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ECFSPR 2024 Annual Data Report

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Message from the ECFSPR Director

I am pleased to present the 2024 Annual Report from the European Cystic Fibrosis Society Patient Registry (ECFSPR). The report provides analyses of key clinical and demographic indicators across Europe, with detailed data tables available in Appendix 1. Starting with the 2023 data cycle and fully implemented for 2024, the ECFSPR has also created an online report which is hosted on its website; this allows for continuous updates, faster dissemination and improved accessibility. A PowerPoint slide deck, with selected figures from 2024, can also be found on the website. The slides can be downloaded and used by anyone.

Highly effective CFTR modulators continue to transform outcomes for people with cystic fibrosis. In 2025 attention focused on regulatory developments, the extension of marketing authorisation for some of the modulators, including Kaftrio®, and the introduction of Alyftrek®. Substantial disparities in access still persist across Europe however, due to regulatory barriers and non-reimbursement of treatment, resulting in ongoing health inequities and reinforcing the need for high-quality, real-world data to inform policy (Sermet-Gaudelus et al., Health inequity in people with cystic fibrosis: can we close the gap?, Annals of the American Thoracic Society 2026).

The 2024 ECFSPR report is based on data provided by national CF registries and individual CF centres from 46 European countries and more than 57,000 consenting individuals. The ECFSPR remains a cornerstone resource for quality improvement, research and health system evaluation, offering population-level insights beyond those available from clinical trials.

The ECFSPR Partnership Project, established through a dedicated call outside Europe for low- and middle-income countries, commenced in late 2025. This extends the work of the ECFSPR globally and strengthens the evidence base for CF care across multiple continents. The first data collection is planned for 2025 and results from this initiative will be reported separately.

Maintaining high data quality remains essential, particularly for registry-based pharmacoepidemiology studies that assess the safety and effectiveness of newly introduced CF therapies, including CFTR modulators approved under new or expanded indications. Our partnership with CF Europe and national patient organisations helps ensure that registry findings translate into tangible benefits for the CF community.

We are deeply grateful to the people with cystic fibrosis and their families who contribute their data. We also thank the ECFSPR staff, Executive and Scientific Committees, volunteers, working groups, partners, and sponsors whose continued commitment and support make this work possible.

Sincerely,

Egil Bakkeheim
ECFSPR Director

To the people with cystic fibrosis

This report is about you and how cystic fibrosis (CF) affects you and other people all over Europe. The report is based on demographic, diagnostic and clinical data about people with CF (PwCF) collected by individual CF centres and the national CF registries that participate in the European Cystic Fibrosis Society Patient Registry (ECFSPR). We have tried to make the presentation of these data as clear as possible and hope that you will find the report interesting and easy to understand.

This year we also published a highlights report, as well as a dynamic online report; both display key information from the full annual report and we believe they are interesting for anyone who wants to know more about the disease but prefers not to read all the detailed information in this document.

For news and regular updates and to know more about the ECFSPR, we invite you to visit our website; you can also find us on LinkedIn.

We will continue to work with patient organisations to increase awareness of the Registry amongst PwCF and their families. If you have suggestions on how we can improve, or if anything in this report is not clear, you are welcome to contact us via email at info@ecfregistry.eu.

If you want to discuss further the results presented in this report from your country, we encourage you to contact your CF centre. For more information about the ECFSPR please visit our website.

Information on how we handle your data and how you can exercise your rights can be found in the ECFSPR Privacy Notice.

Last but not least we would like to extend a huge thanks to all of you, and your families, for allowing us to collect, and include in the European CF Society Patient Registry, data about you and your lives with CF.

Introduction

The European Cystic Fibrosis Society Patient Registry (ECFSPR)

The ECFSPR collects demographic, diagnostic and clinical data of consenting people with cystic fibrosis (PwCF) from countries in the geographical area of Europe (as defined by the World Health Organisation). Data are collected using a common set of variables and definitions and are sent to the ECFSPR in one of the following ways:

- National CF registries (or individual centres with local databases) extract data from their own database and import the data into the secure, online ECFSPR data-collection software.
- Individual centres enter data directly into the ECFSPR software.

Collection of data at a local level must be approved by local data protection authorities and done in accordance with European data protection legislation. Data stored in the central database are pseudonymised; only year/ month of birth and randomised centre and patient codes are used as identifiers.

The data in the ECFSPR can be analysed for scientific purposes and we invite applications for specific projects from independent researchers, institutions and Industry. All research project applications are reviewed by the ECFSPR Scientific Committee; based on the Committee's recommendation, the country coordinators in the ECFSPR Steering Group (composed of national representatives of the countries that contribute data to the ECFSPR) decide if the data from their country can be used for a project. This decision is final. Project applications that originate from Industry are also reviewed by the ECFS Clinical Trials Network. All applications must meet the European and individual country data protection legislation regarding patient anonymity.

For more information, please visit our website.

General Considerations

It is possible that some national registries use data definitions and parameters that do not fully correspond to those employed by the ECFSPR, either because some types of information are not collected, or they are collected by the national registry using a different method. When the national registries upload their data they must state, for each variable, whether their definitions meet those of the ECFSPR or not. If there is a significant difference between definitions, that variable was omitted from this annual report for that country; if the difference is minor, we included the variable but added an explanatory footnote to the graphs and tables.

For example, the ECFSPR collects information on chronic Pseudomonas aeruginosa infection and uses the modified Leeds criteria and/or the presence of elevated anti-Pseudomonas antibodies (see the list of variables and definitions in our website). If a national registry collected such information as “at least one positive Pseudomonas aeruginosa culture this year”, this information would be significantly different from the ECFSPR definition of chronic Pseudomonas aeruginosa, and we would set this variable to “missing” for that particular country. If a country defined chronic Pseudomonas aeruginosa as “the presence of more than four positive cultures in 6 months”, this is much closer to the ECFSPR definition and we would include the variable and data in the annual report, with a footnote added to the relevant tables and graphs.

The countries with fewer than 5 individuals in an age group (e.g. fewer than 5 adults) are excluded from both the graphs and the tables.

The number of missing values, for any given question, is important when interpreting the results, since it is impossible to know if a pw CF with a missing value for a given complication has this complication or not, meaning given frequencies are less accurate. For example, in a country where 7% of the people with CF have liver disease but for 20% the information on liver disease is unknown/missing, the true frequency of liver disease will be anything between 7 and 27%.

You will find some differences between the findings in the reports of some national registries and the ECFSPR report. This is because some variable values are recoded or computed in different ways. For example, some national registries compute the age of the individual at the date of the annual visit and consider 16 years as the cut-off for adult age. The ECFSPR computes the age at FEV1/height/weight measurement and the age at follow-up (the end of the year) and considers 18 years as the cut-off for adult age. Another example: for lung function values such as FEV1 the raw data values, reported in litres, are not informative unless they are expressed in relation to the age, sex, and height of the

individual. We therefore needed to transform the raw values into new variables to compare lung function between people with CF in different countries. We used common reference populations for all data when calculating the values as a percentage of predicted from the raw data. Slightly different values can be obtained when using another reference population on the same raw data. It is important to use a common method of calculation when comparing different countries, just as the national registries choose a common method of calculation when they compare the individual centres in that country.
The estimated coverage, i.e. the percentage of people with CF included in the national registry or national data presented by the country, varies; see table 1.1. These differences can influence how the data are interpreted and we therefore advise comparisons to be made only between countries with similar coverage.

The date of the database that was used to create the tables and graphs in this report is 20 November 2025.

Overview for 2024 and previous years (2014 and 2019)

Outcome		2024		2019		2014	
PwCF registered in the ECFSPR	n	57288		50828		40707	
Age at follow-up (years) (PwCF alive on 31/12/2024)	median (25^{th} pctl-75^{th} pctl)	20.8	(11.1-33.8)	19.0	(9.5-30.9)	18.9	(9.6-29.3)
PwCF ≥ 18 years (PwCF alive on 31/12/2024)	n (%)	32277	(56.6)	26429	(52.4)	21073	(52.4)
Age at diagnosis (months)*	median (25^{th} pctl-75^{th} pctl)	3.6	(1.2-32.4)	3.7	(1.2-32.4)	4.5	(1.2-35.0)
PwCF with at least one F508del allele recorded*	n (%)	43330	(80.1)	39495	(80.8)	31736	(82.6)
PwCF living with lung transplant**	n (%)	2380	(4.4)	2849	(5.8)	1944	(5.1)
PwCF living with liver transplant**	n (%)	355	(0.7)	301	(0.6)	216	(0.6)
PwCF deceased in 2024***	n (%)	276	(0.5)	424	(0.9)	466	(1.2)
Age at death (years)***	median (25^{th} pctl-75^{th} pctl)	36.5	(24.0-49.0)	30.0	(22.0-41.0)	28.0	(21.0-37.0)

* Only people with CF seen during the year by clinical staff. The total number presented for the three years is: 54,241 for 2024, 49,218 for 2019 and 38,786 for 2014.

** Only people with CF alive at the end of each year. The total number of the CF population presented is: 53,988 for 2024, 48,849 for 2019 and 38,359 for 2014.

*** Only people with CF seen during each year. For the United Kingdom, all individuals with a confirmed diagnosis of CF were included (N=11,381 for 2024, N=10,655 for 2019 and N=10,580 for 2014). The total number presented is: 55,199 for 2024, 49,806 for 2019 and 39,936 for 2014.

Note: PwCF is an abbreviation for people with Cystic Fibrosis.

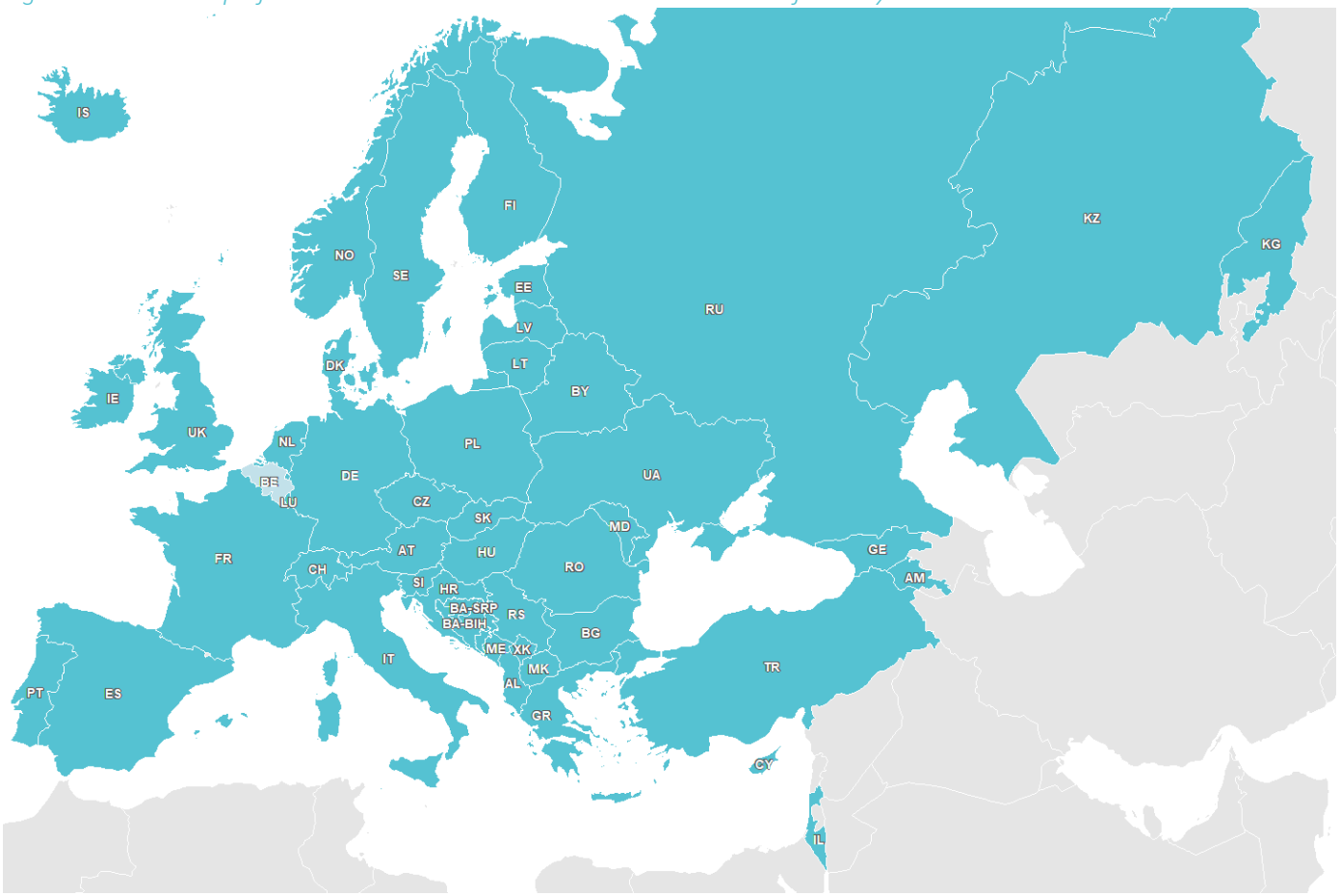
Data report

1. Demographics

The ECFSPR coverage (i.e. the proportion of the estimated total number of people with CF in a country included in the registry) continues to grow. Data come from national registries with their own collection systems or from centres in other countries that input data directly to our custom-designed data collection platform.
Only a few countries in Europe have not yet contributed data to the ECFSPR and we are in contact with those remaining to welcome them. In some countries not everyone with CF has had the opportunity to contribute to the ECFSPR and we invite all CF centres to join. We are confident that over the next few years several more centres and countries will do just that. National Coordinators that have been appointed by their country assist in this process by encouraging local centres to become new ECFSPR contributors.
This chapter gives information on coverage as well as on age and sex distribution in Europe and in the participating countries. In countries with a lower coverage, age distribution and mean age of the people with CF might be skewed since not all CF centres for children and adults in the country have contributed data.
Country-level data for Bosnia-Herzegovina and Kyrgyzstan has not been reported since these two countries reported fewer than 5 people with CF, but they are included in the total. For Kazakhstan, the estimated coverage is low and it is 0% for children and adolescents, therefore for this reason this country will never be shown in the graphs and tables about children/adolescents.
For more details, please refer to the footnotes of the tables and graphs.

1. Demographics

Figure 1.1 Map of countries that contributed data to the ECFSPR for the year 2024.



Note: BE could not provide data due to internal technical software issues and is marked in light blue.

The countries that contributed 2024 data are in turquoise.

1. Demographics

Table 1.1 Number of people with CF in 2024, by country.

Country	People with CF, registered, not lost to follow-up	People with CF seen	Estimated coverage (number of people with CF included in the national data/estimated total number of PwCF in that country)
Albania	79	47	>80%
Armenia	39	36	>70%
Austria	909	884	90%
Belarus*	148	148	64%
BA Federation of Bosnia-Herzegovina[1]	<5	<5	
BA Republika Srpska	25	24	>80%
Bulgaria	264	257	>90%
Croatia**	148	146	>98%
Cyprus	35	33	>80%
Czech Republic*	755	740	99%
Denmark*	574	565	99%
Estonia	45	43	75%
Finland	91	91	>60%
France*	7515	7515	>90%
Georgia	86	61	>90%
Germany*	7704	7372	>80%
Greece*	690	605	90%
Hungary*	547	547	90%
Iceland	16	16	>90%
Ireland*	1403	1378	94.6%
Israel**	597	550	>95%
Italy*	6206	6182	98%
Kazakhstan[2]	29	29	15%
Kosovo	33	33	20%
Kyrgyzstan[1]	<5	<5	
Latvia	53	52	90%
Lithuania	52	50	75%
Luxembourg[3]	25	25	60%
Republic of Moldova	59	52	>90%
Montenegro	42	42	>80%
Netherlands*	1608	1584	95%
North Macedonia**	170	144	>80%
Norway*	395	389	>90%
Poland	1726	1642	90%
Portugal**	413	398	>95%
Romania	424	401	50%
Russian Federation*	4294	3449	90%
Serbia	229	192	>90%
Slovak Republic**	325	290	>90%
Slovenia**	126	125	>95%
Spain**	2780	2620	85%
Sweden*	814	795	>99%
Switzerland**	1118	1037	>99%
Türkiye*	2765	2749	>60%
Ukraine[4]	546	475	>50%
United Kingdom*	11381	10424	99%
Total * **	57288	54241	

* Countries with an established national CF registry.

** These countries are considered national registries because all centres in the country participate in the ECFSPR.

*** In the Total the 2 countries with <5 PwCF are included.

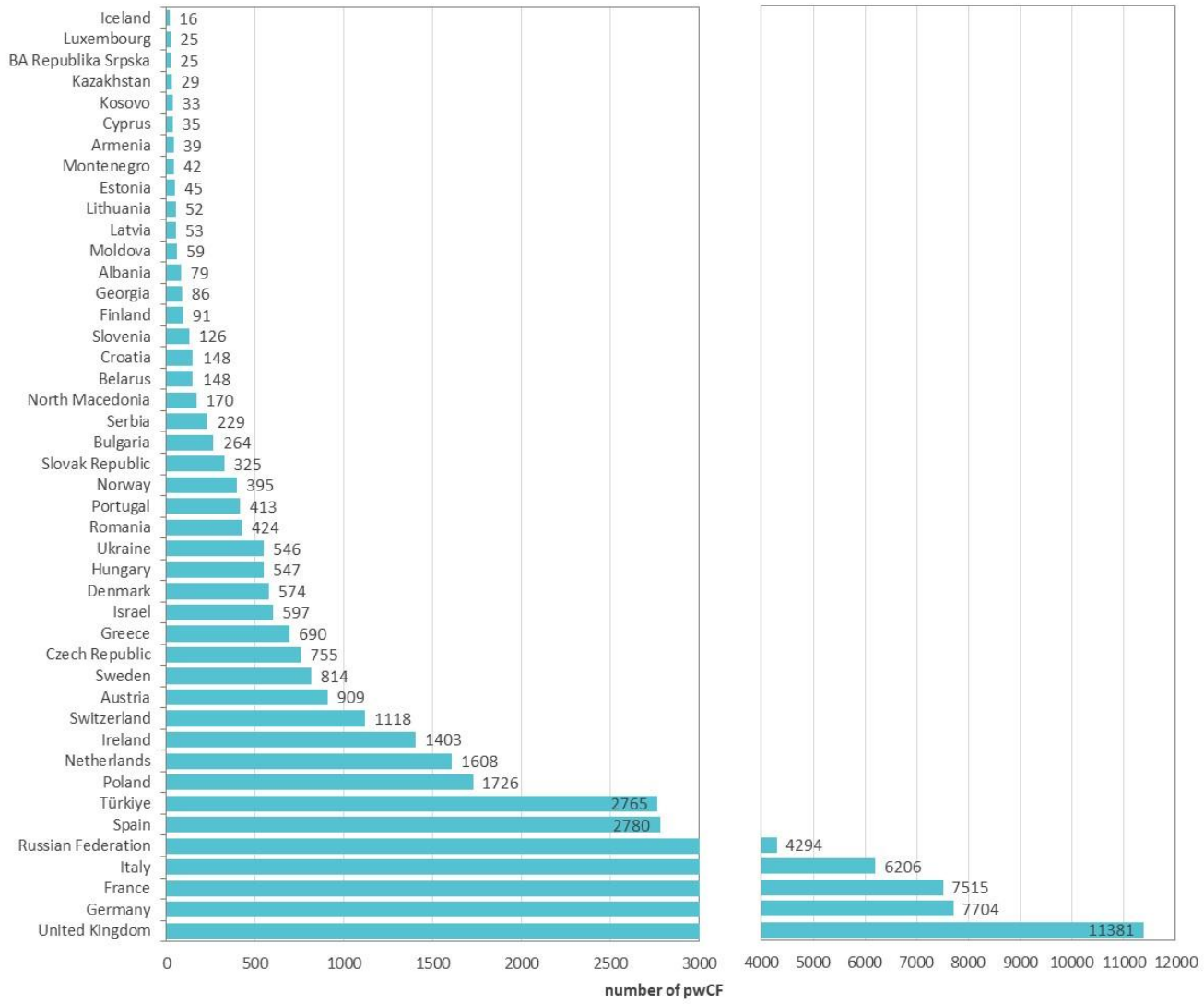
1 This country has fewer than 5 PwCF and is therefore not reported in country-level tables and figures.
2 Kazakhstan only sent data for people with CF older than 16 and therefore it will not be reported in the tables/figures on children and adolescents.
3 For Luxembourg the coverage for children with CF in 2024 was >80% and for all people with CF it was 60%.
4 It is unknown how many people with CF left the country after the start of the war.
BA Bosnia Herzegovina

The column “People with CF, registered, not lost to follow-up” displays the numbers of individuals with CF that attended clinic and also those who were not seen by clinical staff during the year but were known to be alive that year. The column “People with CF seen” presents only the numbers of individuals with CF who attended the clinic during the year. The column “Estimated coverage” shows the estimated percentage of people with CF living in that country who were included in the national registry / national data collection as reported by the country. Some countries may only have one centre where all / almost all the people with CF in the country are cared for. From chapter 4 onwards, only people with CF seen during the year and who have never had a transplant are considered for the analyses (total number 51,294).

1. Demographics

Figure 1.2 The number of people with CF registered in the ECFSPR varies across countries.

Number of people with CF registered in the ECFSPR in 2024.



Note: The x-axis scales differ between the left and right panels.

Each bar shows the number of registered people with CF (excludes those lost to follow-up) living in that country in 2024. Please refer to table 1.1 for the coverage in each country.

1. Demographics

Figure 1.3 The number of countries and people with CF in the ECFSPR has risen continuously over the years.

Number of registered people with CF and number of countries from 2008 to 2024.

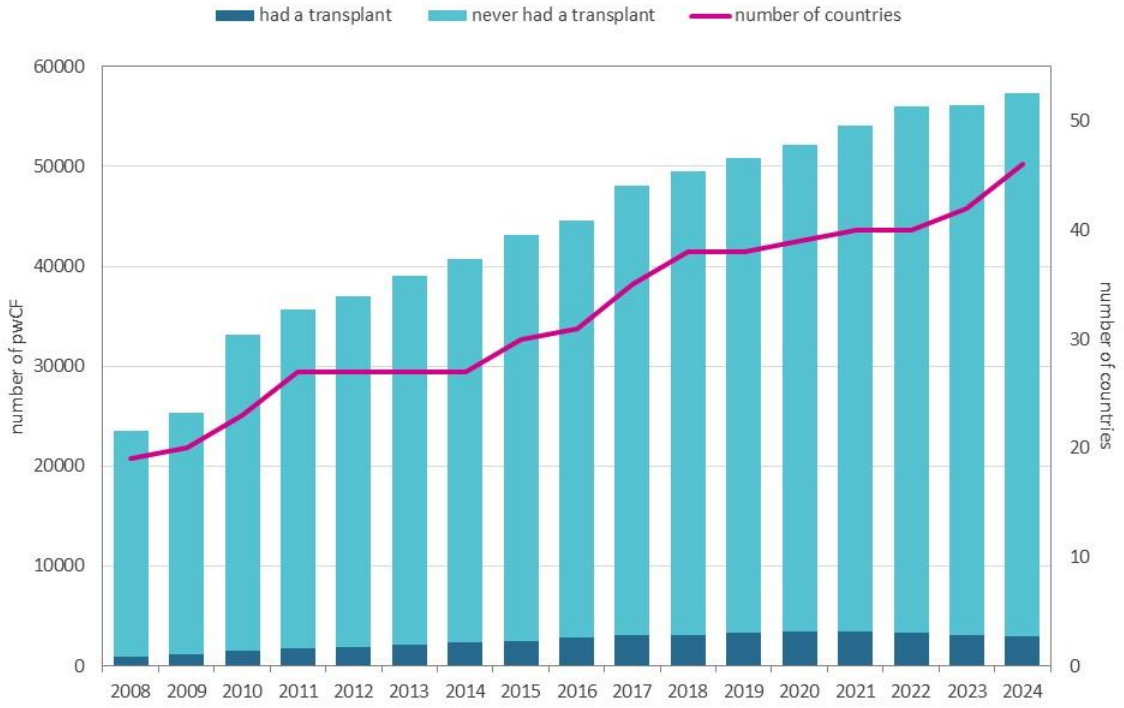
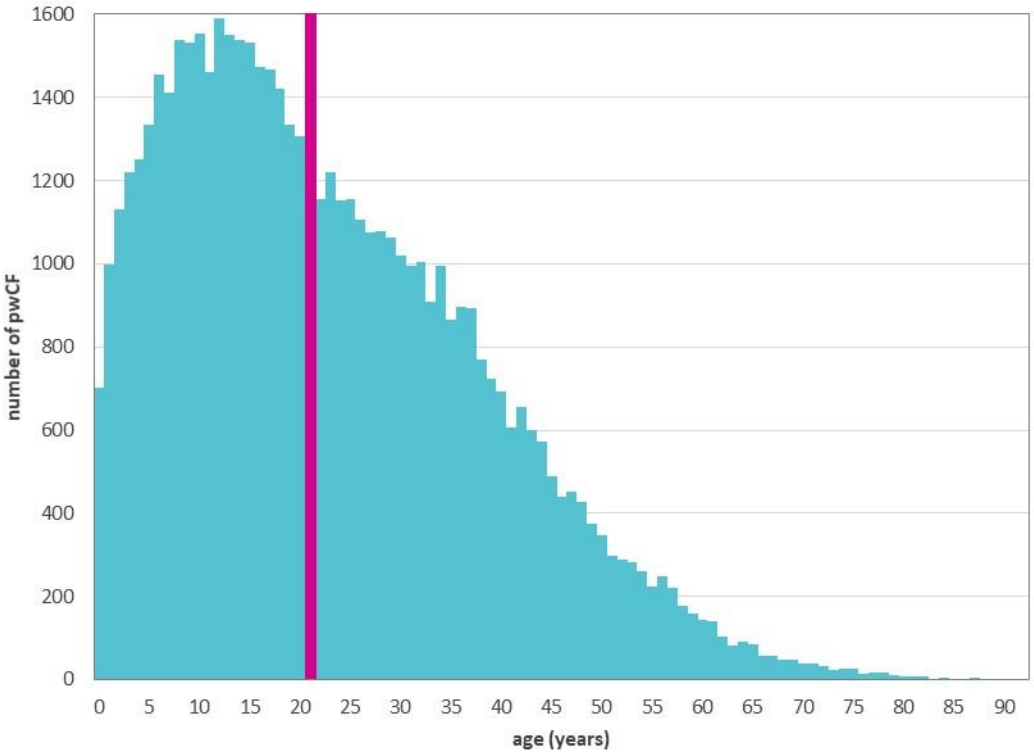


Figure 1.3 presents data over time using cross sectional data per year of people with a confirmed CF diagnosis. All people with CF alive and seen, deceased, or not seen but known to be alive during the year of follow-up were included.

1. Demographics

Figure 1.4 Age distribution demonstrates a sharp decline from the third decade of life.

Distribution of age at follow-up. Registered people with CF and alive on 31/12/2024.

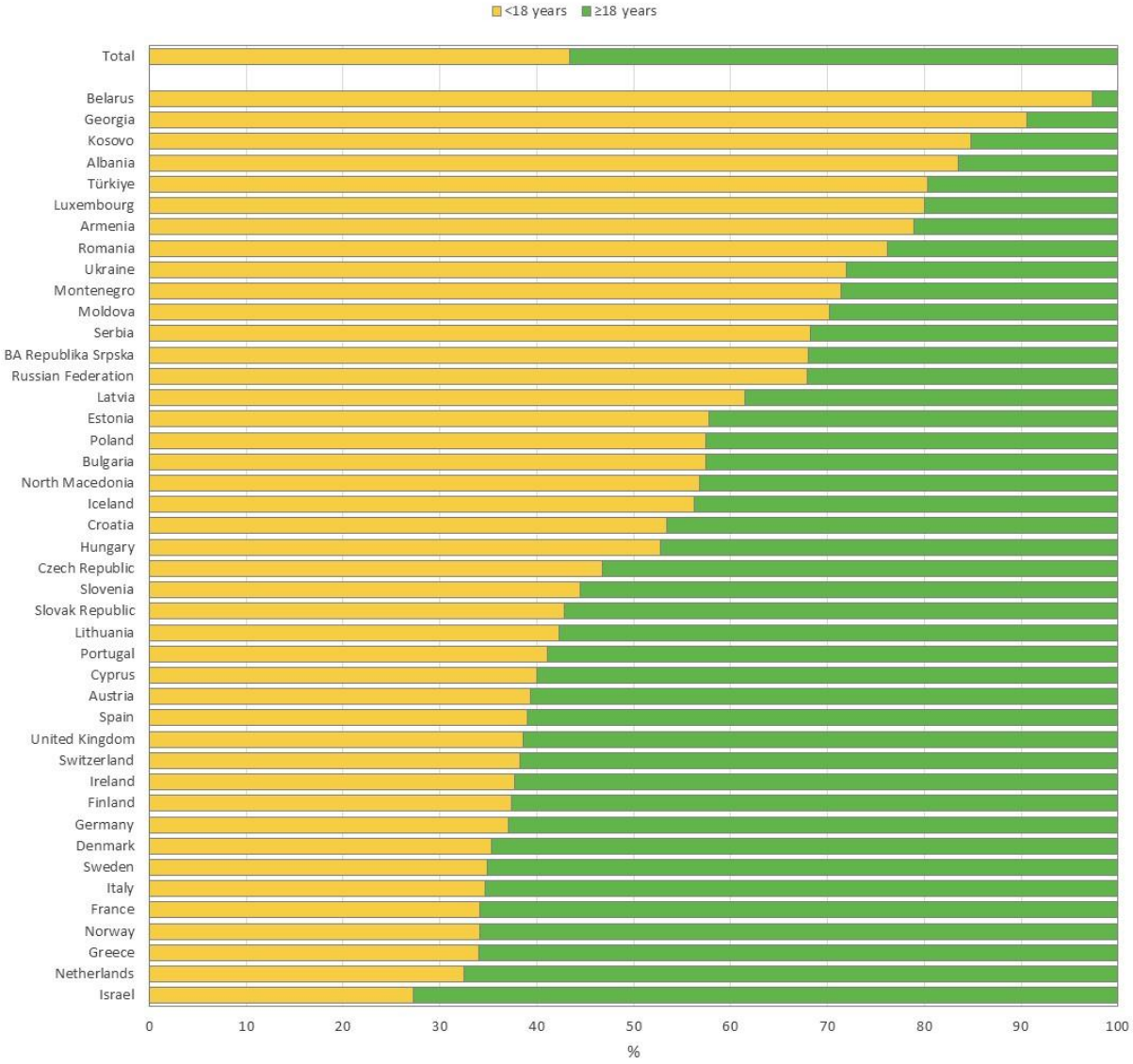


Each vertical bar shows the number of people with CF of that age alive in 2024. The median age of PwCF for 2024 is 21 years; for 2019 and 2014 it was 19 years (table A1.1, Appendix 1).

1. Demographics

Figure 1.5 The proportion of adults with CF varies considerably between European countries.

Proportion of children and adolescents (<18 years) and adults (≥18 years), by country and overall. Registered people with CF alive on 31/12/2024 (table A1.2, Appendix 1).

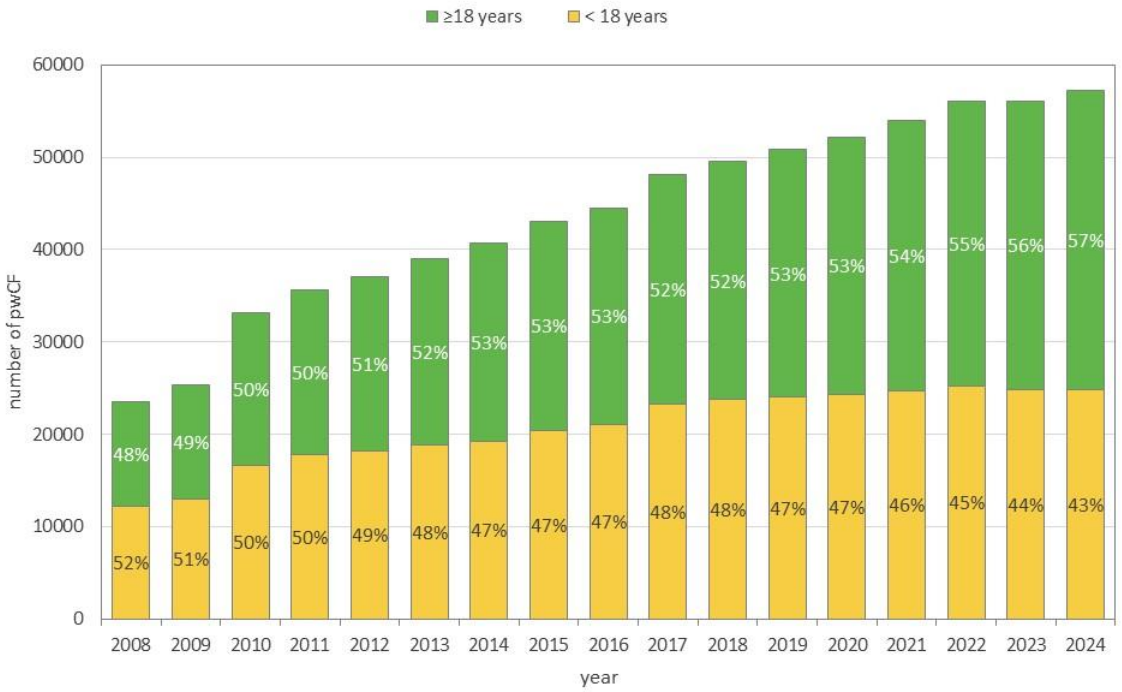


The yellow bars show the percentage of children and adolescents with CF in 2024; the green bars show the percentage of adults. See table A1.1 (Appendix 1) for more information on the age at follow-up, by country and overall, for registered people with CF alive on 31/12/2024. There are more adults (57%) than children (43%) in the ECFSPR, and more males (53%) than females (47%).

1. Demographics

Figure 1.6 In recent years the proportion of adults with CF in Europe has risen significantly; as of 2024, adults made up 57% of the total.

Number of registered people with CF and percentage of adults and children/adolescents from 2008 to 2024.



This graph presents data over time using cross sectional data per year of people with a confirmed CF diagnosis. All people with CF alive and seen, deceased, or not seen but known to be alive during the year of follow-up were included.

2. Diagnosis

In the following tables and figures age at diagnosis and information on newborn screening are shown. The age at diagnosis, particularly in children and adolescents, is strongly influenced by the existence or not of a national CF newborn screening program. Information about the proportion of people with CF per country who were diagnosed through newborn screening is therefore also shown.
Meconium ileus at birth may trigger further investigation in order to exclude or diagnose CF, even though its prevalence differs considerably between the countries, as highlighted in one of the graphs below.
In this chapter and the following ones, only data for people with CF who were seen by a clinician during the year are presented.

2. Diagnosis

Table 2.1 Age at diagnosis in children and adolescents depends on various factors, including the existence or not of a newborn screening programme in the country.

Age at diagnosis (in years): descriptive statistics, by country and overall. All children and adolescents (<18 years) alive and seen by a clinician in 2024.

Country	Number	Mean (average age at diagnosis)	Min (lowest age at diagnosis)	Median (half the PwCF were diagnosed before this age)	Max (highest age at diagnosis)
Albania	38	0.4	0.0	0.2	4.0
Armenia	28	2.6	0.1	1.1	16.0
Austria	346	0.5	0.0	0.1	14.8
Belarus	144	1.6	0.0	0.4	13.0
BA Republika Srpska	16	1.3	0.1	1.0	5.5
Bulgaria	147	2.4	0.0	0.6	15.4
Croatia	76	1.0	0.0	0.4	7.1
Cyprus	10	1.5	0.0	0.6	6.6
Czech Republic	348	0.6	0.0	0.1	16.1
Denmark	202	0.7	0.0	0.0	14.9
Estonia	24	1.7	0.0	0.5	9.1
Finland	34	1.3	0.0	0.5	12.0
France	2525	0.4	0.0	0.1	17.7
Georgia	56	3.2	0.0	1.7	15.0
Germany	2739	1.1	0.0	0.2	16.6
Greece	205	1.0	0.0	0.5	10.0
Hungary	287	1.7	0.0	0.6	14.7
Iceland	9	0.7	0.0	0.2	3.2
Ireland	526	0.7	0.0	0.1	12.7
Israel	147	1.2	0.0	0.4	12.0
Italy	2113	0.7	0.0	0.1	15.4
Kosovo	28	1.0	0.1	0.3	7.5
Latvia	32	0.6	0.0	0.2	4.6
Lithuania	22	2.5	0.0	0.8	16.6
Luxembourg	20	0.3	0.0	0.1	1.3
Rep of Moldova	36	2.0	0.0	0.4	12.3
Montenegro	30	1.4	0.0	0.4	9.4
Netherlands	514	0.7	0.0	0.1	16.0
North Macedonia	78	1.0	0.0	0.3	7.9
Norway	132	0.8	0.0	0.1	11.6
Poland	947	0.6	0.0	0.1	14.2
Portugal	166	1.1	0.0	0.1	12.5
Romania	295	1.5	0.0	0.4	17.0
Russian Fed.	2292	0.9	0.0	0.2	17.2
Serbia	150	1.5	0.0	0.4	15.1
Slovak Republic	121	0.7	0.0	0.2	11.0
Slovenia	56	1.1	0.0	0.4	5.6
Spain	1036	0.6	0.0	0.1	14.7
Sweden	276	1.7	0.0	0.5	14.2
Switzerland	396	0.6	0.0	0.1	15.0
Türkiye	2195	1.1	0.0	0.3	17.0
Ukraine	338	1.9	0.0	0.6	16.0
United Kingdom	4044	0.3	0.0	0.1	17.6
Total	23234	0.8	0.0	0.1	17.7

Note: For Cyprus and Greece, the information on age at diagnosis was missing for more than 10% of the people with CF.

2. Diagnosis

Table 2.2 For adults the age at diagnosis reflects national differences in the diagnostic approach over the last decades.

Age at diagnosis (in years): descriptive statistics, by country and overall. All adults (≥18 years) alive and seen by a clinician in 2024.

Country	Number	Mean (average age at diagnosis)	Min (lowest age at diagnosis)	Median (half the PwCF were diagnosed before this age)	Max (highest age at diagnosis)
Albania	9	0.3	0.0	0.3	0.8
Armenia	6	10.5	0.8	3.9	32.2
Austria	471	3.7	0.0	0.3	60.0
BA Republika Srpska	8	6.9	0.2	1.8	24.0
Bulgaria	108	9.4	0.1	3.1	64.3
Croatia	69	2.8	0.1	0.5	31.0
Cyprus	18	10.7	0.1	3.6	66.1
Czech Republic	382	4.7	0.0	0.9	64.8
Denmark	357	3.9	0.0	0.6	61.7
Estonia	18	4.0	0.1	1.3	25.0
Finland	45	6.4	0.0	2.0	50.3
France	4866	6.9	0.0	0.5	81.2
Germany	4362	5.4	0.0	0.9	72.7
Greece	324	4.9	0.0	0.7	54.9
Hungary	254	5.8	0.0	1.0	42.7
Iceland	7	0.3	0.1	0.3	0.4
Ireland	847	4.7	0.0	0.5	71.8
Israel	389	7.4	0.0	0.7	70.3
Italy	3932	10.7	0.0	1.1	77.6
Kazakhstan	23	12.4	0.5	9.0	43.0
Kosovo	5	4.4	0.6	1.0	16.0
Latvia	19	5.6	0.1	3.0	25.6
Lithuania	27	7.9	0.0	4.0	27.1
Luxembourg	5	9.2	0.3	3.0	24.0
Rep of Moldova	14	5.9	0.3	1.0	23.0
Montenegro	12	4.4	0.2	2.0	20.5
Netherlands	988	6.6	0.0	1.0	68.0
North Macedonia	65	2.7	0.0	0.4	29.2
Norway	252	10.2	0.0	2.2	77.2
Poland	669	6.7	0.0	1.7	55.7
Portugal	226	12.4	0.0	6.8	58.0
Romania	88	7.3	0.0	2.2	43.0
Russian Fed.	1134	7.8	0.0	3.8	59.5
Serbia	39	5.2	0.1	3.8	18.6
Slovak Republic	157	7.0	0.0	1.2	59.0
Slovenia	67	3.8	0.0	0.8	37.4
Spain	1543	9.5	0.0	1.3	73.0
Sweden	503	6.4	0.0	1.0	72.0
Switzerland	535	6.6	0.0	1.0	80.1
Türkiye	534	6.9	0.0	2.0	47.0
Ukraine	130	7.1	0.0	4.0	38.5
United Kingdom	6343	6.8	0.0	0.6	80.2
Total	29856	7.2	0.0	0.9	81.2

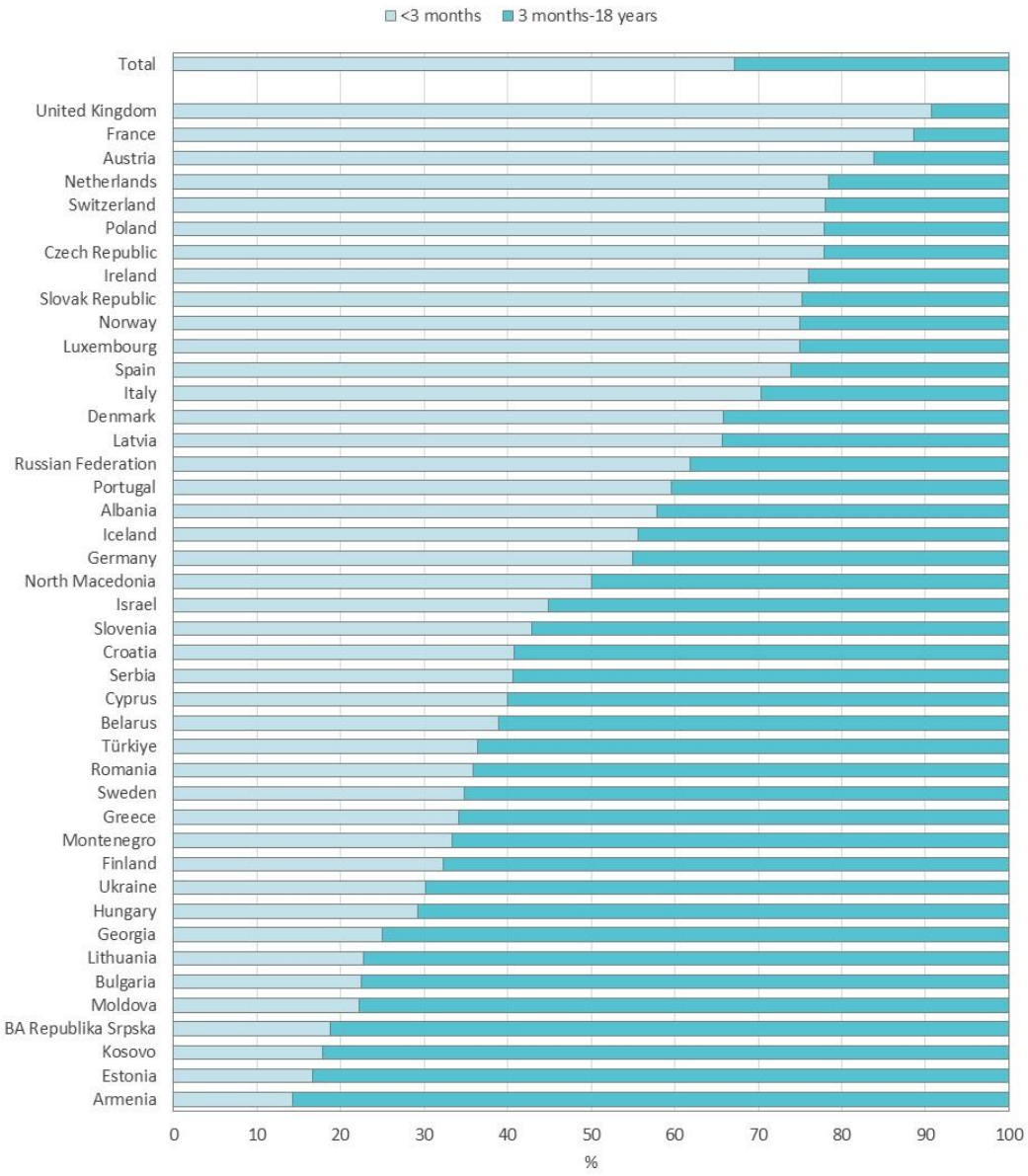
Note: Belarus and Georgia have <5 adults who were seen in 2024 and both countries are excluded from the table, but the people are included in the total number.

Note: For Austria, Cyprus, Greece and Switzerland the information on age at diagnosis is missing for more than 10% of the people with CF.

2. Diagnosis

Figure 2.1 After the implementation of newborn screening programmes, 66% of children are diagnosed with CF before they are 3 months old.

Proportion of children diagnosed with CF at younger than 3 months, between 3 months and 18 years, by country and overall. All children and adolescents with CF seen by a clinician in 2024.

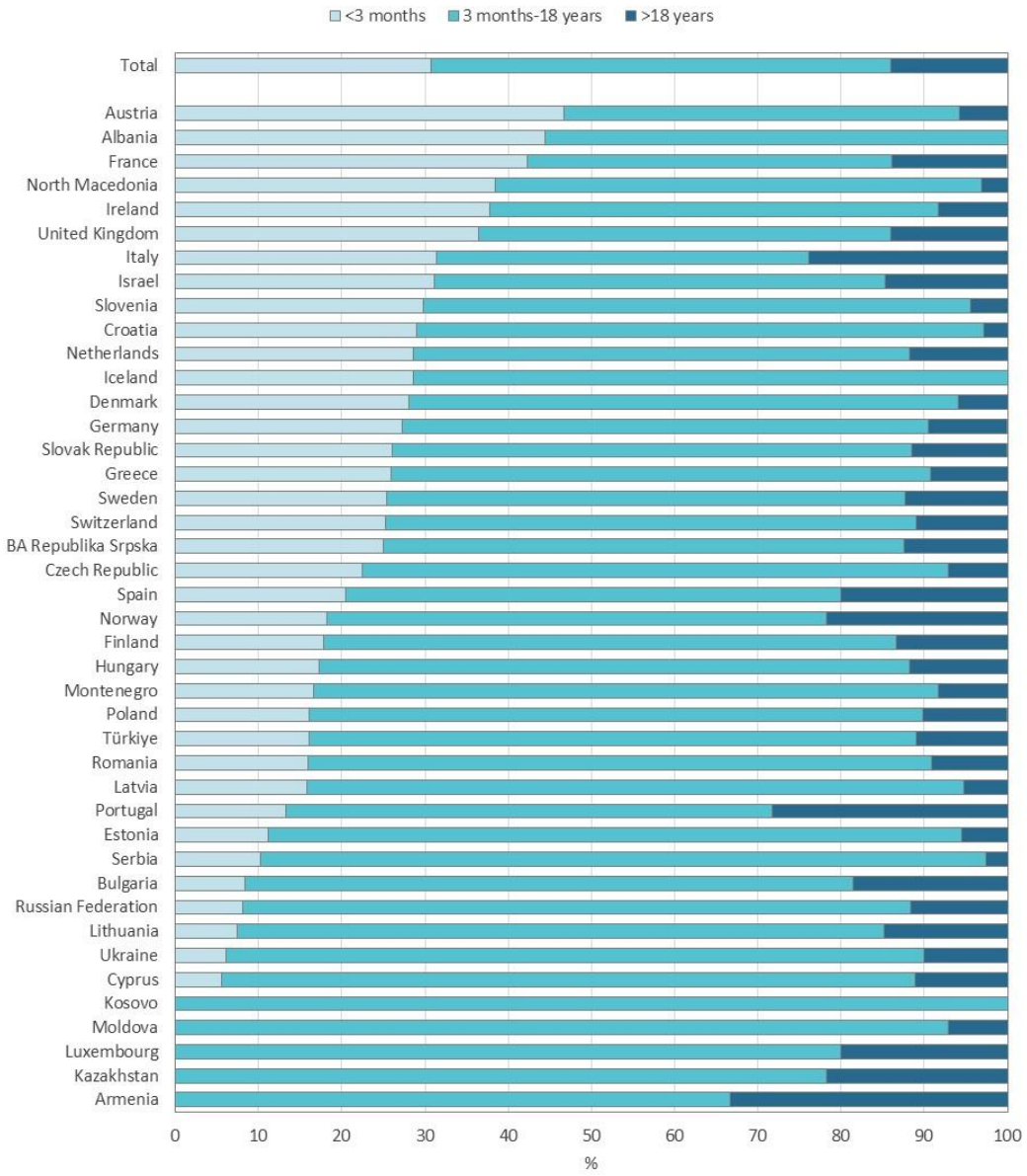


Note: For Cyprus and Greece, the information on age at diagnosis is missing for more than 10% of the people with CF.

2. Diagnosis

Figure 2.2 The age at diagnosis for those who are now adults has shifted to the first 3 months of life in many countries.

Proportion of adults with CF diagnosed at younger than 3 months, between 3 months and 18 years, and older than 18 years, by country and overall. All adults with CF seen by a clinician in 2024.

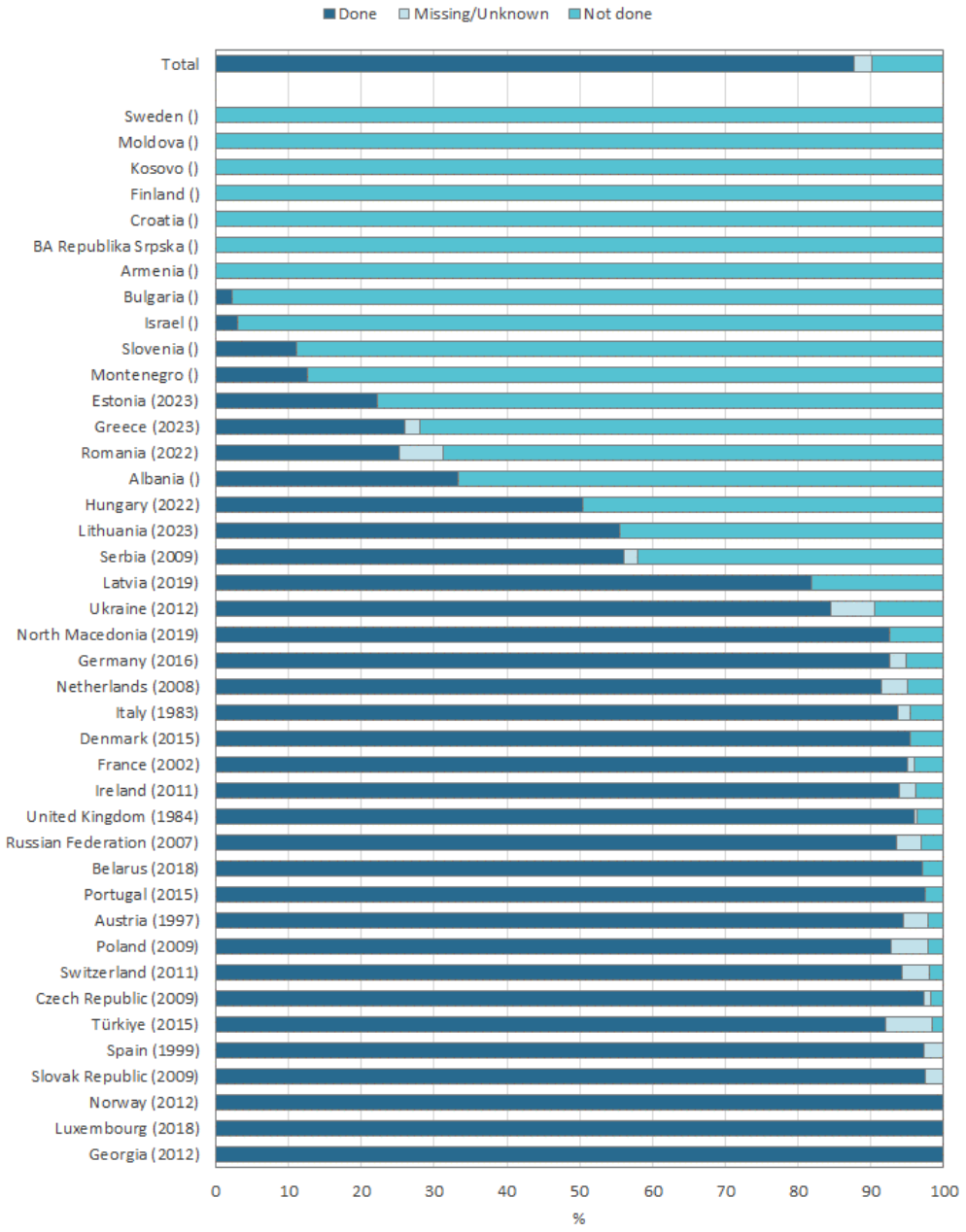


Note: Belarus and Georgia have <5 adults seen in 2024 and both countries are excluded from the table, but the people are included in the total number.
Note: For Austria, Cyprus, Greece and Switzerland the information on age at diagnosis is missing for more than 10% of the people with CF.

