or health challenges may be.

Finally, I want to thank the NHS clinical teams and administrators across the UK who collect and enter this vital information. Their dedication to the Registry makes both this report and the Registry's wider work possible.

A handwritten signature in dark ink, appearing to read 'David Ramsden', written in a cursive style.

**David Ramsden**  
Chief Executive of Cystic Fibrosis Trust

# Executive summary



The landscape of cystic fibrosis (CF) care continues to advance at pace. With this, the age distribution of people living with CF in the UK has changed over the past 10 years (section 1.6). In this report we show that half of people born today with CF in the UK are now predicted to live for at least 70 years (section 1.46). For the first time we now additionally report a different way of looking at predicted survival, called median conditional survival (section 1.47). This is a way to predict survival for people that have already reached a certain age. We show the average number of additional years people with CF may be expected to live for once they've reached a given age, such as 30 or 40 years old. We will continue to update these estimates over the coming years. It's also important to realise that these numbers do not tell individual stories, and that for some people and families the reality will be very different.

We know that the CF community want better quality as well as quantity of life. For the first time, the Registry presents health related quality of life (section 1.14). The UK CF Registry is one of only a few registries globally that collect these data.

As per previous annual reports, we show lung function outcomes, but this year now use an updated way of converting lung function to calculate percent predicted values for the commonly used measurement called FEV1. This uses equations developed by the Global Lung Initiative ("GLI Global"), which take a person's sex, age and height into account to calculate the percent predicted FEV1 value. We have applied the GLI Global equations in the 2025 Registry Annual Data Report (see section on 'Changes in how we evaluate lung health'), replacing the GLI 2012 equations that we've used in reports over recent years which additionally took ethnicity into account. The median best FEV1% predicted continues to rise (section 1.15), while oxygen and non-invasive ventilation use continue to fall (section 1.42), and there were six lung transplants performed for people with CF in the UK last year (section 1.43). The percentage of people receiving at least one course of IV antibiotics has dropped again this year (section 1.25) and the proportion of people with CF that remain on the combination of inhaled antibiotics, DNase and hypertonic saline or mannitol has also dropped (section 1.34).

It is not just lung health which is changing.

Beyond the lungs we see shifts in the nutritional status of the CF population (sections 1.9–1.11), with a smaller proportion of people now underweight. However, new challenges are also emerging as can be seen in the data, with an increasing proportion of adults being overweight or obese (section 1.11). For the first time, we have also included the proportion of people in the highest and lowest Body Mass Index (BMI) groups, in the centre level reports in sections 2 and 3, as well as continuing to report mean BMI. Other challenges include an increase in reports of liver disease, cancer, osteopenia and osteoporosis (section 1.22b) and CF diabetes continues to affect over a third of the UK CF population aged >10 years (section 1.24).

The UK CF Registry remains a hugely valuable asset. It helps to capture improvements in outcomes; identifying emerging challenges and driving forward improvements in CF care. We would like to thank those people living with CF, their families and their clinical teams for their continued involvement in the collaborative effort that is the UK CF Registry.

A handwritten signature in black ink, appearing to read 'Jamie'.

**Jamie Duckers**

Chair of the UK CF Registry Steering Committee

# Introduction

This report is aimed at anyone who is interested in the health, care, and outcomes of people with cystic fibrosis (CF) in the UK. This includes people with CF, their families and clinical teams, healthcare managers, commissioners, and policy makers.

You can find a Glossary of scientific and clinical terms on pages 110–111.

Throughout this report, we have compared data from 2025 to data from 2019 in place of the usual five-year comparisons. This is to avoid comparing to data from 2020 during the COVID-19 pandemic.

An at-a-glance version of this report can be found at [cysticfibrosis.org.uk/registry](https://cysticfibrosis.org.uk/registry).

## Cystic fibrosis

Cystic fibrosis is an inherited disease caused by a faulty version of a gene known as **CFTR**. The gene and the protein it makes help control the movement of salt and water in and out of cells. When the gene is faulty, and the protein it makes is affected, it can cause thicker mucus. People with CF experience a build-up of thick sticky mucus in the lungs, digestive system and other organs, causing a wide range of challenging symptoms affecting the entire body.

## UK Cystic Fibrosis Registry

The UK CF Registry has been sponsored and hosted by Cystic Fibrosis Trust since 2007. It is a database of consenting people with CF in the UK. The Registry collects demographic, treatment and health outcomes data. You can find a full list of the data items we collect at [cysticfibrosis.org.uk/registry](https://cysticfibrosis.org.uk/registry).

The purpose of the UK CF Registry is to improve the health of people with cystic fibrosis. This is done in a number of ways:



helping people with CF and their families understand CF, and make informed decisions



giving clinical teams the evidence they need to improve the quality of care



monitoring the safety and effectiveness of new treatments for cystic fibrosis



providing data for research to find out the best ways to treat cystic fibrosis



helping commissioners provide funding to NHS CF centres that is proportionate to the severity of their patients' condition



supporting clinical trials through feasibility studies and pragmatic data collection

## **Governance**

The Registry Steering Committee (RSC) is responsible for making sure that the UK CF Registry is compliant with data protection legislation, and its Research Ethics Committee-approved Study Protocol. It also makes recommendations about the future development of the Registry. A sub-group of the RSC, the Data Request Review Group, assesses applications for data and guides the Registry research strategy.

**Please see Appendix 2: UK CF Registry Committee Structure.**

Data are only recorded on the UK CF Registry if explicit consent is given by the person with CF, or, if they're a child, their parent or guardian.

When data are provided to third parties, such as the NHS or university researchers, they are either anonymised (all identifiable data removed completely) or pseudonymised (all identifiable data replaced with a unique identification number). Pseudonymisation is used so that data can be traced back to what is in the 'live' database by the Registry team for the purposes of updating the data or answering queries. This means that the Registry data used for research, and the results that come from it, cannot identify the people whose data are stored on the UK CF Registry.

If requests from pharmaceutical companies are granted, for research, or submissions to regulators or the NHS, the data are analysed and aggregated by Registry statisticians and only summary data are provided.

## **Data collection**

Data are entered onto the UK CF Registry by NHS employees at CF centres in the UK using a secure web portal.

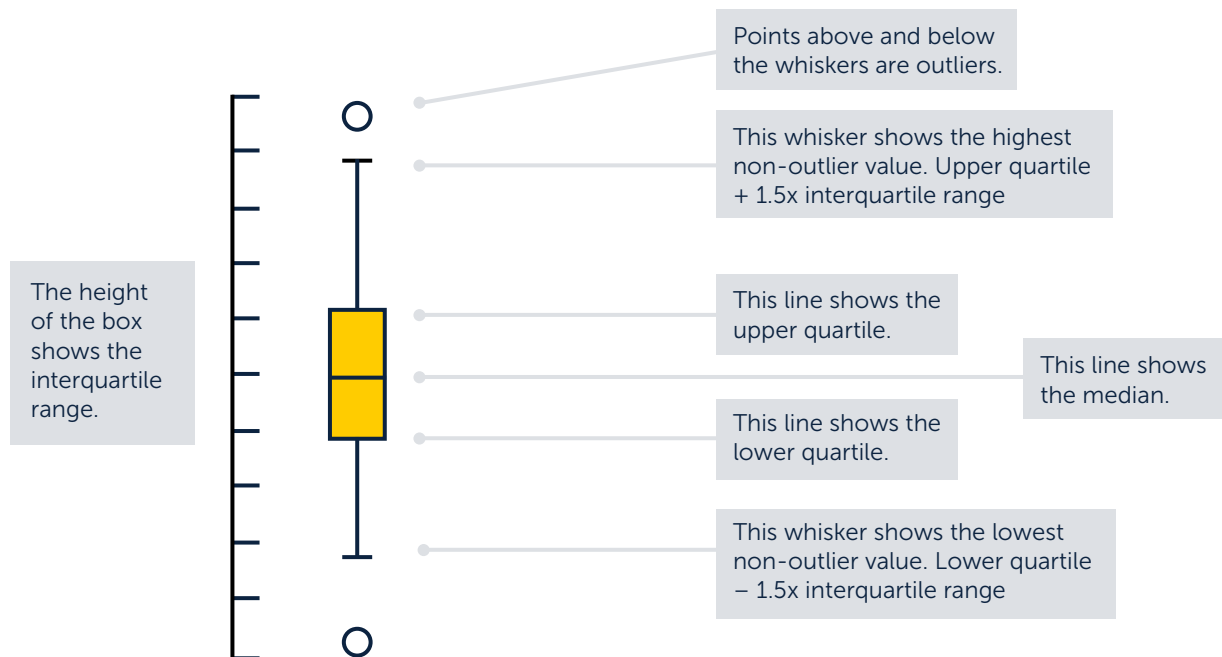
## **Where can I find more information?**

You can find out more about CF, and the UK CF Registry, at **[cysticfibrosis.org.uk/registry](https://cysticfibrosis.org.uk/registry)**.

# Guide to the charts

Some of the data in this report are shown as 'box plots'. We also show data in the centre-level appendices (Sections 2 and 3) as 'funnel plots'.

## Box plots



- The 'box' shows the middle half of the data for that centre, going from the first quartile to the third quartile. The longer the box, the more varied the data for that centre.
- The horizontal line within the box shows the median result for that centre.
- The 'whiskers' above and below the box show the range of non-outlier values, with the limits representing the highest and lowest non-outlier values for that centre. The outlier points are shown above and below the whiskers. Points are considered outliers if they are more than 1.5 times the interquartile range (IQR) away from the upper or lower quartiles.
- The position of the box between the whiskers shows any skew in the data. If a box is towards the top of the whisker, more of the people for this centre were recorded at the high end of the scale.

## Funnel plots

The more people with CF at a care site, the closer to the national average you would expect the results to be. This is because high numbers in one centre affect the overall average across the country, 'pulling' the average towards them. When a small number of people with CF are treated at a site, even a single outcome that is unusual affects the overall result for that site much more.

There will always be some natural variation between centres because of differences between the populations receiving care. Using only the national average as a standard can make it difficult to tell whether a survival rate that sits above the national average is higher than we would expect it to be, or not.

For this reason, the funnel plots also show 'control limits'; the curved lines on the charts that give them the 'funnel' shape. The horizontal line in the middle of the funnel shows the national average. Control limits show the rate we would expect based on the number of people with CF at that site.

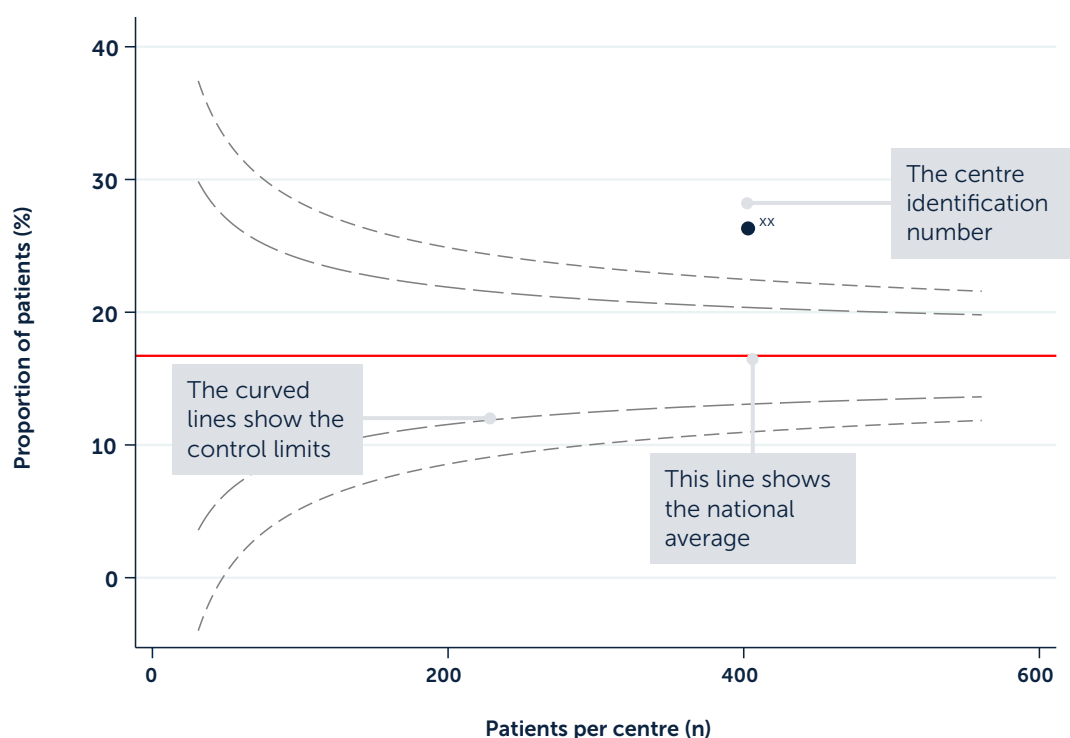
If the result for a CF centre is between the two 'control limits', it is 'as expected' and any variation above or below the national average may be due to chance alone. If a result is below the bottom control it is lower than expected, if it is above the upper control, it is higher than expected. Being outside the control limits can be a good thing, for example if a site's lung function results are exceptionally high.

A centre's data can sit outside of the control limits for a number of reasons, including the characteristics of the people cared for (for example, an adult centre caring for younger people might have a higher average lung function than one caring for older people), problems with data submitted to the Registry, specialist practice, chance, or the care being delivered.

Where charts have been adjusted for age, this means that the data have been fine-tuned to take account of the different spread of ages across centres and clinics. The adjusted values are intended to show what the average lung function or BMI percentile would be for that centre/clinic if the age spread is the same as the spread of age in the whole population. Because it is difficult for adjustment to fully account for all factors that might affect clinical outcomes, we should be very careful about drawing conclusions based on adjusted outcomes alone.

### Key

● Centres with their network clinics    — — — 2 standard deviations    - - - 3 standard deviations



# Changes in how we evaluate lung health: switching to the 2022 Global Lung Initiative (GLI) global equation

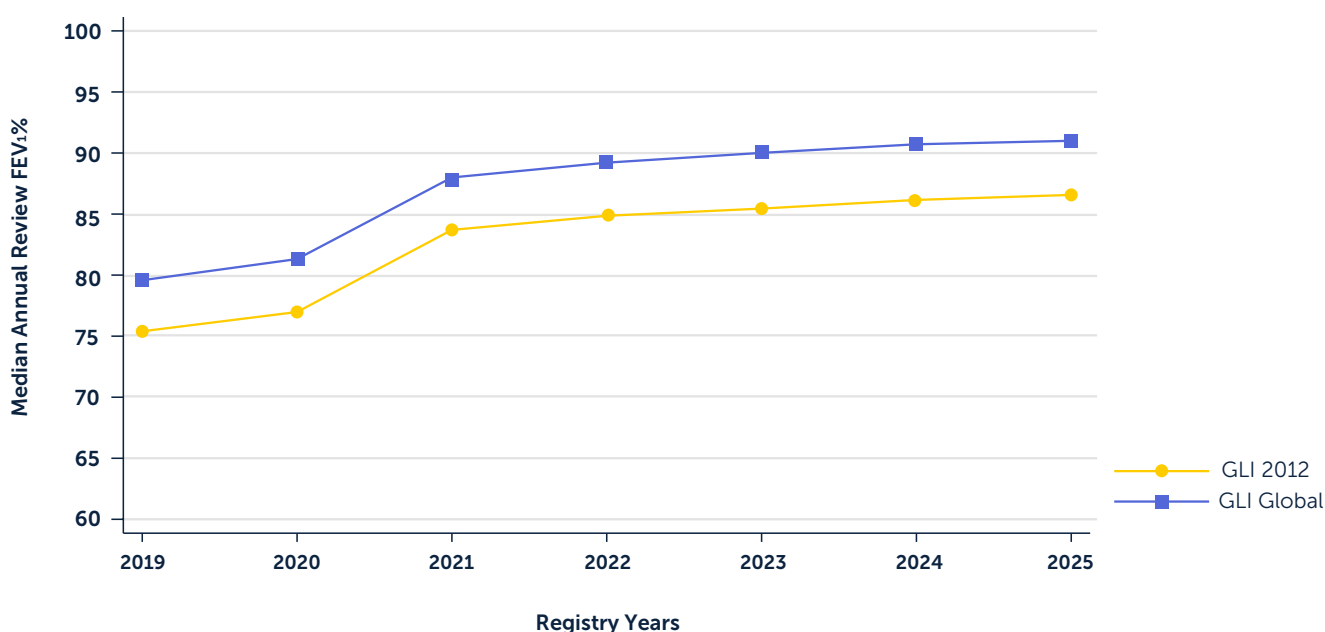
In people with cystic fibrosis (CF) the condition of the lungs is often measured using FEV<sub>1</sub>; the forced expiratory volume of air in the first second of a forced exhaled breath. FEV<sub>1</sub> is compared to the FEV<sub>1</sub> we would expect for a similar person without CF and described as the FEV<sub>1</sub>% predicted. A person with CF who has an FEV<sub>1</sub>% predicted of 50% breathes out half the volume of air that a comparable person without CF would.

In previous UK CF Registry reports, FEV<sub>1</sub>% predicted was based on the FEV<sub>1</sub> we would expect for a person without CF of the same age, sex at birth, height, and ethnicity (GLI 2012 equations<sup>1</sup>). However, ethnicity specific measures assume that FEV<sub>1</sub> differs between people of different ethnicities. For example, FEV<sub>1</sub> of a Black person without CF was estimated to be lower than the FEV<sub>1</sub> for a White person without CF of the same age, sex and height. In using these equations, we may underestimate lung disease severity in Black people with CF. This may increase health inequalities as it may affect the timing of interventions such as lung transplant referral.

In 2022, the Global Lung Initiative developed a single global reference equation (GLI Global) where people are compared based on similar age, sex and height only. The new equation does not assume any differences in lung function between ethnicities. We apply this equation in the UK CF Registry 2025 Annual Data Report. Consequently, FEV<sub>1</sub>% predicted values reported this year will on average be higher than in previous reports (below). This is because median FEV<sub>1</sub>% predicted using the new equation is slightly higher for White populations, lower for Black populations and similar for other ethnicity groups (right).

Importantly for people with CF, their lung function has not changed. The change in equations changes the population of people without CF that we use for comparison.

**Figure 1: Median FEV<sub>1</sub>% predicted at annual review in the UK CF Registry from 2019 to 2025 using the GLI 2012 equations (yellow) and GLI Global 2022 race-neutral equation (blue)**



1 Quanjer et al. Eur respir J. 2012 40(6):1324-1343

**Figure 2: Median FEV<sub>1</sub>% predicted at annual review in the UK CF Registry in 2025 by ethnicity using the GLI 2012 equations (yellow) and GLI Global 2022 race-neutral equation (blue).**

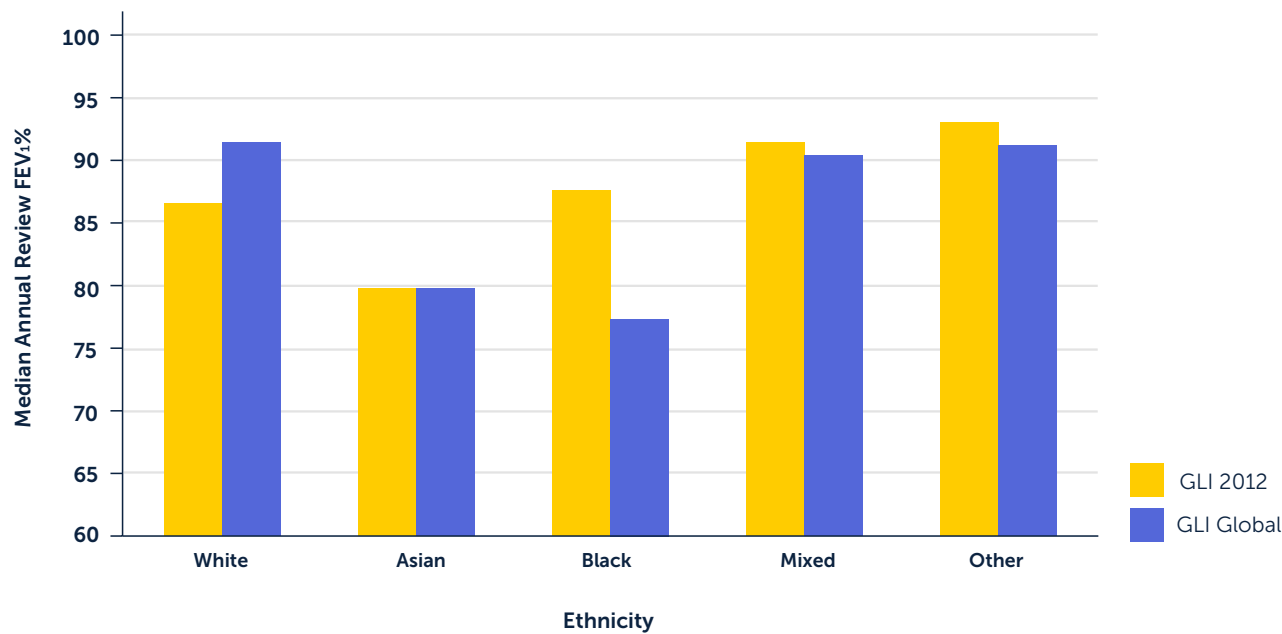
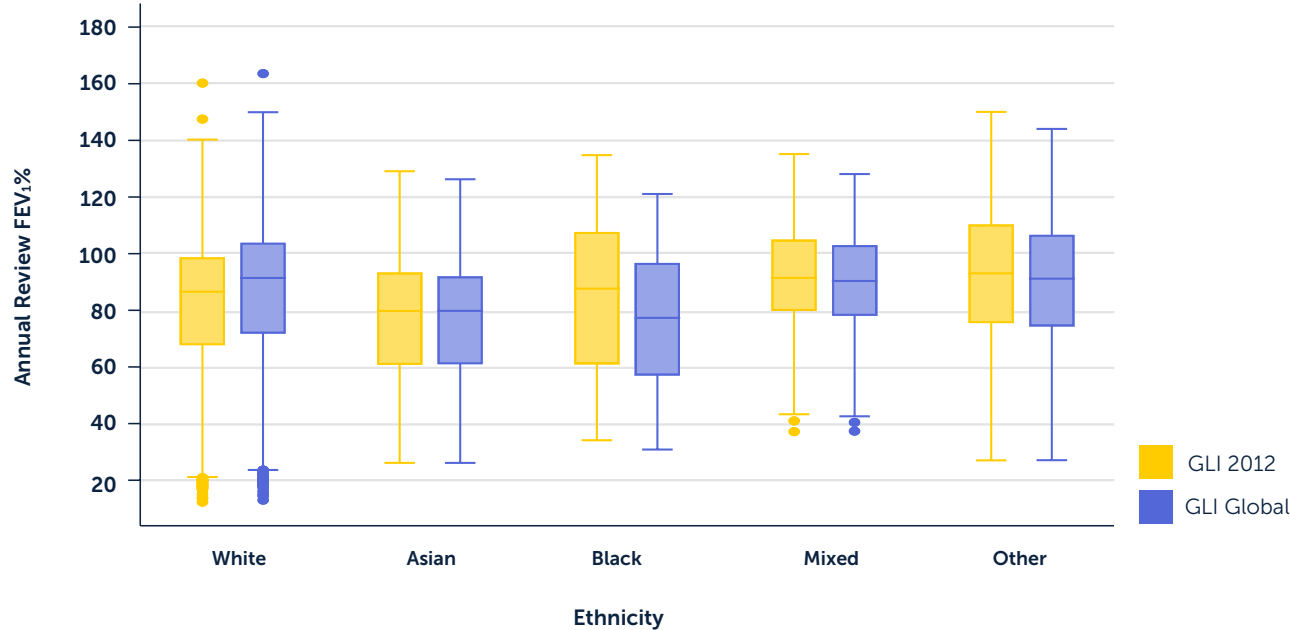


**Figure 3: Boxplots of FEV<sub>1</sub>% predicted at annual review in the UK CF Registry in 2025 by ethnicity using the GLI 2012 equations (yellow) and GLI Global 2022 race-neutral equation (blue).**



# Section 1: UK-wide analysis

This section provides an overview of the cystic fibrosis (CF) population, health outcomes, and care in the United Kingdom, including CF centres in England, Northern Ireland, Scotland, and Wales.

## 1.1 Summary of the UK Cystic Fibrosis Registry

| *                                                              | 2020        | 2021        | 2022        | 2023        | 2024        | 2025        |
|----------------------------------------------------------------|-------------|-------------|-------------|-------------|-------------|-------------|
| People with CF registered; n <sup>1</sup>                      | 10837       | 10908       | 11148       | 11318       | 11381       | 11610       |
| Excluding diagnoses that year; n <sup>2</sup>                  | 10632       | 10716       | 10928       | 11144       | 11216       | 11458       |
| People with CF with an annual review; n(%) <sup>3</sup>        | 9922 (93)** | 10175 (95)  | 10251 (94)  | 10344 (93)  | 10423 (93)  | 10624 (93)  |
| <b>New diagnoses</b>                                           |             |             |             |             |             |             |
| All newly diagnosed people with CF; n <sup>2</sup>             | 205         | 192         | 220***      | 174         | 165         | 152         |
| People with CF identified by NBS; n <sup>2</sup>               | 155         | 135         | 159         | 125         | 124         | 107         |
| People with CF diagnosed age 16 years or older; n <sup>4</sup> | 14          | 21          | 33          | 25          | 17          | 18          |
| <b>Demographics</b>                                            |             |             |             |             |             |             |
| Age in years; median (IQR) <sup>5</sup>                        | 21 (10, 32) | 21 (10, 33) | 22 (11, 33) | 22 (11, 34) | 23 (12, 35) | 23 (12, 36) |
| Adults aged 16 years and over; % <sup>6</sup>                  | 61.0        | 62.0        | 62.9        | 64.0        | 65.2        | 66.5        |
| Males; % <sup>6</sup>                                          | 53.1        | 53.2        | 53.4        | 53.2        | 53.1        | 53.3        |
| Genotyped; % <sup>6</sup>                                      | 99.4        | 99.4        | 99.4        | 99.3        | 99.4        | 99.3        |
| Total deaths during annual review year; n(%) <sup>7</sup>      | 100 (0.9)   | 67 (0.6)    | 68 (0.6)    | 51 (0.5)    | 56 (0.5)    | 40 (0.3)    |
| Age at death in years; median (IQR) <sup>7</sup>               | 36 (28, 47) | 38 (32, 46) | 33 (27, 45) | 42 (35, 63) | 42 (31, 51) | 36 (27, 48) |



**Annual review:** A Registry annual review form records a combination of data relating to a person with CF's once-yearly annual review appointment at their CF centre and their clinical care and health over the past 12 months.

### Notes:

\* Unless otherwise stated in a footnote, all proportions are calculated from all CF patients registered (row 1).

\*\* Corrected from 2020 report.

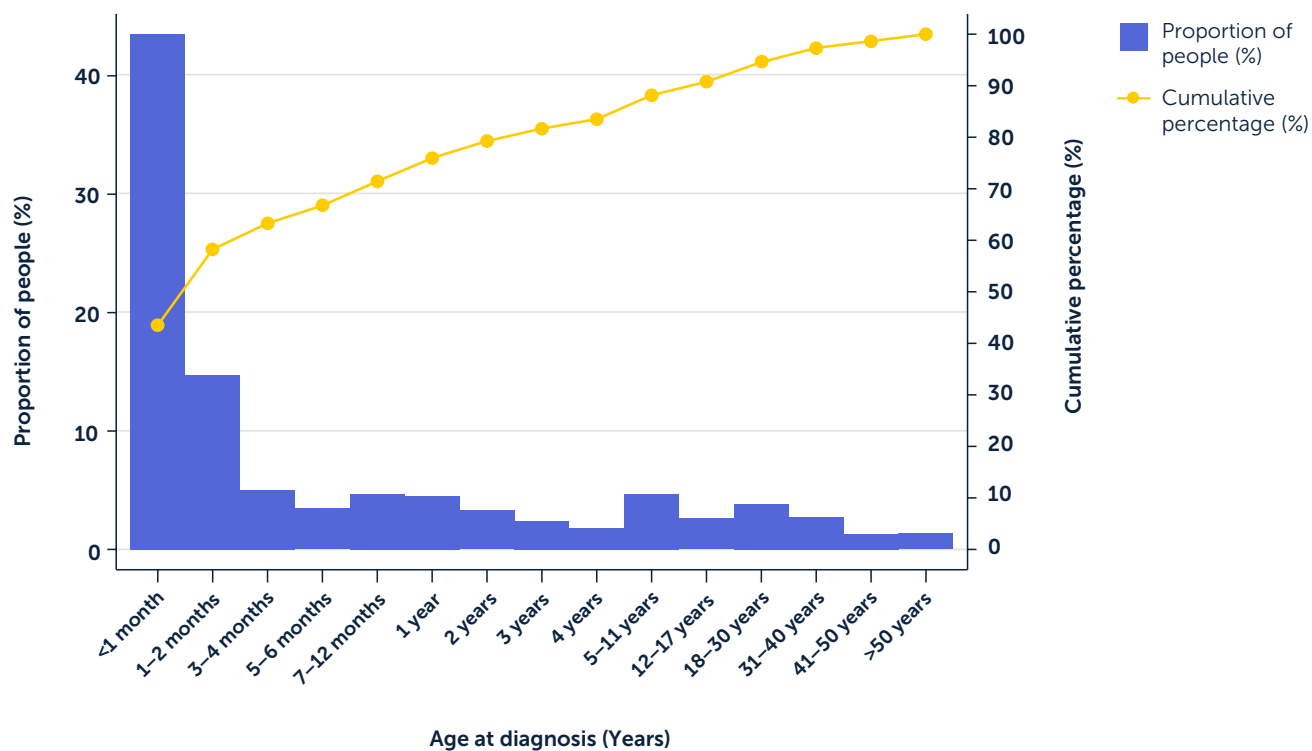
\*\*\* Amended from previously published reports and is a lower figure because individual demographic records were updated and the date of diagnosis was amended to an earlier year.

- 1 Number of patients alive on 1 January in the given year diagnosed with CF, with at least 1 annual review in either the given year or the previous 2 annual review years or at least 1 recorded encounter in the given year, plus any newly diagnosed and/or newly consented individuals. We use this definition as a proxy for the sub-population of people with CF who are actively engaged with NHS services.
- 2 This figure may be amended from previous publications if the diagnosis date of an individual registered in the given year has since been updated. This happens in cases where it was not recorded at the time of publishing or was since corrected. These figures only include new diagnoses among registered patients in the given year. The subsequent diagnosis section details all new diagnoses by calendar year, irrespective of when the individual was registered on the UK CF registry.
- 3 Newly diagnosed patients in the given year may not have their first annual review in the same year, so the proportion with an annual review is calculated from the total registered excluding those diagnosed in the given year.
- 4 This figure is the total number of individuals newly diagnosed in the given year who were 16 years or older at the time of diagnosis.
- 5 Age is taken at the given year's annual review; if the individual did not have an annual review during the year in question, their age was taken on 1 January of the given year.
- 6 Calculated from all registered patients in the given year. Figures may be different from previous reports as they were previously calculated from patients with an annual review in the given year.
- 7 This figure may be amended from previous publications if the date of death for an individual in the given year was unknown at the time of analysis and subsequently entered on to the Registry following the given years annual report publication.

# Diagnosis of cystic fibrosis

## 1.2 Age at diagnosis

N=11610\*

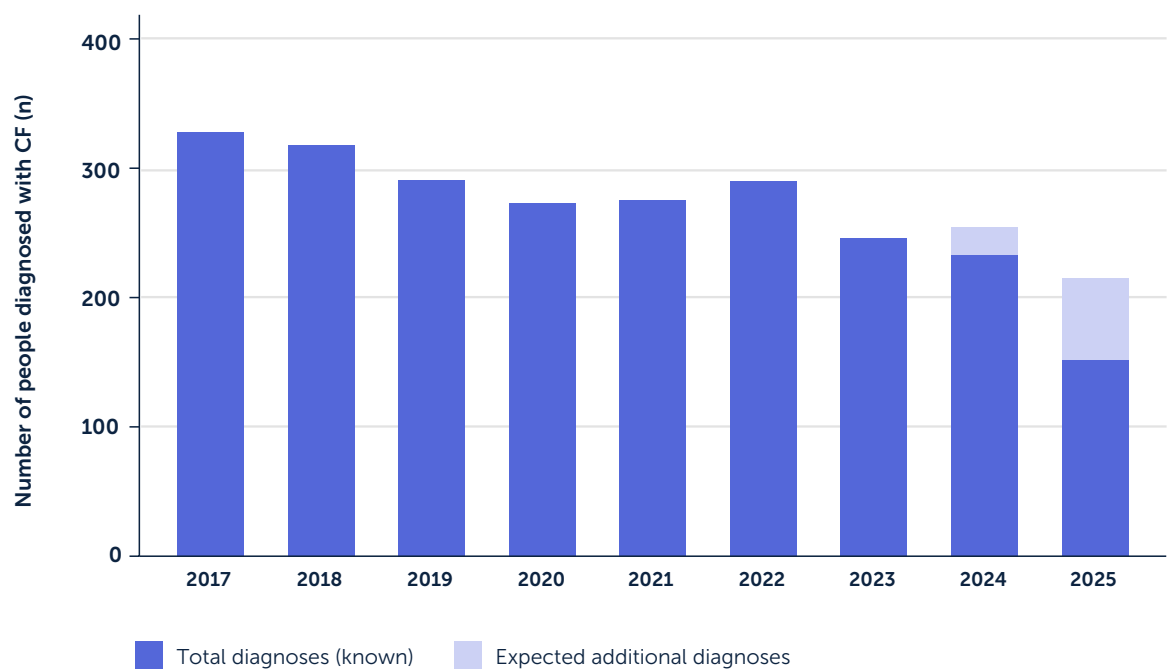


\* There were N=7 people of 11,610 with missing age at diagnosis.

### 1.3 New diagnoses of cystic fibrosis by year, 2017–2025

N=2406

This chart shows all new diagnoses of cystic fibrosis by year in the UK for all people registered between 2017–2025 (see table 1.1 for definition of people registered). Due to timelines in diagnosing CF, obtaining consent to join the Registry, and other factors, individuals are not always registered in the same year in which they were diagnosed; there is typically up to a 2-year lag in registering people with a new diagnosis. For 2024 and 2025 we have also included an estimate<sup>1</sup> of the number of additional diagnoses we expect to see once we have collected and analysed Registry data in future years.



<sup>1</sup> Expected additional diagnoses were estimated by averaging the ratio of “lagged” registrations (people added to the UK CF Registry 1 year after diagnosis and 2+ years after diagnosis) to people registered in the same year they were diagnosed. We used this ratio to estimate the expected additional diagnoses for 2024 and 2025 based on the number of new diagnoses added to the Registry in the year they were diagnosed.

## 1.4 Mode of presentation

### N=1196

The following table shows the most frequent modes of presentation for people diagnosed between 2021–2025. Individuals included in this table were registered and diagnosed between 2021–2025. People not diagnosed through newborn screening (NBS) may present with multiple symptoms so the categories are not mutually exclusive, and percentages may not add up to 100.

|                                                          | All people diagnosed 2021–2025 | Age <1 year at diagnosis | Age ≥1 year & < 16 years at diagnosis | Age ≥16 years at diagnosis |
|----------------------------------------------------------|--------------------------------|--------------------------|---------------------------------------|----------------------------|
| <b>Total number of people with CF</b>                    | <b>1196</b>                    | <b>902</b>               | <b>88</b>                             | <b>206</b>                 |
| Number diagnosed by newborn screening (NBS) <sup>1</sup> | 822                            | 810                      | 12                                    | 0                          |
| Total non-NBS                                            | 374                            | 92                       | 76                                    | 206                        |
| <b>Individuals not diagnosed by NBS</b>                  | <b>374</b>                     | <b>92</b>                | <b>76</b>                             | <b>206</b>                 |
| Genotype                                                 | 102 (27.3)                     | 0 (0.0)                  | 22 (28.9)                             | 80 (38.8)                  |
| Persistent or acute respiratory infection                | 84 (22.5)                      | 10 (10.9)                | 33 (43.4)                             | 41 (19.9)                  |
| Bronchiectasis                                           | 72 (19.3)                      | 0 (0.0)                  | 9 (11.8)                              | 63 (30.6)                  |
| Family history                                           | 54 (14.4)                      | 17 (18.5)                | 13 (17.1)                             | 24 (11.7)                  |
| Meconium ileus                                           | 44 (11.8)                      | 42 (45.7)                | <5                                    | <5                         |
| Fertility                                                | 34 (9.1)                       | 0 (0.0)                  | 0 (0.0)                               | 34 (16.5)                  |
| Unknown                                                  | 28 (7.5)                       | 7 (7.6)                  | 0 (0.0)                               | 21 (10.2)                  |
| Failure to thrive/malnutrition                           | 22 (5.9)                       | 12 (13.0)                | -*                                    | <5                         |
| Prenatal                                                 | 18 (4.8)                       | 16 (17.4)                | -*                                    | <5                         |
| Pancreatitis                                             | 17 (4.5)                       | 0 (0.0)                  | <5                                    | -*                         |

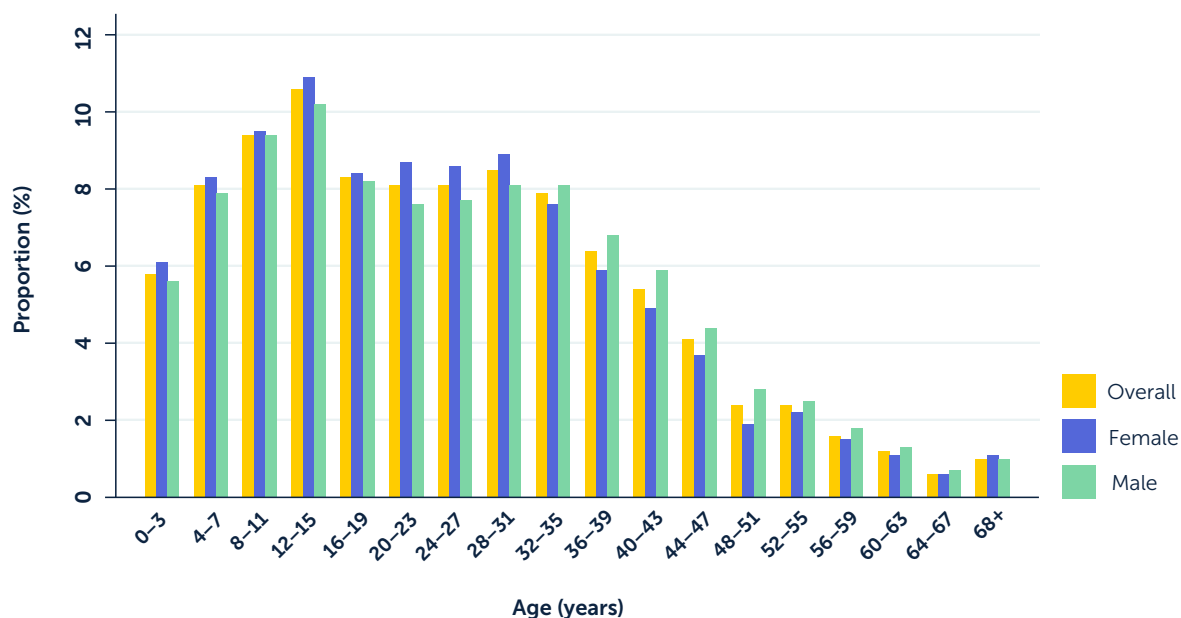
\* Redacted to adhere to statistical disclosure guidelines

1 If the method of diagnosis was genotyping and the age of diagnosis was <1 year, this was counted as a diagnosis by newborn screening (n=44).

# Demographics

## 1.5 Age distribution by sex N=10624

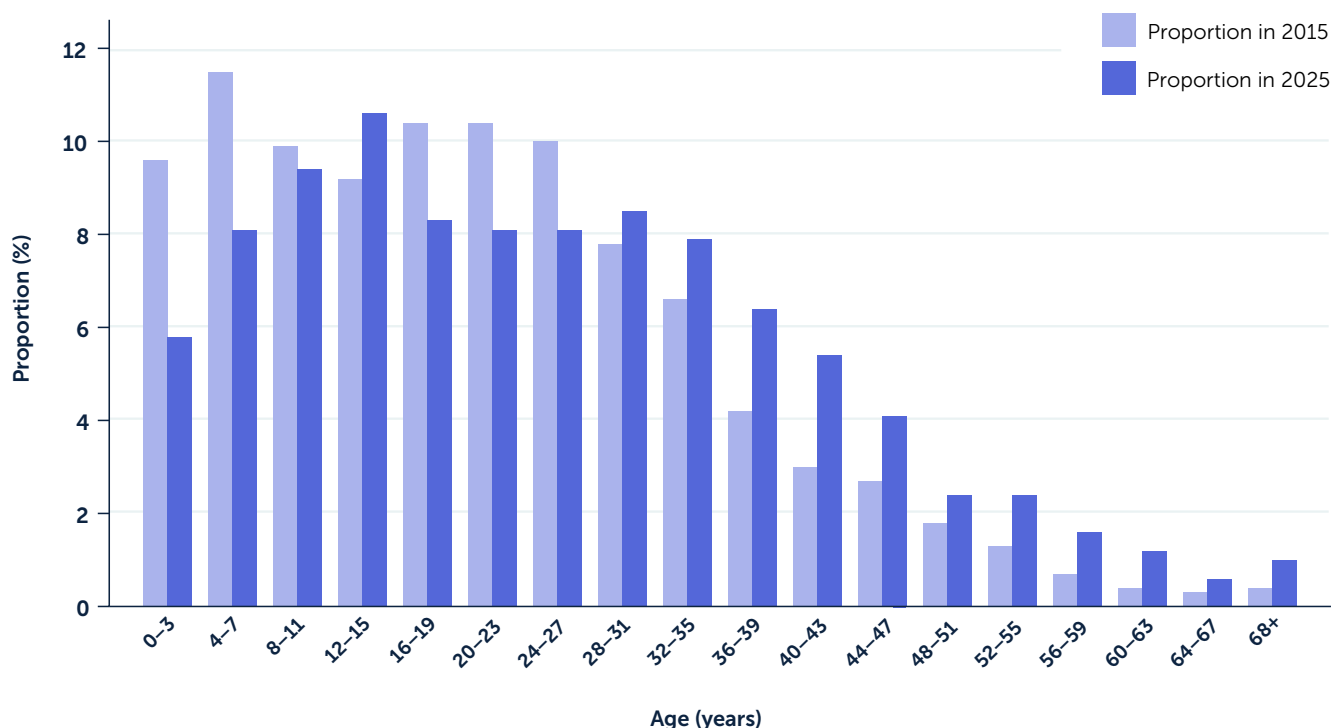
This graph shows the age distribution by sex for people with an annual review in 2025.



| Age     | All; n (%)  | Females; n (%) | Males; n (%) |
|---------|-------------|----------------|--------------|
| 0-3     | 621 (5.8)   | 304 (6.1)      | 317 (5.6)    |
| 4-7     | 861 (8.1)   | 411 (8.3)      | 450 (7.9)    |
| 8-11    | 1002 (9.4)  | 472 (9.5)      | 530 (9.4)    |
| 12-15   | 1122 (10.6) | 542 (10.9)     | 580 (10.2)   |
| 16-19   | 884 (8.3)   | 418 (8.4)      | 466 (8.2)    |
| 20-23   | 864 (8.1)   | 431 (8.7)      | 433 (7.6)    |
| 24-27   | 863 (8.1)   | 429 (8.6)      | 434 (7.7)    |
| 28-31   | 902 (8.5)   | 441 (8.9)      | 461 (8.1)    |
| 32-35   | 835 (7.9)   | 376 (7.6)      | 459 (8.1)    |
| 36-39   | 678 (6.4)   | 293 (5.9)      | 385 (6.8)    |
| 40-43   | 574 (5.4)   | 242 (4.9)      | 332 (5.9)    |
| 44-47   | 432 (4.1)   | 184 (3.7)      | 248 (4.4)    |
| 48-51   | 253 (2.4)   | 96 (1.9)       | 157 (2.8)    |
| 52-55   | 254 (2.4)   | 110 (2.2)      | 144 (2.5)    |
| 56-59   | 173 (1.6)   | 72 (1.5)       | 101 (1.8)    |
| 60-63   | 129 (1.2)   | 56 (1.1)       | 73 (1.3)     |
| 64-67   | 68 (0.6)    | 28 (0.6)       | 40 (0.7)     |
| 68+     | 109 (1.0)   | 55 (1.1)       | 54 (1.0)     |
| <16     | 3606 (33.9) | 1729 (34.9)    | 1877 (33.1)  |
| ≥16     | 7018 (66.1) | 3231 (65.1)    | 3787 (66.9)  |
| <18     | 4060 (38.2) | 1947 (39.3)    | 2113 (37.3)  |
| ≥18     | 6564 (61.8) | 3013 (60.7)    | 3551 (62.7)  |
| Overall | 10624       | 4960           | 5664         |

## 1.6 Age distribution of the UK CF population in 2015 and 2025

N=10624 in 2025, N=9587 in 2015



## 1.7 Ethnicity

| Ethnicity n (%)               | 2015               | 2019               | 2025               |
|-------------------------------|--------------------|--------------------|--------------------|
| Total                         | 9587               | 10070              | 10624              |
| Total known <sup>1</sup>      | 9488               | 9833               | 10404              |
| <b>White<sup>2</sup></b>      | <b>9081 (95.7)</b> | <b>9396 (95.5)</b> | <b>9820 (94.4)</b> |
| White British                 | -                  | 2983 (30.3)        | 4402 (42.3)        |
| White Irish                   | -                  | 18 (0.2)           | 27 (0.3)           |
| White Other                   | -                  | 6395 (65.0)        | 5391 (51.8)        |
| <b>Asian</b>                  | <b>240 (2.5)</b>   | <b>286 (2.9)</b>   | <b>356 (3.4)</b>   |
| Bangladeshi                   | 32 (0.3)           | 38 (0.4)           | 47 (0.5)           |
| Indian                        | 35 (0.4)           | 45 (0.5)           | 61 (0.6)           |
| Pakistani                     | 151 (1.6)          | 173 (1.8)          | 202 (1.9)          |
| Other (Asian)                 | 22 (0.2)           | 30 (0.3)           | 46 (0.4)           |
| <b>Black</b>                  | <b>28 (0.3)</b>    | <b>28 (0.3)</b>    | <b>32 (0.3)</b>    |
| Black African                 | -*                 | -*                 | 12 (0.1)           |
| Black Caribbean               | 13 (0.1)           | 12 (0.1)           | 14 (0.1)           |
| Other (Black)                 | <5                 | <5                 | 6 (0.1)            |
| <b>Mixed<sup>2</sup></b>      | <b>89 (1.0)</b>    | <b>65 (0.7)</b>    | <b>130 (1.3)</b>   |
| Mixed (white-Asian)           | -                  | 15 (0.2)           | 33 (0.3)           |
| Mixed (white-Black African)   | -                  | 9 (0.1)            | 14 (0.1)           |
| Mixed (white-Black Caribbean) | -                  | 19 (0.2)           | 38 (0.4)           |
| Other (mixed)                 | -                  | 22 (0.2)           | 45 (0.4)           |
| <b>Other</b>                  | <b>50 (0.5)</b>    | <b>58 (0.6)</b>    | <b>66 (0.6)</b>    |

\* Redacted to adhere to statistical disclosure guidelines

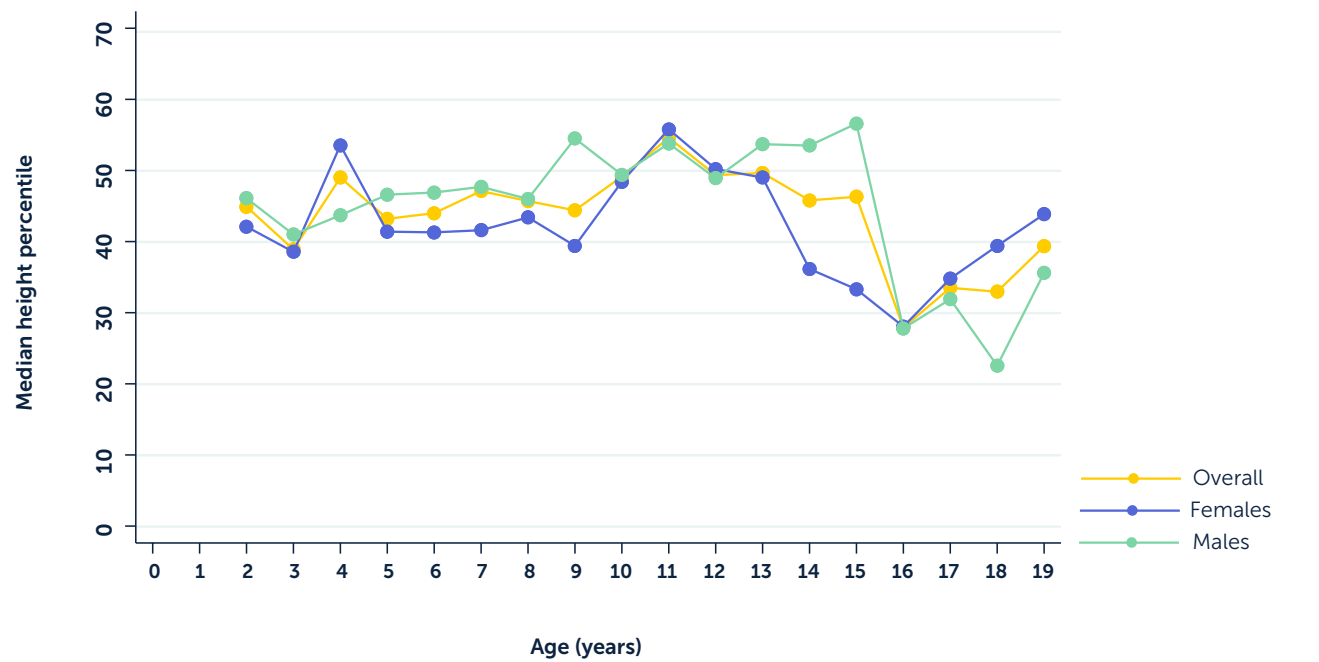
<sup>1</sup> Proportions are calculated from total known ethnicities

<sup>2</sup> Further detail on white and mixed ethnicity categories were collected from 2016 onwards

# 1.8 Height percentiles of children and young people (ages 2–19)<sup>1</sup>

N=4490

The following chart and table show the height percentiles of people with CF, ages 2 to 19, in relation to UK growth data for the general population. If a person with CF is on the 40th percentile, only 40% of people the same age are their height or shorter; 60% are taller.



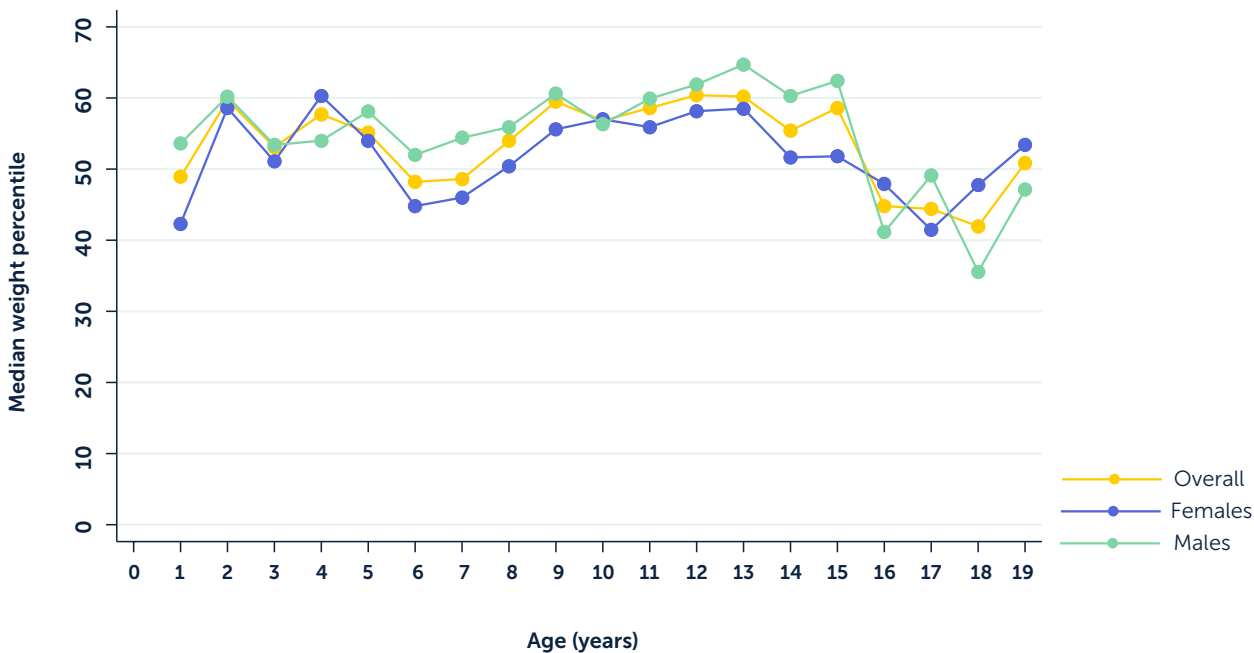
|         | Overall |        |           | Female |        |           | Male |        |           |
|---------|---------|--------|-----------|--------|--------|-----------|------|--------|-----------|
| Age     | n       | Median | IQR       | n      | Median | IQR       | n    | Median | IQR       |
| 2       | 178     | 44.9   | 18.7-74.3 | 86     | 42.1   | 15.2-70.5 | 92   | 46.1   | 20.0-77.6 |
| 3       | 187     | 38.9   | 16.7-67.2 | 90     | 38.6   | 19.3-63.9 | 97   | 41.0   | 14.5-71.0 |
| 4       | 211     | 49.0   | 21.6-75.3 | 102    | 53.5   | 28.7-78.5 | 109  | 43.7   | 17.8-72.1 |
| 5       | 208     | 43.2   | 21.0-74.1 | 111    | 41.4   | 17.6-70.7 | 97   | 46.6   | 21.4-77.4 |
| 6       | 215     | 44.0   | 20.3-73.3 | 106    | 41.3   | 15.5-73.3 | 109  | 46.9   | 22.5-72.1 |
| 7       | 213     | 47.1   | 22.3-67.9 | 86     | 41.6   | 17.7-67.4 | 127  | 47.7   | 23.2-68.1 |
| 8       | 246     | 45.7   | 20.8-76.2 | 117    | 43.4   | 19.7-71.1 | 129  | 46.0   | 22.1-85.3 |
| 9       | 247     | 44.4   | 25.7-74.5 | 117    | 39.4   | 24.4-77.0 | 130  | 54.5   | 26.8-73.9 |
| 10      | 270     | 49.2   | 27.0-74.5 | 119    | 48.4   | 26.8-74.9 | 151  | 49.4   | 27.4-74.1 |
| 11      | 226     | 54.6   | 28.2-77.1 | 109    | 55.8   | 27.4-78.3 | 117  | 53.8   | 31.9-75.3 |
| 12      | 252     | 49.3   | 27.5-74.1 | 113    | 50.2   | 28.9-75.7 | 139  | 48.9   | 25.7-73.8 |
| 13      | 288     | 49.7   | 28.1-78.0 | 143    | 49.0   | 29.6-71.7 | 145  | 53.7   | 27.1-82.6 |
| 14      | 281     | 45.8   | 23.6-70.5 | 134    | 36.2   | 15.5-65.0 | 147  | 53.5   | 34.0-81.2 |
| 15      | 284     | 46.3   | 22.2-70.4 | 147    | 33.3   | 13.5-61.1 | 137  | 56.6   | 30.9-72.7 |
| 16      | 224     | 27.9   | 11.5-55.4 | 104    | 28.0   | 10.8-60.4 | 120  | 27.8   | 11.9-53.7 |
| 17      | 223     | 33.5   | 12.4-56.2 | 110    | 34.8   | 13.9-53.2 | 113  | 31.9   | 12.1-58.1 |
| 18      | 218     | 33.0   | 9.2-54.7  | 98     | 39.4   | 17.6-59.0 | 120  | 22.5   | 7.1-54.3  |
| 19      | 212     | 39.3   | 13.6-65.3 | 102    | 43.8   | 15.1-73.3 | 110  | 35.6   | 11.7-58.4 |
| Overall | 4183*   | 44.5   | 20.1-71.4 | 1994   | 42.1   | 19.3-70.4 | 2189 | 46.0   | 21.2-72.3 |

\* Number with non-missing data.  
1 Based on UK-WHO growth charts, 1990 (updated 1996).

# 1.9 Weight percentiles of children and young people (<20 years)<sup>1</sup>

N=4419

The following chart and table show the weight of people with CF, aged 19 and under, in relation to the UK growth data for the general population. If a person with CF is on the 40th percentile, only 40% of people the same age are their weight or lower; 60% weigh more.

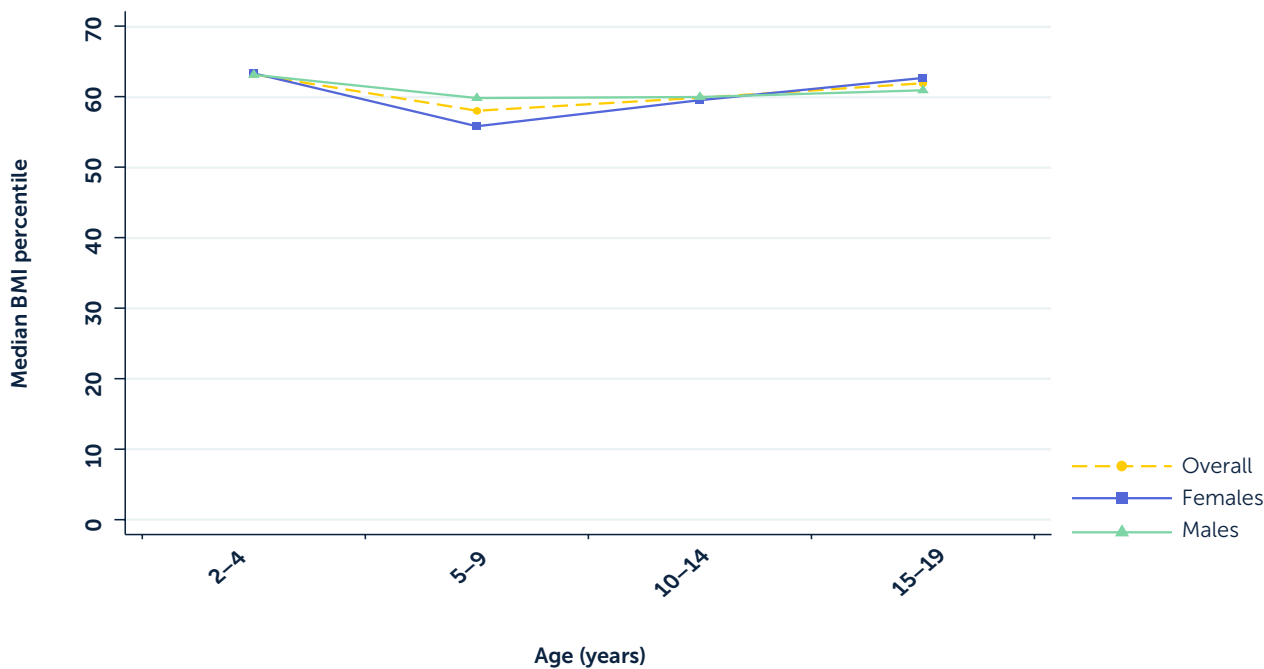


|         | Overall |        |           | Female |        |           | Male |        |           |
|---------|---------|--------|-----------|--------|--------|-----------|------|--------|-----------|
| Age     | n       | Median | IQR       | n      | Median | IQR       | n    | Median | IQR       |
| 1       | 168     | 48.9   | 22.4-76.1 | 85     | 42.3   | 20.9-69.5 | 83   | 53.6   | 28.2-77.9 |
| 2       | 181     | 59.7   | 30.6-77.7 | 86     | 58.6   | 28.2-79.2 | 95   | 60.2   | 32.0-76.8 |
| 3       | 190     | 53.1   | 31.4-74.1 | 92     | 51.1   | 31.0-70.6 | 98   | 53.4   | 34.7-81.9 |
| 4       | 214     | 57.7   | 31.9-79.4 | 104    | 60.3   | 33.1-80.6 | 110  | 54.0   | 29.9-75.7 |
| 5       | 209     | 55.1   | 27.4-81.3 | 111    | 54.0   | 26.3-81.3 | 98   | 58.1   | 29.5-83.1 |
| 6       | 215     | 48.2   | 25.4-77.2 | 106    | 44.8   | 24.6-72.2 | 109  | 52.0   | 28.9-79.5 |
| 7       | 213     | 48.6   | 26.6-80.4 | 86     | 46.0   | 22.7-82.7 | 127  | 54.4   | 29.9-80.1 |
| 8       | 248     | 54.0   | 25.5-83.9 | 119    | 50.4   | 23.7-78.8 | 129  | 55.9   | 27.7-86.8 |
| 9       | 247     | 59.5   | 33.7-81.9 | 117    | 55.6   | 30.0-80.5 | 130  | 60.6   | 36.0-82.8 |
| 10      | 271     | 56.8   | 35.5-85.6 | 119    | 57.0   | 36.4-82.8 | 152  | 56.3   | 34.8-87.9 |
| 11      | 228     | 58.6   | 30.8-83.3 | 110    | 55.9   | 25.8-80.1 | 118  | 59.9   | 37.0-86.9 |
| 12      | 253     | 60.4   | 33.5-80.6 | 114    | 58.2   | 33.2-80.6 | 139  | 61.9   | 34.3-81.5 |
| 13      | 288     | 60.2   | 33.5-86.9 | 143    | 58.5   | 34.8-87.2 | 145  | 64.7   | 29.4-84.9 |
| 14      | 285     | 55.4   | 30.9-82.1 | 136    | 51.7   | 24.8-77.1 | 149  | 60.3   | 35.7-86.2 |
| 15      | 285     | 58.6   | 34.3-82.5 | 147    | 51.8   | 27.7-83.6 | 138  | 62.4   | 40.7-82.5 |
| 16      | 225     | 44.8   | 23.6-71.7 | 105    | 47.9   | 24.1-76.2 | 120  | 41.2   | 22.8-66.7 |
| 17      | 225     | 44.4   | 16.3-71.0 | 110    | 41.4   | 16.1-64.3 | 115  | 49.1   | 20.6-76.2 |
| 18      | 218     | 41.9   | 13.4-77.1 | 98     | 47.8   | 25.2-81.8 | 120  | 35.5   | 9.5-68.6  |
| 19      | 210     | 50.8   | 16.1-76.1 | 101    | 53.4   | 27.3-81.0 | 109  | 47.1   | 10.4-68.3 |
| Overall | 4373*   | 54.3   | 28.0-80.5 | 2089   | 52.7   | 26.3-79.5 | 2284 | 55.2   | 29.1-81.4 |

\* Number with non-missing data.  
1 Based on UK-WHO growth charts, 1990 (updated 1996).

# 1.10a Body Mass Index (BMI) percentiles in children and young people (<20 years)<sup>1</sup> N=4246

The following chart and table show the BMI percentiles of people with CF, ages 2 to 19, in relation to the UK growth data for the general population. If a person with CF is on the 40th percentile, it means that only 40% of the population at the same age have the same BMI or lower; 60% have a higher BMI.

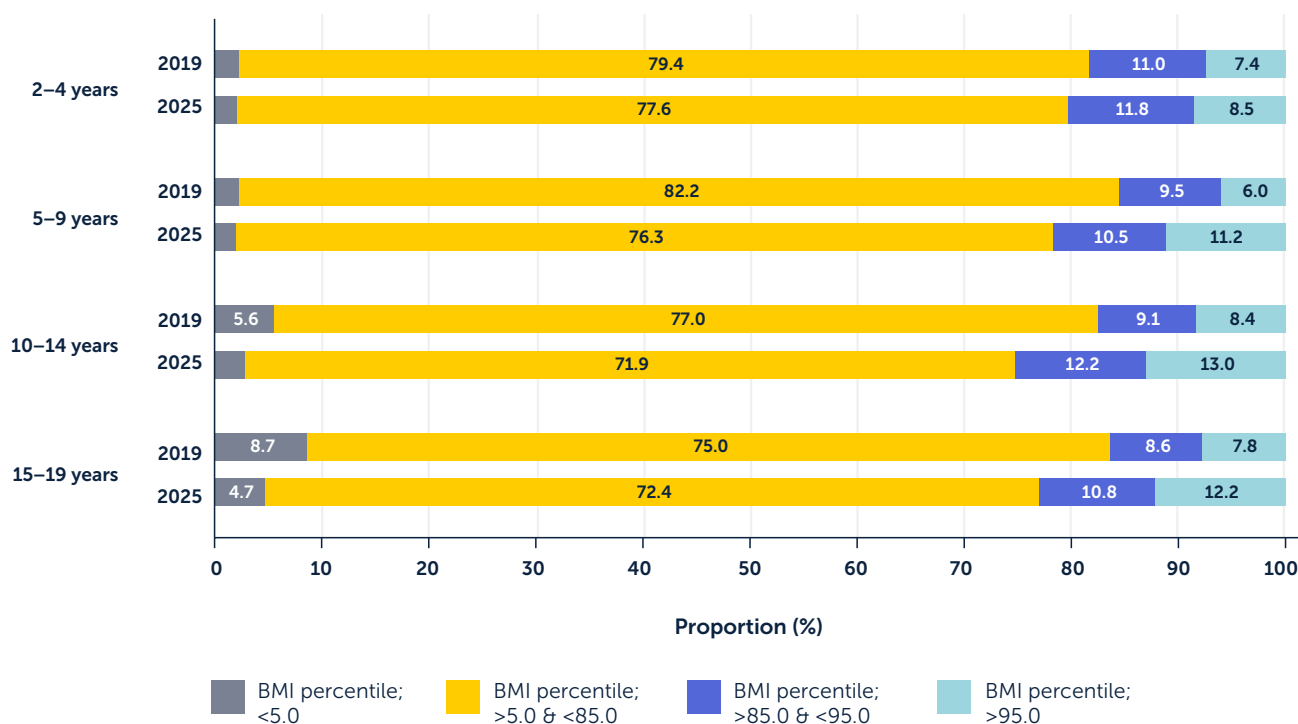


|         | Overall |        |           | Female |        |           | Male |        |           |
|---------|---------|--------|-----------|--------|--------|-----------|------|--------|-----------|
| Age     | n       | Median | IQR       | n      | Median | IQR       | n    | Median | IQR       |
| 2-4     | 576     | 63.2   | 37.7-80.9 | 278    | 63.3   | 38.4-79.9 | 298  | 63.1   | 36.5-81.3 |
| 5-9     | 1129    | 58.0   | 34.6-82.1 | 537    | 55.8   | 34.0-79.9 | 592  | 59.8   | 35.7-82.5 |
| 10-14   | 1316    | 59.8   | 33.0-85.1 | 618    | 59.5   | 32.7-84.0 | 698  | 60.0   | 33.4-86.1 |
| 15-19   | 1159    | 61.9   | 32.6-83.5 | 560    | 62.7   | 34.8-83.9 | 599  | 60.9   | 31.0-83.1 |
| Overall | 4180*   | 60.2   | 34.2-83.4 | 1993   | 59.5   | 34.2-83.0 | 2187 | 60.9   | 34.1-83.8 |

\* Number with non-missing data.  
1 Based on UK-WHO growth charts, 1990 (updated 1996).

## 1.10b Body Mass Index (BMI) percentiles in children and young people (<20 years)<sup>1</sup> for 2019 and 2025

The following graph shows the change in BMI groups for children and young people with CF from 2019 and 2025.

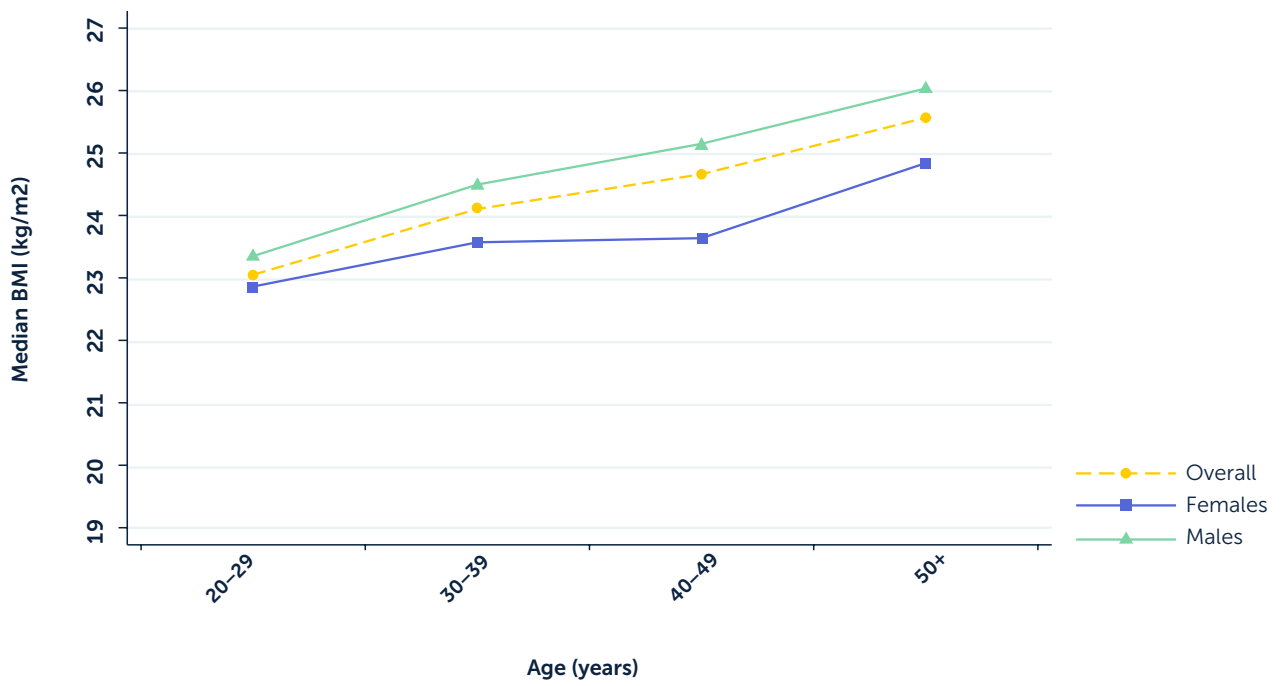


| Age         | Year | BMI percentile category by age and year : n(%) |                      |                              |                               |                       |
|-------------|------|------------------------------------------------|----------------------|------------------------------|-------------------------------|-----------------------|
|             |      | Total number of people in each age group*      | BMI percentile; <5.0 | BMI percentile; ≥5.0 & <85.0 | BMI percentile; ≥85.0 & <95.0 | BMI percentile; ≥95.0 |
| 2-4 years   | 2019 | 746                                            | 17 (2.3)             | 592 (79.4)                   | 82 (11.0)                     | 55 (7.4)              |
|             | 2025 | 576                                            | 12 (2.1)             | 447 (77.6)                   | 68 (11.8)                     | 49 (8.5)              |
| 5-9 years   | 2019 | 1391                                           | 32 (2.3)             | 1144 (82.2)                  | 132 (9.5)                     | 83 (6.0)              |
|             | 2025 | 1129                                           | 23 (2.0)             | 861 (76.3)                   | 119 (10.5)                    | 126 (11.2)            |
| 10-14 years | 2019 | 1257                                           | 70 (5.6)             | 968 (77.0)                   | 114 (9.1)                     | 105 (8.4)             |
|             | 2025 | 1316                                           | 38 (2.9)             | 946 (71.9)                   | 161 (12.2)                    | 171 (13.0)            |
| 15-19 years | 2019 | 1052                                           | 91 (8.7)             | 789 (75.0)                   | 90 (8.6)                      | 82 (7.8)              |
|             | 2025 | 1159                                           | 54 (4.7)             | 839 (72.4)                   | 125 (10.8)                    | 141 (12.2)            |

\* Total in each age group includes people with missing BMI data

1 Based on UK-WHO growth charts, 1990 (updated 1996).

# 1.11a Body Mass Index (BMI) in adults ages 20 and older N=6134

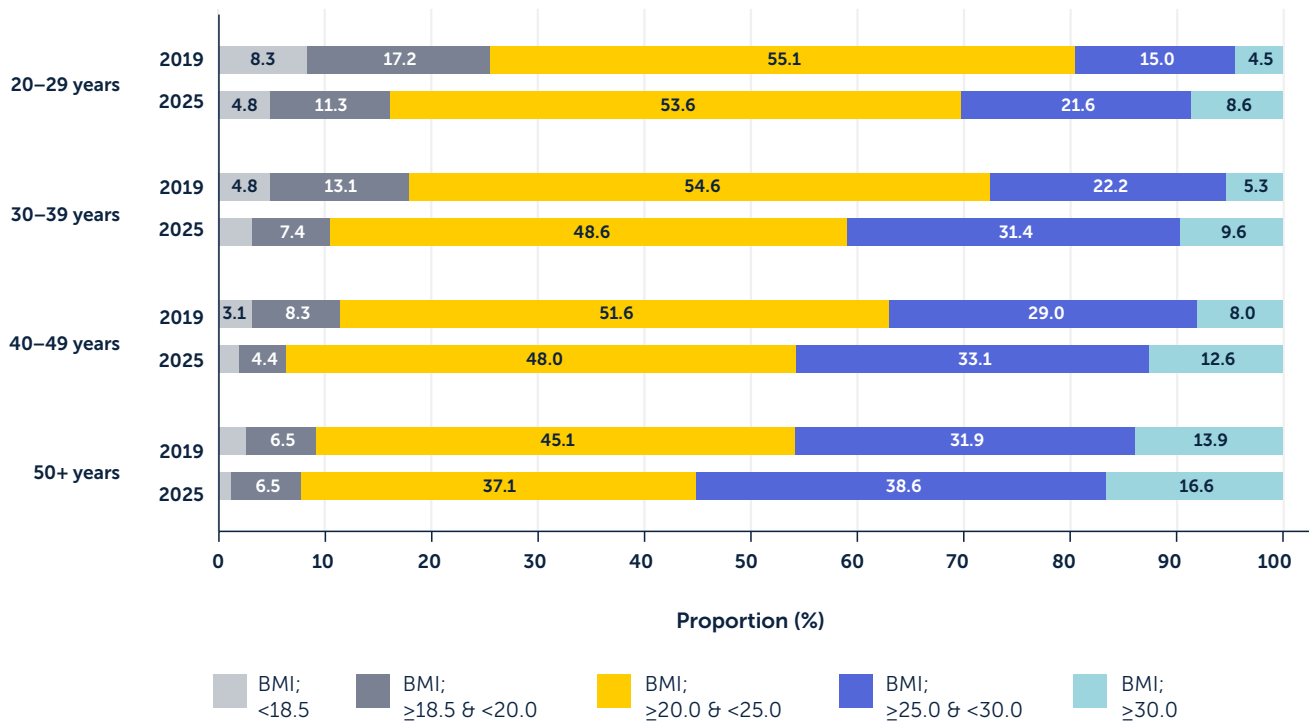


|         | Overall |        |           | Female |        |           | Male |        |           |
|---------|---------|--------|-----------|--------|--------|-----------|------|--------|-----------|
| Age     | n       | Median | IQR       | n      | Median | IQR       | n    | Median | IQR       |
| 20-29   | 2141    | 23.1   | 20.8-25.8 | 1064   | 22.9   | 20.6-25.8 | 1077 | 23.3   | 21.1-25.8 |
| 30-39   | 1901    | 24.1   | 22.0-27.0 | 857    | 23.6   | 21.4-26.5 | 1044 | 24.5   | 22.3-27.2 |
| 40-49   | 1126    | 24.7   | 22.3-27.4 | 469    | 23.6   | 21.7-27.0 | 657  | 25.1   | 23.1-27.7 |
| 50+     | 814     | 25.6   | 23.0-28.5 | 350    | 24.8   | 21.7-28.7 | 464  | 26.0   | 23.7-28.5 |
| Overall | 5982*   | 24.0   | 21.7-27.0 | 2740   | 23.4   | 21.2-26.7 | 3242 | 24.4   | 22.2-27.1 |

\* Number with non-missing data.

### 1.11b Body Mass Index (BMI) in adults for 2019 and 2025

The following graph shows the change in the proportion of people in each BMI group for 2019<sup>1</sup> and 2025.



| Age         | Year | BMI category by age and year : n(%)       |            |                    |                    |                    |            |
|-------------|------|-------------------------------------------|------------|--------------------|--------------------|--------------------|------------|
|             |      | Total number of people in each age group* | BMI; <18.5 | BMI; ≥18.5 & <20.0 | BMI; ≥20.0 & <25.0 | BMI; ≥25.0 & <30.0 | BMI; ≥30   |
| 20-29 years | 2019 | 2359                                      | 195 (8.3)  | 405 (17.2)         | 1300 (55.1)        | 354 (15.0)         | 105 (4.5)  |
|             | 2025 | 2141                                      | 103 (4.8)  | 243 (11.3)         | 1148 (53.6)        | 463 (21.6)         | 184 (8.6)  |
| 30-39 years | 2019 | 1636                                      | 78 (4.8)   | 215 (13.1)         | 893 (54.6)         | 364 (22.2)         | 86 (5.3)   |
|             | 2025 | 1901                                      | 58 (3.1)   | 141 (7.4)          | 924 (48.6)         | 596 (31.4)         | 182 (9.6)  |
| 40-49 years | 2019 | 772                                       | 24 (3.1)   | 64 (8.3)           | 398 (51.6)         | 224 (29.0)         | 62 (8.0)   |
|             | 2025 | 1126                                      | 21 (1.9)   | 50 (4.4)           | 540 (48.0)         | 373 (33.1)         | 142 (12.6) |
| 50+ years   | 2019 | 505                                       | 13 (2.6)   | 33 (6.5)           | 228 (45.1)         | 161 (31.9)         | 70 (13.9)  |
|             | 2025 | 814                                       | 10 (1.2)   | 53 (6.5)           | 302 (37.1)         | 314 (38.6)         | 135 (16.6) |

\* With non-missing BMI data  
1 Numbers for 2019 differ to those reported in 2024 report due to data cleaning carried out on age at annual review.

## 1.12 Education and employment in adults (16 years and over)

N=7018

The following table shows how people with CF aged 16 and older reported their education and employment status in 2025.

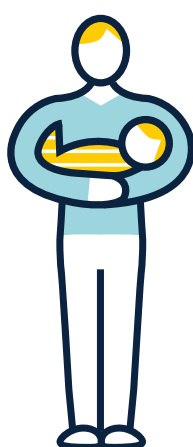
|                                                        | Overall     | Male        | Female      |
|--------------------------------------------------------|-------------|-------------|-------------|
| Number of people with CF                               | 7018        | 3787        | 3231        |
| Number who completed questionnaire; n (%) <sup>1</sup> | 6996 (99.7) | 3774 (99.7) | 3222 (99.7) |
| Full-time employment; n (%)                            | 2635 (37.5) | 1734 (45.8) | 901 (27.9)  |
| Part-time employment; n (%)                            | 1023 (14.6) | 375 (9.9)   | 648 (20.1)  |
| Student; n (%)                                         | 1068 (15.2) | 522 (13.8)  | 546 (16.9)  |
| Homemaker; n (%)                                       | 258 (3.7)   | 31 (0.8)    | 227 (7.0)   |
| Unemployed; n (%)                                      | 829 (11.8)  | 481 (12.7)  | 348 (10.8)  |
| Disabled; n (%)                                        | 224 (3.2)   | 113 (3.0)   | 111 (3.4)   |
| Retired; n (%)                                         | 197 (2.8)   | 109 (2.9)   | 88 (2.7)    |
| Volunteer; n (%)                                       | 19 (0.3)    | 8 (0.2)     | 11 (0.3)    |
| Unknown entered; n (%)                                 | 743 (10.6)  | 401 (10.6)  | 342 (10.6)  |
| No. in work or study; n (%)                            | 4726 (67.6) | 2631 (69.7) | 2095 (65.0) |

## 1.13 Live births

|                                                 | 2022       | 2023       | 2024       | 2025       |
|-------------------------------------------------|------------|------------|------------|------------|
| Women with CF who had babies; n(%) <sup>2</sup> | 140 (5.2)  | 116 (4.2)  | 111 (4.0)  | 102 (3.5)  |
| Men with CF whose partners had babies; n        | 33         | 31         | 35         | 31         |
| Mean maternal age (min-max)                     | 30 (19-41) | 30 (17-42) | 30 (18-43) | 30 (20-40) |
| Mean paternal age (min-max)                     | 34 (28-47) | 35 (18-45) | 35 (29-45) | 37 (28-55) |



**102 women** with CF had babies in 2025



The partners of **31 men** with CF had babies in 2025

<sup>1</sup> Proportions below are calculated from the total who completed the questionnaire

<sup>2</sup> Percentage of women aged 16 to 49 in the given year

# Health related quality of life

The Cystic Fibrosis Questionnaire-Revised (CFQ-R<sup>1</sup>) is a validated disease-specific health-related quality of life (HRQoL) measure for individuals with cystic fibrosis. It captures the daily experiences, challenges, and overall wellbeing of people living with CF, providing crucial insights from the individual's perspective.

The CFQ-R evaluates various aspects of daily life, referred to as 'domains' (such as physical functioning, vitality, emotional wellbeing, and respiratory symptoms). CFQ-R domain scores are standardised on a scale from 0 to 100, where higher scores indicate a better quality of life or fewer perceived symptoms.

Rather than looking at a single overall number or clinical measure, domain scores allow us to pinpoint specific areas of impact, such as physical health, treatment burden, or social functioning. For instance, higher respiratory scores reflect fewer respiratory symptoms and less perceived impact on daily breathing, whereas lower scores may highlight areas where additional support or clinical intervention may be most beneficial.

When CFQ-R surveys are completed by individuals with CF or their parents / carers the data can be added to the UK CF Registry by CF teams (since 2021). However, as a measure of HRQoL is not always part of routine clinical care in the UK, the data presented below may not be representative of the population of people with CF.

## 1.14 Health related quality of life (6 years and over)

|                               | 2024    |             |      |             | 2025    |             |      |             |
|-------------------------------|---------|-------------|------|-------------|---------|-------------|------|-------------|
| Age* (years)                  | 6 to 13 |             | 14+  |             | 6 to 13 |             | 14+  |             |
| Number of people in age group | 221     |             | 1019 |             | 178     |             | 1033 |             |
|                               | N**     | Mean (sd)   | N**  | Mean (sd)   | N**     | Mean (sd)   | N**  | Mean (sd)   |
| Domain name                   |         |             |      |             |         |             |      |             |
| physical                      | 221     | 87.9 (16.8) | 1018 | 73.8 (27.2) | 178     | 87.1 (16.5) | 1033 | 75.2 (27.0) |
| vitality                      | 112     | 65.5 (28.9) | 1018 | 55.6 (22.8) | 69      | 55.2 (32.9) | 1031 | 55.7 (22.8) |
| emotion                       | 221     | 77.3 (19.4) | 1019 | 74.8 (22.1) | 178     | 73.9 (16.4) | 1033 | 75.6 (22.4) |
| eat                           | 221     | 83.6 (21.7) | 1019 | 89.2 (18.7) | 176     | 85.5 (18.4) | 1032 | 89.1 (19.3) |
| treat                         | 221     | 73.2 (21.4) | 1018 | 69.5 (22.5) | 177     | 76.8 (20.6) | 1030 | 71.5 (22.0) |
| health                        | 112     | 72.0 (31.7) | 1019 | 67.8 (24.9) | 69      | 65.1 (36.6) | 1030 | 68.2 (24.8) |
| social                        | 188     | 58.4 (35.1) | 1017 | 72.1 (20.9) | 163     | 63.5 (31.9) | 1031 | 73.6 (19.4) |
| body                          | 221     | 84.9 (21.3) | 1019 | 77.1 (23.9) | 174     | 86.7 (18.5) | 1031 | 77.2 (23.5) |
| weight                        | 112     | 72.6 (37.5) | 1019 | 84.2 (29.2) | 69      | 63.3 (41.3) | 1032 | 83.1 (30.4) |
| respiratory                   | 220     | 86.1 (16.0) | 1018 | 81.3 (20.0) | 177     | 88.1 (14.1) | 1027 | 81.7 (19.7) |
| digestive                     | 221     | 79.9 (21.9) | 1009 | 83.0 (19.3) | 178     | 80.0 (23.7) | 1017 | 83.1 (19.2) |
| school or role                | n/a     | n/a         | 1013 | 83.0 (19.3) | n/a     | n/a         | 1020 | 83.1 (19.6) |

1. Quittner AL et al. Development and Validation of the Cystic Fibrosis Questionnaire in the United States Chest. 2005;128(4).

\* Age at CFQ-R completion: age groups align with age specific version of CFQ-R

\*\* Number of people with valid domain scores

# Lung health

For people with CF, mucus in the lungs is linked to repeat or chronic infections. This can result in repeated cycles of inflammation, which can cause permanent lung damage, making it harder to breathe.

In CF, the condition of the lungs is often measured using FEV<sub>1</sub>; the Forced Expiratory Volume of air in the first second of a forced exhaled breath. In this report, an FEV<sub>1</sub>% predicted is based on the FEV<sub>1</sub> we would expect for a person without CF of the same age, sex and height, regardless of ethnicity. The way that FEV<sub>1</sub> is calculated in this year's report has changed from previous UK CF Registry reports and is explained in detail on pages 14 and 15.

For people with CF, an FEV<sub>1</sub>% predicted of 85% or higher is the target, as this indicates normal or near-normal lung health. Each individual with CF will have their own FEV<sub>1</sub> target, based on their own lung function results and trends.

One aim of CF care is to prevent FEV<sub>1</sub>% predicted from falling as much as possible, for as long as possible. This is often a team effort between people with CF, their family, and their medical team, which can include doctors, nurses, physiotherapists, dietitians, and psychologists.

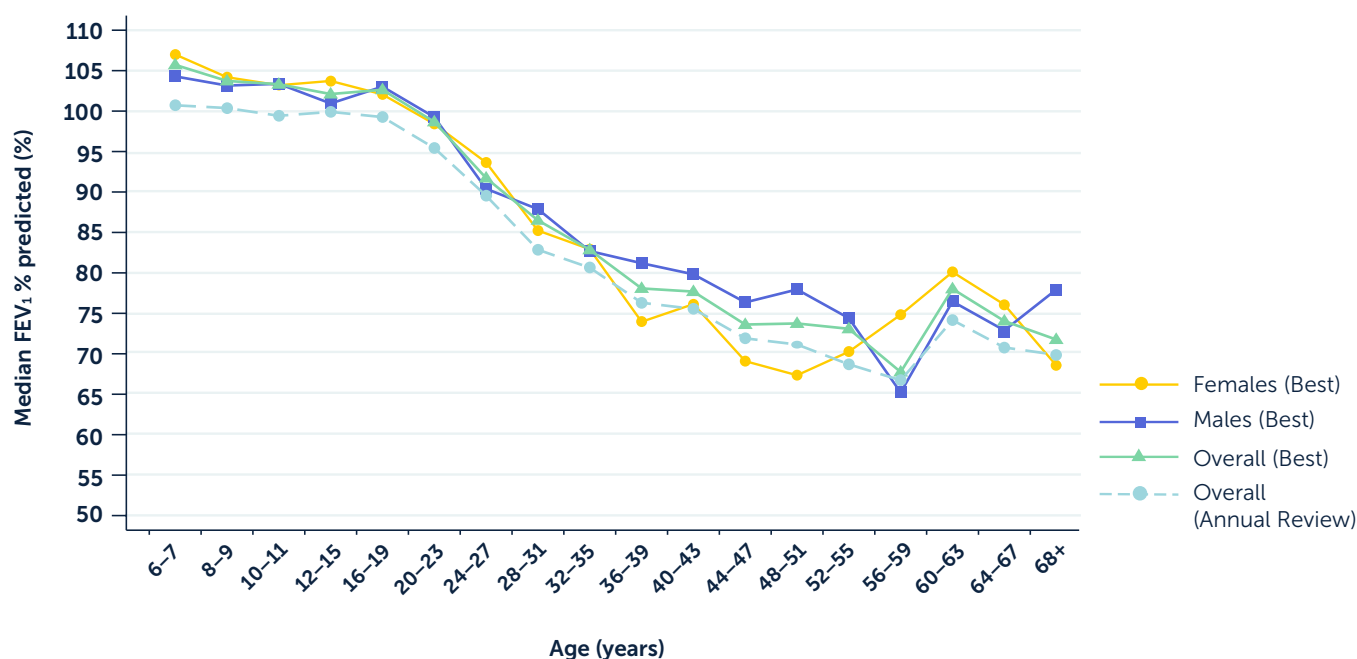
## 1.15 Annual review FEV<sub>1</sub>% predicted (GLI Global equation) in people aged 6 years and older who have not had a lung transplant N=9298

People with CF who have had a lung transplant are excluded, as their new 'non-CF' lungs may have lung health similar to a person without cystic fibrosis.

| Age (years) | Overall |        |            | Female |        |            | Male |        |            |
|-------------|---------|--------|------------|--------|--------|------------|------|--------|------------|
|             | n       | Median | IQR        | n      | Median | IQR        | n    | Median | IQR        |
| 6-7         | 384     | 100.7  | 90.2-109.4 | 173    | 101.5  | 91.6-110.4 | 211  | 99.8   | 88.5-107.9 |
| 8-9         | 477     | 100.4  | 91.8-107.7 | 229    | 102.1  | 92.8-107.3 | 248  | 99.3   | 90.2-108.5 |
| 10-11       | 478     | 99.4   | 91.4-108.6 | 220    | 99.7   | 92.6-109.8 | 258  | 99.2   | 90.6-108.0 |
| 12-15       | 1061    | 99.9   | 89.4-109.2 | 515    | 100.6  | 90.6-110.1 | 546  | 98.8   | 88.7-107.6 |
| 16-19       | 844     | 99.3   | 88.5-108.7 | 400    | 98.4   | 87.3-107.7 | 444  | 100.0  | 88.7-109.9 |
| 20-23       | 813     | 95.4   | 80.7-106.4 | 404    | 95.4   | 80.1-106.2 | 409  | 95.5   | 81.8-106.8 |
| 24-27       | 803     | 89.6   | 70.7-102.0 | 400    | 91.0   | 71.1-104.8 | 403  | 87.9   | 70.1-99.4  |
| 28-31       | 830     | 82.9   | 63.0-99.7  | 405    | 80.8   | 61.8-99.2  | 425  | 84.3   | 64.4-100.7 |
| 32-35       | 735     | 80.7   | 58.9-95.8  | 334    | 80.7   | 59.2-93.9  | 401  | 80.6   | 58.5-97.0  |
| 36-39       | 603     | 76.3   | 56.0-93.4  | 254    | 72.1   | 53.9-90.8  | 349  | 79.6   | 57.8-94.7  |
| 40-43       | 475     | 75.6   | 52.6-89.5  | 195    | 72.2   | 50.0-87.6  | 280  | 77.8   | 56.7-92.2  |
| 44-47       | 377     | 71.9   | 53.4-88.2  | 155    | 66.7   | 50.9-86.7  | 222  | 73.9   | 56.2-92.2  |
| 48-51       | 214     | 71.1   | 54.0-90.4  | 80     | 61.6   | 47.0-84.8  | 134  | 75.5   | 58.8-93.3  |
| 52-55       | 214     | 68.7   | 52.9-86.5  | 94     | 67.8   | 54.3-84.7  | 120  | 72.1   | 51.6-91.0  |
| 56-59       | 153     | 66.7   | 47.1-88.0  | 65     | 71.8   | 51.6-91.4  | 88   | 64.8   | 40.9-84.0  |
| 60-63       | 119     | 74.2   | 53.5-90.0  | 53     | 78.3   | 57.2-87.1  | 66   | 71.9   | 51.1-94.1  |
| 64-67       | 62      | 70.8   | 49.2-93.5  | 27     | 72.0   | 54.8-93.5  | 35   | 69.7   | 42.0-94.3  |
| 68+         | 102     | 69.9   | 46.7-90.9  | 52     | 66.2   | 46.5-85.2  | 50   | 77.9   | 50.3-97.2  |
| <16         | 2400    | 100.0  | 90.3-108.8 | 1137   | 100.7  | 91.7-109.7 | 1263 | 99.2   | 89.1-107.9 |
| ≥16         | 6344    | 85.1   | 62.9-100.4 | 2918   | 84.6   | 61.8-99.8  | 3426 | 85.5   | 63.8-100.7 |
| <18         | 2834    | 100.1  | 90.4-109.0 | 1345   | 100.6  | 91.8-109.4 | 1489 | 99.6   | 89.3-108.4 |
| ≥18         | 5910    | 83.6   | 61.6-99.1  | 2710   | 82.6   | 59.9-98.6  | 3200 | 84.0   | 62.5-99.5  |
| Overall     | 8744*   | 91.0   | 71.4-103.7 | 4055   | 91.4   | 71.0-104.0 | 4689 | 90.6   | 71.8-103.4 |

\* Number with non-missing data

## 1.16 Best\* FEV<sub>1</sub>% predicted (GLI Global equation) in people aged 6 years and older who have not had a lung transplant N=9298



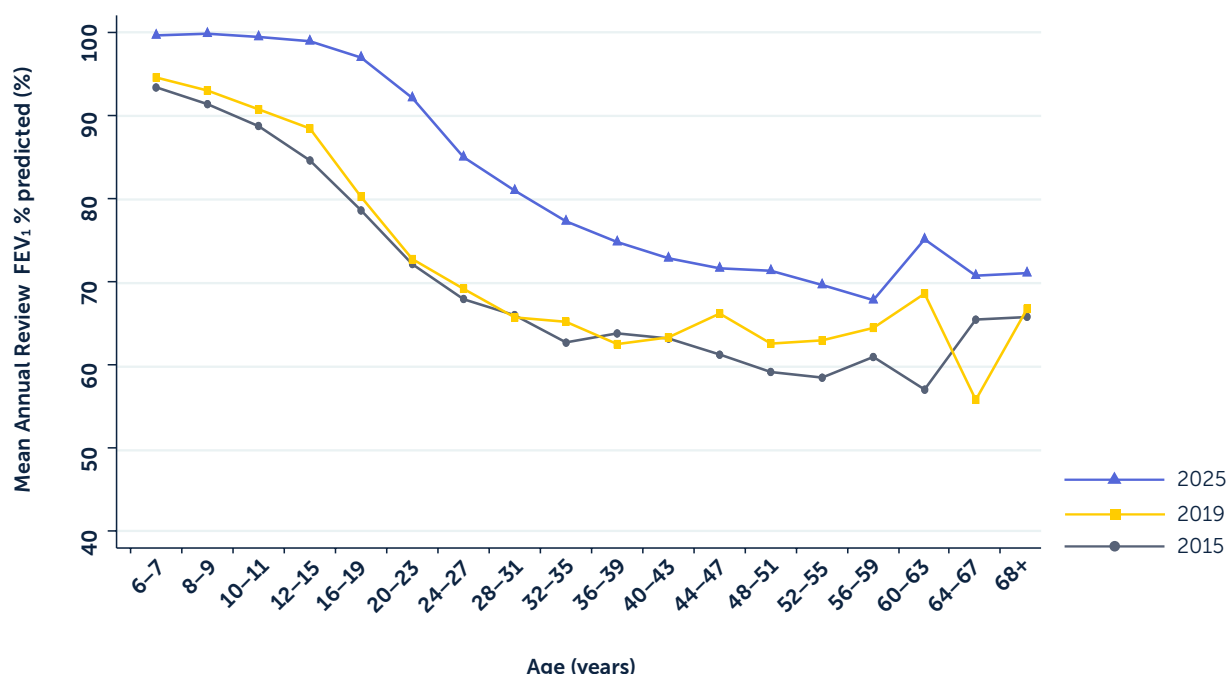
|             | Overall |        |            | Female |        |            | Male |        |            |
|-------------|---------|--------|------------|--------|--------|------------|------|--------|------------|
| Age (years) | n       | Median | IQR        | n      | Median | IQR        | n    | Median | IQR        |
| 6-7         | 406     | 105.7  | 95.9-113.7 | 184    | 107.0  | 96.5-114.4 | 222  | 104.3  | 95.2-113.2 |
| 8-9         | 487     | 103.7  | 95.8-111.6 | 235    | 104.2  | 96.8-112.2 | 252  | 103.2  | 94.7-111.2 |
| 10-11       | 491     | 103.3  | 95.4-111.8 | 225    | 103.2  | 95.8-112.0 | 266  | 103.4  | 95.2-111.6 |
| 12-15       | 1101    | 102.1  | 92.8-111.7 | 533    | 103.7  | 94.0-112.6 | 568  | 100.9  | 92.0-110.8 |
| 16-19       | 868     | 102.6  | 92.7-111.5 | 410    | 102.1  | 92.1-110.9 | 458  | 103.0  | 93.4-112.3 |
| 20-23       | 843     | 98.7   | 84.7-109.3 | 422    | 98.4   | 84.5-108.6 | 421  | 99.3   | 85.4-109.8 |
| 24-27       | 836     | 91.7   | 74.0-104.4 | 415    | 93.7   | 74.4-106.5 | 421  | 90.4   | 73.3-102.0 |
| 28-31       | 862     | 86.5   | 67.1-102.0 | 422    | 85.2   | 65.8-101.7 | 440  | 87.9   | 67.7-103.0 |
| 32-35       | 780     | 82.9   | 63.3-97.4  | 355    | 82.9   | 64.0-97.0  | 425  | 82.7   | 61.6-98.1  |
| 36-39       | 627     | 78.1   | 58.8-95.4  | 267    | 74.0   | 57.9-94.1  | 360  | 81.2   | 60.3-97.3  |
| 40-43       | 502     | 77.7   | 55.1-92.6  | 207    | 76.1   | 52.7-89.9  | 295  | 79.8   | 58.6-94.7  |
| 44-47       | 393     | 73.6   | 56.7-92.2  | 162    | 69.1   | 55.0-91.4  | 231  | 76.4   | 56.7-94.0  |
| 48-51       | 224     | 73.8   | 57.2-93.3  | 84     | 67.4   | 51.5-87.4  | 140  | 77.9   | 60.5-94.2  |
| 52-55       | 220     | 73.1   | 55.3-90.4  | 95     | 70.3   | 55.4-88.6  | 125  | 74.4   | 55.2-92.2  |
| 56-59       | 154     | 67.7   | 50.1-92.5  | 66     | 74.8   | 54.9-95.0  | 88   | 65.2   | 44.3-86.8  |
| 60-63       | 123     | 78.0   | 54.6-90.7  | 55     | 80.1   | 55.8-88.7  | 68   | 76.5   | 52.3-94.7  |
| 64-67       | 63      | 74.1   | 53.7-95.8  | 27     | 76.1   | 57.3-94.2  | 36   | 72.9   | 48.5-96.8  |
| 68+         | 104     | 71.8   | 50.8-94.5  | 52     | 68.6   | 50.9-89.8  | 52   | 77.9   | 49.9-97.3  |
| <16         | 2485    | 103.4  | 94.3-112.0 | 1177   | 104.2  | 95.2-112.4 | 1308 | 102.7  | 93.4-111.4 |
| ≥16         | 6599    | 87.8   | 66.5-102.9 | 3039   | 87.4   | 65.7-102.8 | 3560 | 88.1   | 67.2-103.0 |
| <18         | 2929    | 103.4  | 94.5-112.1 | 1391   | 104.1  | 95.2-112.4 | 1538 | 102.8  | 93.4-111.5 |
| ≥18         | 6155    | 86.4   | 64.6-101.5 | 2825   | 86.0   | 64.1-101.3 | 3330 | 86.8   | 65.4-101.7 |
| Overall     | 9084**  | 94.1   | 75.1-106.5 | 4216   | 94.4   | 74.5-106.7 | 4868 | 93.8   | 75.5-106.2 |

\* Where Best FEV<sub>1</sub>% was missing or less than the FEV<sub>1</sub>% at annual review, annual review FEV<sub>1</sub>% was used instead.