2. Diagnosis

Figure 2.3 More than 85% of the young children with CF who were in the ECFSPR in 2024 underwent newborn screening.

Proportion of children with CF who underwent neonatal screening, by country (year of NBS program start) and overall. Children 5 years old or younger and seen by a clinician in 2024.



Note: Cyprus and Iceland have <5 children who were 5 years old or younger and seen by a clinician in 2024 and both countries are excluded from the graph (neither country had implemented a national NBS programme as of 2024).

Note: Where there is no year in brackets after the country name the country did not have an NBS programme as of 2024.

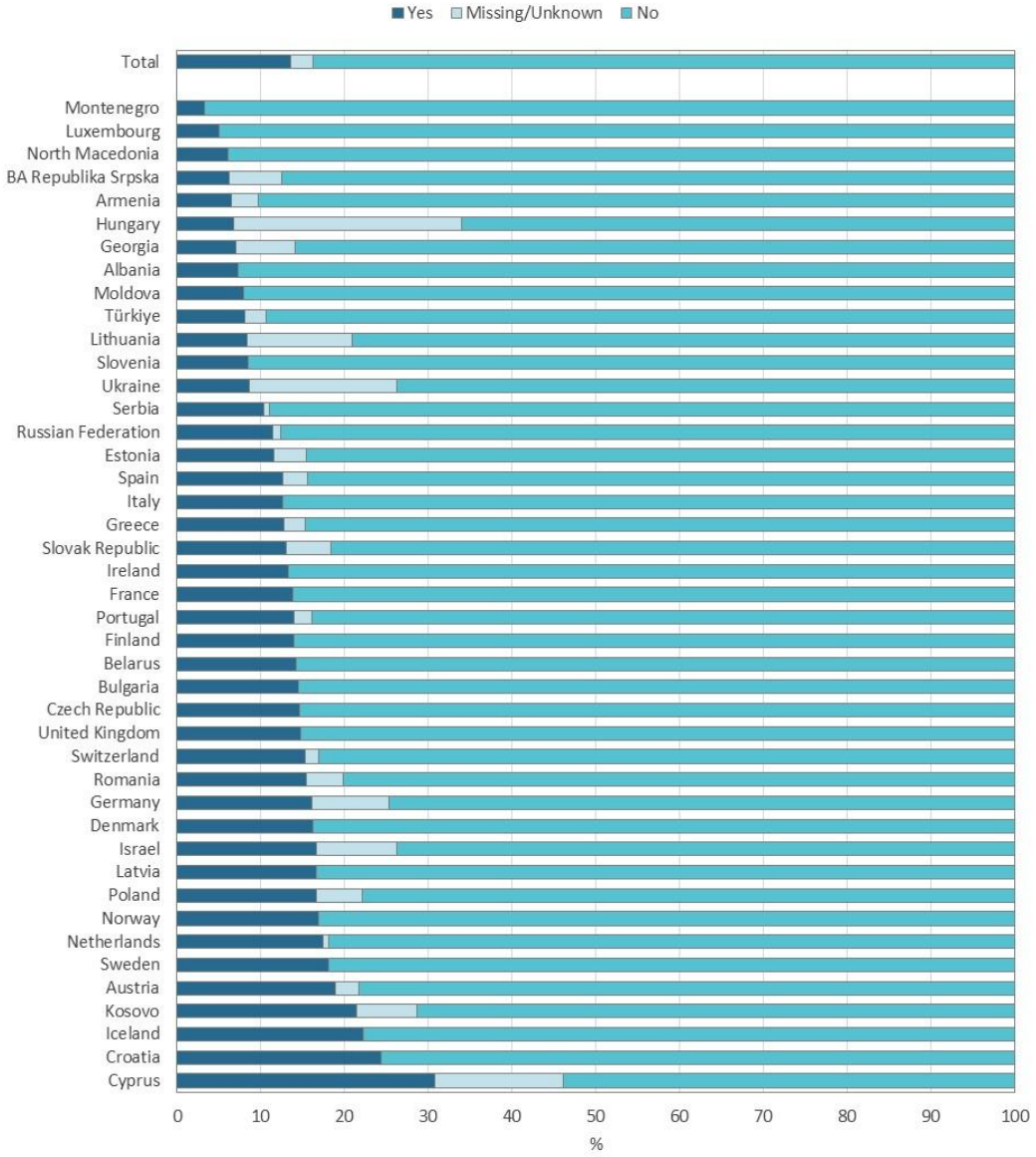
Note: For Italy, Netherlands, Serbia, Spain, Ukraine and the United Kingdom the year in brackets corresponds to the start of the first regional NBS programme.

Note: For France and the United Kingdom positive answers ("neonatal screening done") are reported only when neonatal screening is one of the factors that led to CF diagnosis.

2. Diagnosis

Figure 2.4 Meconium ileus at birth is not rare and may be the first symptom of CF detected in newborns.

Children and adolescents with CF who had meconium ileus at birth, by country and overall. All children and adolescents with CF seen by a clinician in 2024.

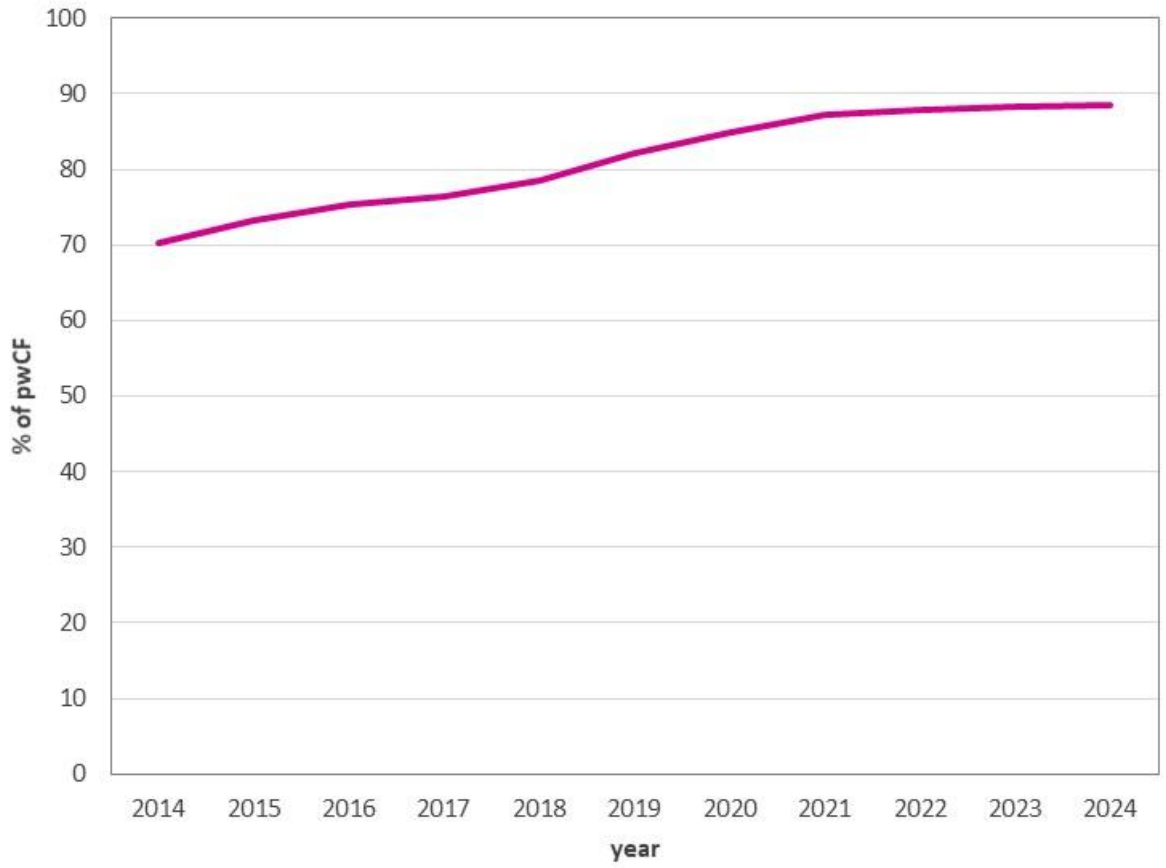


Note: For Cyprus, Hungary, Lithuania and Ukraine, the information on meconium ileus is missing for more than 10% of the children and adolescents.

2. Diagnosis

Figure 2.5 In the last decade the proportion of children diagnosed with CF through newborn screening has increased to almost 90% in Europe.

Neonatal screening in children diagnosed with CF who were 5 years old or younger in the years from 2014 to 2024.



In this graph data over time are presented using cross sectional data per year of children with a confirmed CF diagnosis. Children with CF who are alive and seen by a clinician, deceased, or not seen during the year of follow-up were included; those who were lost to follow-up and/or had transplanted lung/s and/or liver were excluded.

3. Genetics

Cystic fibrosis is caused by pathogenic variants, also called mutations, of the *CFTR* (cystic fibrosis transmembrane conductance regulator) gene. At least one variant on each allele, or copy, of the gene is inherited from both the mother and the father. If the variants on both alleles are the same, the person is said to be homozygous for this variant; if the variants on the two alleles are different the person is considered to be heterozygous.
We provided the countries with a list of the 1600 most common variants based on the Cystic Fibrosis Mutation Database (CFTR1). If an individual with CF has a variant that is not in this database, the CF centre or national registry can submit it as free text. During the data quality controls carried out on submitted data by the ECFSPR statistical team, any variant not on our list was checked for obvious misspellings or alternative names and, if identified as a known variant, renamed. There are different naming conventions for variants; in this report we use the original variant name (legacy name), if it exists; more than 90% of the variants in the CFTR1 database have this nomenclature.
If DNA analysis of the *CFTR* gene has not been carried out, we asked the countries to report "Not done". If DNA analysis has been done, but only one or no variants were found, we asked the countries to report this as "Unknown" for the unidentified variants.
How DNA testing is carried out differs from country to country; some use standard kits to test only a limited number of the most common variants (e.g. 28), while other countries perform DNA-analyses of the whole gene until the variant is detected.

Please note that, although not presented in this report, information on complex alleles is also captured and available.

3. Genetics

Table 3.1 Genotyping has been done for more than 99% of people with CF in the ECFSPR; for 97% of those tested, at least two variants have been identified. More than 98% of CFTR variants have been identified.

Proportion of people with CF with two variants identified among those with DNA analysis, by country and overall. People with CF seen in 2024.

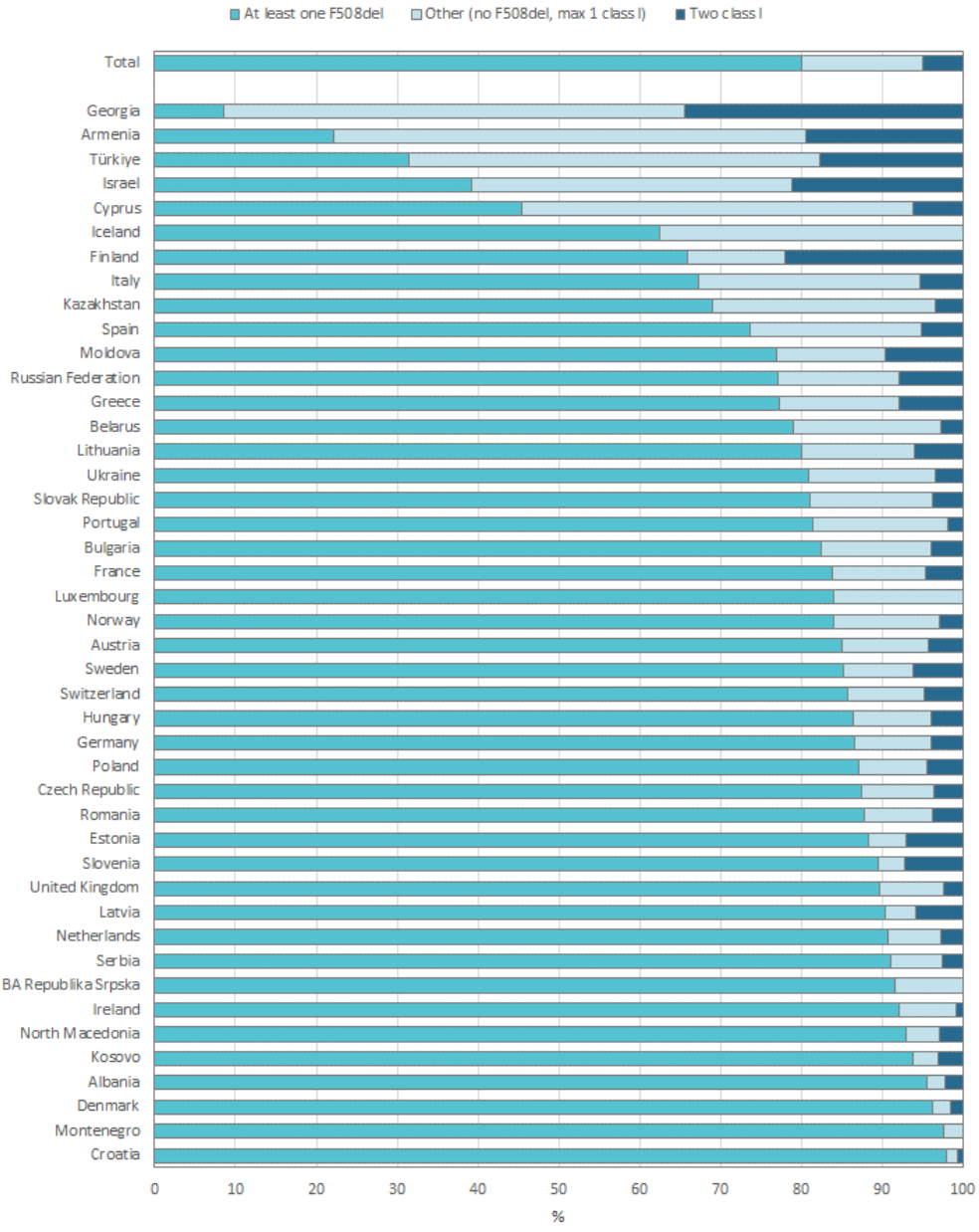
Country	Among genotyping done			
	At least one variant unknown		Two variants identified	
	Number	%	Number	%
Albania	0	0.0	46	100
Armenia	3	8.3	33	91.7
Austria	40	4.5	843	95.5
Belarus	48	32.4	100	67.6
BA Republika Srpska	0	0.0	24	100
Bulgaria	13	5.1	244	94.9
Croatia	2	1.4	144	98.6
Cyprus	3	9.1	30	90.9
Czech Republic	8	1.1	731	98.9
Denmark	1	0.2	564	99.8
Estonia	0	0.0	43	100
Finland	0	0.0	91	100
France	97	1.3	7418	98.7
Georgia	2	3.5	56	96.6
Germany	116	1.6	7249	98.4
Greece	19	3.1	586	96.9
Hungary	46	8.4	501	91.6
Iceland	0	0.0	16	100
Ireland	18	1.3	1359	98.7
Israel	39	7.1	510	92.9
Italy	140	2.3	6038	97.7
Kazakhstan	2	6.9	27	93.1
Kosovo	2	6.1	31	93.9
Latvia	0	0.0	52	100
Lithuania	2	4.0	48	96.0
Luxembourg	0	0.0	25	100
Rep of Moldova	10	19.2	42	80.8
Montenegro	0	0.0	42	100
Netherlands	15	1.0	1569	99.1
North Macedonia	0	0.0	143	100
Norway	3	0.8	386	99.2
Poland	28	1.7	1613	98.3
Portugal	6	1.5	392	98.5
Romania	36	9.0	365	91.0
Russian Federation	170	5.0	3214	95.0
Serbia	18	9.4	174	90.6
Slovak Republic	25	8.6	265	91.4
Slovenia	3	2.4	121	97.6
Spain	103	3.9	2516	96.1
Sweden	1	0.1	794	99.9
Switzerland	34	3.3	1001	96.7
Türkiye	234	8.6	2482	91.4
Ukraine	76	16.1	395	83.9
United Kingdom	259	2.5	10142	97.5
Total	1624	3.0	52467	97.0

This table shows the percentage of people with CF with two known variants for those who had DNA analysis done, by country and overall. The number of variants not identified on one of the 2 alleles varies greatly from country to country; this is partly due to different approaches to DNA testing. Overall, 1.9% of variants remain unidentified after DNA analysis, leaving 3.0% of the people with CF with at least one unidentified variant.

3. Genetics

Figure 3.1 The prevalence of the F508del variant and two class I variants vary considerably between the countries in Europe.

Prevalence of the F508del variant and two class I variants in people with CF, by country and overall. All people with CF seen in 2024.



F508del is the name of the most commonly occurring CFTR variant in the world. People with CF who carry two F508del variants, one on each allele, are often described as having "classic CF", but other variant combinations can cause similar degree of disease. "Unknown" variants have been classified as "other" because F508del is included in all genotyping kits and would have been identified. Please note that the genotype grouping in this graph does not reflect the severity of the disease in the countries. CFTR variants are classified into groups based on their effect on the CFTR protein. Class I variants are traditionally considered to result in no functional CFTR protein production. In 2025, the European Medicines Agency authorised elexacaftor/tezacaftor/ivacaftor and vanzacaftor/tezacaftor/deutivacaftor for PwCF carrying at least one non–Class I CFTR variant. Pierre-Régis Burgel et al. published an overview of Class I variants, distinguishing non-responsive ("true") and responsive ("exceptional") Class I variants (EClinicalMedicine 2025;103476), and subsequently identified two non-responsive Class II variants (non-responsive to elexacaftor/tezacaftor/ivacaftor) (European Respiratory Journal 2026;67:2501783).

3. Genetics

Table 3.2 Allelic frequencies of most common (≥0.50%) variants in the 2024 ECFSPR data.

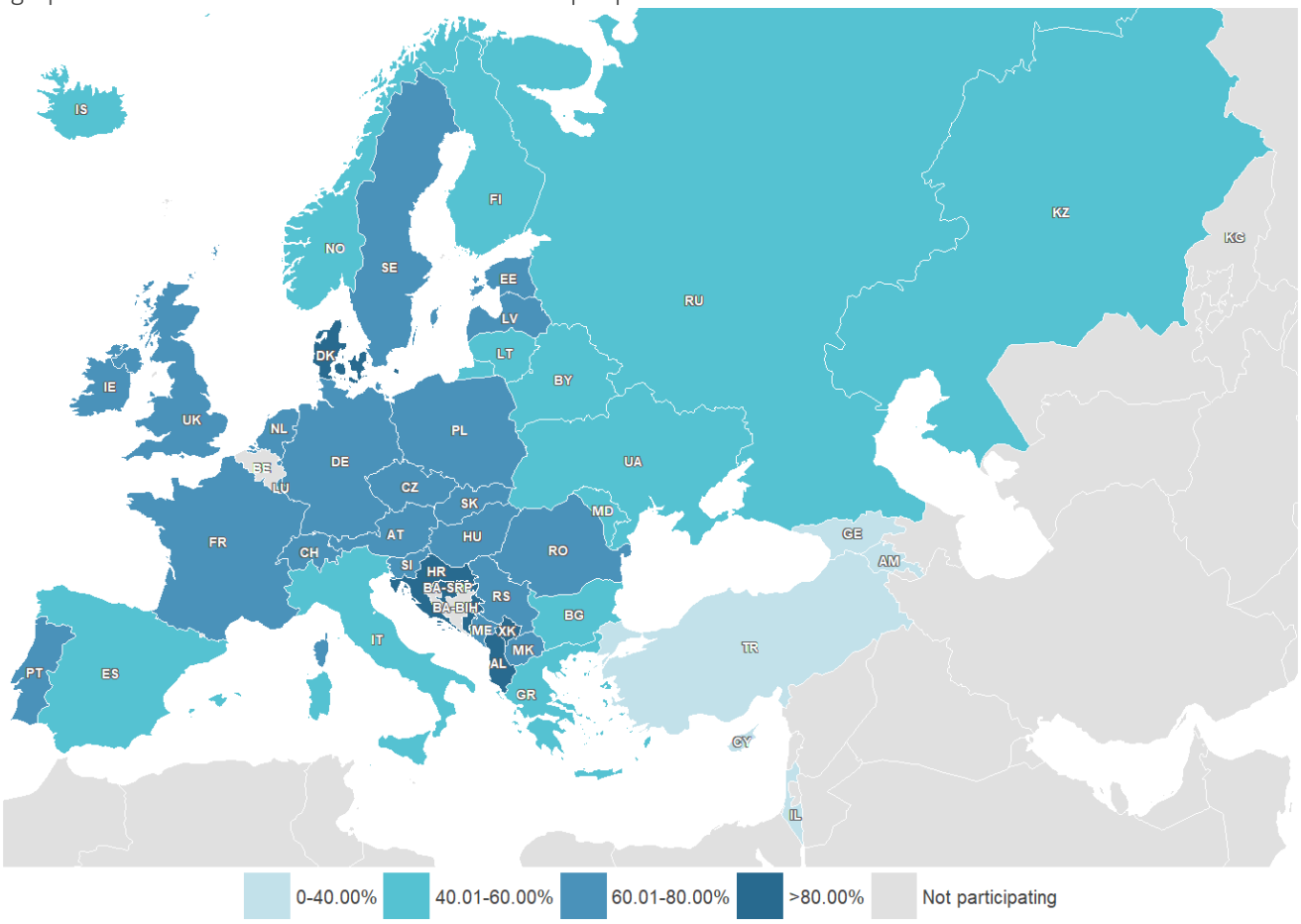
Variant name	Number of alleles with the variant	Allelic frequency	Country with highest allelic frequency for the variant
F508del	64332	59.47	BA Republika Srpska (85.4%)
G542X	2960	2.74	Montenegro (14.3%)
N1303K	2341	2.16	Iceland (40.6%)
G551D	1293	1.20	Ireland (8.3%)
2789+5G->A	1220	1.13	Armenia (4.2%)
3849+10kbC->T	1206	1.11	Lithuania (7.0%)
CFTRdele2,3	1202	1.11	Belarus (9.1%)
W1282X	1179	1.09	Israel (22.4%)
R117H	934	0.86	Ireland (3.1%)
1717-1G->A	871	0.81	Switzerland (2.4%)
R553X	846	0.78	Lithuania (6.0%)
D1152H	830	0.77	Israel (5.8%)
2183AA->G	745	0.69	Armenia (12.5%)
621+1G->T	739	0.68	Kosovo (9.1%)
1677delTA	680	0.63	Georgia (44.8%)
R347P	678	0.63	Luxembourg (6.0%)
G85E	612	0.57	Israel (2.5%)
E92K	562	0.52	Georgia (6.0%)
3272-26A->G	548	0.51	Portugal (2.0%)
2184insA	542	0.50	Belarus (7.8%)

This table presents the most common variants found in the ECFSPR 2024 data. The last column indicates in which country this particular variant is most frequent. F508del is, by far, the most common variant. The following maps (figure 3.2-3.6) show the distribution of the allelic frequency of the first five most prevalent, or most commonly occurring, variants.

3. Genetics

Figure 3.2 The allelic frequency of F508del variant is higher in Central Europe

Geographical distribution of the F508del variant. All people with CF seen in 2024.



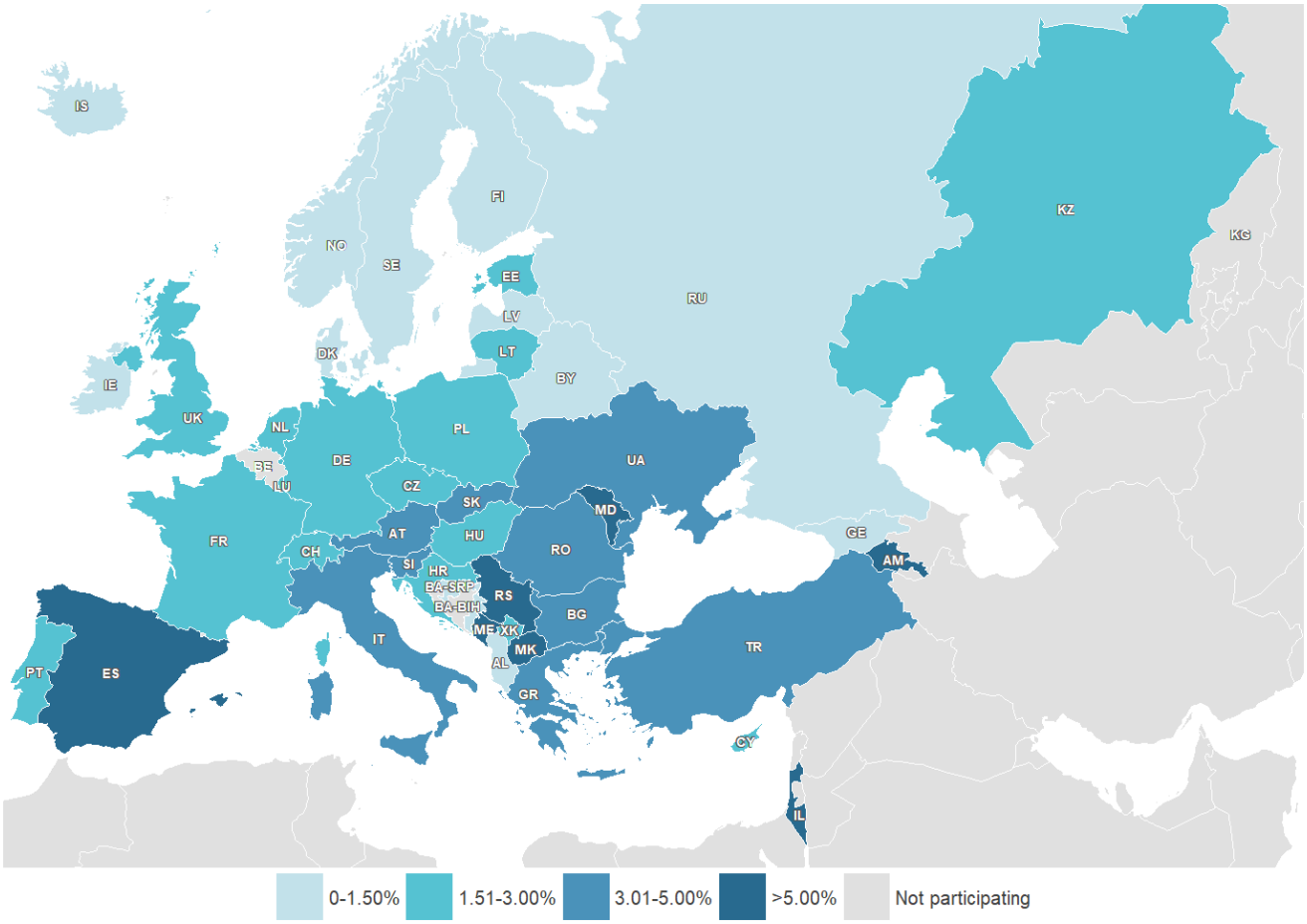
Note: Bosnia-Herzegovina and Kyrgyzstan are not "Not participating", but their data are omitted because <5 PwCF were reported.

F508del is the most common variant in all countries; the highest allele frequency in the 2024 ECFSPR data occurs in BA-Republika Srpska (85.4%), followed by Denmark (85.6%) and Kosovo (81.8%).

3. Genetics

Figure 3.3 The G542X variant is more prevalent in Southern Europe.

Geographical distribution of the G542X variant. All people with CF seen in 2024.



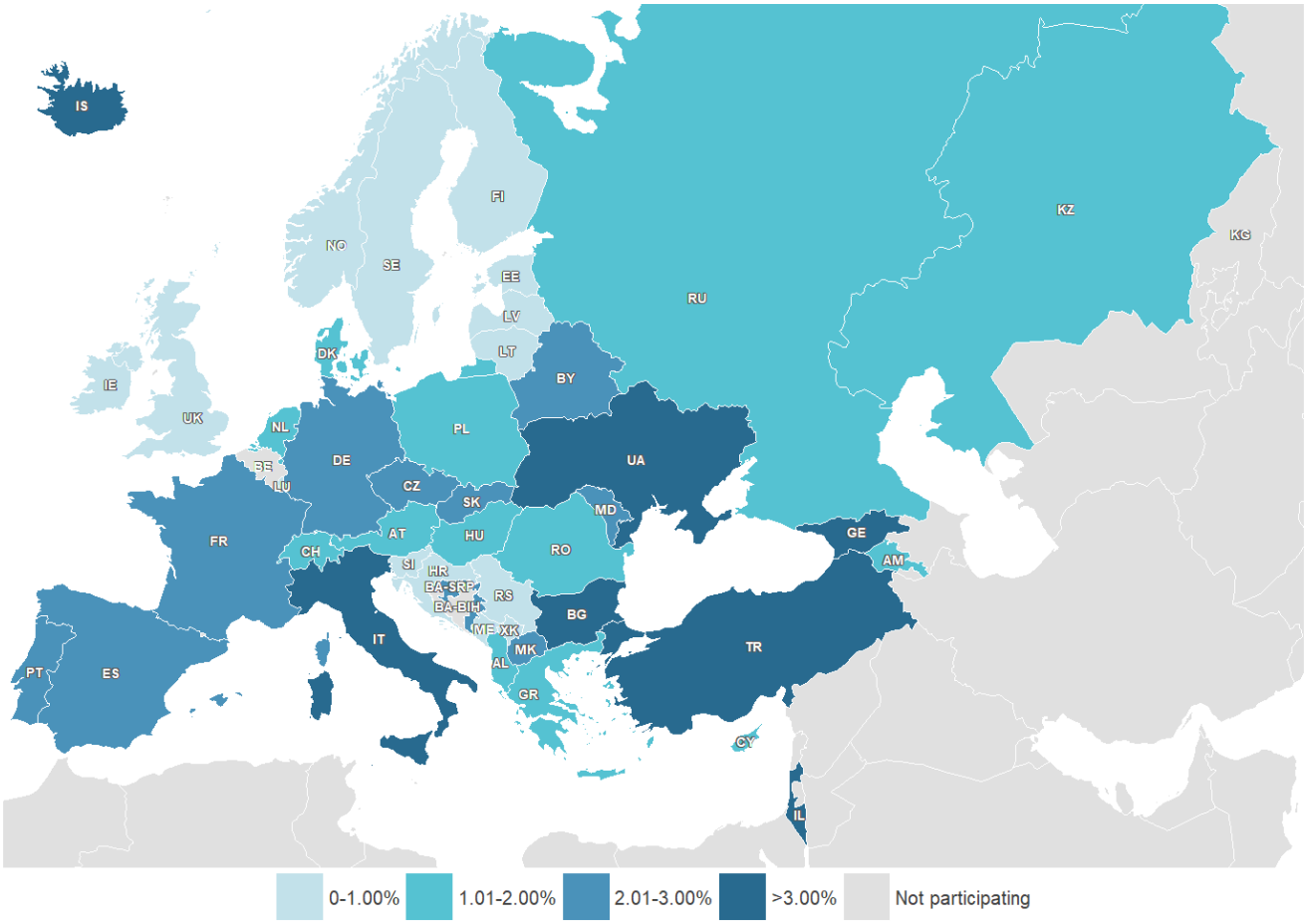
Note: Bosnia-Herzegovina and Kyrgyzstan are not "Not participating", but their data are omitted because <5 PwCF were reported.

The *G542X* variant is more common in Southern Europe, with the highest allele frequency being in Montenegro (14.3%), whereas it is very rarely found in Ireland, the Scandinavian countries or the Russian Federation.

3. Genetics

Figure 3.4 The N1303K variant is more prevalent in Southern and Eastern Europe

Geographical distribution of the N1303K variant. All people with CF seen in 2024.



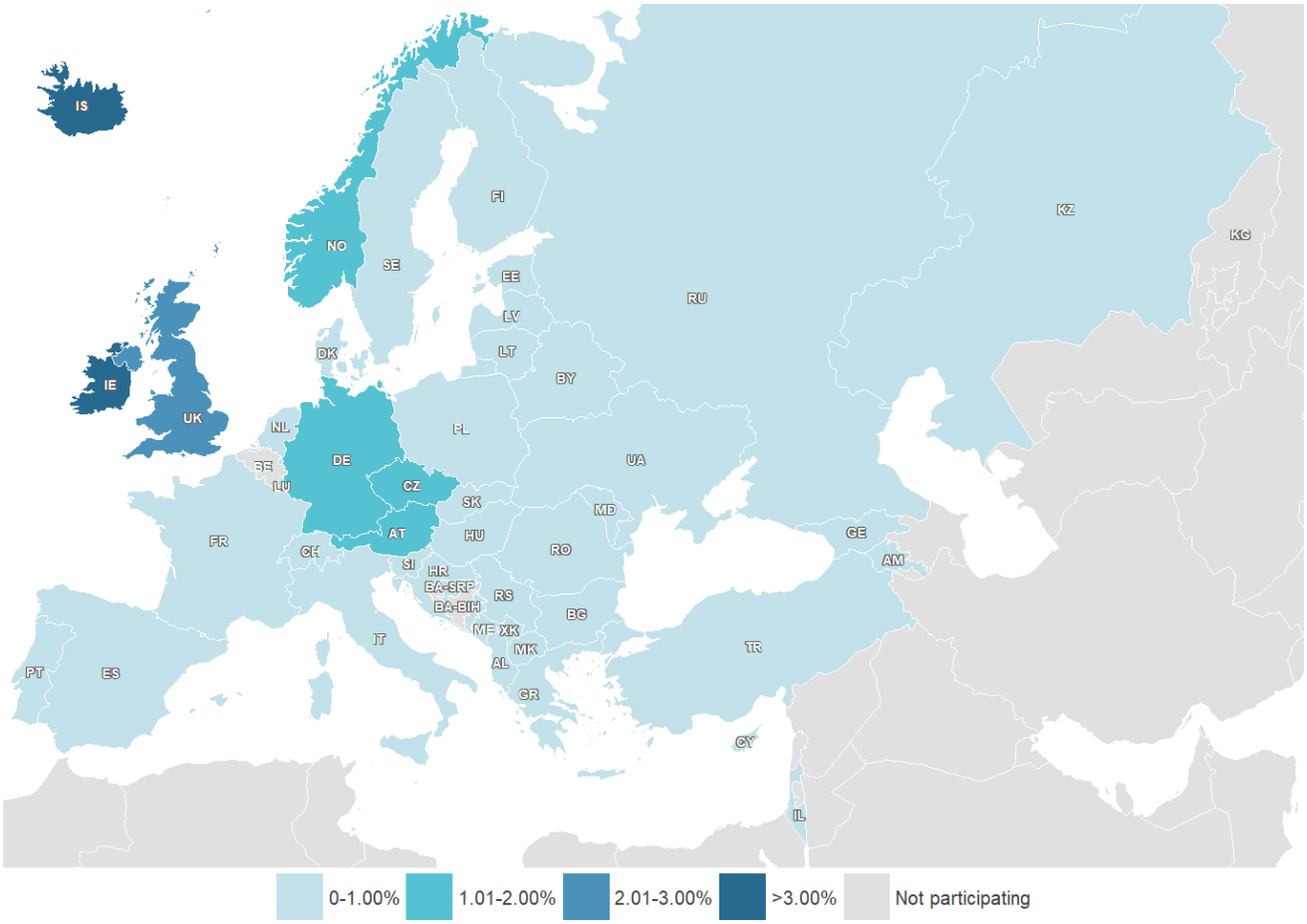
Note: Bosnia-Herzegovina and Kyrgyzstan are not "Not participating", but their data are omitted because <5 PwCF were reported.

The *N1303K* variant is most frequent in Iceland (40.6%). This is an exception in Northern Europe where it is otherwise rare; it is much more frequent in the countries of Southern and Eastern Europe.

3. Genetics

Figure 3.5 The G551D variant is more frequent in the northern and central regions of Europe.

Geographical distribution of the G551D variant. All people with CF seen in 2024.



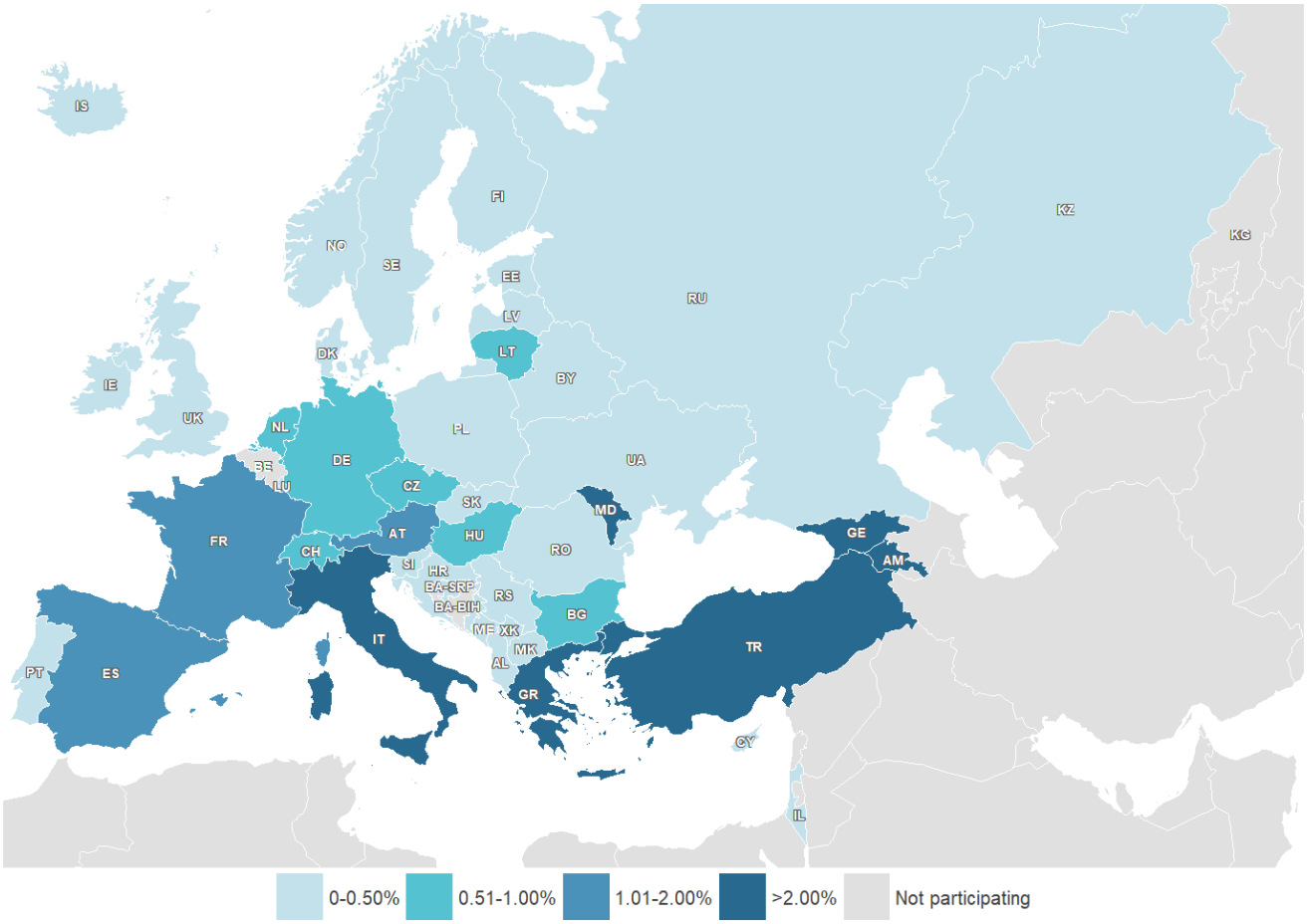
Note: Bosnia-Herzegovina and Kyrgyzstan are not "Not participating", but their data are omitted because <5 PwCF were reported.

The *G551D* variant is most frequent in Ireland (8.3%) and in northern and central regions of Europe but rare in the rest of Europe.

3. Genetics

Figure 3.6 The 2789+5G->A variant is more common in Türkiye and the southern regions of Europe.

Geographical distribution of the 2789+5G->A variant. All people with CF seen in 2024.



Note: Bosnia-Herzegovina and Kyrgyzstan are not "Not participating", but their data are omitted because <5 PwCF were reported.

The *2789+5G->A* variant is most frequent in Armenia (4.2%) and in Southern Europe, and less common in Eastern Europe.

4. Lung function

Lung function, or lung capacity, is measured through spirometry, a test which determines how much air can be forced out of the lungs in the first second of a single breath. The measurement used is called FEV_1 (Forced Expiratory $Volume_1$) and it is measured in litres, but the lung capacity is normally expressed as a percentage of the expected (or predicted) value - FEV_1% of predicted or FEV1pp. The predicted value is determined from healthy individuals of the same age, sex, ethnicity and height; this is called the reference population. A FEV_1% of predicted value of 100 means that the lung function measurement is equal to the mean lung function measurement of a person of the same age, sex, ethnicity and height of the healthy reference population. Spirometry testing requires a certain amount of coordination and usually cannot be performed reliably and consistently until a child is about five to six years of age; for this reason, we report only calculated FEV_1% of predicted values for people with CF who are aged 6 or older.
We asked the countries to report the FEV_1, measured in litres, from the best FEV_1% of predicted (computed at the centres during spirometry testing) recorded throughout the year.
We excluded people from the analyses of FEV_1 who have had one or more lung transplants since their lung function does not reflect the severity of their CF lung disease. Moreover, we also excluded people with CF who have had other transplants since follow-up data for them is sometimes missing.

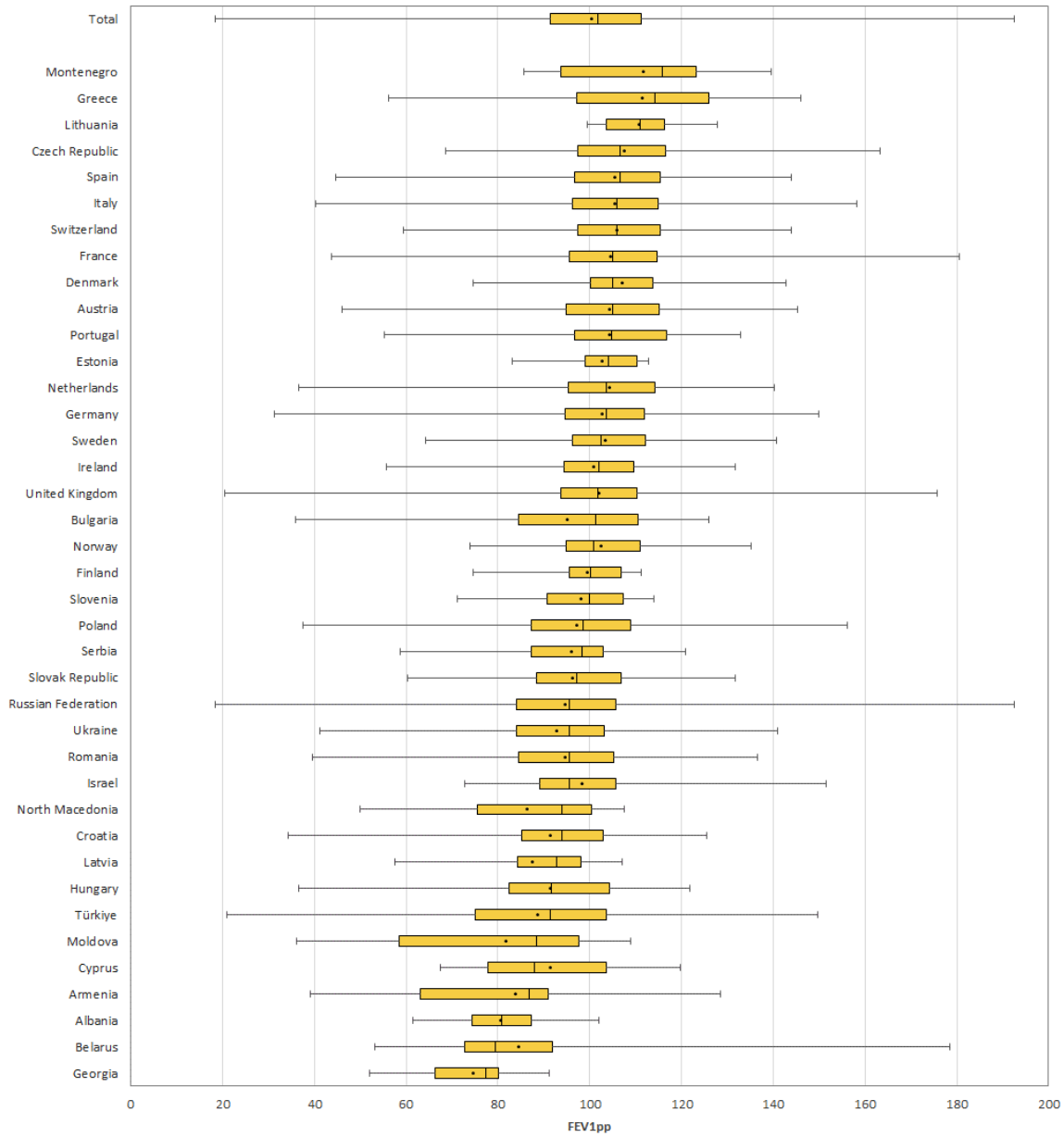
In 2012, the Global Lung Initiative (GLI)* introduced multi-ethnic, or "race-specific," reference equations derived from a large international dataset comprised of individuals aged 3 to 95 years. These equations were endorsed by both the European Respiratory Society (ERS) and the American Thoracic Society and became standard within the CF community for clinical care, clinical trials, and patient registries. To calculate the FEV_1% of predicted for this report we used the 2012 GLI equations and the ethnicity categories described by Quanjer PH et al. (for the full reference refer to our website).
Over time, however, it became increasingly necessary to understand if using race-specific equations contributed to health inequities. The GLI published a new set of race-neutral reference equations in 2022 which no longer incorporate race into the calculation of FEV1pp (Bowerman C et al., Am J Respir Crit Care Med 2023;207(6):768–74. https://doi.org/10.1164/rccm.202205-0963OC).
Appendix 1 reports FEV_1% predicted according to both sets of reference equations; we have compared FEV1pp values in PwCF calculated using both the GLI 2012 race-specific equations and the GLI 2022 race-neutral equations.
We analysed information from PwCF aged 6 years and older with a recorded FEV1 measurement in 2024 and no history of transplant. Our dataset was made up of 16,116 children and adolescents (<18 years) and 26,095 adults.
Of those under 18, 95.6% were white, 0.7% were black and 3.7% were of mixed/other ethnicity. For white PwCF under 18, the median difference in the FEV1pp value calculated using the two sets of equations (GLI 2022 and the GLI 2012) was 4.2 (IQR: 2.5—6.2) percentage points; for black children and adolescents the difference was -10.8 (IQR: -13.8— -7.7) percentage points and for those of mixed/other ethnicity, it was -2.3 (IQR: -4.3— -0.1) percentage points.
In the adult group 97.5% were white, 0.3% were black and 2.2% were of mixed/other ethnicity. For white adults with CF the median difference in the FEV1pp value calculated using the two sets of equations was 5.0 (IQR: 3.5—6.4) percentage points; for black adults it was -5.8 (IQR: -8.2— -4.4) percentage points and for those of mixed/other ethnicity it was -0.2 (IQR: -0.9 — 0.4).
Overall, the percentage of white children with CF who had a FEV1pp value >80 increased by 3 percentage points when the 2022 GLI equations were used. In contrast, the percentage decreased by 10 percentage points for black children with CF. Overall, the percentage of white adults with CF who had a FEV1pp value >80 increased by 6 percentage points when the 2022 GLI equations were used. In contrast, the percentage decreased by 7 percentage points for black adults with CF.

* The Global Lung Initiative (GLI) is an international collaborative project led by the European Respiratory Society (ERS). Its main aim is to standardise lung function reference values worldwide so that pulmonary function tests are interpreted consistently across ages, sexes, ethnic groups and countries.

4. Lung function

Figure 4.1 The median FEV_1% of predicted is >90% for children with CF (between 6 and 11 years of age) in almost all countries in Europe.

FEV1pp: boxplot by country. Children with CF aged 6-11 years who have never had a transplant, seen by a clinician in 2024 (table A4.1, Appendix 1).



Note: BA-Republika Srpska, Iceland, Kazakhstan, Kosovo and Luxembourg have <5 individuals aged 6-11 years at the date of FEV_1 measurement and the countries are excluded from the graph.

Note: For Albania, Belarus, Cyprus, Georgia, Latvia, Moldova, North Macedonia, Romania, Serbia, the Russian Federation, Türkiye and Ukraine no FEV1 value was reported for more than 10% of the people with CF in the 6-11 year old age group.

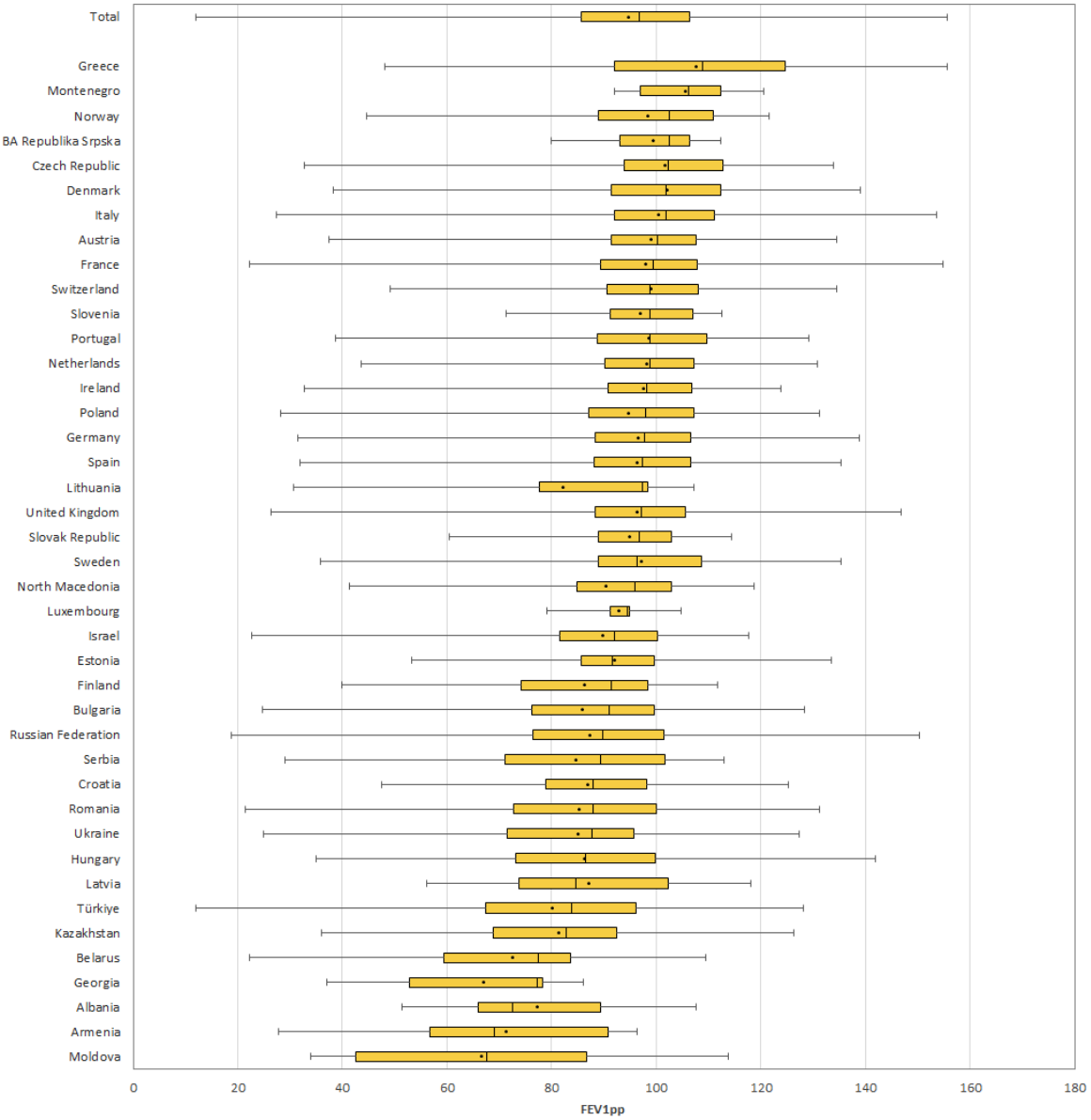
Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review; this means the value could be from 2023 or 2024.
The UK reported the FEV1 of the best FEV1pp from the period between annual reviews. This also means that the value could be from 2023 or 2024.

This boxplot is a graphic representation of the FEV1pp in children with CF detailed in table A4.1 (Appendix 1). For each country, the vertical borders of the box are the first and third quartiles, the dash (vertical black line crossing the yellow box) is the median, the black dot is the mean, and the whiskers (vertical lines with a T-shaped end) are the minimum and the maximum.

4. Lung function

Figure 4.2 The median FEV_1% of predicted is >80% for adolescents with CF (between 12 and 17 years of age) in almost all countries in Europe.

FEV1pp: boxplot by country. Adolescents with CF aged 12-17 years who have never had a transplant, seen by a clinician in 2024 (table A4.2, Appendix 1).