\*\* Number with non-missing data.

## 1.17 Annual review FEV<sub>1</sub>% predicted (GLI Global equation) over time in people aged 6 years and older who have not had a lung transplant N=9298 in 2025, N=8389 in 2019, N=7764 in 2015

As we learn more about CF and how to treat it, we hope to improve the outcomes of people with the condition. The chart below shows how FEV<sub>1</sub>% predicted in 2025 compares to Registry data from 2015 and 2019.



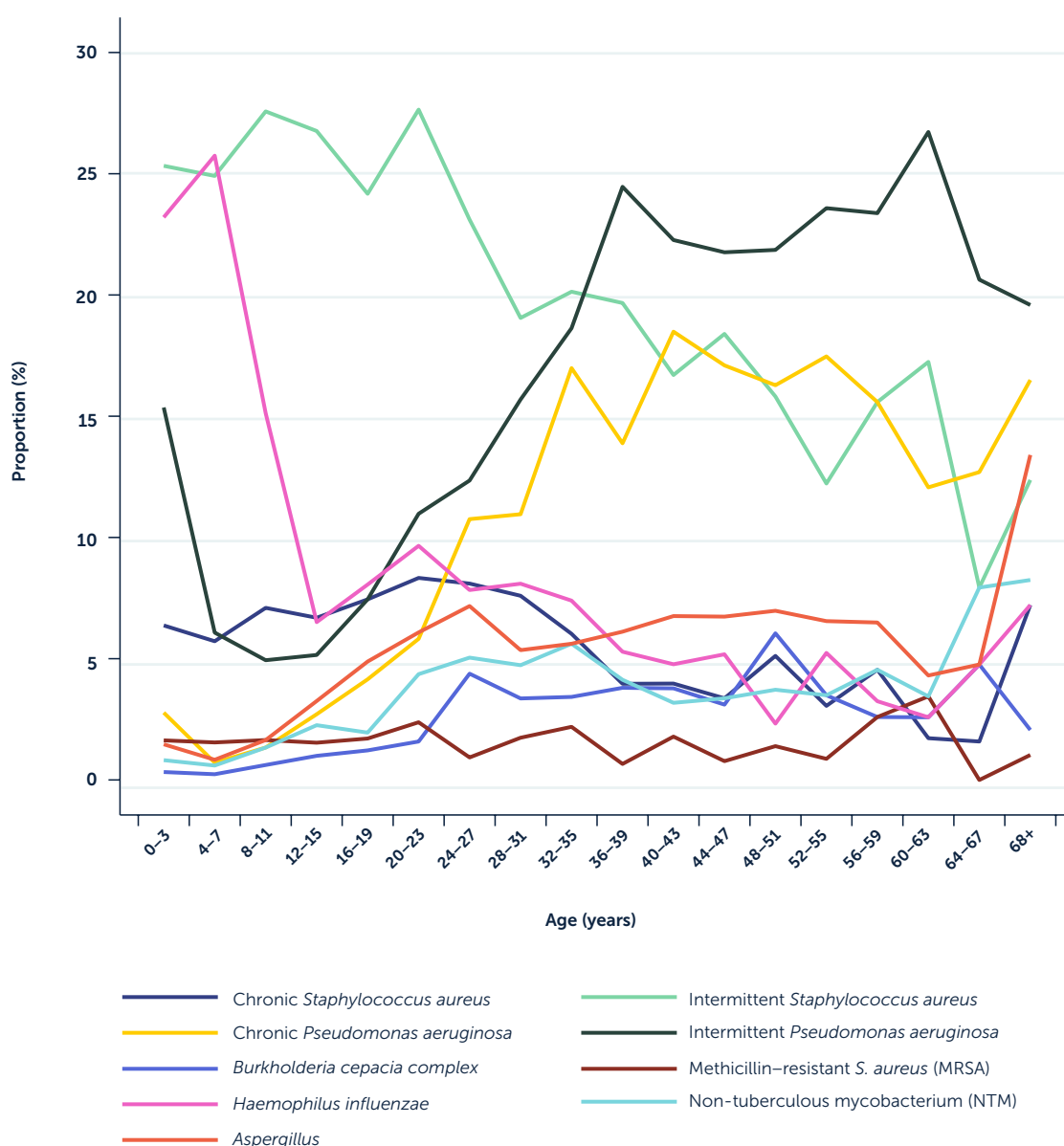
|             | 2015  |                                | 2019 |                                | 2025 |                                |
|-------------|-------|--------------------------------|------|--------------------------------|------|--------------------------------|
| Age (years) | n     | FEV <sub>1</sub> % : Mean (SD) | n    | FEV <sub>1</sub> % : Mean (SD) | n    | FEV <sub>1</sub> % : Mean (SD) |
| 6-7         | 476   | 93.4 (17.0)                    | 529  | 94.6 (16.4)                    | 384  | 99.6 (14.5)                    |
| 8-9         | 471   | 91.4 (15.7)                    | 555  | 93.0 (15.3)                    | 477  | 99.8 (14.2)                    |
| 10-11       | 446   | 88.7 (16.1)                    | 509  | 90.7 (17.0)                    | 478  | 99.5 (14.3)                    |
| 12-15       | 857   | 84.6 (17.8)                    | 962  | 88.4 (18.4)                    | 1061 | 98.9 (15.2)                    |
| 16-19       | 935   | 78.6 (22.9)                    | 791  | 80.2 (21.9)                    | 844  | 97.0 (18.9)                    |
| 20-23       | 939   | 72.1 (24.7)                    | 954  | 72.7 (25.0)                    | 813  | 92.1 (21.2)                    |
| 24-27       | 864   | 67.9 (25.4)                    | 844  | 69.1 (25.0)                    | 803  | 85.0 (23.5)                    |
| 28-31       | 684   | 66.0 (24.8)                    | 772  | 65.7 (24.6)                    | 830  | 81.0 (24.4)                    |
| 32-35       | 551   | 62.7 (25.0)                    | 616  | 65.2 (25.0)                    | 735  | 77.3 (24.6)                    |
| 36-39       | 363   | 63.8 (24.9)                    | 484  | 62.5 (25.6)                    | 603  | 74.8 (24.8)                    |
| 40-43       | 234   | 63.2 (24.2)                    | 335  | 63.3 (25.4)                    | 475  | 72.8 (24.4)                    |
| 44-47       | 216   | 61.2 (23.6)                    | 216  | 66.2 (23.8)                    | 377  | 71.6 (24.5)                    |
| 48-51       | 145   | 59.1 (24.9)                    | 198  | 62.6 (24.2)                    | 214  | 71.3 (24.5)                    |
| 52-55       | 104   | 58.5 (25.0)                    | 144  | 62.9 (25.4)                    | 214  | 69.6 (22.7)                    |
| 56-59       | 52    | 60.9 (24.4)                    | 97   | 64.4 (25.9)                    | 153  | 67.8 (26.2)                    |
| 60-63       | 29    | 57.0 (21.5)                    | 53   | 68.6 (27.0)                    | 119  | 75.1 (25.4)                    |
| 64-67       | 22    | 65.4 (25.1)                    | 31   | 55.8 (19.5)                    | 62   | 70.7 (27.2)                    |
| 68+         | 35    | 65.7 (27.3)                    | 48   | 66.7 (27.5)                    | 102  | 71.0 (26.0)                    |
| <16         | 2250  | 88.7 (17.2)                    | 2555 | 91.2 (17.2)                    | 2400 | 99.3 (14.7)                    |
| ≥16         | 5173  | 68.4 (25.2)                    | 5583 | 68.8 (25.2)                    | 6344 | 81.5 (25.1)                    |
| <18         | 2700  | 87.3 (18.3)                    | 2943 | 90.2 (17.9)                    | 2834 | 99.3 (15.2)                    |
| ≥18         | 4723  | 67.3 (25.3)                    | 5195 | 67.7 (25.2)                    | 5910 | 80.1 (25.0)                    |
| Overall     | 7423* | 74.6 (24.9)                    | 8138 | 75.8 (25.2)                    | 8744 | 86.4 (24.0)                    |

\* Number with non-missing data

# Lung infections

Lung infections can permanently reduce lung function in people with cystic fibrosis. Some lung infections can become 'chronic', meaning that they can't ever be removed completely using existing treatments. All other infections are reported if they have occurred at least once as a positive growth in the 12 months prior to the individual's annual review.

## 1.18 Lung infections in 2025 N=9758\*



\* Proportions are calculated from the number of people with at least one sample taken in the relevant age group. This is a change from the 2020 data report where they were calculated from the number of people with annual reviews in the age group.

## 1.18 Lung infections in 2025 (cont.)

<16 years N=3606, ≥16 years N=7018

Infections in this table reflect those grown in the 12 months prior to the 2025 annual review.  
The UK CF Registry definition of 'chronic' is three or more isolates in the last 12 months.

|                                        | Paediatric age range (years) |            |            |            | Overall                |
|----------------------------------------|------------------------------|------------|------------|------------|------------------------|
|                                        | 0-3                          | 4-7        | 8-11       | 12-15      | Paediatric (<16 years) |
| Number in age range                    | 621                          | 861        | 1002       | 1122       | 3606                   |
| Number who had culture taken*          | 612                          | 839        | 972        | 1106       | 3529                   |
| Chronic <i>S. aureus</i> n(%)          | 39 (6.4)                     | 48 (5.7)   | 69 (7.1)   | 74 (6.7)   | 230 (6.5)              |
| Intermittent <i>S. aureus</i> n(%)     | 155 (25.3)                   | 209 (24.9) | 268 (27.6) | 296 (26.8) | 928 (26.3)             |
| Chronic <i>P. aeruginosa</i> n(%)      | 17 (2.8)                     | 6 (0.7)    | 13 (1.3)   | 30 (2.7)   | 66 (1.9)               |
| Intermittent <i>P. aeruginosa</i> n(%) | 94 (15.4)                    | 51 (6.1)   | 48 (4.9)   | 57 (5.2)   | 250 (7.1)              |
| <i>B. cepacia</i> complex n(%)         | <5                           | <5         | 6 (0.6)    | 11 (1.0)   | 21 (0.6)               |
| <i>B. cenocepacia</i> n(%)             | <5                           | <5         | <5         | <5         | 5 (0.1)                |
| <i>B. multivorans</i> n(%)             | <5                           | <5         | <5         | 6 (0.5)    | 8 (0.2)                |
| <i>B. other cepacia</i> n(%)           | <5                           | <5         | <5         | <5         | <5                     |
| MRSA n(%)                              | 10 (1.6)                     | 13 (1.5)   | 16 (1.6)   | 17 (1.5)   | 56 (1.6)               |
| <i>H. influenza</i> n(%)               | 142 (23.2)                   | 216 (25.7) | 147 (15.1) | 72 (6.5)   | 577 (16.4)             |
| NTM n(%)                               | 5 (0.8)                      | 5 (0.6)    | 13 (1.3)   | 25 (2.3)   | 48 (1.4)               |
| <i>Aspergillus fumigatus</i> n(%)      | 9 (1.5)                      | 7 (0.8)    | 16 (1.6)   | 36 (3.3)   | 68 (1.9)               |

\* Proportions are calculated from the number of people who were recorded as having at least one respiratory culture sample taken.

## 1.17 Lung infections in 2025 (cont.)

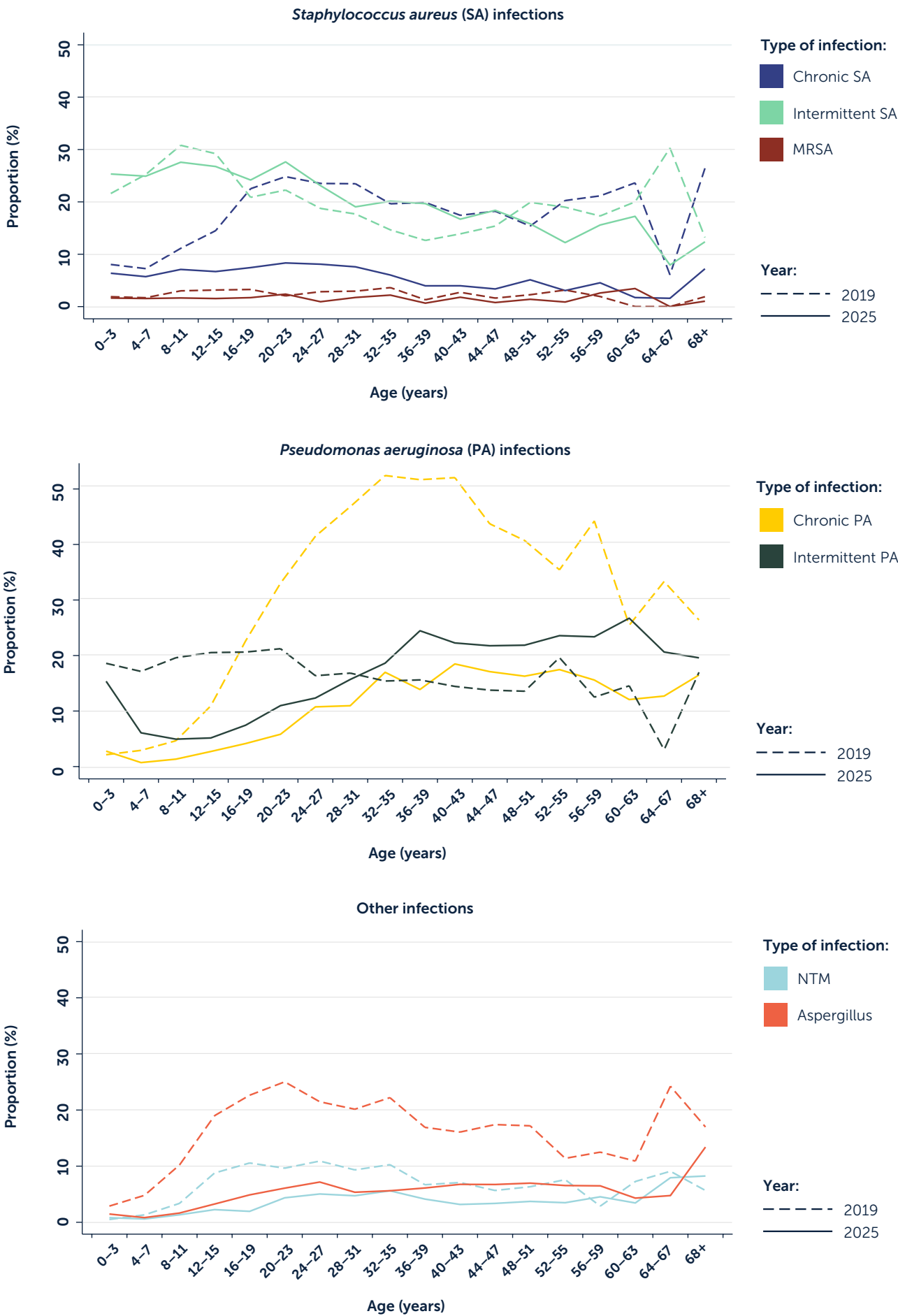
<16 years N=3606, ≥16 years N=7018

|                                        | Adult age range (years) |            |            |            |            |            |            | Overall               |
|----------------------------------------|-------------------------|------------|------------|------------|------------|------------|------------|-----------------------|
|                                        | 16-19                   | 20-23      | 24-27      | 28-31      | 32-35      | 36-39      | 40-43      | Adults<br>(≥16 years) |
| Number in age range                    | 884                     | 864        | 863        | 902        | 835        | 678        | 574        | 7018                  |
| Number who had culture taken*          | 819                     | 756        | 753        | 803        | 730        | 605        | 503        | 6229                  |
| Chronic <i>S. aureus</i> n(%)          | 61 (7.4)                | 63 (8.3)   | 61 (8.1)   | 61 (7.6)   | 44 (6.0)   | 24 (4.0)   | 20 (4.0)   | 382 (6.1)             |
| Intermittent <i>S. aureus</i> n(%)     | 198 (24.2)              | 209 (27.6) | 174 (23.1) | 153 (19.1) | 147 (20.1) | 119 (19.7) | 84 (16.7)  | 1278 (20.5)           |
| Chronic <i>P. aeruginosa</i> n(%)      | 34 (4.2)                | 44 (5.8)   | 81 (10.8)  | 88 (11.0)  | 124 (17.0) | 84 (13.9)  | 93 (18.5)  | 751 (12.1)            |
| Intermittent <i>P. aeruginosa</i> n(%) | 61 (7.4)                | 83 (11.0)  | 93 (12.4)  | 126 (15.7) | 136 (18.6) | 148 (24.5) | 112 (22.3) | 1043 (16.7)           |
| <i>B. cepacia</i> complex n(%)         | 10 (1.2)                | 12 (1.6)   | 33 (4.4)   | 27 (3.4)   | 25 (3.4)   | 23 (3.8)   | 19 (3.8)   | 194 (3.1)             |
| <i>B. cenocepacia</i> n(%)             | <5                      | <5         | 7 (0.9)    | 8 (1.0)    | 7 (1.0)    | 6 (1.0)    | <5         | 47 (0.8)              |
| <i>B. multivorans</i> n(%)             | 5 (0.6)                 | <5         | 12 (1.6)   | 11 (1.4)   | 12 (1.6)   | 13 (2.1)   | 13 (2.6)   | 87 (1.4)              |
| <i>B. other cepacia</i> n(%)           | <5                      | <5         | 10 (1.3)   | 8 (1.0)    | <5         | <5         | <5         | 45 (0.7)              |
| MRSA n(%)                              | 14 (1.7)                | 18 (2.4)   | 7 (0.9)    | 14 (1.7)   | 16 (2.2)   | <5         | 9 (1.8)    | 99 (1.6)              |
| <i>H. influenza</i> n(%)               | 66 (8.1)                | 73 (9.7)   | 59 (7.8)   | 65 (8.1)   | 54 (7.4)   | 32 (5.3)   | 24 (4.8)   | 428 (6.9)             |
| NTM n(%)                               | 16 (2.0)                | 33 (4.4)   | 38 (5.0)   | 38 (4.7)   | 41 (5.6)   | 25 (4.1)   | 16 (3.2)   | 260 (4.2)             |
| <i>Aspergillus fumigatus</i> n(%)      | 40 (4.9)                | 46 (6.1)   | 54 (7.2)   | 43 (5.4)   | 41 (5.6)   | 37 (6.1)   | 34 (6.8)   | 382 (6.1)             |

|                                        | Adult age range (years) |           |           |           |           |           |           | Overall               |
|----------------------------------------|-------------------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------------------|
|                                        | 44-47                   | 48-51     | 52-55     | 56-59     | 60-63     | 64-67     | 68+       | Adults<br>(≥16 years) |
| Number in age range                    | 432                     | 253       | 254       | 173       | 129       | 68        | 109       | 7018                  |
| Number who had culture taken*          | 386                     | 215       | 229       | 154       | 116       | 63        | 97        | 6229                  |
| Chronic <i>S. aureus</i> n(%)          | 13 (3.4)                | 11 (5.1)  | 7 (3.1)   | 7 (4.5)   | <5        | <5        | 7 (7.2)   | 382 (6.1)             |
| Intermittent <i>S. aureus</i> n(%)     | 71 (18.4)               | 34 (15.8) | 28 (12.2) | 24 (15.6) | 20 (17.2) | 5 (7.9)   | 12 (12.4) | 1278 (20.5)           |
| Chronic <i>P. aeruginosa</i> n(%)      | 67 (17.4)               | 36 (16.7) | 41 (17.9) | 24 (15.6) | 15 (12.9) | 8 (12.7)  | 16 (16.5) | 767 (12.3)            |
| Intermittent <i>P. aeruginosa</i> n(%) | 83 (21.5)               | 46 (21.4) | 53 (23.1) | 36 (23.4) | 30 (25.9) | 13 (20.6) | 19 (19.6) | 1027 (16.5)           |
| <i>B. cepacia</i> complex n(%)         | 12 (3.1)                | 13 (6.0)  | 8 (3.5)   | <5        | <5        | <5        | <5        | 194 (3.1)             |
| <i>B. cenocepacia</i> n(%)             | <5                      | <5        | <5        | <5        | <5        | <5        | <5        | 47 (0.8)              |
| <i>B. multivorans</i> n(%)             | 5 (1.3)                 | 6 (2.8)   | <5        | <5        | <5        | <5        | <5        | 87 (1.4)              |
| <i>B. other cepacia</i> n(%)           | <5                      | <5        | <5        | <5        | <5        | <5        | <5        | 45 (0.7)              |
| MRSA n(%)                              | <5                      | <5        | <5        | <5        | <5        | <5        | <5        | 99 (1.6)              |
| <i>H. influenza</i> n(%)               | 20 (5.2)                | 5 (2.3)   | 12 (5.2)  | 5 (3.2)   | <5        | <5        | 7 (7.2)   | 428 (6.9)             |
| NTM n(%)                               | 13 (3.4)                | 8 (3.7)   | 8 (3.5)   | 7 (4.5)   | <5        | -*        | 8 (8.2)   | 260 (4.2)             |
| <i>Aspergillus fumigatus</i> n(%)      | 26 (6.7)                | 15 (7.0)  | 15 (6.6)  | 10 (6.5)  | -*        | <5        | 13 (13.4) | 382 (6.1)             |

\* Proportions are calculated from the number of people who were recorded as having at least one respiratory culture sample taken.

# 1.19 Lung infections 2019–2025



## 1.20 Respiratory culture sample type

| Overall                                                          | 2019        | 2025        |
|------------------------------------------------------------------|-------------|-------------|
| Number of people with an annual review (n)                       | 10070       | 10624       |
| Number of people with at least 3 samples of any type taken n(%)* | 8656 (86.0) | 6705 (63.1) |
| Number of people with at least 1 sample of any type taken n(%)*  | 9847 (97.8) | 9806 (92.3) |
| Sample type <sup>1**</sup>                                       |             |             |
| Sputum; n(%)                                                     | 6865 (69.7) | 5712 (58.3) |
| Cough; n(%)                                                      | 6198 (62.9) | 6831 (69.7) |
| Bronchoalveolar lavage; n(%)                                     | 485 (4.9)   | 261 (2.7)   |
|                                                                  |             |             |
| Age <16 years                                                    | 2019        | 2025        |
| Number of people with an annual review (n)                       | 3966        | 3607        |
| Number of people with at least 3 samples of any type taken n(%)* | 3817 (96.2) | 3328 (92.3) |
| Number of people with at least 1 sample of any type taken n(%)*  | 3937 (99.3) | 3533 (97.9) |
| Sample type <sup>1**</sup>                                       |             |             |
| Sputum; n(%)                                                     | 1668 (42.4) | 1017 (28.8) |
| Cough; n(%)                                                      | 3767 (95.7) | 3482 (98.6) |
| Bronchoalveolar lavage; n(%)                                     | 343 (8.7)   | 137 (3.9)   |
|                                                                  |             |             |
| Age ≥16 years                                                    | 2019        | 2025        |
| Number of people with an annual review (n)                       | 6104        | 7017        |
| Number of people with at least 3 samples of any type taken n(%)* | 4839 (79.3) | 3377 (48.1) |
| Number of people with at least 1 sample of any type taken n(%)*  | 5910 (96.8) | 6273 (89.4) |
| Sample type <sup>1**</sup>                                       |             |             |
| Sputum; n(%)                                                     | 5197 (87.9) | 4695 (74.8) |
| Cough; n(%)                                                      | 2431 (41.1) | 3349 (53.4) |
| Bronchoalveolar lavage; n(%)                                     | 142 (2.4)   | 124 (2.0)   |

\* % is of those people with an annual review.

\*\* People can have more than one sample taken so the % total may not add up to 100%.

1 Proportions are calculated from the number of people with at least 1 sample of any type taken.

## 1.21 Non-tuberculous mycobacteria (NTM) or atypical mycobacteria

Non-tuberculous mycobacterium is slow to grow and takes time to treat. It may be present for several years before eradication or may never be cleared. In the table below, prevalence represents all people reported in that year as having a positive culture. Incidence represents all positive cultures in individuals that have not reported having any in the previous two years of data.

|                                                                              | 2023       | 2024       | 2025      |
|------------------------------------------------------------------------------|------------|------------|-----------|
| Number with annual review                                                    | (n=10344)  | (n=10424)  | (n=10624) |
| NTM Prevalence; n(%)                                                         | 273 (2.6)  | 271 (2.6)  | 308 (2.9) |
| On NTM treatment in the given year;<br>n (% of NTM prevalence in given year) | 111 (40.7) | 101 (37.3) | 97 (31.5) |
| NTM Incidence <sup>1</sup>                                                   | 144 (1.5)  | 151 (1.5)  | 173 (1.7) |
| <i>M. abscessus</i> prevalence                                               | 81 (0.8)   | 74 (0.7)   | 89 (0.8)  |
| <i>M. abscessus</i> incidence <sup>2</sup>                                   | 32 (0.3)   | 34 (0.3)   | 49 (0.5)  |

1 Proportion based on the number of patients with non-positive NTM tests in the previous two data years

2 Proportion based on the number of patients with non-positive *M. abscessus* tests in the previous two data years



# Complications

## 1.22a Complications 2019 and 2025 in young people (<16 years)<sup>1</sup> N=3608 in 2025; N=3966 in 2019

The number shown is for a complication that has been present in the 12 months prior to the 2019 and 2025 annual reviews respectively. Proportions are from all people younger than 16 years at annual review.

| Complications                                  | 2019 n(%) | 2025 n(%) |
|------------------------------------------------|-----------|-----------|
| <b>Respiratory related</b>                     |           |           |
| Nasal polyps*                                  | 120 (3.0) | 47 (1.3)  |
| Sinus disease                                  | 52 (1.3)  | 29 (0.8)  |
| Asthma                                         | 272 (6.9) | 88 (2.4)  |
| Allergic Bronchopulmonary Aspergillosis (ABPA) | 138 (3.5) | 37 (1.0)  |
| Haemoptysis (massive, severe and/or moderate)  | 16 (0.4)  | <5        |
| Massive haemoptysis                            | <5        | 0         |
| Pneumothorax requiring chest tube              | 0         | 0         |
| <b>Cardiac complications<sup>1</sup></b>       |           |           |
| Tachyarrhythmia                                | <5        | <5        |
| Bradycardia                                    | 0         | 0         |
| Cardiac arrest                                 | 0         | 0         |
| Cardiomyopathy                                 | 0         | 0         |
| Congenital heart disease                       | 12 (0.3)  | 11 (0.3)  |
| Heart failure                                  | 0         | 0         |
| Ischaemic heart disease                        | 0         | 0         |
| Valvular disease                               | <5        | 6 (0.2)   |
| Other                                          | <5        | 6 (0.2)   |
| <b>Pancreas and hepatobiliary disease</b>      |           |           |
| Raised liver enzymes                           | 302 (7.6) | 318 (8.8) |
| Liver disease                                  | 357 (9.0) | 325 (9.0) |
| Cirrhosis with no portal hypertension          | 15 (0.4)  | 6 (0.2)   |
| Cirrhosis with portal hypertension             | 28 (0.7)  | 11 (0.3)  |
| Gall bladder disease requiring surgery         | 24 (0.6)  | 23 (0.6)  |
| Pancreatitis                                   | 9 (0.2)   | <5        |
| <b>Upper gastrointestinal (GI)</b>             |           |           |
| Gastro-oesophageal reflux disease (GORD)       | 252 (6.4) | 173 (4.8) |
| Peptic ulcer                                   | 0         | 0         |
| GI bleed (varices as source)                   | <5        | <5        |
| GI bleed (non varices as source)               | <5        | <5        |

\* Previous reports listed this complication as "Nasal polyps requiring surgery". The UK CF registry does not specify a difference between nasal polyps and nasal polyps requiring surgery therefore we have changed the wording.

1 Numbers of cardiac complications in 2019 differ from 2019 data included in 2024 report due to re-classification of 'Other' cardiac complications by a clinician.

## 1.22a Complications 2019 and 2025 in young people (<16 years) (cont.)

N=3608 in 2025; N=3966 in 2019

| Complications                                 | 2019 n(%) | 2025 n(%) |
|-----------------------------------------------|-----------|-----------|
| <b>Lower gastrointestinal</b>                 |           |           |
| Intestinal obstruction                        | 12 (0.3)  | 9 (0.2)   |
| Distal Intestinal Obstruction Syndrome (DIOS) | 100 (2.5) | 52 (1.4)  |
| Fibrosing colonopathy / colonic stricture     | 0         | 0         |
| Rectal prolapse                               | 7 (0.2)   | 6 (0.2)   |
| <b>Renal</b>                                  |           |           |
| Kidney stones                                 | 11 (0.3)  | 6 (0.2)   |
| Renal failure                                 | 5 (0.1)   | <5        |
| <b>Musculoskeletal</b>                        |           |           |
| Arthritis                                     | 9 (0.2)   | <5        |
| Arthropathy                                   | 14 (0.4)  | <5        |
| Bone fracture                                 | 13 (0.3)  | 9 (0.2)   |
| Osteopenia                                    | 25 (0.6)  | 12 (0.3)  |
| Osteoporosis                                  | 5 (0.1)   | <5        |
| <b>Other</b>                                  |           |           |
| Cancer confirmed by histology                 | 0         | 0         |
| Port inserted or replaced                     | 85 (2.1)  | 23 (0.6)  |
| Depression                                    | 14 (0.4)  | <5        |
| Hearing loss                                  | 39 (1.0)  | 26 (0.7)  |
| Hypertension                                  | 5 (0.1)   | <5        |
| Urinary incontinence                          | 81 (2.0)  | 64 (1.8)  |
| Faecal incontinence                           | 25 (0.6)  | 28 (0.8)  |
| Postural anomaly                              | 81 (2.0)  | 30 (0.8)  |

## 1.22b Complications 2019 and 2025 in adults (ages 16 years and older) N=7018 in 2025; N=6104 in 2019

The number shown is for a complication that has been present in the 12 months prior to the 2019 and 2025 annual reviews respectively. Proportions are from all people ages 16 years and older at annual review.

| Complications                                 | 2019 n(%)   | 2025 n(%)   |
|-----------------------------------------------|-------------|-------------|
| <b>Respiratory related</b>                    |             |             |
| Nasal polyps*                                 | 306 (5.0)   | 300 (4.3)   |
| Sinus disease                                 | 745 (12.2)  | 853 (12.2)  |
| Asthma                                        | 653 (10.7)  | 619 (8.8)   |
| ABPA                                          | 616 (10.1)  | 469 (6.7)   |
| Haemoptysis (massive, severe and/or moderate) | 404 (6.6)   | 129 (1.8)   |
| Massive haemoptysis                           | 36 (0.6)    | 9 (0.1)     |
| Pneumothorax requiring chest tube             | 27 (0.4)    | 5 (0.1)     |
| <b>Cardiac complications<sup>1</sup></b>      |             |             |
| Tachyarrhythmia                               | 29 (0.5)    | 36 (0.5)    |
| Bradycardia                                   | 7 (0.1)     | 6 (0.1)     |
| Cardiac arrest                                | <5          | <5          |
| Cardiomyopathy                                | 8 (0.1)     | 14 (0.2)    |
| Congenital heart disease                      | 10 (0.2)    | 18 (0.3)    |
| Heart failure                                 | <5          | 23 (0.3)    |
| Ischaemic heart disease                       | 8 (0.1)     | 14 (0.2)    |
| Valvular disease                              | 14 (0.2)    | 22 (0.3)    |
| Other                                         | 37 (0.6)    | 53 (0.8)    |
| <b>Pancreas and hepatobiliary disease</b>     |             |             |
| Raised liver enzymes                          | 708 (11.6)  | 979 (13.9)  |
| Liver disease                                 | 1110 (18.2) | 1627 (23.2) |
| Cirrhosis with no portal hypertension         | 48 (0.8)    | 102 (1.5)   |
| Cirrhosis with portal hypertension            | 107 (1.8)   | 128 (1.8)   |
| Gall bladder disease requiring surgery        | 119 (1.9)   | 271 (3.9)   |
| Pancreatitis                                  | 56 (0.9)    | 76 (1.1)    |
| <b>Upper gastrointestinal (GI)</b>            |             |             |
| Gastro-oesophageal reflux disease (GORD)      | 1444 (23.7) | 1558 (22.2) |
| Peptic ulcer                                  | <5          | <5          |
| GI bleed (varices as source)                  | 10 (0.2)    | 9 (0.1)     |
| GI bleed (non varices as source)              | 11 (0.2)    | 6 (0.1)     |

\* Previous reports listed this complication as "Nasal polyps requiring surgery". The UK CF registry does not specify a difference between nasal polyps and nasal polyps requiring surgery therefore we have changed the wording.

1 Numbers of cardiac complications in 2019 differ from 2019 data included in 2024 report due to re-classification of 'Other' cardiac complications by a clinician.

## 1.22b Complications 2019 and 2025 in adults (ages 16 years and older) (cont.)

N=7018 in 2025; N=6104 in 2019

| Complications                             | 2019 n(%)  | 2025 n(%)   |
|-------------------------------------------|------------|-------------|
| <b>Lower gastrointestinal</b>             |            |             |
| Intestinal obstruction                    | 22 (0.4)   | 29 (0.4)    |
| DIOS                                      | 470 (7.7)  | 338 (4.8)   |
| Fibrosing colonopathy / colonic stricture | <5         | <5          |
| Rectal prolapse                           | 5 (0.1)    | 6 (0.1)     |
| <b>Renal</b>                              |            |             |
| Kidney stones                             | 100 (1.6)  | 198 (2.8)   |
| Renal failure                             | 92 (1.5)   | 113 (1.6)   |
| <b>Musculoskeletal</b>                    |            |             |
| Kidney stones                             | 100 (1.6)  | 198 (2.8)   |
| Renal failure                             | 92 (1.5)   | 113 (1.6)   |
| Bone fracture                             | 34 (0.6)   | 24 (0.4)    |
| Osteopenia                                | 950 (15.6) | 1123 (16.7) |
| Osteoporosis                              | 409 (6.7)  | 536 (8.0)   |
| <b>Other</b>                              |            |             |
| Cancer confirmed by histology             | 28 (0.5)   | 45 (0.6)    |
| Port inserted or replaced                 | 188 (3.1)  | 62 (0.9)    |
| Depression                                | 432 (7.1)  | 519 (7.4)   |
| Hearing loss                              | 300 (4.9)  | 392 (5.6)   |
| Hypertension                              | 121 (2.0)  | 198 (2.8)   |
| Urinary Incontinence                      | 858 (14.1) | 668 (9.5)   |
| Faecal Incontinence                       | 49 (0.8)   | 81 (1.2)    |
| Postural Anomaly                          | 883 (14.5) | 483 (6.9)   |

## 1.23 Incidence of complications

The table below describes new cases of a complication that have not been reported for an individual in at least the previous two years.

|                                      | 2024                 |                       |                       | 2025                 |                       |                       |
|--------------------------------------|----------------------|-----------------------|-----------------------|----------------------|-----------------------|-----------------------|
|                                      | Overall<br>(n=10423) | <16 years<br>(n=3688) | ≥16 years<br>(n=6735) | Overall<br>(n=10624) | <16 years<br>(n=3606) | ≥16 years<br>(n=7018) |
| ABPA                                 | 120 (1.2)            | 17 (0.5)              | 103 (1.5)             | 124 (1.2)            | 15 (0.4)              | 109 (1.6)             |
| Cirrhosis - no portal hypertension   | -*                   | <5                    | 41 (0.6)              | -*                   | <5                    | 48 (0.7)              |
| Cirrhosis - with portal hypertension | -*                   | <5                    | 28 (0.4)              | 35 (0.3)             | 5 (0.1)               | 30 (0.4)              |
| Cancer confirmed by histology        | -*                   | <5                    | 21 (0.3)              | 31 (0.3)             | 0                     | 31 (0.4)              |

## 1.24 CF diabetes\*\* N=8642

Cystic fibrosis diabetes (CFD) is common in adults and adolescents with cystic fibrosis. This is because, for many people with CF, the pancreas does not work properly. This can mean that not enough insulin is produced, or it may not work properly, causing CFD. CFD is different from type 1 and type 2 diabetes, but has features of both.

|                                                                  | All ≥10 years<br>N=8642 | 10-15 years<br>N=1624 | ≥16 years<br>N=7018 |
|------------------------------------------------------------------|-------------------------|-----------------------|---------------------|
| <b>CFD treatment</b>                                             |                         |                       |                     |
| People diagnosed with CFD; n (%) <sup>1</sup>                    | 2893 (33.5)             | 163 (10.0)            | 2730 (38.9)         |
| <b>CFD Treatment</b>                                             |                         |                       |                     |
| People on CFD treatment; n (%) <sup>1</sup>                      | 2418 (28.0)             | 137 (8.4)             | 2281 (32.5)         |
| <b>Treatment Type</b>                                            |                         |                       |                     |
| Insulin; n (%) <sup>2</sup>                                      | 1916 (79.2)             | 132 (96.4)            | 1784 (78.2)         |
| Treatment unknown; n (%) <sup>2</sup>                            | 6 (0.2)                 | 0 (0.0)               | 6 (0.3)             |
| <i>For people not on insulin:</i>                                |                         |                       |                     |
| Dietary change alone; n (%) <sup>2</sup>                         | -*                      | <5                    | 261 (11.4)          |
| Oral hypoglycaemic agents alone; n (%) <sup>2</sup>              | -*                      | <5                    | 162 (7.1)           |
| Dietary change and oral hypoglycaemic agents; n (%) <sup>2</sup> | 68 (2.8)                | 0 (0.0)               | 68 (3.0)            |
| <b>CFD Screening</b>                                             |                         |                       |                     |
| Not screened (as prior CFD diagnosis); n (%) <sup>1</sup>        | 2264 (26.2)             | 83 (5.1)              | 2181 (31.1)         |
| <i>Of those eligible:</i>                                        |                         |                       |                     |
| People not screened (other); n (%) <sup>3</sup>                  | 1962 (30.8)             | 356 (23.1)            | 1606 (33.2)         |
| People screened; n (%) <sup>3</sup>                              | 4157 (65.2)             | 1043 (67.7)           | 3114 (64.4)         |
| <b>Screening Type</b>                                            |                         |                       |                     |
| Continuous glucose monitoring; n (%) <sup>4</sup>                | 1642 (39.5)             | 370 (35.5)            | 1272 (40.8)         |
| Oral glucose tolerance test; n (%) <sup>4</sup>                  | 1534 (36.9)             | 474 (45.4)            | 1060 (34.0)         |
| Screen test unknown; n (%) <sup>4</sup>                          | 1871 (45.0)             | 382 (36.6)            | 1489 (47.8)         |
| Unknown if screened; n (%) <sup>1</sup>                          | 259 (3.0)               | 142 (8.7)             | 117 (1.7)           |

\* Redacted to adhere to statistical disclosure guidelines.

\*\* Alternatively known as CF related diabetes.

1 Proportion of people with CF

2 Proportion of people on treatment.

3 Proportion of people without prior CFD diagnosis

4 Proportion of people screened.

# Antibiotics

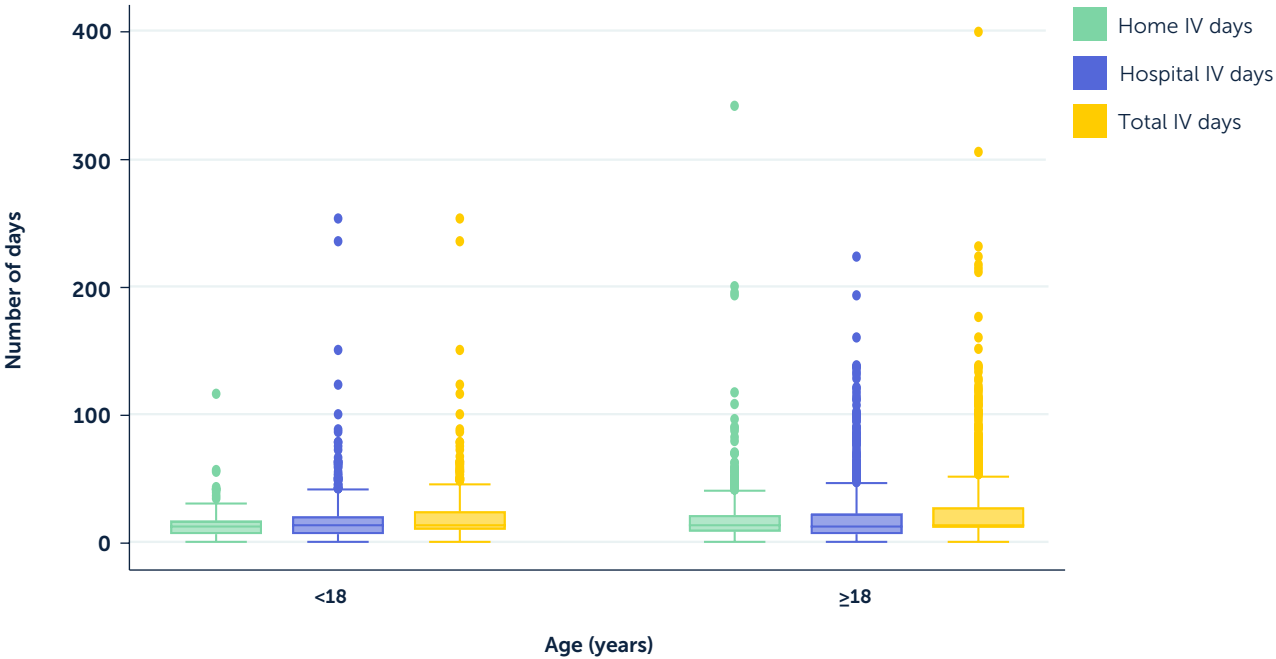
## 1.25 Intravenous (IV) antibiotics N=10624

When someone with CF becomes unwell with an infection, they might be prescribed intravenous (IV) antibiotics. This treatment can take a number of days and may take place as a hospital inpatient, or at home.

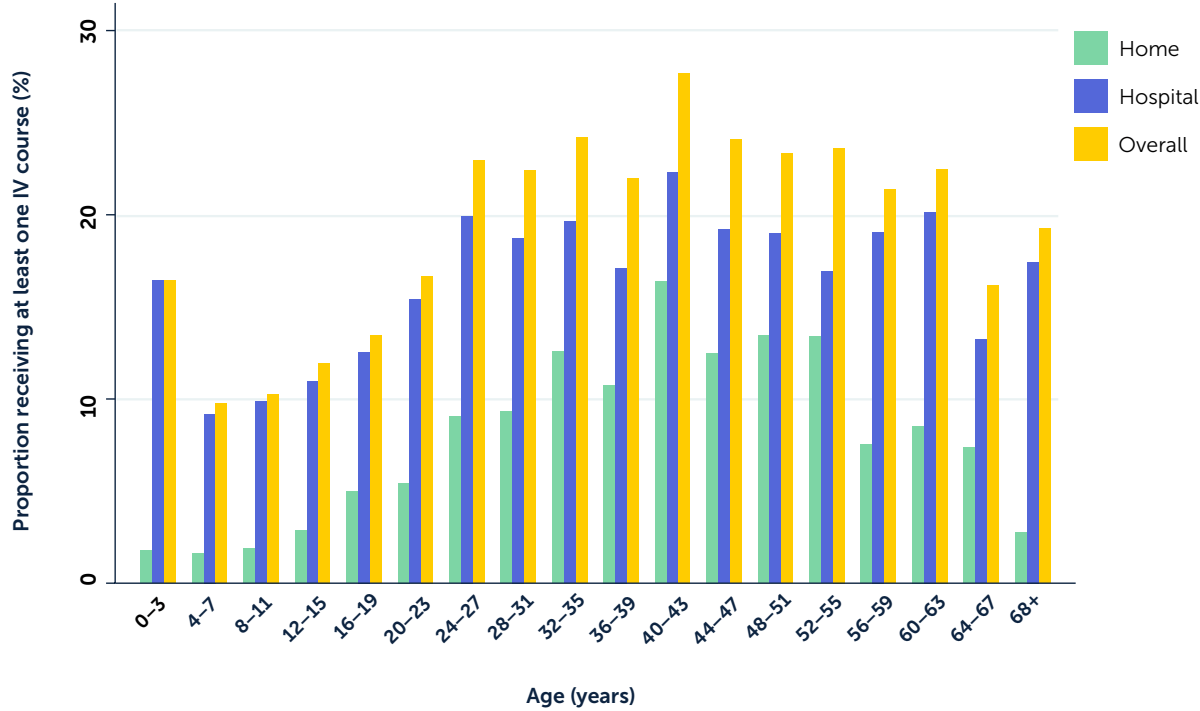
| Age     | n     | Home             |                      | Hospital         |                      | Total            |                      |
|---------|-------|------------------|----------------------|------------------|----------------------|------------------|----------------------|
|         |       | Patients<br>n(%) | Median<br>days (IQR) | Patients<br>n(%) | Median<br>days (IQR) | Patients<br>n(%) | Median<br>days (IQR) |
| 0-3     | 621   | 11 (1.8)         | 7 (4-14)             | 102 (16.4)       | 13 (6-15)            | 102 (16.4)       | 13 (7-16)            |
| 4-7     | 861   | 14 (1.6)         | 13 (10-14)           | 79 (9.2)         | 13 (6-14)            | 84 (9.8)         | 14 (7-21)            |
| 8-11    | 1002  | 19 (1.9)         | 12 (8-15)            | 99 (9.9)         | 14 (8-23)            | 103 (10.3)       | 14 (11-28)           |
| 12-15   | 1122  | 32 (2.9)         | 14 (8-19)            | 123 (11.0)       | 14 (10-32)           | 134 (11.9)       | 14 (13-35)           |
| 16-19   | 884   | 44 (5.0)         | 14 (7-24)            | 111 (12.6)       | 14 (8-26)            | 119 (13.5)       | 17 (13-34)           |
| 20-23   | 864   | 47 (5.4)         | 14 (7-19)            | 133 (15.4)       | 13 (7-25)            | 144 (16.7)       | 14 (11-28)           |
| 24-27   | 863   | 78 (9.0)         | 14 (9-16)            | 172 (19.9)       | 14 (7-26)            | 198 (22.9)       | 14 (12-28)           |
| 28-31   | 902   | 84 (9.3)         | 14 (10-21)           | 169 (18.7)       | 13 (7-21)            | 202 (22.4)       | 14 (11-28)           |
| 32-35   | 835   | 105 (12.6)       | 14 (9-19)            | 164 (19.6)       | 11 (6-20)            | 202 (24.2)       | 14 (13-28)           |
| 36-39   | 678   | 73 (10.8)        | 14 (13-29)           | 116 (17.1)       | 13 (8-18)            | 149 (22.0)       | 14 (12-28)           |
| 40-43   | 574   | 94 (16.4)        | 14 (10-23)           | 128 (22.3)       | 12 (7-20)            | 159 (27.7)       | 15 (12-32)           |
| 44-47   | 432   | 54 (12.5)        | 14 (7-23)            | 83 (19.2)        | 11 (6-28)            | 104 (24.1)       | 14 (12-30)           |
| 48-51   | 253   | 34 (13.4)        | 13 (10-20)           | 48 (19.0)        | 10 (5-17)            | 59 (23.3)        | 14 (13-28)           |
| 52-55   | 254   | 34 (13.4)        | 14 (12-28)           | 43 (16.9)        | 14 (6-42)            | 60 (23.6)        | 20 (14-44)           |
| 56-59   | 173   | 13 (7.5)         | 14 (8-20)            | 33 (19.1)        | 14 (8-21)            | 37 (21.4)        | 14 (10-28)           |
| 60-63   | 129   | 11 (8.5)         | 13 (6-21)            | 26 (20.2)        | 14 (9-24)            | 29 (22.5)        | 15 (14-27)           |
| 64-67   | 68    | -*               | 14 (7-14)            | 9 (13.2)         | 12 (9-14)            | 11 (16.2)        | 14 (12-14)           |
| 68+     | 109   | <5               | -*                   | 19 (17.4)        | 14 (11-28)           | 21 (19.3)        | 14 (11-27)           |
| <16     | 3606  | 76 (2.1)         | 13 (8-14)            | 403 (11.2)       | 14 (7-21)            | 423 (11.7)       | 14 (10-24)           |
| ≥16     | 7018  | 679 (9.7)        | 14 (9-23)            | 1254 (17.9)      | 13 (7-23)            | 1494 (21.3)      | 14 (12-29)           |
| <18     | 4060  | 92 (2.3)         | 13 (7-18)            | 450 (11.1)       | 14 (7-21)            | 476 (11.7)       | 14 (10-25)           |
| ≥18     | 6564  | 663 (10.1)       | 14 (9-22)            | 1207 (18.4)      | 13 (7-23)            | 1441 (22.0)      | 14 (12-28)           |
| Overall | 10624 | 755 (7.1)        | 14 (9-22)            | 1657 (15.6)      | 13 (7-22)            | 1917 (18.0)      | 14 (12-28)           |

\* Redacted to adhere to statistical disclosure guidelines.