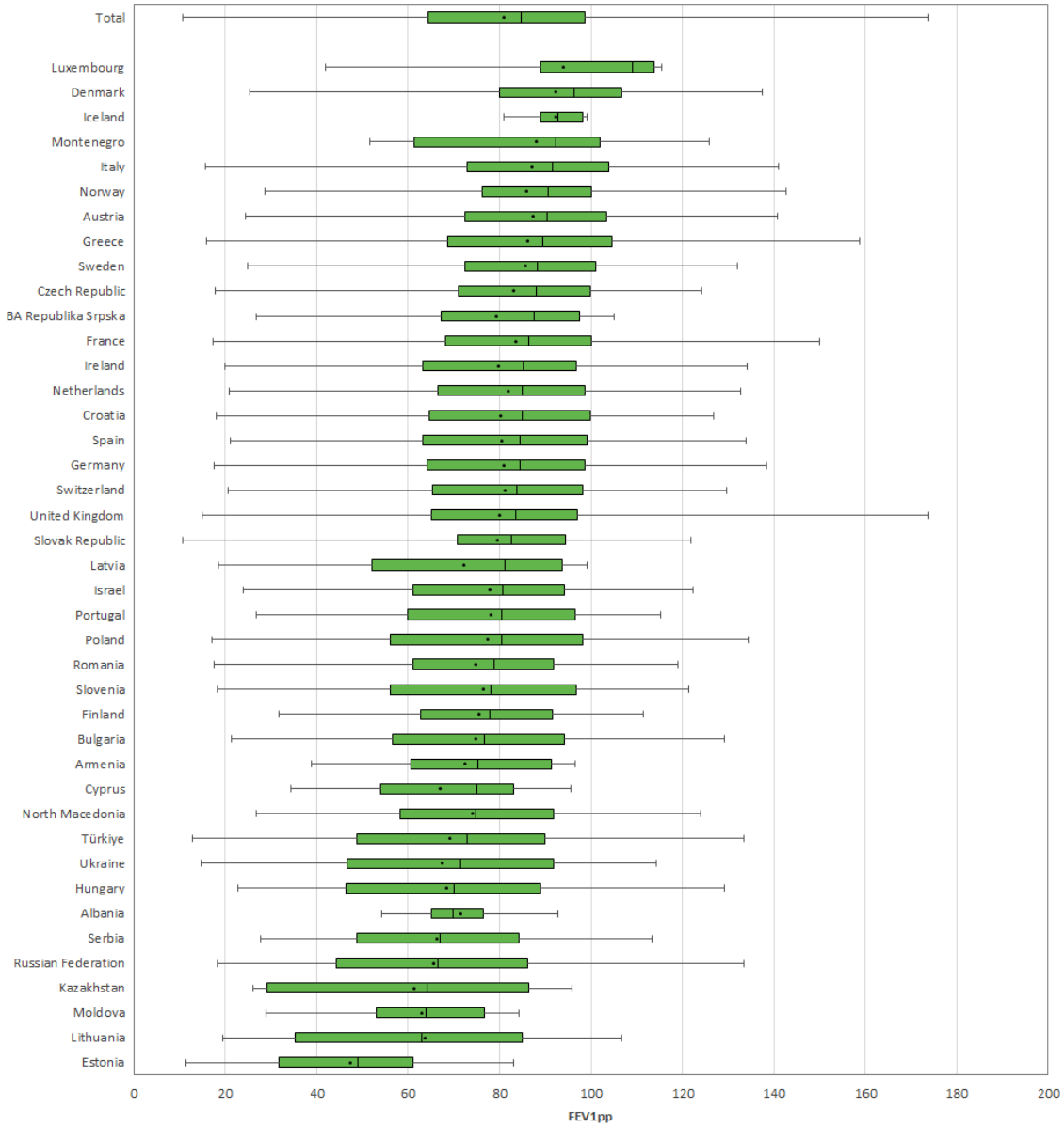
Note: Cyprus, Iceland and Kosovo have <5 individuals aged 12-17 years at the date of FEV_1 measurement and the countries are excluded from the graph.
Note: For Belarus, Georgia, Lithuania, the Russian Federation, Türkiye and Ukraine no FEV1 value was reported for more than 10% of the 12-17 year olds.
Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024.
The UK reported the FEV1 of the best FEV1pp from the period between annual reviews which also means that the value could be from2023 or 2024.

This boxplot is a graphic representation of the FEV1pp in adolescents with CF, detailed in table A4.2 (Appendix 1). For each country, the vertical borders of the box are the first and third quartiles, the dash (vertical black line crossing the yellow box) is the median, the black dot is the mean, and the whiskers (vertical lines with a T-shaped end) are the minimum and the maximum.

4. Lung function

Figure 4.3 The median FEV_1% of predicted for adults with CF (between 18 and 39 years of age) varies between 50% and 110% depending on the country.

FEV1pp: boxplot by country. Adults with CF aged 18-39 years who have never had a transplant, seen by a clinician in 2024 (table A4.3, Appendix 1).



Note: Belarus, Georgia and Kosovo have <5 individuals aged 18-39 years with FEV_1 measurement and the countries are excluded from the graph.

Note: For Moldova, the Russian Federation and Ukraine no FEV1 value was reported for more than 10% of the people with CF aged between 18 and 39.

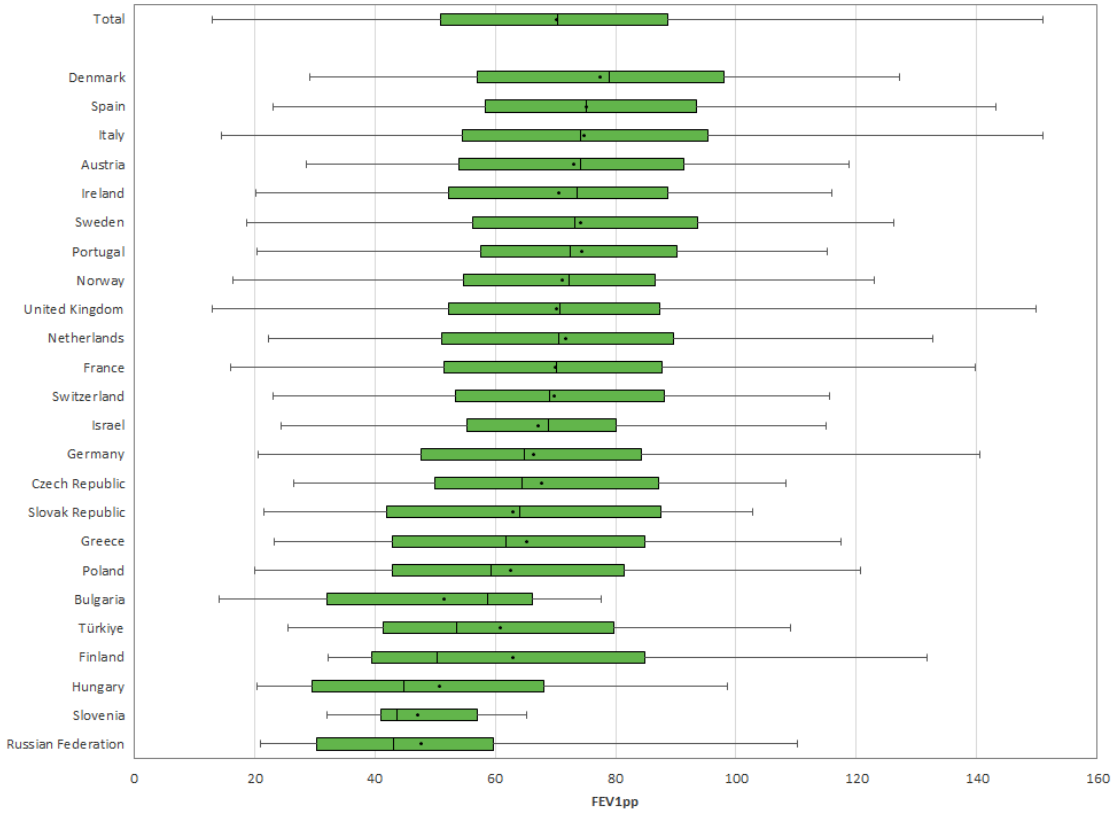
Note: Sweden reported the FEV of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews; this also means that the value could be from 2023 or 2024.

This boxplot is a graphic representation of the FEV1pp in adults detailed in table A4.3 (Appendix 1). For each country the vertical borders of the box are the first and third quartiles, the dash (vertical black line crossing the green box) is the median, the black dot is the mean, and the whiskers (vertical lines with a T-shaped end) are the minimum and the maximum.

4. Lung function

Figure 4.4 The median FEV_1% of predicted for adults with CF who are more than 40 years old varies between 43% and 80%, depending on the country.

FEV1pp: boxplot by country. Adults with CF aged 40+ years who have never had a transplant, seen in 2024 (table A4.4, Appendix 1).



Note: Albania, Armenia, Belarus, BA-Republika Srpska, Croatia, Cyprus, Estonia, Georgia, Kazakhstan, Kosovo, Iceland, Latvia, Lithuania, Luxembourg, Montenegro, North Macedonia, Republic of Moldova, Romania, Serbia, and Ukraine all have <5 individuals over 40 with a FEV1 value recorded in 2024 and all these countries were excluded from the graph.

Note: For Hungary, Italy, the Russian Federation and Slovenia no FEV1 value was reported for more than 10% of the over 40s with CF.

Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews; this also means that the value could be from 2023 or 2024.

This boxplot is a graphic representation of the FEV1pp in adults detailed in table A4.4 (Appendix 1). For each country the vertical borders of the box are the first and third quartiles, the dash (vertical black line crossing the green box) is the median, the black dot is the mean, and the whiskers (vertical lines with a T-shaped end) are the minimum and the maximum.

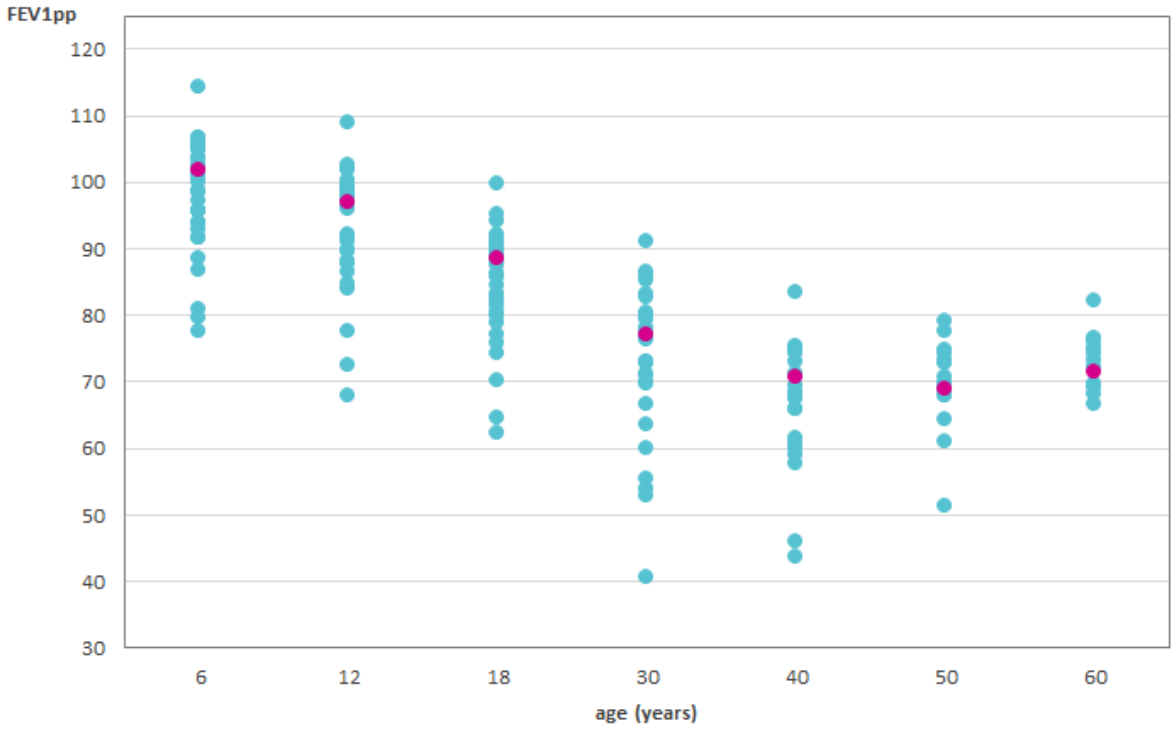
4. Lung function

Table 4.1 FEV_1% of predicted: descriptive statistics by age group (people with CF aged 6 years or older) who have never had a transplant.

Age at FEV1 measurement	Number	Number of missing (%)	Mean (average FEV_1% of predicted value)	Min (lowest FEV_1% of predicted value)	25th pctl (25% of the PwCF have a FEV_1% of predicted lower than the value)	Median (half the PwCF have a FEV_1% or predicted lower than the value)	75th pctl (75% of the PwCF have a FEV_1% of predicted lower than the value)	Max (highest FEV_1% of predicted value)
6-11	7825	788 (9.1)	100.5	18.4	91.5	101.7	111.2	192.5
12-17	8099	427 (5.0)	94.7	12.0	85.6	96.8	106.4	155.7
18-29	12195	472 (3.7)	84.5	10.7	70.5	88.5	101.0	174.0
30-39	7154	288 (3.9)	74.9	11.4	56.5	76.9	93.1	143.9
40-49	3851	201 (5.0)	70.3	13.0	51.3	70.6	88.9	151.1
50-59	1848	99 (5.1)	69.5	18.6	50.3	68.8	87.8	149.9
60+	884	49 (5.2)	71.4	20.3	52.3	71.5	89.3	137.7

This table shows FEV_1% of predicted by age group for the total 2024 ECFSPR dataset. The median values reported in this table are shown as pink dots in Figure 4.5 below.

Figure 4.5 Lung function declines between the third and fifth decade of life but stabilises in older people with CF.
Median FEV_1% of predicted by age group and by country.



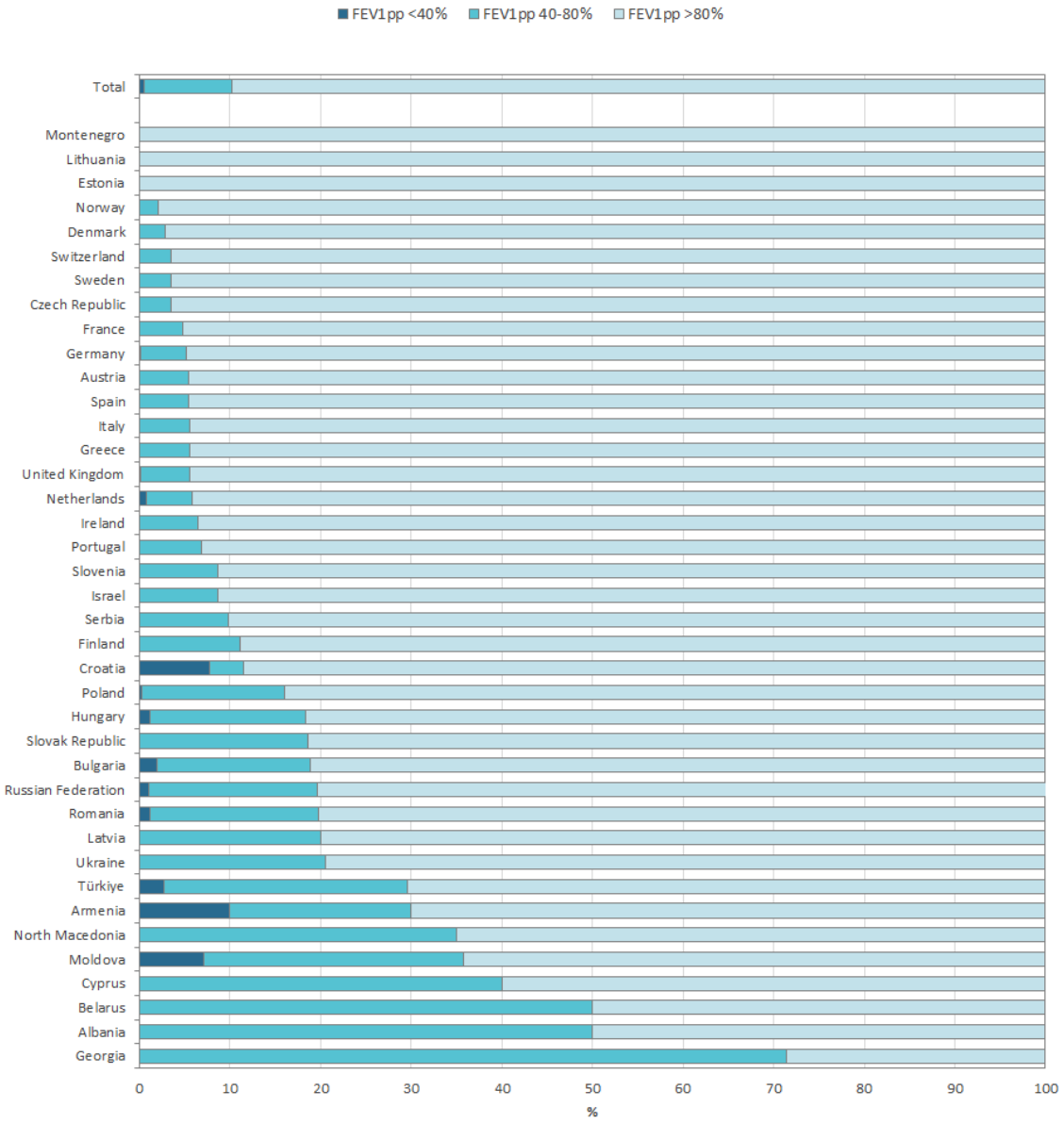
Note: We excluded from the graph those age groups where the number of individuals was <10.

This graph shows the median (the value that separates the higher half from the lower half) FEV1% of predicted by age group. Each country median is represented by a dot (in turquoise), and the overall median is in pink. The general pattern shows that the FEV1% of predicted slowly decreases until the ages of 40-49 and then levels out. The people in the older age groups may have a less severe form of the disease and therefore live longer. There is considerable variation amongst the countries.

4. Lung function

Figure 4.6 The majority of all children with CF in the ECFSPR have a FEV_1 % of predicted >80%.

FEV1pp severity group, by country and overall. Children with CF aged 6-11 years who have never had a transplant.



Note: BA-Republika Srpska, Iceland, Kazakhstan, Kosovo and Luxembourg have <5 individuals aged 6-11 years at the date of FEV1 measurement and these countries are excluded from the graph.

Note: For Albania, Belarus, Cyprus, Georgia, Latvia, Moldova, North Macedonia, Romania, Serbia, the Russian Federation, Türkiye and Ukraine no FEV1 value was reported for more than 10% of the people with CF aged 6-11.

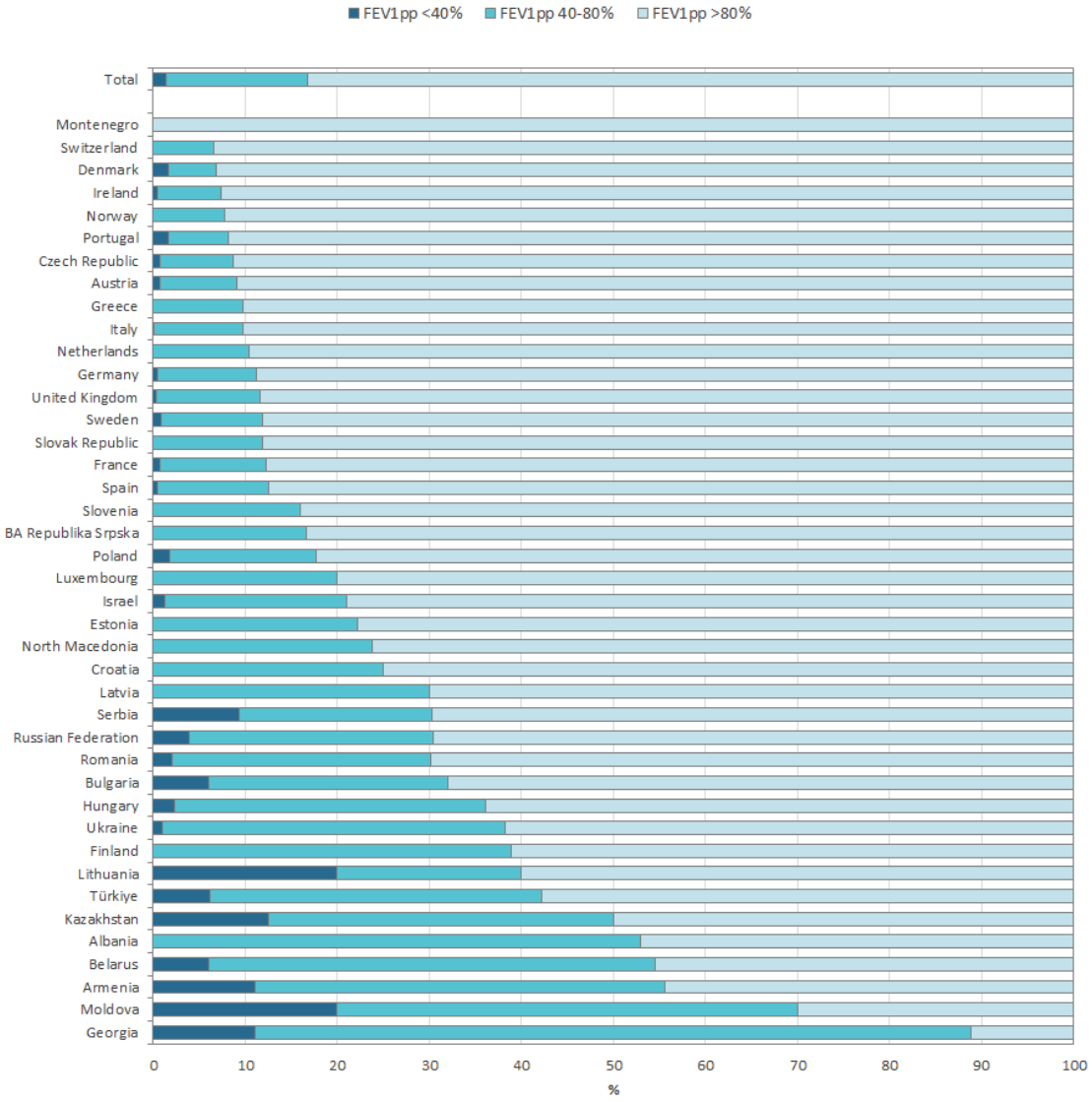
Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews which also means that the value could be from 2023 or 2024.

Figures 4.6, 4.7, 4.8 and 4.9 show the FEV1pp severity, by country and overall. People with CF with a FEV1pp > 80% are generally considered to have mild lung disease, those with a value between 80% and 40% to have moderate lung disease, and those with FEV1pp < 40% to have severe lung disease. However, since a 10-year-old child with a lung function of 50% of predicted has considerably worse lung disease than a 50-year-old with the same value, and the age distribution is not the same in all countries, we have chosen to present children 6-11 (Figure 4.6), adolescents 12-17 (Figure 4.7), adults 18-39 (Figure 4.8) and adults 40+ (Figure 4.9) separately.

4. Lung function

Figure 4.7 The majority of all adolescents with CF in Europe have a FEV_1% of predicted greater than 80% predicted.

FEV1pp severity group, by country and overall. Adolescents with CF aged 12-17 years who have never had a transplant.

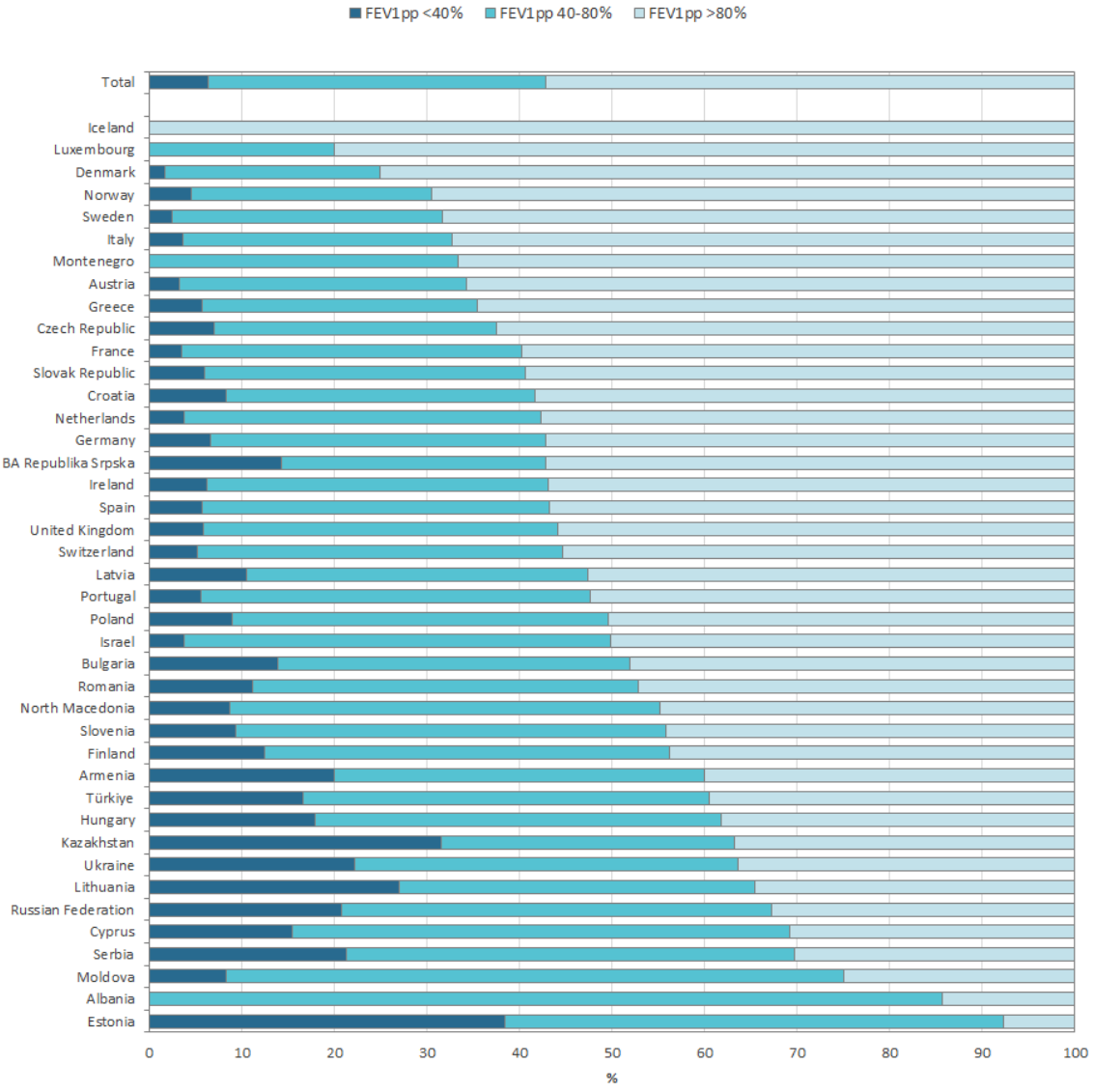


Note: Cyprus, Iceland and Kosovo have <5 individuals aged 12-17 years at the date of FEV1 measurement and the countries were excluded from the graph.
Note: For Belarus, Georgia, Lithuania, the Russian Federation, Türkiye and Ukraine the information on FEV1% of predicted is missing for more than 10% of the people with CF aged 12-17.
Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews which also means that the value could be from 2023 or 2024.

4. Lung function

Figure 4.8 In the majority of countries, most adults with CF aged 18-39 years have a FEV1 of >80% predicted.

FEV1pp severity group, by country and overall. Adults with CF aged 18-39 years who have never had a transplant.



Note: Belarus, Georgia and Kosovo have <5 individuals aged 18-39 years with a FEV1 measurement recorded in 2024 and the countries are excluded from the graph.

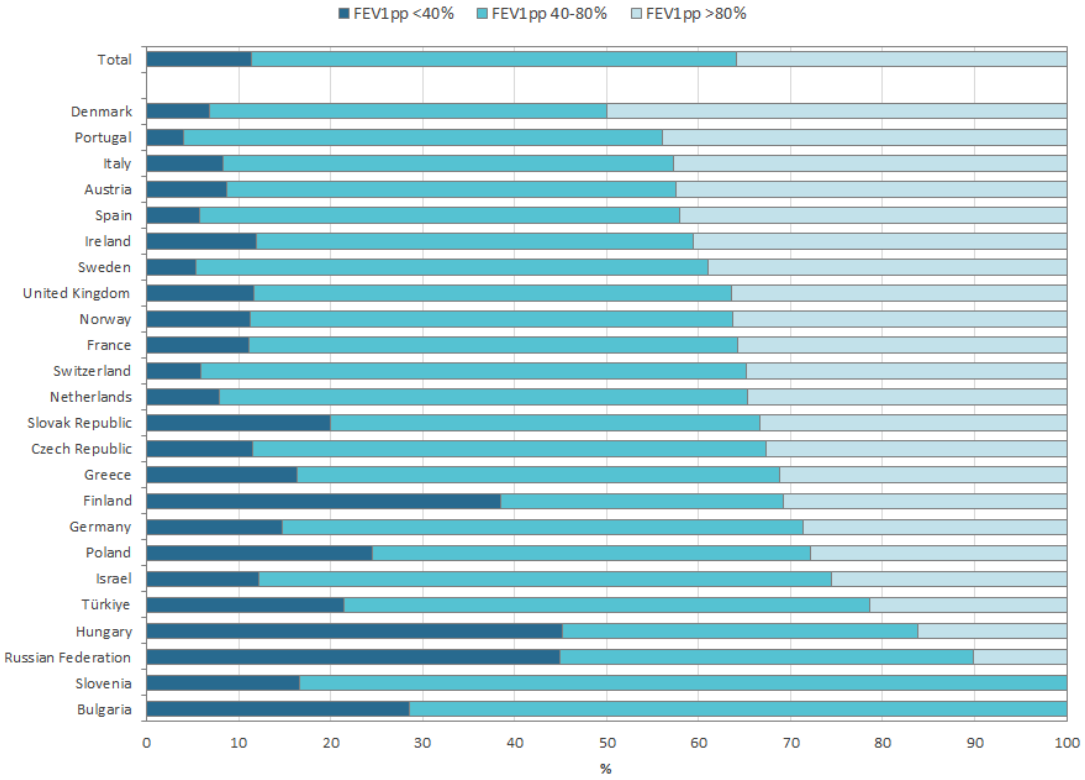
Note: For Moldova, Russia Federation and Ukraine no FEV1 value was reported for more than 10% of the people with CF in the 18-39 age group.

Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews which also means that the value could be from 2023 or 2024.

4. Lung function

Figure 4.9 In the majority of countries in the ECFSPR, most adults with CF aged 40 years or older have a FEV_1% of predicted between 40% and 80%.

FEV1pp severity, by country and overall. Adults with CF aged 40 years or older who have never had a transplant.



Note: Albania, Armenia, Belarus, BA Republika Srpska, Croatia, Cyprus, Estonia, Georgia, Kazakhstan, Kosovo, Iceland, Latvia, Lithuania, Luxembourg, Montenegro, North Macedonia, Republic of Moldova, Romania, Serbia, Ukraine have <5 individuals over 40 years of age with a FEV_1 measurement recorded in 2024 and they are excluded from the graph.

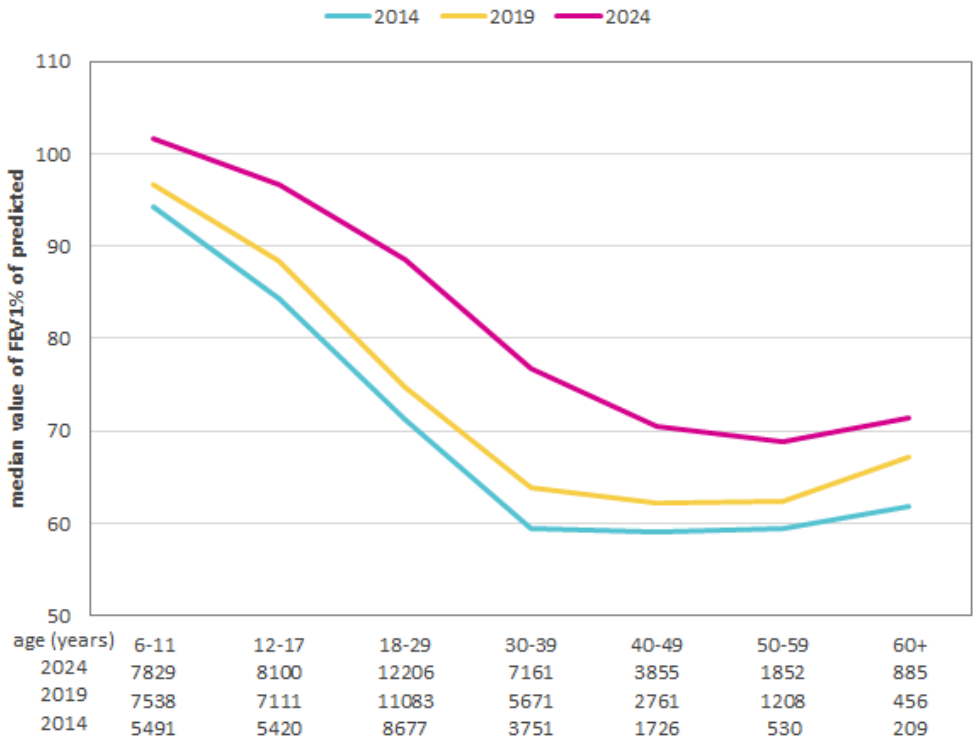
Note: For Hungary, Italy, the Russian Federation and Slovenia no FEV1 value was recorded for more than 10% of the people with CF over 40 years of age..

Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews which means that the value could be from 2023 or 2024.

4. Lung function

Figure 4.10 Pulmonary function, expressed as FEV_1% of predicted, has been increasing over the years in all age groups, with a clear improvement since the introduction of CFTR modulators.

Median FEV1% of predicted by age group in 2014, 2019 and 2024.



Note: People with CF who were aged 6 or older at the date of lung function measurement and who have never had a lung or liver transplant.

In this graph we present data over time using cross sectional data per year of people with a confirmed CF diagnosis. The years 2014, 2019 and 2024 were used for the analysis. All people with CF, alive and deceased, were included. Exclusion criteria were people who have had a lung or liver transplant at any time during their life and children younger than 6 years at the date of the lung function measurement.

5. Microbiology

We collected data on a number of pulmonary infections common in CF and whether the infection was either chronic or not chronic/intermittent (with the exception of certain types of non-tuberculous mycobacteria where we asked only if the pathogen was found at any time during the follow-up year).
In the microbiology category there are discrepancies between the ECFSPR definition of chronicity and those of some national registries. The ECFSPR definition of chronic infection (modified Leeds criteria for chronic infection, applied also to gram negative bacteria) (see the definition in our website) is as follows:
The individual should be defined as chronically infected if he/she fulfils the criteria now or has done in recent years and the physician has no reason to believe the status has changed, when:

- >50% of respiratory samples collected during the last 12 months (at least 4 samples) are positive;

and/or

- significantly raised bacteria-specific antibodies, according to local laboratories, are present.

When minor differences exist, the alternative definition is in a footnote; when differences are major, or if the information on the pathogen was not collected at all, we set the corresponding data to missing for that country.
In the following graphs and tables, we excluded data from people with CF who have had a transplant at some point in their life.

5. Microbiology

Figure 5.1 Pseudomonas aeruginosa, together with Staphylococcus aureus and Haemophilus influenzae, is the predominant respiratory pathogen in people with CF, though prevalence varies between age and countries.

Prevalence of chronic *Pseudomonas aeruginosa* in people with CF seen by a clinician in 2024 who have never had a transplant, by country (table A5.1, Appendix 1). The graph on the left presents the data for children and adolescents under 18 years of age and that on the right presents the data for adults.

Note: Information was missing for more than 10% of children in Kosovo, and for more than 10% of adults in Armenia, Iceland, Kosovo, and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note: Ireland: Chronicity for *Pseudomonas aeruginosa* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.

Italy: chronicity for *Pseudomonas aeruginosa* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.

The United Kingdom: chronicity for *Pseudomonas aeruginosa* was defined as: 3 or more positive isolates during the 12 months preceding the last annual review.

Pseudomonas aeruginosa is a frequent infection, but prevalence varied considerably between countries.

5. Microbiology

Figure 5.2 Burkholderia cepacia complex species belongs to the emerging respiratory pathogens, with a prevalence of >5% in some countries.

Prevalence of chronic *Burkholderia cepacia complex* species in people with CF seen by a clinician in 2024 who have never had a transplant, by country (table A5.2, Appendix 1). The graph on the left presents the data for children and adolescents under 18 years of age and that on the right presents the data for adults.

Note: Information was missing for more than 10% of children in Armenia and Kosovo, and for more than 10% of adults in Armenia, BA-Republika Srpska, Iceland, Kosovo, Latvia and Moldova. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

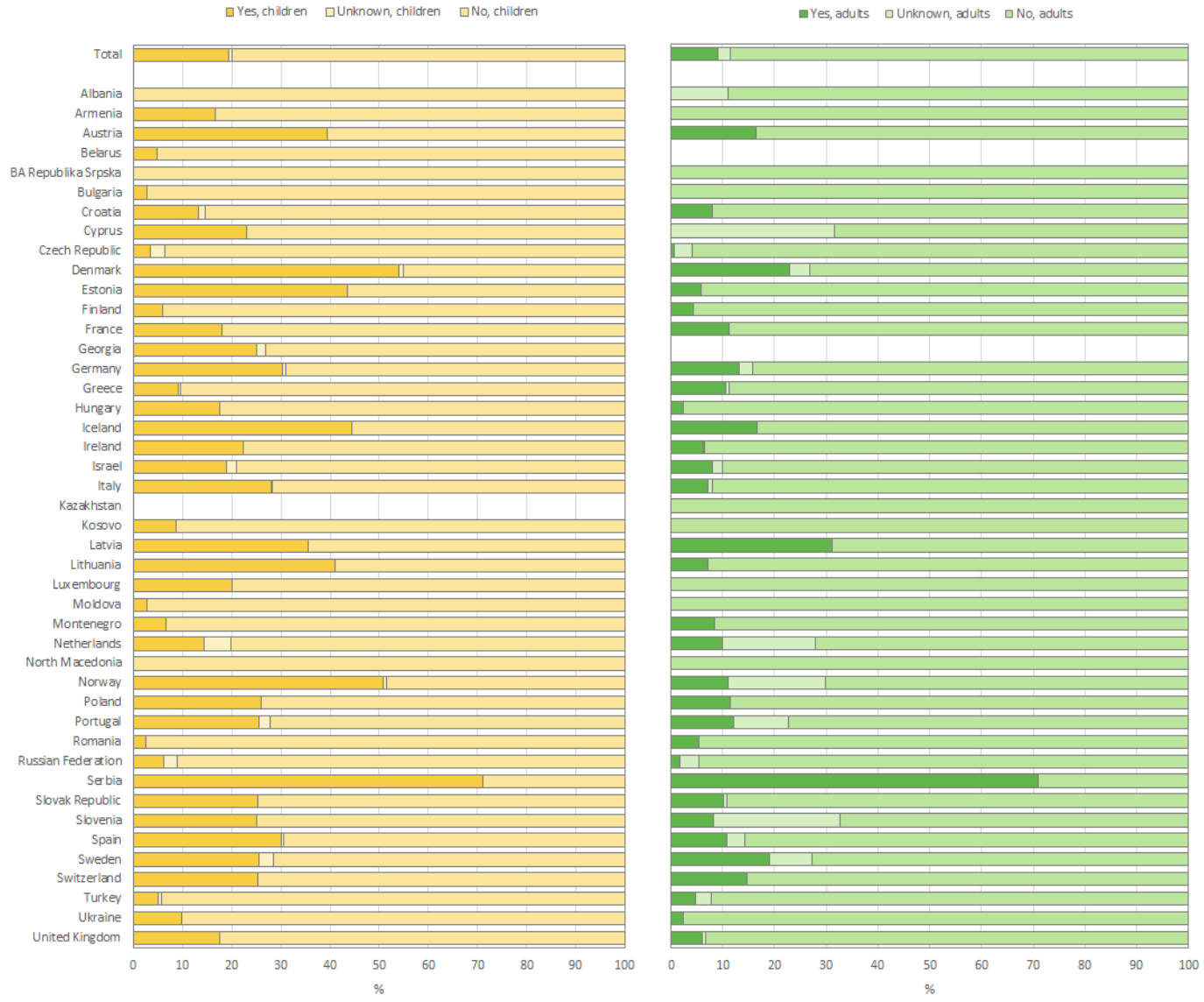
Note: Ireland: Chronicity for *Burkholderia cepacia complex* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.
Italy: chronicity for *Burkholderia cepacia complex* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.
The United Kingdom: chronicity for *Burkholderia cepacia complex* was not collected.

Chronic infection by *Burkholderia cepacia complex* species in people with CF was less frequent than chronic *Pseudomonas aeruginosa* infection (note the different scale on the horizontal axis). There is some variation among countries.

5. Microbiology

Figure 5.3 Haemophilus influenzae, together with Pseudomonas aeruginosa and Staphylococcus aureus, is one of the predominant respiratory pathogens in people with CF, though prevalence varies between age and countries.

Prevalence of *Haemophilus influenzae* (detected at least once a year) in people with CF seen by a clinician in 2024 who have never had a transplant, by country (table A5.3, Appendix 1). The graph on the left presents the data for children and adolescents under the age of 18 and that on the right presents the data for adults.



Note: Information was missing for more than 10% of children in Kosovo, and for more than 10% of adults in Armenia, BA-Republika Srpska, Iceland, Kosovo and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note: France and United Kingdom: chronicity for *Haemophilus influenza* was not collected.
Ireland: Chronicity for *Haemophilus influenzae* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.
Italy: chronicity for *Haemophilus influenzae* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.

This infection was as frequent as *Pseudomonas aeruginosa* infection and there is a similar degree of variation between the countries.

5. Microbiology

Figure 5.4 Staphylococcus aureus, together with Pseudomonas aeruginosa and Haemophilus influenzae, is a predominant respiratory pathogen in people with CF, though prevalence varies by age and between countries.

Prevalence of chronic methicillin-sensitive *Staphylococcus aureus* (MSSA) in people with CF seen by a clinician in 2024 who have never had a transplant, by country (table A5.4, Appendix 1). The graph on the left presents the data for children and adolescents under the age of 18 and that on the right presents the data for adults.

Note: Information was missing for more than 10% of children in Kosovo, and for more than 10% of adults in Armenia, BA-Republika Srpska, Iceland, Kosovo and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note: Ireland: Chronicity for *Staphylococcus aureus* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.

Italy: chronicity for *Staphylococcus aureus* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.

The United Kingdom: chronicity for *Staphylococcus aureus* was defined as: 3 or more positive isolates during the 12 months preceding the last annual review.

This infection was as frequent as *Pseudomonas aeruginosa* infection with a similar degree of variation between the countries.

5. Microbiology

Figure 5.5 Prevalence of methicillin-resistant Staphylococcus aureus (MRSA) in the airways is very heterogeneous in people with CF throughout Europe.

Prevalence of methicillin-resistant *Staphylococcus aureus* (MRSA) (detected at least once a year) in people with CF seen by a clinician in 2024 who have never had a transplant, by country (table A5.5, Appendix 1). The graph on the left presents the data for children and adolescents under the age of 18 and that on the right presents the data for adults.

Note: Information was missing for more than 10% of children in Armenia and Kosovo, and for more than 10% of adults in Armenia, BA-Republika Srpska, Iceland, Kosovo and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note: Ireland: Chronicity for methicillin-resistant *Staphylococcus aureus* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.
Italy: chronicity for methicillin-resistant *Staphylococcus aureus* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.
The United Kingdom: chronicity for methicillin-resistant *Staphylococcus aureus* was not collected.

5. Microbiology

Figure 5.6 In the majority of countries, Stenotrophomonas maltophilia is found in less than 10% in children and adults with CF.

Prevalence of *Stenotrophomonas maltophilia* (detected at least once a year) in people with CF seen by a clinician in 2024 who have never had a transplant, by country (table A5.6, Appendix 1). The graph on the left presents the data for children and adolescents under the age of 18 and that on the right presents the data for adults. Note the different scale on the horizontal axis.

Note: Information was missing for more than 10% of children in Armenia and Kosovo, and for more than 10% of adults in Armenia, BA-Republika Srpska, Iceland, Kosovo and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note: Ireland: Chronicity for *Stenotrophomonas maltophilia* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.
Italy: chronicity for *Stenotrophomonas maltophilia* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.
The United Kingdom: chronicity for *Stenotrophomonas maltophilia* was not collected.

5. Microbiology

Figure 5.7 Achromobacter species can be found in up to 20% of the airways of people with CF, with a higher prevalence in adults.

Prevalence of *Achromobacter species* infection (detected at least once a year) in people with CF seen by a clinician in 2024 who have never had a transplant, by country (table A5.7, Appendix 1). The graph on the left presents the data for children and adolescents under the age of 18 and that on the right presents the data for adults. Note the different scale on the horizontal axis.

Note: Information was missing for more than 10% of children in Armenia and Kosovo, and for more than 10% of adults in Albania, Armenia, BA-Republika Srpska, Iceland, Kosovo and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note: Ireland: Chronicity for *Achromobacter species* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.

Italy: chronicity for *Achromobacter species* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.

The United Kingdom: chronicity for *Achromobacter species* was not collected.

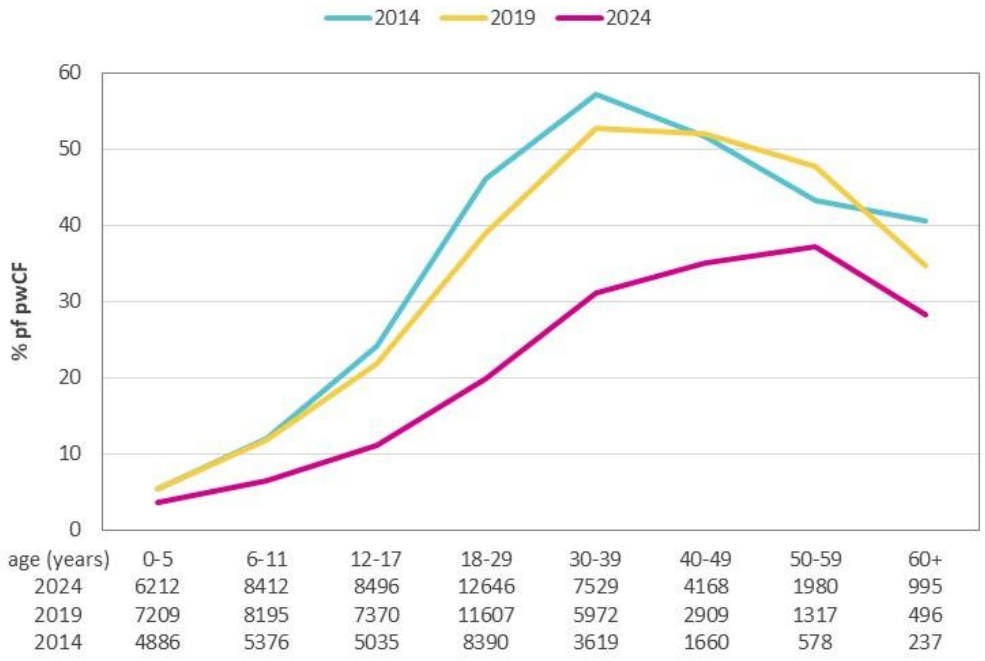
5. Microbiology

Table 5.1 Prevalence of non-tuberculous mycobacteria in children (<18 years) and adults (≥ 18 years) with CF seen in 2024 who have never had a transplant, overall.

	Sputum/BAL investigated for non-tuberculous mycobacteria infection						If yes, investigated			
	Missing/Unknown		No, not investigated		Yes, investigated		only negative cultures		at least one positive culture	
	N	%	N	%	N	%	N	%	N	%
Children	1197	5.1	16503	70.8	5608	24.1	5436	96.9	172	3.1
Adults	1892	6.8	14390	51.4	11704	41.8	10912	93.2	792	6.8

Figure 5.8 The prevalence of chronic Pseudomonas aeruginosa infection has decreased in the CF population in Europe since increased availability of CFTR modulators.

Prevalence of chronic *Pseudomonas aeruginosa* infection in people with CF, by age group, in 2014, 2019 and 2024.

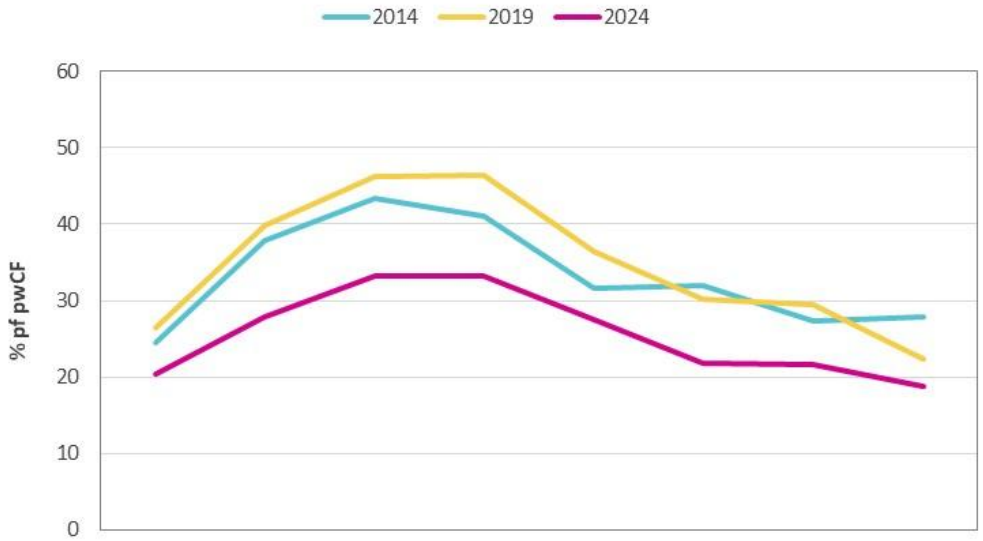


In this graph we present data over time using cross sectional data per year of people with a confirmed CF diagnosis. All people with CF alive, deceased, or not seen during the year of follow-up were included. Individuals who have had a lung or/and liver transplant at some point during their life were excluded.

5. Microbiology

Figure 5.9 The prevalence of chronic Methicillin-sensitive Staphylococcus aureus infection has decreased in the CF population in Europe since increased availability of CFTR modulators.

Prevalence of chronic *Methicillin-sensitive Staphylococcus aureus* infection in people with CF, by age group, in 2014, 2019 and 2024.



age (years)	0-5	6-11	12-17	18-29	30-39	40-49	50-59	60+
2024	6209	8415	8503	12647	7496	4153	1974	994
2019	7080	8030	7210	11254	5791	2810	1272	473
2014	3757	3946	3681	6222	2664	1246	422	158

In this graph we present data over time using cross sectional data per year of people with a confirmed CF diagnosis. All people with CF alive, deceased, or not seen during the year of follow-up were included. Individuals who have had a lung or/and liver transplant at some point during their life were excluded.

6. Nutrition

Pancreatic insufficiency is usually defined as the absence of pancreatic enzymes in two stool samples or elevated levels of fat in stools (faecal fat). Since information on faecal fat is rarely collected by the national registries we consider the use of pancreatic enzymes as an indicator of pancreatic insufficiency.

We collected height and weight measured on the date of the reported FEV_1 value (the FEV_1 of the highest FEV_1% predicted of the year). Where no FEV_1 value was reported (for children under 6 or because spirometry was not done) the latest height and weight measurements of the year were considered. From these raw values we calculated body mass index (BMI). BMI is an effective measurement to illustrate the nutritional status of a person because it describes the weight/height relationship; an individual with a low weight is not necessarily underweight if the height is also low. The ECFS Standards of Care guidelines recommend:

- a BMI of above 20 kg/m2 for adults;
- for older children and adolescents, that they achieve the 50th percentile for BMI;
- for infants and children up to two years of age, weight and height percentiles similar to those for the non-
- CF population.[1]

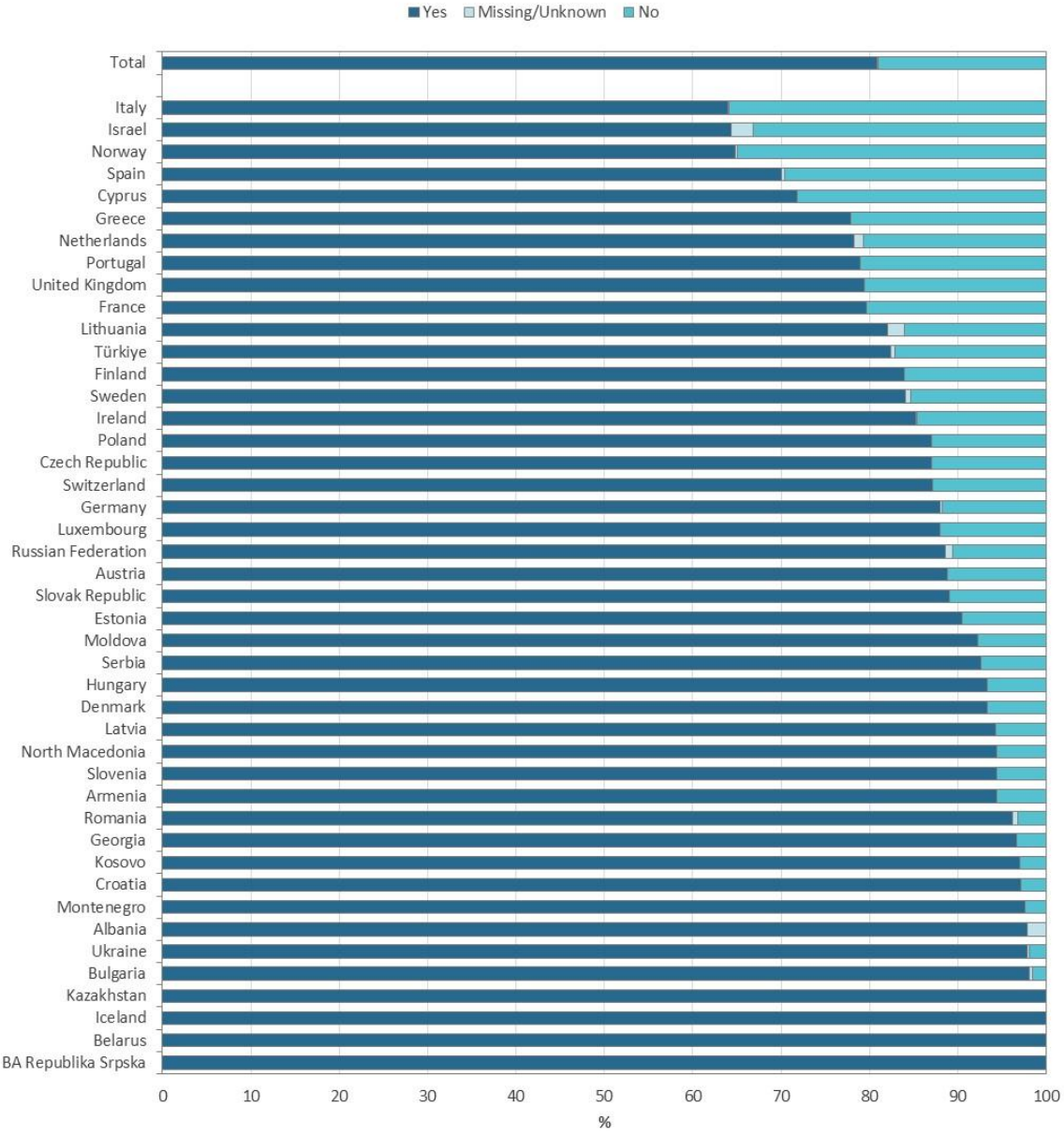
Weight, height and BMI were then expressed in terms of z-scores using a reference population of healthy individuals (in this case the US population with reference values issued by the Centre for Disease Control, USA, see the website for details). A z-score of 0 means that the height/weight/BMI is equal to the mean height/weight/BMI of people of the same age and sex in the reference population. A z-score of -2 indicates that the height/weight/BMI value is 2 standard deviations below the mean height/weight/BMI of people of the same age and sex in the reference population; a z-score of +2 means that the value is 2 standard deviations above that mean. In the reference population, 95% of all individuals have a z-score for weight between -2 and +2 (the same for height) and it is expected that the same happens for approximately 95% of individuals in a population without conditions that affect weight (or height). The average z-score for a largely healthy population should be very close to zero.

[1] A.R. Smyth et al, JCF 2014;13, S23–S42.

6. Nutrition

Figure 6.1 In the majority of countries in the ECFSPR more than 80% of the people with CF are pancreatic insufficient.

Use of pancreatic enzymes in 2024 for all people with CF who have never had a transplant, by country.

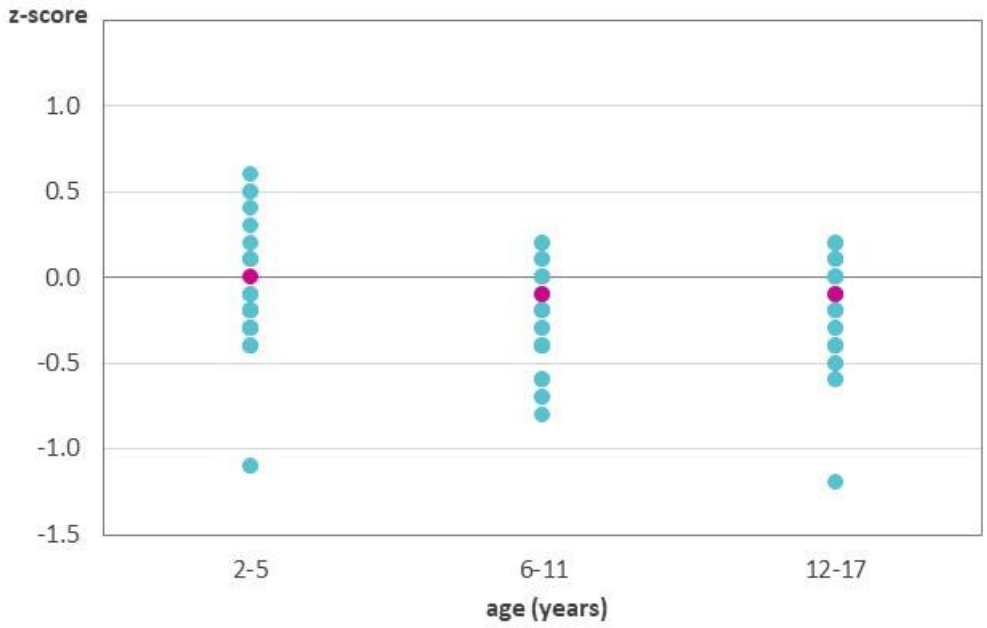


This graph shows the use of pancreatic enzymes by country. This can be seen as an indication of pancreatic insufficiency.

6. Nutrition

Figure 6.2 While the median BMI z-score for children and adolescents with CF in Europe is close to normal for all age groups, a lot of variation amongst the countries can be observed.

Median z-score for BMI by age group and by country (table A6.1, Appendix 1). Children and adolescents with CF aged 2-17 years in 2024 who have never had a transplant.



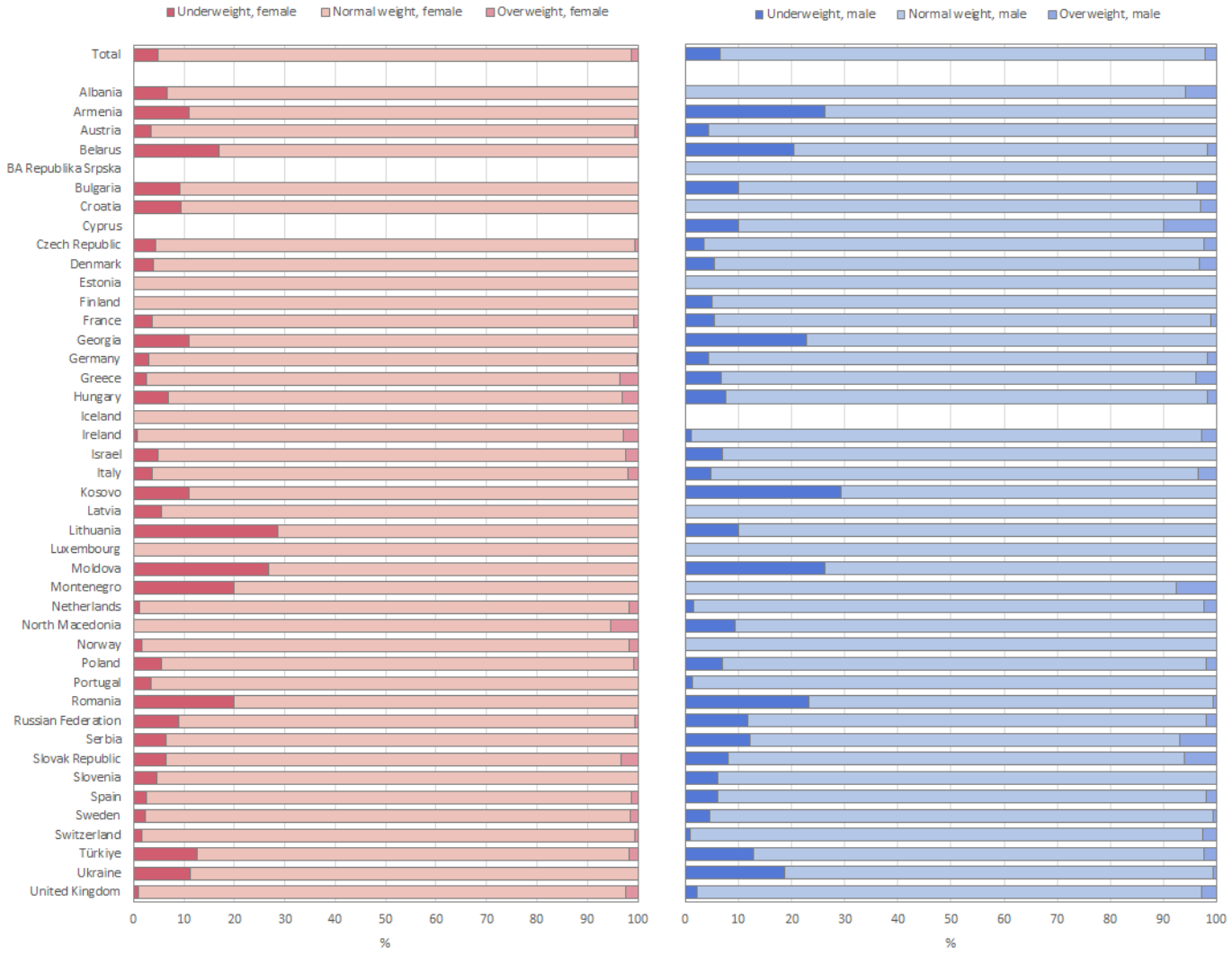
Note: We excluded from the graph those age groups where the number of individuals was <10.

This graph shows the median z-score for BMI (the value that separates the higher and lower half of the people with CF) by age group. Each country median is represented by a turquoise dot and the median overall for the age group by a pink dot. There was a lot of variation between countries.

6. Nutrition

Figure 6.3 Being underweight is a clinical feature in children and adolescents with CF. There are considerable differences amongst the countries.

Proportion of children and adolescents with CF who are underweight (z-score of BMI <-2), normal (-2 ≤ z-score of BMI ≤ +2) and overweight (z-score of BMI >+2) by sex and by country, aged 2-17 years in 2024 and who have never had a transplant. The graph on the left presents the data for females and that on the right presents the data for males.

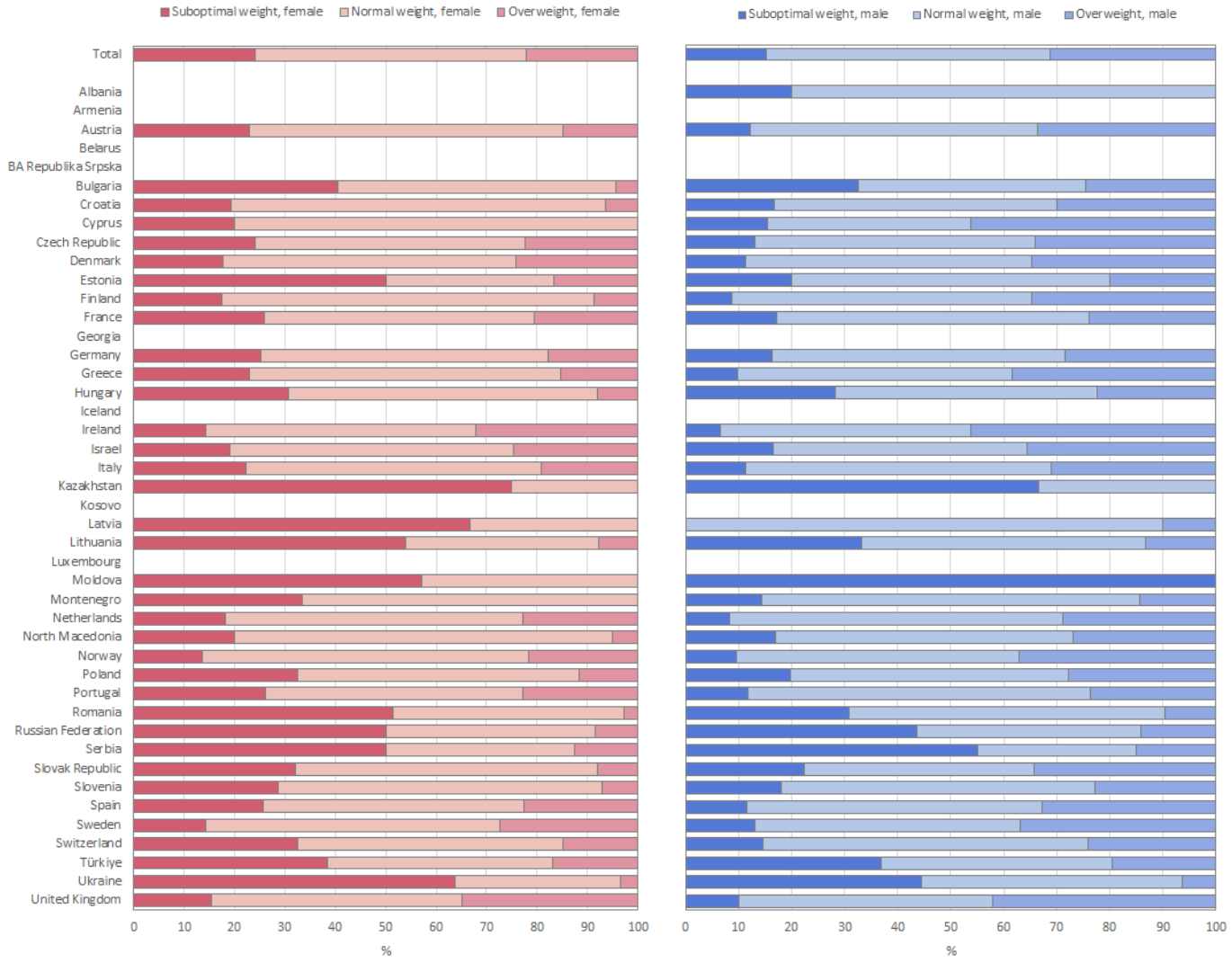


Note: BA-Republika Srpska and Cyprus have been excluded from the graph for females because the number of children and adolescents was <5. Iceland has been excluded from the graph for males because the number of children and adolescents was less than 5.

6. Nutrition

Figure 6.4 Having suboptimal weight is a clinical feature in adults with CF and more common in females. There are considerable differences amongst the countries.

Proportion of adults with suboptimal weight (BMI <20), normal (20 ≤ BMI ≤ 25) and overweight (BMI >25) by sex and by country, aged 18 years or older in 2024 who never had a transplant. The graph on the left presents the data for females and that on the right presents the data for males.



Note: Information was missing for more than 10% of adults in Georgia and Ireland.

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from both the graphs for adults.

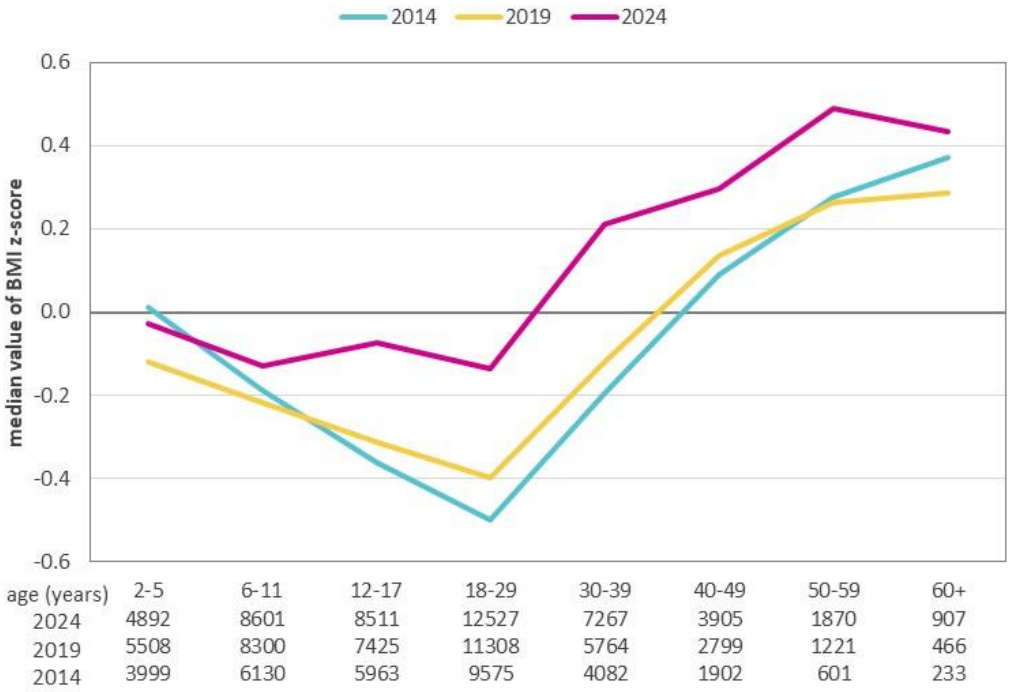
Note: Albania, Armenia, BA-Republika Srpska, Iceland, Kosovo, Luxemburg and Montenegro have been excluded from the graph for females because the number of female adults was <5.

Note Armenia, BA-Republika Srpska, Iceland, Kosovo and Luxemburg have been excluded from the graph for males because the number of male adults was <5.

6. Nutrition

Figure 6.5 A significant improvement in BMI in 2024 from the age of 6 years reflects the efficacy of CFTR modulator therapy in Europe.

Median z-score for BMI by age group in 2014, 2019 and 2024.



age (years)	2-5	6-11	12-17	18-29	30-39	40-49	50-59	60+
2024	4892	8601	8511	12527	7267	3905	1870	907
2019	5508	8300	7425	11308	5764	2799	1221	466
2014	3999	6130	5963	9575	4082	1902	601	233

Note: Only people with CF aged 2 years or more at measurements and who have never had a lung or liver transplant.

In this graph we present data over time using cross sectional data per year of people with a confirmed CF. All people with CF alive, deceased, or not seen during the year of follow-up were included. Individuals who have had a transplant in their lifetime (lung and/or liver) were excluded.

7. Complications

Respiratory complications in CF include allergic bronchopulmonary aspergillosis, haemoptysis and pneumothorax. For pulmonary exacerbations (PEx), we present data on the number of people with CF who have had at least one pulmonary exacerbation treated with intravenous (IV) antibiotics, the number of exacerbation episodes and the number of days on IV antibiotics. In this chapter we also present statistics on gastro-intestinal complications such as distal intestinal obstruction syndrome (DIOS) and CF-related diabetes (CFRD).

Data on liver disease are also included, despite the observation that the definitions for the types of liver disease may be interpreted differently from country to country and even from centre to centre within a country.

Newly diagnosed malignancy data are also reported in this section. We asked centres and countries to use the main ICD10 categories (from C00 to C97) for malignant neoplasms; for this report we grouped these under broader category headings.

Some of the tables do not show numbers by country, because for some countries the number of people with a particular complication was very low and presenting these data could lead to people being identified.

The information in this section should not be considered complete for a number of reasons: national CF registries may use a different definition or different parameters for a complication; data about one or more of the complications are not collected; the status of a given complication is unknown.

For a full list of complications and the definitions used by the ECFSPR please see the website.

7. Complications

Figure 7.1 Prevalence in people with CF of at least 1 day on intravenous antibiotics varies between countries.

Prevalence in people with CF of at least 1 day on intravenous (IV) antibiotics (for CF-related reasons) at home and/or in hospital (table A7.1, Appendix 1). People with CF seen in 2024, who have never had a transplant, by country and overall. The graph on the left presents the data for children and that on the right presents the data for adults.

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults, but the people are included in the total number.

7. Complications

Figure 7.2 Prevalence in people with CF of at least 1 day in hospital varies between countries.

Prevalence in people with CF of at least 1 day in hospital, for any reason (routine check-up days not included) (table A7.2, Appendix 1). People with CF seen in 2024, who have never had a transplant, by country and overall. The graph on the left presents the data for children and that on the right presents the data for adults.

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults, but the people are included in the total number.

7. Complications

Table 7.1 Prevalence of at least one pulmonary exacerbation treated with IV antibiotics in children and adolescents (<18 years) with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Missing/Unknown		No		Yes, at least one PEx treated with IV antibiotics	
	N	%	N	%	N	%
Albania	0	0.0	23	60.5	15	39.5
Armenia	0	0.0	20	66.7	10	33.3
Austria	5	1.4	318	90.6	28	8.0
Belarus	0	0.0	68	47.2	76	52.8
BA Rep Srpska	0	0.0	13	81.3	3	18.8
Bulgaria	0	0.0	115	77.7	33	22.3
Croatia	1	1.3	66	86.8	9	11.8
Cyprus	0	0.0	11	84.6	2	15.4
Czech Republic	0	0.0	329	94.8	18	5.2
Denmark	0	0.0	186	92.1	16	7.9
Estonia	0	0.0	21	84.0	4	16.0
Finland	0	0.0	33	97.1	1	2.9
France	2544	100	-	-	-	-
Georgia	1	1.8	48	85.7	7	12.5
Germany	1	0.0	2664	96.2	104	3.8
Greece	7	3.1	202	88.2	20	8.7
Hungary	0	0.0	244	85.3	42	14.7
Iceland	0	0.0	9	100	0	0.0
Ireland	0	0.0	489	93.1	36	6.9
Israel	5	3.2	136	87.7	14	9.0
Italy	152	7.1	1652	77.3	332	15.5
Kosovo	0	0.0	16	57.1	12	42.9
Latvia	1	3.0	24	72.7	8	24.2
Lithuania	1	4.6	13	59.1	8	36.4
Luxembourg	1	5.0	16	80.0	3	15.0
Rep of Moldova	0	0.0	8	22.2	28	77.8
Montenegro	0	0.0	30	100	0	0.0
Netherlands	9	2.2	384	91.9	25	6.0
North Macedonia	0	0.0	32	41.0	46	59.0
Norway	0	0.0	128	95.5	6	4.5
Poland	17	1.8	756	79.2	182	19.1
Portugal	3	1.8	159	95.2	5	3.0
Romania	10	3.3	230	75.2	66	21.6
Russian Fed.	88	3.8	1516	66.2	685	29.9
Serbia	5	3.3	123	81.5	23	15.2
Slovak Republic	0	0.0	114	89.8	13	10.2
Slovenia	0	0.0	51	91.1	5	8.9
Spain	34	3.3	944	90.7	63	6.1
Sweden	0	0.0	245	88.1	33	11.9
Switzerland	0	0.0	389	96.3	15	3.7
Türkiye	9	0.4	1798	81.6	397	18.0
Ukraine	8	2.3	132	38.6	202	59.1
United Kingdom	0	0.0	3713	91.8	333	8.2

Note: Total not shown because the Missing/Unknown percentage is higher than 10%.

7. Complications

Table 7.2 Prevalence of at least one pulmonary exacerbation in adults (≥18 years) with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Missing/Unknown		No		Yes, at least one PEx treated with IV antibiotics	
	N	%	N	%	N	%
Albania	0	0.0	4	44.4	5	55.6
Armenia	0	0.0	6	100	0	0.0
Austria	10	2.3	386	87.3	46	10.4
BA Rep Srpska	0	0.0	8	100	0	0.0
Bulgaria	0	0.0	91	85.1	16	15.0
Croatia	0	0.0	59	93.7	4	6.4
Cyprus	0	0.0	16	84.2	3	15.8
Czech Republic	0	0.0	314	91.8	28	8.2
Denmark	0	0.0	286	87.5	41	12.5
Estonia	0	0.0	10	58.8	7	41.2
Finland	0	0.0	42	89.4	5	10.6
France	4133	100	-	-	-	-
Germany	12	0.3	3817	90.2	401	9.5
Greece	11	3.0	316	85.6	42	11.4
Hungary	0	0.0	138	66.0	71	34.0
Iceland	0	0.0	6	85.7	1	14.3
Ireland	2	0.3	637	83.6	123	16.1
Israel	9	2.4	320	84.0	52	13.7
Italy	493	13.2	2691	71.8	565	15.1
Kosovo	1	4.4	9	39.1	13	56.5
Kazakhstan	0	0.0	4	80.0	1	20.0
Latvia	0	0.0	14	73.7	5	26.3
Lithuania	1	3.6	13	46.4	14	50.0
Luxembourg	1	20.0	3	60.0	1	20.0
Rep of Moldova	0	0.0	6	37.5	10	62.5
Montenegro	0	0.0	12	100	0	0.0
Netherlands	6	0.6	866	88.7	104	10.7
North Macedonia	0	0.0	12	18.8	52	81.3
Norway	1	0.5	198	90.8	19	8.7
Poland	24	3.8	449	70.2	167	26.1
Portugal	11	5.3	190	91.4	7	3.4
Romania	1	1.1	81	88.0	10	10.9
Russian Fed.	22	2.0	477	43.1	609	55.0
Serbia	1	2.6	34	87.2	4	10.3
Slovak Republic	0	0.0	135	87.1	20	12.9
Slovenia	0	0.0	50	96.2	2	3.9
Spain	22	1.6	1217	88.8	131	9.6
Sweden	1	0.2	327	75.9	103	23.9
Switzerland	0	0.0	499	90.4	53	9.6
Türkiye	6	1.1	431	80.7	97	18.2
Ukraine	7	5.3	27	20.6	97	74.1
United Kingdom	0	0.0	4814	79.3	1259	20.7

Note: Total not shown because the Missing/Unknown percentage is higher than 10%.
Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults, but the people are included in the total number.

7. Complications

Table 7.3 Prevalence of rare complications in all people with CF seen in 2024 who have never had a transplant.

Complication	Children (<18 years)						Adults (≥18 years)					
	Missing/ Unknown		No		Yes		Missing/ Unknown		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Allergic bronchopulmonary aspergillosis	205	0.9	22858	98.1	245	1.0	274	1.0	26646	95.2	1066	3.8
Pneumothorax	181	0.8	23109	99.1	18	0.1	329	1.2	27609	98.6	48	0.2
Major haemoptysis (≥250 ml over the course of a day)	371	1.6	22903	98.3	34	0.1	277	1.0	27413	98.0	296	1.0
Malignancy newly diagnosed this year	457	2.0	22842	98.0	9	0.0	617	2.2	27170	97.1	199	0.7
Distal intestinal obstruction syndrome (DIOS)	109	0.5	22870	98.1	329	1.4	166	0.6	27173	97.1	647	2.3

Note: Germany and the United Kingdom defined haemoptysis major > 240 ml.
Ireland: haemoptysis major was defined as haemoptysis massive > 240ml/day or > 100ml/day for several days.
Note: Denmark only reported DIOS requiring hospitalisation.

Table 7.4 Type of malignancy newly diagnosed in 2024 year in people with CF seen in 2024 by a clinician who have never had a transplant.

Country	Type of malignancy															
	Colorectal cancer		Lung cancer		Breast cancer		Prostate cancer		Testicular cancer		Thyroid gland cancer		Other type of cancer		Unknown type	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Children	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	6	66.7	3	33.3
Adults	25	12.6	9	4.5	38	19.2	9	4.5	10	5.0	9	4.5	81	40.7	18	9.1

8. Therapies

In this chapter we report on the use of mucolytics (hypertonic saline, rhDNAse and mannitol), inhaled antibiotics, macrolides, bronchodilators and anti-inflammatories (inhaled and oral steroids). We also present data on the use of oxygen and non-invasive positive pressure ventilation. We collected information using the generic name of the medication, not the brand name.

The therapeutic options for the treatment of gastro-intestinal complications are limited; here we show the data on the use of ursodeoxycholic acid and proton pump inhibitors (PPI). We collected information using the generic name of the medications, not the brand name.

For a number or reasons, the information in this section should not be considered complete: national CF registries may use a different definition or different parameters for data about a therapy; data about one or more of the therapies are not collected; the use of a given therapy is unknown. For a full list of therapies and the definitions used by the ECFSPR about the data presented in this section please see the website.

8. Therapies

Figure 8.1 Variation in the use of inhaled hypertonic saline indicates both inequalities in availability and different therapeutic approaches.

Use of inhaled hypertonic saline in children and adolescents (<18 years of age) and adults seen by a clinician in 2024 who have never had a transplant, by country (table A8.1, Appendix 1). The graph on the left presents the data for children and that on the right presents the data for adults.

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note: Inhaled hypertonic saline was reimbursed in most countries except in Albania, Armenia, Bulgaria, Estonia, Georgia, Kazakhstan, Lithuania, the Republic of Moldova and Poland. In Kosovo in 2024 there was no system for the reimbursement of medication but inhaled hypertonic saline was offered free of charge for PwCF in hospital. In Türkiye it is reimbursed for children ≥ 6 years.

This graph shows the use of inhaled hypertonic saline (≥ 3%) for at least three consecutive months during the survey year.

8. Therapies

Figure 8.2 Variation in the use of rhDNAse indicates both inequalities in the availability of the medication and different therapeutic approaches.

Use of rhDNase in children and adolescents (<18 years of age) and adults seen by a clinician in 2024 who have never had a transplant, by country (table A8.2, Appendix 1). The graph on the left presents the data for children and that on the right presents the data for adults.

Note: Information was missing for more than 10% of adults in Armenia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note: Inhaled rhDNase was reimbursed in most countries except in Albania, Armenia and Belarus. It was reimbursed in Georgia for people with CF ≥ 2 years, in Bulgaria, Estonia, France, Germany, Greece, Luxembourg, Macedonia, the Republic of Moldova, Norway, Romania, Serbia, Spain, and the United Kingdom for individuals ≥ 5 years and in Latvia and Hungary for individuals ≥ 6 years. In Kosovo in 2024 there was no system for the reimbursement of medication but inhaled rhDNase was offered free of charge for PwCF in hospital.

This graph shows the use of inhaled rhDNase for at least 3 consecutive months during the survey year.

8. Therapies

Figure 8.3 Inhaled antibiotics are still an important therapeutic strategy in the prevention of pulmonary exacerbations, especially in adults with CF.

Use of inhaled antibiotics in children and adolescents (<18 years of age) and adults seen by a clinician in 2024 who have never had a transplant, by country (table A8.3, Appendix 1). The graph on the left presents the data for children and that on the right presents the data for adults.

Note: Information was missing for more than 10% of adults in Albania. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.
Inhaled antibiotics were reimbursed in all countries except Armenia and Georgia. In Bulgaria, colistin was reimbursed for all PwCF, tobramycin for those > 7 years old, and levofloxacin for those > 18 years old. In Estonia, tobramycin and colistin were reimbursed. In Romania, only tobramycin solution and colistin dry powder were reimbursed and only for PwCF aged 6 and older. In Kosovo in 2024 there was no system for the reimbursement of medication but when the intravenous formulation of colistin is adapted as an inhaled formulation, it is offered free of charge for PwCF in hospital.

This graph shows the use of inhaled antibiotics (of any kind) for at least three months (consecutively or cyclic therapy) during the survey year.

8. Therapies

Figure 8.4 Bronchodilators (both short and long acting) are used as widespread supporting treatment in many countries in Europe.

Use of bronchodilators (short- or long-acting) in children and adolescents (<18 years of age) and adults seen by a clinician in 2024 who have never had a transplant, by country (table A8.4, Appendix 1). The graph on the left presents the data for children and that on the right presents the data for adults.

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Inhaled bronchodilators were reimbursed in most countries except in Bulgaria, Georgia, the Republic of Moldova (reimbursed for PwCF also diagnosed with asthma), Poland and Serbia. In Kazakhstan its availability depends on the regional budget. In Estonia long- and short-acting bronchodilators were reimbursed for PwCF also diagnosed with asthma. In Kosovo in 2024 there was no system for the reimbursement of medication and PwCF must cover the cost of the therapy themselves.

This graph shows the use of bronchodilators, both long-acting and short-acting, for at least three consecutive months during the survey year. This is the most widely used inhaled medication but there are significant differences in frequency of use in the countries.

8. Therapies

Figure 8.5 Azithromycin is used as an antibiotic and anti-inflammatory mediator throughout Europe, mostly by adults with CF.

Use of macrolides in children & adolescents (<18 years of age) and adults seen by a clinician in 2024 who have never had a transplant, by country (table A8.5, Appendix 1). The graph on the left presents the data for children and that on the right presents the data for adults.

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Oral macrolides were reimbursed in most countries except in Bulgaria, Georgia, Kazakhstan, BA-Republika Srpska and Serbia. In Armenia, they were reimbursed for some outpatients. In Kosovo in 2024 there was no system for the reimbursement of medication PwCF cover the cost of the therapy themselves.

This graph shows the use of macrolides (e.g. azithromycin or another macrolide) for at least 3 consecutive months during 2024. Macrolides are antibiotics but, when taken continuously, they can also modulate the immune system, probably due to their anti-inflammatory properties. Clinical studies have shown that people with chronic *Pseudomonas aeruginosa* infection benefit from continuous azithromycin treatment with regard to lung function and pulmonary exacerbation rates.

8. Therapies

Table 8.1 Use of Oxygen treatment, & non-invasive positive pressure ventilation (NIPPV) for ≥3 consecutive months in all people with CF seen in 2024 who have never had a transplant, overall.

	Oxygen						NIPPV									
	Missing/ Unknown		No		Yes		Missing/ Unknown		No		Yes - BiPAP (Bilevel Positive Airways Pressure)		Yes - CPAP (Continuous Positive Airways Pressure)		Yes - type unknown	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Children	66	0.3	23046	98.9	196	0.8	231	1.0	22917	98.3	63	0.3	70	0.3	27	0.1
Adults	83	0.3	26879	96.0	1024	3.7	591	2.1	26939	96.3	199	0.7	161	0.6	96	0.3

Note: NIPPV was reimbursed in most countries except in Albania, Armenia, Belarus, Bulgaria, Kazakhstan, the Republic of Moldova, BA-Republika Srpska, Serbia and Ukraine. In Georgia it was reimbursed if the individual was hospitalised. In Kosovo in 2024 there was no system for the reimbursement of medication but NIPPV is offered free of charge for PwCF in hospital.

Note: Oxygen therapy was reimbursed in most countries except in Bulgaria, Kazakhstan and the Republic of Moldova. In Armenia and Georgia, it was only reimbursed if the individual was hospitalised. In Serbia oxygen therapy at home is reimbursed. In Kosovo in 2024 there was no system for the reimbursement of medication; if needed at home PwCF must secure an oxygen concentrator at their own expense.

8. Therapies

Figure 8.6 Pulmonary inflammation, including obstructive symptoms, is often treated with corticosteroids.

Use of inhaled steroids in children and adolescents (<18 years of age) and adults seen by a clinician in 2024 who have never had a transplant, by country (table A8.6, Appendix 1). The graph on the left presents the data for children and that on the right presents the data for adults.

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note Inhaled steroids were reimbursed in most countries except Armenia, Georgia, Kazakhstan, Lithuania, Poland, Serbia. In Bulgaria, they were reimbursed for PwCF who were also diagnosed with asthma or chronic obstructive pulmonary disease (COPD). In Estonia, Romania and the Republic of Moldova inhaled steroids were reimbursed for PwCF who were also diagnosed with asthma. In Kosovo in 2024 there was no system for the reimbursement of medication and PwCF cover the cost of the therapy themselves.

This graph shows the use of inhaled steroids for at least 3 consecutive months during the survey year.

8. Therapies

Figure 8.7 Oral steroids are prescribed less often than inhaled steroids.

Use of oral steroids in children and adolescents (<18 years of age) and adults seen by a clinician in 2024 who have never had a transplant, by country (table A8.7, Appendix 1). The graph on the left presents the data for children and that on the right presents the data for adults.

Note: Information was missing for more than 10% of adults in Cyprus. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

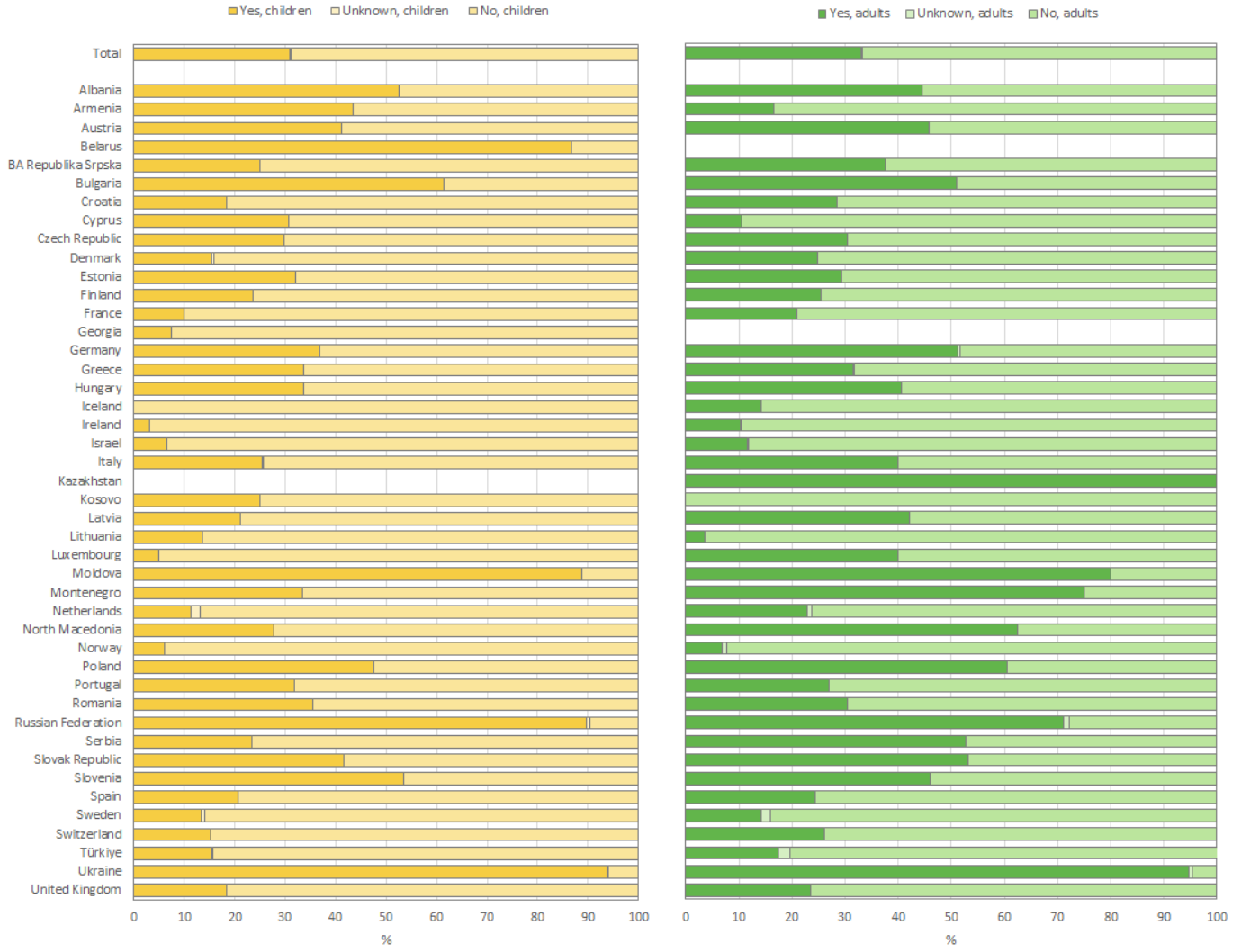
Note: Oral steroids were reimbursed in most countries except in Armenia, Bulgaria, Georgia, Kazakhstan, Lithuania, the Republic of Moldova, BA-Republika Srpska and Serbia. In Kosovo in 2024 there was no system for the reimbursement of medication and PwCF cover the cost of the therapy themselves.

This graph shows the use of oral steroids for at least three consecutive months during the survey year. Note the different scale.

8. Therapies

Figure 8.8 Ursodeoxycholic acid is often prescribed to treat cholestasis and liver disease in people with CF.

Use of ursodeoxycholic acid in children and adolescents (<18 years of age) and adults seen by a clinician in 2024 who have never had a transplant, by country (table A8.8, Appendix 1). The graph on the left presents the data for children and that on the right presents the data for adults.



Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note: Oral ursodeoxycholic acid was reimbursed in most countries in Europe, except in Armenia, Bulgaria, Georgia, Lithuania and Serbia. In the Republic of Moldova it was reimbursed at 100% for children and at 70% for adults. In Kazakhstan, availability depends on the regional budget. In Kosovo in 2024 there was no system for the reimbursement of medication PwCF cover the cost of the therapy themselves.

This graph shows how many people with CF used ursodeoxycholic acid for at least three consecutive months during 2024. Ursodeoxycholic acid is used as a treatment for CF liver disease.

8. Therapies

Figure 8.9 Proton Pump Inhibitors are used to treat gastroesophageal reflux and gastritis, both common complications in CF, and to enhance pancreatic enzyme efficacy.

Use of proton pump inhibitors (PPI) in children and adolescent (<18 years of age) and adults seen by a clinician in 2024 who have never had a transplant, by country (table A8.9, Appendix 1). The graph on the left presents the data for children and that on the right presents the data for adults.

Note: Information was missing for more than 10% of adults in Republic of Moldova. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the graph for adults.

Note: Oral proton pump inhibitors were reimbursed in most countries except in Bulgaria, Georgia, Kazakhstan, Lithuania and Serbia. In Armenia they were reimbursed for some outpatients. In Kosovo in 2024 there was no system for the reimbursement of medication PwCF cover the cost of the therapy themselves.

This graph shows the use of proton pump inhibitors (PPI) for at least three consecutive months during the survey year.

8. Therapies

Figure 8.10 The increased use of CFTR modulators in children with CF in Europe goes hand in hand with a decrease in the prescription of azithromycin and inhaled antibiotics, while that of inhaled mucolytics remains mostly unchanged.

Therapy use in children and adolescents (<18 years of age) between 2014 and 2024.

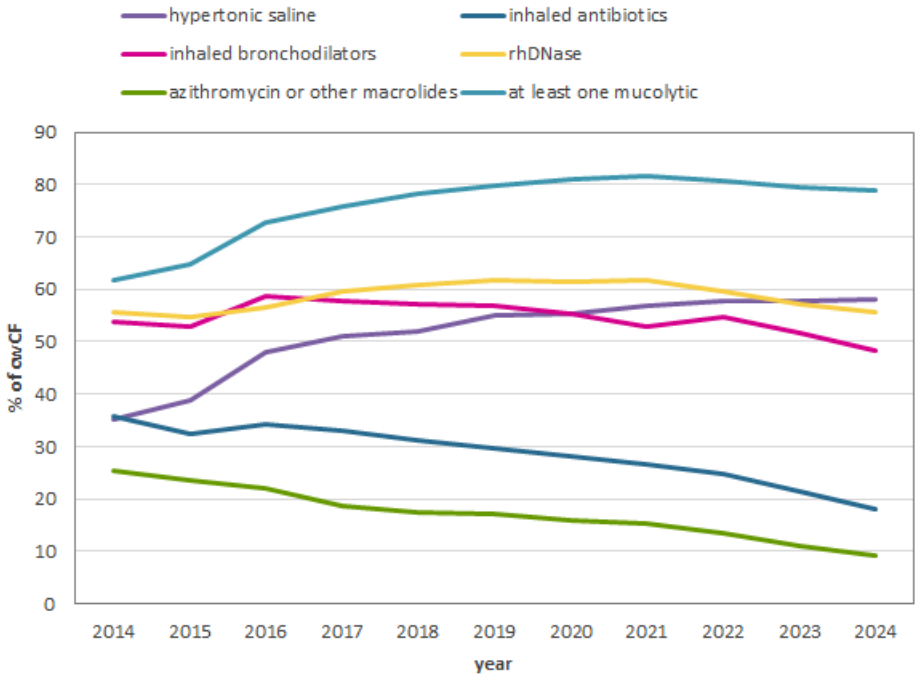
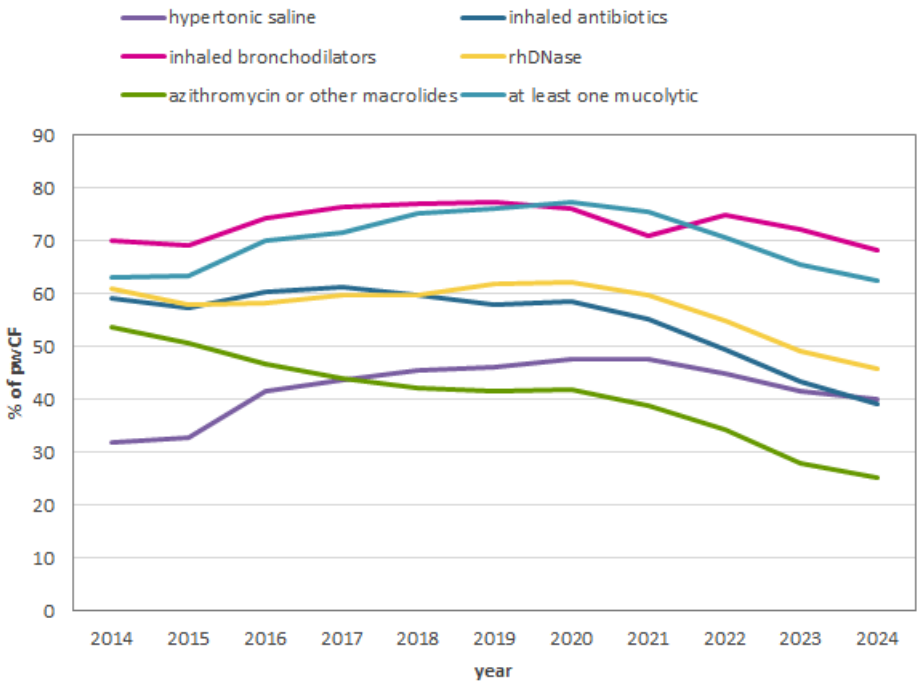


Figure 8.11 The increased use of CFTR modulators in adults with CF in Europe goes hand in hand with a decrease in the prescription of azithromycin, inhaled antibiotics and inhaled mucolytics.

Therapy use in adults between 2014 and 2024.



Figures 8.10 and 8.11 present data over time using cross sectional data per year of people with a confirmed CF. All people with CF alive, deceased or not seen during the year of follow-up were included. We excluded individuals who have had a lung or/and liver transplant during their lifetime.

9. CFTR modulator therapies

The introduction of CFTR modulator therapies has had a significant impact on the health and quality of life of people with CF and also on CF care. These therapies target defects in the structure and function of the cystic fibrosis transmembrane conductance regulator (CFTR) protein. CFTR modulators are not effective in all people with CF since different variants cause different defects in the protein and/or its function.
In this chapter we present information about the use of the different CFTR modulators for people with CF.

We adopted the 2024 eligibility criteria of the European Medicines Agency (EMA) for all countries in the ECFSPR except Israel, the Russian Federation and Switzerland, where country-specific eligibility criteria laid down by the national regulatory authorities were applied. Where these are different from EMA criteria it is stated as such. The country-specific eligibility criteria for the CFTR modulators in 2024 were provided by the medical Authorisation Holder:
Ivacaftor:

- at least 1 month old with at least one of the following variants: G551D, G1244E, G1349D, G178R, G551S, S1251N, S1255P, S549N, S549R, R117H (for R117H: people must be at least 6 months old);
- at least 4 months old in Switzerland with at least one of the following variants: G551D, G1244E, G1349D, G178R, G551S, S1251N, S1255P, S549N, S549R, R117H (for R117H: people must be at least 6 months old);
- at least 2 years old in Israel with at least one of the following variants: G551D, G1244E, G1349D, G178R, G551S, S1251N, S1255P, S549N, S549R.

Lumacaftor/ivacaftor:

- at least 1 year old (2 years old in the Russian Federation, 6 years old in Israel) and F508del homozygous.

Tezacaftor/ivacaftor:

- at least 6 years old and F508del homozygous, or F508del heterozygous with one of the following variants: P67L, R117C, L206W, R352Q, A455E, D579G, 711+3A→G, S945L, S977F, R1070W, D1152H, 2789+5G→A, 327226A→G, or 3849+10kbC→T (also E56K, R74W, D110E, D110H, E193K, E831X, F1052V, K1060T, A1067T, F1074L, D1270N and R347H in Israel).

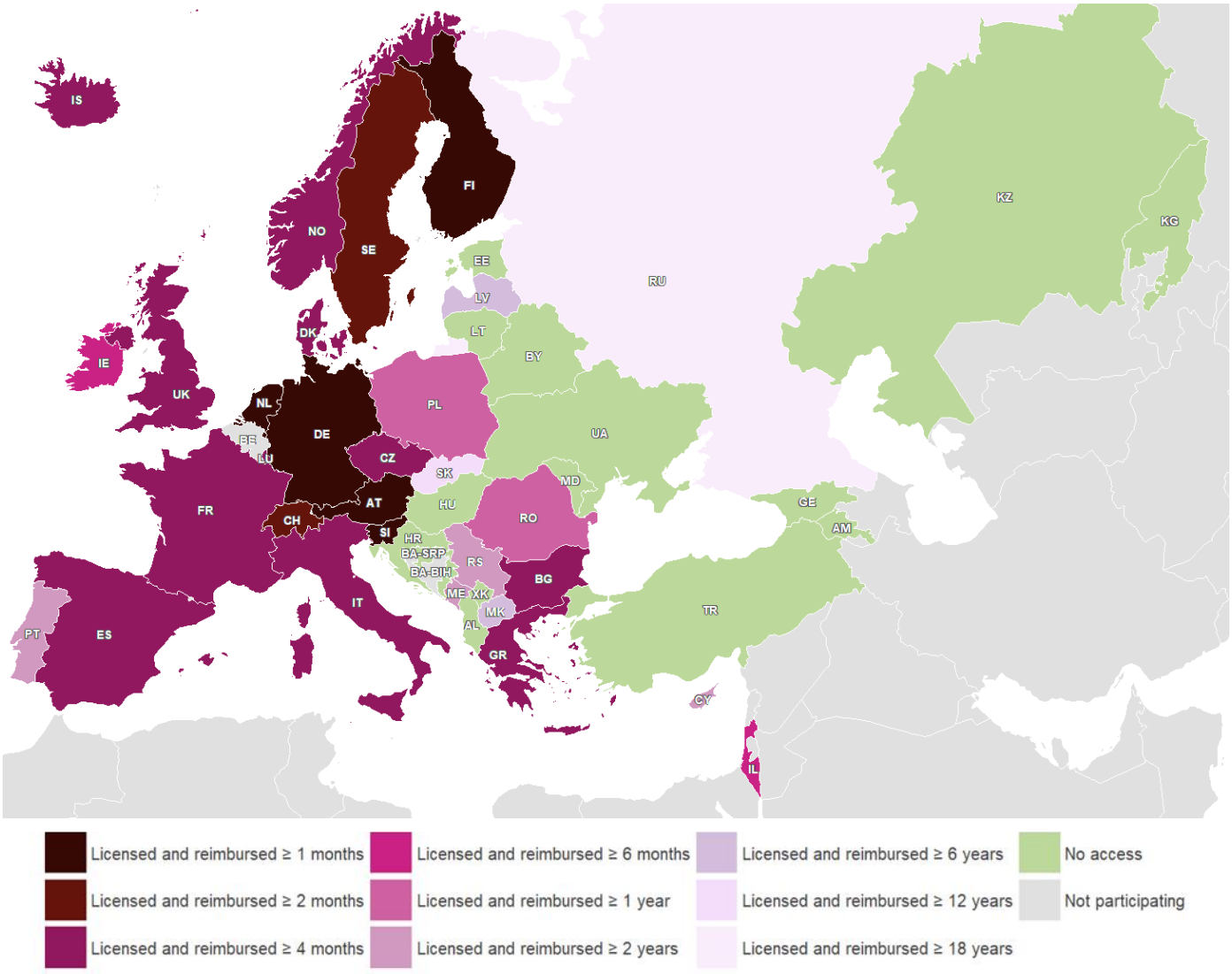
Elexacaftor/tezacaftor/ivacaftor:

- at least 2 years old (6 years old in Israel and in the Russian Federation) with at least one F508del variant (or a mutation in the CFTR gene that is responsive, based on in vitro data, in Israel and the Russian Federation).

The maps in this chapter show whether or not the CFTR modulators were licensed and reimbursed by national health services (information provided by the nominated country representative) in the countries participating in the ECFSPR in 2024 (Figure 9.1-9.4). These maps help with the interpretation of the country-specific variations in therapy use in people with CF who were eligible in each country (Figure 9.5, 9.6).