This box plot graph illustrates the spread of the number of days on IV antibiotics in the UK CF population, stratified by age.<sup>1, 2, 3</sup> A guide on how to correctly interpret this box plot graph can be found on page 12.



The bar graph below summarises the proportion of people receiving at least one course of IV antibiotics across different age groups within the UK CF population. Overall, the proportion of people receiving at least one IV course at home was 7.3% and in hospital was 15.6%. The proportion receiving any IVs was 18.1%.



1. Median and inter-quartile ranges of number of home and hospital IV days included in boxplots are detailed in table in 1.25.
2. Outlying points are for people with numbers of IV days over 1.5x the inter-quartile range over the upper quartile. The number of people with numbers of IV days represented by these points are: 150 (hospital), 55 (home) and 167 (total days).
3. Total numbers of IV days in a reporting year may be greater than 365 days as annual reviews from consecutive years may be more than 365 days apart.

## 1.26 Inhaled antibiotic use

N=10624

|                                     | 2025        |            |             |
|-------------------------------------|-------------|------------|-------------|
|                                     | Overall     | <16 years  | ≥16 years   |
| Number of people                    | 10624       | 3606       | 7018        |
| Tobramycin solution; n (%)          | 746 (7.0)   | 131 (3.6)  | 615 (8.8)   |
| Other aminoglycoside; n (%)         | 44 (0.4)    | 5 (0.1)    | 39 (0.6)    |
| Colistin; n (%)                     | 1011 (9.5)  | 273 (7.6)  | 738 (10.5)  |
| Promixin; n (%)                     | 901 (8.5)   | 122 (3.4)  | 779 (11.1)  |
| Aztreonam; n (%)                    | 617 (5.8)   | 24 (0.7)   | 593 (8.4)   |
| Colistimethate (DPI); n (%)         | 868 (8.2)   | 43 (1.2)   | 825 (11.8)  |
| Tobramycin Inhalation Powder; n (%) | 482 (4.5)   | 12 (0.3)   | 470 (6.7)   |
| Levofloxacin ; n(%)                 | 69 (0.6)    | 0 (0.0)    | 69 (1.0)    |
| At least one of the above; n (%)    | 3357 (31.6) | 466 (12.9) | 2891 (41.2) |

## 1.27 Inhaled antibiotic use among people with chronic *Pseudomonas aeruginosa*

The consensus view in the UK is that 90% of people chronically infected with *Pseudomonas aeruginosa* should be prescribed at least one of the below inhaled antibiotics.

|                                          | 2015        |            |             | 2019        |            |             | 2025       |           |            |
|------------------------------------------|-------------|------------|-------------|-------------|------------|-------------|------------|-----------|------------|
|                                          | Overall     | <16 years  | ≥16 years   | Overall     | <16 years  | ≥16 years   | Overall    | <16 years | ≥16 years  |
| People with chronic <i>P. aeruginosa</i> | 2859        | 239        | 2625        | 2609        | 206        | 2403        | 817        | 66        | 751        |
| Tobramycin solution; n(%)                | 653 (22.8)  | 86 (36.8)  | 567 (21.6)  | 623 (23.9)  | 87 (42.2)  | 536 (22.3)  | 160 (19.6) | 20 (30.3) | 140 (18.6) |
| Other aminoglycoside; n(%)               | 95 (3.3)    | 15 (6.4)   | 80 (3.1)    | 29 (1.1)    | 0          | 29 (1.2)    | 8 (1.0)    | 0         | 8 (1.1)    |
| Colistin; n(%)                           | 840 (29.4)  | 108 (46.2) | 732 (28.0)  | 615 (23.6)  | 81 (39.3)  | 534 (22.2)  | 186 (22.8) | 31 (47.0) | 155 (20.6) |
| Promixin; n(%)                           | 896 (31.3)  | 111 (47.4) | 785 (29.9)  | 771 (29.6)  | 97 (47.1)  | 674 (28.0)  | 121 (14.8) | 16 (24.2) | 105 (14.0) |
| Aztreonam; n(%)                          | 485 (17.0)  | 8 (3.4)    | 477 (18.2)  | 690 (26.4)  | 15 (7.3)   | 675 (28.1)  | 182 (22.3) | 8 (12.1)  | 174 (23.2) |
| Colistimethate (DPI); n(%)               | 537 (18.8)  | 22 (9.4)   | 515 (19.6)  | 457 (17.5)  | 11 (5.3)   | 446 (18.6)  | 168 (20.6) | 7 (10.6)  | 161 (21.4) |
| Tobramycin Inhalation Powder; n(%)       | 888 (31.1)  | 25 (10.7)  | 863 (32.9)  | 573 (22.0)  | 9 (4.4)    | 564 (23.5)  | -*         | <5        | 80 (10.7)  |
| Levofloxacin; n(%)                       | -**         | -**        | -**         | <5          | 0          | <5          | 36 (4.4)   | 0         | 36 (4.8)   |
| At least one of the above; n(%)          | 2547 (89.1) | 226 (96.6) | 2321 (96.6) | 2315 (88.7) | 189 (91.7) | 2126 (88.5) | 627 (76.7) | 57 (86.4) | 570 (75.9) |

\* Redacted to adhere to statistical disclosure guidelines

\*\* No data in the given year as the drug in question was not licensed for use on the NHS

## 1.28 Long-term azithromycin use

Azithromycin is an antibiotic with some anti-inflammatory properties. It is recommended for long-term use as a prophylactic antibiotic in people with chronic *Pseudomonas aeruginosa*.

|      |            | Number of people on azithromycin; n | People with chronic <i>P. aeruginosa</i> ; n(%) | People without chronic <i>P. aeruginosa</i> ; n(%) |
|------|------------|-------------------------------------|-------------------------------------------------|----------------------------------------------------|
| 2015 | Overall    | 3790                                | 1916 (50.6)                                     | 1874 (49.4)                                        |
|      | 0-3 years  | _*                                  | 18 (85.7)                                       | <5                                                 |
|      | 4-15 years | _*                                  | 491 (85.5)                                      | _*                                                 |
|      | ≥ 16 years | 3195                                | 1407 (44.0)                                     | 1788 (56.0)                                        |
| 2019 | Overall    | 4130                                | 1772 (42.9)                                     | 2358 (57.1)                                        |
|      | 0-3 years  | _*                                  | <5                                              | 44 (95.7)                                          |
|      | 4-15 years | _*                                  | _*                                              | 573 (85.3)                                         |
|      | ≥ 16 years | 3412                                | 1671 (49.0)                                     | 1741 (51.0)                                        |
| 2025 | Overall    | 3156                                | 473 (15.0)                                      | 2683 (85.0)                                        |
|      | 0-3 years  | _*                                  | <5                                              | 57 (93.4)                                          |
|      | 4-15 years | _*                                  | _*                                              | 275 (93.9)                                         |
|      | ≥ 16 years | 2802                                | 451 (16.1)                                      | 2351 (83.9)                                        |

## 1.29 Prophylactic flucloxacillin use\*\*

Flucloxacillin is an antibiotic that is used prophylactically to prevent infection with bacteria.

|           | 2019                          |                                             | 2025                          |                                             |
|-----------|-------------------------------|---------------------------------------------|-------------------------------|---------------------------------------------|
| Age       | Number of people in age group | People on prophylactic flucloxacillin; n(%) | Number of people in age group | People on prophylactic flucloxacillin; n(%) |
| 0-3       | 804                           | 455 (56.6)                                  | 621                           | 310 (49.9)                                  |
| 4-7       | 1075                          | 297 (27.6)                                  | 861                           | 179 (20.8)                                  |
| 8-11      | 1104                          | 293 (26.5)                                  | 1002                          | 132 (13.2)                                  |
| 12-15     | 983                           | 229 (23.3)                                  | 1122                          | 124 (11.1)                                  |
| 16-19     | 812                           | 172 (21.2)                                  | 884                           | 85 (9.6)                                    |
| 20-23     | 996                           | 113 (11.3)                                  | 864                           | 95 (11.0)                                   |
| 24-27     | 902                           | 69 (7.6)                                    | 863                           | 70 (8.1)                                    |
| 28-31     | 852                           | 66 (7.7)                                    | 902                           | 41 (4.5)                                    |
| 32-35     | 695                           | 35 (5.0)                                    | 835                           | 40 (4.8)                                    |
| 36-39     | 564                           | 37 (6.6)                                    | 678                           | 26 (3.8)                                    |
| 40-43     | 379                           | 32 (8.4)                                    | 574                           | 16 (2.8)                                    |
| 44-47     | 256                           | 16 (6.2)                                    | 432                           | 24 (5.6)                                    |
| 48-51     | 229                           | 14 (6.1)                                    | 253                           | 5 (2.0)                                     |
| 52-55     | 164                           | 9 (5.5)                                     | 254                           | 9 (3.5)                                     |
| 56-59     | 110                           | 5 (4.5)                                     | 173                           | 10 (5.8)                                    |
| 60-63     | 57                            | <5                                          | 129                           | <5                                          |
| 64-67     | 33                            | <5                                          | 68                            | <5                                          |
| 68+       | 55                            | <5                                          | 109                           | <5                                          |
| <16 years | 3966                          | 1274 (32.1)                                 | 3606                          | 745 (20.7)                                  |
| ≥16 years | 6104                          | 576 (9.4)                                   | 7018                          | 428 (6.1)                                   |
| <18 years | 4366                          | 1375 (31.5)                                 | 4060                          | 793 (19.5)                                  |
| ≥18 years | 5704                          | 475 (8.3)                                   | 6564                          | 380 (5.8)                                   |
| Overall   | 10070                         | 1850 (18.4)                                 | 10624                         | 1173 (11.0)                                 |

\* Redacted to adhere to statistical disclosure guidelines.

\*\* Data includes people that have been recruited and randomised for the CF START trial from 2018 – 2023. The CF START trial is investigating the use of prophylactic flucloxacillin use in infants. You can learn more about this trial here: [cfstart.org.uk](https://cfstart.org.uk)

# Bronchodilators and corticosteroids

## 1.30 Inhaled bronchodilators and corticosteroids

| Age          | Number of people in age group | People on inhaled bronchodilators; n(%) | People on inhaled corticosteroids; n(%) | People on inhaled combination corticosteroids/ bronchodilators; n(%) |
|--------------|-------------------------------|-----------------------------------------|-----------------------------------------|----------------------------------------------------------------------|
| <6 years     | 1050                          | 227 (21.6)                              | 71 (6.8)                                | <5                                                                   |
| 6 - 15 years | 2556                          | 1065 (41.7)                             | 338 (13.2)                              | - *                                                                  |
| 6 - 17 years | 3010                          | 1305 (43.4)                             | 384 (12.8)                              | - *                                                                  |
| ≥16 years    | 7018                          | 4507 (64.2)                             | 1079 (15.4)                             | 1702 (24.3)                                                          |
| ≥18 years    | 6564                          | 4267 (65.0)                             | 1033 (15.7)                             | 1636 (24.9)                                                          |
| Overall      | 10624                         | 5799 (54.6)                             | 1488 (14.0)                             | 1941 (18.3)                                                          |

\* Redacted to adhere to statistical disclosure guidelines.

# Muco-active therapies

Muco-active therapies, such as mannitol, DNase and hypertonic saline, break down mucus, making it easier to clear from the lungs.

## 1.31 Mannitol\*\*

|           | 2019                          |                           | 2025                          |                           |
|-----------|-------------------------------|---------------------------|-------------------------------|---------------------------|
| Age       | Number of people in age group | People on Mannitol; n (%) | Number of people in age group | People on Mannitol; n (%) |
| <16 years | 3966                          | <5                        | 3606                          | <5                        |
| ≥16 years | 6104                          | 342 (5.6)                 | 7018                          | 157 (2.2)                 |
| <18 years | 4366                          | –*                        | 4060                          | <5                        |
| ≥18 years | 5704                          | 337 (5.9)                 | 6564                          | 156 (2.4)                 |
| Overall   | 10070                         | –*                        | 10624                         | –*                        |

## 1.32 DNase\*\*

|           | 2015                          |                       | 2019                          |                       | 2025                          |                       |
|-----------|-------------------------------|-----------------------|-------------------------------|-----------------------|-------------------------------|-----------------------|
| Age       | Number of people in age group | People on DNase; n(%) | Number of people in age group | People on DNase; n(%) | Number of people in age group | People on DNase; n(%) |
| 0-3       | 921                           | 121 (13.1)            | 804                           | 155 (19.3)            | 621                           | 109 (17.6)            |
| 4-7       | 1098                          | 478 (43.5)            | 1075                          | 584 (54.3)            | 861                           | 402 (46.7)            |
| 8-11      | 946                           | 665 (70.3)            | 1104                          | 858 (77.7)            | 1002                          | 622 (62.1)            |
| 12-15     | 880                           | 654 (74.3)            | 983                           | 841 (85.6)            | 1122                          | 769 (68.5)            |
| 16-19     | 999                           | 733 (73.4)            | 812                           | 682 (84.0)            | 884                           | 558 (63.1)            |
| 20-23     | 1000                          | 654 (65.4)            | 996                           | 795 (79.8)            | 864                           | 479 (55.4)            |
| 24-27     | 954                           | 609 (63.8)            | 902                           | 684 (75.8)            | 863                           | 472 (54.7)            |
| 28-31     | 749                           | 470 (62.8)            | 852                           | 615 (72.2)            | 902                           | 480 (53.2)            |
| 32-35     | 634                           | 376 (59.3)            | 695                           | 477 (68.6)            | 835                           | 421 (50.4)            |
| 36-39     | 407                           | 225 (55.3)            | 564                           | 376 (66.7)            | 678                           | 360 (53.1)            |
| 40-43     | 286                           | 135 (47.2)            | 379                           | 235 (62.0)            | 574                           | 277 (48.3)            |
| 44-47     | 260                           | 140 (53.8)            | 256                           | 145 (56.6)            | 432                           | 222 (51.4)            |
| 48-51     | 170                           | 89 (52.4)             | 229                           | 133 (58.1)            | 253                           | 136 (53.8)            |
| 52-55     | 121                           | 64 (52.9)             | 164                           | 84 (51.2)             | 254                           | 109 (42.9)            |
| 56-59     | 63                            | 32 (50.8)             | 110                           | 62 (56.4)             | 173                           | 85 (49.1)             |
| 60-63     | 36                            | 16 (44.4)             | 57                            | 31 (54.4)             | 129                           | 64 (49.6)             |
| 64-67     | 27                            | 16 (59.3)             | 33                            | 18 (54.5)             | 68                            | 35 (51.5)             |
| 68+       | 36                            | 18 (50.0)             | 55                            | 26 (47.3)             | 109                           | 59 (54.1)             |
| <16 years | 3845                          | 1918 (49.9)           | 3966                          | 2438 (61.5)           | 3606                          | 1902 (52.7)           |
| ≥16 years | 5742                          | 3577 (62.3)           | 6104                          | 4363 (71.5)           | 7018                          | 3757 (53.5)           |
| <18 years | 4336                          | 2300 (53.0)           | 4366                          | 2774 (63.5)           | 4060                          | 2192 (54.0)           |
| ≥18 years | 5251                          | 3195 (60.8)           | 5704                          | 4027 (70.6)           | 6564                          | 3467 (52.8)           |
| Overall   | 9587                          | 5495 (57.3)           | 10070                         | 6801 (67.5)           | 10624                         | 5659 (53.3)           |

\* Redacted to adhere to statistical disclosure guidelines.

\*\* 'CF STORM, a clinical trial investigating the withdrawal of mucoactive therapies, was ongoing during 2025. See [cfstorm.org.uk](https://cfstorm.org.uk) for more information.

## 1.33 Hypertonic saline\*

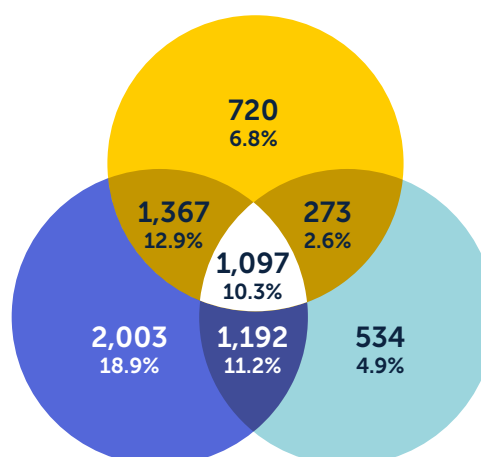
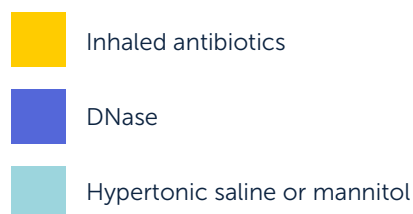
This treatment helps to thin mucus so that it is easier to cough out of the body.

| Age       | 2015                          |                                   | 2019                          |                                   | 2025                          |                                   |
|-----------|-------------------------------|-----------------------------------|-------------------------------|-----------------------------------|-------------------------------|-----------------------------------|
|           | Number of people in age group | People on hypertonic saline; n(%) | Number of people in age group | People on hypertonic saline; n(%) | Number of people in age group | People on hypertonic saline; n(%) |
| 0-3       | 921                           | 55 (6.0)                          | 804                           | 92 (11.4)                         | 621                           | 131 (21.1)                        |
| 4-7       | 1098                          | 198 (18.0)                        | 1075                          | 304 (28.3)                        | 861                           | 311 (36.1)                        |
| 8-11      | 946                           | 282 (29.8)                        | 1104                          | 415 (37.6)                        | 1002                          | 357 (35.6)                        |
| 12-15     | 880                           | 359 (40.8)                        | 983                           | 458 (46.6)                        | 1122                          | 438 (39.0)                        |
| 16-19     | 999                           | 354 (35.4)                        | 812                           | 409 (50.4)                        | 884                           | 309 (35.0)                        |
| 20-23     | 1000                          | 290 (29.0)                        | 996                           | 389 (39.1)                        | 864                           | 234 (27.1)                        |
| 24-27     | 954                           | 277 (29.0)                        | 902                           | 307 (34.0)                        | 863                           | 217 (25.1)                        |
| 28-31     | 749                           | 246 (32.8)                        | 852                           | 269 (31.6)                        | 902                           | 199 (22.1)                        |
| 32-35     | 634                           | 197 (31.1)                        | 695                           | 233 (33.5)                        | 835                           | 160 (19.2)                        |
| 36-39     | 407                           | 122 (30.0)                        | 564                           | 202 (35.8)                        | 678                           | 133 (19.6)                        |
| 40-43     | 286                           | 60 (21.0)                         | 379                           | 123 (32.5)                        | 574                           | 140 (24.4)                        |
| 44-47     | 260                           | 63 (24.2)                         | 256                           | 80 (31.2)                         | 432                           | 99 (22.9)                         |
| 48-51     | 170                           | 50 (29.4)                         | 229                           | 65 (28.4)                         | 253                           | 59 (23.3)                         |
| 52-55     | 121                           | 34 (28.1)                         | 164                           | 46 (28.0)                         | 254                           | 62 (24.4)                         |
| 56-59     | 63                            | 16 (25.4)                         | 110                           | 28 (25.5)                         | 173                           | 40 (23.1)                         |
| 60-63     | 36                            | 8 (22.2)                          | 57                            | 12 (21.1)                         | 129                           | 30 (23.3)                         |
| 64-67     | 27                            | 8 (29.6)                          | 33                            | 8 (24.2)                          | 68                            | 19 (27.9)                         |
| 68+       | 36                            | 9 (25.0)                          | 55                            | 20 (36.4)                         | 109                           | 23 (21.1)                         |
| <16 years | 3845                          | 894 (23.3)                        | 3966                          | 1269 (32.0)                       | 3606                          | 1237 (34.3)                       |
| ≥16 years | 5742                          | 1734 (30.2)                       | 6104                          | 2191 (35.9)                       | 7018                          | 1724 (24.6)                       |
| <18 years | 4336                          | 1084 (25.0)                       | 4366                          | 1477 (33.8)                       | 4060                          | 1403 (34.6)                       |
| ≥18 years | 5251                          | 1544 (29.4)                       | 5704                          | 1983 (34.8)                       | 6564                          | 1558 (23.7)                       |
| Overall   | 9587                          | 2628 (27.4)                       | 10070                         | 3460 (34.4)                       | 10624                         | 2961 (27.9)                       |

## 1.34 Inhaled therapies\*

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

**None of these inhaled medications:  
3,448 (32.5%)**



\* CF STORM, a clinical trial investigating the withdrawal of mucoactive therapies, was ongoing during 2025.. See <https://www.cfstorm.org.uk/> for more information.

# CFTR modulators

Here we describe changes to eligibility for and access to CFTR modulators throughout 2025. This includes the approval of vanzacaftor/tezacaftor/deutivacaftor in England, Northern Ireland and Wales, and the extension to eligibility for elexacaftor/tezacaftor/ivacaftor.

## **Vanzacaftor/tezacaftor/deutivacaftor (VTD)**

Vanzacaftor/tezacaftor/deutivacaftor (VTD) was approved by the Medicines and Healthcare products Regulatory Agency (MHRA) on 7 March 2025 for use in people with CF aged six years or older who have at least one F508del variant or at least one CFTR variant that produces a CFTR protein (alternatively described as not having two class 1 variants). The National Institute for Health and Care Excellence (NICE) approved the use of VTD in England on the 15 July 2025. VTD was available in Northern Ireland and Wales by November 2025. The Scottish Medicines Consortium (SMC) advised that access could be requested on a case-by-case basis, where a large health benefit was expected, while their independent assessment process was ongoing.

## **Elexacaftor/tezacaftor/ivacaftor (ETI)**

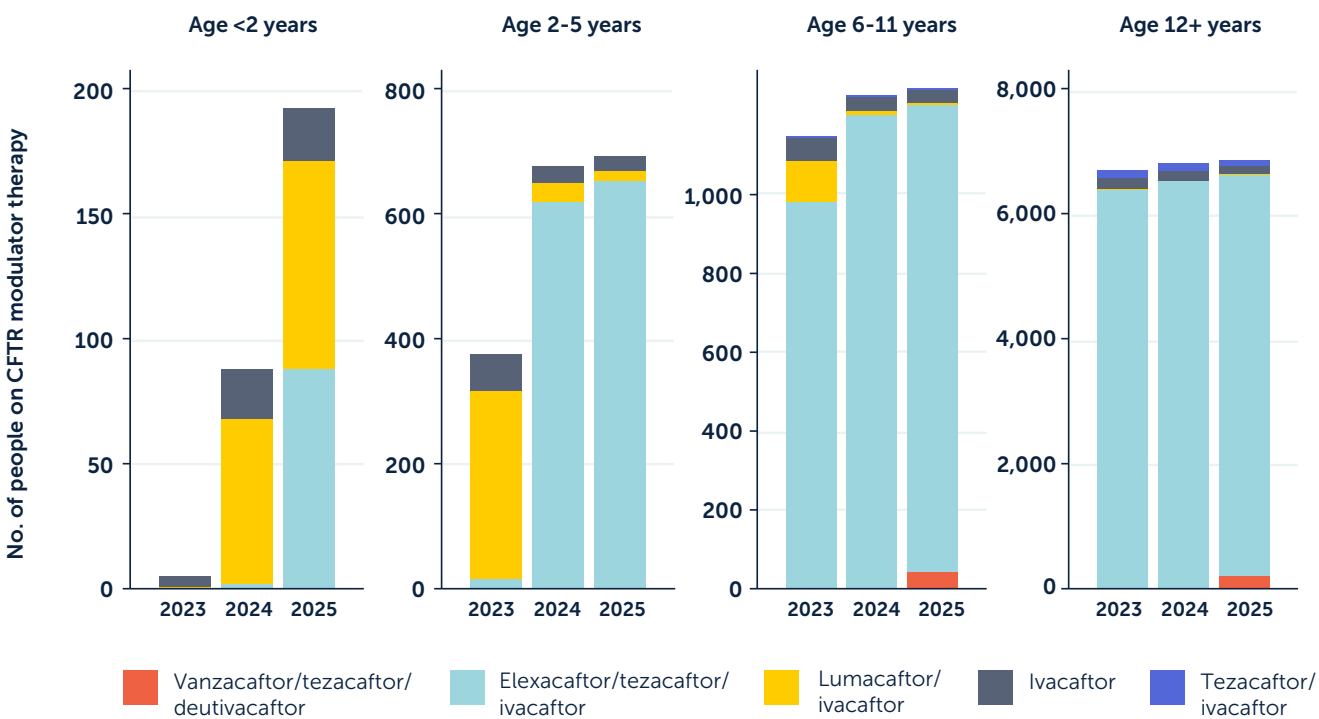
At the start of 2025, elexacaftor/tezacaftor/ivacaftor (ETI) was available in the UK for people with CF aged two years and over with at least one F508del variant. However, guidance from NHS commissioning continued to support the prescribing of ETI "off-label" to people with CF, with named eligible variants (outlined in 2024 Annual Data Report). In July 2025, the availability of ETI was expanded, in line with the approach taken by the European Medicines Agency (EMA), to include people with CF aged two years or older who have at least one variant that produces CFTR protein (alternatively described as not having two class 1 variants). This is in line with the prescribing criteria according to genotype for VTD.

## **Lumacaftor/ivacaftor, Tezacaftor/ivacaftor and Ivacaftor**

The eligibility and access arrangements for lumacaftor/ivacaftor, tezacaftor/ivacaftor and ivacaftor remain the same as detailed in the UK CF Registry 2024 Annual Data Report.

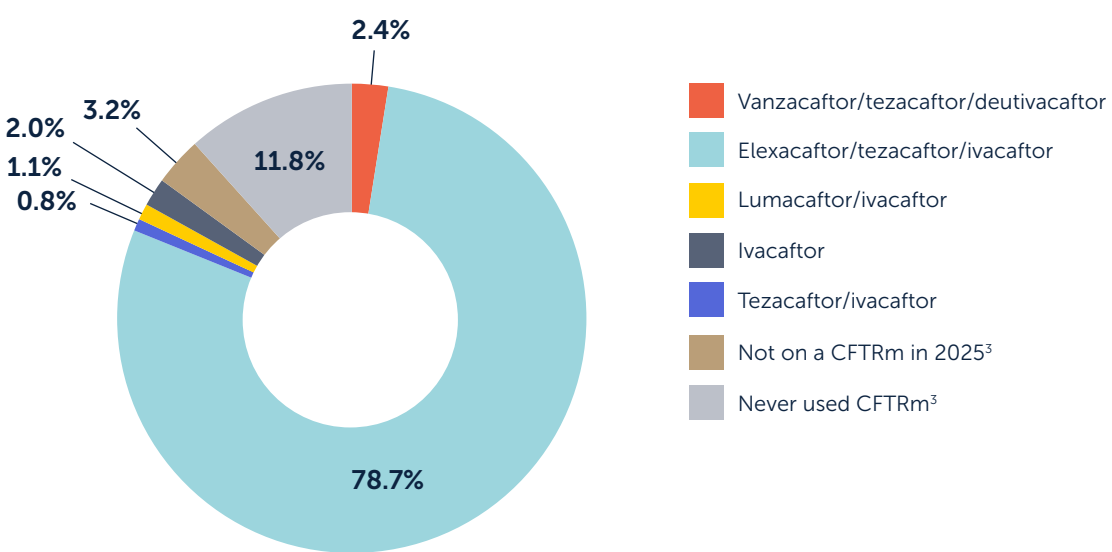
### 1.35 CFTR modulator usage in December of 2023, 2024 and 2025 among people with a 2025 annual review (by age group)<sup>1</sup> N=10,624

The graph below shows the number of people taking each drug in the December of 2023–2025. Only people who had an annual review in 2025 are included.



### 1.36 CFTR modulator use in 2025 N=10,614<sup>2</sup>

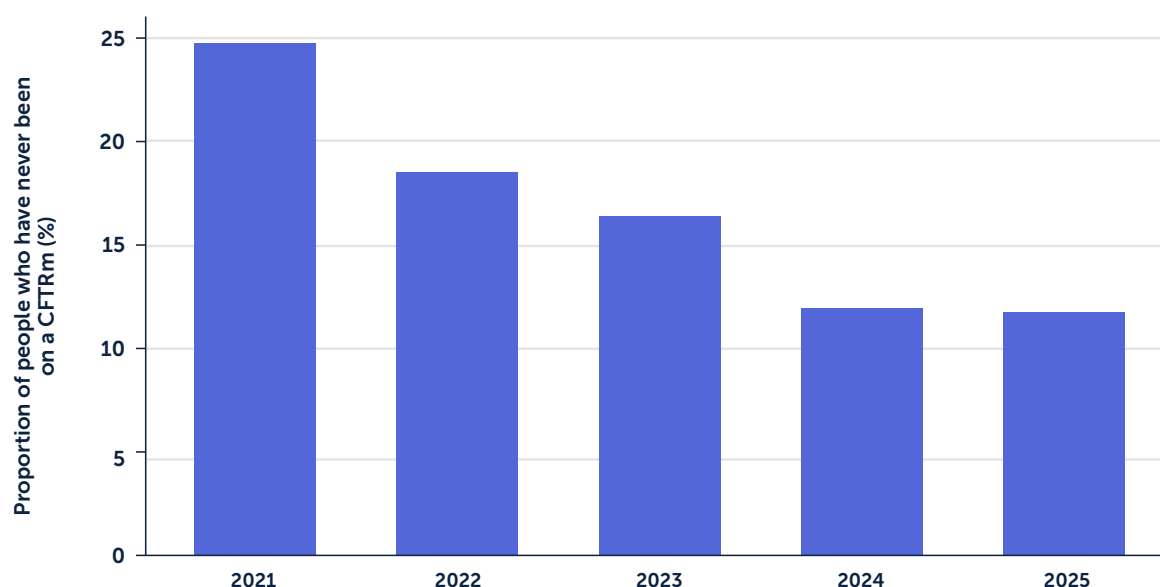
This chart shows the distribution of CFTR modulators taken during 2025. Where an individual had multiple prescriptions, only the most recent one was counted. 9028 people had a record of using a CFTRm in 2025.



1 All people of all ages with a 2025 annual review are included.  
2 10 people were excluded because their last prescribed CFTRm treatment was through a clinical trial and specific treatment was unknown.  
3 An individual was categorized as 'Not on a CFTRm in 2025' if they had a previous record of CFTRm use but no record of CFTRm use in 2025. Individuals categorized as 'Never used CFTRm' had no records of CFTRms prior to or in 2025. These figures include eligible and non-eligible people.

## 1.37 Proportion of people who have never used a CFTR modulator 2021–2025\*

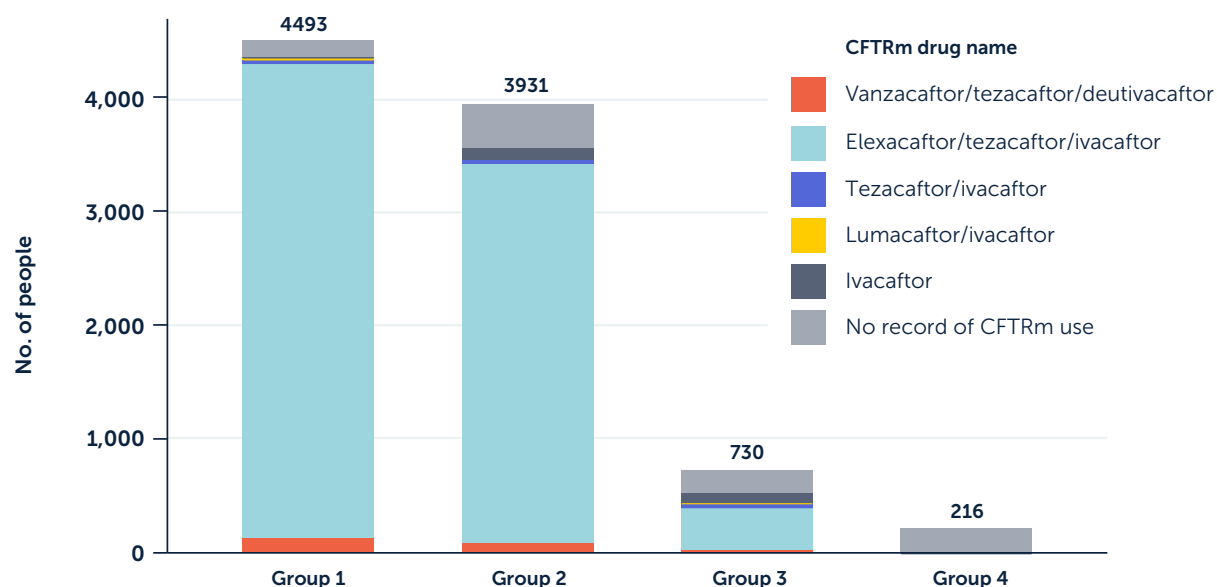
The graph below shows the proportion of people with an annual review in a given year who have never been on a CFTR modulator, including in that year and in previous years. There are many reasons why someone may never have been on a CFTR modulator including: age or genotype ineligibility, living with a transplant, or a decision made between an individual and their care team. We can't always determine why someone might not use a modulator from Registry data.



\* Only people with an annual review in the given year are included.

### 1.38a CFTR modulator use in people aged 6 years and older by genotype group<sup>1</sup>

N=9,460



#### Genotype group definitions

|         |                                                |
|---------|------------------------------------------------|
| Group 1 | F508del Homozygous                             |
| Group 2 | F508del Heterozygous                           |
| Group 3 | No F508del, but at least 1 non-class 1 variant |
| Group 4 | Two class 1 variants                           |

|                                      | Groups      |             |            |            |
|--------------------------------------|-------------|-------------|------------|------------|
|                                      | Group 1     | Group 2     | Group 3    | Group 4    |
| Vanzacaftor/tezacaftor/deutivacaftor | 136 (3.0)   | 89 (2.3)    | -*         | <5         |
| Elexacaftor/tezacaftor/ivacaftor     | 4156 (92.5) | 3327 (84.6) | 364 (49.9) | <5         |
| Tezacaftor/ivacaftor                 | 31 (0.7)    | 37 (0.9)    | 44 (6.0)   | 0 (0.0)    |
| Lumacaftor/ivacaftor                 | -*          | 0 (0.0)     | <5         | 0 (0.0)    |
| Ivacaftor                            | <5          | 100 (2.5)   | 90 (12.3)  | <5         |
| No record of CFTRm use               | 142 (3.2)   | 378 (9.6)   | 201 (27.5) | 211 (97.7) |
| <b>Total</b>                         | <b>4493</b> | <b>3931</b> | <b>730</b> | <b>216</b> |

<sup>1</sup> 48 people were excluded because their genotype data is missing or unknown. 32 people with one class 1 variant and one missing/other genotype not included in groupings.

\* Redacted to adhere to statistical disclosure guidelines.

### 1.38b Demographic characteristics in people aged 6 years and older by genotype group and CFTRm use<sup>1,2</sup>

N=9,460

|                                                                         | Groups 1, 2, and 3 <sup>3</sup> |                        | Group 4 <sup>4</sup>   |
|-------------------------------------------------------------------------|---------------------------------|------------------------|------------------------|
|                                                                         | CFTRm use recorded              | no record of CFTRm use | no record of CFTRm use |
| Number of Individuals (n)                                               | 8443                            | 721                    | 211                    |
| Age                                                                     |                                 |                        |                        |
| 6-11 years; n(%)                                                        | 1288 (15.3)                     | 115 (16)               | 41 (19.4)              |
| 12-17 years; n(%)                                                       | 1421 (16.8)                     | 82 (11.4)              | 44 (20.9)              |
| 18+ years; n(%)                                                         | 5734 (67.9)                     | 524 (72.7)             | 126 (59.7)             |
| Median years (IQR)                                                      | 25 (15, 36)                     | 33 (15, 44)            | 21 (14, 29)            |
| Demographics                                                            |                                 |                        |                        |
| Male; n (%)                                                             | 4530 (53.7)                     | 384 (53.3)             | 127 (60.2)             |
| In full or part time employment or school; n(% of people age 18+ years) | 3833 (66.8)                     | 303 (57.8)             | 88 (69.8)              |
| Ethnicity; n (%)                                                        |                                 |                        |                        |
| White                                                                   | 8026 (96.8)                     | 643 (92.1)             | 114 (56.2)             |
| Asian                                                                   | 171 (2.1)                       | 39 (5.6)               | 80 (39.4)              |
| Black                                                                   | 20 (.2)                         | -*                     | -*                     |
| Mixed                                                                   | 33 (.4)                         | <5                     | 0 (0)                  |
| Other                                                                   | 39 (.5)                         | 9 (1.3)                | <5                     |
| Lung Health                                                             |                                 |                        |                        |
| FEV <sub>1</sub> predicted; median(IQR)                                 | 91 (71, 104)                    | 91 (75, 104)           | 75 (54, 92)            |
| Best FEV <sub>1</sub> pred; median(IQR)                                 | 94 (74, 106)                    | 94 (79, 106)           | 80 (55, 97)            |
| At least 1 pulmonary exacerbation since last annual review; n(%)        | 1224 (14.5)                     | 87 (12.1)              | 90 (42.7)              |
| Nutritional Health                                                      |                                 |                        |                        |
| Individuals ages 20 years and older; n                                  | 5332                            | 510                    | 114                    |
| BMI for individuals ages 20+ years; median (IQR)                        | 23 (20, 26)                     | 23 (20, 27)            | 20 (18, 23)            |

1 10 people were excluded because their last prescribed CFTRm treatment was through a clinical trial and specific treatment was unknown.

2 48 people were excluded because their genotype data is missing or unknown.

3 People in groups 1, 2, and 3 for visual 1.38 are considered potentially eligible for CFTRms.

4 People in group 4 for visual 1.38 are considered likely not to be eligible for CFTRms.

\* Redacted to adhere to statistical disclosure guidelines

# Physiotherapy

## 1.39 Primary airway clearance technique

Physiotherapy helps people with CF clear sticky mucus from their lungs. The listed techniques represent the primary form of physiotherapy recorded for an individual on the Registry. One primary airway clearance technique can be recorded for an individual.

|                                                          | Overall<br>(n=10624) | <16 years<br>(n=3606) | ≥16 years<br>(n=7018) | <18 years<br>(n=4060) | ≥18 years<br>(n=6564) |
|----------------------------------------------------------|----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Active cycle of breathing techniques                     | 499 (4.7)            | 28 (0.8)              | 471 (6.7)             | 35 (0.9)              | 464 (7.1)             |
| Assisted autogenic drainage                              | 122 (1.1)            | 17 (0.5)              | 105 (1.5)             | 26 (0.6)              | 96 (1.5)              |
| Autogenic drainage                                       | 850 (8.0)            | 28 (0.8)              | 822 (11.7)            | 42 (1.0)              | 808 (12.3)            |
| Exercise                                                 | 1930 (18.2)          | 482 (13.4)            | 1448 (20.6)           | 561 (13.8)            | 1369 (20.9)           |
| Forced expiration                                        | 71 (0.7)             | 10 (0.3)              | 61 (0.9)              | 11 (0.3)              | 60 (0.9)              |
| High pressure PEP                                        | 47 (0.4)             | 29 (0.8)              | 18 (0.3)              | 31 (0.8)              | 16 (0.2)              |
| Incentive spirometer                                     | -*                   | <5                    | 10 (0.1)              | <5                    | 10 (0.2)              |
| Manual in/ex-sufflation (cough assist)                   | -*                   | <5                    | 10 (0.1)              | <5                    | 9 (0.1)               |
| Manual techniques (percussion over pressures vibrations) | 299 (2.8)            | 245 (6.8)             | 54 (0.8)              | 246 (6.1)             | 53 (0.8)              |
| NIV (non-invasive ventilation)                           | 36 (0.3)             | 0 (0.0)               | 36 (0.5)              | <5                    | -*                    |
| Oscillating PEP                                          | 2798 (26.3)          | 1221 (33.9)           | 1577 (22.5)           | 1418 (34.9)           | 1380 (21.0)           |
| Positive expiratory pressure (PEP)                       | 1730 (16.3)          | 1052 (29.2)           | 678 (9.7)             | 1129 (27.8)           | 601 (9.2)             |
| Postural drainage                                        | 119 (1.1)            | 97 (2.7)              | 22 (0.3)              | 98 (2.4)              | 21 (0.3)              |
| VEST                                                     | 29 (0.3)             | 12 (0.3)              | 17 (0.2)              | 14 (0.3)              | 15 (0.2)              |
| Other                                                    | 545 (5.1)            | 230 (6.4)             | 315 (4.5)             | 251 (6.2)             | 294 (4.5)             |
| None                                                     | 1512 (14.2)          | 149 (4.1)             | 1363 (19.4)           | 190 (4.7)             | 1322 (20.1)           |

\* Redacted to adhere to statistical disclosure guidelines

## 1.40 Primary or secondary airway clearance technique

People with CF may use more than one airway clearance technique. These techniques are not mutually exclusive and represent both primary and secondary forms of physiotherapy received by people with CF.

|                                                          | Overall<br>(n=10624) | <16 years<br>(n=3606) | ≥16 years<br>(n=7018) | <18 years<br>(n=4060) | ≥18 years<br>(n=6564) |
|----------------------------------------------------------|----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Active cycle of breathing techniques                     | 1077 (10.1)          | 161 (4.5)             | 916 (13.1)            | 193 (4.8)             | 884 (13.5)            |
| Assisted autogenic drainage                              | 193 (1.8)            | 66 (1.8)              | 127 (1.8)             | 77 (1.9)              | 116 (1.8)             |
| Autogenic drainage                                       | 1476 (13.9)          | 62 (1.7)              | 1414 (20.1)           | 89 (2.2)              | 1387 (21.1)           |
| Exercise; of which:                                      | 6313 (59.4)          | 2416 (67.0)           | 3897 (55.5)           | 2748 (67.7)           | 3565 (54.3)           |
| Exercise listed as only airway clearance technique       | 1031 (9.7)           | 121 (3.4)             | 910 (13.0)            | 151 (3.7)             | 880 (13.4)            |
| Forced expiration                                        | 646 (6.1)            | 352 (9.8)             | 294 (4.2)             | 402 (9.9)             | 244 (3.7)             |
| High pressure PEP                                        | 61 (0.6)             | 39 (1.1)              | 22 (0.3)              | 41 (1.0)              | 20 (0.3)              |
| Incentive spirometer                                     | 41 (0.4)             | 8 (0.2)               | 33 (0.5)              | 8 (0.2)               | 33 (0.5)              |
| Manual in/ex-sufflation (cough assist)                   | 32 (0.3)             | 5 (0.1)               | 27 (0.4)              | 7 (0.2)               | 25 (0.4)              |
| Manual techniques (percussion over pressures vibrations) | 583 (5.5)            | 438 (12.1)            | 145 (2.1)             | 446 (11.0)            | 137 (2.1)             |
| NIV (non-invasive ventilation)                           | -*                   | <5                    | 92 (1.3)              | <5                    | 90 (1.4)              |
| Oscillating PEP                                          | 3880 (36.5)          | 1568 (43.5)           | 2312 (32.9)           | 1820 (44.8)           | 2060 (31.4)           |
| PEP                                                      | 2371 (22.3)          | 1353 (37.5)           | 1018 (14.5)           | 1455 (35.8)           | 916 (14.0)            |
| Postural drainage                                        | 368 (3.5)            | 292 (8.1)             | 76 (1.1)              | 307 (7.6)             | 61 (0.9)              |
| VEST                                                     | 72 (0.7)             | 24 (0.7)              | 48 (0.7)              | 29 (0.7)              | 43 (0.7)              |
| Other                                                    | 1269 (11.9)          | 610 (16.9)            | 659 (9.4)             | 654 (16.1)            | 615 (9.4)             |

## 1.41 Exercise testing

Exercise testing provides valuable information on an individual's physical abilities, which gives insights into prognosis or oxygen requirements. Physiotherapists and exercise specialists use test results to individualise exercise programmes and target specific needs. Results of exercise tests can also be motivating to the individual and can be used to set future exercise goals.

| Exercise test                              | Overall<br>(n=10624) | <16 years<br>(n=3606) | ≥16 years<br>(n=7018) | <18 years<br>(n=4060) | ≥18 years<br>(n=6564) |
|--------------------------------------------|----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Yes <sup>1</sup>                           | 1567 (14.7)          | 467 (13.0)            | 1100 (15.7)           | 555 (13.7)            | 1012 (15.4)           |
| No                                         | 7115 (67.0)          | 2351 (65.2)           | 4764 (67.9)           | 2633 (64.9)           | 4482 (68.3)           |
| Not known or missing                       | 1942 (18.3)          | 788 (21.9)            | 1154 (16.4)           | 872 (21.5)            | 1070 (16.3)           |
| <b>Type of exercise test<sup>2,3</sup></b> |                      |                       |                       |                       |                       |
| Cardiopulmonary exercise testing (CPET)    | 167 (10.7)           | 51 (10.9)             | 116 (10.5)            | 61 (11.0)             | 106 (10.5)            |
| Shuttle test                               | 268 (17.1)           | 204 (43.7)            | 64 (5.8)              | 228 (41.1)            | 40 (4.0)              |
| Step test                                  | 439 (28.0)           | 95 (20.3)             | 344 (31.3)            | 112 (20.2)            | 327 (32.3)            |
| 6 minute walk test                         | 84 (5.4)             | 6 (1.3)               | 78 (7.1)              | 9 (1.6)               | 75 (7.4)              |
| Other                                      | 283 (18.1)           | 89 (19.1)             | 194 (17.6)            | 100 (18.0)            | 183 (18.1)            |
| Missing                                    | 510 (32.5)           | 132 (28.3)            | 378 (34.4)            | 168 (30.3)            | 342 (33.8)            |

\* Redacted to adhere to statistical disclosure guidelines

1 Exercise test represents all types of testing listed including submaximal, shuttle test, 6 minute walk test, step test and other test.

2 Proportion of patients who answered 'Yes' above

3 More than one type of test can be recorded so percentages may not sum to 100%

# Other therapies

## 1.42 Oxygen and non-invasive ventilation

|                                        | Overall<br>(n=10624) | <16 years<br>(n=3606) | ≥16 years<br>(n=7018) | <18 years<br>(n=4060) | ≥18 years<br>(n=6564) |
|----------------------------------------|----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Non invasive ventilation (NIV); n (%)  | 124 (1.2)            | 17 (0.5)              | 107 (1.5)             | 22 (0.5)              | 102 (1.6)             |
| Any oxygen use; n (%)                  | 249 (2.3)            | 26 (0.7)              | 223 (3.2)             | 29 (0.7)              | 220 (3.4)             |
| <b>Among those who had oxygen use:</b> |                      |                       |                       |                       |                       |
| Continuously                           | -*                   | <5                    | 33 (14.8)             | <5                    | 32 (14.5)             |
| Nocturnal or with exertion             | -*                   | <5                    | 83 (37.2)             | <5                    | 83 (37.7)             |
| As required (PRN)                      | -*                   | <5                    | 20 (9.0)              | <5                    | 20 (9.1)              |
| With exacerbation                      | 110 (44.2)           | 23 (88.5)             | 87 (39.0)             | 25 (86.2)             | 85 (38.6)             |

## 1.43 Transplants

Lung transplantation has been available to people with CF for almost 30 years. Today the most common operation carried out is a double lung transplant, or bilateral sequential lung transplant. The following table gives information about transplant activity over time. Only individuals with an annual review in the given year are considered. N=10,624 in 2025.

|                                           | 2020 | 2021 | 2022 | 2023 | 2024 | 2025 |
|-------------------------------------------|------|------|------|------|------|------|
| Number evaluated                          | 175  | 78   | 41   | 37   | 28   | 34   |
| Number accepted                           | 66   | 23   | 22   | 21   | 14   | 27   |
| <b>Number receiving aged &lt;16 years</b> | 0    | 0    | 0    | 0    | 0    | 0    |
| Bilateral lung                            | 0    | 0    | 0    | 0    | 0    | 0    |
| Liver                                     | 0    | 0    | 0    | 0    | 0    | 0    |
| Other                                     | 0    | 0    | 0    | 0    | 0    | 0    |
| <b>Number receiving aged 16+ years</b>    | 15   | 5    | 6    | <5   | 6    | -*   |
| Bilateral lung                            | 12   | <5   | <5   | <5   | <5   | 6    |
| Liver                                     | <5   | 0    | 0    | <5   | <5   | <5   |
| Other                                     | <5   | <5   | <5   | 0    | <5   | <5   |

\* Redacted to adhere to statistical disclosure guidelines.

## 1.44 Feeding

Supplementary feeding, often using a nasogastric (via the nose) or gastrostomy (via the abdomen) tube directly to the stomach, is considered when a person with CF has poor weight gain, or progressive weight loss, despite efforts to increase oral intake. The category "Any supplemental feeding" includes the subsequent categories: oral, nasogastric tube, gastrostomy tube/button, jejunal, and total parenteral nutrition, and unknown or other supplemental feeding. The subsequent categories are not mutually exclusive.

| Year |                                        | Overall     | <16 years   | ≥16 years   | <18 years   | ≥18 years   |
|------|----------------------------------------|-------------|-------------|-------------|-------------|-------------|
| 2015 | Total; n                               | 9587        | 3846        | 5741        | 4337        | 5250        |
|      | Any supplemental feeding; n(%)         | 3126 (32.6) | 1120 (29.1) | 2006 (34.9) | 1284 (29.6) | 1842 (35.1) |
|      | Oral; n(%)                             | 2671 (27.9) | 944 (24.5)  | 1727 (30.1) | 1075 (24.8) | 1596 (30.4) |
|      | Nasogastric tube; n(%)                 | 109 (1.1)   | 15 (0.4)    | 94 (1.6)    | 17 (0.4)    | 92 (1.8)    |
|      | Gastrostomy tube/Button; n(%)          | 557 (5.8)   | 220 (5.7)   | 337 (5.9)   | 269 (6.2)   | 288 (5.5)   |
|      | Jejunal; n(%)                          | 7 (0.1)     | <5          | <5          | <5          | <5          |
|      | Total Parenteral Nutrition (TPN); n(%) | <5          | <5          | <5          | <5          | <5          |
| 2019 | Total; n                               | 10070       | 3966        | 6104        | 4366        | 5704        |
|      | Any supplemental feeding; n(%)         | 3683 (36.6) | 1243 (31.3) | 2440 (40.0) | 1405 (32.2) | 2278 (39.9) |
|      | Oral; n(%)                             | 2501 (24.8) | 912 (23.0)  | 1589 (26.0) | 1015 (23.2) | 1486 (26.1) |
|      | Nasogastric tube; n(%)                 | 98 (1.0)    | 16 (0.4)    | 82 (1.3)    | 19 (0.4)    | 79 (1.4)    |
|      | Gastrostomy tube/Button; n(%)          | 532 (5.3)   | 212 (5.3)   | 320 (5.2)   | 240 (5.5)   | 292 (5.1)   |
|      | Jejunal; n(%)                          | 12 (0.1)    | <5          | 10 (0.2)    | <5          | 10 (0.2)    |
|      | Total Parenteral Nutrition (TPN); n(%) | 13 (0.1)    | <5          | 9 (0.1)     | <5          | 9 (0.2)     |
| 2025 | Total; n                               | 10624       | 3606        | 7018        | 4060        | 6564        |
|      | Any supplemental feeding; n(%)         | 2291 (21.6) | 829 (23.0)  | 1462 (20.8) | 935 (23.0)  | 1356 (20.7) |
|      | Oral; n(%)                             | 1311 (12.3) | 451 (12.5)  | 860 (12.3)  | 505 (12.4)  | 806 (12.3)  |
|      | Nasogastric tube; n(%)                 | 27 (0.3)    | 5 (0.1)     | 22 (0.3)    | 6 (0.1)     | 21 (0.3)    |
|      | Gastrostomy tube/Button; n(%)          | 270 (2.5)   | 88 (2.4)    | 182 (2.6)   | 106 (2.6)   | 164 (2.5)   |
|      | Jejunal; n(%)                          | 10 (0.1)    | <5          | 7 (0.1)     | <5          | 7 (0.1)     |
|      | Total Parenteral Nutrition (TPN); n(%) | 12 (0.1)    | 8 (0.2)     | <5          | 8 (0.2)     | <5          |

## 1.45 Pancreatic enzyme supplementation

In many people with CF, thick mucus blocks the ducts of the pancreas, preventing digestive enzymes from reaching the intestine. Pancreatic enzyme supplements can be taken to help digest food.

| Year |                                     | Overall     | <16 years   | ≥16 years   | <18 years   | ≥18 years   |
|------|-------------------------------------|-------------|-------------|-------------|-------------|-------------|
| 2015 | Total; n                            | 9587        | 3846        | 5741        | 4337        | 5250        |
|      | Pancreatic enzyme supplements; n(%) | 8148 (85.0) | 3296 (85.7) | 4852 (84.5) | 3736 (86.1) | 4412 (84.0) |
| 2019 | Total; n                            | 10070       | 3966        | 6104        | 4366        | 5704        |
|      | Pancreatic enzyme supplements; n(%) | 8268 (82.1) | 3238 (81.6) | 5030 (82.4) | 3587 (82.2) | 4681 (82.1) |
| 2025 | Total; n                            | 10624       | 3606        | 7018        | 4060        | 6564        |
|      | Pancreatic enzyme supplements; n(%) | 8412 (79.2) | 2787 (77.3) | 5625 (80.2) | 3169 (78.1) | 5243 (79.9) |

Note: 2018 figures reported erroneously for 2019 in these tables in 2024 report fixed here.

\* Redacted to adhere to statistical disclosure guidelines.

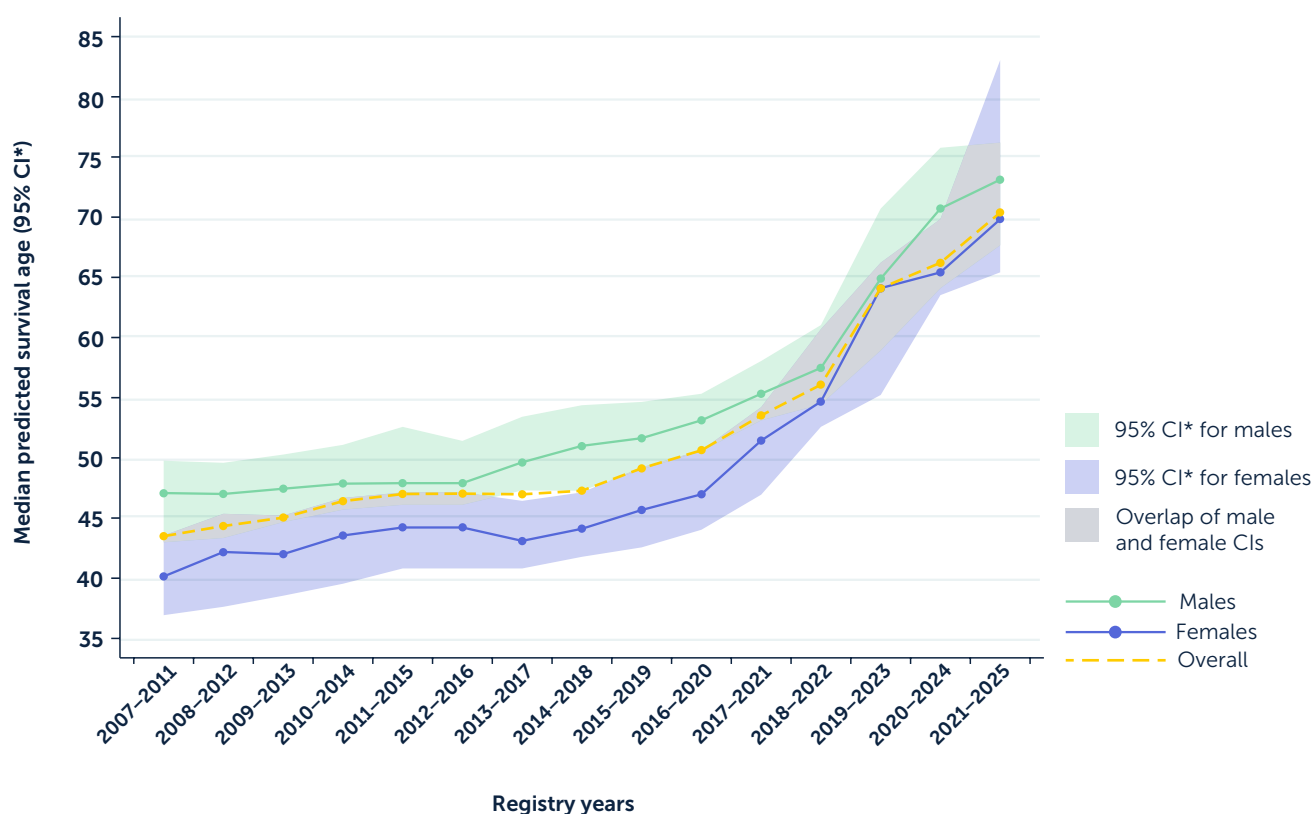
# Survival

## 1.46 Median predicted survival age

We predict the age that 50% of people with CF born within a given time period will live to if there are no changes to treatment, standards of care or mortality rates.<sup>1</sup> This is called the median predicted survival age. We can make these predictions by calculating survival probabilities using a mathematical formula<sup>2</sup> based on the number and age of people with CF recorded as alive in the Registry and the number and age of people with deaths recorded in the Registry in a given time period.

Based on the most recent Registry data from 2021–2025, half of the people with CF born today are predicted to live to at least 70.4 years; therefore, half are predicted to die before they reach this age. As with all statistical predictions, there is a degree of uncertainty in this estimate which is represented by the confidence interval of 67.1–74.2 years. The graph below shows the median predicted survival age that was estimated using the Registry data available during those time windows. We do not update these figures based on new information we have now.

Importantly, these estimates do not consider individual variation in survival; for example, the median predicted survival age is likely to be lower for those who are not eligible for CFTR modulators. These estimates also do not consider any future improvements in the treatment and care of people with CF and their impact on mortality and overall survival. Improvements in the future could mean that people with CF born today live longer than our current estimates.



1 Keogh, RH et al. J Cyst Fibros. 2018;17(2):213 - 217.

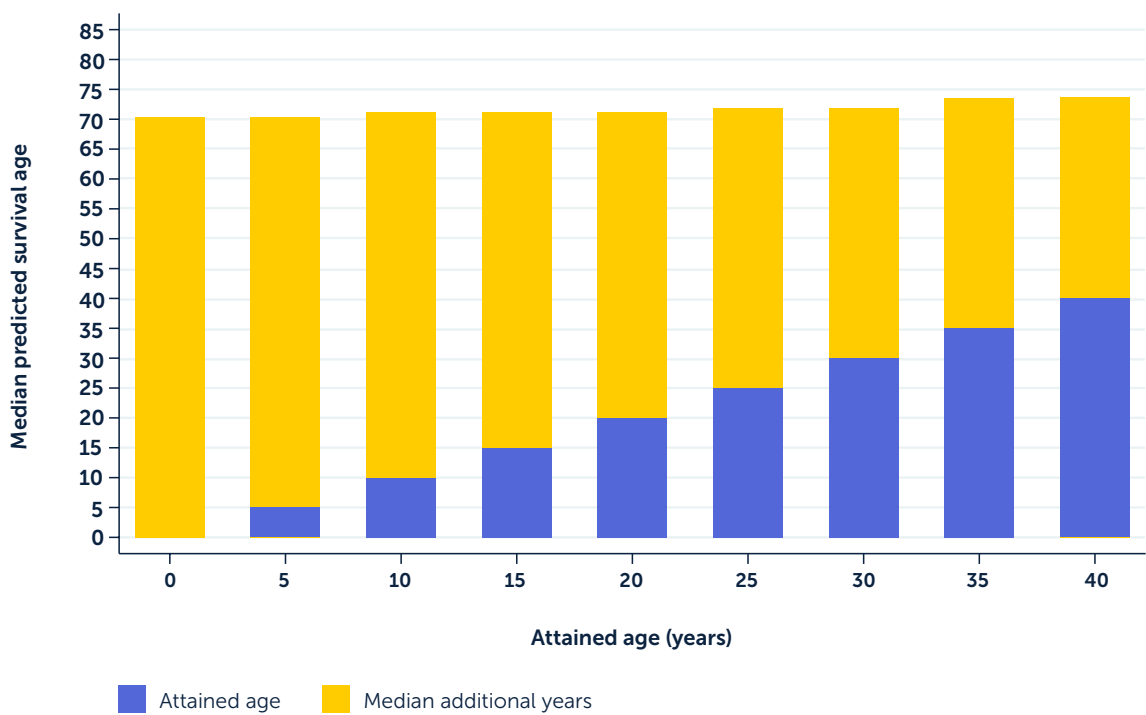
2 Sykes, Jenna et al. J Clin Epidemiol. 2016;70:206-213.

\* Confidence interval.

# 1.47 Median predicted survival age based on current age<sup>1</sup>

Median predicted conditional survival age is the age that 50% of people are predicted to survive to if they have already attained a given age. This is another way to understand survival among people currently living with CF, particularly as the distribution of the age of people with CF is changing. We calculate median predicted conditional survival using the same mathematical formula as described for 1.46 which assumes that treatment, care and mortality rates remain the same. The key difference in these predictions is that the median predicted survival age is calculated separately for people who have survived to ages from 5 to 40 years. For example, based on data from 2021–2025, we estimate that half of individuals with CF who are at least 20 years old now will live to at least 71.2 years. It is more difficult to predict median conditional survival reliably at older ages as we have less information about older people. This figure ends at age 40 because the data we have now on individuals beyond that age is insufficient to reliably predict survival using our formulas. As the CF population ages we expect to be able to improve our estimates.

As with the previous graph, these estimates are at a population level and do not consider individual level variation such as whether an individual is eligible for or taking CFTRm treatment.

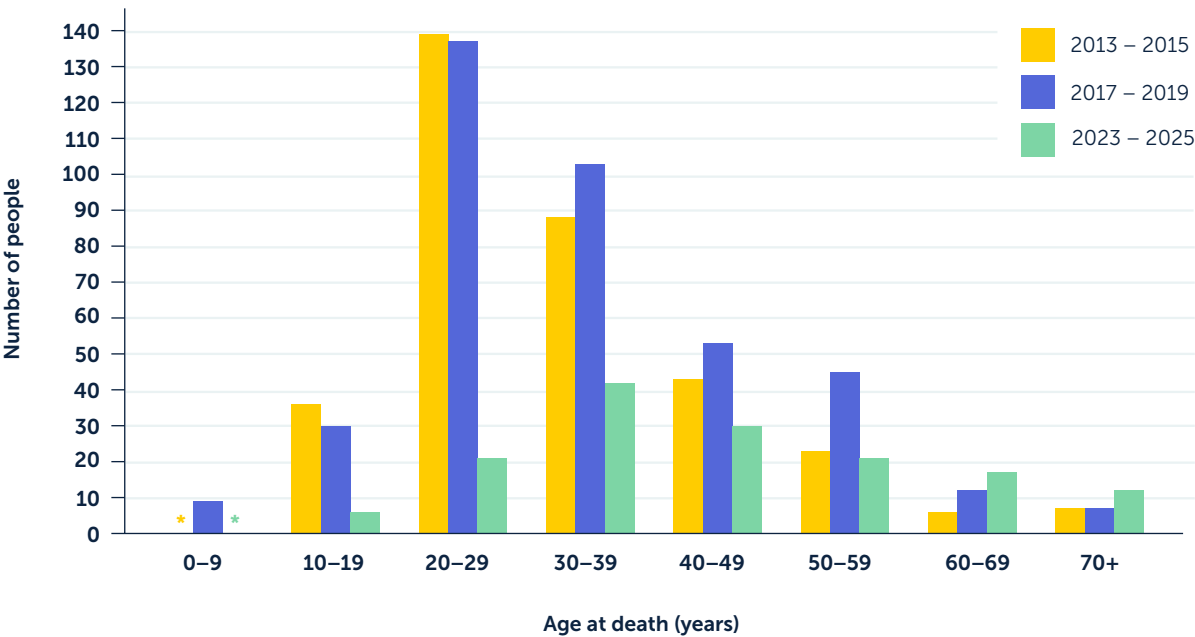


| Attained age (years) | Median predicted survival (95% CI) |
|----------------------|------------------------------------|
| 0                    | 70.4 (67.1, 74.2)                  |
| 5                    | 70.4 (67.1, 74.2)                  |
| 10                   | 71.2 (67.1, 74.2)                  |
| 15                   | 71.2 (67.1, 74.2)                  |
| 20                   | 71.2 (67.1, 74.2)                  |
| 25                   | 71.8 (67.7, 75.9)                  |
| 30                   | 71.8 (68.4, 76.2)                  |
| 35                   | 73.6 (69.8, 77.9)                  |
| 40                   | 73.7 (70.4, 83.0)                  |

1 Also known as median predicted conditional survival age.  
2 Keogh, RH et al. J Cyst Fibros. 2018;17(2):213 - 217.

# 1.48 Age distribution of deaths in 2023–2025, 2017–2019, and 2013–2015

The table below shows the age distribution of people with CF who died in the last three years (2023–2025) compared to a three-year period about five years ago (2017–2019) and 10 years ago (2013–2015).



| Age Group | 2013 - 2015 | 2017 - 2019 | 2023 - 2025 |
|-----------|-------------|-------------|-------------|
| 0-9       | <5          | 9           | <5          |
| 10-19     | 36          | 30          | 6           |
| 20-29     | 139         | 137         | 21          |
| 30-39     | 88          | 103         | 42          |
| 40-49     | 43          | 53          | 30          |
| 50-59     | 23          | 45          | 21          |
| 60-69     | 6           | 12          | 16          |
| 70+       | 7           | 7           | 12          |

# 1.49 Causes of death

This table shows all the recorded causes of death between 2023–2025.

| Cause of death                | 2023 n(%) | 2024 n(%) | 2025 n(%) |
|-------------------------------|-----------|-----------|-----------|
| Respiratory/cardiorespiratory | 29 (56.9) | 31 (55.4) | 16 (40.0) |
| Cancer                        | 5 (9.8)   | 5 (8.9)   | 5 (12.5)  |
| Not known                     | <5        | 7 (12.5)  | 6 (15.0)  |
| Liver disease/liver failure   | <5        | <5        | 6 (15.0)  |
| Transplant-related            | <5        | <5        | <5        |
| Renal Failure                 | <5        | <5        | <5        |
| Trauma or Suicide             | <5        | <5        | <5        |
| Other                         | <5        | <5        | <5        |
| Sepsis                        | <5        | <5        | 0 (0.0)   |
| Total                         | 51        | 56        | 40        |

Note: Numbers in other category different to 2024 report due to re-classification of causes of death by a clinician.

\* Redacted to adhere to statistical disclosure guidelines.

# Genotypes\*

Genotypes are part of the genetic makeup of an individual that usually control a particular characteristic, known as a phenotype. For people with CF, their genotype reveals which variants of the CF gene cause their cystic fibrosis. Everyone living with CF has two variants in the CFTR gene, one on each allele. One is inherited from their mother, and one from their father. If both variants are the same, the person is said to be homozygous. Someone who has two different variants is heterozygous.

| Data completeness                                          | n(%)         |
|------------------------------------------------------------|--------------|
| Patients genotyped with at least one CFTR variant recorded | 11531 (99.3) |
| Patients genotyped with both CFTR variants recorded        | 11252 (96.9) |
| <b>F508del variants<sup>1</sup></b>                        |              |
| Homozygous F508del                                         | 5484 (47.2)  |
| Heterozygous F508del                                       | 4856 (41.8)  |

## 1.50 CFTR variant combinations in the UK population

This tabulation shows the proportion (%) of people with the most common CFTR variant combinations in their genotype. For example, 4.1% of the UK population have one copy of F508del and one copy of G551D.

| CFTR variant | F508del     | R117H      | G551D      | G542X      | 621+1G->T  | Other      | Unknown    | Total        |
|--------------|-------------|------------|------------|------------|------------|------------|------------|--------------|
| F508del      | 47.1        |            |            |            |            |            |            | 47.1         |
| R117H        | 4.8         | 0.1        |            |            |            |            |            | 4.9          |
| G551D        | 4.1         | 0.2        | 0.2        |            |            |            |            | 4.5          |
| G542X        | 2.5         | 0.1        | 0.1        | 0.1        |            |            |            | 2.8          |
| 621+1G->T    | 1.8         | 0.1        | 0.1        | 0.1        | 0.1        |            |            | 2.1          |
| Other        | 26.9        | 0.6        | 1.0        | 0.7        | 0.5        | 5.7        |            | 35.5         |
| Unknown      | 1.6         | 0.1        | 0.1        | 0.1        | 0.0        | 0.5        | 0.7        | 3.1          |
| <b>Total</b> | <b>88.9</b> | <b>1.2</b> | <b>1.4</b> | <b>0.9</b> | <b>0.6</b> | <b>6.2</b> | <b>0.7</b> | <b>100.0</b> |

\* In this section, we include everyone who is registered (see table 1.1) with known genotypes.

1 The complex cis-allele F508del; I1027T is grouped with F508del in here and for 1.50, 1.52 and 1.53.

## 1.51 CFTR variants in the UK population

The table below shows the number of people with CF who carry at least one of each CFTR variant. The groups are not mutually exclusive because people with heterozygous variants may appear twice in the table.

These are the 20 most common variants in the UK population. The full list of recorded variants can be found in Appendix 4.

| Nucleotide     | Protein           | Legacy name   | N     | %    |
|----------------|-------------------|---------------|-------|------|
| c.1521_1523del | p.Phe508del       | F508del       | 10321 | 88.9 |
| c.350G>A       | p.Arg117His       | R117H         | 707   | 6.1  |
| c.1652G>A      | p.Gly551Asp       | G551D         | 666   | 5.7  |
| c.1624G>T      | p.Gly542X         | G542X         | 425   | 3.7  |
| c.489+1G>T     |                   | 621+1G->T     | 307   | 2.6  |
| c.3909C>G      | p.Asn1303Lys      | N1303K        | 191   | 1.6  |
| c.1585-1G>A    |                   | 1717-1G->A    | 190   | 1.6  |
| c.1766+1G>A    |                   | 1898+1G->A    | 164   | 1.4  |
| c.3454G>C      | p.Asp1152His      | D1152H        | 162   | 1.4  |
| c.200C>T       | p.Pro67Leu        | P67L          | 161   | 1.4  |
| c.3140-26A>G   |                   | 3272-26A->G   | 140   | 1.2  |
| c.3718-2477C>T |                   | 3849+10kbC->T | 137   | 1.2  |
| c.3528del      | p.Lys1177SerfsX15 | 3659delC      | 132   | 1.1  |
| c.1679G>C      | p.Arg560Thr       | R560T         | 107   | 0.9  |
| c.1519_1521del | p.Ile507del       | I507del       | 101   | 0.9  |
| c.1021_1022dup | p.Phe342HisfsX28  | 1154insTC     | 99    | 0.9  |
| c.1477C>T      | p.Gln493X         | Q493X         | 98    | 0.8  |
| c.1657C>T      | p.Arg553X         | R553X         | 93    | 0.8  |
| c.254G>A       | p.Gly85Glu        | G85E          | 90    | 0.8  |
| c.2657+5G>A    |                   | 2789+5G->A    | 88    | 0.8  |

## 1.52 CFTR variant prevalence by devolved nation

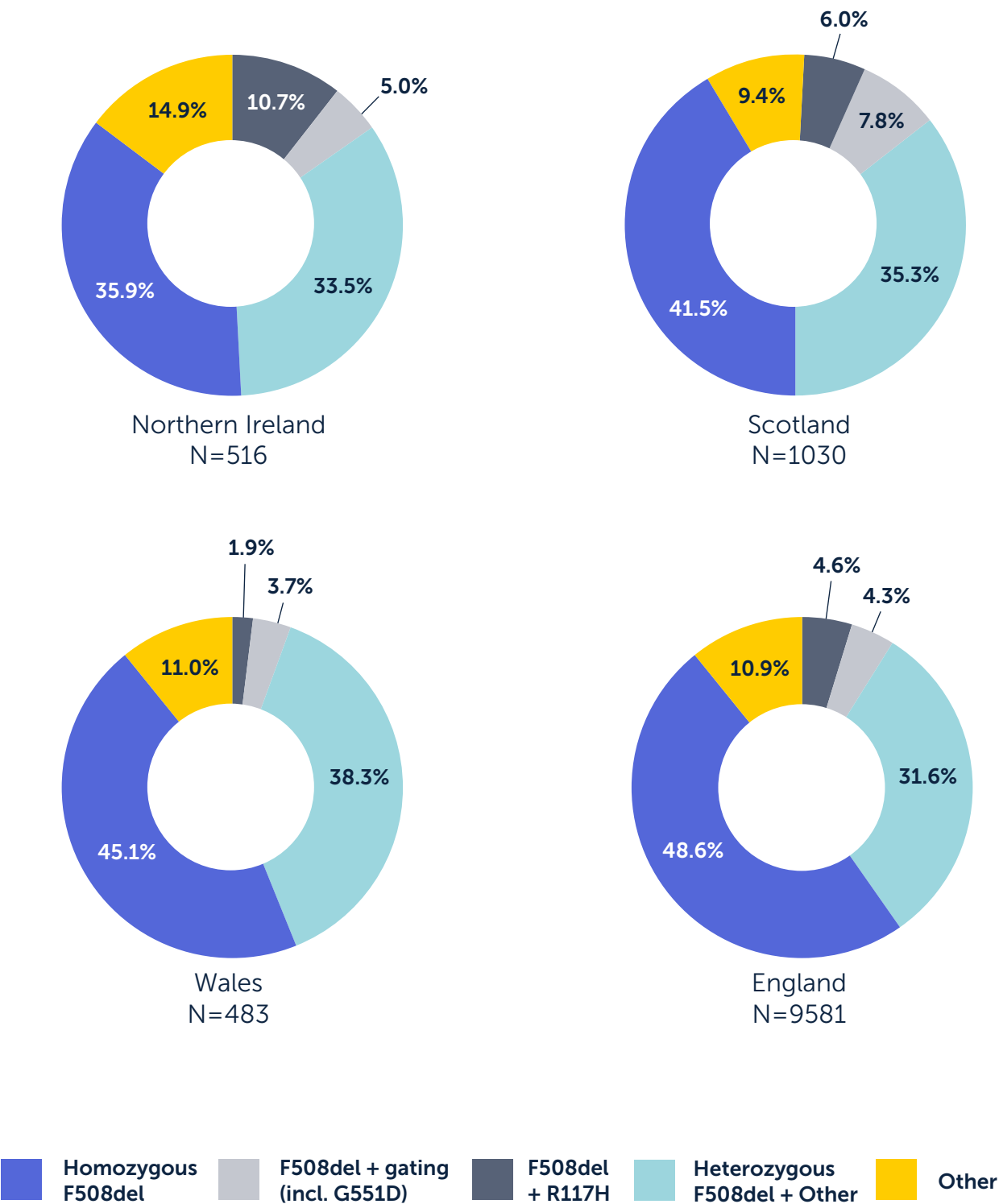
This table shows the distribution of individual variants across the devolved nations. The number of people in each devolved nation is based on the location of the CF centre at which the person receives care and does not account for people who travel between devolved nations for care. The groups are not mutually exclusive because people with heterozygous variants may appear twice in the table.

| Legacy name | England<br>N=9581 |     | Scotland<br>N=1030 |      | Wales<br>N=483 |      | Northern Ireland<br>N=516 |      |
|-------------|-------------------|-----|--------------------|------|----------------|------|---------------------------|------|
|             | n                 | %   | n                  | %    | n              | %    | n                         | %    |
| F508del     | 8524              | 89  | 929                | 90.2 | 430            | 89   | 438                       | 84.9 |
| R117H       | 539               | 5.6 | 75                 | 7.3  | 19             | 3.9  | 74                        | 14.3 |
| G551D       | 495               | 5.2 | 105                | 10.2 | 19             | 3.9  | 47                        | 9.1  |
| G542X       | 312               | 3.3 | 58                 | 5.6  | 24             | 5    | 31                        | 6    |
| 621+1G->T   | 222               | 2.3 | 13                 | 1.3  | 54             | 11.2 | 18                        | 3.5  |
| N1303K      | 159               | 1.7 | 14                 | 1.4  | 7              | 1.4  | 11                        | 2.1  |
| 1717-1G->A  | 165               | 1.7 | 19                 | 1.8  | <5             | -*   | <5                        | -*   |
| 1898+1G->A  | 129               | 1.3 | -*                 | -*   | 29             | 6    | <5                        | -*   |
| D1152H      | 120               | 1.3 | 26                 | 2.5  | <5             | -*   | -*                        | -*   |
| P67L        | 81                | 0.8 | 55                 | 5.3  | <5             | -*   | -*                        | -*   |

\* Redacted to adhere to statistical disclosure guidelines.

### 1.53 Genotype prevalence by devolved nation

These charts show the distribution of CFTR variant combinations across the devolved nations. The number of people for each devolved nation is based on the location of the CF centre at which the person receives care and does not account for people who travel between devolved nations for care.



\* The complex cis-allele F508del; I1027T is grouped with F508del in above frequencies.

# Sections 2 and 3: Centre-level analysis

Cystic fibrosis care in the UK is led by 56 regional centres, 2 standalone clinics, and 74 networked clinics. The breakdown between centres and clinics delivering paediatric and adult care is shown below:

|                    | Paediatric | Adult | Total |
|--------------------|------------|-------|-------|
| Centres            | 29         | 27    | 56    |
| Standalone clinics | 1          | 1     | 2     |
| Networked clinics  | 67         | 7     | 74    |

Sections 2 and 3 show analysis of data for individual CF centres. This allows people with CF, their families, and healthcare providers to review a centre's use of some medications and outcome data alongside national averages. This transparency is intended to help improve standards of care overall. Data from smaller networked clinics is included in the centre data.

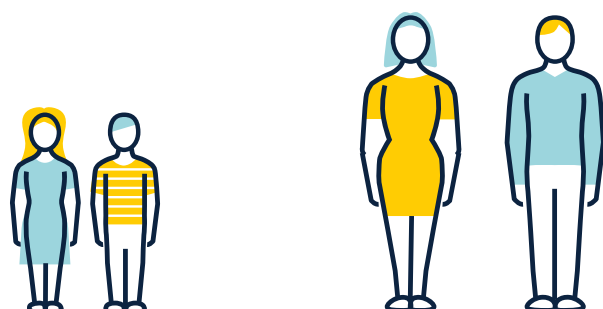
**Lots of different factors can affect the outcomes of people with CF in centres, not all of which are within a centre's control. This might include the economic profile of the area, the age at which the person with CF was diagnosed and referred to the centre, and certain characteristics of the people cared for, such as their gender, as well as facilities, care pathways, and the medical team providing care.**

If a person with CF or a member of their family has questions about the results for their CF centre or clinic, they should discuss this with their CF team.

Full tables of the data are shown in Appendix 2.

A guide on how to interpret the different graphs (funnel plots and box plots) can be found in a guide to the charts on pages 12 and 13.

## Key to Sections 2 and 3



Paediatric centre

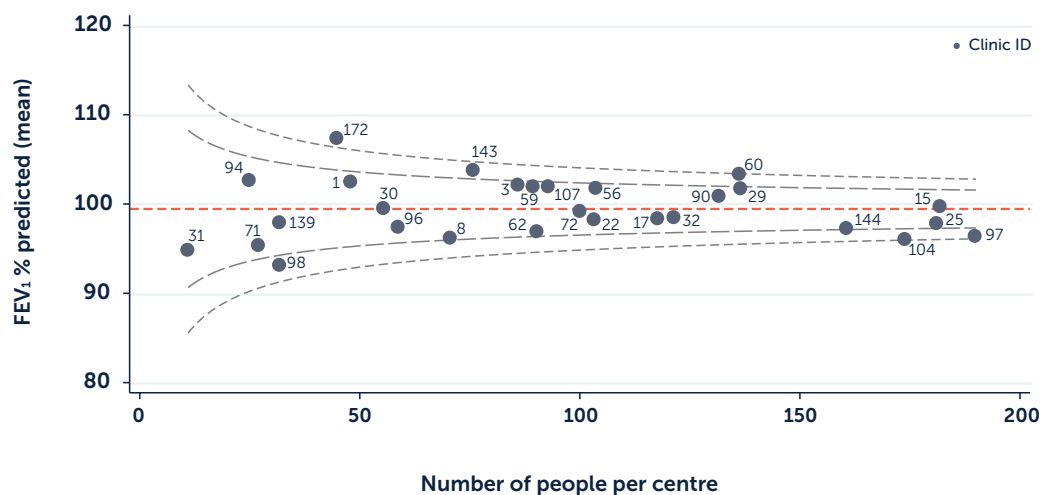
Adult centre

## Section 2: Paediatric centre analysis

N=3912

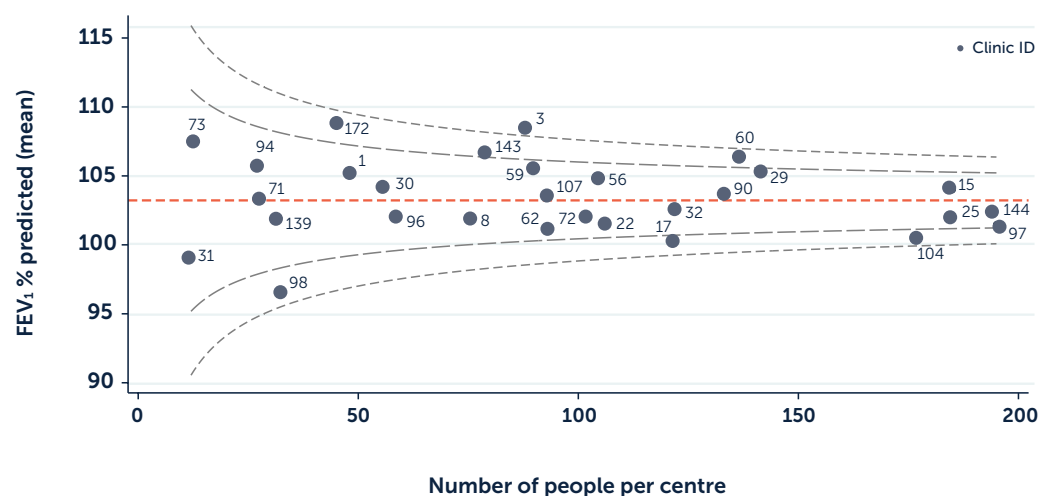


### 2.1 Age-adjusted FEV<sub>1</sub> % predicted at annual review, in people aged 6 and over without a history of lung transplant



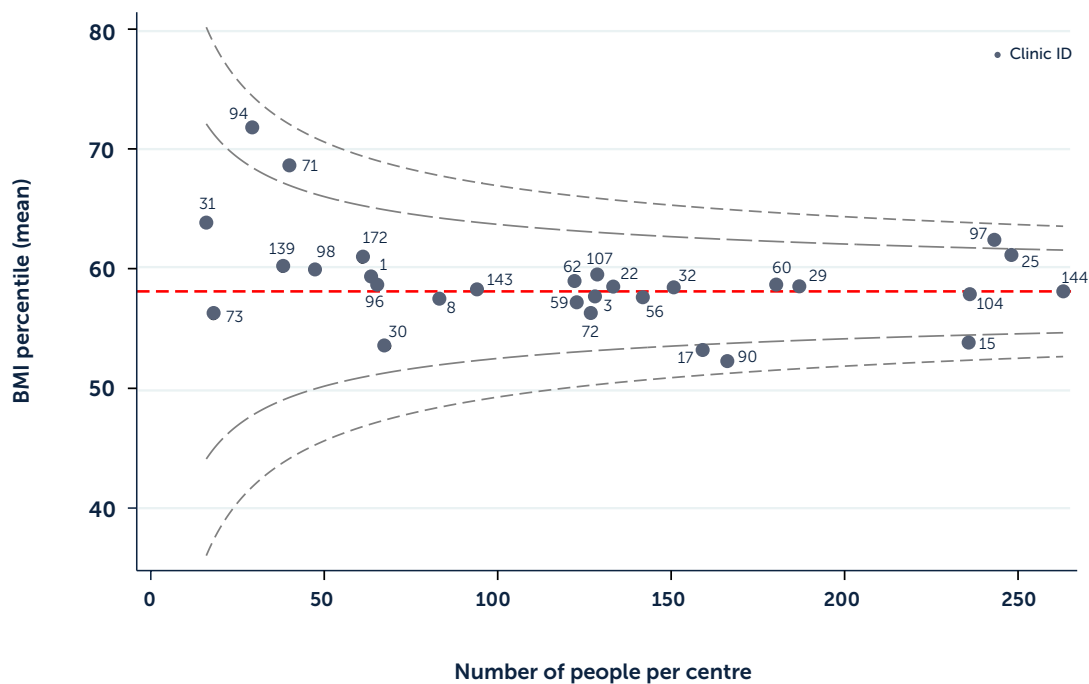
The mean FEV<sub>1</sub>% predicted for people attending paediatric centres/clinics is 99.4% predicted.

### 2.2 Age-adjusted Best FEV<sub>1</sub> % predicted, in people aged 6 and over without a history of lung transplant



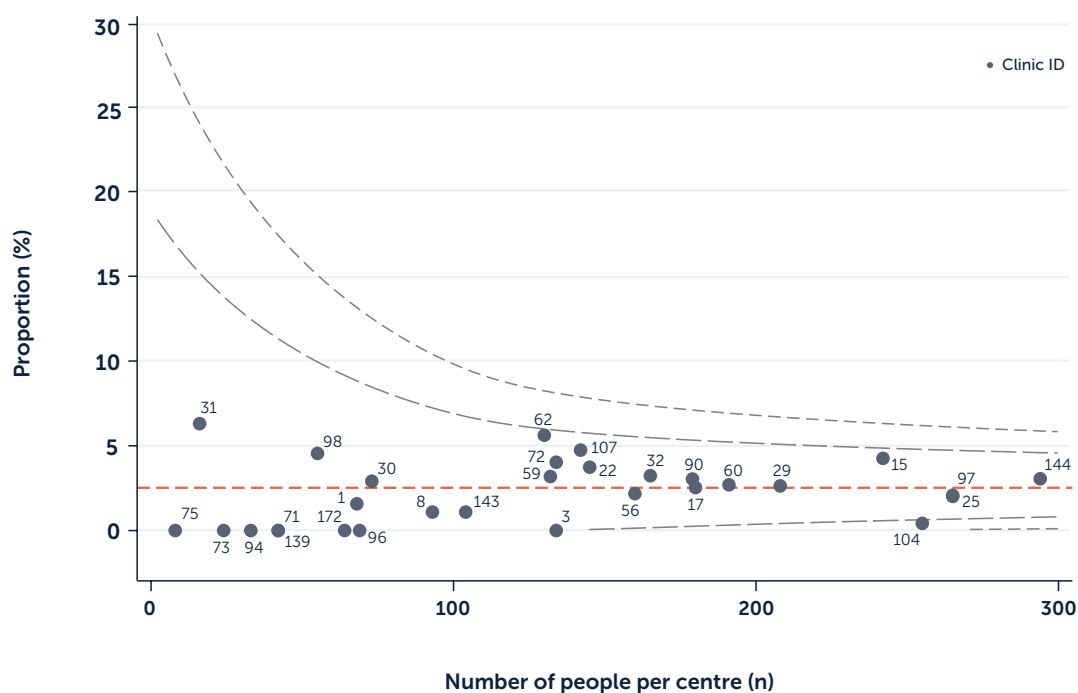
The mean Best FEV<sub>1</sub>% predicted for people attending paediatric centres/clinics is 103.2% predicted. Where Best FEV<sub>1</sub>% predicted was missing, the FEV<sub>1</sub>% predicted at annual review was used.

## 2.3 Age-adjusted Body Mass Index (BMI) percentile in people aged 1–15 years



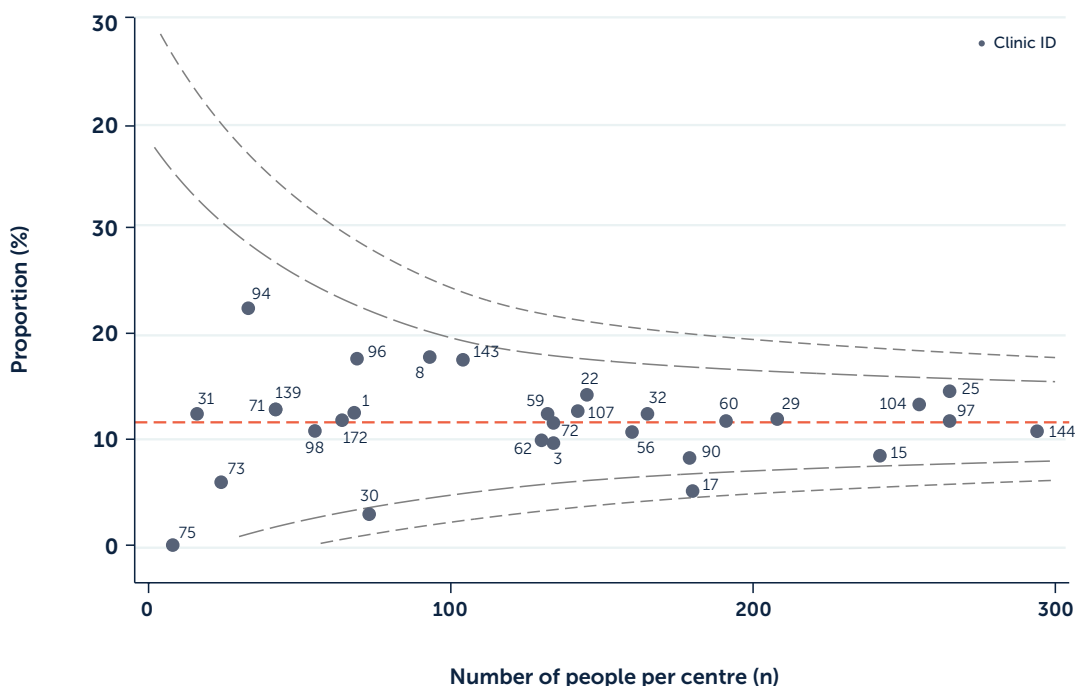
The mean BMI percentile for people attending paediatric centres/clinics is 58.1%.

## 2.4 Age-adjusted proportion of people with BMI < 5th percentile



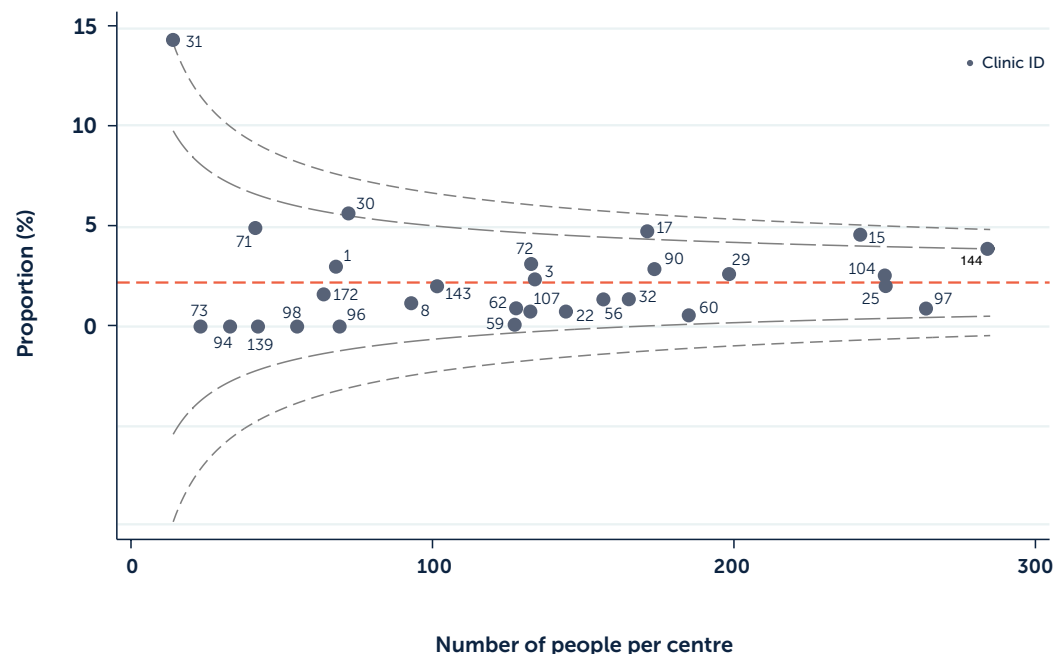
The age-adjusted proportion of people with BMI < 5th percentile attending paediatric centres/clinics is 2.5%.

## 2.5 Age-adjusted proportion of people with BMI $\geq$ 95th percentile



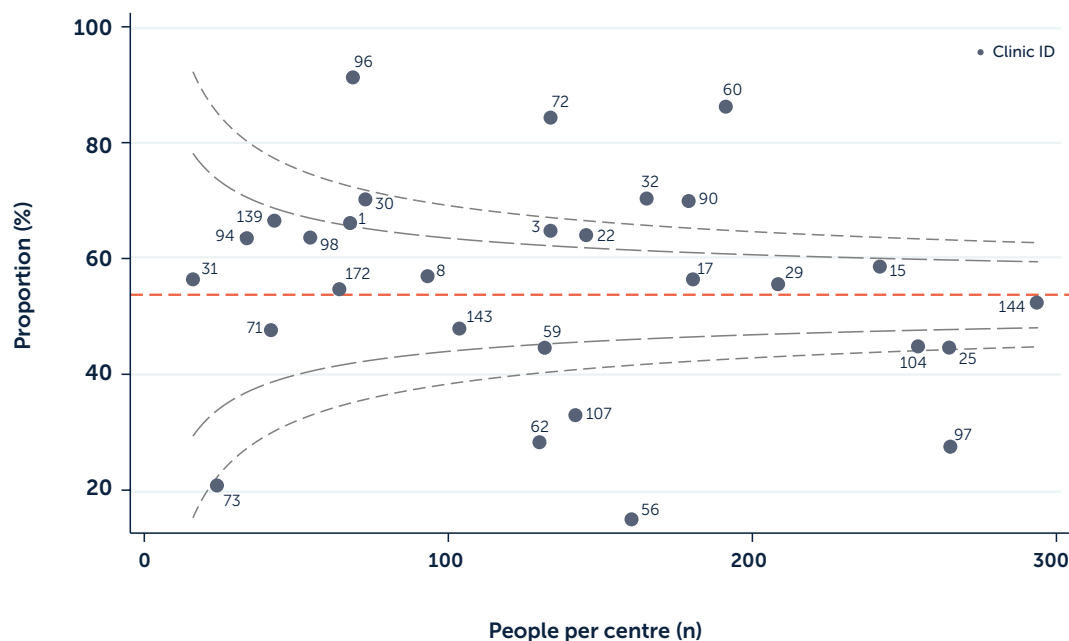
The age-adjusted proportion of people with BMI  $\geq$  95th percentile, attending paediatric centres/clinics is 11.6%.