9. CFTR modulator therapies

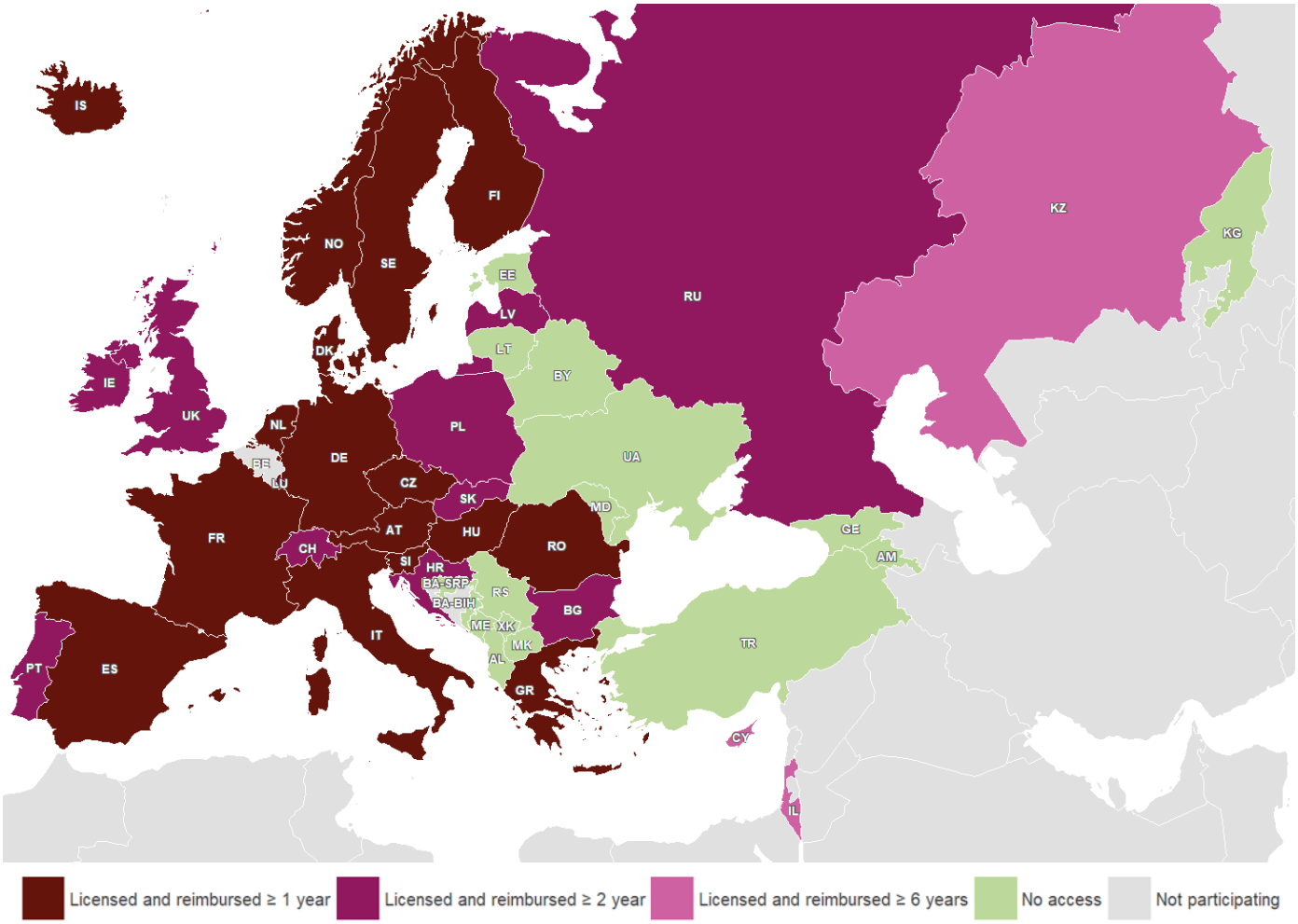
Figure 9.1 Countries where ivacaftor was licensed and reimbursed in 2024.



Note: Norway: ivacaftor was reimbursed for children with CF if weight ≥ 5 kg.
United Kingdom: ivacaftor was reimbursed for people with CF with the variant R117H who were ≥ 6 months old.
Note: BA-Bosnia-Herzegovina: shown as "not participating" because the data were missing for 2024.

9. CFTR modulator therapies

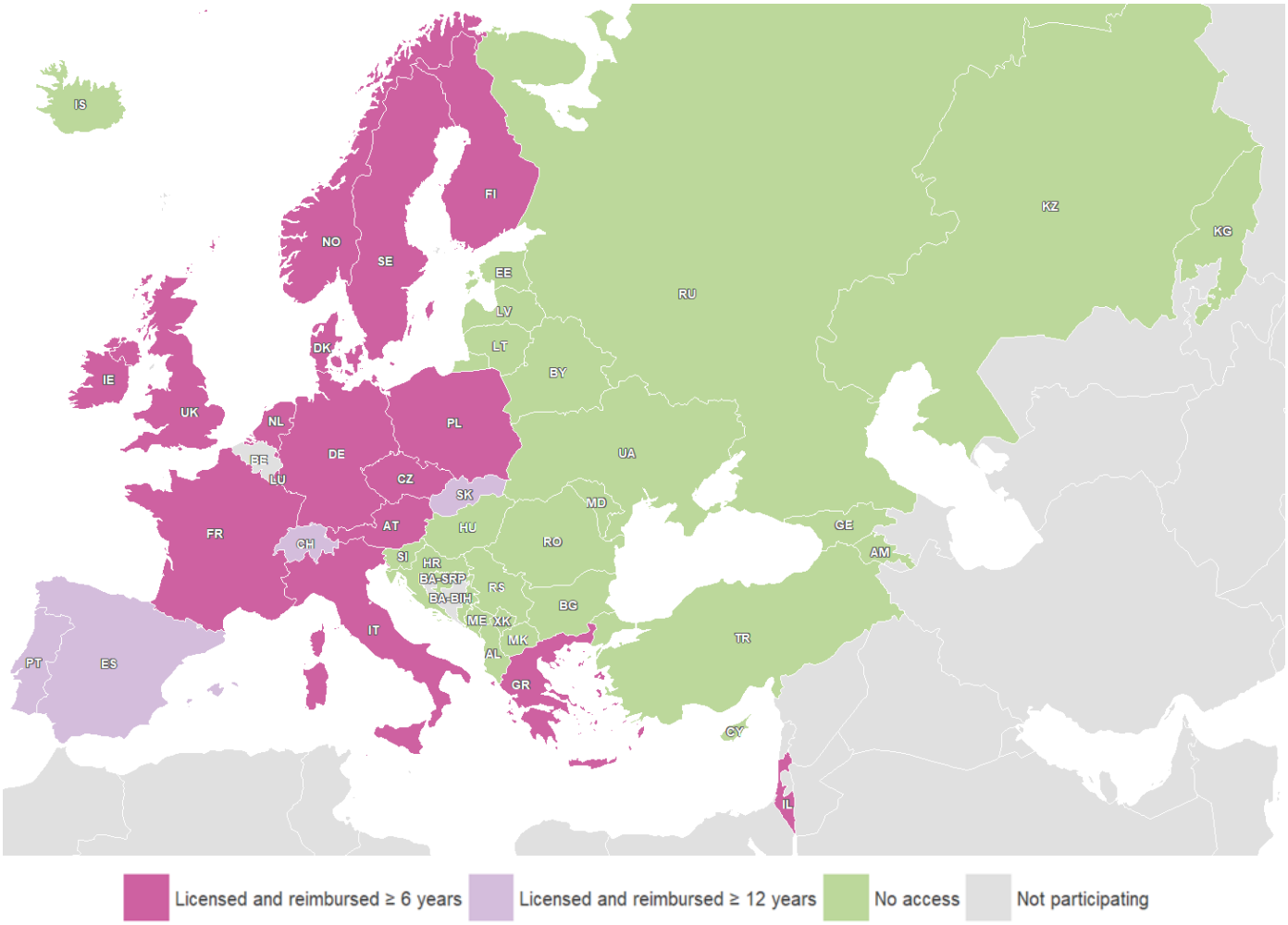
Figure 9.2 Countries where lumacaftor/ivacaftor was licensed and reimbursed in 2024.



Note: France: ≥ 1 year from April 2024.
Hungary: ≥ 1 years (F508 homozygous) from July 2023.
Note: BA-Bosnia-Herzegovina: shown as "not participating" because the data were missing for 2024.

9. CFTR modulator therapies

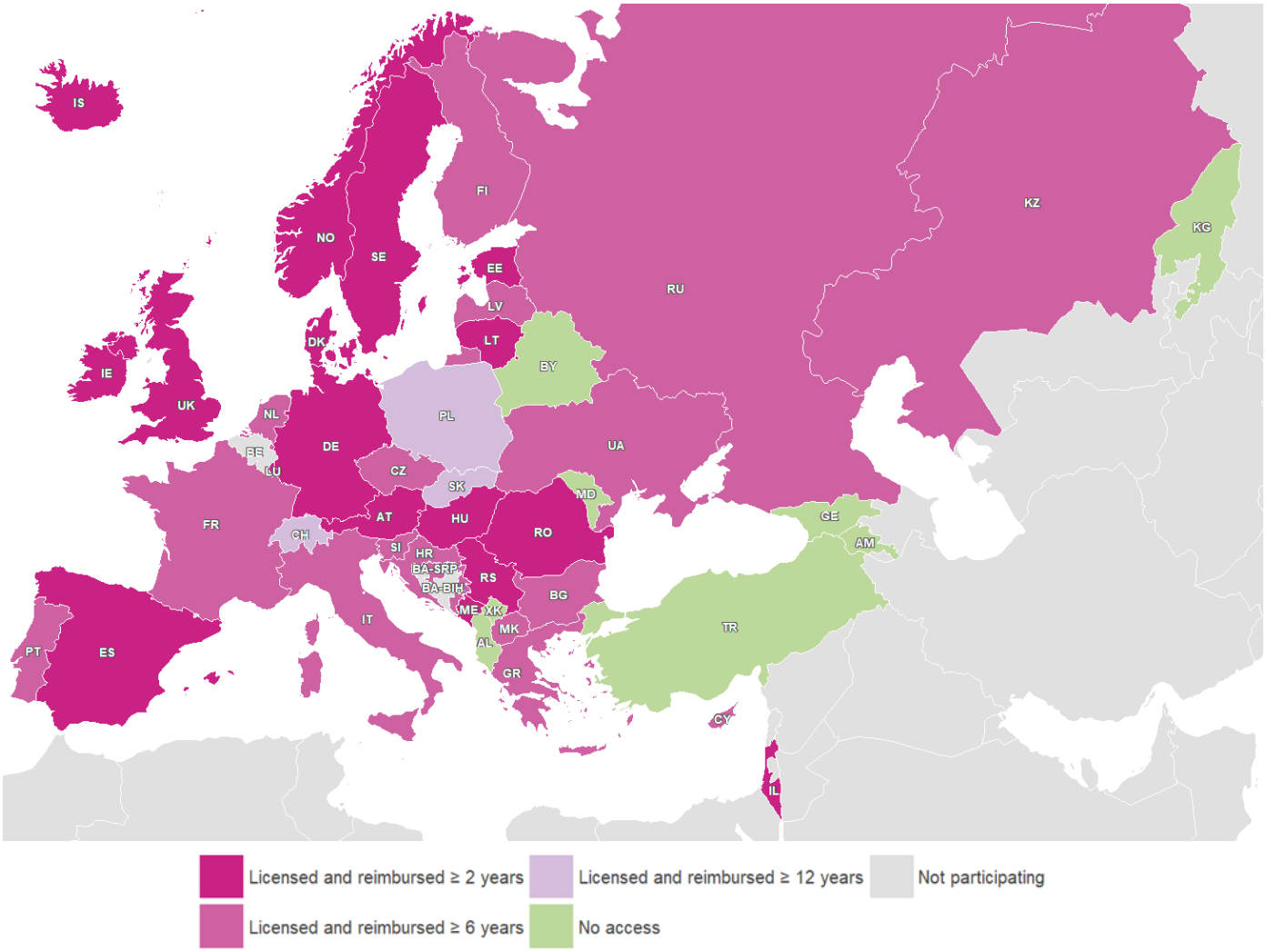
Figure 9.3 Countries where tezacaftor/ivacaftor was licensed and reimbursed in 2024.



Note: BA-Bosnia-Herzegovina: shown as "not participating" because the data were missing for 2024.

9. CFTR modulator therapies

Figure 9.4 Countries where elexacaftor/tezacaftor/ivacaftor was licensed and reimbursed in 2024.



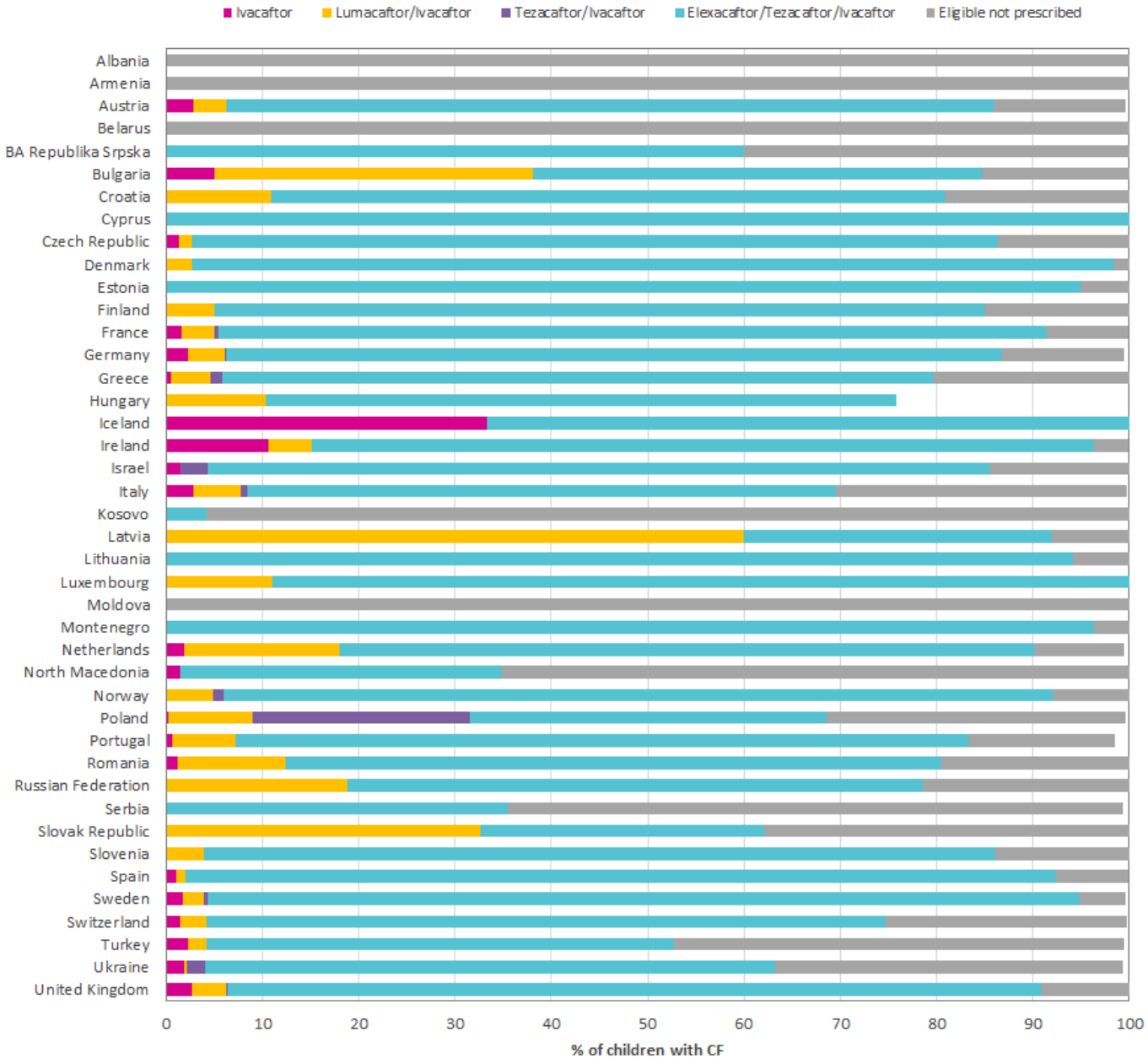
Note: Czech Republic: individual reimbursement system for 2-5 years old.
France: from September 2023 elexacaftor/tezacaftor/ivacaftor was reimbursed for people with CF 2-5 years (early access programme)
Hungary: ≥ 2 years old with at least one F508del mutation from March 2024.
Lithuania: ≥ 2 years old from October 2024.
Norway: ≥ 2 years old from July 2024.
Romania: ≥ 2 years old from December 2024.
Spain: ≥ 2 years old from August 2024.
Sweden: ≥ 2 years old from February 2024.

Note: BA-Bosnia-Herzegovina: shown as "not participating" because the data were missing for 2024.

9. CFTR modulator therapies

Figure 9.5 Elexacaftor/tezacaftor/ivacaftor is the CFTR modulator most commonly used in children, followed by lumacaftor/ivacaftor.

Children and adolescents with CF (<18 years), eligible for at least one modulator, by country and last CFTR modulator prescribed, seen by a clinician in 2024 and who have never had a transplant.

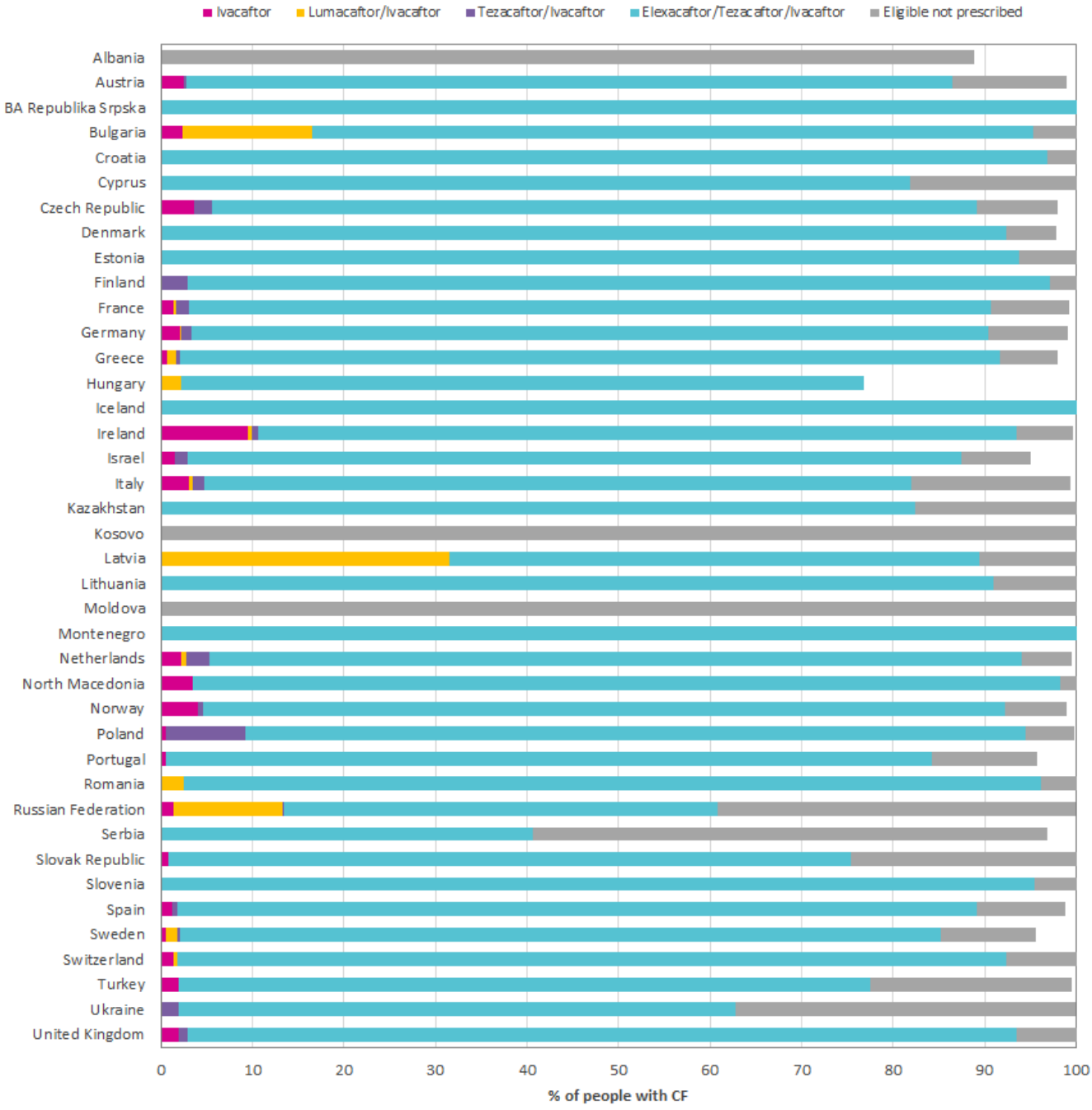


Note: Georgia has <5 eligible children seen in 2024 and are excluded from the graph.

9. CFTR modulator therapies

Figure 9.6 Elexacaftor/tezacaftor/ivacaftor is the CFTR modulator most commonly used in adults.

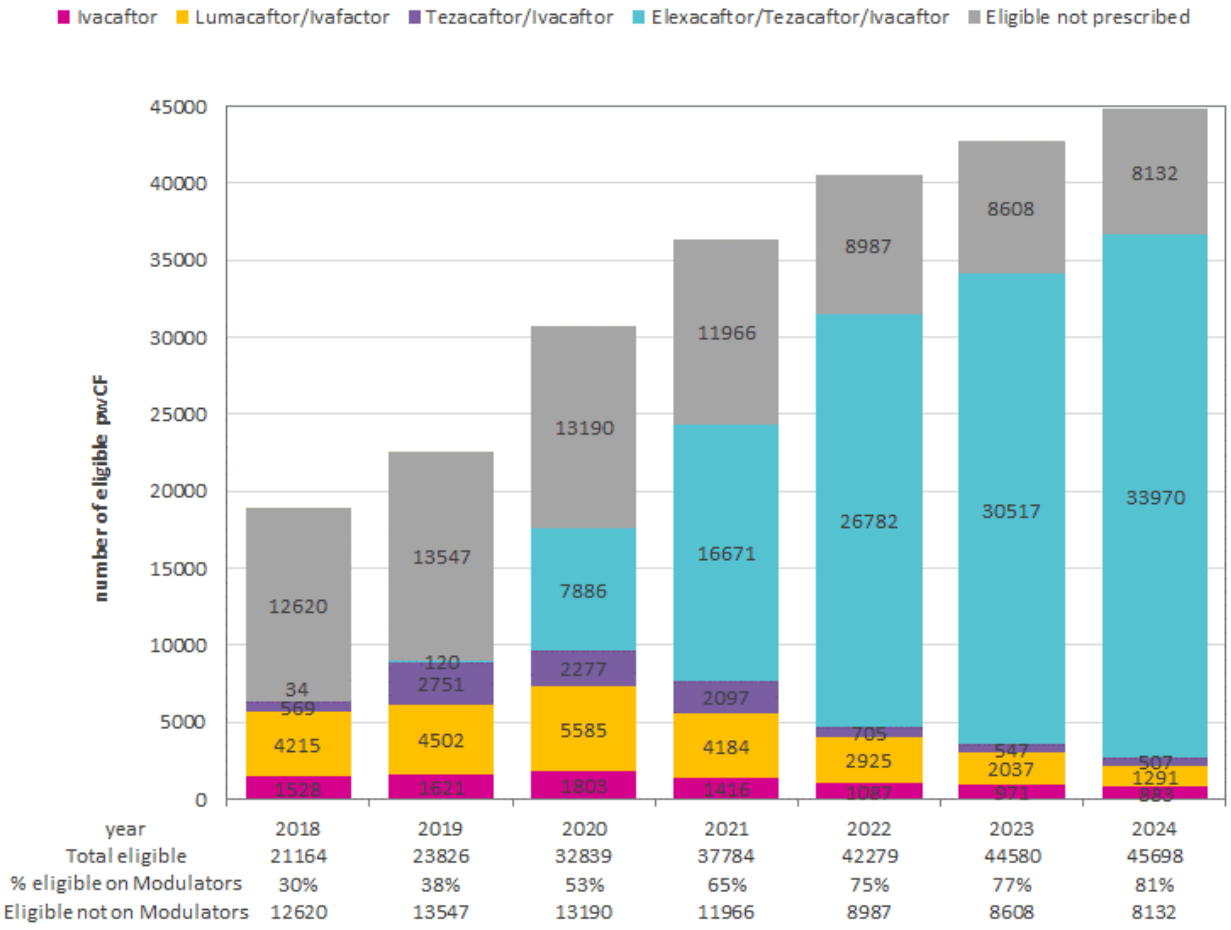
Adults with CF (≥18 years), eligible for at least one modulator, by country and last CFTR modulator prescribed, seen by a clinician in 2024 and who have never had a transplant.



Note: Armenia, Belarus, Georgia and Luxembourg have <5 eligible adults seen in 2024 and are excluded from the graph.

9. CFTR modulator therapies

Figure 9.7 With the expansion of the eligibility criteria and a more extensive reimbursement programme for CFTR modulators in many of the countries in the ECFSPR there has been a considerable increase in their use since 2020.
Use of CFTR modulator therapy from 2018 to 2024.



In this graph we present data over time using cross sectional data per year of people with a confirmed CF diagnosis. All people with CF alive, deceased or not seen during the year of follow-up were included.

10. Pregnancy

Previous patient registry data demonstrated no difference in survival for women with CF who have had one or more pregnancies compared with those who have never been pregnant[1]. There is, however, a higher risk of pregnancy-related complications in women with CF (e.g. gestational diabetes, the need for a caesarean section, premature birth and congenital anomalies).

The introduction of CFTR modulators has significantly improved lung function, nutritional status and overall health in individuals with cystic fibrosis. Before modulators, many women with CF experienced reduced fertility due to thick cervical mucus and overall poor health, however, with improved airway hydration and nutritional status, and better systemic health, more women with CF are conceiving naturally.

While pregnancy is now more achievable it presents unique challenges. The safety of CFTR modulator therapy during pregnancy is still to be ascertained and is under study, with some evidence suggesting potential benefits for both mother and baby, though long-term effects remain unknown. Increased metabolic demands and the need for optimised respiratory and nutritional care make close medical supervision essential. Careful planning and multidisciplinary management are crucial to ensure the best outcome for both mother and child.

We collected information about pregnancies and pregnancy outcome during the year of follow-up.

[1] C.H. Goss at al., Chest 2003;124(4):1460-8.

10. Pregnancy

Table 10.1 Pregnancy and pregnancy outcomes in women with CF (≥16 years) seen in 2024 who have never had a transplant.

Pregnancy and outcome	Number	Percentage
Pregnant, don't know if stopped during the year	13	0.1
Pregnant, ongoing at the end of 2024	263	1.8
Pregnant, stopped during the year	482	3.3
Pregnancy outcome:		
Live birth	375	77.8
Spontaneous abortion (<28weeks)	39	8.1
Still birth (≥28weeks)	3	0.6
Therapeutic abortion for medical reasons	15	3.1
Other	18	3.7
Missing/Unknown	32	6.6
Not Pregnant	13538	93.8
Missing/Unknown	133	0.9

Table 10.2 Pregnancy and pregnancy outcomes in women with CF (≥16 years) seen in 2023 who have never had a transplant.

Pregnancy and outcome	Number	Percentage
Pregnant, ongoing at the end of 2023	247	1.8
Pregnant, stopped during the year	501	3.6
Pregnancy outcome:		
Live birth	410	81.8
Spontaneous abortion (<28weeks)	47	9.4
Still birth (≥28weeks)	1	0.2
Therapeutic abortion for medical reasons	26	5.2
Other	8	1.6
Missing/Unknown	9	1.8
Not pregnant	12566	91.0
Missing/Unknown	495	3.6

11. Lung and other organ transplants

Despite the advent of highly effective CFTR modulators lung transplant is still a realistic scenario for some people with CF. The existence or not of a lung transplant programme varies amongst the countries participating in the ECFSPR and transplant eligibility criteria also vary. The numbers presented in the tables and figures that follow should be considered an indication of accessibility to a regional or national lung transplant programme rather than a reflection of the standards of patient care and health status of the people with CF in a specific country. The same applies to liver transplant, the second most common organ that is transplanted in CF. In this chapter, we also give information on kidney transplant and other (unspecified) organ transplant.

We asked if people have had a transplant or not and, if yes, the year of their (latest) transplant. In some countries people who have had a transplant are no longer registered in the CF centres or the national CF registry because they have been transferred to a transplant centre. For this reason, the figures may report a lower number than the reality but it was not possible to acquire more accurate data.

11. Lung and other organ transplants

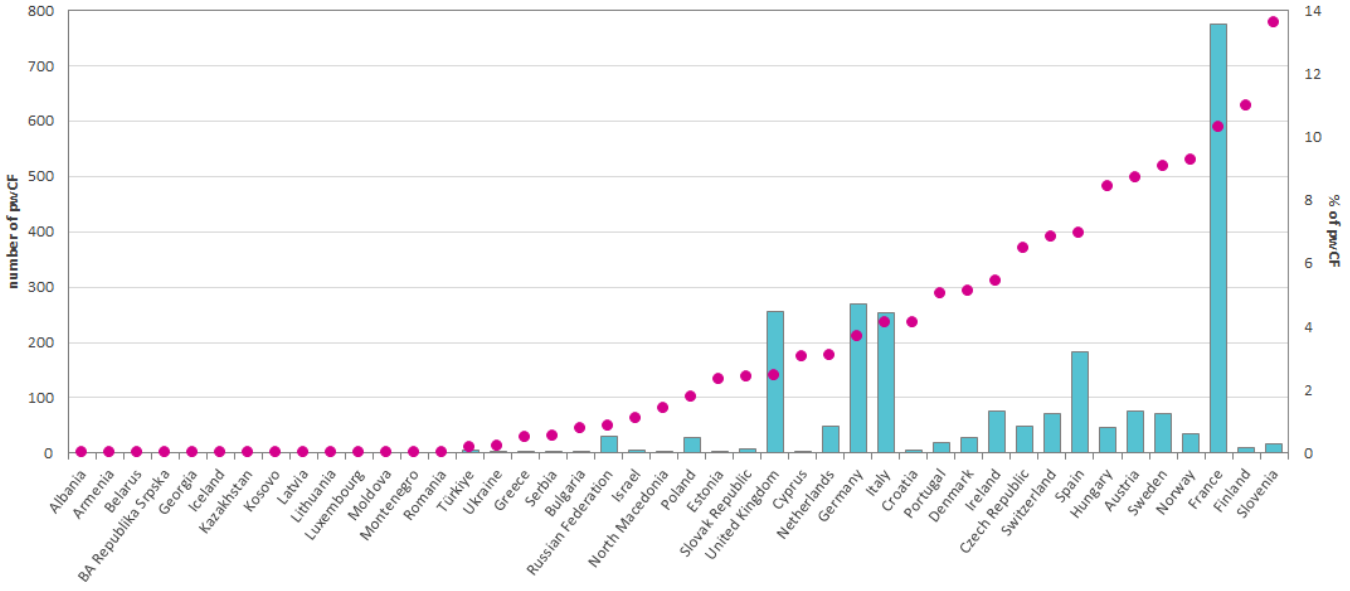
Table 11.1 Number of people with CF alive in 2024 with transplanted lung(s), by age and sex.

Age	Males	Females	Total	Transplants carried out in 2024
0-5	0	0	0	0
6-11	2	1	3	1
12-17	4	14	18	4
18-29	130	206	336	19
30-39	399	406	805	14
40-49	417	375	792	6
50-59	189	162	351	2
60+	42	33	75	1
Total	1183	1197	2380	47

This table shows the number of people with CF alive in 2024 who have had one or more lung transplant(s) at some time in their life, by age group, as well as the number of people who had a lung transplant in 2024.

Figure 11.1 The number and proportion of people with CF living with transplanted lung/s is heterogenous across Europe.

Number of people with CF living in 2024 with transplanted lungs, by country.



This graph shows the number of people with CF alive at 31/12/2024 who have had a lung transplant (light turquoise bars) at some point in their life. The pink dots (right axis) show the percentage of people that were living with transplanted lung in 2024 out of all people with CF that were seen by a clinician in 2024.

11. Lung and other organ transplants

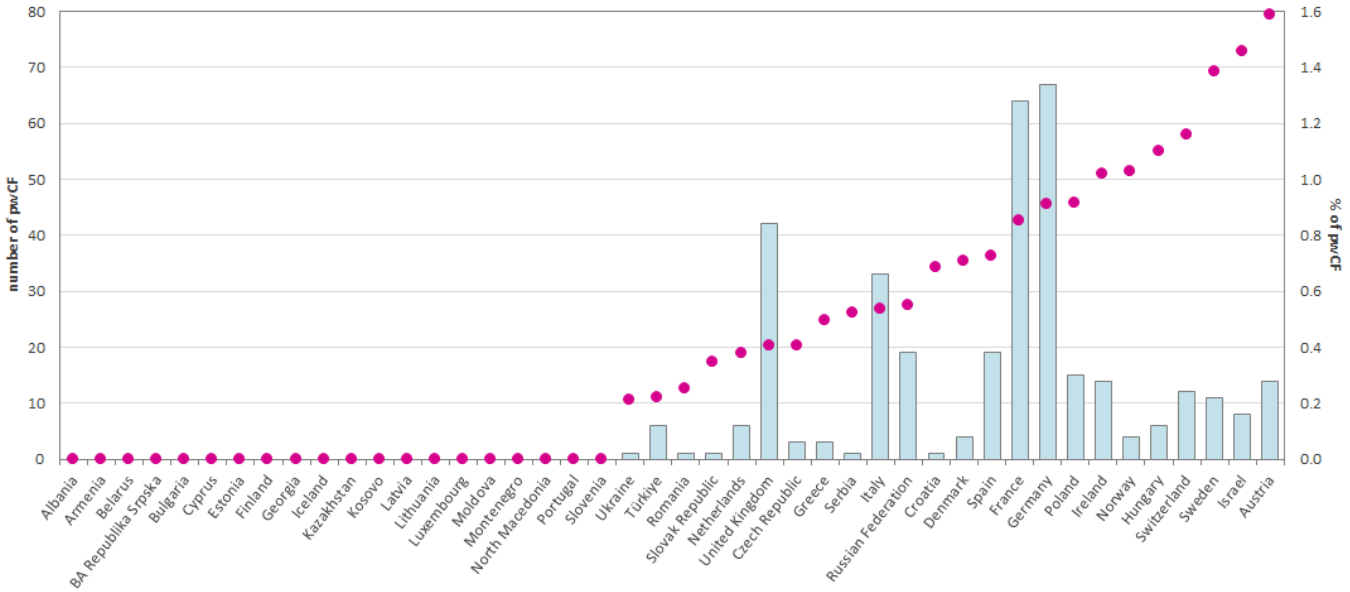
Table 11.2 Number of people with CF living in 2024 with transplanted liver, by age and sex.

Age	Males	Females	Total	Transplants carried out in 2024
0-5	2	0	2	0
6-11	10	2	12	4
12-17	27	7	34	3
18-29	79	54	133	5
30-39	77	33	110	6
40-49	35	10	45	2
50-59	10	8	18	0
60+	1	0	1	0
Total	241	114	355	20

This table shows the number of people with CF alive in 2024 who have had a liver transplant at some time in their life, by age group, as well as the number of people who had a transplant in 2024.

Figure 11.2 The number and proportion of people with CF living with a liver transplant is extremely heterogenous throughout Europe.

Number of people with CF living in 2024 with transplanted liver, by country.



This graph shows the number of people with CF alive at 31/12/2024 who have had a liver transplant (light turquoise bars) at some point in their life. The pink dots (right axis) show the percentage of people living with transplanted liver in 2024 out of all people with CF that were seen in 2024. Note that (left vertical axis) the number of people who have had a liver transplant is much lower than the number of people with transplanted lungs. The main reason for this is that liver disease is only found in a subset of people with CF, whereas lung disease affects almost all people with CF.

11. Lung and other organ transplants

Table 11.3 Number of people with CF living in 2024 with transplanted kidney(s), by age and sex.

Age	Males	Females	Total	Transplants carried out in 2024
0-5	0	0	0	0
6-11	1	0	1	0
12-17	0	0	0	0
18-29	8	11	19	4
30-39	25	30	55	4
40-49	45	40	85	8
50-59	21	16	37	3
60+	9	4	13	0
Total	109	101	210	19

This table shows the number of people with CF alive in 2024 who have had a kidney transplant at some time in their life, by age group, as well as the number of people who had a transplant during 2024.

Table 11.4 Number of people with CF living in 2024 with other transplanted organs (not lung, liver, kidney), by age and sex.

Age	Males	Females	Total	Transplants carried out in 2024
0-5	0	0	0	0
6-11	1	1	2	0
12-17	1	2	3	0
18-29	8	6	14	0
30-39	6	12	18	0
40-49	9	10	19	1
50-59	7	2	9	0
60+	0	0	0	0
Total	32	33	65	1

This table shows the number of people with CF alive in 2024 who have had an organ transplant that is not lung, liver or kidney (other) at some time in their life, by age group, as well as the number of people who had a transplant during 2024.

12. Mortality

Information on mortality and survival in the era of highly effective CFTR modulators is currently a major area of focus in CF. Although we can speculate that these drugs will increase life expectancy in people with CF, the effects can only be monitored in the long-term. In this chapter we present the number of deaths by age group, for males and females. Respiratory disease continues to be the predominant cause of death in people with CF.

We do not present data on survival prediction in this report since mortality data are heterogenous and may be incomplete in the participating countries. However, information on survival is collected and reported by selected National Registries and we refer you to their country-specific annual reports for further reading.

12. Mortality

Table 12.1 Number of deaths in 2024, by age and sex.

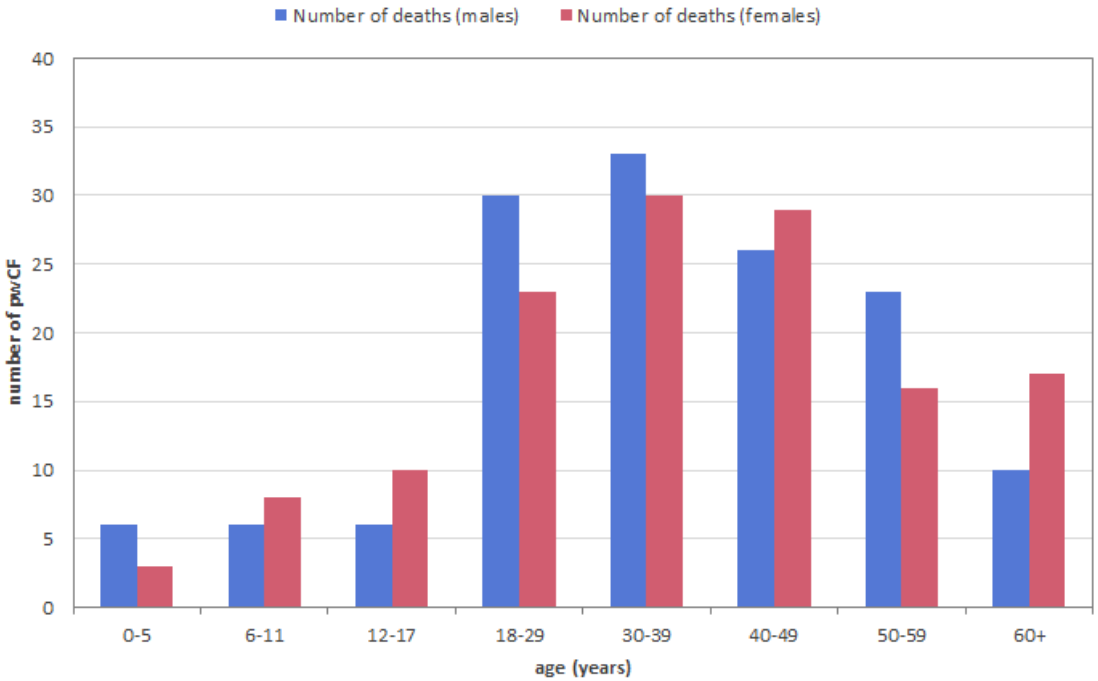
Age at death	Number of male PwCF	% of deaths in this age group (of all male deaths)	Number of female PwCF	% of deaths in this age group (of all female deaths)	Total	% Total
0-5	6	4.3	3	2.2	9	3.3
6-11	6	4.3	8	5.9	14	5.1
12-17	6	4.3	10	7.3	16	5.8
18-29	30	21.4	23	16.9	53	19.2
30-39	33	23.6	30	22.1	63	22.8
40-49	26	18.6	29	21.3	55	19.9
50-59	23	16.4	16	11.8	39	14.1
60+	10	7.1	17	12.5	27	9.8
Total	140		136		276	

Note: For the United Kingdom, all people with a confirmed diagnosis of CF were included (N=11,381). The total number of the CF population presented is 55,198.

This table shows the number of deaths in 2024 by age group and sex. Death in small children is very rare, and the most frequent range of age at death for both sexes is 30-39 years. It is possible that the numbers are under reported because some of the people who died may not have been seen at the CF centre during the year and the information may not have been recorded.

Figure 12.1 Most of the deaths occur between the third and the fifth decade of life in people with CF in Europe.

Age at death distribution of people with CF deceased in 2024, by sex.



This graph shows the distribution of age at death of people with CF who died in 2024, separated by males (blue) and females (red).

12. Mortality

Table 12.2 Cause of death distribution in 2024.

Cause of death in 2024	Number of deaths	Percentage of all deaths
Respiratory	128	46.4
Transplantation	37	13.4
Unknown	26	9.4
Cancer	25	9.1
Non-CF related	23	8.3
Other CF related	17	6.2
Liver-GI	13	4.7
Suicide	5	1.8
Trauma	2	0.7
Total	276	

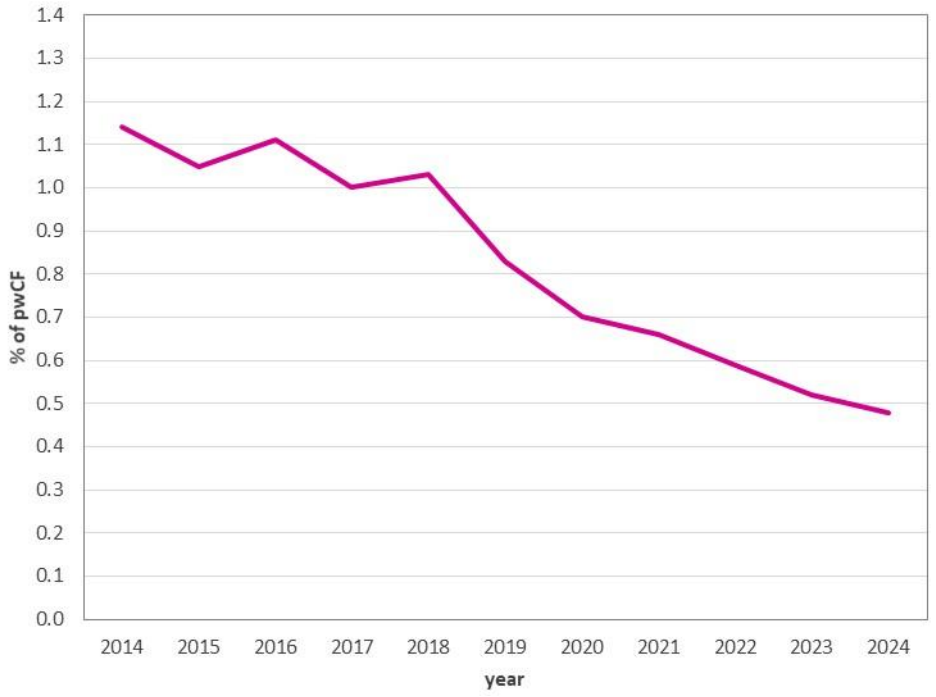
Note: For the United Kingdom, all people with a confirmed diagnosis of CF were included (N=11,381). The total number of the CF population presented is 55,198.

Note: For "Respiratory". Ireland, Germany and the United Kingdom use “cardio/respiratory”.

The table shows cause of death for people with CF who died in 2024. The most frequent cause of death was respiratory disease.

Figure 12.2 In the last decade the proportion of PwCF deceased in a year relative to the total number of PwCF in the year has decreased throughout Europe.

PwCF deceased as a percentage of all PwCF in the years from 2014 to 2024.



In this graph data over time are presented using cross sectional data per year. People with CF who are alive, deceased, or not seen during the year of follow-up were included and those who were lost to follow-up were excluded.

13. Data quality

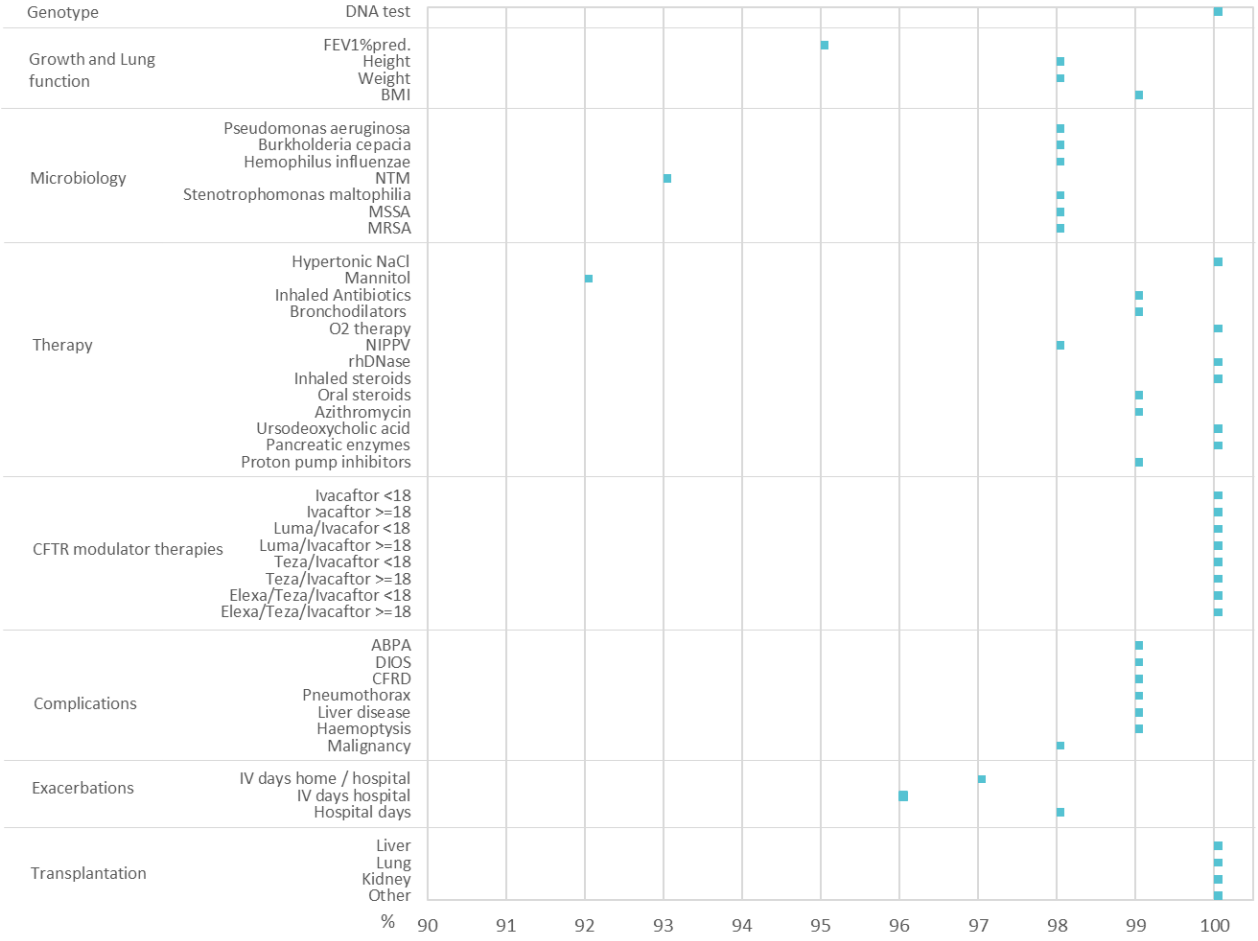
Data that will be employed in vital research and pharmacoepidemiology studies, inform public health planning and serve as an instrument to monitor and review a range of patient outcomes need to be of demonstrably high quality.
Several measures are in place in the ECFSPR that demonstrate both our ongoing commitment to quality and our support for the contributing centres and national registries, namely: guidance documentation, training, on-demand assistance to participants on all aspects of the data cycle, a customised software with inbuilt controls and other rigorous checks.
In addition, in 2018 we launched an initiative to verify and validate data at source in participating centres; objectives are to quantify data completeness, consistency and the accuracy of the data submitted to the ECFSPR. The visits also offer an invaluable opportunity to discuss the quality, relevance and reliability of the data and the methods and procedures employed to collect and archive them.
By "Consistency" we mean adherence by the centre to the variable definitions, options, and parameters used by the Registry.
"Accuracy" of data-input is the proportion of values recorded in the ECFSPR software that matches the medical records and is consistent with the ECFSPR definitions and limits.
Consistency was determined for a selection of variables by comparing the data submitted to the ECFSPR with the data in the patient medical health record at the centres. The variables checked are the same for each centre and we chose these specific ones because they are more challenging to collect and/or more open to misinterpretation (based on ECFSPR experience and participant feedback); they are also statistically significant.
Based on the outcomes from data quality visits to participating countries in the ECFSPR between November 2018 and April 2024, we published a manuscript in the Journal of Rare Diseases in December 2025 where we present the results. We visited and validated data in 34 out of 40 (85%) countries encompassing 7.5% of the ECFSPR dataset from 2021. Validated demographic data (month and year of birth and sex) and transplantation status was 99% accurate while annual clinical data on disease progression (selected data on microbiology, medication and complications) was 94% correct. Accuracy for genetic data was 96.6% (based on 85% original genetic report availability). Anthropometric measurements and lung function data were accurate at 87-88% while data on liver disease was 92% accurate[1].
In this chapter we present a synopsis of the overall quality of the ECFPSR data based on the factors of completeness and accuracy. Unlike the rest of this report, data quality results refer to both 2023 and 2024; the overall results have been shown in order to illustrate areas where improvement has been demonstrated.

[1]Naehrlich et al., Orphanet J Rare Dis. 2025;20(1):622.

13. Data quality

Figure 13.1 The overall completeness of data for all variables for the countries participating in the ECFSPR in 2024 is 99%.

Completeness of the data in 2024, for all PwCF seen by a clinician, in all participating countries, overall percentages by variable.



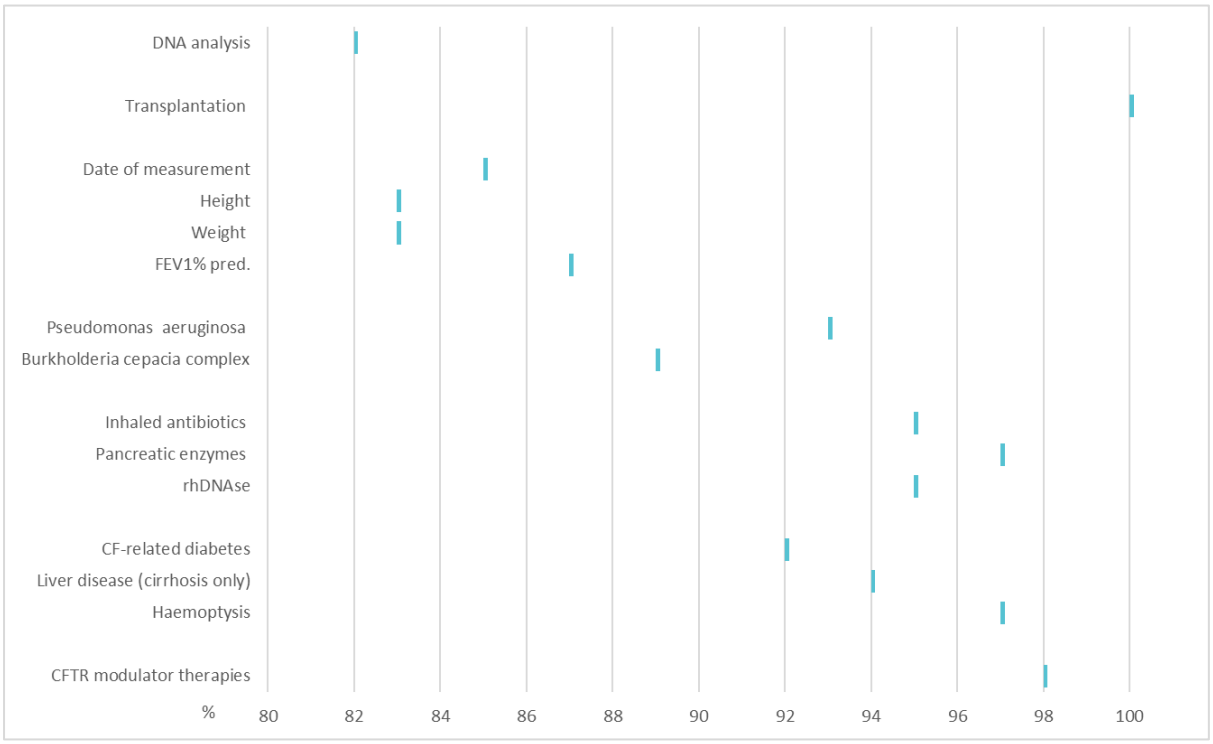
Note: Completeness for FEV1 is evaluated only for individuals with CF ≥ 6 years.
Completeness for BMI is evaluated only for individuals with CF ≥ 2 years.