## 2.6 Proportion of people with chronic *Pseudomonas aeruginosa*



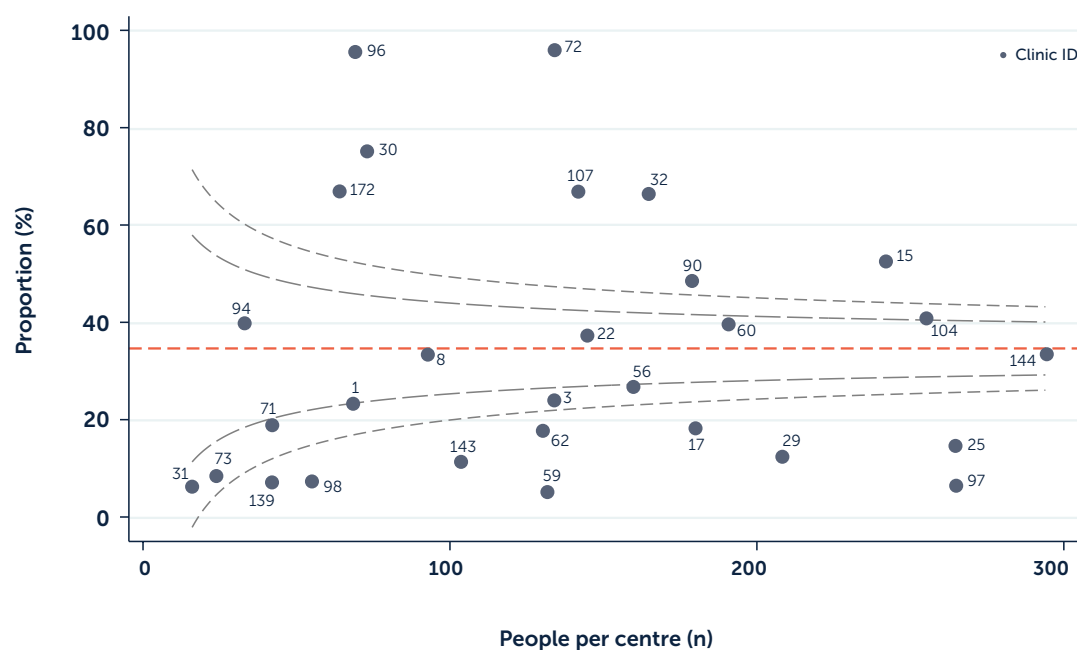
The proportion of people with chronic *Pseudomonas aeruginosa* in paediatric centres/clinics is 2.1%.

## 2.7 Proportion of people receiving DNase treatment



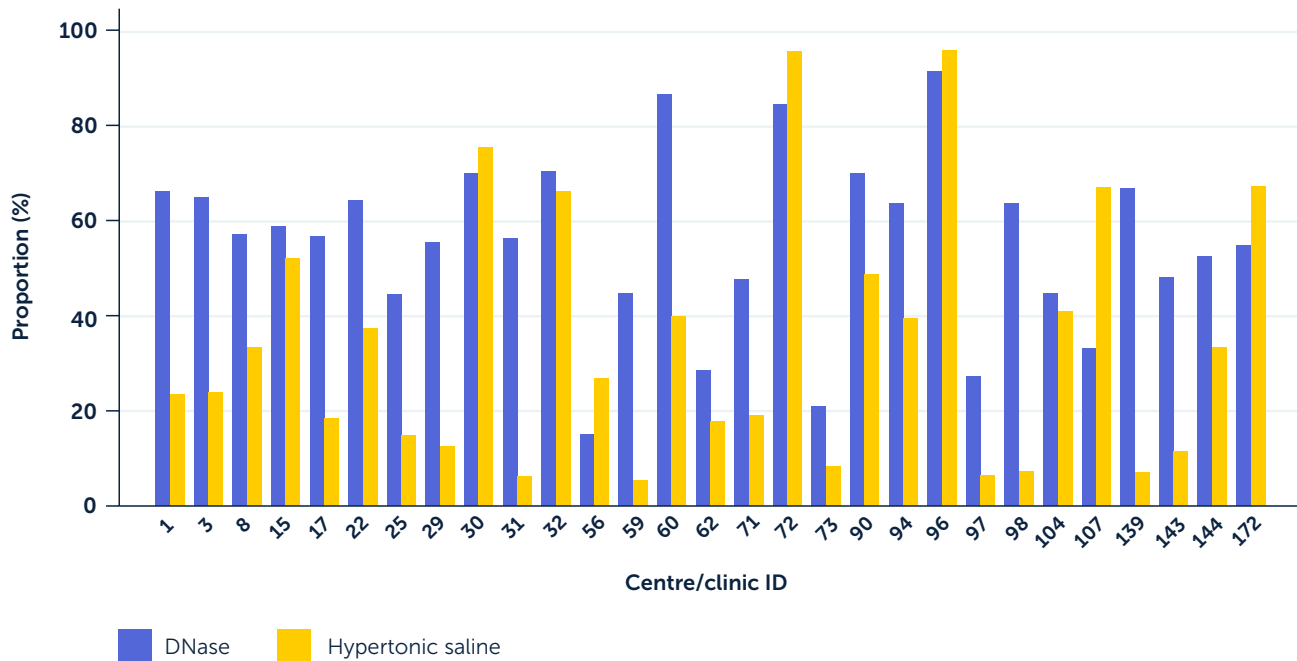
The proportion of people receiving DNase treatment in paediatric centres/clinics is 53.7%.

## 2.8 Proportion of people on hypertonic saline or mannitol treatment



The proportion of people receiving hypertonic saline or mannitol treatment in paediatric centres/clinics is 34.6%.

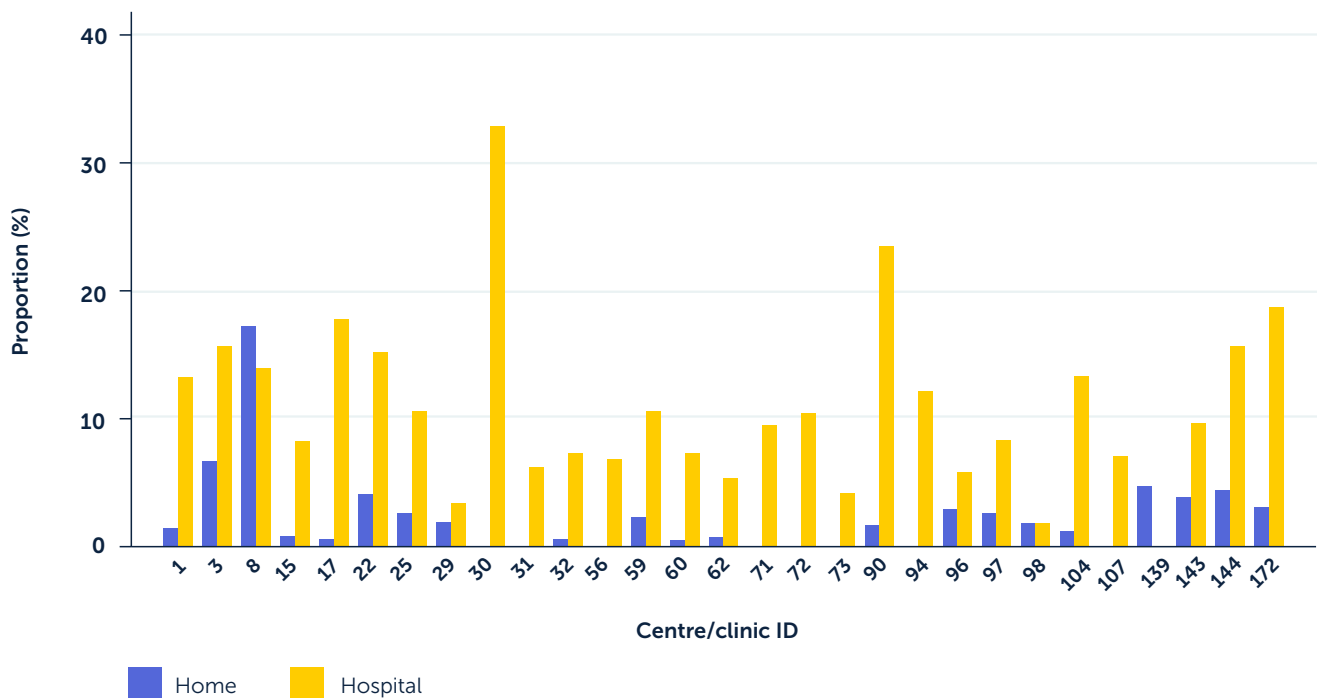
## 2.9 Proportion of people receiving DNase/hypertonic saline/mannitol treatment



Due to the small number of people in paediatric centres that received mannitol (<5 across all clinics/centres), receipt of mannitol is omitted from the above graph.

## 2.10 Intravenous (IV) antibiotic use

The chart below shows the proportion of people with at least one IV day at home and/or in hospital. People may have a combination of home and hospital IV days.



The proportion of people receiving IVs at home was 2.4% and in hospital was 11.4%. The proportion receiving any IVs was 12.0%.

## 2.11 Inhaled antibiotic use for people with chronic *Pseudomonas aeruginosa*

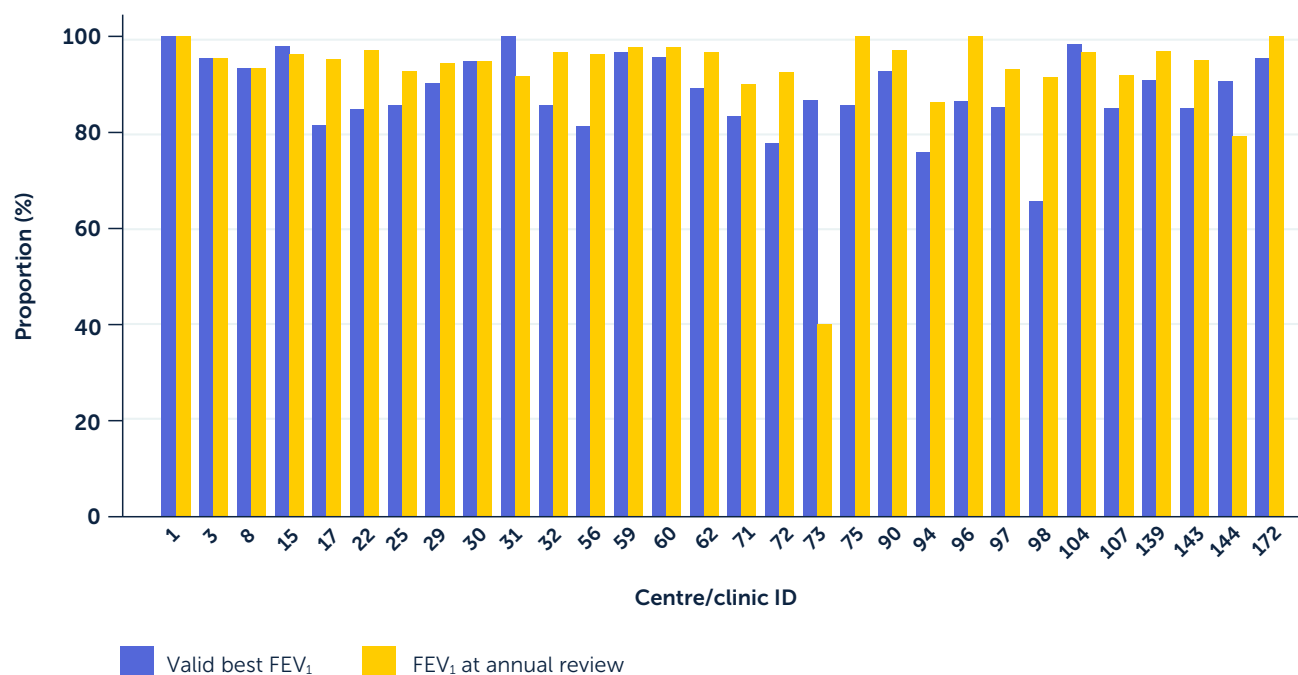


This table excludes centres where fewer than 10 people had chronic *P. aeruginosa*.

| Centre ID | Proportion (%) |
|-----------|----------------|
| 15        | 100.0          |
| 144       | 63.6           |

86.6% of people with chronic *P. aeruginosa* received inhaled antibiotics.

## 2.12 Data completeness<sup>1</sup>



<sup>1</sup> The chart above shows the proportion of people who had a valid Best FEV<sub>1</sub>% and an FEV<sub>1</sub>% at annual review, excluding people under six years of age. Best FEV<sub>1</sub>% was considered valid if it was not missing, and the percent predicted was not more than 0.5% lower than the annual review value. For some people there may be medical reasons why FEV<sub>1</sub> could not be taken, so centres may not be able to get 100% completeness.

**N=6712**



Mean age (years)

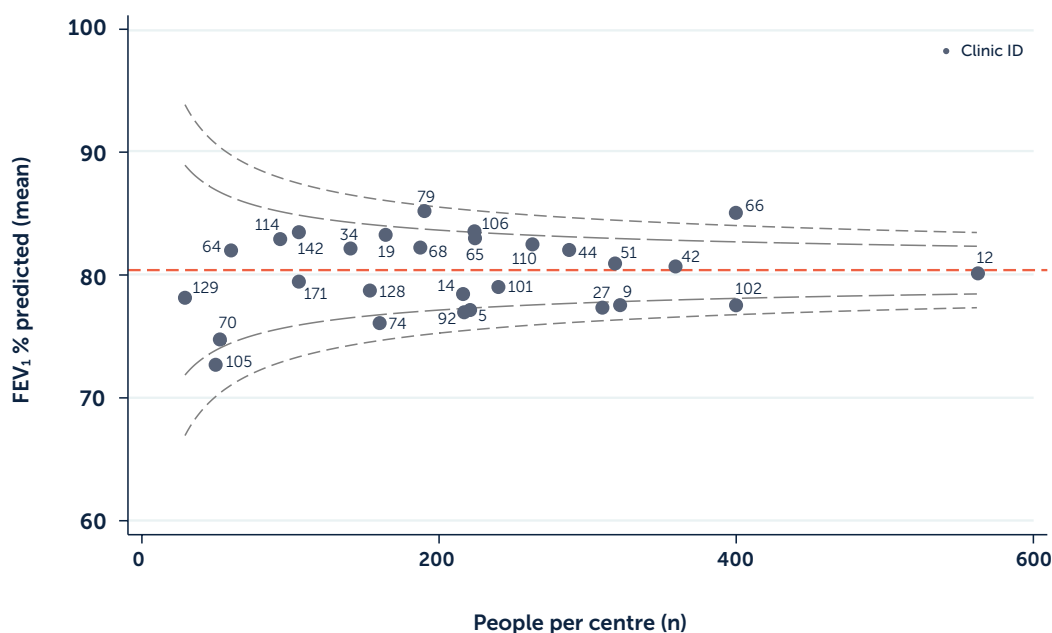
People per centre (n)

• Clinic ID

| Clinic ID | People per centre (n) | Mean age (years) |
|-----------|-----------------------|------------------|
| 129       | 50                    | 35.8             |
| 105       | 60                    | 33.8             |
| 64        | 70                    | 37.5             |
| 70        | 80                    | 36.5             |
| 171       | 100                   | 36.2             |
| 142       | 110                   | 33.5             |
| 114       | 120                   | 32.5             |
| 128       | 140                   | 33.2             |
| 19        | 150                   | 33.8             |
| 34        | 160                   | 36.2             |
| 74        | 170                   | 31.5             |
| 79        | 180                   | 34.5             |
| 68        | 190                   | 34.2             |
| 14        | 220                   | 38.2             |
| 5         | 230                   | 32.5             |
| 92        | 240                   | 30.5             |
| 106       | 250                   | 34.8             |
| 65        | 260                   | 33.2             |
| 110       | 280                   | 35.8             |
| 101       | 290                   | 32.2             |
| 44        | 310                   | 34.8             |
| 51        | 330                   | 33.8             |
| 9         | 340                   | 34.5             |
| 27        | 350                   | 35.8             |
| 42        | 420                   | 37.8             |
| 66        | 430                   | 33.8             |
| 102       | 530                   | 34.5             |
| 12        | 630                   | 37.8             |

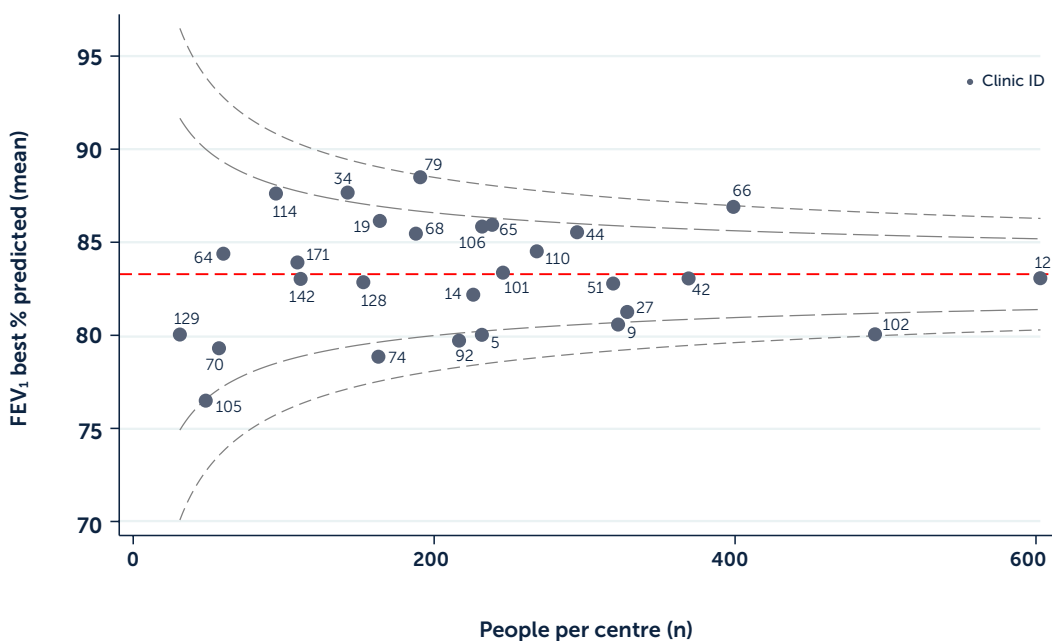


### 3.2 Age adjusted FEV<sub>1</sub> % predicted at annual review in people without a history of lung transplant



The mean FEV<sub>1</sub>% predicted in adult centres/clinics is 80.4%.

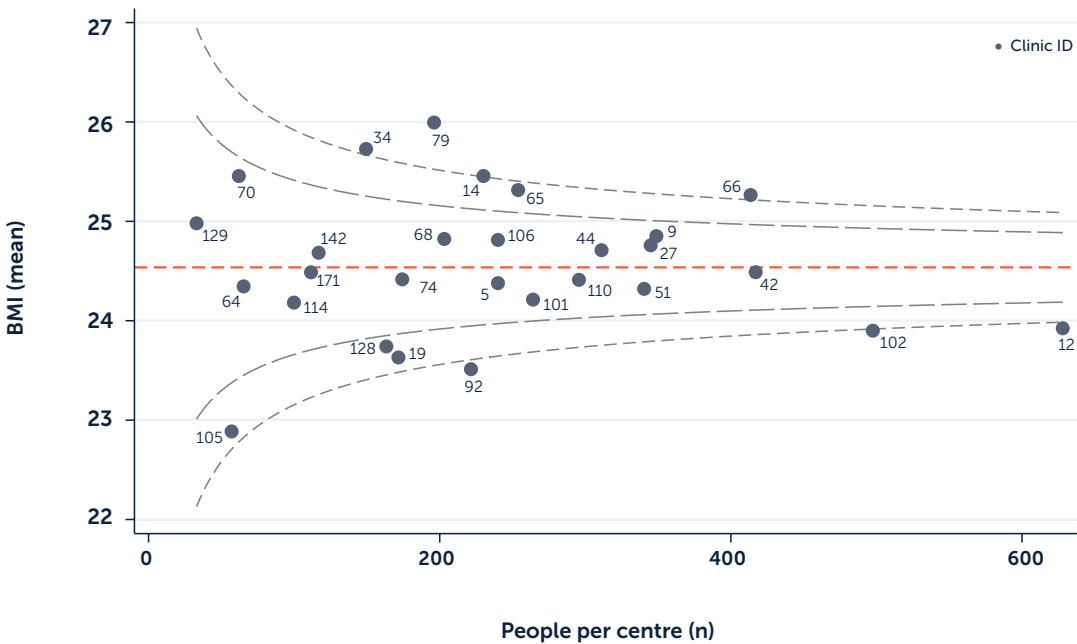
### 3.3 Age adjusted Best FEV<sub>1</sub> % predicted in people without a history of lung transplant



In 2025, the national mean was 83.3%. Where Best FEV<sub>1</sub>% predicted was missing, or lower than the FEV<sub>1</sub> at annual review, the FEV<sub>1</sub>% value at annual review was used.

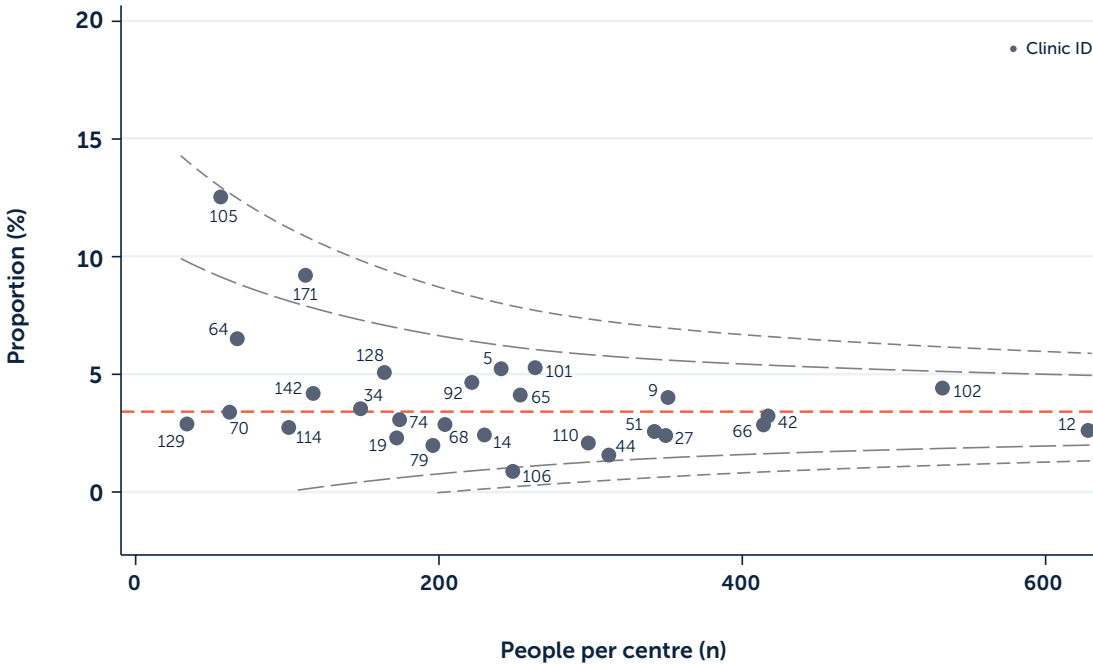


### 3.4 Age-adjusted Body Mass Index (BMI) among people aged 16 years and older



The mean BMI in adult centres/clinics is 24.5.

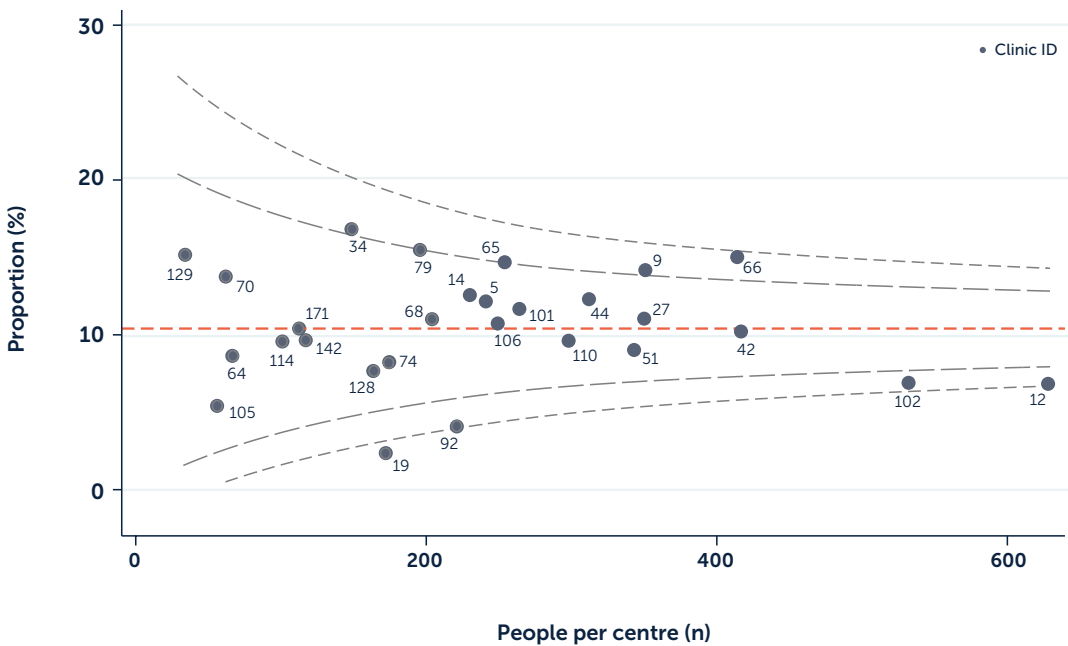
### 3.5 Age-adjusted proportion of people aged 16 years and older with BMI < 18.5



The age-adjusted proportion of people with BMI < 18.5 in adult centres/clinics is 3.4%.

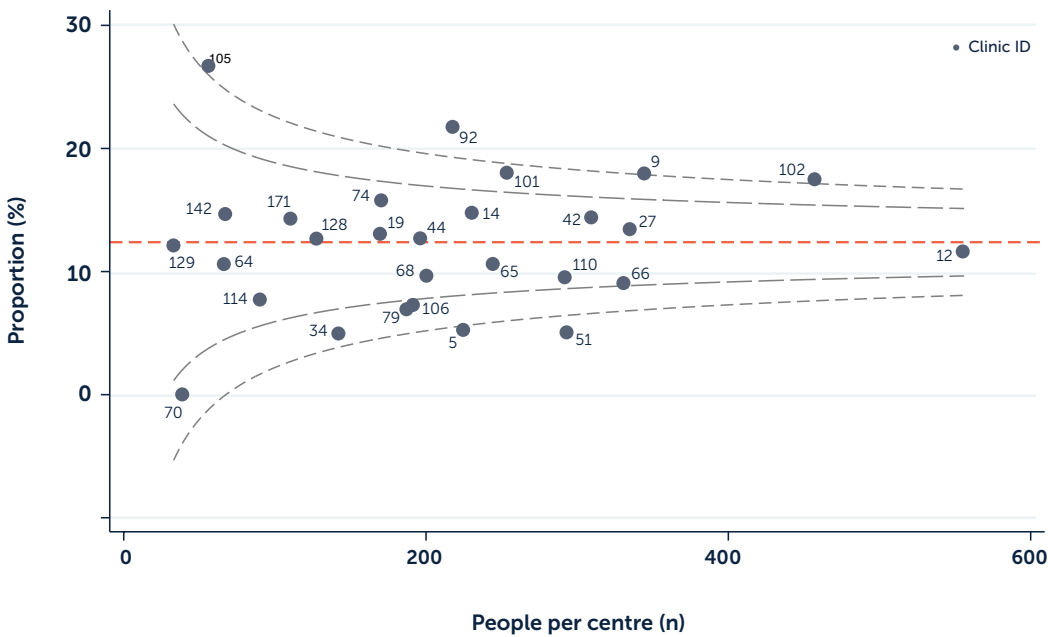


### 3.6 Age-adjusted proportion of people aged 16 years and older with BMI $\geq 30$



The age-adjusted proportion of people with BMI  $\geq 30$  in adult centres/clinics is 10.4%.

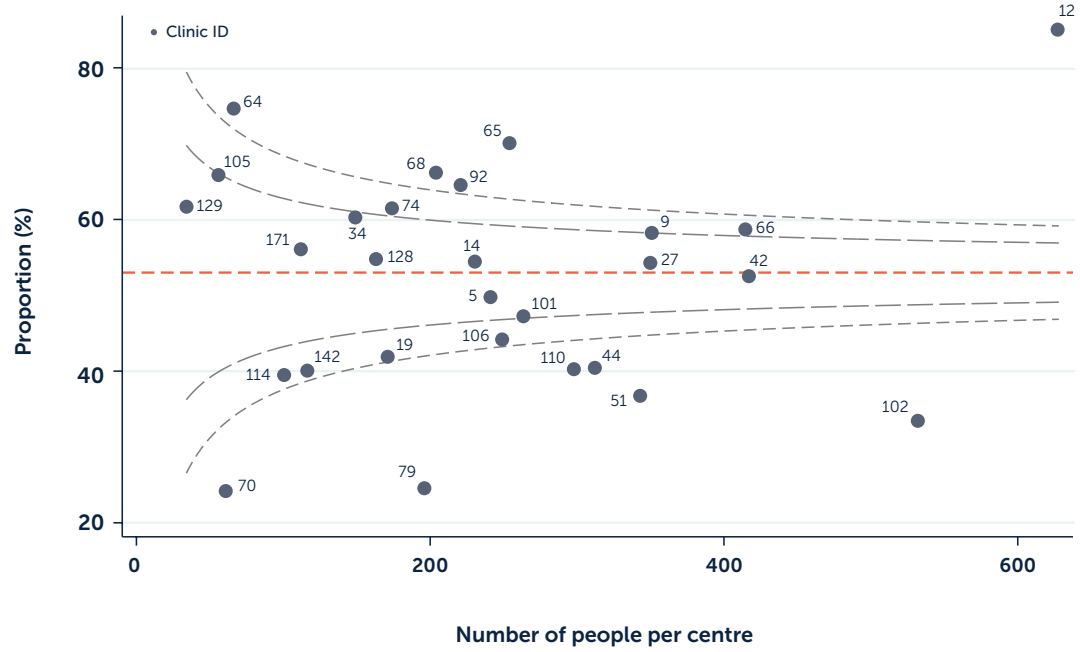
### 3.7 Proportion of people with chronic *Pseudomonas aeruginosa*



The proportion of people with chronic *P. aeruginosa* in adult centres/clinics is 12.7%.

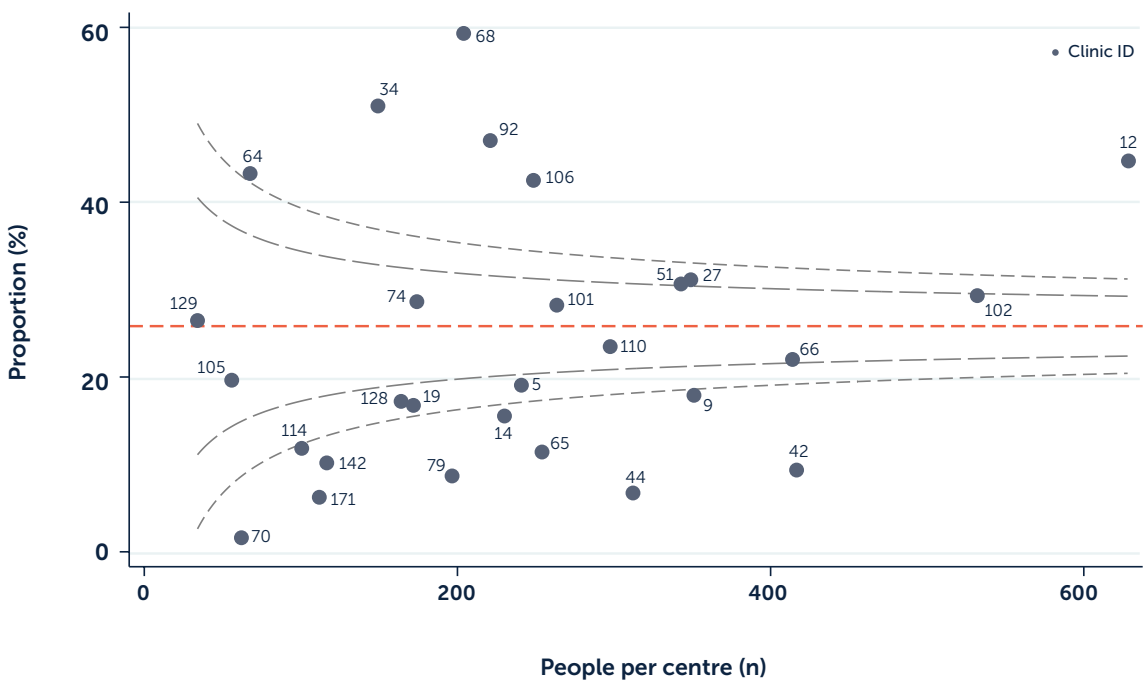


### 3.8 Proportion of people receiving DNase treatment



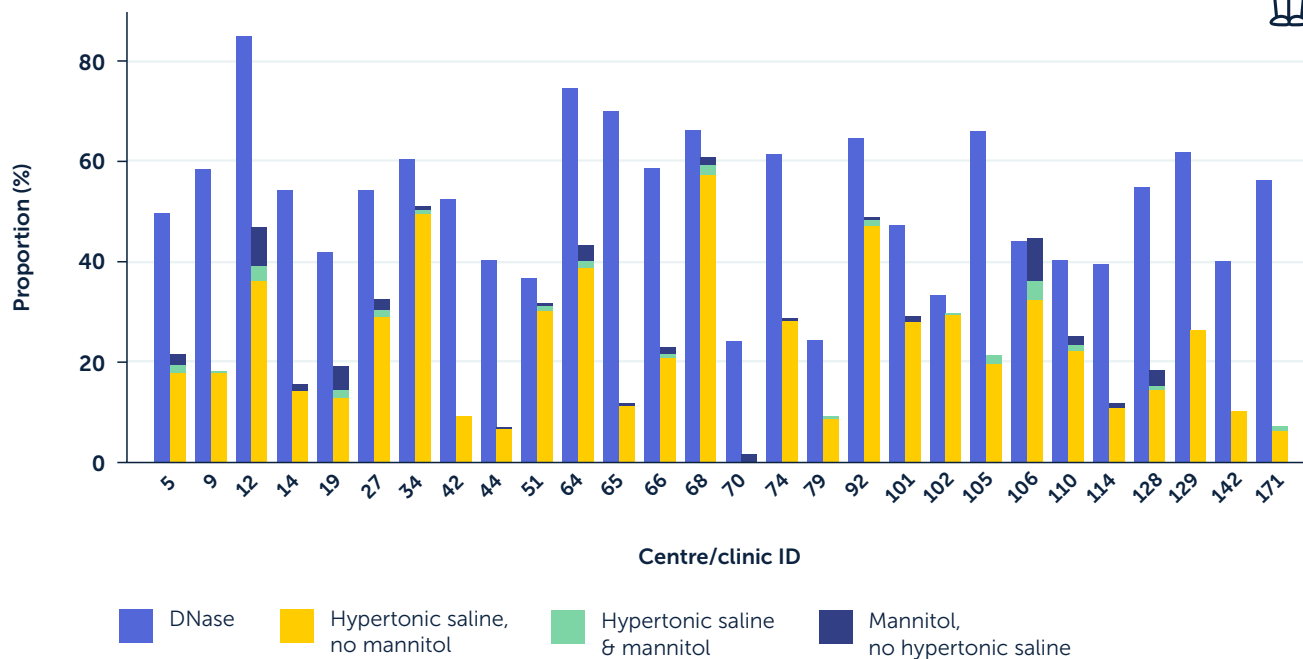
The proportion of people receiving DNase treatment in adult centres/clinics is 53.0%.

### 3.9 Proportion of people receiving hypertonic saline or mannitol



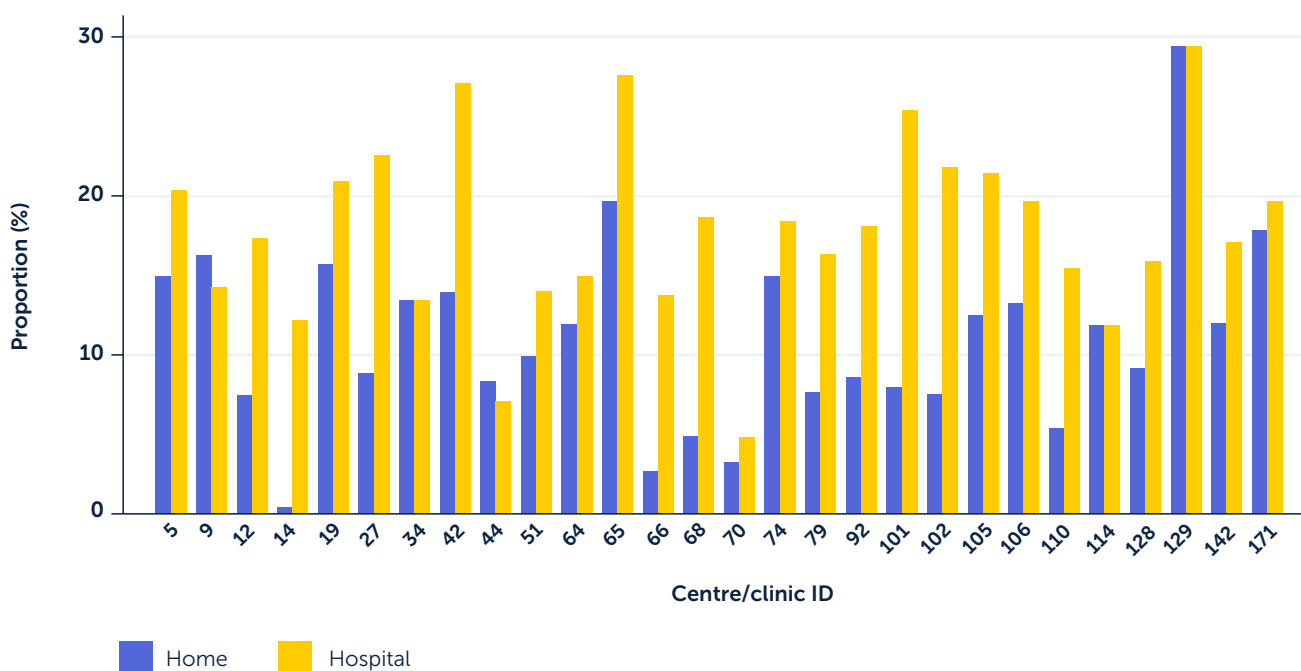
The proportion of people receiving hypertonic saline or mannitol treatment in adult centres/clinics is 25.8%.

### 3.10 Proportion of people receiving DNase/hypertonic saline/mannitol treatment



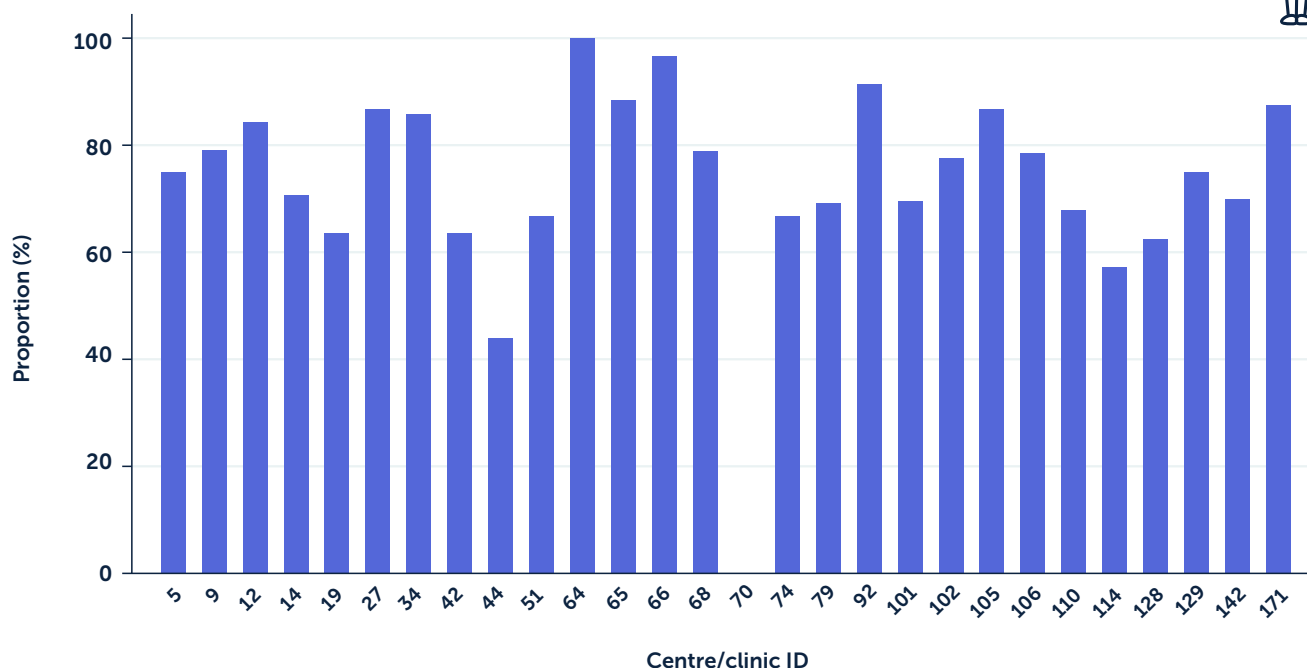
### 3.11 Intravenous (IV) antibiotic use

The chart below shows the proportion of people with at least one IV day at home and/or in hospital. People may have a combination of home and hospital IV days.



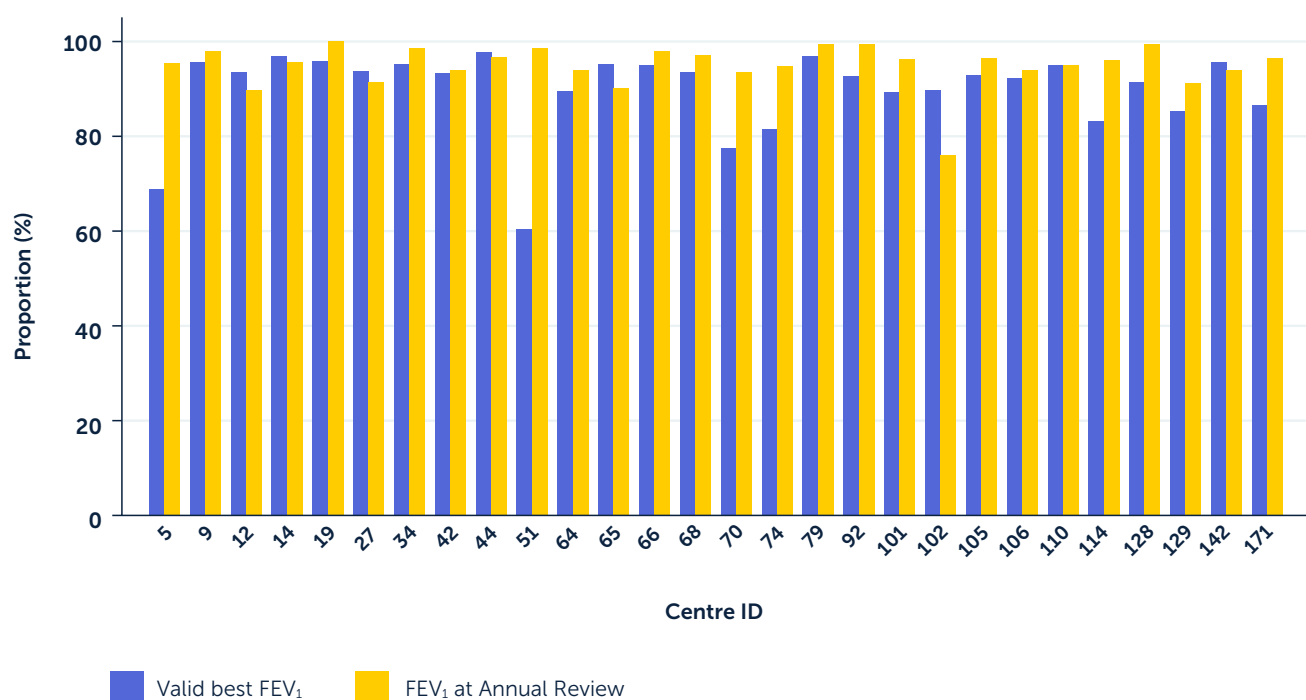
The proportion of people in adult centres receiving IV antibiotics at home was 10.2% and in hospital was 18.0%. The proportion receiving any IVs was 21.7%.

### 3.12 Inhaled antibiotic use for people with chronic *Pseudomonas aeruginosa*



76.6% of people in adult centres with chronic *P. aeruginosa* received inhaled antibiotics. Centres with fewer than 10 people with chronic *P. aeruginosa* were excluded.

### 3.13 Data completeness<sup>1</sup>



<sup>1</sup> FEV<sub>1</sub> was considered valid if it was not missing, and the percent predicted was not more than 0.5% lower than the annual review value. For some people there may be medical reasons why FEV<sub>1</sub> could not be taken, so centres may not be able to get 100% completeness.