For lung function and microbiology, data completion is in the range 93-98%. Lung function data are dependent on the ability of a person with CF to perform spirometry correctly and the existence of the corresponding backup documentation. Likewise, data completeness for microbiology depends on sample availability and access to testing laboratories.

13. Data quality

Figure 13.2 The validated clinical data amounts to 4% of the PwCF in these countries from 2023 and 2024.

Data accuracy for the follow-up years 2023 and 2024 in the countries visited, overall percentages by variable.



We validated data (from 2023 and 2024) for 4% of the PwCF from 15 countries. Eight countries with established national CF registries (France, Germany, Ireland, Italy, the Netherlands, Sweden, Türkiye and United Kingdom) have their own internal data validation programme and they provided us with the results presented in this report.

Table 13.1 Accuracy of data (quartiles) for PwCF, for the follow-up years 2023 and 2024 for the countries visited.

Data variables	25th percentile	50th percentile	75th percentile
DNA analysis	81	86	92
Transplantation	100	100	100
Date of measurement	79	89	96
Height	76	89	94.5
Weight	78	88	95.5
FEV1% pred.	87	93	96.5
Pseudomonas aeruginosa	92	95	98
Burkholderia cepacia complex	94	98	99.5
Inhaled antibiotics	96	98	98.5
Pancreatic enzymes	99	100	100
rhDNase	95	97	99
CF-related diabetes	95	98	99
Liver disease (cirrhosis only)	93	97	98.5
Haemoptysis	98	100	100
CFTR modulator therapies	99	99	100

The overall accuracy of validated data in the years 2023 and 2024 is 91%. Genotype, height, weight and lung function and the corresponding date of measurement are the variables that proved most challenging for data providers. The accuracy of genetic data can only be verified if the original genetic report is available. For the other four variables, in order to minimise errors and improve adherence to the ECFSPR definitions, the centres agreed to review their procedures and the organisation of supporting documentation across the various hospital departments.

Publications

The ECFSPR database is an excellent and unique resource for researchers and the data are actively used by many individuals, institutions and companies. Applications for projects are handled in accordance with the ECFSPR guidelines. You will find more information on the rigorous research project application process on our website here: Research Projects - Applications.
From 2011 to March 2026 (time of writing) we had received a total of 146 applications to use Registry data for projects. The majority of these requests, 85%, originated from researchers from the European Cystic Fibrosis Society members and other institutes; 15% of the applications came from Industry. Many of these research projects resulted in publications and other publications are in the pipeline.

In 2025 the following publications and abstracts were accepted:

Publications

- Variability in disease severity among cystic fibrosis patients carrying residual-function variants: data from the European Cystic Fibrosis Society Patient Registry. Mei-Zahav M, Orenti A, Jung A, Kerem E. ERJ Open Res. 2025 Jan 13;11(1):00587-2024. doi: 10.1183/23120541.00587-2024.

- Methicillin-resistant *Staphylococcus aureus* and pulmonary outcome in people with cystic fibrosis: a European Cystic Fibrosis Patient Registry data analysis. Mei-Zahav M, Dotan M, Annicchiarico L, Orenti A, Prais D. ERJ Open Res. 2025 Sep 1;11(5):01284-2024. doi: 10.1183/23120541.01284-2024.

- Respiratory infections after elexacaftor/tezacaftor/ivacaftor treatment in people with cystic fibrosis: analysis of the European Cystic Fibrosis Society Patient Registry. Pollak M, Gambazza S, Orenti A, De Rose V, Prais D, Kerem E, Mei Zahav M. ERJ Open Res. 2025 Aug 4;11(4):01248-2024. doi: 10.1183/23120541.01248-2024.

- Factors associated with sustained Pseudomonas aeruginosa infection following elexacaftor/tezacaftor/ivacaftor treatment: Real-world data from the European cystic fibrosis society patient registry. Pollak M, Gambazza S, Orenti A, Prais D, Kerem E, Mei-Zahav M; ECFSPR Steering Group. J Cyst Fibros. 2025 Nov;24(6):1098-1104. doi: 10.1016/j.jcf.2025.08.019.

- Global prevalence of CFTR variants with respect to their responsiveness to elexacaftor-tezacaftor-ivacaftor. Burgel PR, Orenti A, Cromwell E, Macek M, Gutierrez HH, Karadag B, Faro A, van Rens JG, Naehrlich L, Bakkeheim E, Carr SB, Lindblad A, Zolin A, Lammertyn E, Ruseckaite R, Zampoli M, Byrnes CA, da Silva-Filho L, Elbert A, Cheng SY, Stephenson AL; on the behalf of the ECFSPR scientific committee and the Global CF Registry Collaboration. J Cyst Fibros. 2025 Nov;24(6):1017-1026. doi: 10.1016/j.jcf.2025.10.007.

- Health Inequity in People with Cystic Fibrosis: Can We Close the Gap? Sermet-Gaudelus I, Orenti A, Hatziagorou E, Bakkeheim E, Naehrlich L, Kerem E. Ann Am Thorac Soc. 2025 Sep 10. doi: 10.1513/AnnalsATS.202501-052OC.

- Changes in use of inhaled chronic antibiotics in the European CF population: an ECFS patient registry study. Muhlebach MS, Naehrlich L, Carr SB, Orenti A, Gambazza S. Respir Med. 2025 Dec;250:108465. doi: 10.1016/j.rmed.2025.108465.

- Heterogeneous use of multiple breath washout in cystic fibrosis across age groups and European countries: an ECFSPR analysis. Zolin A, Gambazza S, Lindblad A, Gkolia P, Saunders C, Naehrlich L; European Cystic Fibrosis

Society Patient Registry Steering Group. J Cyst Fibros. 2025 Dec 6:S1569-1993(25)02532-9. doi: 10.1016/j.jcf.2025.12.001.

- Data accuracy in the European Cystic Fibrosis Society Patient Registry: results of an on-site data validation project. Naehrlich L, Fox A, Krasnyk M, Wollscheid N, Mayor SL, Zolin A, Prasad V; ECFS Patient Registry Steering Group. Orphanet J Rare Dis. 2025 Dec 2;20(1):622. doi: 10.1186/s13023-025-04153-w.

Abstracts

- Evaluating The Real-World Effectiveness Of A New Class Of Drugs For Cystic Fibrosis: A Study Based On European Cystic Fibrosis Society Patient Registry Data. Adamoli A, Orenti A, Gambazza S, Zolin, A., Ambrogi F, De Rose V, on behalf of ECFSPR Steering Group. XIIIth Società Italiana di Statistica Medica ed Epidemiologia Clinica (SISMEC) National Congress 2025 – Pavia (IT), Volume 20 Supplement 1, September 2025.

- Clinical Outcomes and Survival Differences in People with Cystic Fibrosis Living in Europe. Orenti A, Naehrlich L, Bakkeheim E, Hatziagorou E, Kerem E, Sermet-Gaudelus I., on behalf of ECFSPR Steering Group. XIIIth Società Italiana di Statistica Medica ed Epidemiologia Clinica (SISMEC) National Congress 2025 – Pavia (IT), Volume 20 Supplement 1, September 2025.

- Incidence, Prevalence and Patterns of Stenotrophomonas Maltophilia Infection in People with Cystic Fibrosis across Europe. Zanzi R, Orenti A, Zolin A, Mei-Zahav M, Prais D, Gambazza S, on behalf of ECFSPR Steering Group. XIIIth Società Italiana di Statistica Medica ed Epidemiologia Clinica (SISMEC) National Congress 2025 – Pavia (IT), Volume 20 Supplement 1, June 2025.

- Changes in prescription of inhaled antibiotics between 2012-2019 in the European Cystic Fibrosis Patient Registry. Muhlebach MS, Carr S, Naehrlich L, Orenti A, Gambazza S, on behalf of ECFSPR Steering Group. Journal of Cystic Fibrosis, Volume 24, Supplement 1, S181-S182, June 2025.

- Transitioning to race-neutral reference equations on lung function for people with cystic fibrosis: which consequences for Europe? Zolin A, Gambazza S, Burgel PR, Carr S, Lammertyn E, Lindblad A, Macek M, Bakkeheim E, Naehrlich L, on behalf of ECFSPR Steering Group. Journal of Cystic Fibrosis, Volume 24, Supplement 1, S45, June 2025.

- Factors associated with persistent Pseudomonas aeruginosa infection following elexacaftor/tezacaftor/ivacaftor treatment: insights from the European Cystic Fibrosis Society Patient Registry. Pollak M, Gambazza S, Orenti A, De Rose V, Prais D, Kerem E, Mei-Zahav M, on behalf of ECFSPR Steering Group. Journal of Cystic Fibrosis, Volume 24, Supplement 1, S2, June 2025.

A complete overview of publications is available on our website.

Sponsors

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LIFC
Lega Italiana
Fibrosi Cistica

Cystische Fibrose Schweiz
Mucoviscidose Suisse
Fibrosi Cistica Svizzera
Cystic Fibrosis Switzerland

association luxembourgeoise
de lutte contre la mucoviscidose

Appendix 1 Tables

1. Demographics

Table A1.1 Age at follow-up: descriptive statistics, by country and overall. People with CF alive on 31/12/2024.

Country	Number	Mean (average age)	Min (age of the youngest PwCF)	Median (half the PwCF are younger than this age)	Max (age of the oldest PwCF)
Albania	79	12.6	1.5	12.6	23.4
Armenia	38	11.3	1.2	10.3	33.0
Austria	905	23.7	0.2	22.0	70.5
Belarus	148	10.1	0.2	10.8	18.6
BA Republika Srpska	25	15.1	3.3	14.7	44.7
Bulgaria	263	17.9	0.5	15.2	70.5
Croatia	148	18.1	1.3	17.7	40.5
Cyprus	35	25.7	5.5	22.1	70.2
Czech Republic	753	20.8	0.1	19.4	69.0
Denmark	572	26.1	0.3	25.7	75.0
Estonia	45	18.5	1.0	15.1	55.1
Finland	91	25.3	0.3	23.0	60.9
France	7470	26.2	0.0	24.7	89.0
Georgia	85	10.7	1.2	9.9	39.1
Germany	7664	25.2	0.0	24.2	87.7
Greece	687	25.1	0.4	24.4	77.8
Hungary	544	19.3	0.0	16.8	75.9
Iceland	16	18.7	2.5	16.3	44.0
Ireland	1398	25.0	0.0	23.7	75.7
Israel	594	28.3	0.5	26.3	82.7
Italy	6189	27.3	0.0	24.9	92.1
Kazakhstan	29	22.8	15.3	20.5	44.3
Kosovo	33	10.6	0.5	9.0	23.3
Latvia	52	15.2	1.2	13.5	38.0
Lithuania	52	19.1	0.5	20.0	40.5
Luxembourg	25	11.3	1.3	7.2	34.2
Rep of Moldova	57	14.6	0.6	12.4	38.7
Montenegro	42	13.4	0.2	11.9	44.4
Netherlands	1600	27.5	0.0	26.0	76.2
North Macedonia	169	17.1	0.3	16.2	45.6
Norway	393	28.2	0.7	27.5	81.3
Poland	1722	17.8	0.2	15.9	64.5
Portugal	409	23.6	0.4	21.5	71.0
Romania	421	12.6	0.1	11.6	47.0
Russian Fed.	4271	15.4	0.1	13.5	67.0
Serbia	227	14.7	0.1	12.9	51.1
Slovak Republic	322	22.5	0.1	21.2	85.0
Slovenia	126	21.9	0.4	20.3	69.1
Spain	2768	25.5	0.0	22.5	80.5
Sweden	806	27.9	0.5	26.3	80.6
Switzerland	1114	25.5	0.1	24.0	84.0
Türkiye	2745	11.8	0.1	10.3	51.0
Ukraine	545	14.1	0.2	13.1	44.7
United Kingdom	11330	25.3	0.0	23.6	90.4
Total	57012	23.5	0.0	20.8	92.1

Back to fig. 1.4

1. Demographics

Table A1.2 Proportion of children (<18 years) and adults (≥18 years), by country and overall. People with CF alive on 31/12/2024.

Country	Children (<18 years)		Adults (≥18 years)	
	Number	%	Number	%
Albania	66	83.5	13	16.5
Armenia	30	79.0	8	21.1
Austria	356	39.3	549	60.7
Belarus	144	97.3	4	2.7
BA Republika Srpska	17	68.0	8	32.0
Bulgaria	151	57.4	112	42.6
Croatia	79	53.4	69	46.6
Cyprus	14	40.0	21	60.0
Czech Republic	352	46.8	401	53.3
Denmark	202	35.3	370	64.7
Estonia	26	57.8	19	42.2
Finland	34	37.4	57	62.6
France	2551	34.2	4919	65.9
Georgia	77	90.6	8	9.4
Germany	2844	37.1	4820	62.9
Greece	234	34.1	453	65.9
Hungary	287	52.8	257	47.2
Iceland	9	56.3	7	43.8
Ireland	528	37.8	870	62.2
Israel	162	27.3	432	72.7
Italy	2149	34.7	4040	65.3
Kosovo	28	84.9	5	15.2
Latvia	32	61.5	20	38.5
Lithuania	22	42.3	30	57.7
Luxembourg	20	80.0	5	20.0
Rep of Moldova	40	70.2	17	29.8
Montenegro	30	71.4	12	28.6
Netherlands	520	32.5	1080	67.5
North Macedonia	96	56.8	73	43.2
Norway	134	34.1	259	65.9
Poland	990	57.5	732	42.5
Portugal	168	41.1	241	58.9
Romania	321	76.3	100	23.8
Russian Federation	2900	67.9	1371	32.1
Serbia	155	68.3	72	31.7
Slovak Republic	138	42.9	184	57.1
Slovenia	56	44.4	70	55.6
Spain	1081	39.1	1687	61.0
Sweden	281	34.9	525	65.1
Switzerland	426	38.2	688	61.8
Türkiye	2207	80.4	538	19.6
Ukraine	392	71.9	153	28.1
United Kingdom	4375	38.6	6955	61.4
Total	24735	43.4	32277	56.6

Back to fig. 1.5

4. Lung function

Table A4.1 FEV_1% of predicted for children: descriptive statistics, by country and overall. People with CF aged 6-11 years who have never had a transplant.

Country	Number	Number of missing	Mean (average FEV1% value)	Min (lowest FEV1% value)	25th pctl (25% of the PwCF have a FEV1% lower than the value)	Median (half the PwCF have a FEV1% lower than the value)	75th pctl (75% of the PwCF have a FEV1% lower than the value)	Max (highest FEV1% value)
Albania	10	3	80.5	61.5	74.4	80.9	87.2	102.1
Armenia	10	1	83.8	39.2	63.0	86.7	91.0	128.4
Austria	130	0	104	46.0	94.8	105.0	115.2	145.3
Belarus	24	20	84.6	53.2	72.7	79.5	91.8	178.4
Bulgaria	53	2	95.2	35.9	84.5	101.3	110.6	126.0
Croatia	26	1	91.3	34.3	85.2	93.9	103.0	125.5
Cyprus	5	1	91.3	67.4	77.8	87.9	103.7	119.8
Czech Republic	116	3	108	68.6	97.3	106.7	116.5	163.3
Denmark	72	0	107	74.6	100.2	105.1	113.7	142.8
Estonia	8	0	103	83.1	99.0	104.1	110.3	112.9
Finland	9	0	99.4	74.6	95.5	100.1	106.9	111.3
France	831	35	105	43.7	95.6	105.1	114.7	180.5
Georgia	14	7	74.6	52.0	66.4	77.4	80.2	91.2
Germany	1026	15	103	31.4	94.6	103.5	111.8	150.0
Greece	72	4	112	56.1	97.1	114.3	126.0	146.0
Hungary	82	8	91.5	36.6	82.5	91.6	104.2	121.9
Ireland	169	12	101	55.6	94.5	102.1	109.6	131.7
Israel	46	3	98.2	72.8	89.0	95.5	105.6	151.5
Italy	777	44	105.5	40.2	96.2	105.9	114.9	158.1
Latvia	10	2	87.4	57.6	84.2	92.7	98.0	107.0
Lithuania	7	0	111	99.4	103.5	110.9	116.2	127.9
Rep of Moldova	14	3	81.7	36.1	58.4	88.5	97.7	109.0
Montenegro	12	0	112	85.7	93.7	115.8	123.1	139.5
Netherlands	137	2	104	36.7	95.3	103.6	114.2	140.3
North Macedonia	20	5	86.4	50.0	75.6	93.9	100.3	107.6
Norway	47	0	103	74.0	94.9	100.8	110.9	135.2
Poland	312	35	97.2	37.6	87.3	98.6	108.9	156.1
Portugal	58	6	104	55.3	96.7	104.8	116.7	132.9
Romania	91	15	94.7	39.5	84.5	95.5	105.2	136.5
Russian Federation	696	193	94.6	18.4	84.0	95.6	105.6	192.5
Serbia	41	6	95.9	58.7	87.2	98.3	102.9	120.8
Slovak Republic	43	1	96.2	60.4	88.4	97.2	106.8	131.6
Slovenia	23	0	98	71.1	90.8	100	107.4	113.9
Spain	384	15	105	44.6	96.6	106.6	115.4	144.0
Sweden	87	3	103	64.2	96.2	102.5	112.2	140.8
Switzerland	145	0	106	59.3	97.4	105.9	115.4	144.0
Türkiye	654	226	88.6	20.9	75.0	91.5	103.5	149.7
Ukraine	107	21	92.8	41.1	84.0	95.5	103.2	141.0
United Kingdom	1448	83	102	20.5	93.7	101.8	110.3	175.7
Total	7825	788	100.5	18.4	91.5	101.7	111.2	192.5

Note: BA-Republika Srpska, Iceland, Kazakhstan, Kosovo and Luxembourg have <5 individuals aged 6-11 years at the date of FEV_1 measurement and the countries are excluded from the table.

Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review; this means the value could be from 2023 or 2024.
The UK reported the FEV1 of the best FEV1pp from the period between annual reviews. This also means that the value could be from 2023 or 2024.

Back to fig. 4.1

4. Lung function

Table A4.2 FEV_1% of predicted for children: descriptive statistics, by country and overall. People with CF aged 12-17 years who have never had a transplant.

Country	Number	Number of missing	Mean (average FEV1% value)	Min (lowest FEV1% value)	25th pctl (25% of the PwCF have a FEV1% lower than the value)	Median (half the PwCF have a FEV1% lower than the value)	75th pctl (75% of the PwCF have a FEV1% lower than the value)	Max (highest FEV1% value)
Albania	17	1	77.2	51.4	65.9	72.5	89.3	107.7
Armenia	9	0	71.3	27.8	56.7	69.1	90.8	96.3
Austria	133	1	99.0	37.4	91.5	100.2	107.7	134.5
Belarus	33	17	72.5	22.3	59.4	77.5	83.6	109.4
BA Rep Srpska	6	0	99.4	79.9	93.0	102.4	106.4	112.3
Bulgaria	50	0	85.9	24.7	76.2	91.1	99.7	128.3
Croatia	28	1	86.8	47.5	78.9	88.0	98.2	125.2
Czech Republic	127	0	101.7	32.8	93.9	102.2	112.8	133.9
Denmark	59	0	102.0	38.2	91.4	101.9	112.3	139.0
Estonia	9	0	92.0	53.3	85.6	91.7	99.7	133.5
Finland	18	0	86.3	40.0	74.1	91.5	98.3	111.8
France	1012	9	97.9	22.3	89.4	99.4	107.9	154.9
Georgia	9	7	67.0	37.0	52.9	77.2	78.2	86.0
Germany	923	9	96.6	31.4	88.4	97.7	106.6	138.9
Greece	103	2	107.6	48.2	92.0	108.8	124.6	155.7
Hungary	86	4	86.2	34.9	73.1	86.5	99.9	141.9
Ireland	203	4	97.6	32.8	90.7	98.2	106.8	123.9
Israel	76	1	89.7	22.7	81.5	92.1	100.3	117.7
Italy	840	15	100.5	27.4	92.1	101.8	111.1	153.6
Kazakhstan	8	0	81.3	36.0	68.8	82.7	92.4	126.4
Latvia	10	0	87.1	56.1	73.8	84.7	102.2	118.0
Lithuania	5	1	82.2	30.6	77.6	97.3	98.4	107.2
Luxembourg	5	0	92.9	79.0	91.3	94.5	95.0	104.8
Rep of Moldova	10	1	66.5	34.0	42.5	67.7	86.6	113.8
Montenegro	8	0	105.5	92.1	96.9	106.2	112.4	120.5
Netherlands	174	2	98.2	43.7	90.2	98.7	107.3	130.9
North Macedonia	21	0	90.3	41.3	84.9	95.9	102.9	118.8
Norway	39	1	98.4	44.6	88.9	102.4	110.9	121.6
Poland	378	9	94.6	28.3	87.1	97.9	107.2	131.3
Portugal	61	4	98.6	38.6	88.8	98.8	109.6	129.1
Romania	96	12	85.2	21.5	72.7	88.0	100.1	131.3
Russian Federation	680	148	87.3	18.7	76.5	89.7	101.4	150.4
Serbia	43	0	84.6	29.1	71.2	89.4	101.7	113.0
Slovak Republic	42	0	95.0	60.5	89.0	96.7	103.0	114.3
Slovenia	25	0	96.9	71.4	91.3	98.9	107.0	112.6
Spain	385	4	96.4	32.0	88.1	97.3	106.6	135.3
Sweden	110	3	97.2	35.8	88.9	96.4	108.7	135.4
Switzerland	153	1	99.1	49.2	90.6	98.9	108.0	134.6
Türkiye	531	74	80.1	12.0	67.4	83.9	96.2	128.2
Ukraine	102	20	85.1	25.0	71.5	87.8	95.8	127.3
United Kingdom	1462	72	96.4	26.4	88.4	97.1	105.6	146.9
Total	8099	427	94.7	12.0	85.6	96.8	106.4	155.7

Note: Cyprus, Iceland and Kosovo have <5 individuals aged 12-17 years at the date of FEV_1 measurement and the countries are excluded from the table.
Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024.
The UK reported the FEV1 of the best FEV1pp from the period between annual reviews which also means that the value could be from2023 or 2024.

Back to fig. 4.2

4. Lung function

Table A4.3 FEV_1% of predicted for adults: descriptive statistics, by country for adults with CF aged 18-39 years who have never had a transplant.

Country	Number	Number of missing	Mean (average FEV1% value)	Min (lowest FEV1% value)	25th pctl (25% of the PwCF have a FEV1% lower than the value)	Median (half the PwCF have a FEV1% lower than the value)	75th pctl (75% of the PwCF have a FEV1% lower than the value)	Max (highest FEV1% value)
Albania	7	0	71.5	54.3	65.1	69.9	76.4	92.8
Armenia	5	0	72.5	38.8	60.6	75.2	91.4	96.6
Austria	344	2	87.3	24.4	72.5	90.5	103.3	140.8
BA Rep Srpska	7	0	79.2	26.8	67.2	87.5	97.6	105.0
Bulgaria	79	2	74.7	21.4	56.6	76.8	94.2	129.3
Croatia	60	0	80.2	18.0	64.7	84.9	99.9	126.9
Cyprus	13	0	67.1	34.3	53.9	75.0	83.0	95.6
Czech Republic	272	3	83.0	17.9	70.9	88.0	99.8	124.3
Denmark	233	0	92.3	25.4	80.1	96.3	106.8	137.4
Estonia	13	0	47.4	11.4	31.8	49.1	61.1	83.1
Finland	32	1	75.4	31.8	62.7	77.9	91.7	111.4
France	2994	29	83.5	17.3	68.2	86.4	100.2	150.1
Germany	3012	26	80.9	17.5	64.1	84.4	98.8	138.5
Greece	279	5	86.1	16.0	68.6	89.4	104.6	158.8
Hungary	162	5	68.3	22.8	46.5	70.0	89.0	129.2
Iceland	6	0	92.2	80.9	89.1	92.8	98.3	99.2
Ireland	534	30	79.7	20.0	63.3	85.1	96.9	134.2
Israel	267	6	77.8	24.0	61.1	80.6	94.3	122.4
Italy	2228	140	87.1	15.6	72.9	91.6	103.8	141.0
Kazakhstan	19	1	61.2	26.1	29.2	64.1	86.3	95.9
Latvia	19	0	72.3	18.4	52.2	81.1	93.8	99.2
Lithuania	26	1	63.7	19.4	35.4	62.9	84.9	106.8
Luxembourg	5	0	93.9	41.9	88.9	109.1	113.9	115.5
Rep of Moldova	12	2	62.9	29.0	53.1	63.9	76.7	84.2
Montenegro	9	0	88.1	51.6	61.4	92.4	102.1	125.8
Netherlands	652	7	82.0	20.9	66.6	85.0	98.8	132.7
North Macedonia	58	1	74.1	26.9	58.2	74.9	91.8	124.0
Norway	131	0	85.9	28.7	76.1	90.7	100.1	142.6
Poland	529	6	77.5	17.0	56.0	80.5	98.2	134.4
Portugal	145	2	78.0	26.9	60.0	80.5	96.6	115.2
Romania	72	2	74.9	17.6	61.1	78.7	91.8	119.1
Russian Federation	666	289	65.6	18.2	44.2	66.6	86.2	133.5
Serbia	33	0	66.4	27.8	48.7	67.0	84.2	113.4
Slovak Republic	118	3	79.6	10.7	70.8	82.7	94.5	121.8
Slovenia	43	0	76.5	18.3	56.0	78.1	96.9	121.5
Spain	880	16	80.4	21.1	63.3	84.6	99.2	133.9
Sweden	284	1	85.7	25.0	72.4	88.2	101.1	132.0
Switzerland	385	2	81.1	20.6	65.4	83.8	98.3	129.7
Türkiye	427	43	69.2	12.9	48.7	73.0	89.9	133.4
Ukraine	99	18	67.4	14.7	46.6	71.5	91.9	114.3
United Kingdom	4184	114	80.1	15.0	65.1	83.5	97.0	174.0
Total	19349	760	81.0	10.7	64.5	84.7	98.7	174.0

Note: Belarus, Georgia and Kosovo have <5 individuals aged 18-39 years with FEV_1 measurement and the countries are excluded from the table.

Note: Sweden reported the FEV of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews; this also means that the value could be from 2023 or 2024.

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4. Lung function

Table A4.4 FEV_1% of predicted for adults: descriptive statistics, by country for adults with CF aged 40+ years who have never had a transplant.

Country	Number	Number of missing	Mean (average FEV1% value)	Min (lowest FEV1% value)	25th pctl (25% of the PwCF have a FEV1% lower than the value)	Median (half the PwCF have a FEV1% lower than the value)	75th pctl (75% of the PwCF have a FEV1% lower than the value)	Max (highest FEV1% value)
Austria	80	0	73.0	28.6	54.0	74.2	91.3	118.8
Bulgaria	14	1	51.5	14.1	32.1	58.8	66.2	77.7
Czech Republic	52	0	67.7	26.5	50.0	64.5	87.1	108.4
Denmark	88	0	77.4	29.1	57.1	79.0	98.0	127.1
Finland	13	0	63.0	32.2	39.4	50.4	84.8	131.7
France	985	11	69.9	16.1	51.4	70.2	87.8	139.7
Germany	1080	17	66.3	20.7	47.6	64.8	84.2	140.5
Greece	61	0	65.3	23.3	43.0	61.8	84.8	117.5
Hungary	31	6	50.7	20.5	29.5	44.8	68.1	98.6
Ireland	175	11	70.6	20.2	52.2	73.7	88.6	115.9
Israel	98	1	67.1	24.5	55.3	68.9	80.1	114.9
Italy	1040	213	74.7	14.6	54.6	74.2	95.3	151.1
Netherlands	291	2	71.7	22.4	51.2	70.6	89.7	132.8
Norway	80	1	71.2	16.5	54.7	72.2	86.6	122.9
Poland	61	2	62.5	20.0	42.9	59.3	81.4	120.7
Portugal	50	0	74.3	20.4	57.6	72.5	90.2	115.2
Russian Federation	49	22	47.7	20.9	30.3	43.1	59.6	110.3
Slovak Republic	30	0	62.9	21.5	42.0	64.1	87.5	102.7
Slovenia	6	1	47.2	32.1	41.1	43.7	57.1	65.3
Spain	421	4	75.1	23.1	58.3	75.2	93.5	143.2
Sweden	131	4	74.2	18.7	56.2	73.3	93.6	126.3
Switzerland	152	1	69.8	23.1	53.4	69.0	88.1	115.5
Türkiye	14	0	60.8	25.6	41.3	53.6	79.7	109.1
United Kingdom	1558	51	70.1	13.0	52.3	70.8	87.4	149.9
Total	6583	349	70.2	13.0	51.0	70.4	88.7	151.1

Note: Albania, Armenia, Belarus, BA-Republika Srpska, Croatia, Cyprus, Estonia, Georgia, Kazakhstan, Kosovo, Iceland, Latvia, Lithuania, Luxembourg, Montenegro, North Macedonia, Republic of Moldova, Romania, Serbia, and Ukraine all have <5 individuals over 40 with a FEV1 value recorded in 2024 and all these countries were excluded from the table.

Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews; this also means that the value could be from 2023 or 2024.

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4. Lung function

Table A4.5 FEV_1% of predicted for children using race neutral equations: descriptive statistics, by country and overall. People with CF aged 6-11 years who have never had a transplant.

Country	Number	Number of missing	Mean (average FEV1% value)	Min (lowest FEV1% value)	25th pctl (25% of the PwCF have a FEV1% lower than the value)	Median (half the PwCF have a FEV1% lower than the value)	75th pctl (75% of the PwCF have a FEV1% lower than the value)	Max (highest FEV1% value)
Albania	10	3	83.6	65.9	77.4	83.1	89.7	105
Armenia	10	1	86.7	41.7	65.4	90.1	94.4	133.9
Austria	130	0	106.7	47.8	97.1	107.6	118.5	153.6
Belarus	24	20	86.9	56.1	73.8	83.2	93.5	185.0
Bulgaria	53	2	98.4	38.7	89.9	103.7	113.9	128.9
Croatia	26	1	93.4	35.9	87.8	97.3	104.6	124.7
Cyprus	5	1	93.1	72.4	79.4	88.2	105.9	119.8
Czech Republic	116	3	110.0	71.1	99.7	109.3	119.0	168.4
Denmark	72	0	109.8	75.8	103.0	108.1	117.7	145.9
Estonia	8	0	104.8	85.8	101.3	104.7	113.2	114.3
Finland	9	0	101.8	77.1	98.2	103.8	109.4	113.0
France	831	35	106.3	44.5	96.7	107.1	117.0	183.7
Georgia	14	7	76.4	52.8	69.2	79.5	82.3	91.7
Germany	1026	15	105.1	33.1	96.5	106.1	114.1	151.3
Greece	72	4	114.4	56.8	100.2	118.6	129.0	151.3
Hungary	82	8	93.7	37.0	84.7	94.1	105.4	133.8
Ireland	169	12	103.2	57.0	96.9	105.2	112.2	134.6
Israel	46	3	99.8	76.3	90.2	98.3	106.8	144.4
Italy	777	44	107.9	40.2	98.4	108.1	118.1	161.7
Latvia	10	2	89.4	61.1	84.3	93.9	101.2	109.1
Lithuania	7	0	112.5	104.1	106.3	111.9	116.2	129.8
Rep of Moldova	14	3	84.1	37.2	61.8	91.3	99.6	111.0
Montenegro	12	0	114.3	88.4	95.9	117.6	128.0	147.1
Netherlands	137	2	106.3	38.2	97.4	106.6	115.9	138.5
North Macedonia	20	5	88.9	53.6	77.8	95.2	103.1	110.6
Norway	47	0	104.9	76.1	96.8	103.6	113.0	135.9
Poland	312	35	99.7	38.6	89.6	101.8	111.7	159.6
Portugal	58	6	107.1	58.2	100.1	107.7	119.0	135.7
Romania	91	15	97.3	40.2	86.0	98.4	108.1	141.3
Russian Federation	696	193	97.2	19.3	86.6	98.4	108.3	200.1
Serbia	41	6	98.4	60.5	90.2	99.8	106.2	125.3
Slovak Republic	43	1	98.2	62.9	91.3	99.3	108.0	133.3
Slovenia	23	0	100	73.5	93.2	102.6	108.8	116.2
Spain	384	15	107.9	45.8	99.4	108.8	118.2	148.2
Sweden	87	3	105.8	65.3	98.9	104.9	115.3	147.4
Switzerland	145	0	108.6	62.8	99.5	109.1	118.5	150.6
Türkiye	654	226	91.3	20.7	77.8	94.3	106.4	162.2
Ukraine	107	21	95.4	42.9	85.5	97.6	106.2	143.9
United Kingdom	1487	44	103.9	19.7	95.6	104.1	112.5	185.9
Total	7864	749	102.9	19.3	93.7	104.0	113.7	200.1

Note: BA-Republika Srpska, Iceland, Kazakhstan, Kosovo and Luxembourg have <5 individuals aged 6-11 years at the date of FEV_1 measurement and are excluded from the table.

Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review; this means the value could be from 2023 or 2024.
The UK reported the FEV1 of the best FEV1pp from the period between annual reviews. This also means that the value could be from 2023 or 2024.

4. Lung function

Table A4.6 FEV_1% of predicted for children using race neutral equations: descriptive statistics, by country and overall. People with CF aged 12-17 years who have never had a transplant.

Country	Number	Number of missing	Mean (average FEV1% value)	Min (lowest FEV1% value)	25th pctl (25% of the PwCF have a FEV1% lower than the value)	Median (half the PwCF have a FEV1% lower than the value)	75th pctl (75% of the PwCF have a FEV1% lower than the value)	Max (highest FEV1% value)
Albania	17	1	82.2	54.0	70.9	78.2	94.9	111.5
Armenia	9	0	77.1	30.5	61.6	74.0	97.5	104.2
Austria	133	1	105.0	40.9	98.0	106.2	114.2	139.4
Belarus	33	17	76.9	25.4	63.9	81.9	87.9	119.6
BA Rep Srpska	6	0	105.5	85.1	99.1	108.8	112.8	118.4
Bulgaria	50	0	91.7	27.5	82.2	96.9	105.3	138.9
Croatia	28	1	92.5	52.4	84.7	93.7	107.0	133.1
Czech Republic	127	0	107.8	35.0	99.7	108.5	118.9	142.8
Denmark	59	0	108.3	41.3	96.9	109.2	120.9	148.3
Estonia	9	0	96.9	57.7	91.5	98.1	102.0	138.5
Finland	18	0	91.4	43.8	76.8	97.1	101.6	117.1
France	1012	9	103.7	24.9	94.8	105.3	114.5	163.0
Georgia	9	7	71.4	39.8	58.3	82.1	84.1	90.2
Germany	923	9	102.4	34.0	93.3	103.4	113.0	144.6
Greece	103	2	114.9	52.1	98.8	114.6	131.8	166.8
Hungary	86	4	91.3	37.7	78.0	90.2	106.0	154.4
Ireland	203	4	103.7	36.0	96.4	104.7	113.5	131.3
Israel	76	1	94.8	25.1	86.9	97.0	107.3	125.6
Italy	840	15	107.0	29.9	98.0	108.3	118.5	166.5
Kazakhstan	8	0	84.6	38.1	71.1	86.2	98.3	127.3
Latvia	10	0	92.3	59.7	80.7	90.0	106.2	124.3
Lithuania	5	1	88.0	33.6	82.7	104.4	105.1	114.5
Luxembourg	5	0	98.0	83.4	96.2	99.0	100.7	110.4
Rep of Moldova	10	1	71.3	36.5	46.1	72.9	92.3	121.4
Montenegro	8	0	111.5	99.5	101.7	111.7	117.8	129.7
Netherlands	174	2	103.5	47.7	94.3	104.7	113.6	138.6
North Macedonia	21	0	97.0	45.6	89.7	103.3	111.1	130.3
Norway	39	1	104.4	47.9	94.2	106.8	115.6	129.5
Poland	378	9	100.5	29.1	92.3	103.5	113.4	142.2
Portugal	61	4	105.0	42.7	95.5	104.1	117.1	137.3
Romania	96	12	90.9	23.4	77.6	93.5	106.7	138.2
Russian Federation	680	148	92.8	20.0	81.4	95.2	107.5	156.6
Serbia	43	0	90.0	31.3	76.9	95.1	107.8	119.5
Slovak Republic	42	0	100.8	66.6	96.0	102.7	108.1	121.2
Slovenia	25	0	102.4	75.5	97.6	103.6	111.3	120.3
Spain	385	4	102.2	32.8	93.4	103.5	112.8	139.7
Sweden	110	3	103.1	39.2	94.9	102.8	115.3	144.4
Switzerland	153	1	105.2	52.4	96.8	105.1	115.4	138.9
Türkiye	531	74	85.6	13.2	71.1	89.1	102.1	135.6
Ukraine	102	20	90.6	27.2	75.8	93.9	102.3	133.2
United Kingdom	1501	33	101.8	27.3	92.8	102.6	111.6	156.7
Total	8138	388	100.4	13.2	90.9	102.4	112.7	166.8

Note: Cyprus, Iceland and Kosovo have <5 individuals aged 12-17 years at the date of FEV_1 measurement and are excluded from the table.

Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews which also means that the value could be from2023 or 2024.

4. Lung function

Table A4.7 FEV_1% of predicted for adults using race neutral equations: descriptive statistics, by country for adults with CF aged 18-39 years who have never had a transplant.

Country	Number	Number of missing	Mean (average FEV1% value)	Min (lowest FEV1% value)	25th pctl (25% of the PwCF have a FEV1% lower than the value)	Median (half the PwCF have a FEV1% lower than the value)	75th pctl (75% of the PwCF have a FEV1% lower than the value)	Max (highest FEV1% value)
Albania	7	0	77.1	58.1	71.1	75.9	82.0	98.8
Armenia	5	0	78.1	42.5	65.9	80.1	97.4	104.7
Austria	344	2	92.9	25.3	77.2	96.0	110.5	151.5
BA Rep Srpska	7	0	84.5	29.0	71.0	93.2	103.9	112.4
Bulgaria	79	2	79.6	22.2	60.4	83.8	99.8	141.5
Croatia	60	0	85.2	19.0	68.6	90.3	105.7	137.1
Cyprus	13	0	71.6	36.6	57.6	78.9	88.7	101.3
Czech Republic	272	3	88.4	19.2	74.9	93.7	106.1	133.1
Denmark	233	0	97.9	27.0	84.8	102.6	113.5	146.5
Estonia	13	0	50.5	12.2	33.9	51.9	65.3	88.1
Finland	32	1	80.4	33.6	66.6	83.1	97.6	120.2
France	2994	29	88.9	17.4	72.4	92.0	106.8	161.5
Germany	3012	26	85.9	18.9	67.9	89.8	104.6	148.6
Greece	279	5	92.1	16.8	73.6	96.2	111.5	171.5
Hungary	162	5	72.7	24.4	48.5	73.7	95.5	134.4
Iceland	6	0	98.0	87.0	94.6	98.2	104.1	105.8
Ireland	534	30	85.0	21.4	67.5	90.6	103.5	142.8
Israel	267	6	82.6	25.7	63.9	86.2	100.5	129.6
Italy	2228	140	93.1	16.4	77.6	97.8	110.9	151.6
Kazakhstan	19	1	63.1	26.1	31.0	64.0	90.8	94.8
Latvia	19	0	76.7	19.5	55.3	87.9	97.9	105.2
Lithuania	26	1	67.4	20.6	37.2	66.7	91.1	112.8
Luxembourg	5	0	100.2	45.7	95.3	116.3	121.4	122.5
Rep of Moldova	12	2	67.5	31.9	56.9	68.8	82.5	91.3
Montenegro	9	0	93.9	55.1	66.4	98.0	109.8	134.1
Netherlands	652	7	86.7	22.3	70.6	90.2	104.0	143.3
North Macedonia	58	1	79.4	29.2	62.8	79.4	99.3	132.5
Norway	131	0	90.9	30.5	79.6	95.5	106.3	151.8
Poland	529	6	82.6	18.4	59.9	85.3	105.0	144.3
Portugal	145	2	83.5	29.8	64.1	85.5	103.3	125.0
Romania	72	2	80.2	18.7	65.3	84.1	98.6	127.5
Russian Federation	666	289	70.0	19.6	47.3	70.9	92.2	141.3
Serbia	33	0	70.8	29.8	51.9	72.5	89.9	122.7
Slovak Republic	118	3	84.5	11.4	74.6	88.0	100.7	130.9
Slovenia	43	0	81.2	19.4	60.1	83.9	102.8	126.9
Spain	880	16	85.9	22.9	67.7	90.0	105.8	143.4
Sweden	284	1	90.8	26.2	76.4	93.6	107.1	139.8
Switzerland	385	2	86.4	22.1	68.7	89.4	104.6	138.1
Türkiye	427	43	74.2	14.0	52.1	77.6	96.3	145.4
Ukraine	99	18	72.0	15.7	50.2	75.6	98.5	121.2
United Kingdom	4214	84	85.2	16.3	69.1	88.7	103.3	184.2
Total	19379	730	86.2	11.4	68.5	90.1	105.1	184.2

Note: Belarus, Georgia and Kosovo have <5 individuals aged 18-39 years with FEV_1 measurement and are excluded from the table.

Note: Sweden reported the FEV of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews; this also means that the value could be from 2023 or 2024.

4. Lung function

Table A4.8 FEV_1% of predicted for adults using race neutral equations: descriptive statistics, by country for adults with CF aged 40+ years who have never had a transplant.

Country	Number	Number of missing	Mean (average FEV1% value)	Min (lowest FEV1% value)	25th pctl (25% of the PwCF have a FEV1% lower than the value)	Median (half the PwCF have a FEV1% lower than the value)	75th pctl (75% of the PwCF have a FEV1% lower than the value)	Max (highest FEV1% value)
Austria	80	0	76.9	30.4	57.0	77.7	96.5	123.8
Bulgaria	14	1	54.1	14.7	33.8	62.0	70.6	79.6
Czech Republic	52	0	71.3	27.6	53.0	67.3	92.0	116.0
Denmark	88	0	81.3	31.0	60.1	82.7	102.4	132.6
Finland	13	0	66.3	34.0	41.3	52.3	90.5	136.2
France	985	11	73.6	17.2	54.3	73.7	92.7	147.5
Germany	1080	17	69.8	22.0	50.1	68.2	88.7	145.6
Greece	61	0	69.0	24.8	45.5	65.9	88.8	123.4
Hungary	31	6	53.2	22.1	30.7	46.8	71.4	101.2
Ireland	175	11	74.8	21.2	55.0	77.9	93.8	124.2
Israel	98	1	70.4	25.8	58.7	71.8	85.0	120.0
Italy	1040	213	79.0	15.5	57.6	78.2	100.5	158.6
Netherlands	291	2	75.0	23.3	53.3	74.1	94.2	136.9
Norway	80	1	74.6	17.7	57.8	76.6	91.4	128.8
Poland	61	2	66.0	21.4	45.0	63.0	86.4	128.9
Portugal	50	0	78.6	21.7	61.1	76.9	95.3	123.6
Russian Federation	49	22	50.3	22.0	31.7	45.1	62.4	117.9
Slovak Republic	30	0	66.0	22.9	44.2	67.5	91.4	108.2
Slovenia	6	1	49.7	33.4	44.2	45.9	60.1	69.0
Spain	421	4	79.4	24.8	62.3	79.6	98.5	148.9
Sweden	131	4	77.8	19.7	58.5	76.5	98.6	133.0
Switzerland	152	1	73.3	24.6	56.2	72.9	91.6	119.8
Türkiye	14	0	64.5	27.3	43.8	56.7	85.4	116.4
United Kingdom	1564	45	73.8	13.7	55.2	74.4	92.4	158.9
Total	6589	343	74.0	13.7	53.9	73.9	93.3	158.9

Note: Albania, Armenia, Belarus, BA-Republika Srpska, Croatia, Cyprus, Estonia, Georgia, Kazakhstan, Kosovo, Iceland, Latvia, Lithuania, Luxembourg, Montenegro, North Macedonia, Republic of Moldova, Romania, Serbia, Ukraine have <5 individuals aged 40+ with FEV_1 measurement and are excluded from the table.

Note: Sweden reported the FEV1 of the best FEV1pp in the 12 months prior to the annual review which means that the value could be from 2023 or 2024. The UK reported the FEV1 of the best FEV1pp from the period between annual reviews; this also means that the value could be from 2023 or 2024.

5. Microbiology

Table A5.1 Prevalence of Pseudomonas aeruginosa in people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)								Adults (≥18 years)							
	Unknown		No		Yes, chronic		Yes, not chronic/ intermittent		Unknown		No		Yes, chronic		Yes, not chronic/ intermittent	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	20	52.6	10	26.3	8	21.1	0	0.0	2	22.2	5	55.6	2	22.2
Armenia	0	0.0	20	66.7	4	13.3	6	20.0	0	0.0	4	80	1	20.0	0	0.0
Austria	0	0.0	313	89.4	14	4.0	23	6.6	0	0.0	263	59.9	139	31.7	37	8.4
Belarus	0	0.0	111	77.1	33	22.9	0	0.0								
BA Rep Srpska	0	0.0	15	93.8	0	0.0	1	6.3	0	0.0	7	87.5	1	12.5	0	0.0
Bulgaria	0	0.0	112	75.7	19	12.8	17	11.5	0	0.0	75	70.1	22	20.6	10	9.4
Croatia	1	1.3	62	82.7	3	4.0	9	12.0	0	0.0	46	73	14	22.2	3	4.8
Cyprus	0	0.0	9	69.2	4	30.8	0	0.0	6	31.6	7	36.8	3	15.8	3	15.8
Czech Rep	3	0.9	313	90.2	15	4.3	16	4.6	9	2.6	219	64	92	26.9	22	6.4
Denmark	1	0.5	184	91.1	4	2.0	13	6.4	11	3.4	225	68.8	58	17.7	33	10.1
Estonia	0	0.0	18	78.3	0	0.0	5	21.7	0	0.0	8	47.1	9	52.9	0	0.0
Finland	0	0.0	30	88.2	2	5.9	2	5.9	0	0.0	33	70.2	12	25.5	2	4.3
France	0	0.0	2266	89.1	77	3.0	201	7.9	0	0.0	2943	71.2	877	21.2	313	7.6
Georgia	1	1.9	38	73.1	7	13.5	6	11.5								
Germany	18	0.7	2460	88.8	152	5.5	139	5.0	116	2.7	2115	50	1847	43.7	152	3.6
Greece	0	0.0	181	79	21	9.2	27	11.8	0	0.0	177	48.6	164	45.1	23	6.3
Hungary	0	0.0	208	72.7	32	11.2	46	16.1	0	0.0	90	43.1	89	42.6	30	14.4
Iceland	0	0.0	9	100	0	0.0	0	0.0	0	0.0	5	83.3	0	0.0	1	16.7
Ireland	0	0.0	502	95.6	9	1.7	14	2.7	2	0.3	644	84.5	64	8.4	52	6.8
Israel	3	2.0	108	73.5	18	12.2	18	12.2	7	1.9	177	49	98	27.2	79	21.9
Italy	5	0.2	1724	80.7	111	5.2	296	13.9	30	0.8	2112	56.3	1107	29.5	500	13.3
Kazakhstan									0	0.0	6	26.1	17	73.9	0	0.0
Kosovo	0	0.0	12	52.2	3	13.0	8	34.8	0	0.0	4	100	0	0.0	0	0.0
Latvia	0	0.0	25	80.7	5	16.1	1	3.2	0	0.0	7	43.8	9	56.3	0	0.0
Lithuania	0	0.0	16	72.7	2	9.1	4	18.2	0	0.0	16	57.1	10	35.7	2	7.1
Luxembourg	0	0.0	20	100	0	0.0	0	0.0	0	0.0	3	60	2	40.0	0	0.0
Rep Moldova	0	0.0	9	25	19	52.8	8	22.2	0	0.0	1	6.3	14	87.5	1	6.3
Montenegro	0	0.0	28	93.3	0	0.0	2	6.7	0	0.0	10	83.3	2	16.7	0	0.0
Netherlands	28	6.7	367	87.8	11	2.6	12	2.9	176	18.0	547	56.1	168	17.2	85	8.7
N. Macedonia	0	0.0	52	68.4	6	7.9	18	23.7	0	0.0	34	53.1	16	25.0	14	21.9
Norway	2	1.5	124	92.5	1	0.8	7	5.2	31	14.2	135	61.9	44	20.2	8	3.7
Poland	0	0.0	796	84.8	61	6.5	82	8.7	1	0.2	365	57.6	197	31.1	71	11.2
Portugal	5	3.0	124	75.2	17	10.3	19	11.5	21	10.6	110	55.6	49	24.8	18	9.1
Romania	1	0.3	224	73.2	63	20.6	18	5.9	0	0.0	54	58.7	27	29.4	11	12.0
Russian Fed	52	2.3	1547	67.6	399	17.4	291	12.7	71	6.4	497	44.9	514	46.4	26	2.4
Serbia	0	0.0	103	69.1	22	14.8	24	16.1	0	0.0	14	36.8	18	47.4	6	15.8
Slovak Rep	0	0.0	114	89.8	4	3.2	9	7.1	2	1.4	106	72.1	30	20.4	9	6.1
Slovenia	0	0.0	50	89.3	1	1.8	5	8.9	9	18.4	23	46.9	12	24.5	5	10.2
Spain	4	0.4	858	83.1	51	4.9	119	11.5	30	2.3	851	66.1	301	23.4	106	8.2
Sweden	5	1.8	243	87.4	11	4.0	19	6.8	16	3.7	237	55	158	36.7	20	4.6
Switzerland	0	0.0	364	90.1	24	5.9	16	4.0	0	0.0	357	64.7	159	28.8	36	6.5
Türkiye	19	0.9	1700	77.2	288	13.1	196	8.9	12	2.3	303	56.7	155	29.0	64	12.0
Ukraine	0	0.0	207	61.2	91	26.9	40	11.8	1	0.8	41	31.5	83	63.9	5	3.9
United Kingdom	1	0.0	3595	88.9	99	2.5	351	8.7	36	0.60	4342	71.5	704	11.6	991	16.3
Total	149	0.6	19287	83	1717	7.4	2096	9.0	587	2.10	17218	61.8	7296	26.2	2740	9.8

Note: Information was missing for more than 10% of children in Kosovo, and for more than 10% of adults in Armenia, Iceland, Kosovo, and Latvia. Belarus and Georgia had <5 adults seen in 2024 and are excluded from the table for adults.

Note: Ireland: Chronicity for *Pseudomonas aeruginosa* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.
Italy: chronicity for *Pseudomonas aeruginosa* was defined as: at least 3 or more positive isolates during the l12 months preceding the last reported culture in 2024.

The United Kingdom: chronicity for *Pseudomonas aeruginosa* was defined as: 3 or more positive isolates during the 12 months preceding the last annual review.

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5. Microbiology

Table A5.2 Prevalence of Burkholderia cepacia complex species in people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)								Adults (≥18 years)							
	Unknown		No		Yes, chronic		Yes, not chronic/ intermittent		Unknown		No		Yes, chronic		Yes, not chronic/ intermittent	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	38	100	0	0.0	0	0.0	1	11.10	7	77.8	0	0.0	1	11.1
Armenia	0	0.0	19	100	0	0.0	0	0.0	0	0.00	4	100	0	0.0	0	0.0
Austria	0	0.0	346	99.4	0	0.0	2	0.6	0	0.00	420	96.3	13	3.0	3	0.7
Belarus	0	0.0	141	97.9	3	2.1	0	0.0								
BA Rep Srpska	0	0.0	16	100	0	0.0	0	0.0	0	0.00	7	100	0	0.0	0	0.0
Bulgaria	0	0.0	148	100	0	0.0	0	0.0	0	0.00	107	100	0	0.0	0	0.0
Croatia	1	1.3	75	98.7	0	0.0	0	0.0	0	0.00	63	100	0	0.0	0	0.0
Cyprus	0	0.0	13	100	0	0.0	0	0.0	6	31.60	13	68.4	0	0.0	0	0.0
Czech Rep	3	0.9	343	98.9	1	0.3	0	0.0	9	2.60	304	88.9	29	8.5	0	0.0
Denmark	1	0.5	200	99	0	0.0	1	0.5	2	0.60	305	93.3	15	4.6	5	1.5
Estonia	0	0.0	23	100	0	0.0	0	0.0	0	0.00	17	100	0	0.0	0	0.0
Finland	0	0.0	34	100	0	0.0	0	0.0	0	0.00	47	100	0	0.0	0	0.0
France	0	0.0	2524	99.2	9	0.4	11	0.4	0	0.00	4070	98.5	43	1.0	20	0.5
Georgia	7	12.5	49	87.5	0	0.0	0	0.0								
Germany	18	0.7	2736	98.8	11	0.4	4	0.1	109	2.60	4004	94.7	101	2.4	16	0.4
Greece	1	0.4	228	99.6	0	0.0	0	0.0	5	1.40	350	98.3	0	0.0	1	0.3
Hungary	0	0.0	280	97.9	1	0.4	5	1.8	0	0.00	197	94.3	8	3.8	4	1.9
Iceland	0	0.0	8	88.9	0	0.0	1	11.1	0	0.00	6	100	0	0.0	0	0.0
Ireland	0	0.0	523	99.6	1	0.2	1	0.2	2	0.30	749	98.3	6	0.8	5	0.7
Israel	3	2.0	144	97.3	1	0.7	0	0.0	7	2.00	348	96.9	2	0.6	2	0.6
Italy	5	0.2	2123	99.4	4	0.2	4	0.2	32	0.90	3629	96.8	61	1.6	27	0.7
Kazakhstan									0	0.00	23	100	0	0.0	0	0.0
Kosovo	0	0.0	22	95.7	0	0.0	1	4.4	0	0.00	4	100	0	0.0	0	0.0
Latvia	0	0.0	31	100	0	0.0	0	0.0	0	0.00	15	93.8	1	6.3	0	0.0
Lithuania	0	0.0	22	100	0	0.0	0	0.0	0	0.00	24	85.7	2	7.1	2	7.1
Luxembourg	0	0.0	20	100	0	0.0	0	0.0	0	0.00	5	100	0	0.0	0	0.0
Rep Moldova	0	0.0	35	100	0	0.0	0	0.0	0	0.00	14	100	0	0.0	0	0.0
Montenegro	0	0.0	29	96.7	0	0.0	1	3.3	0	0.00	12	100	0	0.0	0	0.0
Netherlands	33	7.9	383	91.6	2	0.5	0	0.0	177	18.10	782	80.1	9	0.9	8	0.8
N. Macedonia	0	0.0	75	98.7	0	0.0	1	1.3	0	0.00	64	100	0	0.0	0	0.0
Norway	1	0.8	132	98.5	1	0.8	0	0.0	40	18.40	175	80.3	3	1.4	0	0.0
Poland	0	0.0	935	99.6	2	0.2	2	0.2	0	0.00	626	98.6	5	0.8	4	0.6
Portugal	4	2.4	159	95.2	2	1.2	2	1.2	21	10.60	168	84.9	7	3.5	2	1.0
Romania	0	0.0	305	99.7	0	0.0	1	0.3	0	0.00	91	100	0	0.0	0	0.0
Russian Fed	65	2.8	2181	95.3	22	1.0	21	0.9	38	3.40	971	87.6	92	8.3	7	0.6
Serbia	0	0.0	144	96	5	3.3	1	0.7	0	0.00	31	81.6	7	18.4	0	0.0
Slovak Rep	0	0.0	127	100	0	0.0	0	0.0	0	0.00	148	95.5	4	2.6	3	1.9
Slovenia	0	0.0	56	100	0	0.0	0	0.0	12	24.50	37	75.5	0	0.0	0	0.0
Spain	3	0.3	1015	98.5	6	0.6	7	0.7	43	3.40	1189	92.6	43	3.4	9	0.7
Sweden	6	2.2	269	96.8	1	0.4	2	0.7	34	7.90	385	89.3	11	2.6	1	0.2
Switzerland	0	0.0	403	99.8	1	0.3	0	0.0	0	0.00	545	98.7	3	0.5	4	0.7
Türkiye	18	0.8	2174	98.7	3	0.1	8	0.4	17	3.20	513	96.1	3	0.6	1	0.2
Ukraine	0	0.0	328	98.2	3	0.9	3	0.9	0	0.00	128	98.5	2	1.5	0	0.0
United Kingdom	1	0.0	4013	99.2	0	0.0	32	0.8	37	0.60	5865	96.6	0	0.0	171	2.8
Total	170	0.7	22879	98.5	79	0.3	111	0.5	592	2.10	26470	95.1	470	1.7	296	1.1

Note: Information was missing for more than 10% of children in Armenia and Kosovo, and for more than 10% of adults in Armenia, BA-Republika Srpska, Iceland, Kosovo, Latvia and Moldova. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Ireland: Chronicity for *Burkholderia cepacia complex* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.

Italy: chronicity for *Burkholderia cepacia complex* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.

The United Kingdom: chronicity for Burkholderia cepacia complex was not collected.

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5. Microbiology

Table A5.3 Prevalence of Haemophilus influenzae in people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)								Adults (≥18 years)							
	Unknown		No		Yes, chronic		Yes, not chronic/ intermittent		Unknown		No		Yes, chronic		Yes, not chronic/ intermittent	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	38	100	0	0.0	0	0.0	1	11.1	8	88.9	0	0.0	0	0.0
Armenia	0	0.0	25	83.3	0	0.0	5	16.7	0	0.0	5	100	0	0.0	0	0.0
Austria	0	0.0	213	60.7	34	9.7	104	29.6	0	0.0	364	83.5	20	4.6	52	11.9
Belarus	0	0.0	137	95.1	7	4.9	0	0.0								
BA Rep Srpska	0	0.0	16	100	0	0.0	0	0.0	0	0.0	7	100	0	0.0	0	0.0
Bulgaria	0	0.0	144	97.3	0	0.0	4	2.7	0	0.0	107	100	0	0.0	0	0.0
Croatia	1	1.3	65	85.5	0	0.0	10	13.2	0	0.0	58	92.1	0	0.0	5	7.9
Cyprus	0	0.0	10	76.9	0	0.0	3	23.1	6	31.6	13	68.4	0	0.0	0	0.0
Czech Rep	10	2.9	325	93.7	2	0.6	10	2.9	12	3.5	328	95.9	0	0.0	2	0.6
Denmark	2	1.0	91	45.1	39	19.3	70	34.7	13	4.0	239	73.1	10	3.1	65	19.9
Estonia	0	0.0	13	56.5	1	4.4	9	39.1	0	0.0	16	94.1	1	5.9	0	0.0
Finland	0	0.0	32	94.1	2	5.9	0	0.0	0	0.0	45	95.7	0	0.0	2	4.3
France	0	0.0	2086	82.0	0	0.0	458	18.0	0	0.0	3670	88.8	0	0.0	463	11.2
Georgia	1	1.9	38	73.1	0	0.0	13	25.0								
Germany	18	0.7	1909	68.9	98	3.5	744	26.9	109	2.6	3567	84.3	122	2.9	432	10.2
Greece	1	0.4	207	90.4	1	0.4	20	8.7	2	0.6	316	88.8	1	0.3	37	10.4
Hungary	0	0.0	236	82.5	3	1.1	47	16.4	0	0.0	204	97.6	2	1.0	3	1.4
Iceland	0	0.0	5	55.6	1	11.1	3	33.3	0	0.0	5	83.3	0	0.0	1	16.7
Ireland	0	0.0	408	77.7	25	4.8	92	17.5	2	0.3	712	93.4	4	0.5	44	5.8
Israel	3	2.0	117	79.1	5	3.4	23	15.5	7	1.9	324	90.0	2	0.6	27	7.5
Italy	6	0.3	1530	71.6	54	2.5	546	25.6	32	0.9	3448	92.0	34	0.9	235	6.3
Kazakhstan									0	0.0	23	100	0	0.0	0	0.0
Kosovo	0	0.0	21	91.3	0	0.0	2	8.7	0	0.0	4	100	0	0.0	0	0.0
Latvia	0	0.0	20	64.5	5	16.1	6	19.4	0	0.0	11	68.8	1	6.3	4	25.0
Lithuania	0	0.0	13	59.1	3	13.6	6	27.3	0	0.0	26	92.9	0	0.0	2	7.1
Luxembourg	0	0.0	16	80.0	1	5.0	3	15.0	0	0.0	5	100	0	0.0	0	0.0
Rep Moldova	0	0.0	35	97.2	0	0.0	1	2.8	0	0.0	15	100	0	0.0	0	0.0
Montenegro	0	0.0	28	93.3	0	0.0	2	6.7	0	0.0	11	91.7	0	0.0	1	8.3
Netherlands	23	5.5	335	80.1	3	0.7	57	13.6	176	18.0	704	72.1	21	2.2	75	7.7
N. Macedonia	0	0.0	76	100	0	0.0	0	0.0	0	0.0	64	100	0	0.0	0	0.0
Norway	1	0.8	65	48.5	17	12.7	51	38.1	41	18.8	153	70.2	4	1.8	20	9.2
Poland	0	0.0	694	74.0	26	2.8	218	23.2	1	0.2	559	88.5	6	1.0	66	10.4
Portugal	4	2.4	119	72.1	6	3.6	36	21.8	21	10.6	153	77.3	6	3.0	18	9.1
Romania	0	0.0	298	97.4	0	0.0	8	2.6	0	0.0	87	94.6	0	0.0	5	5.4
Russian Fed	62	2.7	2084	91.0	18	0.8	125	5.5	40	3.6	1049	94.7	5	0.5	14	1.3
Serbia	0	0.0	43	28.9	91	61.1	15	10.1	0	0.0	11	29.0	15	39.5	12	31.6
Slovak Rep	0	0.0	95	74.8	2	1.6	30	23.6	1	0.7	131	89.1	0	0.0	15	10.2
Slovenia	0	0.0	42	75.0	3	5.4	11	19.6	12	24.5	33	67.4	1	2.0	3	6.1
Spain	3	0.3	714	69.5	63	6.1	247	24.1	44	3.4	1102	85.8	21	1.6	118	9.2
Sweden	8	2.9	199	71.6	3	1.1	68	24.5	35	8.1	314	72.9	5	1.2	77	17.9
Switzerland	0	0.0	302	74.8	19	4.7	83	20.5	0	0.0	471	85.3	28	5.1	53	9.6
Türkiye	18	0.8	2075	94.2	18	0.8	92	4.2	17	3.2	492	92.1	4	0.8	21	3.9
Ukraine	0	0.0	303	90.2	3	0.9	30	8.9	0	0.0	126	97.7	0	0.0	3	2.3
United Kingdom	1	0.0	3332	82.4	0	0.0	713	17.6	37	0.6	5673	93.4	0	0.0	363	6.0
Total	162	0.7	18564	79.9	553	2.4	3965	17.1	609	2.2	24659	88.6	314	1.1	2239	8.1

Note: Information was missing for more than 10% of children in Kosovo, and for more than 10% of adults in Armenia, BA-Republika Srpska, Iceland, Kosovo and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: France and United Kingdom: chronicity for *Haemophilus influenza* was not collected.
Ireland: Chronicity for *Haemophilus influenzae* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.
Italy: chronicity for *Haemophilus influenzae* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.

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5. Microbiology

Table A5.4 Prevalence of methicillin-sensitive Staphylococcus aureus (MSSA) in people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)								Adults (≥18 years)							
	Unknown		No		Yes, chronic		Yes, not chronic/ intermittent		Unknown		No		Yes, chronic		Yes, not chronic/ intermittent	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	15	39.5	8	21.1	15	39.5	0	0.0	3	33.3	6	66.7	0	0.0
Armenia	0	0.0	6	20.0	5	16.7	19	63.3	0	0.0	0	0.0	1	20.0	4	80.0
Austria	0	0.0	95	27.1	151	43.1	104	29.7	0	0.0	164	37.4	194	44.3	80	18.3
Belarus	0	0.0	54	37.5	90	62.5	0	0.0								
BA Rep Srpska	0	0.0	16	100	0	0.0	0	0.0	0	0.0	7	100	0	0.0	0	0.0
Bulgaria	0	0.0	118	80.3	2	1.4	27	18.4	0	0.0	90	84.1	1	0.9	16	15.0
Croatia	1	1.3	23	30.3	18	23.7	34	44.7	0	0.0	21	33.3	29	46.0	13	20.6
Cyprus	0	0.0	9	69.2	1	7.7	3	23.1	6	31.6	8	42.1	1	5.3	4	21.1
Czech Rep	3	0.9	127	36.6	121	34.9	96	27.7	10	2.9	148	43.3	115	33.6	69	20.2
Denmark	3	1.5	75	37.1	36	17.8	88	43.6	33	10.1	141	43.1	74	22.6	79	24.2
Estonia	0	0.0	11	47.8	5	21.7	7	30.4	0	0.0	5	29.4	10	58.8	2	11.8
Finland	0	0.0	22	64.7	7	20.6	5	14.7	0	0.0	24	51.1	21	44.7	2	4.3
France	0	0.0	904	35.5	794	31.2	846	33.3	0	0.0	2328	56.3	1288	31.2	517	12.5
Georgia	1	1.9	12	23.1	23	44.2	16	30.8								
Germany	18	0.7	821	29.7	1060	38.3	870	31.4	111	2.6	1244	29.4	2159	51.0	716	16.9
Greece	0	0.0	105	45.9	65	28.4	59	25.8	1	0.3	183	50.8	126	35.0	50	13.9
Hungary	0	0.0	75	26.2	56	19.6	155	54.2	0	0.0	47	22.5	110	52.6	52	24.9
Iceland	0	0.0	3	33.3	4	44.4	2	22.2	0	0.0	3	50.0	1	16.7	2	33.3
Ireland	0	0.0	261	49.7	130	24.8	134	25.5	2	0.3	611	80.2	51	6.7	98	12.9
Israel	3	2.0	66	44.6	34	23.0	45	30.4	8	2.2	205	56.9	58	16.1	89	24.7
Italy	6	0.3	732	34.3	565	26.5	833	39.0	33	0.9	1591	42.4	1096	29.2	1029	27.5
Kazakhstan									0	0.0	23	100	0	0.0	0	0.0
Kosovo	0	0.0	20	87.0	0	0.0	3	13.0	0	0.0	1	25.0	0	0.0	3	75.0
Latvia	0	0.0	6	19.4	20	64.5	5	16.1	0	0.0	4	25.0	12	75.0	0	0.0
Lithuania	0	0.0	3	13.6	13	59.1	6	27.3	0	0.0	6	21.4	14	50.0	8	28.6
Luxembourg	0	0.0	8	40.0	7	35.0	5	25.0	0	0.0	1	20.0	1	20.0	3	60.0
Rep Moldova	0	0.0	2	5.6	30	83.3	4	11.1	0	0.0	0	0.0	15	100	0	0.0
Montenegro	0	0.0	20	66.7	1	3.3	9	30.0	0	0.0	11	91.7	0	0.0	1	8.3
Netherlands	20	4.8	223	53.4	57	13.6	118	28.2	174	17.8	461	47.2	171	17.5	170	17.4
N. Macedonia	0	0.0	55	72.4	0	0.0	21	27.6	0	0.0	37	58.7	5	7.9	21	33.3
Norway	1	0.8	29	21.6	41	30.6	63	47.0	34	15.6	58	26.6	68	31.2	58	26.6
Poland	0	0.0	217	23.1	428	45.5	295	31.4	0	0.0	233	36.9	208	32.9	191	30.2
Portugal	4	2.4	101	60.5	26	15.6	36	21.6	21	10.6	119	60.1	35	17.7	23	11.6
Romania	0	0.0	277	90.5	6	2.0	23	7.5	0	0.0	84	91.3	3	3.3	5	5.4
Russian Fed	57	2.5	671	29.3	1234	53.9	327	14.3	51	4.6	423	38.2	598	54.0	36	3.3
Serbia	0	0.0	42	28.0	80	53.3	28	18.7	0	0.0	12	31.6	21	55.3	5	13.2
Slovak Rep	0	0.0	51	40.5	17	13.5	58	46.0	1	0.7	92	62.6	32	21.8	22	15.0
Slovenia	0	0.0	8	14.3	35	62.5	13	23.2	11	22.5	11	22.5	18	36.7	9	18.4
Spain	3	0.3	383	37.3	283	27.5	359	34.9	35	2.7	644	50.0	332	25.8	277	21.5
Sweden	7	2.5	124	44.6	40	14.4	107	38.5	26	6.0	189	43.9	146	33.9	70	16.2
Switzerland	0	0.0	102	25.3	200	49.5	102	25.3	0	0.0	206	37.3	262	47.5	84	15.2
Türkiye	13	0.6	1610	73.1	281	12.8	299	13.6	17	3.2	319	59.7	113	21.2	85	15.9
Ukraine	0	0.0	61	18.1	196	58.0	81	24.0	0	0.0	40	31.3	75	58.6	13	10.2
United Kingdom	1	0.0	3435	84.9	259	6.4	351	8.7	37	0.6	4758	78.4	287	4.7	991	16.3
Total	141	0.6	11003	47.3	6429	27.7	5676	24.4	611	2.2	14559	52.3	7760	27.9	4898	17.6

Note: Information was missing for more than 10% of children in Kosovo, and for more than 10% of adults in Armenia, BA-Republika Srpska, Iceland, Kosovo and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Ireland: chronicity for methicillin-sensitive *Staphylococcus aureus* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.

Italy: chronicity for methicillin-sensitive *Staphylococcus aureus* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.

The United Kingdom: chronicity for methicillin sensitive *Staphylococcus aureus* was defined as: 3 or more positive isolates during the 12 months preceding the last annual review.

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5. Microbiology

Table A5.5 Prevalence of methicillin-resistant Staphylococcus aureus (MRSA) in people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)								Adults (≥18 years)							
	Unknown		No		Yes, chronic		Yes, not chronic/ intermittent		Unknown		No		Yes, chronic		Yes, not chronic/ intermittent	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	31	81.6	3	7.9	4	10.5	0	0.0	9	100	0	0.0	0	0.0
Armenia	0	0.0	15	83.3	0	0.0	3	16.7	0	0.0	4	100	0	0.0	0	0.0
Austria	0	0.0	344	98.3	1	0.3	5	1.4	0	0.0	420	96.6	8	1.8	7	1.6
Belarus	0	0.0	131	91.0	13	9.0	0	0.0								
BA Rep Srpska	0	0.0	10	62.5	0	0.0	6	37.5	0	0.0	6	85.7	0	0.0	1	14.3
Bulgaria	0	0.0	147	99.3	0	0.0	1	0.7	0	0.0	104	100	0	0.0	0	0.0
Croatia	1	1.3	72	94.7	1	1.3	2	2.6	0	0.0	61	96.8	0	0.0	2	3.2
Cyprus	0	0.0	9	69.2	2	15.4	2	15.4	7	36.8	11	57.9	0	0.0	1	5.3
Czech Rep	3	0.9	344	99.1	0	0.0	0	0.0	11	3.2	322	94.2	0	0.0	9	2.6
Denmark	1	0.5	200	99.0	0	0.0	1	0.5	4	1.2	321	98.2	1	0.3	1	0.3
Estonia	0	0.0	23	100	0	0.0	0	0.0	0	0.0	15	93.8	1	6.3	0	0.0
Finland	0	0.0	34	100	0	0.0	0	0.0	0	0.0	47	100	0	0.0	0	0.0
France	0	0.0	2487	97.8	18	0.7	39	1.5	0	0.0	4018	97.2	76	1.8	39	0.9
Georgia	1	1.9	51	98.1	0	0.0	0	0.0								
Germany	20	0.7	2666	96.3	48	1.7	35	1.3	120	2.8	3874	91.6	195	4.6	41	1.0
Greece	1	0.4	198	86.8	10	4.4	19	8.3	3	0.8	319	89.6	11	3.1	23	6.5
Hungary	0	0.0	275	96.2	7	2.5	4	1.4	0	0.0	202	96.7	2	1.0	5	2.4
Iceland	0	0.0	9	100	0	0.0	0	0.0	0	0.0	6	100	0	0.0	0	0.0
Ireland	0	0.0	507	96.6	7	1.3	11	2.1	2	0.3	755	99.1	3	0.4	2	0.3
Israel	3	2.0	137	93.2	3	2.0	4	2.7	8	2.2	332	92.5	7	2.0	12	3.3
Italy	6	0.3	1956	91.6	54	2.5	120	5.6	32	0.9	3491	93.1	97	2.6	129	3.4
Kazakhstan									0	0.0	19	82.6	1	4.4	3	13.0
Kosovo	0	0.0	22	95.7	0	0.0	1	4.4	0	0.0	4	100	0	0.0	0	0.0
Latvia	0	0.0	31	100	0	0.0	0	0.0	0	0.0	16	100	0	0.0	0	0.0
Lithuania	0	0.0	22	100	0	0.0	0	0.0	0	0.0	28	100	0	0.0	0	0.0
Luxembourg	0	0.0	20	100	0	0.0	0	0.0	0	0.0	5	100	0	0.0	0	0.0
Rep Moldova	0	0.0	35	100	0	0.0	0	0.0	0	0.0	15	100	0	0.0	0	0.0
Montenegro	0	0.0	30	100	0	0.0	0	0.0	0	0.0	12	100	0	0.0	0	0.0
Netherlands	29	6.9	386	92.3	0	0.0	3	0.7	183	18.8	780	79.9	9	0.9	4	0.4
N. Macedonia	0	0.0	49	64.5	5	6.6	22	29.0	0	0.0	48	75.0	5	7.8	11	17.2
Norway	1	0.8	132	98.5	0	0.0	1	0.8	41	18.8	176	80.7	0	0.0	1	0.5
Poland	0	0.0	913	97.2	12	1.3	14	1.5	0	0.0	600	95.4	13	2.1	16	2.5
Portugal	4	2.4	151	92.1	1	0.6	8	4.9	21	10.7	168	85.3	2	1.0	6	3.1
Romania	0	0.0	278	90.9	11	3.6	17	5.6	0	0.0	83	90.2	4	4.4	5	5.4
Russian Fed	67	2.9	2055	89.8	64	2.8	103	4.5	45	4.1	1028	92.8	23	2.1	12	1.1
Serbia	0	0.0	137	92.6	5	3.4	6	4.1	0	0.0	34	89.5	2	5.3	2	5.3
Slovak Rep	0	0.0	120	94.5	1	0.8	6	4.7	0	0.0	147	95.5	2	1.3	5	3.3
Slovenia	0	0.0	51	91.1	4	7.1	1	1.8	11	22.9	36	75.0	1	2.1	0	0.0
Spain	3	0.3	973	95.5	13	1.3	30	2.9	43	3.4	1167	91.4	36	2.8	31	2.4
Sweden	6	2.2	266	95.7	1	0.4	5	1.8	36	8.4	392	91.0	2	0.5	1	0.2
Switzerland	0	0.0	397	98.3	6	1.5	1	0.3	0	0.0	528	95.7	17	3.1	7	1.3
Türkiye	19	0.9	1955	88.7	84	3.8	145	6.6	17	3.2	467	87.5	30	5.6	20	3.8
Ukraine	0	0.0	320	97.0	5	1.5	5	1.5	1	0.8	119	93.0	6	4.7	2	1.6
United Kingdom	1	0.0	3962	97.9	0	0.0	83	2.1	36	0.6	5934	97.7	0	0.0	103	1.7
Total	166	0.7	21961	94.6	379	1.6	707	3.1	621	2.2	26131	94.0	554	2.0	501	1.8

Note: Information was missing for more than 10% of children in Armenia and Kosovo, and for more than 10% of adults in Armenia, BA-Republika Srpska, Iceland, Kosovo and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Ireland: chronicity for methicillin-resistant *Staphylococcus aureus* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.
Italy: chronicity for methicillin-resistant *Staphylococcus aureus* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.
The United Kingdom: chronicity for methicillin-resistant *Staphylococcus aureus* was not collected.

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5. Microbiology

Table A5.6 Prevalence of Stenotrophomonas maltophilia in people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)								Adults (≥18 years)							
	Unknown		No		Yes, chronic		Yes, not chronic/ intermittent		Unknown		No		Yes, chronic		Yes, not chronic/ intermittent	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	37	100	0	0.0	0	0.0	1	11.1	8	88.9	0	0.0	0	0.0
Armenia	0	0.0	17	100	0	0.0	0	0.0	0	0.0	4	100	0	0.0	0	0.0
Austria	0	0.0	331	94.6	2	0.6	17	4.9	0	0.0	404	92.9	13	3.0	18	4.1
Belarus	0	0.0	142	98.6	2	1.4	0	0.0								
BA Rep Srpska	0	0.0	16	100	0	0.0	0	0.0	0	0.0	7	100	0	0.0	0	0.0
Bulgaria	0	0.0	147	99.3	0	0.0	1	0.7	0	0.0	106	99.1	0	0.0	1	0.9
Croatia	1	1.3	63	82.9	0	0.0	12	15.8	0	0.0	61	98.4	0	0.0	1	1.6
Cyprus	0	0.0	12	92.3	0	0.0	1	7.7	6	31.6	13	68.4	0	0.0	0	0.0
Czech Rep	3	0.9	343	98.9	0	0.0	1	0.3	10	2.9	331	96.8	0	0.0	1	0.3
Denmark	1	0.5	190	94.1	2	1.0	9	4.5	10	3.1	284	86.9	5	1.5	28	8.6
Estonia	0	0.0	22	95.7	0	0.0	1	4.4	0	0.0	17	100	0	0.0	0	0.0
Finland	0	0.0	31	91.2	2	5.9	1	2.9	0	0.0	46	97.9	1	2.1	0	0.0
France	0	0.0	2368	93.1	17	0.7	159	6.3	0	0.0	3960	95.8	42	1.0	131	3.2
Georgia	1	1.9	51	98.1	0	0.0	0	0.0								
Germany	18	0.7	2646	95.6	15	0.5	90	3.3	109	2.6	3710	87.7	243	5.7	168	4.0
Greece	0	0.0	213	93.0	2	0.9	14	6.1	2	0.6	336	94.4	3	0.8	15	4.2
Hungary	0	0.0	273	95.5	1	0.4	12	4.2	0	0.0	208	99.5	0	0.0	1	0.5
Iceland	0	0.0	9	100	0	0.0	0	0.0	0	0.0	5	83.3	0	0.0	1	16.7
Ireland	0	0.0	516	98.3	2	0.4	7	1.3	2	0.3	752	98.7	1	0.1	7	0.9
Israel	3	2.0	133	89.9	0	0.0	12	8.1	7	2.0	338	94.2	3	0.8	11	3.1
Italy	5	0.2	1978	92.6	6	0.3	147	6.9	33	0.9	3489	93.1	47	1.3	180	4.8
Kazakhstan									0	0.0	22	95.7	0	0.0	1	4.4
Kosovo	0	0.0	21	95.5	0	0.0	1	4.6	0	0.0	4	100	0	0.0	0	0.0
Latvia	0	0.0	27	87.1	0	0.0	4	12.9	0	0.0	14	87.5	1	6.3	1	6.3
Lithuania	0	0.0	19	86.4	0	0.0	3	13.6	0	0.0	23	82.1	1	3.6	4	14.3
Luxembourg	0	0.0	19	95.0	0	0.0	1	5.0	0	0.0	5	100	0	0.0	0	0.0
Rep Moldova	0	0.0	34	94.4	0	0.0	2	5.6	0	0.0	15	100	0	0.0	0	0.0
Montenegro	0	0.0	30	100	0	0.0	0	0.0	0	0.0	11	91.7	0	0.0	1	8.3
Netherlands	28	6.7	380	90.9	0	0.0	10	2.4	180	18.4	763	78.2	12	1.2	21	2.2
N. Macedonia	0	0.0	70	93.3	0	0.0	5	6.7	0	0.0	60	93.8	0	0.0	4	6.3
Norway	1	0.8	124	92.5	0	0.0	9	6.7	40	18.4	153	70.2	8	3.7	17	7.8
Poland	0	0.0	907	96.7	2	0.2	29	3.1	0	0.0	607	95.9	7	1.1	19	3.0
Portugal	4	2.4	156	94.0	2	1.2	4	2.4	21	10.7	170	86.3	0	0.0	6	3.1
Romania	0	0.0	302	100	0	0.0	0	0.0	0	0.0	88	98.9	0	0.0	1	1.1
Russian Fed	61	2.7	2153	94.1	16	0.7	59	2.6	38	3.4	1041	94.0	13	1.2	16	1.4
Serbia	0	0.0	126	84.6	0	0.0	23	15.4	0	0.0	36	94.7	0	0.0	2	5.3
Slovak Rep	0	0.0	123	99.2	0	0.0	1	0.8	1	0.7	140	95.2	4	2.7	2	1.4
Slovenia	0	0.0	53	94.6	1	1.8	2	3.6	12	25.0	34	70.8	1	2.1	1	2.1
Spain	3	0.3	965	93.9	3	0.3	57	5.5	43	3.4	1177	91.6	12	0.9	53	4.1
Sweden	5	1.8	259	93.2	2	0.7	12	4.3	36	8.4	370	85.9	5	1.2	20	4.6
Switzerland	0	0.0	388	96.0	2	0.5	14	3.5	0	0.0	521	94.4	20	3.6	11	2.0
Türkiye	17	0.8	2154	97.8	5	0.2	27	1.2	17	3.2	505	94.6	3	0.6	9	1.7
Ukraine	0	0.0	320	96.1	3	0.9	10	3.0	1	0.8	126	96.9	0	0.0	3	2.3
United Kingdom	1	0.0	3915	96.8	0	0.0	130	3.2	37	0.6	5845	96.3	0	0.0	191	3.2
Total	152	0.7	22092	95.2	87	0.4	888	3.8	606	2.2	25817	92.8	445	1.6	946	3.4

Note: Information was missing for more than 10% of children in Armenia and Kosovo, and for more than 10% of adults in Armenia, BA-Republika Srpska, Iceland, Kosovo and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Ireland: chronicity for *Stenotrophomonas maltophilia* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.

Italy: chronicity for *Stenotrophomonas maltophilia* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.

The United Kingdom: chronicity for *Stenotrophomonas maltophilia* was not collected.

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5. Microbiology

Table A5.7 Prevalence of Achromobacter species infection in people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)								Adults (≥18 years)							
	Unknown		No		Yes, chronic		Yes, not chronic/ intermittent		Unknown		No		Yes, chronic		Yes, not chronic/ intermittent	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	38	100	0	0.0	0	0.0	0	0.0	8	100	0	0.0	0	0.0
Armenia	0	0.0	17	100	0	0.0	0	0.0	0	0.0	3	75.0	0	0.0	1	25.0
Austria	0	0.0	345	98.6	2	0.6	3	0.9	0	0.0	416	95.4	13	3.0	7	1.6
Belarus	0	0.0	135	93.8	9	6.3	0	0.0								
BA Rep Srpska	0	0.0	16	100	0	0.0	0	0.0	0	0.0	7	100	0	0.0	0	0.0
Bulgaria	0	0.0	147	99.3	0	0.0	1	0.7	0	0.0	106	100	0	0.0	0	0.0
Croatia	1	1.3	73	96.1	0	0.0	2	2.6	0	0.0	63	100	0	0.0	0	0.0
Cyprus	0	0.0	13	100	0	0.0	0	0.0	6	31.6	12	63.2	0	0.0	1	5.3
Czech Rep	3	0.9	344	99.1	0	0.0	0	0.0	9	2.6	329	96.2	0	0.0	4	1.2
Denmark	1	0.5	198	98.0	1	0.5	2	1.0	7	2.1	296	90.5	12	3.7	12	3.7
Estonia	0	0.0	23	100	0	0.0	0	0.0	0	0.0	14	87.5	1	6.3	1	6.3
Finland	0	0.0	34	100	0	0.0	0	0.0	0	0.0	47	100	0	0.0	0	0.0
France	0	0.0	2483	97.6	12	0.5	49	1.9	0	0.0	3947	95.5	104	2.5	82	2.0
Georgia	1	1.9	51	98.1	0	0.0	0	0.0								
Germany	18	0.7	2726	98.5	12	0.4	13	0.5	109	2.6	3894	92.1	179	4.2	48	1.1
Greece	0	0.0	216	95.6	1	0.4	9	4.0	3	0.8	338	94.9	9	2.5	6	1.7
Hungary	0	0.0	285	99.7	0	0.0	1	0.4	0	0.0	188	90.0	19	9.1	2	1.0
Iceland	0	0.0	9	100	0	0.0	0	0.0	0	0.0	5	83.3	0	0.0	1	16.7
Ireland	0	0.0	521	99.2	0	0.0	4	0.8	2	0.3	752	98.7	3	0.4	5	0.7
Israel	3	2.0	142	96.0	2	1.4	1	0.7	7	2.0	338	94.2	8	2.2	6	1.7
Italy	6	0.3	2062	96.5	10	0.5	58	2.7	32	0.9	3513	93.7	87	2.3	117	3.1
Kazakhstan									0	0.0	23	100	0	0.0	0	0.0
Kosovo	0	0.0	22	95.7	0	0.0	1	4.4	0	0.0	4	100	0	0.0	0	0.0
Latvia	0	0.0	28	90.3	2	6.5	1	3.2	0	0.0	14	87.5	0	0.0	2	12.5
Lithuania	0	0.0	20	90.9	0	0.0	2	9.1	0	0.0	26	92.9	1	3.6	1	3.6
Luxembourg	0	0.0	20	100	0	0.0	0	0.0	0	0.0	5	100	0	0.0	0	0.0
Rep Moldova	0	0.0	35	100	0	0.0	0	0.0	0	0.0	15	100	0	0.0	0	0.0
Montenegro	0	0.0	30	100	0	0.0	0	0.0	0	0.0	12	100	0	0.0	0	0.0
Netherlands	29	6.9	387	92.6	0	0.0	2	0.5	205	21.0	752	77.1	8	0.8	11	1.1
N. Macedonia	0	0.0	74	98.7	0	0.0	1	1.3	0	0.0	62	98.4	0	0.0	1	1.6
Norway	1	0.8	131	97.8	1	0.8	1	0.8	40	18.4	174	79.8	1	0.5	3	1.4
Poland	0	0.0	923	98.3	5	0.5	11	1.2	0	0.0	600	95.5	17	2.7	11	1.8
Portugal	4	2.4	160	97.0	0	0.0	1	0.6	21	10.7	166	84.3	4	2.0	6	3.1
Romania	0	0.0	295	98.7	1	0.3	3	1.0	0	0.0	91	100	0	0.0	0	0.0
Russian Fed	64	2.8	2125	92.8	38	1.7	62	2.7	47	4.2	959	86.6	84	7.6	18	1.6
Serbia	0	0.0	141	94.0	2	1.3	7	4.7	0	0.0	37	97.4	1	2.6	0	0.0
Slovak Rep	0	0.0	124	98.4	0	0.0	2	1.6	1	0.7	140	95.9	3	2.1	2	1.4
Slovenia	0	0.0	56	100	0	0.0	0	0.0	12	24.5	35	71.4	1	2.0	1	2.0
Spain	3	0.3	1003	98.1	3	0.3	13	1.3	42	3.3	1175	91.7	44	3.4	21	1.6
Sweden	5	1.8	270	97.1	3	1.1	0	0.0	39	9.1	373	86.5	10	2.3	9	2.1
Switzerland	0	0.0	400	99.0	2	0.5	2	0.5	0	0.0	531	96.2	14	2.5	7	1.3
Türkiye	18	0.8	2167	98.4	6	0.3	12	0.5	17	3.2	505	94.6	4	0.8	8	1.5
Ukraine	0	0.0	322	97.0	2	0.6	8	2.4	1	0.8	126	96.9	2	1.5	1	0.8
United Kingdom	1	0.0	4021	99.4	0	0.0	24	0.6	37	0.6	5891	97.0	0	0.0	145	2.4
Total	158	0.7	22642	97.6	114	0.5	296	1.3	637	2.3	25999	93.5	630	2.3	540	1.9

Note: Information was missing for more than 10% of children in Armenia and Kosovo, and for more than 10% of adults in Albania, Armenia, BA-Republika Srpska, Iceland, Kosovo and Latvia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Ireland: chronicity for *Achromobacter species* was defined as: a) 4 or more unique cultures in 2024 and greater than 50% positive b) at least 3 or more positive cultures during the 12 months preceding the last reported culture in 2024 or c) if chronic in 2023 and any cultures taken in 2024 were still positive.
Italy: chronicity for *Achromobacter species* was defined as: at least 3 or more positive isolates during the 12 months preceding the last reported culture in 2024.
The United Kingdom: chronicity for Achromobacter species was not collected.

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6. Nutrition

Table A6.1 Z-score for BMI: descriptive statistics by country and overall. All children and adolescents with CF seen in 2024 aged 2-17 years who have never had a transplant.

Country	Number	Number of missing	Mean	Min	25th pctl (25% of the PwCF are below this z-score for BMI)	Median (half the PwCF are below this z-score for BMI)	75th pctl (75% of the PwCF are below this z-score for BMI)	Max
Albania	32	1	-0.2	-2.1	-0.9	-0.1	0.3	2.1
Armenia	28	0	-0.8	-2.8	-1.9	-0.8	0.1	1.7
Austria	331	0	-0.1	-4.3	-0.6	0.0	0.5	2.0
Belarus	118	0	-0.8	-5.2	-1.5	-0.5	0.1	2.3
BA Rep Srpska	8	0	0.1	-0.9	-0.8	-0.4	0.8	2.4
Bulgaria	135	0	-0.4	-5.1	-1.0	-0.4	0.5	2.8
Croatia	74	1	-0.2	-4.1	-0.8	-0.1	0.7	2.3
Cyprus	13	0	-0.7	-2.9	-1.7	-0.6	-0.3	2.3
Czech Republic	328	0	-0.1	-3.7	-0.8	-0.1	0.5	2.5
Denmark	190	0	-0.1	-3.2	-0.7	0.0	0.6	2.4
Estonia	23	0	-0.1	-1.8	-0.8	-0.4	0.9	1.2
Finland	32	0	-0.3	-2.3	-0.9	-0.2	0.4	1.3
France	2377	9	-0.2	-4.9	-0.8	-0.2	0.5	2.5
Georgia	49	1	-1.1	-4.6	-1.7	-1.0	-0.5	1.8
Germany	2629	1	-0.2	-5.1	-0.8	-0.1	0.5	2.9
Greece	219	1	0.2	-3.5	-0.3	0.2	0.8	3.1
Hungary	248	0	-0.3	-6.9	-1.0	-0.2	0.5	2.3
Iceland	9	0	0.3	-0.3	-0.1	0.1	0.9	1.4
Ireland	501	0	0.3	-3.2	-0.3	0.3	0.9	2.4
Israel	154	0	-0.2	-5.1	-0.9	-0.1	0.7	2.5
Italy	2043	3	0.0	-8.0	-0.7	0.1	0.8	3.4
Kosovo	26	0	-0.9	-5.1	-1.7	-0.6	0.6	1.8
Latvia	30	0	-0.4	-2.4	-1.0	-0.5	0.1	1.3
Lithuania	17	0	-1.1	-3.3	-1.4	-0.5	-0.2	0.1
Luxembourg	18	0	-0.1	-1.8	-0.5	-0.2	0.5	1.4
Moldova	34	0	-1.2	-4.4	-2.2	-0.9	-0.2	1.7
Montenegro	28	0	0.0	-2.4	-0.7	0.1	0.9	2.0
Netherlands	387	0	0.0	-2.8	-0.6	-0.1	0.6	3.2
North Macedonia	69	0	-0.2	-2.8	-0.8	-0.2	0.5	2.3
Norway	124	0	0.1	-3.2	-0.5	0.0	0.7	2.2
Poland	923	4	-0.3	-5.9	-0.8	-0.2	0.5	2.9
Portugal	160	0	-0.2	-2.7	-0.7	-0.1	0.4	1.8
Romania	271	9	-0.8	-7.0	-1.8	-0.6	0.2	2.9
Russian Federation	2168	0	-0.5	-10.1	-1.1	-0.4	0.3	4.6
Serbia	135	0	-0.3	-4.3	-1.1	-0.3	0.5	2.5
Slovak Republic	111	0	-0.1	-6.9	-0.9	-0.1	0.6	3.5
Slovenia	55	0	-0.3	-3.0	-0.8	-0.4	0.3	1.8
Spain	978	3	-0.1	-5.1	-0.6	0.0	0.5	2.9
Sweden	266	2	0.1	-3.0	-0.5	0.2	0.8	2.5
Switzerland	372	1	-0.1	-2.7	-0.7	-0.1	0.5	2.2
Türkiye	2050	0	-0.5	-14.3	-1.3	-0.4	0.4	3.1
Ukraine	298	15	-0.7	-10.5	-1.4	-0.4	0.3	2.1
United Kingdom	3918	19	0.2	-5.9	-0.4	0.2	0.9	3.3
Total	21990	70	-0.2	-14.3	-0.8	-0.1	0.6	4.6

Note: Sweden: height and weight are from the date of the best FEV1pp in the 12 months prior to the annual review date, where in some cases the values can be from the previous calendar year. If no spirometry is done, the height and weight are from the date of the annual review.
The United Kingdom: If best FEV1pp is reported, the height and weight are taken from that date, and it is made sure that the date is between the annual review dates. If the annual review FEV1 is used, because the best lung function is missing, height and weight at the annual review is reported.

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6. Nutrition

Table A6.2 BMI: descriptive statistics by country and overall. All adults with CF seen in 2024 who have never had a transplant.

Country	Number	Number of missing	Mean	Min	25th pctl (25% of the PwCF are below this z-score for BMI)	Median (half the PwCF are below this z-score for BMI)	75th pctl (75% of the PwCF are below this z-score for BMI)	Max
Albania	7	0	22.3	19.2	19.5	23.5	24.7	24.8
Armenia	5	0	20.6	19.3	19.7	20.0	20.2	23.8
Austria	424	2	23.2	14.3	20.8	22.4	24.9	39.3
BA Rep Srpska	7	0	20.7	17.1	19.4	21.1	22.5	22.7
Bulgaria	96	0	21.5	15.8	19.3	20.5	23.2	39.8
Croatia	61	0	22.8	13.9	20.7	23.0	24.6	30.1
Cyprus	18	0	24.6	17.9	21.5	23.2	25.3	49.9
Czech Republic	327	0	23.1	14.7	20.5	22.8	25.5	36.8
Denmark	320	1	23.6	15.9	20.9	23.2	25.4	46.4
Estonia	16	0	21.6	14.7	19.6	21.0	23.2	29.1
Finland	46	0	23.8	17.2	21.3	23.6	24.7	35.2
France	4006	13	22.9	13.0	20.3	22.2	24.7	51.8
Germany	4113	22	22.9	12.8	20.4	22.4	24.8	53.7
Greece	344	1	23.3	15.5	20.8	22.8	25.4	36.8
Hungary	204	0	21.8	14.1	19.6	21.4	23.8	36.3
Iceland	6	0	24.3	21.7	22.5	24.0	25.1	28.7
Ireland	647	103	24.6	17.0	21.9	24.0	26.8	42.3
Israel	369	3	23.6	14.6	20.7	23.1	25.8	42.8
Italy	3309	312	23.3	14.5	20.7	22.7	25.1	53.7
Kazakhstan	21	0	18.8	15.0	16.8	19.0	20.1	23.8
Kosovo	5	0	21.5	18.4	18.6	21.2	23.1	26.1
Latvia	19	0	21.5	17.2	19.9	21.1	23.3	28.0
Lithuania	28	0	21.0	14.3	19.1	20.7	22.8	27.1
Luxembourg	5	0	20.4	17.5	18.7	21.8	21.8	22.4
Moldova	14	0	18.5	13.1	17.5	18.0	19.8	22.8
Montenegro	10	0	21.9	18.1	20.1	21.5	23.5	28.7
Netherlands	951	1	23.6	16.6	21.3	23.0	25.2	57.8
North Macedonia	61	0	22.4	17.0	20.3	21.8	24.7	36.8
Norway	212	0	23.9	15.5	21.4	23.4	25.7	41.8
Poland	595	3	22.5	13.9	19.9	22.1	24.4	42.6
Portugal	197	0	23.1	16.4	20.8	22.5	24.7	44.6
Romania	77	0	20.9	14.6	18.4	20.8	22.5	30.1
Russian Federation	1026	0	20.8	12.4	18.5	20.2	22.6	36.9
Serbia	36	0	20.4	15.2	18.7	19.8	22.2	26.8
Slovak Republic	151	0	22.4	14.1	19.6	22.0	24.2	34.7
Slovenia	50	0	21.7	15.7	20.1	21.7	24.1	28.0
Spain	1310	11	23.4	14.7	20.8	22.7	25.4	51.1
Sweden	418	2	23.7	15.4	21.2	23.0	25.6	47.0
Switzerland	537	3	22.6	15.0	20.2	22.0	24.3	38.4
Türkiye	484	0	21.7	13.4	18.9	21.1	24.2	37.7
Ukraine	121	0	19.9	13.6	17.8	19.7	21.5	30.5
United Kingdom	5790	117	24.5	12.9	21.5	23.8	26.7	62.1
Total	26443	598	23.3	12.4	20.5	22.7	25.3	62.1

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table.

Note: Sweden: height and weight are from the date of the best FEV1pp in the 12 months prior to the annual review date, where in some cases the values can be from the previous calendar year. If no spirometry is done, the height and weight are from the date of the annual review.
The United Kingdom: If best FEV1pp is reported, the height and weight are taken from that date, and it is made sure that the date is between the annual review dates. If the annual review FEV1 is used, because the best lung function is missing, height and weight at the annual review is reported.

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7. Complications

Table A7.1 Prevalence in people with CF of at least 1 day on intravenous (IV) antibiotics (for CF-related reasons) at home and/or in hospital. People with CF seen in 2024, who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Missing/ Unknown		No days on IV		Yes, at least one day on IV		Missing/ Unknown		No days on IV		Yes, at least one day on IV	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	23	60.5	15	39.5	0	0.0	0	44.4	5	55.6
Armenia	0	0.0	20	66.7	10	33.3	0	0.0	6	100	0	0.0
Austria	4	1.1	313	89.2	34	9.7	10	2.3	371	83.9	61	13.8
Belarus	0	0.0	68	47.2	76	52.8						
BA Rep Srpska	0	0.0	13	81.3	3	18.8	0	0.0	8	100	0	0.0
Bulgaria	0	0.0	111	75.0	37	25.0	0	0.0	90	84.1	17	15.9
Croatia	1	1.3	66	86.8	9	11.8	0	0.0	59	93.7	4	6.4
Cyprus	0	0.0	11	84.6	2	15.4	0	0.0	16	84.2	3	15.8
Czech Republic	0	0.0	329	94.8	18	5.2	0	0.0	314	91.8	28	8.2
Denmark	0	0.0	186	92.1	16	7.9	0	0.0	286	87.5	41	12.5
Estonia	0	0.0	21	84.0	4	16.0	0	0.0	10	58.8	7	41.2
Finland	0	0.0	31	91.2	3	8.8	0	0.0	42	89.4	5	10.6
France	18	0.7	2356	92.6	170	6.7	66	1.6	3528	85.4	539	13.0
Georgia	12	21.4	37	66.1	7	12.5						
Germany	0	0.0	2665	96.2	104	3.8	12	0.3	3817	90.2	401	9.5
Greece	13	5.7	193	84.3	23	10.0	25	6.8	292	79.1	52	14.1
Hungary	286	100	0	0.0	0	0.0	209	100	0	0.0	0	0.0
Iceland	0	0.0	9	100	0	0.0	0	0.0	6	85.7	1	14.3
Ireland	0	0.0	476	90.7	49	9.3	2	0.3	628	82.4	132	17.3
Israel	1	0.7	139	89.7	15	9.7	3	0.8	324	85.0	54	14.2
Italy	154	7.2	1650	77.3	332	15.5	495	13.2	2689	71.7	565	15.1
Kazakhstan							0	0.0	10	43.5	13	56.5
Kosovo	0	0.0	16	57.1	12	42.9	0	0.0	4	80.0	1	20.0
Latvia	0	0.0	25	75.8	8	24.2	0	0.0	14	73.7	5	26.3
Lithuania	0	0.0	14	63.6	8	36.4	0	0.0	14	50.0	14	50.0
Luxembourg	0	0.0	17	85.0	3	15.0	1	20.0	3	60.0	1	20.0
Rep of Moldova	0	0.0	8	22.2	28	77.8	0	0.0	6	37.5	10	62.5
Montenegro	0	0.0	30	100	0	0.0	0	0.0	12	100	0	0.0
Netherlands	5	1.2	385	92.1	28	6.7	6	0.6	863	88.4	107	11.0
North Macedonia	0	0.0	32	41.0	46	59.0	0	0.0	12	18.8	52	81.3
Norway	0	0.0	128	95.5	6	4.5	1	0.5	198	90.8	19	8.7
Poland	4	0.4	758	79.4	193	20.2	5	0.8	468	73.1	167	26.1
Portugal	1	0.6	161	96.4	5	3.0	1	0.5	200	96.2	7	3.4
Romania	0	0.0	230	75.2	76	24.8	0	0.0	82	89.1	10	10.9
Russian Fed	81	3.5	1533	67.0	675	29.5	23	2.1	472	42.6	613	55.3
Serbia	1	0.7	127	84.1	23	15.2	1	2.6	33	84.6	5	12.8
Slovak Republic	0	0.0	114	89.8	13	10.2	0	0.0	135	87.1	20	12.9
Slovenia	0	0.0	51	91.1	5	8.9	0	0.0	50	96.2	2	3.9
Spain	4	0.4	973	93.5	64	6.2	7	0.5	1231	89.9	132	9.6
Sweden	1	0.4	244	87.8	33	11.9	9	2.1	319	74.0	103	23.9
Switzerland	0	0.0	389	96.3	15	3.7	1	0.2	498	90.2	53	9.6
Türkiye	1	0.1	1806	81.9	397	18.0	0	0.0	437	81.8	97	18.2
Ukraine	32	9.4	103	30.1	207	60.5	12	9.2	21	16.0	98	74.8
United Kingdom	0	0.0	3452	85.3	594	14.7	0	0.0	4667	76.9	1406	23.2
Total	619	2.7	19318	82.9	3371	14.5	889	3.2	22242	79.5	4855	17.4

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

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7. Complications

Table A7.2 Prevalence in people with CF of at least 1 day in hospital, for any reason (routine check-up days not included). People with CF seen in 2024, who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Missing/ Unknown		No days on IV		Yes, at least one day on IV		Missing/ Unknown		No days on IV		Yes, at least one day on IV	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	23	60.5	15	39.5	0	0.0	4	44.4	5	55.6
Armenia	0	0.0	16	53.3	14	46.7	0	0.0	6	100	0	0.0
Austria	10	2.9	267	76.1	74	21.1	11	2.5	366	82.8	65	14.7
Belarus	0	0.0	68	47.2	76	52.8						
BA Rep Srpska	0	0.0	13	81.3	3	18.8	0	0.0	8	100	0	0.0
Bulgaria	0	0.0	99	66.9	49	33.1	0	0.0	89	83.2	18	16.8
Croatia	1	1.3	62	81.6	13	17.1	0	0.0	59	93.7	4	6.4
Cyprus	0	0.0	11	84.6	2	15.4	0	0.0	16	84.2	3	15.8
Czech Republic	0	0.0	306	88.2	41	11.8	0	0.0	292	85.4	50	14.6
Denmark	2	1.0	154	76.2	46	22.8	1	0.3	236	72.2	90	27.5
Estonia	0	0.0	21	84.0	4	16.0	0	0.0	10	58.8	7	41.2
Finland	0	0.0	29	85.3	5	14.7	0	0.0	40	85.1	7	14.9
France	340	13.4	1879	73.9	325	12.8	331	8.0	3308	80.0	494	12.0
Georgia	12	21.4	37	66.1	7	12.5						
Germany	0	0.0	2239	80.9	530	19.1	11	0.3	3527	83.4	692	16.4
Greece	13	5.7	190	83.0	26	11.4	10	2.7	300	81.3	59	16.0
Hungary	0	0.0	143	50.0	143	50.0	0	0.0	113	54.1	96	45.9
Iceland	0	0.0	8	88.9	1	11.1	0	0.0	7	100	0	0.0
Ireland	0	0.0	456	86.9	69	13.1	2	0.3	600	78.7	160	21.0
Israel	0	0.0	129	83.2	26	16.8	1	0.3	326	85.6	54	14.2
Italy	3	0.1	1582	74.1	551	25.8	4	0.1	2878	76.8	867	23.1
Kazakhstan							0	0.0	18	78.3	5	21.7
Kosovo	0	0.0	17	60.7	11	39.3	0	0.0	5	100	0	0.0
Latvia	0	0.0	22	66.7	11	33.3	0	0.0	12	63.2	7	36.8
Lithuania	0	0.0	11	50.0	11	50.0	0	0.0	14	50.0	14	50.0
Luxembourg	0	0.0	14	70.0	6	30.0	1	20.0	3	60.0	1	20.0
Rep of Moldova	0	0.0	7	19.4	29	80.6	0	0.0	6	37.5	10	62.5
Montenegro	0	0.0	30	100	0	0.0	0	0.0	12	100	0	0.0
Netherlands	1	0.2	347	83.0	70	16.8	0	0.0	789	80.8	187	19.2
North Macedonia	0	0.0	32	41.0	46	59.0	0	0.0	10	15.6	54	84.4
Norway	1	0.8	117	87.3	16	11.9	2	0.9	191	87.6	25	11.5
Poland	3	0.3	557	58.3	395	41.4	4	0.6	386	60.3	250	39.1
Portugal	0	0.0	157	94.0	10	6.0	2	1.0	195	93.8	11	5.3
Romania	0	0.0	108	35.3	198	64.7	0	0.0	75	81.5	17	18.5
Russian Fed	75	3.3	1454	63.5	760	33.2	21	1.9	543	49.0	544	49.1
Serbia	1	0.7	126	83.4	24	15.9	1	2.6	32	82.1	6	15.4
Slovak Republic	0	0.0	104	81.9	23	18.1	0	0.0	133	85.8	22	14.2
Slovenia	0	0.0	47	83.9	9	16.1	0	0.0	44	84.6	8	15.4
Spain	5	0.5	946	90.9	90	8.7	4	0.3	1255	91.6	111	8.1
Sweden	1	0.4	240	86.3	37	13.3	7	1.6	365	84.7	59	13.7
Switzerland	0	0.0	382	94.6	22	5.5	1	0.2	490	88.8	61	11.1
Türkiye	1	0.1	1515	68.7	688	31.2	0	0.0	386	72.3	148	27.7
Ukraine	21	6.1	98	28.7	223	65.2	10	7.6	23	17.6	98	74.8
United Kingdom	0	0.0	3143	77.7	903	22.3	0	0.0	4564	75.2	1509	24.9
Total	**490**	**2.1**	**17212**	**73.9**	**5606**	**24.1**	**425**	**1.5**	**21740**	**77.7**	**5821**	**20.8**

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

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7. Complications

Table A7.3 Prevalence of allergic bronchopulmonary aspergillosis in children and adults seen in 2024 who have never had a transplant, by country.