# Appendix 1: UK CF Registry Committee structure

## UK CF Registry Steering Committee

| Role                                                               | Forename  | Surname   | Organisation                                                  |
|--------------------------------------------------------------------|-----------|-----------|---------------------------------------------------------------|
| Director Research and Healthcare Data (non-voting member)          | Lucy      | Allen     | Cystic Fibrosis Trust                                         |
| Commissioner, England                                              | Kathy     | Blacker   | NHS England                                                   |
| CF Physician – Paediatrics                                         | Malcolm   | Brodlie   | Great North Children's Hospital, Newcastle                    |
| CF Physician – Paediatrics                                         | Siobhán   | Carr      | Royal Brompton and Harefield hospitals, London                |
| Analytical team representative (non-voting member)                 | Susan     | Charman   | Cystic Fibrosis Trust                                         |
| Associate Director of Data and QI, and Caldicott Guardian          | Sarah     | Clarke    | Cystic Fibrosis Trust                                         |
| CF Physician – Paediatrics                                         | Gwyneth   | Davies    | UCL and Great Ormond Street Institute of Child Health, London |
| Chair, UK CF Registry Steering Committee and CF Physician – Adults | Jamie     | Duckers   | University Hospital of Wales, Cardiff                         |
| Parent of child with CF                                            | Catherine | Farrer    | N/A                                                           |
| Person with CF                                                     | Hannah    | Gales     | N/A                                                           |
| CF Physician – Paediatrics                                         | Francis   | Gilchrist | Royal Stoke University Hospital, Stoke                        |
| Registry Clinical Data Manager (non-voting member)                 | Elaine    | Gunn      | Cystic Fibrosis Trust                                         |
| Allied Health Professional                                         | Rebecca   | Heise     | King's College Hospital, London                               |
| Cystic Fibrosis Centre Data Manager                                | Erin      | Hodgetts  | Royal Stoke University Hospital, Stoke                        |
| Head of Registry Operations (non-voting member)                    | Mary      | Kisanga   | Cystic Fibrosis Trust                                         |
|                                                                    | Joanne    | Osmond    |                                                               |
| Registry Systems Development Manager (non-voting member)           | Kerry     | Laidlaw   | Cystic Fibrosis Trust                                         |
| Welsh Commissioner                                                 | Emma      | King      | NHS Wales                                                     |
| CF Physician – Adults                                              | Dilip     | Nazareth  | Liverpool Heart and Chest Hospital, Liverpool                 |
| Scotland Representative                                            | Helen     | Rodgers   | NHS Scotland                                                  |
| Allied Health Professional                                         | Joanna    | Snowball  | John Radcliffe Hospital, Oxford                               |

## Appendix 2: Centre-level data tables



### Paediatric centres/clinics providing data in 2025 – ordered alphabetically by country/city

| Location                | Name                                         | Clinic ID | Total Active | Number with annual review |
|-------------------------|----------------------------------------------|-----------|--------------|---------------------------|
| <b>England</b>          |                                              |           |              |                           |
| Birmingham              | Birmingham Children's Hospital               | 104       | 276          | 255                       |
| Brighton                | Royal Alexandra Children's Hospital          | 172       | 68           | 64                        |
| Bristol                 | Bristol Royal Hospital for Children          | 32        | 183          | 165                       |
| Cambridge               | Addenbrookes Hospital                        | 107       | 156          | 142                       |
| Cornwall                | Royal Cornwall Hospital                      | 94        | 36           | 33                        |
| Exeter                  | Royal Devon and Exeter Hospital              | 96        | 73           | 69                        |
| Leeds                   | St James' University Hospital                | 25        | 278          | 265                       |
| Leicester               | Leicester Royal Infirmary                    | 1         | 73           | 68                        |
| Liverpool               | Alder Hey Children's Hospital                | 97        | 278          | 265                       |
| London – East           | The Royal London Hospital                    | 30        | 78           | 73                        |
| London – South East     | King's College Hospital                      | 17        | 194          | 180                       |
| London – South West     | Royal Brompton Hospital                      | 15        | 257          | 242                       |
| London – Central        | Great Ormond Street Hospital for Children    | 90        | 188          | 179                       |
| Manchester              | Royal Manchester Children's Hospital         | 144       | 320          | 294                       |
| Newcastle               | Great North Children's Hospital              | 59        | 199          | 132                       |
| North West Midlands     | University Hospital of North Midlands        | 8         | 102          | 93                        |
| Norwich                 | Norfolk and Norwich University Hospital      | 98        | 56           | 55                        |
| Nottingham              | Nottingham University Hospitals              | 62        | 144          | 130                       |
| Oxford                  | John Radcliffe Hospital                      | 22        | 161          | 145                       |
| Plymouth                | Derriford Hospital                           | 139       | 42           | 42                        |
| Sheffield               | Sheffield Children's Hospital                | 3         | 140          | 134                       |
| Southampton             | Southampton General Hospital                 | 29        | 224          | 208                       |
| Teeside                 | The James Cook University Hospital           | 71        | 53           | 42                        |
| <b>Northern Ireland</b> |                                              |           |              |                           |
| Belfast                 | Royal Belfast Hospital for Sick Children     | 60        | 211          | 191                       |
| <b>Scotland</b>         |                                              |           |              |                           |
| Aberdeen                | Royal Aberdeen Children's Hospital           | 75        | 27           | 8                         |
| Dundee                  | Ninewells Hospital                           | 73        | 25           | 24                        |
| Edinburgh               | Royal Hospital for Children and Young People | 143       | 114          | 104                       |
| Glasgow                 | Royal Hospital for Children and Young People | 56        | 186          | 160                       |
| Inverness               | Raigmore Hospital                            | 31        | 17           | 16                        |
| <b>Wales</b>            |                                              |           |              |                           |
| Cardiff                 | Noah's Ark Children's Hospital for Wales     | 72        | 138          | 134                       |



| Clinic ID | Age  |        | BMI Percentile |                   |                 |        | Proportion (%) with BMI in lowest and highest percentile groups |                     |           |                      |
|-----------|------|--------|----------------|-------------------|-----------------|--------|-----------------------------------------------------------------|---------------------|-----------|----------------------|
|           | Mean | Median | Number*        | Mean – unadjusted | Mean – adjusted | Median | BMI <5th                                                        | BMI <5th – adjusted | BMI ≥95th | BMI ≥95th – adjusted |
| 104       | 9.2  | 9.1    | 236            | 57.8              | 57.8            | 58.8   | 0.4                                                             | 0.4                 | 13.1      | 13.3                 |
| 172       | 9.2  | 9.5    | 61             | 60.8              | 60.8            | 61.4   | 0.0                                                             | 0.0                 | 11.5      | 11.8                 |
| 32        | 9.9  | 10.1   | 151            | 58.4              | 58.4            | 62.2   | 3.3                                                             | 3.2                 | 12.6      | 12.4                 |
| 107       | 9.0  | 9.0    | 129            | 59.4              | 59.5            | 64.9   | 4.7                                                             | 4.7                 | 12.4      | 12.7                 |
| 94        | 10.5 | 11.2   | 29             | 71.8              | 71.8            | 75.7   | 0.0                                                             | 0.0                 | 24.1      | 22.4                 |
| 96        | 10.7 | 11.0   | 65             | 58.8              | 58.7            | 56.7   | 0.0                                                             | 0.0                 | 18.5      | 17.6                 |
| 25        | 9.6  | 10.4   | 248            | 61.0              | 61.0            | 64.9   | 2.0                                                             | 2.0                 | 14.5      | 14.5                 |
| 1         | 9.4  | 9.7    | 64             | 59.2              | 59.2            | 63.7   | 1.6                                                             | 1.6                 | 12.5      | 12.5                 |
| 97        | 9.8  | 10.1   | 243            | 62.5              | 62.5            | 63.9   | 2.1                                                             | 2.1                 | 11.9      | 11.7                 |
| 30        | 10.0 | 10.4   | 68             | 53.5              | 53.5            | 53.3   | 2.9                                                             | 2.9                 | 2.9       | 2.9                  |
| 17        | 9.0  | 9.1    | 159            | 53.3              | 53.3            | 56.1   | 2.5                                                             | 2.5                 | 5.0       | 5.1                  |
| 15        | 10.0 | 10.5   | 236            | 53.9              | 53.9            | 52.8   | 4.2                                                             | 4.2                 | 8.5       | 8.5                  |
| 90        | 9.8  | 10.5   | 166            | 52.4              | 52.4            | 51.2   | 3.0                                                             | 3.0                 | 8.4       | 8.2                  |
| 144       | 9.4  | 9.7    | 263            | 58.0              | 58.0            | 58.7   | 3.0                                                             | 3.1                 | 10.6      | 10.8                 |
| 59        | 9.5  | 9.2    | 123            | 57.1              | 57.1            | 59.6   | 3.3                                                             | 3.2                 | 12.2      | 12.4                 |
| 8         | 11.1 | 11.9   | 83             | 57.6              | 57.6            | 59.3   | 1.2                                                             | 1.1                 | 18.1      | 17.7                 |
| 98        | 7.7  | 7.9    | 47             | 59.9              | 59.9            | 64.4   | 4.3                                                             | 4.6                 | 10.6      | 10.8                 |
| 62        | 9.8  | 10.7   | 122            | 58.9              | 58.9            | 63.9   | 5.7                                                             | 5.6                 | 9.8       | 9.9                  |
| 22        | 9.6  | 9.9    | 133            | 58.5              | 58.5            | 62.0   | 3.8                                                             | 3.7                 | 14.3      | 14.2                 |
| 139       | 9.9  | 10.1   | 38             | 60.1              | 60.0            | 67.9   | 0.0                                                             | 0.0                 | 13.2      | 12.8                 |
| 3         | 8.9  | 9.7    | 128            | 57.8              | 57.8            | 59.2   | 0.0                                                             | 0.0                 | 9.4       | 9.6                  |
| 29        | 9.2  | 9.1    | 187            | 58.4              | 58.4            | 64.2   | 2.7                                                             | 2.6                 | 11.8      | 11.9                 |
| 71        | 9.4  | 9.4    | 40             | 68.6              | 68.6            | 72.7   | 0.0                                                             | 0.0                 | 12.5      | 12.8                 |
| 60        | 9.9  | 10.0   | 180            | 58.6              | 58.6            | 61.2   | 2.8                                                             | 2.7                 | 11.7      | 11.7                 |
| 75        | 9.6  | 7.6    | 8              | 41.4              | 41.4            | 37.5   | 0.0                                                             | 0.0                 | 0.0       | 0.0                  |
| 73        | 9.4  | 10.0   | 18             | 56.1              | 56.1            | 54.4   | 0.0                                                             | 0.0                 | 5.6       | 6.0                  |
| 143       | 9.6  | 9.6    | 94             | 58.1              | 58.1            | 58.1   | 1.1                                                             | 1.1                 | 18.1      | 17.5                 |
| 56        | 8.6  | 8.8    | 142            | 57.7              | 57.7            | 59.4   | 2.1                                                             | 2.2                 | 10.6      | 10.7                 |
| 31        | 10.0 | 10.0   | 16             | 63.9              | 63.9            | 71.6   | 6.2                                                             | 6.3                 | 12.5      | 12.4                 |
| 72        | 9.7  | 10.1   | 127            | 56.3              | 56.3            | 55.6   | 3.9                                                             | 4.0                 | 11.8      | 11.5                 |

\* Number with non-missing data.



## Paediatric centres/clinics providing data in 2025 – ordered alphabetically by country/city

|                         |                                              |           | FEV <sub>1</sub> % predicted at annual review |                   |                 |        |
|-------------------------|----------------------------------------------|-----------|-----------------------------------------------|-------------------|-----------------|--------|
| Location                | Name                                         | Clinic ID | Number*                                       | Mean – unadjusted | Mean – adjusted | Median |
| <b>England</b>          |                                              |           |                                               |                   |                 |        |
| Birmingham              | Birmingham Children's Hospital               | 104       | 174                                           | 96.1              | 96.3            | 97.1   |
| Brighton                | Royal Alexandra Children's Hospital          | 172       | 45                                            | 106.9             | 107.1           | 107.2  |
| Bristol                 | Bristol Royal Hospital for Children          | 32        | 121                                           | 98.5              | 98.7            | 98.5   |
| Cambridge               | Addenbrookes Hospital                        | 107       | 92                                            | 101.9             | 102.1           | 103.4  |
| Cornwall                | Royal Cornwall Hospital                      | 94        | 25                                            | 102.5             | 102.8           | 101.6  |
| Exeter                  | Royal Devon and Exeter Hospital              | 96        | 59                                            | 97.2              | 97.5            | 98.3   |
| Leeds                   | St James' University Hospital                | 25        | 181                                           | 97.5              | 97.7            | 98.4   |
| Leicester               | Leicester Royal Infirmary                    | 1         | 48                                            | 102.3             | 102.5           | 100.8  |
| Liverpool               | Alder Hey Children's Hospital                | 97        | 190                                           | 96.3              | 96.6            | 97.7   |
| London – East           | The Royal London Hospital                    | 30        | 55                                            | 99.6              | 99.8            | 100.4  |
| London – South East     | King's College Hospital                      | 17        | 118                                           | 98.4              | 98.6            | 99.8   |
| London – South West     | Royal Brompton Hospital                      | 15        | 182                                           | 99.4              | 99.6            | 99.8   |
| London – Central        | Great Ormond Street Hospital for Children    | 90        | 132                                           | 100.9             | 101.2           | 102.7  |
| Manchester              | Royal Manchester Children's Hospital         | 144       | 161                                           | 97.1              | 97.3            | 98.3   |
| Newcastle               | Great North Children's Hospital              | 59        | 90                                            | 101.8             | 102.0           | 101.7  |
| North West Midlands     | University Hospital of North Midlands        | 8         | 71                                            | 96.1              | 96.3            | 97.4   |
| Norwich                 | Norfolk and Norwich University Hospital      | 98        | 32                                            | 93.2              | 93.3            | 93.4   |
| Nottingham              | Nottingham University Hospitals              | 62        | 90                                            | 96.7              | 97.0            | 98.7   |
| Oxford                  | John Radcliffe Hospital                      | 22        | 103                                           | 98.3              | 98.5            | 98.2   |
| Plymouth                | Derriford Hospital                           | 139       | 32                                            | 97.8              | 97.9            | 97.4   |
| Sheffield               | Sheffield Children's Hospital                | 3         | 86                                            | 102.0             | 102.3           | 102.5  |
| Southampton             | Southampton General Hospital                 | 29        | 136                                           | 101.9             | 102.1           | 102.6  |
| Teeside                 | The James Cook University Hospital           | 71        | 27                                            | 95.3              | 95.5            | 96.1   |
| <b>Northern Ireland</b> |                                              |           |                                               |                   |                 |        |
| Belfast                 | Royal Belfast Hospital for Sick Children     | 60        | 136                                           | 102.8             | 103.0           | 59.3   |
| <b>Scotland</b>         |                                              |           |                                               |                   |                 |        |
| Aberdeen                | Royal Aberdeen Children's Hospital           | 75        | 7                                             | 110.4             | 110.4           | 115.4  |
| Dundee                  | Ninewells Hospital                           | 73        | 6                                             | 107.3             | 107.6           | 109.0  |
| Edinburgh               | Royal Hospital for Children and Young People | 143       | 76                                            | 103.9             | 104.1           | 104.4  |
| Glasgow                 | Royal Hospital for Children and Young People | 56        | 103                                           | 101.5             | 101.7           | 101.2  |
| Inverness               | Raigmore Hospital                            | 31        | 11                                            | 94.6              | 94.9            | 98.4   |
| <b>Wales</b>            |                                              |           |                                               |                   |                 |        |
| Cardiff                 | Noah's Ark Children's Hospital for Wales     | 72        | 100                                           | 99.3              | 99.5            | 100.2  |

\* Number with non-missing data.



| Clinic ID | Best** FEV <sub>1</sub> % predicted |                   |                 |        | Chronic <i>pseudomonas</i> |                | Having at least 1 IV day |                | Inhaled antibiotic use among people with chronic <i>pseudomonas</i> |                |
|-----------|-------------------------------------|-------------------|-----------------|--------|----------------------------|----------------|--------------------------|----------------|---------------------------------------------------------------------|----------------|
|           | Number*                             | Mean – unadjusted | Mean – adjusted | Median | Number*                    | Proportion (%) | Number*                  | Proportion (%) | Number*                                                             | Proportion (%) |
| 104       | 177                                 | 100.4             | 100.5           | 100.3  | 6                          | 2.4            | 34                       | 13.3           | 6                                                                   | 100.0          |
| 172       | 45                                  | 108.8             | 108.9           | 107.2  | <5                         | 1.6            | 12                       | 18.8           | <5                                                                  | 100.0          |
| 32        | 122                                 | 102.5             | 102.8           | 102.3  | <5                         | 1.2            | 12                       | 7.3            | <5                                                                  | 50.0           |
| 107       | 93                                  | 103.3             | 103.4           | 103.5  | <5                         | 0.8            | 10                       | 7.0            | <5                                                                  | 100.0          |
| 94        | 27                                  | 105.5             | 105.7           | 105.6  | 0                          | 0.0            | <5                       | 12.1           | 0                                                                   | 0.0            |
| 96        | 59                                  | 101.8             | 102.0           | 100.6  | 0                          | 0.0            | <5                       | 5.8            | 0                                                                   | 0.0            |
| 25        | 185                                 | 101.7             | 102.0           | 102.4  | 5                          | 2.0            | 29                       | 10.9           | <5                                                                  | 80.0           |
| 1         | 48                                  | 105.0             | 105.2           | 104.6  | <5                         | 2.9            | 9                        | 13.2           | <5                                                                  | 100.0          |
| 97        | 195                                 | 101.3             | 101.5           | 102.6  | <5                         | 0.8            | 23                       | 8.7            | <5                                                                  | 100.0          |
| 30        | 55                                  | 104.0             | 104.2           | 103.9  | <5                         | 5.6            | 24                       | 32.9           | <5                                                                  | 100.0          |
| 17        | 122                                 | 100.2             | 100.3           | 103.5  | 8                          | 4.7            | 32                       | 17.8           | <5                                                                  | 50.0           |
| 15        | 185                                 | 103.8             | 104.0           | 103.9  | 11                         | 4.5            | 20                       | 8.3            | 11                                                                  | 100.0          |
| 90        | 133                                 | 103.4             | 103.6           | 103.8  | 5                          | 2.9            | 42                       | 23.5           | 5                                                                   | 100.0          |
| 144       | 194                                 | 102.0             | 102.2           | 101.5  | 11                         | 3.9            | 50                       | 17.0           | 7                                                                   | 63.6           |
| 59        | 90                                  | 105.5             | 105.8           | 105.2  | 0                          | 0.0            | 15                       | 11.4           | 0                                                                   | 0.0            |
| 8         | 75                                  | 101.7             | 102.0           | 105.3  | <5                         | 1.1            | 24                       | 25.8           | <5                                                                  | 100.0          |
| 98        | 33                                  | 96.7              | 96.6            | 98.7   | 0                          | 0.0            | <5                       | 3.6            | 0                                                                   | 0.0            |
| 62        | 93                                  | 100.9             | 101.2           | 101.2  | <5                         | 0.8            | 7                        | 5.4            | <5                                                                  | 100.0          |
| 22        | 106                                 | 101.5             | 101.7           | 100.3  | <5                         | 0.7            | 23                       | 15.9           | 0                                                                   | 0.0            |
| 139       | 32                                  | 101.8             | 101.9           | 101.2  | 0                          | 0.0            | <5                       | 4.8            | 0                                                                   | 0.0            |
| 3         | 88                                  | 108.1             | 108.4           | 109.1  | <5                         | 2.2            | 21                       | 15.7           | <5                                                                  | 100.0          |
| 29        | 142                                 | 105.2             | 105.3           | 105.2  | 5                          | 2.5            | 7                        | 3.4            | 5                                                                   | 100.0          |
| 71        | 28                                  | 103.1             | 103.4           | 99.9   | <5                         | 4.9            | <5                       | 9.5            | <5                                                                  | 100.0          |
| 60        | 137                                 | 106.2             | 106.5           | 106.3  | <5                         | 0.5            | 14                       | 7.3            | <5                                                                  | 100.0          |
| 75        | 7                                   | 116.8             | 116.3           | 115.4  | 0                          | 0.0            | <5                       | 25.0           | 0                                                                   | 0.0            |
| 73        | 13                                  | 107.0             | 107.5           | 106.8  | 0                          | 0.0            | <5                       | 4.2            | 0                                                                   | 0.0            |
| 143       | 79                                  | 106.4             | 106.6           | 106.3  | <5                         | 2.0            | 12                       | 11.5           | <5                                                                  | 100.0          |
| 56        | 105                                 | 104.7             | 104.8           | 103.7  | <5                         | 1.3            | 11                       | 6.9            | <5                                                                  | 100.0          |
| 31        | 12                                  | 98.8              | 99.1            | 104.0  | <5                         | 14.3           | <5                       | 6.3            | <5                                                                  | 100.0          |
| 72        | 102                                 | 102.0             | 102.1           | 103.1  | <5                         | 3.0            | 14                       | 10.4           | <5                                                                  | 100.0          |

\*\* Where 'Best' values were missing, or lower than FEV<sub>1</sub>% predicted taken at annual review, the annual review value was used.

\* Number with non-missing data.



## Paediatric centres/clinics providing data in 2025 – ordered alphabetically by country/city

|                         |                                              |           | Receiving DNase treatment |                | Receiving hypertonic saline of mannitol treatment |                |
|-------------------------|----------------------------------------------|-----------|---------------------------|----------------|---------------------------------------------------|----------------|
| Location                | Name                                         | Clinic ID | Number*                   | Proportion (%) | Number*                                           | Proportion (%) |
| <b>England</b>          |                                              |           |                           |                |                                                   |                |
| Birmingham              | Birmingham Children's Hospital               | 104       | 114                       | 44.7           | 104                                               | 40.8           |
| Brighton                | Royal Alexandra Children's Hospital          | 172       | 35                        | 54.7           | 43                                                | 67.2           |
| Bristol                 | Bristol Royal Hospital for Children          | 32        | 116                       | 70.3           | 109                                               | 66.1           |
| Cambridge               | Addenbrookes Hospital                        | 107       | 47                        | 33.1           | 95                                                | 66.9           |
| Cornwall                | Royal Cornwall Hospital                      | 94        | 21                        | 63.6           | 13                                                | 39.4           |
| Exeter                  | Royal Devon and Exeter Hospital              | 96        | 63                        | 91.3           | 66                                                | 95.7           |
| Leeds                   | St James' University Hospital                | 25        | 118                       | 44.5           | 39                                                | 14.7           |
| Leicester               | Leicester Royal Infirmary                    | 1         | 45                        | 66.2           | 16                                                | 23.5           |
| Liverpool               | Alder Hey Children's Hospital                | 97        | 72                        | 27.2           | 17                                                | 6.4            |
| London – East           | The Royal London Hospital                    | 30        | 51                        | 69.9           | 55                                                | 75.3           |
| London – South East     | King's College Hospital                      | 17        | 102                       | 56.7           | 33                                                | 18.3           |
| London – South West     | Royal Brompton Hospital                      | 15        | 142                       | 58.7           | 127                                               | 52.5           |
| London – Central        | Great Ormond Street Hospital for Children    | 90        | 125                       | 69.8           | 87                                                | 48.6           |
| Manchester              | Royal Manchester Children's Hospital         | 144       | 154                       | 52.4           | 98                                                | 33.3           |
| Newcastle               | Great North Children's Hospital              | 59        | 59                        | 44.7           | 7                                                 | 5.3            |
| North West Midlands     | University Hospital of North Midlands        | 8         | 53                        | 57.0           | 31                                                | 33.3           |
| Norwich                 | Norfolk and Norwich University Hospital      | 98        | 35                        | 63.6           | <5                                                | 7.3            |
| Nottingham              | Nottingham University Hospitals              | 62        | 37                        | 28.5           | 23                                                | 17.7           |
| Oxford                  | John Radcliffe Hospital                      | 22        | 93                        | 64.1           | 54                                                | 37.2           |
| Plymouth                | Derriford Hospital                           | 139       | 28                        | 66.7           | <5                                                | 7.1            |
| Sheffield               | Sheffield Children's Hospital                | 3         | 87                        | 64.9           | 32                                                | 23.9           |
| Southampton             | Southampton General Hospital                 | 29        | 115                       | 55.3           | 26                                                | 12.5           |
| Teeside                 | The James Cook University Hospital           | 71        | 20                        | 47.6           | 8                                                 | 19.0           |
| <b>Northern Ireland</b> |                                              |           |                           |                |                                                   |                |
| Belfast                 | Royal Belfast Hospital for Sick Children     | 60        | 165                       | 86.4           | 76                                                | 39.8           |
| <b>Scotland</b>         |                                              |           |                           |                |                                                   |                |
| Aberdeen                | Royal Aberdeen Children's Hospital           | 75        | <5                        | 50.0           | <5                                                | 12.5           |
| Dundee                  | Ninewells Hospital                           | 73        | 5                         | 20.8           | <5                                                | 8.3            |
| Edinburgh               | Royal Hospital for Children and Young People | 143       | 50                        | 48.1           | 12                                                | 11.5           |
| Glasgow                 | Royal Hospital for Children and Young People | 56        | 24                        | 15.0           | 43                                                | 26.9           |
| Inverness               | Raigmore Hospital                            | 31        | 9                         | 56.2           | <5                                                | 6.2            |
| <b>Wales</b>            |                                              |           |                           |                |                                                   |                |
| Cardiff                 | Noah's Ark Children's Hospital for Wales     | 72        | 113                       | 84.3           | 128                                               | 95.5           |

\* Number with non-missing data.





## Adult centres/clinics providing data in 2025 – ordered alphabetically by country/city

| Location                | Name                                    | Clinic ID | Total Active | Number with annual review |
|-------------------------|-----------------------------------------|-----------|--------------|---------------------------|
| <b>England</b>          |                                         |           |              |                           |
| Birmingham              | Heartlands Hospital                     | 27        | 365          | 350                       |
| Bristol                 | Bristol Royal Infirmary                 | 106       | 261          | 249                       |
| Cambridge               | Royal Papworth Hospital                 | 51        | 401          | 343                       |
| Cornwall                | Royal Cornwall Hospital                 | 129       | 41           | 34                        |
| Exeter                  | Royal Devon and Exeter Hospital         | 34        | 153          | 149                       |
| Frimley                 | Frimley Park Hospital                   | 19        | 183          | 172                       |
| Leeds                   | St James' University Hospital           | 42        | 428          | 417                       |
| Leicester               | Glenfield Hospital                      | 142       | 124          | 117                       |
| Liverpool               | Liverpool Heart and Chest Hospital      | 66        | 421          | 414                       |
| London – East           | St. Bartholomew's Hospital              | 92        | 249          | 221                       |
| London – South East     | University Hospital Lewisham            | 105       | 59           | 56                        |
| London – South East     | King's College Hospital                 | 5         | 275          | 241                       |
| London – South West     | Royal Brompton Hospital                 | 12        | 635          | 628                       |
| Manchester              | Wythenshawe Hospital                    | 102       | 540          | 532                       |
| Newcastle               | Royal Victoria Infirmary                | 9         | 363          | 351                       |
| North West Midlands     | University Hospital of North Midlands   | 74        | 181          | 174                       |
| Norwich                 | Norfolk and Norwich University Hospital | 114       | 102          | 101                       |
| Nottingham              | Nottingham University Hospitals         | 101       | 265          | 264                       |
| Oxford                  | Oxford University Hospitals             | 128       | 179          | 164                       |
| Plymouth                | Derriford Hospital                      | 64        | 73           | 67                        |
| Sheffield               | Northern General Hospital               | 65        | 259          | 254                       |
| Southampton             | Southampton General Hospital            | 110       | 331          | 298                       |
| York                    | York Hospital                           | 171       | 114          | 112                       |
| <b>Northern Ireland</b> |                                         |           |              |                           |
| Belfast                 | Belfast City Hospital                   | 14        | 305          | 230                       |
| <b>Scotland</b>         |                                         |           |              |                           |
| Aberdeen                | Aberdeen Royal Infirmary                | 70        | 70           | 62                        |
| Edinburgh               | Western General Hospital                | 44        | 320          | 312                       |
| Glasgow                 | Queen Elizabeth University Hospital     | 79        | 271          | 196                       |
| <b>Wales</b>            |                                         |           |              |                           |
| Llandough               | University Hospital Llandough           | 68        | 345          | 204                       |



| Clinic ID | Age  |        | BMI     |                   |                 |        | Proportion (%) with BMI in lowest and highest groups |                      |         |                    |
|-----------|------|--------|---------|-------------------|-----------------|--------|------------------------------------------------------|----------------------|---------|--------------------|
|           | Mean | Median | Number* | Mean – unadjusted | Mean – adjusted | Median | BMI <18.5                                            | BMI <18.5 – adjusted | BMI ≥30 | BMI ≥30 – adjusted |
| 27        | 35.7 | 33.9   | 345     | 24.8              | 24.8            | 24.4   | 2.3                                                  | 2.4                  | 11.3    | 11.1               |
| 106       | 34.9 | 33.0   | 240     | 24.9              | 24.8            | 24.1   | 0.8                                                  | 0.9                  | 10.8    | 10.7               |
| 51        | 34.1 | 31.3   | 340     | 24.3              | 24.3            | 23.6   | 2.6                                                  | 2.6                  | 8.8     | 9.0                |
| 129       | 35.8 | 31.1   | 33      | 24.9              | 25.0            | 23.5   | 3.0                                                  | 2.9                  | 15.2    | 15.2               |
| 34        | 36.1 | 34.3   | 149     | 25.8              | 25.7            | 24.7   | 3.4                                                  | 3.5                  | 17.4    | 16.8               |
| 19        | 34.1 | 32.8   | 172     | 23.6              | 23.6            | 23.3   | 2.3                                                  | 2.3                  | 2.3     | 2.3                |
| 42        | 37.8 | 36.1   | 417     | 24.8              | 24.5            | 24.1   | 2.9                                                  | 3.2                  | 11.0    | 10.2               |
| 142       | 33.9 | 32.1   | 117     | 24.6              | 24.7            | 23.8   | 4.3                                                  | 4.2                  | 9.4     | 9.6                |
| 66        | 34.0 | 32.5   | 414     | 25.2              | 25.3            | 24.5   | 2.9                                                  | 2.8                  | 14.7    | 15.0               |
| 92        | 30.4 | 26.9   | 221     | 23.1              | 23.5            | 22.5   | 5.4                                                  | 4.7                  | 3.6     | 4.1                |
| 105       | 34.1 | 33.4   | 56      | 22.9              | 22.9            | 22.4   | 12.5                                                 | 12.5                 | 5.4     | 5.4                |
| 5         | 32.9 | 32.0   | 240     | 24.3              | 24.4            | 23.2   | 5.4                                                  | 5.2                  | 11.7    | 12.2               |
| 12        | 37.7 | 35.7   | 628     | 24.1              | 23.9            | 23.7   | 2.4                                                  | 2.6                  | 7.3     | 6.8                |
| 102       | 34.6 | 32.2   | 497     | 23.9              | 23.9            | 23.5   | 4.4                                                  | 4.4                  | 6.8     | 6.9                |
| 9         | 34.7 | 32.4   | 349     | 24.8              | 24.9            | 23.9   | 4.0                                                  | 4.0                  | 14.0    | 14.2               |
| 74        | 31.4 | 28.7   | 174     | 24.1              | 24.4            | 23.9   | 3.4                                                  | 3.1                  | 7.5     | 8.2                |
| 114       | 32.4 | 31.3   | 100     | 24.0              | 24.2            | 23.1   | 3.0                                                  | 2.7                  | 9.0     | 9.6                |
| 101       | 32.4 | 30.6   | 264     | 24.0              | 24.2            | 23.1   | 5.7                                                  | 5.3                  | 11.0    | 11.7               |
| 128       | 33.4 | 29.4   | 164     | 23.6              | 23.7            | 22.8   | 5.5                                                  | 5.1                  | 7.3     | 7.7                |
| 64        | 37.9 | 35.9   | 66      | 24.5              | 24.4            | 24.1   | 6.1                                                  | 6.5                  | 9.1     | 8.6                |
| 65        | 33.2 | 31.6   | 254     | 25.2              | 25.3            | 24.0   | 4.3                                                  | 4.1                  | 14.2    | 14.7               |
| 110       | 35.6 | 33.1   | 296     | 24.5              | 24.4            | 23.8   | 2.0                                                  | 2.1                  | 9.8     | 9.6                |
| 171       | 36.3 | 33.4   | 112     | 24.6              | 24.5            | 24.1   | 8.9                                                  | 9.2                  | 10.7    | 10.4               |
| 14        | 38.4 | 36.0   | 230     | 25.7              | 25.5            | 24.8   | 2.2                                                  | 2.4                  | 13.5    | 12.6               |
| 70        | 36.4 | 34.1   | 62      | 25.6              | 25.5            | 24.6   | 3.2                                                  | 3.4                  | 14.5    | 13.8               |
| 44        | 34.9 | 32.6   | 311     | 24.7              | 24.7            | 23.6   | 1.6                                                  | 1.6                  | 12.2    | 12.3               |
| 79        | 34.6 | 31.4   | 196     | 25.9              | 26.0            | 25.3   | 2.0                                                  | 2.0                  | 15.3    | 15.5               |
| 68        | 34.4 | 32.1   | 203     | 24.8              | 24.8            | 23.9   | 3.0                                                  | 2.9                  | 10.8    | 11.0               |

\* Number with non-missing data.



## Adult centres/clinics providing data in 2025 – ordered alphabetically by country/city

|                         |                                         |           | FEV <sub>1</sub> % predicted at annual review |                   |                 |        |
|-------------------------|-----------------------------------------|-----------|-----------------------------------------------|-------------------|-----------------|--------|
| Location                | Name                                    | Clinic ID | Number*                                       | Mean – unadjusted | Mean – adjusted | Median |
| <b>England</b>          |                                         |           |                                               |                   |                 |        |
| Birmingham              | Heartlands Hospital                     | 27        | 310                                           | 77.2              | 77.4            | 80.2   |
| Bristol                 | Bristol Royal Infirmary                 | 106       | 224                                           | 82.9              | 83.4            | 87.6   |
| Cambridge               | Royal Papworth Hospital                 | 51        | 318                                           | 81.8              | 80.9            | 86.7   |
| Cornwall                | Royal Cornwall Hospital                 | 129       | 29                                            | 79.3              | 78.3            | 84.7   |
| Exeter                  | Royal Devon and Exeter Hospital         | 34        | 140                                           | 81.3              | 82.2            | 84.1   |
| Frimley                 | Frimley Park Hospital                   | 19        | 164                                           | 83.5              | 83.3            | 87.1   |
| Leeds                   | St James' University Hospital           | 42        | 360                                           | 78.9              | 80.7            | 82.9   |
| Leicester               | Glenfield Hospital                      | 142       | 105                                           | 84.3              | 83.5            | 88.9   |
| Liverpool               | Liverpool Heart and Chest Hospital      | 66        | 399                                           | 85.9              | 85.1            | 89.8   |
| London-East             | St. Bartholomew's Hospital              | 92        | 217                                           | 80.1              | 77.0            | 82.3   |
| London-South East       | University Hospital Lewisham            | 105       | 49                                            | 72.9              | 72.7            | 74.9   |
| London-South East       | King's College Hospital                 | 5         | 221                                           | 77.7              | 77.2            | 80.9   |
| London-South West       | Royal Brompton Hospital                 | 12        | 562                                           | 78.4              | 80.1            | 80.2   |
| Manchester              | Wythenshawe Hospital                    | 102       | 401                                           | 77.2              | 77.4            | 79.2   |
| Newcastle               | Royal Victoria Infirmary                | 9         | 321                                           | 78.1              | 77.6            | 81.9   |
| North West Midlands     | University Hospital of North Midlands   | 74        | 160                                           | 78.8              | 76.1            | 84.2   |
| Norwich                 | Norfolk and Norwich University Hospital | 114       | 93                                            | 84.7              | 82.9            | 91.9   |
| Nottingham              | Nottingham University Hospitals         | 101       | 240                                           | 81.1              | 79.1            | 85.2   |
| Oxford                  | Oxford University Hospitals             | 128       | 153                                           | 80.8              | 78.7            | 83.1   |
| Plymouth                | Derriford Hospital                      | 64        | 60                                            | 81.2              | 82.1            | 85.0   |
| Sheffield               | Northern General Hospital               | 65        | 224                                           | 84.3              | 83.2            | 89.5   |
| Southampton             | Southampton General Hospital            | 110       | 263                                           | 82.7              | 82.5            | 83.6   |
| York                    | York Hospital                           | 171       | 106                                           | 79.1              | 79.6            | 81.7   |
| <b>Northern Ireland</b> |                                         |           |                                               |                   |                 |        |
| Belfast                 | Belfast City Hospital                   | 14        | 217                                           | 76.8              | 78.5            | 81.2   |
| <b>Scotland</b>         |                                         |           |                                               |                   |                 |        |
| Aberdeen                | Aberdeen Royal Infirmary                | 70        | 54                                            | 74.1              | 74.6            | 71.6   |
| Edinburgh               | Western General Hospital                | 44        | 288                                           | 82.8              | 82.1            | 87.6   |
| Glasgow                 | Queen Elizabeth University Hospital     | 79        | 190                                           | 86.1              | 85.2            | 90.8   |
| <b>Wales</b>            |                                         |           |                                               |                   |                 |        |
| Llandough               | University Hospital Llandough           | 68        | 187                                           | 83.3              | 82.3            | 87.0   |

\* Number with non-missing data.



| Clinic ID | Best** FEV <sub>1</sub> % predicted |                   |                 |        | Chronic <i>pseudomonas</i> |                | Having at least 1 IV days |                | Inhaled antibiotic use among patients with chronic <i>pseudomonas</i> |                |
|-----------|-------------------------------------|-------------------|-----------------|--------|----------------------------|----------------|---------------------------|----------------|-----------------------------------------------------------------------|----------------|
|           | Number*                             | Mean – unadjusted | Mean – adjusted | Median | Number*                    | Proportion (%) | Number*                   | Proportion (%) | Number*                                                               | Proportion (%) |
| 27        | 328                                 | 80.9              | 81.2            | 84.7   | 45                         | 13.4           | 85                        | 24.3           | 39                                                                    | 86.7           |
| 106       | 232                                 | 85.1              | 85.8            | 88.6   | 14                         | 7.3            | 66                        | 26.5           | 11                                                                    | 78.6           |
| 51        | 319                                 | 83.6              | 82.8            | 88.6   | 15                         | 5.1            | 66                        | 19.2           | 10                                                                    | 66.7           |
| 129       | 31                                  | 81.5              | 80.1            | 84.7   | <5                         | 12.1           | 14                        | 41.2           | <5                                                                    | 75.0           |
| 34        | 142                                 | 86.8              | 87.7            | 89.6   | 7                          | 4.9            | 26                        | 17.4           | 6                                                                     | 85.7           |
| 19        | 164                                 | 86.4              | 86.1            | 87.6   | 22                         | 13.0           | 46                        | 26.7           | 14                                                                    | 63.6           |
| 42        | 369                                 | 81.1              | 83.1            | 85.1   | 44                         | 14.2           | 130                       | 31.2           | 28                                                                    | 63.6           |
| 142       | 111                                 | 83.8              | 83.0            | 88.5   | 10                         | 14.7           | 24                        | 20.5           | 7                                                                     | 70.0           |
| 66        | 399                                 | 87.7              | 86.9            | 91.5   | 30                         | 9.1            | 61                        | 14.7           | 29                                                                    | 96.7           |
| 92        | 217                                 | 83.0              | 79.7            | 86.0   | 47                         | 21.7           | 46                        | 20.8           | 43                                                                    | 91.5           |
| 105       | 49                                  | 76.7              | 76.5            | 77.7   | 15                         | 26.8           | 60                        | 24.9           | 13                                                                    | 86.7           |
| 5         | 231                                 | 80.8              | 80.1            | 85.7   | 12                         | 5.3            | 16                        | 28.6           | 9                                                                     | 75.0           |
| 12        | 603                                 | 81.3              | 83.1            | 83.1   | 64                         | 11.5           | 124                       | 19.7           | 54                                                                    | 84.4           |
| 102       | 493                                 | 80.0              | 80.1            | 81.3   | 80                         | 17.5           | 134                       | 25.2           | 62                                                                    | 77.5           |
| 9         | 323                                 | 81.2              | 80.6            | 84.8   | 62                         | 18.0           | 75                        | 21.4           | 49                                                                    | 79.0           |
| 74        | 163                                 | 81.7              | 78.9            | 86.6   | 27                         | 15.8           | 41                        | 23.6           | 18                                                                    | 66.7           |
| 114       | 95                                  | 89.6              | 87.6            | 93.8   | 7                          | 7.8            | 17                        | 16.8           | <5                                                                    | 57.1           |
| 101       | 246                                 | 85.3              | 83.4            | 89.0   | 46                         | 18.1           | 73                        | 27.7           | 32                                                                    | 69.6           |
| 128       | 153                                 | 85.1              | 82.8            | 87.1   | 16                         | 12.6           | 29                        | 17.7           | 10                                                                    | 62.5           |
| 64        | 61                                  | 83.4              | 84.4            | 87.2   | 7                          | 10.6           | 12                        | 17.9           | 7                                                                     | 100.0          |
| 65        | 238                                 | 87.1              | 86.0            | 91.9   | 26                         | 10.6           | 91                        | 35.8           | 23                                                                    | 88.5           |
| 110       | 268                                 | 84.6              | 84.5            | 86.5   | 28                         | 9.6            | 47                        | 15.8           | 19                                                                    | 67.9           |
| 171       | 109                                 | 83.3              | 83.9            | 86.2   | 16                         | 14.4           | 29                        | 25.9           | 14                                                                    | 87.5           |
| 14        | 226                                 | 80.5              | 82.2            | 84.3   | 34                         | 14.8           | 28                        | 12.2           | 24                                                                    | 70.6           |
| 70        | 57                                  | 78.6              | 79.3            | 74.0   | 0                          | 0.0            | <5                        | 6.5            | 0                                                                     | 0.0            |
| 44        | 295                                 | 86.4              | 85.5            | 91.6   | 25                         | 12.8           | 33                        | 10.6           | 11                                                                    | 44.0           |
| 79        | 191                                 | 89.5              | 88.6            | 91.5   | 13                         | 7.0            | 37                        | 18.9           | 9                                                                     | 69.2           |
| 68        | 189                                 | 86.5              | 85.5            | 91.4   | 19                         | 9.5            | 38                        | 18.6           | 15                                                                    | 78.9           |

\* Number with non-missing data.

\*\* Where 'Best' values were missing, or lower than FEV1% predicted taken at annual review, the annual review value was used.



## Adult centres/clinics providing data in 2025 – ordered alphabetically by country/city

|                         |                                         |           | Receiving DNase treatment |                | Receiving hypertonic saline or mannitol treatment |                |
|-------------------------|-----------------------------------------|-----------|---------------------------|----------------|---------------------------------------------------|----------------|
| Location                | Name                                    | Clinic ID | Number*                   | Proportion (%) | Number*                                           | Proportion (%) |
| <b>England</b>          |                                         |           |                           |                |                                                   |                |
| Birmingham              | Heartlands Hospital                     | 27        | 190                       | 54.3           | 109                                               | 31.1           |
| Bristol                 | Bristol Royal Infirmary                 | 106       | 110                       | 44.2           | 106                                               | 42.6           |
| Cambridge               | Royal Papworth Hospital                 | 51        | 126                       | 36.7           | 105                                               | 30.6           |
| Cornwall                | Royal Cornwall Hospital                 | 129       | 21                        | 61.8           | 9                                                 | 26.5           |
| Exeter                  | Royal Devon and Exeter Hospital         | 34        | 90                        | 60.4           | 76                                                | 51.0           |
| Frimley                 | Frimley Park Hospital                   | 19        | 72                        | 41.9           | 29                                                | 16.9           |
| Leeds                   | St James' University Hospital           | 42        | 219                       | 52.5           | 39                                                | 9.4            |
| Leicester               | Glenfield Hospital                      | 142       | 47                        | 40.2           | 12                                                | 10.3           |
| Liverpool               | Liverpool Heart and Chest Hospital      | 66        | 243                       | 58.7           | 91                                                | 22.0           |
| London – East           | St. Bartholomew's Hospital              | 92        | 143                       | 64.7           | 104                                               | 47.1           |
| London – South East     | University Hospital Lewisham            | 105       | 37                        | 66.1           | 11                                                | 19.6           |
| London – South East     | King's College Hospital                 | 5         | 120                       | 49.8           | 46                                                | 19.1           |
| London – South West     | Royal Brompton Hospital                 | 12        | 534                       | 85.0           | 281                                               | 44.7           |
| Manchester              | Wythenshawe Hospital                    | 102       | 178                       | 33.5           | 156                                               | 29.3           |
| Newcastle               | Royal Victoria Infirmary                | 9         | 205                       | 58.4           | 63                                                | 17.9           |
| North West Midlands     | University Hospital of North Midlands   | 74        | 107                       | 61.5           | 50                                                | 28.7           |
| Norwich                 | Norfolk and Norwich University Hospital | 114       | 40                        | 39.6           | 12                                                | 11.9           |
| Nottingham              | Nottingham University Hospitals         | 101       | 125                       | 47.3           | 75                                                | 28.4           |
| Oxford                  | Oxford University Hospitals             | 128       | 90                        | 54.9           | 28                                                | 17.1           |
| Plymouth                | Derriford Hospital                      | 64        | 50                        | 74.6           | 29                                                | 43.3           |
| Sheffield               | Northern General Hospital               | 65        | 178                       | 70.1           | 29                                                | 11.4           |
| Southampton             | Southampton General Hospital            | 110       | 120                       | 40.3           | 70                                                | 23.5           |
| York                    | York Hospital                           | 171       | 63                        | 56.2           | 7                                                 | 6.2            |
| <b>Northern Ireland</b> |                                         |           |                           |                |                                                   |                |
| Belfast                 | Belfast City Hospital                   | 14        | 125                       | 54.3           | 36                                                | 15.7           |
| <b>Scotland</b>         |                                         |           |                           |                |                                                   |                |
| Aberdeen                | Aberdeen Royal Infirmary                | 70        | 15                        | 24.2           | <5                                                | 1.6            |
| Edinburgh               | Western General Hospital                | 44        | 126                       | 40.4           | 21                                                | 6.7            |
| Glasgow                 | Queen Elizabeth University Hospital     | 79        | 48                        | 24.5           | 17                                                | 8.7            |
| <b>Wales</b>            |                                         |           |                           |                |                                                   |                |
| Llandough               | University Hospital Llandough           | 68        | 135                       | 66.2           | 121                                               | 59.3           |

\* Number with non-missing data.



## Appendix 3: Full list of CFTR variants in the UK CF population

The table below shows the number of people with CF who carry at least one of each variant.

The groups are not mutually exclusive, as people with heterozygous variants appear twice in the table.

| Nucleotide          | Protein           | Legacy name   | N     | %    |
|---------------------|-------------------|---------------|-------|------|
| c.1521_1523del      | p.Phe508del       | F508del       | 10321 | 88.9 |
| c.350G>A            | p.Arg117His       | R117H         | 707   | 6.1  |
| c.1652G>A           | p.Gly551Asp       | G551D         | 666   | 5.7  |
| c.1624G>T           | p.Gly542X         | G542X         | 425   | 3.7  |
| c.489+1G>T          |                   | 621+1G->T     | 307   | 2.6  |
| c.3909C>G           | p.Asn1303Lys      | N1303K        | 191   | 1.6  |
| c.1585-1G>A         |                   | 1717-1G->A    | 190   | 1.6  |
| c.1766+1G>A         |                   | 1898+1G->A    | 164   | 1.4  |
| c.3454G>C           | p.Asp1152His      | D1152H        | 162   | 1.4  |
| c.200C>T            | p.Pro67Leu        | P67L          | 161   | 1.4  |
| c.3140-26A>G        |                   | 3272-26A->G   | 140   | 1.2  |
| c.3718-2477C>T      |                   | 3849+10kbC->T | 137   | 1.2  |
| c.3528del           | p.Lys1177SerfsX15 | 3659delC      | 132   | 1.1  |
| c.1679G>C           | p.Arg560Thr       | R560T         | 107   | 0.9  |
| c.1519_1521del      | p.Ile507del       | I507del       | 101   | 0.9  |
| c.1021_1022dup      | p.Phe342HisfsX28  | 1154insTC     | 99    | 0.9  |
| c.1477C>T           | p.Gln493X         | Q493X         | 98    | 0.8  |
| c.1657C>T           | p.Arg553X         | R553X         | 93    | 0.8  |
| c.254G>A            | p.Gly85Glu        | G85E          | 90    | 0.8  |
| c.2657+5G>A         |                   | 2789+5G->A    | 88    | 0.8  |
| c.178G>T            | p.Glu60X          | E60X          | 80    | 0.7  |
| c.3845G>A c.3846G>A | p.Trp1282X        | W1282X        | 70    | 0.6  |
| c.617T>G            | p.Leu206Trp       | L206W         | 62    | 0.5  |
| c.948del            | p.Phe316LeufsX12  | 1078delT      | 59    | 0.5  |
| c.1646G>A           | p.Ser549Asn       | S549N         | 58    | 0.5  |
| c.1364C>A           | p.Ala455Glu       | A455E         | 56    | 0.5  |
| c.2052del           | p.Lys684AsnfsX38  | 2184delA      | 56    | 0.5  |
| c.1210-11T>G        |                   | 5T;TG12       | 55    | 0.5  |
| c.2657+2_2657+3insA |                   | 2789+2insA    | 49    | 0.4  |
| c.1040G>C           | p.Arg347Pro       | R347P         | 48    | 0.4  |
| c.1210-12T[5]       |                   | 5T            | 42    | 0.4  |
| c.579+3A>G          |                   | 711+3A->G     | 40    | 0.3  |
| c.3484C>T           | p.Arg1162X        | R1162X        | 37    | 0.3  |
| c.1367T>C           | p.Val456Ala       | V456A         | 37    | 0.3  |
| c.1040G>A           | p.Arg347His       | R347H         | 36    | 0.3  |
| c.1523T>G           | p.Phe508Cys       | F508C         | 32    | 0.3  |
| c.1558G>T           | p.Val520Phe       | V520F         | 32    | 0.3  |
| c.1753G>T           | p.Glu585X         | E585X         | 31    | 0.3  |
| c.1000C>T           | p.Arg334Trp       | R334W         | 31    | 0.3  |
| c.3472C>T           | p.Arg1158X        | R1158X        | 30    | 0.3  |

| Nucleotide                         | Protein                  | Legacy name    | N  | %   |
|------------------------------------|--------------------------|----------------|----|-----|
| c.2988+1G>A                        |                          | 3120+1G->A     | 28 | 0.2 |
| c.3197G>A                          | p.Arg1066His             | R1066H         | 27 | 0.2 |
| c.1705T>G                          | p.Tyr569Asp              | Y569D          | 26 | 0.2 |
| c.1006_1007insG                    | p.Ile336SerfsX28         | 1138insG       | 26 | 0.2 |
| c.1327_1330dup                     | p.Ile444ArgfsX3          | 1461ins4       | 26 | 0.2 |
| c.[1521_1523del;3080T>C]           | p.[Phe508del;Ile1027Thr] | F508del;I1027T | 25 | 0.2 |
| c.2052dup                          | p.Gln685ThrfsX4          | 2184insA       | 25 | 0.2 |
| c.1055G>A                          | p.Arg352Gln              | R352Q          | 25 | 0.2 |
| c.1393-1G>A                        |                          | 1525-1G->A     | 23 | 0.2 |
| c.2583del                          | p.Phe861LeufsX3          | 2711delT       | 23 | 0.2 |
| c.349C>T                           | p.Arg117Cys              | R117C          | 23 | 0.2 |
| c.2125C>T                          | p.Arg709X                | R709X          | 22 | 0.2 |
| c.(53+1_54-1)_<br>(273+1_274-1)del |                          | CFTRdele2,3    | 22 | 0.2 |
| c.653T>A                           | p.Leu218X                | L218X          | 21 | 0.2 |
| c.3873G>C                          | p.Gln1291His             | Q1291H         | 21 | 0.2 |
| c.3737C>T                          | p.Thr1246Ile             | T1246I         | 21 | 0.2 |
| c.2490+1G>A                        |                          | 2622+1G->A     | 20 | 0.2 |
| c.532G>A                           | p.Gly178Arg              | G178R          | 19 | 0.2 |
| c.2834C>T                          | p.Ser945Leu              | S945L          | 19 | 0.2 |
| c.3806T>A                          | p.Ile1269Asn             | I1269N         | 19 | 0.2 |
| c.658C>T                           | p.Gln220X                | Q220X          | 16 | 0.1 |
| c.3874-4522A>G                     |                          | 4006-4522A->G  | 16 | 0.1 |
| c.2537G>A c.2538G>A                | p.Trp846X                | W846X          | 15 | 0.1 |
| c.1029del                          | p.Cys343X                | 1161delC       | 14 | 0.1 |
| c.2875del                          | p.Ala959HisfsX9          | 3007delG       | 14 | 0.1 |
| c.579+1G>T                         |                          | 711+1G->T      | 14 | 0.1 |
| c.2T>C                             |                          | M1T            | 13 | 0.1 |
| c.1210-11delinsGTG                 |                          | 5T;TG13        | 13 | 0.1 |
| c.[350G>A;1210-12T[7]]             | p.[Arg117His;7T]         | R117H;7T       | 13 | 0.1 |
| c.4197_4198del                     | p.Cys1400X               | 4326delTC      | 13 | 0.1 |
| c.292C>T                           | p.Gln98X                 | Q98X           | 13 | 0.1 |
| c.1679+1G>C                        |                          | 1811+1G->C     | 13 | 0.1 |
| c.2051_2052delinsG                 | p.Lys684SerfsX38         | 2183AA->G      | 13 | 0.1 |
| c.3874-2A>G                        |                          | 4006-2A->G     | 12 | 0.1 |
| c.3196C>T                          | p.Arg1066Cys             | R1066C         | 12 | 0.1 |
| c.3761T>A c.3761T>G                | p.Leu1254X               | L1254X         | 11 | 0.1 |
| c.1466C>A c.1466C>G                | p.Ser489X                | S489X          | 11 | 0.1 |
| c.(53+1_54-1)_<br>(489+1_490-1)del |                          | CFTRdele2-4    | 10 | 0.1 |

| Nucleotide                         | Protein          | Legacy name  | N  | %   |
|------------------------------------|------------------|--------------|----|-----|
| c.1675G>A                          | p.Ala559Thr      | A559T        | 10 | 0.1 |
| c.695T>A                           | p.Val232Asp      | V232D        | 10 | 0.1 |
| c.2252G>T                          | p.Arg751Leu      | R751L        | 10 | 0.1 |
| c.224G>A                           | p.Arg75Gln       | R75Q         | 10 | 0.1 |
| c.2988G>A                          |                  | 3120G->A     | 10 | 0.1 |
| c.494T>C                           | p.Leu165Ser      | L165S        | 10 | 0.1 |
| c.2353C>T                          | p.Arg785X        | R785X        | 10 | 0.1 |
| c.1645A>C c.1647T>A c.1647T>G      | p.Ser549Arg      | S549R        | 10 | 0.1 |
| c.1210-7_1210-6del                 |                  | 5T;TG11      | 10 | 0.1 |
| c.1721C>A                          | p.Pro574His      | P574H        | 9  | 0.1 |
| c.3208C>T                          | p.Arg1070Trp     | R1070W       | 9  | 0.1 |
| c.3468G>A                          |                  | 3600G->A     | 9  | 0.1 |
| c.1687T>A                          | p.Tyr563Asn      | Y563N        | 9  | 0.1 |
| c.3353C>T                          | p.Ser1118Phe     | S1118F       | 9  | 0.1 |
| c.709C>G                           | p.Gln237Glu      | Q237E        | 9  | 0.1 |
| c.3276C>A c.3276C>G                | p.Tyr1092X       | Y1092X       | 9  | 0.1 |
| c.3889dup                          | p.Ser1297PhefsX5 | 4016insT     | 8  | 0.1 |
| c.3705T>G                          | p.Ser1235Arg     | S1235R       | 8  | 0.1 |
| c.2290C>T                          | p.Arg764X        | R764X        | 8  | 0.1 |
| c.1538A>G                          | p.Asp513Gly      | D513G        | 7  | 0.1 |
| c.1210-12T[7]                      |                  | 7T           | 7  | 0.1 |
| c.262_263del                       | p.Leu88IlefsX22  | 394delTT     | 7  | 0.1 |
| c.(273+1_274-1)_(1679+1_1680-1)del |                  | CFTRdele4-11 | 7  | 0.1 |
| c.(743+1_744-1)_(1584+1_1585-1)dup |                  | CFTRdup6b-10 | 7  | 0.1 |
| c.2012del                          | p.Leu671X        | 2143delT     | 7  | 0.1 |
| c.2128A>T                          | p.Lys710X        | K710X        | 7  | 0.1 |
| c.3367G>C                          | p.Gly1123Arg     | G1123R       | 7  | 0.1 |
| c.349C>G                           | p.Arg117Gly      | R117G        | 7  | 0.1 |
| c.2991G>C                          | p.Leu997Phe      | L997F        | 6  | 0.1 |
| c.2900T>C                          | p.Leu967Ser      | L967S        | 6  | 0.1 |
| c.2601dup                          | p.Val868SerfsX28 | 2732insA     | 6  | 0.1 |
| c.1545_1546del                     | p.Tyr515X        | 1677delTA    | 6  | 0.1 |
| c.1986_1989del                     | p.Thr663ArgfsX8  | 2118del4     | 6  | 0.1 |
| c.1766+1G>T                        |                  | 1898+1G->T   | 6  | 0.1 |
| c.1116+1G>A                        |                  | 1248+1G->A   | 6  | 0.1 |
| c.(53+1_54-1)_(164+1_165-1)del     |                  | CFTRdele2    | 6  | 0.1 |
| c.223C>T                           | p.Arg75X         | R75X         | 6  | 0.1 |
| c.3822G>A                          | p.Trp1274X       | W1274X       | 6  | 0.1 |
| c.4147dup                          | p.Ile1383AsnfsX3 | 4279insA     | 6  | 0.1 |
| c.3292T>C                          | p.Trp1098Arg     | W1098R       | 5  | 0.0 |
| c.1393-2A>G                        |                  | 1525-2A->G   | 5  | 0.0 |
| c.2491G>T                          | p.Glu831X        | E831X        | 5  | 0.0 |
| c.4004T>C                          | p.Leu1335Pro     | L1335P       | 5  | 0.0 |
| c.168del                           | p.Glu56AspfsX35  | 300delA      | 5  | 0.0 |

| Nucleotide                               | Protein           | Legacy name   | N  | %   |
|------------------------------------------|-------------------|---------------|----|-----|
| c.(273+1_274-1)_<br>(1584+1_1585-1)del   |                   | CFTRdele4-10  | 5  | 0.0 |
| c.575A>G                                 | p.Asp192Gly       | D192G         | 5  | 0.0 |
| c.165-3C>T                               |                   | 297-3C->T     | 5  | 0.0 |
| c.4077_4080delinsAA                      | p.Val1360ThrfsX3  | 4209TGTT->AA  | 5  | 0.0 |
| c.2551C>T                                | p.Arg851X         | R851X         | 5  | 0.0 |
| c.3848G>T                                | p.Arg1283Met      | R1283M        | 5  | 0.0 |
| c.2464G>T                                | p.Glu822X         | E822X         | 5  | 0.0 |
| c.(3963+1_3964-1)_<br>(4242+1_4243-1)del |                   | CFTRdele22,23 | 5  | 0.0 |
| c.3718-1G>A                              |                   | 3850-1G->A    | 5  | 0.0 |
| c.2249C>T                                | p.Pro750Leu       | P750L         | 5  | 0.0 |
| c.1397C>A c.1397C>G                      | p.Ser466X         | S466X         | 5  | 0.0 |
| c.2909G>A                                | p.Gly970Asp       | G970D         | <5 | -   |
| c.429del                                 | p.Phe143LeufsX10  | 557delT       | <5 | -   |
| c.2597G>A                                | p.Cys866Tyr       | C866Y         | <5 | -   |
| c.1219G>T                                | p.Glu407X         | E407X         | <5 | -   |
| c.1081T>A c.1081T>C                      | p.Trp361Arg       | W361R         | <5 | -   |
| c.1680A>C c.1680A>T                      | p.Arg560Ser       | R560S         | <5 | -   |
| c.54-1G>A                                |                   | 186-1G->A     | <5 | -   |
| c.933C>A c.933C>G                        | p.Phe311Leu       | F311L         | <5 | -   |
| c.4028dup                                | p.Cys1344LeufsX15 | 4160insG      | <5 | -   |
| c.1736A>G                                | p.Asp579Gly       | D579G         | <5 | -   |
| c.1572C>A                                | p.Cys524X         | C524X         | <5 | -   |
| c.350G>T                                 | p.Arg117Leu       | R117L         | <5 | -   |
| c.274G>A                                 | p.Glu92Lys        | E92K          | <5 | -   |
| c.3988C>T                                | p.Gln1330X        | Q1330X        | <5 | -   |
| c.595C>T                                 | p.His199Tyr       | H199Y         | <5 | -   |
| c.2896del                                | p.Thr966ArgfsX2   | 3028delA      | <5 | -   |
| c.3095A>G                                | p.Tyr1032Cys      | Y1032C        | <5 | -   |
| c.442del                                 | p.Ile148LeufsX5   | 574delA       | <5 | -   |
| c.489+2T>C                               |                   | 621+2T->C     | <5 | -   |
| c.850dup                                 | p.Met284AsnfsX3   | 977insA       | <5 | -   |
| c.443T>C                                 | p.Ile148Thr       | I148T         | <5 | -   |
| c.2215del                                | p.Val739TyrfsX16  | 2347delG      | <5 | -   |
| c.1680-886A>G                            |                   | 1811+1634A->G | <5 | -   |
| c.263T>C                                 | p.Leu88Ser        | L88S          | <5 | -   |
| c.3763T>C                                | p.Ser1255Pro      | S1255P        | <5 | -   |
| c.869+3A>C                               |                   | 1001+3A->C    | <5 | -   |
| c.940G>A c.940G>C                        | p.Gly314Arg       | G314R         | <5 | -   |
| c.577G>T                                 | p.Glu193X         | E193X         | <5 | -   |
| c.4139del                                | p.Thr1380AsnfsX4  | 4271delC      | <5 | -   |
| c.1327G>T                                | p.Asp443Tyr       | D443Y         | <5 | -   |
| c.4046G>A                                | p.Gly1349Asp      | G1349D        | <5 | -   |
| c.3872A>G                                | p.Gln1291Arg      | Q1291R        | <5 | -   |
| c.1696G>A                                | p.Ala566Thr       | A566T         | <5 | -   |
| c.3495del                                | p.Lys1165AsnfsX27 | c.3495delG    | <5 | -   |
| c.91C>T                                  | p.Arg31Cys        | R31C          | <5 | -   |

| Nucleotide                               | Protein          | Legacy name           | N  | % |
|------------------------------------------|------------------|-----------------------|----|---|
| c.4111G>T                                | p.Glu1371X       | E1371X                | <5 | - |
| c.1135G>T                                | p.Glu379X        | E379X                 | <5 | - |
| c.1651G>A                                | p.Gly551Ser      | G551S                 | <5 | - |
| c.2374C>T                                | p.Arg792X        | R792X                 | <5 | - |
| c.233dup                                 | p.Trp79LeufsX32  | 365-366insT           | <5 | - |
| c.2805_2810delins TCAGA                  | p.Pro936GlnfsX6  | 2937_2942delins TCAGA | <5 | - |
| c.1243_1247del                           | p.Asn415X        | 1367del5              | <5 | - |
| c.3752G>A                                | p.Ser1251Asn     | S1251N                | <5 | - |
| c.1724T>A                                | p.Phe575Tyr      | F575Y                 | <5 | - |
| c.1505T>C                                | p.Ile502Thr      | I502T                 | <5 | - |
| c.1175T>G                                | p.Val392Gly      | V392G                 | <5 | - |
| c.509G>A                                 | p.Arg170His      | R170H                 | <5 | - |
| c.328G>C                                 | p.Asp110His      | D110H                 | <5 | - |
| c.2810dup                                | p.Val938GlyfsX37 | 2942insT              | <5 | - |
| c.1688A>G                                | p.Tyr563Cys      | Y563C                 | <5 | - |
| c.79G>T                                  | p.Gly27X         | G27X                  | <5 | - |
| c.461dup                                 | p.Ala155SerfsX4  | 593insT               | <5 | - |
| c.482A>C                                 | p.Tyr161Ser      | Y161S                 | <5 | - |
| c.3254A>C                                | p.His1085Pro     | H1085P                | <5 | - |
| c.3659del                                | p.Thr1220LysfsX8 | 3791delC              | <5 | - |
| c.1679G>A                                | p.Arg560Lys      | R560K                 | <5 | - |
| c.2924_2925del                           | p.Arg975IlefsX10 | 3056delGA             | <5 | - |
| c.2036G>A c.2037G>A                      | p.Trp679X        | W679X                 | <5 | - |
| c.3743C>A c.3743C>G                      | p.Ser1248X       | S1248X                | <5 | - |
| c.1340del                                | p.Lys447ArgfsX2  | 1471delA              | <5 | - |
| c.1585-8G>A                              |                  | 1717-8G->A            | <5 | - |
| c.1727G>C                                | p.Gly576Ala      | G576A                 | <5 | - |
| c.3310G>T                                | p.Glu1104X       | E1104X                | <5 | - |
| c.1682C>A                                | p.Ala561Glu      | A561E                 | <5 | - |
| c.3397del                                | p.Leu1133X       | 3528delC              | <5 | - |
| c.1766+1G>C                              |                  | 1898+1G->C            | <5 | - |
| c.2523_2548del                           | p.Ala842SerfsX45 | 2655del26             | <5 | - |
| c.220C>T                                 | p.Arg74Trp       | R74W                  | <5 | - |
| c.(3963+1_3964-1)_<br>(4136+1_4137-1)dup |                  | CFTRdup22             | <5 | - |
| c.1001G>A                                | p.Arg334Gln      | R334Q                 | <5 | - |
| c.3746G>A                                | p.Gly1249Glu     | G1249E                | <5 | - |
| c.3080T>C                                | p.Ile1027Thr     | I1027T                | <5 | - |
| c.743+1G>C                               |                  | 875+1G->C             | <5 | - |
| c.3874-1G>A                              |                  | 4006-1G->A            | <5 | - |
| c.1202G>A c.1203G>A                      | p.Trp401X        | W401X                 | <5 | - |
| c.2668C>T                                | p.Gln890X        | Q890X                 | <5 | - |
| c.3371_3373del                           | p.Glu1124del     | E1124del              | <5 | - |
| c.273+1G>A                               |                  | 405+1G>A              | <5 | - |
| c.1584G>A                                | p.Glu528=        | 1716G/A               | <5 | - |
| c.3476C>T                                | p.Ser1159Phe     | S1159F                | <5 | - |
| c.2846A>T                                | p.His949Leu      | H949L                 | <5 | - |

| Nucleotide                               | Protein              | Legacy name      | N  | % |
|------------------------------------------|----------------------|------------------|----|---|
| c.3618del                                | p.Gly1208AlafsX3     | 3750delA         | <5 | - |
| c.470_483del                             | p.Phe157X            | 602del14         | <5 | - |
| c.3929G>A c.3930G>A                      | p.Trp1310X           | W1310X           | <5 | - |
| c.3883_3886del                           | p.Ile1295PhefsX32    | 4010del4         | <5 | - |
| c.2002C>T                                | p.Arg668Cys          | R668C            | <5 | - |
| c.3835_3836del                           | p.Leu1279AlafsX22    | 3967delTT        | <5 | - |
| c.3017C>A                                | p.Ala1006Glu         | A1006E           | <5 | - |
| c.915C>T                                 | p.Phe305=            | 1047C/T          | <5 | - |
| c.3546C>G                                | p.Tyr1182X           | Y1182X           | <5 | - |
| c.1013C>T                                | p.Thr338Ile          | T338I            | <5 | - |
| c.1735G>T                                | p.Asp579Tyr          | D579Y            | <5 | - |
| c.3158C>T                                | p.Thr1053Ile         | T1053I           | <5 | - |
| c.2930C>T                                | p.Ser977Phe          | S977F            | <5 | - |
| c.263T>A c.263T>G                        | p.Leu88X             | L88X             | <5 | - |
| c.3475T>C                                | p.Ser1159Pro         | S1159P           | <5 | - |
| c.601G>A                                 | p.Val201Met          | V201M            | <5 | - |
| c.(1392+1_1393-1)_<br>(1584+1_1585-1)del |                      | CFTRdele10       | <5 | - |
| c.2855T>C                                | p.Met952Thr          | M952T            | <5 | - |
| c.413_415dup                             | p.Leu138dup          | L138ins          | <5 | - |
| c.3067_3072del                           | p.Ile1023_Val1024del | 3199del6         | <5 | - |
| c.627A>G                                 | p.Ala209=            | A209A            | <5 | - |
| c.608T>A                                 | p.Ile203Asn          | I203N            | <5 | - |
| c.3365del                                | p.Thr1122LysfsX12    | 3497delC         | <5 | - |
| c.1766+3A>G                              |                      | 1898+3A->G       | <5 | - |
| c.1766+5G>T                              |                      | 1898+5G->T       | <5 | - |
| c.1046C>T                                | p.Ala349Val          | A349V            | <5 | - |
| c.2274_2275delinsT                       | p.Thr760ArgfsX11     | 2406_2407delinsT | <5 | - |
| c.164+2T>C                               |                      | 296+2T->C        | <5 | - |
| c.1369G>C                                | p.Ala457Pro          | A457P            | <5 | - |
| c.2780T>C                                | p.Leu927Pro          | L927P            | <5 | - |
| c.3205G>A                                | p.Gly1069Arg         | G1069R           | <5 | - |
| c.3266G>A                                | p.Trp1089X           | W1089X           | <5 | - |
| c.613C>T                                 | p.Pro205Ser          | P205S            | <5 | - |
| c.3717G>C                                | p.Arg1239Ser         | R1239S           | <5 | - |
| c.1117-1G>A                              |                      | 1249-1G->A       | <5 | - |
| c.1679+2T>C                              |                      | 1811+2T->C       | <5 | - |
| c.1007T>A                                | p.Ile336Lys          | I336K            | <5 | - |
| c.3908del                                | p.Asn1303ThrfsX25    | 4040delA         | <5 | - |
| c.[350G>A;1210-11T>G]                    | p.[Arg117His;5T]     | R117H;5T         | <5 | - |
| c.2195T>G                                | p.Leu732X            | L732X            | <5 | - |
| c.2148del                                | p.Thr717LeufsX5      | c.2148delG       | <5 | - |
| c.1579G>T                                | p.Glu527X            | E527X            | <5 | - |
| c.221G>A                                 | p.Arg74Gln           | R74Q             | <5 | - |
| c.296C>T                                 | p.Pro99Leu           | P99L             | <5 | - |
| c.307G>T                                 | p.Gly103X            | G103X            | <5 | - |
| c.3717+5G>A                              |                      | 3849+5G->A       | <5 | - |
| c.164+12T>C                              |                      | 296+12T->C       | <5 | - |

| Nucleotide                               | Protein          | Legacy name | N  | % |
|------------------------------------------|------------------|-------------|----|---|
| c.743+1G>A                               |                  | 875+1G->A   | <5 | - |
| c.1670del                                | p.Ser557PhefsX2  | 1802delC    | <5 | - |
| c.2260G>A                                | p.Val754Met      | V754M       | <5 | - |
| c.1302del                                | p.Leu435PhefsX7  | 1434delA    | <5 | - |
| c.2051_2052del                           | p.Lys684ThrfsX4  | 2183delAA   | <5 | - |
| c.266A>G                                 | p.Tyr89Cys       | Y89C        | <5 | - |
| c.2175dup                                | p.Glu726ArgfsX4  | 2307insA    | <5 | - |
| c.50dup                                  | p.Ser18GlnfsX27  | 175insT     | <5 | - |
| c.2738A>G                                | p.Tyr913Cys      | Y913C       | <5 | - |
| c.179A>G                                 | p.Glu60Gly       | E60G        | <5 | - |
| c.(2490+1_2491-1)_<br>(2619+1_2620-1)del |                  | CFTRdele14a | <5 | - |
| c.614C>T                                 | p.Pro205Leu      | P205L       | <5 | - |
| c.1518C>G                                | p.Ile506Met      | I506M       | <5 | - |
| c.1270G>A                                | p.Gly424Ser      | G424S       | <5 | - |
| c.(3873+1_3874-1)_<br>(3963+1_3964-1)del |                  | CFTRdele21  | <5 | - |
| c.3353C>G                                | p.Ser1118Cys     | S1118C      | <5 | - |
| c.1037T>C                                | p.Leu346Pro      | L346P       | <5 | - |
| c.4200_4201del                           | p.Cys1400X       | 4332delTG   | <5 | - |
| c.2735C>A                                | p.Ser912X        | S912X       | <5 | - |
| c.1687T>C                                | p.Tyr563His      | Y563H       | <5 | - |
| c.4123C>A                                | p.His1375Asn     | H1375N      | <5 | - |
| c.3176T>G                                | p.Leu1059X       | L1059X      | <5 | - |
| c.482A>G                                 | p.Tyr161Cys      | Y161C       | <5 | - |
| c.476T>A                                 | p.Leu159X        | L159X       | <5 | - |
| c.2881A>C c.2881A>T                      | p.Met961Leu      | M961L       | <5 | - |
| c.1418del                                | p.Gly473GluX54   | 1548delG    | <5 | - |
| c.3038C>A                                | p.Pro1013His     | P1013H      | <5 | - |
| c.3844T>C                                | p.Trp1282Arg     | W1282R      | <5 | - |
| c.1301C>G c.1301C>A                      | p.Ser434X        | S434X       | <5 | - |
| c.1116+2T>A                              |                  | 1248+2T->A  | <5 | - |
| c.3964-3C>G                              |                  | 4096-3C->G  | <5 | - |
| c.2936A>C                                | p.Asp979Ala      | D979A       | <5 | - |
| c.273+2T>G                               |                  | 405+2T->G   | <5 | - |
| c.1477_1478del                           | p.Gln493ValfsX10 | 1609delCA   | <5 | - |
| c.472dup                                 | p.Ser158LysfsX5  | 604insA     | <5 | - |
| c.1811C>T                                | p.Thr604Ile      | T604I       | <5 | - |
| c.53+2T>G                                |                  | 185+2T->G   | <5 | - |
| c.1209+43T>G                             |                  | 1341+43T->G | <5 | - |
| c.890G>A                                 | p.Arg297Gln      | R297Q       | <5 | - |
| c.1573C>T                                | p.Gln525X        | Q525X       | <5 | - |
| c.3808G>A                                | p.Asp1270Asn     | D1270N      | <5 | - |
| c.1393-1G>C                              |                  | 1525-1G->C  | <5 | - |
| c.1680-2A>C                              |                  | 1812-2A->C  | <5 | - |
| c.377G>A                                 | p.Gly126Asp      | G126D       | <5 | - |
| c.3700A>G                                | p.Ile1234Val     | I1234V      | <5 | - |
| c.1469del                                | p.Phe490SerfsX37 | 1601delT    | <5 | - |

| Nucleotide                               | Protein            | Legacy name           | N  | % |
|------------------------------------------|--------------------|-----------------------|----|---|
| c.1384G>T                                | p.Ala462Ser        | A462S                 | <5 | - |
| c.1704G>T                                | p.Leu568Phe        | L568F                 | <5 | - |
| c.1210-9_1210-6del                       |                    | 3T;TG11               | <5 | - |
| c.2433_2437delinsATA                     | p.Leu812TyrfsX10   | c.2433_2437delinsATA  | <5 | - |
| c.1A>C                                   |                    | M1L                   | <5 | - |
| c.1586A>G                                | p.Asp529Gly        | D529G                 | <5 | - |
| c.3322G>C                                | p.Val1108Leu       | V1108L                | <5 | - |
| c.895del                                 | p.Ala299GlnfsX4    | 1027delG              | <5 | - |
| c.4035_4038dup                           | p.Ser1347ProfsX13  | p.S1347PfsX13         | <5 | - |
| c.(2988+1_2989-1)_<br>(3468+1_3469-1)del |                    | CFTRdele17a-18        | <5 | - |
| c.980T>C                                 | p.Leu327Pro        | L327P                 | <5 | - |
| c.4121C>A                                | p.Ala1374Asp       | A1374D                | <5 | - |
| c.(3963+1_3964-1)_<br>(4136+1_4137-1)del |                    | CFTRdele22            | <5 | - |
| c.110T>G                                 | p.Ile37Arg         | I37R                  | <5 | - |
| c.1081del                                | p.Trp361GlyfsX8    | 1213delT              | <5 | - |
| c.1954C>T                                | p.Gln652X          | Q652X                 | <5 | - |
| c.3847A>G                                | p.Arg1283Gly       | R1283G                | <5 | - |
| c.2989-3C>G                              |                    | 3121-3C->G            | <5 | - |
| c.2800G>C                                | p.Gly934Arg        | G934R                 | <5 | - |
| c.1820_1903del                           | p.Met607_Gln634del | 1949del84             | <5 | - |
| c.561C>A   c.561C>G                      | p.Asn187Lys        | N187K                 | <5 | - |
| c.3849G>C                                | p.Arg1283Ser       | R1283S                | <5 | - |
| c.53+1G>T                                |                    | 185+1G->T             | <5 | - |
| c.3587C>A c.3587C>G                      | p.Ser1196X         | S1196X                | <5 | - |
| c.1898T>C                                | p.Leu633Pro        | L633P                 | <5 | - |
| c.(2619+1_2620-1)_<br>(2657+1_2658-1)del |                    | CFTRdele14b           | <5 | - |
| c.571T>G                                 | p.Phe191Val        | F191V                 | <5 | - |
| c.1882G>C c.1882G>A                      | p.Gly628Arg        | G628R                 | <5 | - |
| c.3932_3933delinsAATATG                  | p.Ser1311LysfsX12  | 4064-4065delinsAATATG | <5 | - |
| c.3209G>A                                | p.Arg1070Gln       | R1070Q                | <5 | - |
| c.1697C>A                                | p.Ala566Asp        | A566D                 | <5 | - |
| c.11C>A                                  | p.Ser4X            | S4X                   | <5 | - |
| c.1472G>T                                | p.Cys491Phe        | C491F                 | <5 | - |
| c.1772T>C                                | p.Val591Ala        | V591A                 | <5 | - |
| c.323C>T                                 | p.Ser108Phe        | S108F                 | <5 | - |
| c.(1584+1_1585-1)_<br>(1679+1_1680-1)del |                    | CFTRdele11            | <5 | - |
| c.(3963+1_3964-1)_<br>(4242+1_4243-1)dup |                    | CFTRdup22,23          | <5 | - |
| c.(2988+1_2989-1)_<br>(3367+1_3368-1)del |                    | CFTRdele17a,17b       | <5 | - |
| c.2380del                                | p.Val794CysfsX9    | 2512delG              | <5 | - |
| c.274-1G>A                               |                    | 406-1G->A             | <5 | - |
| c.169T>C                                 | p.Trp57Arg         | W57R                  | <5 | - |
| c.2963C>G                                | p.Pro988Arg        | P988R                 | <5 | - |

\* Redacted to adhere to statistical disclosure guidelines.

| Nucleotide                               | Protein              | Legacy name   | N  | % |
|------------------------------------------|----------------------|---------------|----|---|
| c.1208del                                | p.Glu403GlyfsX39     | 1340delA      | <5 | - |
| c.3302T>A                                | p.Met1101Lys         | M1101K        | <5 | - |
| c.473G>A                                 | p.Ser158Asn          | S158N         | <5 | - |
| c.4170del                                | p.Ala1391HisfsX7     | 4301delA      | <5 | - |
| c.3262A>G                                | p.Asn1088Asp         | N1088D        | <5 | - |
| c.416A>T                                 | p.His139Leu          | H139L         | <5 | - |
| c.1920_1921dup                           | p.Ser641IlefsX23     | 2053insTA     | <5 | - |
| c.3368-2A>G                              |                      | 3500-2A->G    | <5 | - |
| c.3458T>A                                | p.Val1153Glu         | V1153E        | <5 | - |
| c.2909del                                | p.Gly970ValfsX11     | 3041delG      | <5 | - |
| c.3611G>A c.3612G>A                      | p.Trp1204X           | W1204X        | <5 | - |
| c.3209G>C                                | p.Arg1070Pro         | R1070P        | <5 | - |
| c.1969A>T                                | p.Arg657X            | R657X         | <5 | - |
| c.4364C>G                                | p.Ser1455X           | S1455X        | <5 | - |
| c.1210-7_1210-6dup                       |                      | 9T            | <5 | - |
| c.2277del                                | p.Thr760ArgfsX11     | 2409delC      | <5 | - |
| c.3415A>G                                | p.Ile1139Val         | I1139V        | <5 | - |
| c.3717+1G>A                              |                      | 3849+1G->A    | <5 | - |
| c.3964-7A>G                              |                      | 4096-7A->G    | <5 | - |
| c.3011_3019del                           | p.Ala1004_Ala1006del | 3143del9      | <5 | - |
| c.531dup                                 | p.Gly178TrpfsX5      | 663insT       | <5 | - |
| c.2836A>T                                | p.Lys946X            | K946X         | <5 | - |
| c.1837G>A                                | p.Ala613Thr          | A613T         | <5 | - |
| c.(2908+1_2909-1)_<br>(3873+1_3874-1)dup |                      | CFTRdup16-20  | <5 | - |
| c.3367+3A>G                              |                      | 3499+3A->G    | <5 | - |
| c.3181G>A c.3181G>C                      | p.Gly1061Arg         | G1061R        | <5 | - |
| c.1546A>G                                | p.Arg516Gly          | R516G         | <5 | - |
| c.490-3T>G                               |                      | 622-3T->G     | <5 | - |
| c.3971T>C                                | p.Leu1324Pro         | L1324P        | <5 | - |
| c.3678del                                | p.Leu1227X           | c.3678delA    | <5 | - |
| c.1801A>T                                | p.Ile601Phe          | I601F         | <5 | - |
| c.3530del                                | p.Lys1177SerfsX15    | 3662delA      | <5 | - |
| c.3629T>A                                | p.Met1210Lys         | M1210K        | <5 | - |
| c.1585-1G>T                              |                      | 1717-1G->T    | <5 | - |
| c.2859_2890del                           | p.Leu953PhefsX11     | 2991del32     | <5 | - |
| c.2908+1G>A                              |                      | 3040+1G->A    | <5 | - |
| c.1177del                                | p.Val393X            | 1309delG      | <5 | - |
| c.1116+31A>C                             |                      | 1248+31A/C    | <5 | - |
| c.743+40A>G                              |                      | 875+40A/G     | <5 | - |
| c.3134C>A                                | p.Ser1045Tyr         | S1045Y        | <5 | - |
| c.54-4235_164+377dup                     |                      | CFTRdup2      | <5 | - |
| c.927del                                 | p.Phe310SerfsX18     | 1058delC      | <5 | - |
| c.(3367+1_3368-1)_<br>(3873+1_3874-1)del |                      | CFTRdele18-20 | <5 | - |
| c.234del                                 | p.Trp79GlyfsX12      | c.234delC     | <5 | - |
| c.828C>A                                 | p.Cys276X            | C276X         | <5 | - |
| c.490-1G>C                               |                      | 622-1G->C     | <5 | - |

| Nucleotide                               | Protein                  | Legacy name    | N  | % |
|------------------------------------------|--------------------------|----------------|----|---|
| c.1439G>A                                | p.Gly480Asp              | G480D          | <5 | - |
| c.3745G>A c.3745G>C                      | p.Gly1249Arg             | G1249R         | <5 | - |
| c.4243-7del                              |                          | 4375-7delT     | <5 | - |
| c.137C>A                                 | p.Ala46Asp               | A46D           | <5 | - |
| c.1315C>T                                | p.Pro439Ser              | P439S          | <5 | - |
| c.2476G>A                                | p.Glu826Lys              | E826K          | <5 | - |
| c.2143C>T                                | p.Gln715X                | Q715X          | <5 | - |
| c.1517T>C                                | p.Ile506Thr              | I506T          | <5 | - |
| c.1106_1111dup                           | p.Asn369_Lys370dup       | 1234insACAAAA  | <5 | - |
| c.697C>G                                 | p.Leu233Val              | L233V          | <5 | - |
| c.1807G>T                                | p.Val603Phe              | V603F          | <5 | - |
| c.278T>A                                 | p.Val93Asp               | V93D           | <5 | - |
| c.1420G>A                                | p.Glu474Lys              | E474K          | <5 | - |
| c.3232T>A                                | p.Phe1078Ile             | F1078I         | <5 | - |
| c.2619+2T>C                              |                          | 2751+2T->C     | <5 | - |
| c.579+2T>C                               |                          | 711+2T->C      | <5 | - |
| c.1209+1G>A                              |                          | 1341+1G->A     | <5 | - |
| c.869+5G>A                               |                          | 1001+5G->A     | <5 | - |
| c.(2490+1_2491-1)_<br>(2908+1_2909-1)del |                          | CFTRdele14a-15 | <5 | - |
| c.445G>A                                 | p.Gly149Arg              | G149R          | <5 | - |
| c.88_89del                               | p.Gln30AlafsX14          | c.88_89delCA   | <5 | - |
| c.819_824del                             | p.Lys273_Tyr275delinsAsn | 951delGGCATA   | <5 | - |
| c.2978A>G                                | p.Asp993Gly              | D993G          | <5 | - |
| c.1040G>T                                | p.Arg347Leu              | R347L          | <5 | - |
| c.349C>A                                 | p.Arg117Ser              | R117S          | <5 | - |
| c.1684G>A                                | p.Val562Ile              | V562I          | <5 | - |
| c.3469-3C>G                              |                          | 3601-3C->G     | <5 | - |
| c.2421A>G                                | p.Ile807Met              | I807M          | <5 | - |
| c.2620-26A>G                             |                          | 2752-26A->G    | <5 | - |
| c.1654C>T                                | p.Gln552X                | Q552X          | <5 | - |
| c.274-2A>G                               |                          | 406-2A->G      | <5 | - |
| c.710A>G                                 | p.Gln237Arg              | Q237R          | <5 | - |
| c.165-2A>G                               |                          | 297-2A->G      | <5 | - |
| c.1324A>T                                | p.Lys442X                | K442X          | <5 | - |
| c.164+1G>A                               |                          | 296+1G->A      | <5 | - |
| c.4090del                                | p.Ala1364ArgfsX16        | 4222delG       | <5 | - |
| c.3160C>G                                | p.His1054Asp             | H1054D         | <5 | - |
| c.3285A>T                                | p.Thr1095=               | 3417A/T        | <5 | - |
| c.1703del                                | p.Leu568CysfsX4          | 1833delT       | <5 | - |
| c.523A>G                                 | p.Ile175Val              | I175V          | <5 | - |
| c.3718-3T>G                              |                          | 3850-3T->G     | <5 | - |
| c.861_865del                             | p.Asn287LysfsX19         | 991del5        | <5 | - |
| c.1687T>G                                | p.Tyr563Asp              | Y563D          | <5 | - |
| c.3889del                                | p.Ser1297LeufsX31        | c.3889delT     | <5 | - |
| c.50del                                  | p.Phe17SerfsX8           | 182delT        | <5 | - |
| c.717del                                 | p.Leu240X                | 849delG        | <5 | - |
| c.3218A>G                                | p.Tyr1073Cys             | Y1073C         | <5 | - |

| Nucleotide                               | Protein                               | Legacy name       | N   | %   |
|------------------------------------------|---------------------------------------|-------------------|-----|-----|
| c.2739T>A                                | p.Tyr913X                             | Y913X             | <5  | -   |
| c.2089del                                | p.Arg697GlyfsX25                      | c.2089delA        | <5  | -   |
| c.2797A>G                                | p.Arg933Gly                           | R933G             | <5  | -   |
| c.574G>A                                 | p.Asp192Asn                           | D192N             | <5  | -   |
| c.3194T>C                                | p.Leu1065Pro                          | L1065P            | <5  | -   |
| c.2053C>T                                | p.Gln685X                             | Q685X             | <5  | -   |
| c.3230T>C                                | p.Leu1077Pro                          | L1077P            | <5  | -   |
| c.2835del                                | p.Ile947PhefsX21                      | 2967delG          | <5  | -   |
| c.3731G>T                                | p.Gly1244Val                          | G1244V            | <5  | -   |
| c.3758dup                                | p.Leu1253PhefsX12                     | 3889dupT          | <5  | -   |
| c.(3468+1_3469-1)_<br>(3717+1_3718-1)dup |                                       | CFTRdup19         | <5  | -   |
| c.285dup                                 | p.Ala96SerfsX15                       | 415insA           | <5  | -   |
| c.2508del                                | p.Asp836GlufsX8                       | 2640delT          | <5  | -   |
| c.3773dup                                | p.Leu1258PhefsX7                      | 3905insT          | <5  | -   |
| c.3389G>A                                | p.Gly1130Asp                          | G1130D            | <5  | -   |
| c.3038C>T                                | p.Pro1013Leu                          | P1013L            | <5  | -   |
| c.869+1G>C                               |                                       | 1001+1G->C        | <5  | -   |
| c.-8G>C                                  |                                       | 125G/C            | <5  | -   |
| c.3023T>A                                | p.Val1008Asp                          | V1008D            | <5  | -   |
| c.2645G>A c.2646G>A                      | p.Trp882X                             | W882X             | <5  | -   |
| c.3956C>A                                | p.Ala1319Glu                          | A1319E            | <5  | -   |
| c.1196C>G                                | p.Ala399Gly                           | A399G             | <5  | -   |
| c.908_911del                             | p.Arg303ThrfsX24                      | 1040del4          | <5  | -   |
| c.1470_1471del                           | p.Phe490LeufsX13                      | 1601delTC         | <5  | -   |
| c.3274T>C                                | p.Tyr1092His                          | Y1092H            | <5  | -   |
| c.2083del                                | p.Glu695LysfsX27                      | 2215delG          | <5  | -   |
| c.[220C>T;601G>A;<br>3808G>A]            | p.[Arg74Trp;Val201Met;<br>Asp1270Asn] | R74W;V201M;D1270N | <5  | -   |
| c.1125A>C                                | p.Leu375Phe                           | L375F             | <5  | -   |
| c.(2908+1_2909-1)_<br>(3139+1_3140-1)del |                                       | CFTRdele16,17a    | <5  | -   |
| c.2989-1G>A                              |                                       | 3121-1G->A        | <5  | -   |
| c.743+2T>C                               |                                       | 875+2T->C         | <5  | -   |
| c.4231C>T                                | p.Gln1411X                            | Q1411X            | <5  | -   |
| c.1043T>A                                | p.Met348Lys                           | M348K             | <5  | -   |
| c.3717G>A                                | p.Arg1239=                            | 3849G->A          | <5  | -   |
| c.2762G>A                                | p.Gly921Glu                           | G921E             | <5  | -   |
| 'Other' selected                         |                                       |                   | 88  | 0.8 |
| Missing/not known                        |                                       |                   | 358 | 3.1 |

## Appendix 4: Additional tables

### CF population by devolved nation

| Country          | Number registered | Number with annual review |
|------------------|-------------------|---------------------------|
| England          | 9581              | 8983                      |
| Northern Ireland | 516               | 421                       |
| Scotland         | 1030              | 882                       |
| Wales            | 483               | 338                       |

# Glossary

| Word/Phrase                                                | Meaning                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 2025                                                       | 1 January 2025–31 December 2025.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| ABPA (allergic bronchopulmonary aspergillosis)             | When a person develops a respiratory allergic reaction to <i>Aspergillus fumigatus</i> .                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Arthritis                                                  | A condition causing pain and inflammation in the joints.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Arthropathy                                                | A condition causing pain in the joints.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| Asthma                                                     | A respiratory condition causing reversible episodes of difficulty breathing, often associated with wheezing.                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| <i>B. cepacia</i> complex                                  | The <i>Burkholderia cepacia</i> complex is a group of bacteria, some of which threaten the health of people with cystic fibrosis.                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| BMI (Body Mass Index)                                      | A measure designed to show whether a person is a healthy weight for their height.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| CF                                                         | Cystic fibrosis.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| CFTR (cystic fibrosis transmembrane conductance regulator) | A protein at the cell surface that controls the salt and water balance across a cell. The gene that causes cystic fibrosis is the blueprint for the CFTR protein. Everyone has two copies of the gene for CFTR. To be born with cystic fibrosis, both CFTR genes must be affected by a CF-causing variant.                                                                                                                                                                                                                                                                                 |
| Chronic                                                    | Persistent, or long-lasting.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| Cirrhosis                                                  | A chronic liver disease.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| CI (confidence interval)                                   | A way of expressing how certain we are about our statistical estimates of a clinical measure (for example BMI). It gives a range of results that is likely to include the 'true' value for the population. A narrow confidence interval indicates a more precise estimate. A wide confidence interval indicates more uncertainty about the true value of the clinical measure, often because a small group of patients has been studied. The confidence interval is usually stated as '95% CI', which means that the range of values has a 95 in 100 chance of including the 'true' value. |
| Class 1 variant                                            | A genetic variant of CFTR which means that no CFTR protein is produced. People with two class 1 variants are likely not eligible for CFTR modulator treatment.                                                                                                                                                                                                                                                                                                                                                                                                                             |
| Enzymes                                                    | Biological molecules that help complex reactions, such as the digestion of food, occur in the body.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| FEV <sub>1</sub> (forced expiratory volume in one second)  | This is the amount of air that a person can blow out of the lungs in the first second of a forced exhaled breath. People with healthy lungs can blow out most of the air held in this time.                                                                                                                                                                                                                                                                                                                                                                                                |
| FEV <sub>1</sub> % predicted                               | The FEV <sub>1</sub> can be converted from absolute litres of air blown out into a predicted percentage (%). A healthy range for % predicted is calculated from a very large population sample, and is normally considered to be between 80-120% predicted.                                                                                                                                                                                                                                                                                                                                |
| Fibrosing colonopathy                                      | A condition causing narrowing of part of the colon.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| Gall bladder                                               | The small sac-shaped organ under the liver that stores bile after it is secreted by the liver, before it is released into the intestine.                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Gastrointestinal (GI) tract                                | The GI tract is an organ system responsible for digesting food, absorbing nutrients and expelling waste.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Genotype                                                   | Part of the genetic makeup of a cell, organism or individual that usually controls a particular characteristic (known as a phenotype). The combination of CFTR variants that an individual has is called their genotype.                                                                                                                                                                                                                                                                                                                                                                   |
| GORD (gastro-oesophageal reflux disease)                   | A chronic symptom of damage caused by stomach acid coming up from the stomach into the oesophagus.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| GI bleed                                                   | Bleeding in the gastrointestinal tract.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| GLI equations                                              | Global Lung Initiative, the equation used for calculating FEV <sub>1</sub> % predicted from absolute FEV <sub>1</sub> , which takes into account age, gender and height.                                                                                                                                                                                                                                                                                                                                                                                                                   |
| <i>H. influenza</i>                                        | <i>Haemophilus influenza</i> is a bacterium that can cause serious illness.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| Haemoptysis                                                | The coughing up of blood.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| Hepatobiliary disease                                      | A liver or biliary disorder.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |

| Word/Phrase                                        | Meaning                                                                                                                                                                                                                                                        |
|----------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Heterozygous                                       | Everyone living with cystic fibrosis has two variants of the gene for CFTR, one inherited from their mother and one from their father. Someone who has two different CFTR variants is heterozygous.                                                            |
| Homozygous                                         | Everyone living with cystic fibrosis has two variants of the gene for CFTR, one inherited from their mother and one from their father. If both CFTR variants are the same, the person is said to be homozygous.                                                |
| Hypertension                                       | High blood pressure.                                                                                                                                                                                                                                           |
| Incidence                                          | The number of people newly diagnosed with a condition in the given year.                                                                                                                                                                                       |
| IQR (interquartile range)                          | Also called the mid-spread, or middle fifty, IQR is a measure of the spread of data. It shows the difference between the upper and lower quartiles. $IQR = Q3 - Q1$ .                                                                                          |
| Mean                                               | A type of average, calculated by adding up all the values and dividing by the number of values.                                                                                                                                                                |
| Median                                             | The middle number, when all numbers are arranged from smallest to largest.                                                                                                                                                                                     |
| Median age of death                                | Median age of death is based on the people with CF who died in any given year.                                                                                                                                                                                 |
| Median predicted survival age                      | A prediction of how long we expect that half of the people with CF born today will live for assuming no changes to treatment, standards of care or mortality rates.                                                                                            |
| Median predicted survival age based on current age | Also called median predicted conditional survival age. A prediction of how long we expect that half of the people with CF who have already attained a given age will live for assuming no changes to treatment, standards of care or mortality rates.          |
| MRSA                                               | Methicillin-resistant <i>Staphylococcus aureus</i> is a type of bacteria that is resistant to a number of widely used antibiotics.                                                                                                                             |
| Nasal polyps                                       | Small, sac-like growths of inflamed mucus membrane caused by chronic inflammation of the nasal lining.                                                                                                                                                         |
| NBS (newborn screening)                            | Newborn screening is part of the heel prick blood spot testing carried out on all babies at 5–7 days of age. The blood sample is tested for a number of conditions, including cystic fibrosis.                                                                 |
| NTM (non-tuberculous mycobacteria)                 | A mycobacterium that does not cause tuberculosis, but which can cause respiratory infection. There are several types known.                                                                                                                                    |
| Osteopenia                                         | A medical condition less severe than osteoporosis, where the mineral content of bone is reduced.                                                                                                                                                               |
| Osteoporosis                                       | A condition where the bones become brittle from loss of tissue.                                                                                                                                                                                                |
| Pancreas                                           | An organ in the digestive system that produces insulin and digestive enzymes.                                                                                                                                                                                  |
| Pancreatitis                                       | Inflammation of the pancreas.                                                                                                                                                                                                                                  |
| Peptic ulcer                                       | Or stomach ulcer; an open sore that develops in the lining of the stomach.                                                                                                                                                                                     |
| Percentile                                         | A percentile shows where a value stands, relative to the rest of the data. If a value is higher than 90% of the rest of the data, it is on the 90th percentile.                                                                                                |
| Pneumothorax                                       | A collection of air in the cavity between the lungs and the chest wall causing collapse of the lung on the affected side.                                                                                                                                      |
| Portal hypertension                                | High blood pressure in the portal vein system, which is the blood system of the liver.                                                                                                                                                                         |
| Prenatal                                           | Before birth, whilst the baby is still in the womb.                                                                                                                                                                                                            |
| Prevalence                                         | The overall number of people with the condition in the last 12 months.                                                                                                                                                                                         |
| <i>Pseudomonas aeruginosa</i>                      | A tough bacterial strain. Rarely affecting healthy people, it can cause a wide range of infections, particularly in those with a weakened immune system.                                                                                                       |
| Rectal prolapse                                    | When the rectal wall slides through the anus.                                                                                                                                                                                                                  |
| Renal                                              | Relating to the kidneys.                                                                                                                                                                                                                                       |
| <i>Staphylococcus aureus</i>                       | <i>Staphylococcus aureus</i> is a type of bacteria that can cause disease if it enters the body.                                                                                                                                                               |
| Sinus disease                                      | When the sinuses, which are usually filled with air, are typically full of thick sticky mucus.                                                                                                                                                                 |
| Variant                                            | A variant is a change in a gene. When both of a child's parents are carriers of a CF- causing variant there is a 25% chance that the child will have cystic fibrosis. There are over 1,400 different variants of the CFTR gene that can cause cystic fibrosis. |

# Cystic Fibrosis Trust

As the UK's only national CF charity, we fund research, improve care, provide practical support, and campaign on the issues that matter most for everyone affected by CF.

**We're here to lift the limits CF brings. Together we'll help everyone with CF to live a long and full life.**

**[cysticfibrosis.org.uk](https://cysticfibrosis.org.uk)**

© Cystic Fibrosis Trust 2026. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 33 Creechurch Lane, London, EC3A 5EB.

**Lifting limits**  
*Changing lives*