Country	Children (<18 years)						Adults (≥18 years)					
	Missing/ Unknown		No ABPA this year		Yes, current ABPA		Missing/ Unknown		No ABPA this year		Yes, current ABPA	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	1	2.6	37	97.4	0	0.0	0	0.0	9	100	0	0.0
Armenia	0	0.0	30	100	0	0.0	0	0.0	6	100	0	0.0
Austria	1	0.3	346	98.6	4	1.1	5	1.1	422	95.5	15	3.4
Belarus	0	0.0	144	100	0	0.0						
BA Rep Srpska	0	0.0	16	100	0	0.0	0	0.0	7	87.5	1	12.5
Bulgaria	1	0.7	145	98.0	2	1.4	2	1.9	103	96.3	2	1.9
Croatia	0	0.0	76	100	0	0.0	0	0.0	63	100	0	0.0
Cyprus	1	7.7	12	92.3	0	0.0	0	0.0	18	94.7	1	5.3
Czech Republic	0	0.0	346	99.7	1	0.3	2	0.6	336	98.3	4	1.2
Denmark	0	0.0	201	99.5	1	0.5	0	0.0	326	99.7	1	0.3
Estonia	8	32.0	17	68.0	0	0.0	0	0.0	17	100	0	0.0
Finland	0	0.0	34	100	0	0.0	0	0.0	47	100	0	0.0
France	42	1.7	2472	97.2	30	1.2	103	2.5	3864	93.5	166	4.0
Georgia	2	3.6	54	96.4	0	0.0						
Germany	2	0.1	2746	99.2	21	0.8	19	0.5	4088	96.6	123	2.9
Greece	1	0.4	226	98.7	2	0.9	1	0.3	364	98.6	4	1.1
Hungary	0	0.0	283	99.0	3	1.1	0	0.0	182	87.1	27	12.9
Iceland	0	0.0	9	100	0	0.0	0	0.0	7	100	0	0.0
Ireland	5	1.0	512	97.5	8	1.5	9	1.2	685	89.9	68	8.9
Israel	11	7.1	143	92.3	1	0.7	11	2.9	363	95.3	7	1.8
Italy	9	0.4	2112	98.9	15	0.7	15	0.4	3687	98.4	47	1.3
Kazakhstan							0	0.0	23	100	0	0.0
Kosovo	1	3.6	27	96.4	0	0.0	0	0.0	5	100	0	0.0
Latvia	0	0.0	33	100	0	0.0	0	0.0	18	94.7	1	5.3
Lithuania	1	4.6	21	95.5	0	0.0	0	0.0	28	100	0	0.0
Luxembourg	0	0.0	20	100	0	0.0	0	0.0	5	100	0	0.0
Rep of Moldova	33	91.7	3	8.3	0	0.0	14	87.5	2	12.5	0	0.0
Montenegro	0	0.0	30	100	0	0.0	0	0.0	11	91.7	1	8.3
Netherlands	15	3.6	396	94.7	7	1.7	3	0.3	943	96.6	30	3.1
North Macedonia	3	3.9	74	94.9	1	1.3	0	0.0	63	98.4	1	1.6
Norway	0	0.0	133	99.3	1	0.8	3	1.4	215	98.6	0	0.0
Poland	3	0.3	946	99.1	6	0.6	6	0.9	625	97.7	9	1.4
Portugal	2	1.2	165	98.8	0	0.0	2	1.0	206	99.0	0	0.0
Romania	2	0.7	301	98.4	3	1.0	4	4.4	88	95.7	0	0.0
Russian Fed	33	1.4	2221	97.0	35	1.5	22	2.0	1030	93.0	56	5.1
Serbia	1	0.7	150	99.3	0	0.0	1	2.6	38	97.4	0	0.0
Slovak Republic	0	0.0	127	100	0	0.0	3	1.9	148	95.5	4	2.6
Slovenia	0	0.0	56	100	0	0.0	9	17.3	41	78.9	2	3.9
Spain	7	0.7	1024	98.4	10	1.0	8	0.6	1339	97.7	23	1.7
Sweden	8	2.9	268	96.4	2	0.7	13	3.0	415	96.3	3	0.7
Switzerland	0	0.0	403	99.8	1	0.3	0	0.0	511	92.6	41	7.4
Türkiye	3	0.1	2178	98.8	23	1.0	14	2.6	509	95.3	11	2.1
Ukraine	9	2.6	331	96.8	2	0.6	4	3.1	126	96.2	1	0.8
United Kingdom	0	0.0	3980	98.4	66	1.6	0	0.0	5656	93.1	417	6.9
Total	**205**	**0.9**	**22858**	**98.1**	**245**	**1**	**274**	**1.0**	**26646**	**95.2**	**1066**	**3.8**

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

7. Complications

Table A7.4 Prevalence of CF-related diabetes (CFRD) in adults with CF seen in 2024 who have never had a transplant, by country and overall.

Country	CFRD this year											
	Missing/ Unknown		No		Yes, treated with daily insulin		Yes, treated with oral hypo-glycaemic agents		Yes, dietary advice only		Yes, therapy unknown	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	6	66.7	3	33.3	0	0.0	0	0.0	0	0.0
Armenia	0	0.0	4	66.7	0	0.0	0	0.0	2	33.3	0	0.0
Austria	2	0.5	325	73.5	89	20.1	2	0.5	19	4.3	5	1.1
BA Rep Srpska	0	0.0	4	50.0	4	50.0	0	0.0	0	0.0	0	0.0
Bulgaria	1	0.9	96	89.7	10	9.4	0	0.0	0	0.0	0	0.0
Croatia	0	0.0	51	81.0	11	17.5	0	0.0	1	1.6	0	0.0
Cyprus	0	0.0	18	94.7	1	5.3	0	0.0	0	0.0	0	0.0
Czech Republic	0	0.0	227	66.4	83	24.3	1	0.3	18	5.3	13	3.8
Denmark	5	1.5	199	60.9	78	23.9	1	0.3	42	12.8	2	0.6
Estonia	0	0.0	14	82.4	3	17.7	0	0.0	0	0.0	0	0.0
Finland	0	0.0	35	74.5	9	19.2	0	0.0	3	6.4	0	0.0
France	28	0.7	3110	75.3	702	17.0	67	1.6	226	5.5	0	0.0
Germany	20	0.5	2912	68.8	883	20.9	63	1.5	131	3.1	221	5.2
Greece	0	0.0	271	73.4	76	20.6	7	1.9	15	4.1	0	0.0
Hungary	0	0.0	161	77.0	44	21.1	0	0.0	4	1.9	0	0.0
Iceland	0	0.0	3	42.9	3	42.9	0	0.0	1	14.3	0	0.0
Ireland	2	0.3	582	76.4	141	18.5	0	0.0	37	4.9	0	0.0
Israel	5	1.3	251	65.9	102	26.8	10	2.6	11	2.9	2	0.5
Italy	16	0.4	2898	77.3	688	18.4	23	0.6	107	2.9	17	0.5
Kazakhstan	0	0.0	21	91.3	2	8.7	0	0.0	0	0.0	0	0.0
Kosovo	0	0.0	4	80.0	1	20.0	0	0.0	0	0.0	0	0.0
Latvia	0	0.0	14	73.7	1	5.3	0	0.0	4	21.1	0	0.0
Lithuania	0	0.0	26	92.9	0	0.0	0	0.0	2	7.1	0	0.0
Luxembourg	0	0.0	3	60.0	2	40.0	0	0.0	0	0.0	0	0.0
Rep of Moldova	2	12.5	11	68.8	3	18.8	0	0.0	0	0.0	0	0.0
Montenegro	0	0.0	9	75.0	3	25.0	0	0.0	0	0.0	0	0.0
Netherlands	76	7.8	544	55.7	227	23.3	28	2.9	92	9.4	9	0.9
North Macedonia	0	0.0	43	67.2	21	32.8	0	0.0	0	0.0	0	0.0
Norway	0	0.0	173	79.4	35	16.1	4	1.8	6	2.8	0	0.0
Poland	11	1.7	469	73.3	102	15.9	4	0.6	54	8.4	0	0.0
Portugal	1	0.5	176	84.6	23	11.1	2	1.0	6	2.9	0	0.0
Romania	8	8.7	70	76.1	13	14.1	0	0.0	1	1.1	0	0.0
Russian Fed	35	3.2	955	86.2	94	8.5	2	0.2	18	1.6	4	0.4
Serbia	1	2.6	28	71.8	10	25.6	0	0.0	0	0.0	0	0.0
Slovak Republic	2	1.3	126	81.3	17	11.0	1	0.7	9	5.8	0	0.0
Slovenia	1	1.9	40	76.9	9	17.3	0	0.0	2	3.9	0	0.0
Spain	12	0.9	1035	75.6	224	16.4	21	1.5	75	5.5	3	0.2
Sweden	0	0.0	302	70.1	91	21.1	8	1.9	0	0.0	30	7.0
Switzerland	2	0.4	377	68.3	129	23.4	3	0.5	40	7.3	1	0.2
Türkiye	15	2.8	450	84.3	55	10.3	4	0.8	9	1.7	1	0.2
Ukraine	6	4.6	111	84.7	12	9.2	0	0.0	1	0.8	1	0.8
United Kingdom	77	1.3	3730	61.4	1484	24.4	201	3.3	183	3.0	398	6.6
Total	**329**	**1.2**	**19891**	**71.1**	**5488**	**19.6**	**452**	**1.6**	**1119**	**4.0**	**707**	**2.5**

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

7. Complications

Table A7.5 Prevalence of liver disease in people with CF seen in 2024 who have never had a transplant.

Country	Liver disease this year													
	Missing/ Unknown		No		Yes, cirrhosis with portal hypertension/ hypersplenism		Yes, cirrhosis no portal hypertension/ hypersplenism		Yes, cirrhosis, portal hypertension unknown		Yes, liver disease without cirrhosis		Yes, variceal bleeding	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Children	276	1.2	18593	79.8	281	1.2	239	1.0	32	0.1	3883	16.7	4	0.0
Adults	435	1.6	19096	68.2	747	2.7	529	1.9	118	0.4	7060	25.2	1	0.0

Note: Serbia: cirrhosis without portal hypertension/hypersplenism is reported when there are abnormal liver function tests and/or ultrasound changes in liver tissue

8. Therapies

Table A8.1 Use of inhaled hypertonic saline >3% (NaCl) for at least 3 consecutive months this year in all people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Unknown		No		Yes		Unknown		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	0	0.0	38	100	0	0.0	0	0.0	9	100
Armenia	0	0.0	1	3.3	29	96.7	0	0.0	1	16.7	5	83.3
Austria	0	0.0	26	7.4	325	92.6	2	0.5	62	14.1	377	85.5
Belarus	0	0.0	49	34.0	95	66.0						
BA Rep Srpska	0	0.0	1	6.3	15	93.8	0	0.0	1	12.5	7	87.5
Bulgaria	0	0.0	62	41.9	86	58.1	0	0.0	76	72.4	29	27.6
Croatia	0	0.0	0	0.0	76	100	0	0.0	16	25.8	46	74.2
Cyprus	0	0.0	8	61.5	5	38.5	0	0.0	15	83.3	3	16.7
Czech Republic	0	0.0	35	10.1	312	89.9	0	0.0	100	29.2	242	70.8
Denmark	1	0.5	148	73.3	53	26.2	1	0.3	288	88.1	38	11.6
Estonia	0	0.0	5	20.0	20	80.0	0	0.0	13	76.5	4	23.5
Finland	0	0.0	2	5.9	32	94.1	0	0.0	10	21.3	37	78.7
France	0	0.0	2035	80.0	509	20.0	0	0.0	3833	92.7	300	7.3
Georgia	0	0.0	3	5.4	53	94.6						
Germany	1	0.0	153	5.5	2615	94.4	16	0.4	1210	28.6	3004	71.0
Greece	0	0.0	155	67.7	74	32.3	1	0.3	317	85.9	51	13.8
Hungary	0	0.0	31	10.8	255	89.2	0	0.0	33	15.8	176	84.2
Iceland	0	0.0	0	0.0	9	100	0	0.0	4	57.1	3	42.9
Ireland	0	0.0	145	27.6	380	72.4	2	0.3	408	53.5	352	46.2
Israel	1	0.7	20	13.0	133	86.4	20	5.3	108	28.5	251	66.2
Italy	1	0.1	964	45.1	1171	54.8	5	0.1	2093	55.8	1651	44.0
Kazakhstan							0	0.0	2	8.7	21	91.3
Kosovo	0	0.0	0	0.0	28	100	0	0.0	1	20.0	4	80.0
Latvia	0	0.0	5	15.2	28	84.9	0	0.0	1	5.3	18	94.7
Lithuania	0	0.0	8	36.4	14	63.6	0	0.0	27	96.4	1	3.6
Luxembourg	0	0.0	1	5.0	19	95.0	0	0.0	1	20.0	4	80.0
Rep of Moldova	0	0.0	3	8.3	33	91.7	0	0.0	7	46.7	8	53.3
Montenegro	0	0.0	0	0.0	30	100	0	0.0	0	0.0	12	100
Netherlands	8	1.9	227	54.3	183	43.8	6	0.6	725	74.3	245	25.1
North Macedonia	0	0.0	6	7.7	72	92.3	0	0.0	8	12.5	56	87.5
Norway	1	0.8	64	47.8	69	51.5	4	1.8	99	45.4	115	52.8
Poland	1	0.1	98	10.3	854	89.6	0	0.0	185	29.0	452	71.0
Portugal	0	0.0	78	47.0	88	53.0	0	0.0	152	73.1	56	26.9
Romania	0	0.0	55	18.2	248	81.9	0	0.0	21	22.8	71	77.2
Russian Fed	35	1.5	478	20.9	1776	77.6	12	1.1	507	45.8	589	53.2
Serbia	0	0.0	2	1.3	148	98.7	0	0.0	1	2.6	37	97.4
Slovak Republic	0	0.0	46	36.5	80	63.5	0	0.0	129	83.8	25	16.2
Slovenia	0	0.0	1	1.8	55	98.2	0	0.0	10	19.6	41	80.4
Spain	0	0.0	301	29.1	734	70.9	0	0.0	722	52.8	646	47.2
Sweden	2	0.7	28	10.1	248	89.2	3	0.7	170	39.4	258	59.9
Switzerland	0	0.0	103	25.5	301	74.5	0	0.0	280	50.7	272	49.3
Türkiye	5	0.2	1633	74.1	565	25.7	11	2.1	349	65.4	174	32.6
Ukraine	2	0.6	27	8.0	310	91.5	0	0.0	6	4.6	125	95.4
United Kingdom	0	0.0	2661	65.8	1385	34.2	0	0.0	4488	73.9	1585	26.1
Total	59	0.3	9668	41.5	13562	58.2	83	0.3	16479	58.9	11408	40.8

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Inhaled hypertonic saline was reimbursed in most countries except in Albania, Armenia, Bulgaria, Estonia, Georgia, Kazakhstan, Lithuania, the Republic of Moldova and Poland. In Kosovo in 2024 there was no system for the reimbursement of medication but inhaled hypertonic saline was offered free of charge for PwCF in hospital. In Türkiye it is reimbursed for children ≥ 6 years.

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8. Therapies

Table A8.2 Use of inhaled rhDNase for ≥3 months in all people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Unknown		No		Yes		Unknown		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	35	94.6	2	5.4	0	0.0	7	77.8	2	22.2
Armenia	0	0.0	24	80.0	6	20.0	0	0.0	5	100	0	0.0
Austria	0	0.0	190	54.3	160	45.7	2	0.5	216	49.0	223	50.6
Belarus	0	0.0	52	36.1	92	63.9						
BA Rep Srpska	0	0.0	5	31.3	11	68.8	0	0.0	1	12.5	7	87.5
Bulgaria	0	0.0	58	39.2	90	60.8	0	0.0	33	31.1	73	68.9
Croatia	0	0.0	17	22.4	59	77.6	0	0.0	7	11.1	56	88.9
Cyprus	0	0.0	3	23.1	10	76.9	0	0.0	5	26.3	14	73.7
Czech Republic	0	0.0	218	62.8	129	37.2	0	0.0	89	26.0	253	74.0
Denmark	0	0.0	29	14.4	173	85.6	0	0.0	218	66.7	109	33.3
Estonia	0	0.0	13	52.0	12	48.0	0	0.0	4	23.5	13	76.5
Finland	0	0.0	16	47.1	18	52.9	0	0.0	9	19.2	38	80.9
France	0	0.0	1904	74.8	640	25.2	0	0.0	3363	81.4	770	18.6
Georgia	0	0.0	18	32.1	38	67.9						
Germany	2	0.1	1909	68.9	858	31.0	19	0.5	2593	61.3	1618	38.3
Greece	0	0.0	46	20.1	183	79.9	2	0.5	134	36.3	233	63.1
Hungary	0	0.0	194	67.8	92	32.2	0	0.0	25	12.0	184	88.0
Iceland	0	0.0	3	33.3	6	66.7	0	0.0	4	57.1	3	42.9
Ireland	0	0.0	342	65.1	183	34.9	2	0.3	364	47.8	396	52.0
Israel	1	0.7	51	33.1	102	66.2	17	4.5	149	39.1	215	56.4
Italy	1	0.1	1172	54.9	963	45.1	3	0.1	2233	59.6	1513	40.4
Kazakhstan							0	0.0	1	4.4	22	95.7
Kosovo	0	0.0	12	42.9	16	57.1	0	0.0	0	0.0	5	100
Latvia	0	0.0	25	75.8	8	24.2	0	0.0	4	21.1	15	79.0
Lithuania	0	0.0	8	36.4	14	63.6	0	0.0	4	14.3	24	85.7
Luxembourg	0	0.0	2	10.0	18	90.0	0	0.0	3	60.0	2	40.0
Rep of Moldova	1	2.8	14	38.9	21	58.3	0	0.0	2	13.3	13	86.7
Montenegro	0	0.0	11	36.7	19	63.3	0	0.0	6	50.0	6	50.0
Netherlands	8	1.9	174	41.6	236	56.5	7	0.7	574	58.8	395	40.5
North Macedonia	0	0.0	27	34.6	51	65.4	0	0.0	4	6.3	60	93.8
Norway	0	0.0	69	51.5	65	48.5	4	1.8	126	57.8	88	40.4
Poland	0	0.0	153	16.0	801	84.0	0	0.0	82	12.9	556	87.2
Portugal	0	0.0	54	32.3	113	67.7	0	0.0	32	15.4	176	84.6
Romania	1	0.3	63	20.7	240	79.0	0	0.0	1	1.1	91	98.9
Russian Fed	16	0.7	31	1.4	2242	98.0	16	1.4	210	19.0	882	79.6
Serbia	0	0.0	53	35.3	97	64.7	0	0.0	0	0.0	38	100
Slovak Republic	0	0.0	45	35.4	82	64.6	0	0.0	30	19.4	125	80.7
Slovenia	0	0.0	49	87.5	7	12.5	0	0.0	38	73.1	14	26.9
Spain	0	0.0	762	73.3	277	26.7	0	0.0	1021	74.6	348	25.4
Sweden	2	0.7	200	71.9	76	27.3	5	1.2	349	81.0	77	17.9
Switzerland	0	0.0	325	80.5	79	19.6	0	0.0	406	73.6	146	26.5
Türkiye	4	0.2	215	9.8	1984	90.1	9	1.7	83	15.5	442	82.8
Ukraine	1	0.3	87	25.6	252	74.1	1	0.8	23	17.7	106	81.5
United Kingdom	0	0.0	1661	41.1	2385	59.0	0	0.0	2510	41.3	3563	58.7
Total	38	0.2	10339	44.4	12919	55.5	87	0.3	14969	53.5	12921	46.2

Note: Information was missing for more than 10% of adults in Armenia. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Inhaled rhDNase was reimbursed in most countries except in Albania, Armenia and Belarus. It was reimbursed in Georgia for people with CF ≥ 2 years, in Bulgaria, Estonia, France, Germany, Greece, Luxembourg, Macedonia, the Republic of Moldova, Norway, Romania, Serbia, Spain, and the United Kingdom for individuals ≥ 5 years and in Latvia and Hungary for individuals ≥ 6 years. In Kosovo in 2024 there was no system for the reimbursement of medication but inhaled rhDNase was offered free of charge for PwCF in hospital.

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8. Therapies

Table A8.3 Use of inhaled antibiotics for at least 3 months in all people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Unknown		No		Yes		Unknown		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	22	57.9	16	42.1	0	0.0	7	87.5	1	12.5
Armenia	0	0.0	21	70.0	9	30.0	0	0.0	4	66.7	2	33.3
Austria	0	0.0	309	88.5	40	11.5	0	0.0	271	61.9	167	38.1
Belarus	0	0.0	100	69.4	44	30.6						
BA Rep Srpska	0	0.0	11	68.8	5	31.3	0	0.0	3	37.5	5	62.5
Bulgaria	0	0.0	99	66.9	49	33.1	0	0.0	52	49.5	53	50.5
Croatia	0	0.0	53	69.7	23	30.3	0	0.0	32	51.6	30	48.4
Cyprus	0	0.0	11	84.6	2	15.4	0	0.0	16	84.2	3	15.8
Czech Republic	0	0.0	327	94.2	20	5.8	0	0.0	257	75.2	85	24.9
Denmark	0	0.0	192	95.1	10	5.0	0	0.0	215	65.8	112	34.3
Estonia	0	0.0	24	96.0	1	4.0	0	0.0	8	47.1	9	52.9
Finland	0	0.0	32	94.1	2	5.9	0	0.0	33	70.2	14	29.8
France	0	0.0	2225	87.5	319	12.5	0	0.0	3198	77.4	935	22.6
Georgia	0	0.0	46	83.6	9	16.4						
Germany	6	0.2	2447	88.4	316	11.4	33	0.8	2430	57.5	1767	41.8
Greece	0	0.0	138	60.3	91	39.7	1	0.3	186	50.4	182	49.3
Hungary	0	0.0	211	73.8	75	26.2	0	0.0	100	47.9	109	52.2
Iceland	0	0.0	9	100	0	0.0	0	0.0	7	100	0	0.0
Ireland	0	0.0	493	93.9	32	6.1	2	0.3	378	49.6	382	50.1
Israel	0	0.0	119	77.3	35	22.7	11	2.9	225	59.5	142	37.6
Italy	1	0.1	1799	84.2	336	15.7	3	0.1	2365	63.1	1381	36.8
Kazakhstan							0	0.0	7	30.4	16	69.6
Kosovo	0	0.0	26	92.9	2	7.1	0	0.0	5	100	0	0.0
Latvia	0	0.0	27	81.8	6	18.2	0	0.0	8	44.4	10	55.6
Lithuania	0	0.0	17	77.3	5	22.7	0	0.0	24	85.7	4	14.3
Luxembourg	0	0.0	19	95.0	1	5.0	0	0.0	3	60.0	2	40.0
Rep of Moldova	0	0.0	12	33.3	24	66.7	0	0.0	3	20.0	12	80.0
Montenegro	0	0.0	24	80.0	6	20.0	0	0.0	10	83.3	2	16.7
Netherlands	9	2.2	388	92.8	21	5.0	7	0.7	700	71.7	269	27.6
North Macedonia	0	0.0	54	70.1	23	29.9	0	0.0	17	26.6	47	73.4
Norway	1	0.8	132	98.5	1	0.8	4	1.8	194	89.0	20	9.2
Poland	0	0.0	831	87.5	119	12.5	0	0.0	450	70.9	185	29.1
Portugal	0	0.0	126	75.5	41	24.6	0	0.0	124	59.9	83	40.1
Romania	0	0.0	199	65.5	105	34.5	0	0.0	51	55.4	41	44.6
Russian Fed	46	2.0	1514	66.1	729	31.9	18	1.6	528	47.7	562	50.7
Serbia	0	0.0	101	67.3	49	32.7	0	0.0	16	42.1	22	57.9
Slovak Republic	0	0.0	87	68.5	40	31.5	0	0.0	86	55.8	68	44.2
Slovenia	0	0.0	51	91.1	5	8.9	0	0.0	45	86.5	7	13.5
Spain	0	0.0	815	78.4	224	21.6	0	0.0	688	50.8	667	49.2
Sweden	2	0.7	242	87.1	34	12.2	11	2.6	379	87.9	41	9.5
Switzerland	0	0.0	386	95.5	18	4.5	0	0.0	406	73.6	146	26.5
Türkiye	2	0.1	1835	83.3	366	16.6	9	1.7	369	69.1	156	29.2
Ukraine	2	0.6	201	59.1	137	40.3	0	0.0	43	33.6	85	66.4
United Kingdom	0	0.0	3305	81.7	741	18.3	0	0.0	3175	52.3	2898	47.7
Total	70	0.3	19084	81.9	4136	17.8	99	0.4	17121	61.3	10727	38.4

Note: Information was missing for more than 10% of adults in Albania. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Inhaled antibiotics were reimbursed in all countries except Armenia and Georgia. In Bulgaria, colistin was reimbursed for all PwCF, tobramycin for those > 7 years old, and levofloxacin for those > 18 years old. In Estonia, tobramycin and colistin were reimbursed. In Romania, only tobramycin solution and colistin dry powder were reimbursed and only for PwCF aged 6 and older. In Kosovo in 2024 there was no system for the reimbursement of medication but when the intravenous formulation of colistin is adapted as an inhaled formulation, it is offered free of charge for PwCF in hospital.

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8. Therapies

Table A8.4 Use of inhaled bronchodilators for at least 3 months in children with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Unknown		No		Yes		Unknown		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	0	0.0	38	100	0	0.0	1	11.1	8	88.9
Armenia	0	0.0	13	43.3	17	56.7	0	0.0	4	66.7	2	33.3
Austria	0	0.0	25	7.1	325	92.9	0	0.0	38	8.6	404	91.4
Belarus	0	0.0	104	72.2	40	27.8						
BA Rep Srpska	0	0.0	0	0.0	16	100	0	0.0	0	0.0	8	100
Bulgaria	0	0.0	141	95.3	7	4.7	0	0.0	82	78.1	23	21.9
Croatia	0	0.0	73	96.1	3	4.0	0	0.0	35	55.6	28	44.4
Cyprus	0	0.0	10	76.9	3	23.1	0	0.0	10	52.6	9	47.4
Czech Republic	2	0.6	268	77.2	77	22.2	0	0.0	147	43.0	195	57.0
Denmark	0	0.0	168	83.2	34	16.8	1	0.3	195	59.6	131	40.1
Estonia	0	0.0	19	76.0	6	24.0	0	0.0	8	47.1	9	52.9
Finland	0	0.0	23	67.7	11	32.4	0	0.0	24	51.1	23	48.9
France	0	0.0	1488	58.5	1056	41.5	0	0.0	1725	41.7	2408	58.3
Georgia	0	0.0	18	32.1	38	67.9						
Germany	2	0.1	864	31.2	1903	68.7	13	0.3	891	21.1	3326	78.6
Greece	0	0.0	181	79.0	48	21.0	1	0.3	174	47.2	194	52.6
Hungary	0	0.0	236	82.5	50	17.5	0	0.0	36	17.2	173	82.8
Iceland	0	0.0	2	22.2	7	77.8	0	0.0	5	71.4	2	28.6
Ireland	0	0.0	238	45.3	287	54.7	2	0.3	154	20.2	606	79.5
Israel	3	2.0	66	42.9	85	55.2	16	4.2	158	41.8	204	54.0
Italy	3	0.1	670	31.4	1463	68.5	4	0.1	875	23.3	2870	76.6
Kazakhstan							0	0.0	5	21.7	18	78.3
Kosovo	0	0.0	9	32.1	19	67.9	0	0.0	2	40.0	3	60.0
Latvia	0	0.0	3	9.1	30	90.9	0	0.0	0	0.0	19	100
Lithuania	0	0.0	9	40.9	13	59.1	0	0.0	7	25.0	21	75.0
Luxembourg	0	0.0	5	25.0	15	75.0	0	0.0	1	20.0	4	80.0
Rep of Moldova	0	0.0	14	38.9	22	61.1	0	0.0	6	40.0	9	60.0
Montenegro	0	0.0	0	0.0	30	100	0	0.0	0	0.0	12	100
Netherlands	9	2.2	314	75.1	95	22.7	8	0.8	380	38.9	588	60.3
North Macedonia	0	0.0	16	20.5	62	79.5	0	0.0	5	7.8	59	92.2
Norway	0	0.0	90	67.2	44	32.8	2	0.9	68	31.2	148	67.9
Poland	0	0.0	214	22.5	739	77.5	0	0.0	129	20.2	509	79.8
Portugal	0	0.0	99	59.6	67	40.4	0	0.0	81	39.3	125	60.7
Romania	0	0.0	200	66.0	103	34.0	0	0.0	49	53.3	43	46.7
Russian Fed	27	1.2	1633	71.3	629	27.5	11	1.0	417	37.6	680	61.4
Serbia	0	0.0	37	24.7	113	75.3	0	0.0	2	5.3	36	94.7
Slovak Republic	0	0.0	59	46.5	68	53.5	0	0.0	55	35.5	100	64.5
Slovenia	0	0.0	54	96.4	2	3.6	0	0.0	40	76.9	12	23.1
Spain	0	0.0	390	37.6	648	62.4	0	0.0	433	31.7	934	68.3
Sweden	2	0.7	27	9.7	249	89.6	5	1.2	79	18.3	347	80.5
Switzerland	0	0.0	188	46.5	216	53.5	0	0.0	132	23.9	420	76.1
Türkiye	4	0.2	1386	62.9	813	36.9	10	1.9	247	46.3	277	51.9
Ukraine	2	0.6	215	63.6	121	35.8	0	0.0	44	33.6	87	66.4
United Kingdom	0	0.0	2421	61.8	1498	38.2	0	0.0	2305	38.4	3694	61.6
Total	55	0.2	11993	51.8	11116	48.0	73	0.3	9052	32.5	18773	67.3

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Inhaled bronchodilators were reimbursed in most countries except in Bulgaria, Georgia, the Republic of Moldova (reimbursed for PwCF also diagnosed with asthma), Poland and Serbia. In Kazakhstan its availability depends on the regional budget. In Estonia long- and short-acting bronchodilators were reimbursed for PwCF also diagnosed with asthma. In Kosovo in 2024 there was no system for the reimbursement of medication and PwCF must cover the cost of the therapy themselves.

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8. Therapies

Table A8.5 Use of macrolides for at least 3 months in all people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Unknown		No		Yes		Unknown		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	37	97.4	1	2.6	0	0.0	5	55.6	4	44.4
Armenia	0	0.0	29	96.7	1	3.3	0	0.0	6	100	0	0.0
Austria	0	0.0	349	99.4	2	0.6	0	0.0	421	95.7	19	4.3
Belarus	0	0.0	116	80.6	28	19.4						
BA Rep Srpska	0	0.0	15	93.8	1	6.3	0	0.0	8	100	0	0.0
Bulgaria	0	0.0	143	96.6	5	3.4	0	0.0	105	99.1	1	0.9
Croatia	0	0.0	45	59.2	31	40.8	0	0.0	48	77.4	14	22.6
Cyprus	0	0.0	7	53.9	6	46.2	0	0.0	11	57.9	8	42.1
Czech Republic	0	0.0	343	98.9	4	1.2	0	0.0	332	97.1	10	2.9
Denmark	0	0.0	189	93.6	13	6.4	0	0.0	253	77.4	74	22.6
Estonia	0	0.0	20	80.0	5	20.0	0	0.0	8	47.1	9	52.9
Finland	0	0.0	32	94.1	2	5.9	0	0.0	42	89.4	5	10.6
France	0	0.0	2205	86.7	339	13.3	0	0.0	3165	76.6	968	23.4
Georgia	0	0.0	53	96.4	2	3.6						
Germany	15	0.5	2670	96.4	84	3.0	68	1.6	3694	87.3	468	11.1
Greece	0	0.0	181	79.0	48	21.0	1	0.3	304	82.4	64	17.3
Hungary	0	0.0	254	88.8	32	11.2	0	0.0	187	89.5	22	10.5
Iceland	0	0.0	8	88.9	1	11.1	0	0.0	5	71.4	2	28.6
Ireland	0	0.0	460	87.6	65	12.4	2	0.3	377	49.5	383	50.3
Israel	1	0.7	112	73.2	40	26.1	13	3.4	233	61.3	134	35.3
Italy	1	0.1	1895	88.7	240	11.2	3	0.1	2921	77.9	825	22.0
Kazakhstan							0	0.0	6	26.1	17	73.9
Kosovo	0	0.0	28	100	0	0.0	0	0.0	4	80.0	1	20.0
Latvia	0	0.0	33	100	0	0.0	0	0.0	18	94.7	1	5.3
Lithuania	0	0.0	20	90.9	2	9.1	0	0.0	28	100	0	0.0
Luxembourg	0	0.0	14	70.0	6	30.0	0	0.0	3	60.0	2	40.0
Rep of Moldova	0	0.0	27	75.0	9	25.0	0	0.0	15	100	0	0.0
Montenegro	0	0.0	29	96.7	1	3.3	0	0.0	11	91.7	1	8.3
Netherlands	9	2.2	371	88.8	38	9.1	7	0.7	638	65.4	331	33.9
North Macedonia	0	0.0	74	96.1	3	3.9	0	0.0	45	71.4	18	28.6
Norway	2	1.5	131	97.8	1	0.8	2	0.9	188	86.2	28	12.8
Poland	0	0.0	880	92.4	72	7.6	0	0.0	526	82.6	111	17.4
Portugal	0	0.0	151	91.5	14	8.5	0	0.0	150	73.5	54	26.5
Romania	0	0.0	250	83.3	50	16.7	0	0.0	76	83.5	15	16.5
Russian Fed	35	1.5	1984	86.7	270	11.8	18	1.6	809	73.0	281	25.4
Serbia	0	0.0	146	97.3	4	2.7	0	0.0	31	81.6	7	18.4
Slovak Republic	0	0.0	96	79.3	25	20.7	0	0.0	95	62.1	58	37.9
Slovenia	0	0.0	56	100	0	0.0	0	0.0	41	78.9	11	21.2
Spain	0	0.0	886	85.9	146	14.2	0	0.0	890	65.6	467	34.4
Sweden	2	0.7	252	90.7	24	8.6	7	1.6	344	79.8	80	18.6
Switzerland	0	0.0	397	98.3	7	1.7	0	0.0	460	83.5	91	16.5
Türkiye	4	0.2	2067	93.8	132	6.0	13	2.4	471	88.2	50	9.4
Ukraine	1	0.3	149	44.4	186	55.4	0	0.0	47	36.4	82	63.6
United Kingdom	0	0.0	3912	96.7	134	3.3	0	0.0	3951	65.1	2122	34.9
Total	71	0.3	21124	90.8	2075	8.9	134	0.5	20975	75.0	6843	24.5

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Oral macrolides were reimbursed in most countries except in Bulgaria, Georgia, Kazakhstan, BA-Republika Srpska and Serbia. In Armenia, they were reimbursed for some outpatients. In Kosovo in 2024 there was no system for the reimbursement of medication PwCF cover the cost of the therapy themselves.

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8. Therapies

Table A8.6 Use of inhaled steroids >3 months in all people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Unknown		No		Yes		Unknown		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	32	84.2	6	15.8	0	0.0	4	44.4	5	55.6
Armenia	0	0.0	28	93.3	2	6.7	0	0.0	6	100	0	0.0
Austria	0	0.0	328	93.5	23	6.6	0	0.0	362	82.3	78	17.7
Belarus	0	0.0	120	83.3	24	16.7						
BA Rep Srpska	0	0.0	16	100	0	0.0	0	0.0	8	100	0	0.0
Bulgaria	0	0.0	143	98.0	3	2.1	0	0.0	91	85.9	15	14.2
Croatia	0	0.0	72	94.7	4	5.3	0	0.0	40	65.6	21	34.4
Cyprus	0	0.0	10	76.9	3	23.1	0	0.0	12	66.7	6	33.3
Czech Republic	0	0.0	286	82.4	61	17.6	0	0.0	194	56.7	148	43.3
Denmark	0	0.0	169	83.7	33	16.3	0	0.0	258	78.9	69	21.1
Estonia	0	0.0	24	96.0	1	4.0	0	0.0	10	58.8	7	41.2
Finland	0	0.0	29	85.3	5	14.7	0	0.0	33	70.2	14	29.8
France	0	0.0	1579	62.1	965	37.9	0	0.0	1972	47.7	2161	52.3
Georgia	0	0.0	55	100	0	0.0						
Germany	8	0.3	2388	86.2	373	13.5	23	0.5	2609	61.7	1598	37.8
Greece	0	0.0	192	83.8	37	16.2	1	0.3	246	66.7	122	33.1
Hungary	0	0.0	256	89.5	30	10.5	0	0.0	187	89.5	22	10.5
Iceland	0	0.0	8	88.9	1	11.1	0	0.0	7	100	0	0.0
Ireland	0	0.0	378	72.0	147	28.0	2	0.3	221	29.0	539	70.7
Israel	2	1.3	112	72.7	40	26.0	13	3.4	206	54.1	162	42.5
Italy	1	0.1	1819	85.2	316	14.8	3	0.1	2430	64.8	1316	35.1
Kazakhstan							0	0.0	8	34.8	15	65.2
Kosovo	0	0.0	28	100	0	0.0	0	0.0	5	100	0	0.0
Latvia	0	0.0	24	72.7	9	27.3	0	0.0	9	47.4	10	52.6
Lithuania	0	0.0	21	95.5	1	4.6	0	0.0	23	82.1	5	17.9
Luxembourg	0	0.0	11	55.0	9	45.0	0	0.0	1	20.0	4	80.0
Rep of Moldova	0	0.0	21	58.3	15	41.7	0	0.0	7	46.7	8	53.3
Montenegro	0	0.0	26	86.7	4	13.3	0	0.0	10	83.3	2	16.7
Netherlands	8	1.9	363	86.8	47	11.2	9	0.9	514	52.7	453	46.4
North Macedonia	0	0.0	76	98.7	1	1.3	0	0.0	47	73.4	17	26.6
Norway	0	0.0	122	91.0	12	9.0	2	0.9	181	83.0	35	16.1
Poland	0	0.0	852	89.4	101	10.6	0	0.0	434	68.2	202	31.8
Portugal	0	0.0	143	85.6	24	14.4	0	0.0	151	73.0	56	27.1
Romania	0	0.0	289	95.1	15	4.9	0	0.0	69	75.0	23	25.0
Russian Fed	27	1.2	2113	92.3	149	6.5	15	1.4	947	85.5	146	13.2
Serbia	0	0.0	129	86.0	21	14.0	0	0.0	19	50.0	19	50.0
Slovak Republic	0	0.0	77	61.1	49	38.9	0	0.0	67	43.2	88	56.8
Slovenia	0	0.0	52	92.9	4	7.1	0	0.0	50	96.2	2	3.9
Spain	0	0.0	799	77.1	238	23.0	0	0.0	794	58.4	566	41.6
Sweden	3	1.1	255	91.7	20	7.2	5	1.2	274	63.6	152	35.3
Switzerland	0	0.0	344	85.2	60	14.9	0	0.0	315	57.1	237	42.9
Türkiye	4	0.2	1948	88.4	251	11.4	10	1.9	429	80.3	95	17.8
Ukraine	1	0.3	303	89.1	36	10.6	1	0.8	116	89.2	13	10.0
United Kingdom	0	0.0	3559	88.0	487	12.0	0	0.0	5126	84.4	947	15.6
Total	55	0.2	19607	84.2	3628	15.6	84	0.3	18496	66.2	9382	33.6

Note: Albania and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Inhaled steroids were reimbursed in most countries except Armenia, Georgia, Kazakhstan, Lithuania, Poland, Serbia. In Bulgaria, they were reimbursed for PwCF who were also diagnosed with asthma or chronic obstructive pulmonary disease (COPD). In Estonia, Romania and the Republic of Moldova inhaled steroids were reimbursed for PwCF who were also diagnosed with asthma. In Kosovo in 2024 there was no system for the reimbursement of medication and PwCF cover the cost of the therapy themselves.

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8. Therapies

Table A8.7 Use of oral steroids for at least 3 months in all people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Unknown		No		Yes		Unknown		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	38	100	0	0.0	0	0.0	9	100	0	0.0
Armenia	0	0.0	29	96.7	1	3.3	0	0.0	6	100	0	0.0
Austria	0	0.0	350	100	0	0.0	0	0.0	429	98.6	6	1.4
Belarus	0	0.0	142	98.6	2	1.4						
BA Rep Srpska	0	0.0	16	100	0	0.0	0	0.0	8	100	0	0.0
Bulgaria	0	0.0	148	100	0	0.0	0	0.0	105	99.1	1	0.9
Croatia	0	0.0	75	98.7	1	1.3	0	0.0	63	100	0	0.0
Cyprus	0	0.0	13	100	0	0.0	0	0.0	17	100	0	0.0
Czech Republic	0	0.0	346	99.7	1	0.3	0	0.0	340	99.4	2	0.6
Denmark	0	0.0	201	99.5	1	0.5	0	0.0	321	98.2	6	1.8
Estonia	0	0.0	25	100	0	0.0	0	0.0	17	100	0	0.0
Finland	0	0.0	34	100	0	0.0	0	0.0	47	100	0	0.0
France	0	0.0	2530	99.5	14	0.6	0	0.0	4019	97.2	114	2.8
Georgia	0	0.0	55	100	0	0.0						
Germany	14	0.5	2735	98.8	20	0.7	47	1.1	4001	94.6	182	4.3
Greece	0	0.0	226	98.7	3	1.3	1	0.3	365	98.9	3	0.8
Hungary	0	0.0	282	98.6	4	1.4	0	0.0	202	96.7	7	3.4
Iceland	0	0.0	9	100	0	0.0	0	0.0	7	100	0	0.0
Ireland	0	0.0	522	99.4	3	0.6	2	0.3	732	96.1	28	3.7
Israel	0	0.0	154	100	0	0.0	1	0.3	367	96.8	11	2.9
Italy	1	0.1	1948	91.2	187	8.8	7	0.2	2805	74.8	937	25.0
Kazakhstan							0	0.0	22	95.7	1	4.4
Kosovo	0	0.0	28	100	0	0.0	0	0.0	5	100	0	0.0
Latvia	0	0.0	33	100	0	0.0	0	0.0	19	100	0	0.0
Lithuania	0	0.0	22	100	0	0.0	0	0.0	28	100	0	0.0
Luxembourg	0	0.0	20	100	0	0.0	0	0.0	5	100	0	0.0
Rep of Moldova	0	0.0	36	100	0	0.0	0	0.0	15	100	0	0.0
Montenegro	0	0.0	30	100	0	0.0	0	0.0	11	91.7	1	8.3
Netherlands	8	1.9	405	96.9	5	1.2	9	0.9	910	93.2	57	5.8
North Macedonia	0	0.0	77	100	0	0.0	0	0.0	63	98.4	1	1.6
Norway	1	0.8	133	99.3	0	0.0	3	1.4	213	97.7	2	0.9
Poland	0	0.0	946	99.6	4	0.4	0	0.0	625	98.0	13	2.0
Portugal	0	0.0	166	99.4	1	0.6	0	0.0	205	99.0	2	1.0
Romania	0	0.0	298	99.3	2	0.7	0	0.0	92	100	0	0.0
Russian Fed	23	1.0	2238	97.8	28	1.2	11	1.0	1073	96.8	24	2.2
Serbia	0	0.0	150	100	0	0.0	0	0.0	38	100	0	0.0
Slovak Republic	0	0.0	125	99.2	1	0.8	0	0.0	147	94.8	8	5.2
Slovenia	0	0.0	56	100	0	0.0	0	0.0	50	96.2	2	3.9
Spain	0	0.0	1019	99.1	9	0.9	0	0.0	1311	96.6	46	3.4
Sweden	2	0.7	276	99.3	0	0.0	5	1.2	410	95.1	16	3.7
Switzerland	0	0.0	404	100	0	0.0	0	0.0	542	98.2	10	1.8
Türkiye	4	0.2	2193	99.6	6	0.3	13	2.4	517	96.8	4	0.8
Ukraine	1	0.3	334	98.8	3	0.9	0	0.0	128	97.7	3	2.3
United Kingdom	0	0.0	4016	99.3	30	0.7	0	0.0	5755	94.8	318	5.2
Total	55	0.2	22892	98.4	326	1.4	99	0.4	26051	93.2	1806	6.5

Note: Information was missing for more than 10% of adults in Cyprus. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Oral steroids were reimbursed in most countries except in Armenia, Bulgaria, Georgia, Kazakhstan, Lithuania, the Republic of Moldova, BA-Republika Srpska and Serbia. In Kosovo in 2024 there was no system for the reimbursement of medication and PwCF cover the cost of the therapy themselves.

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8. Therapies

Table A8.8 Use of ursodeoxycholic acid for ≥ 3 months in all people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Unknown		No		Yes		Unknown		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	18	47.4	20	52.6	0	0.0	5	55.6	4	44.4
Armenia	0	0.0	17	56.7	13	43.3	0	0.0	5	83.3	1	16.7
Austria	0	0.0	205	58.7	144	41.3	0	0.0	239	54.2	202	45.8
Belarus	0	0.0	19	13.2	125	86.8						
BA Rep Srpska	0	0.0	12	75.0	4	25.0	0	0.0	5	62.5	3	37.5
Bulgaria	0	0.0	57	38.5	91	61.5	0	0.0	52	49.1	54	50.9
Croatia	0	0.0	62	81.6	14	18.4	0	0.0	45	71.4	18	28.6
Cyprus	0	0.0	9	69.2	4	30.8	0	0.0	17	89.5	2	10.5
Czech Republic	0	0.0	244	70.3	103	29.7	0	0.0	238	69.6	104	30.4
Denmark	1	0.5	170	84.2	31	15.4	0	0.0	246	75.2	81	24.8
Estonia	0	0.0	17	68.0	8	32.0	0	0.0	12	70.6	5	29.4
Finland	0	0.0	26	76.5	8	23.5	0	0.0	35	74.5	12	25.5
France	0	0.0	2294	90.2	250	9.8	0	0.0	3270	79.1	863	20.9
Georgia	0	0.0	50	92.6	4	7.4						
Germany	1	0.0	1750	63.2	1018	36.8	16	0.4	2050	48.5	2164	51.2
Greece	0	0.0	152	66.4	77	33.6	1	0.3	252	68.3	116	31.4
Hungary	0	0.0	190	66.4	96	33.6	0	0.0	124	59.3	85	40.7
Iceland	0	0.0	9	100	0	0.0	0	0.0	6	85.7	1	14.3
Ireland	0	0.0	509	97.0	16	3.1	2	0.3	681	89.4	79	10.4
Israel	0	0.0	143	93.5	10	6.5	1	0.3	333	88.1	44	11.6
Italy	1	0.1	1590	74.4	545	25.5	3	0.1	2250	60.0	1496	39.9
Kazakhstan							0	0.0	0	0.0	23	100
Kosovo	0	0.0	21	75.0	7	25.0	0	0.0	5	100	0	0.0
Latvia	0	0.0	26	78.8	7	21.2	0	0.0	11	57.9	8	42.1
Lithuania	0	0.0	19	86.4	3	13.6	0	0.0	27	96.4	1	3.6
Luxembourg	0	0.0	19	95.0	1	5.0	0	0.0	3	60.0	2	40.0
Rep of Moldova	0	0.0	4	11.1	32	88.9	0	0.0	3	20.0	12	80.0
Montenegro	0	0.0	20	66.7	10	33.3	0	0.0	3	25.0	9	75.0
Netherlands	8	1.9	363	86.8	47	11.2	7	0.7	745	76.3	224	23.0
North Macedonia	0	0.0	55	72.4	21	27.6	0	0.0	24	37.5	40	62.5
Norway	0	0.0	126	94.0	8	6.0	2	0.9	201	92.2	15	6.9
Poland	0	0.0	499	52.5	451	47.5	0	0.0	249	39.4	383	60.6
Portugal	0	0.0	114	68.3	53	31.7	0	0.0	152	73.1	56	26.9
Romania	0	0.0	195	64.6	107	35.4	0	0.0	62	69.7	27	30.3
Russian Fed	18	0.8	219	9.6	2052	89.7	12	1.1	307	27.7	789	71.2
Serbia	0	0.0	115	76.7	35	23.3	0	0.0	18	47.4	20	52.6
Slovak Republic	0	0.0	73	58.4	52	41.6	0	0.0	72	46.8	82	53.3
Slovenia	0	0.0	26	46.4	30	53.6	0	0.0	27	54.0	23	46.0
Spain	0	0.0	819	79.4	213	20.6	1	0.1	1027	75.5	332	24.4
Sweden	2	0.7	239	86.0	37	13.3	8	1.9	362	84.0	61	14.2
Switzerland	0	0.0	343	84.9	61	15.1	0	0.0	408	73.9	144	26.1
Türkiye	5	0.2	1860	84.4	338	15.3	12	2.3	429	80.3	93	17.4
Ukraine	1	0.3	20	5.9	320	93.8	1	0.8	6	4.6	124	94.7
United Kingdom	0	0.0	3304	81.7	742	18.3	0	0.0	4648	76.5	1425	23.5
Total	38	0.2	16025	68.8	7214	31.0	66	0.2	18658	66.7	9231	33.0

Note: Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Oral ursodeoxycholic acid was reimbursed in most countries in Europe, except in Armenia, Bulgaria, Georgia, Lithuania and Serbia. In the Republic of Moldova it was reimbursed at 100% for children and at 70% for adults. In Kazakhstan, availability depends on the regional budget. In Kosovo in 2024 there was no system for the reimbursement of medication PwCF cover the cost of the therapy themselves.

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8. Therapies

Table A8.9 Prevalence of the use of proton pump inhibitors (PPI) for ≥ 3 months in all people with CF seen in 2024 who have never had a transplant, by country and overall.

Country	Children (<18 years)						Adults (≥18 years)					
	Unknown		No		Yes		Unknown		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Albania	0	0.0	24	63.2	14	36.8	0	0.0	0	0.0	9	100
Armenia	0	0.0	19	63.3	11	36.7	0	0.0	3	50.0	3	50.0
Austria	1	0.3	342	98.3	5	1.4	0	0.0	388	88.8	49	11.2
Belarus	0	0.0	110	76.4	34	23.6						
BA Rep Srpska	0	0.0	16	100	0	0.0	0	0.0	8	100	0	0.0
Bulgaria	0	0.0	126	86.3	20	13.7	0	0.0	87	83.7	17	16.4
Croatia	0	0.0	68	89.5	8	10.5	0	0.0	59	93.7	4	6.4
Cyprus	0	0.0	13	100	0	0.0	0	0.0	12	63.2	7	36.8
Czech Republic	0	0.0	330	95.1	17	4.9	0	0.0	233	68.1	109	31.9
Denmark	1	0.5	171	84.7	30	14.9	2	0.6	235	71.9	90	27.5
Estonia	0	0.0	21	95.5	1	4.6	0	0.0	17	100	0	0.0
Finland	0	0.0	27	79.4	7	20.6	0	0.0	40	85.1	7	14.9
France	0	0.0	2144	84.3	400	15.7	0	0.0	2550	61.7	1583	38.3
Georgia	0	0.0	53	100	0	0.0						
Germany	2	0.1	2552	92.2	215	7.8	16	0.4	3281	77.6	933	22.1
Greece	1	0.4	206	90.0	22	9.6	1	0.3	322	87.3	46	12.5
Hungary	0	0.0	264	92.3	22	7.7	0	0.0	171	81.8	38	18.2
Iceland	0	0.0	5	55.6	4	44.4	0	0.0	7	100	0	0.0
Ireland	0	0.0	434	82.7	91	17.3	2	0.3	334	43.8	426	55.9
Israel	0	0.0	120	77.9	34	22.1	7	1.8	265	69.6	109	28.6
Italy	1	0.1	1885	88.3	250	11.7	3	0.1	2482	66.2	1264	33.7
Kazakhstan							0	0.0	18	78.3	5	21.7
Kosovo	0	0.0	28	100	0	0.0	0	0.0	5	100	0	0.0
Latvia	0	0.0	30	90.9	3	9.1	0	0.0	16	84.2	3	15.8
Lithuania	0	0.0	22	100	0	0.0	0	0.0	24	85.7	4	14.3
Luxembourg	0	0.0	17	85.0	3	15.0	0	0.0	3	60.0	2	40.0
Rep of Moldova	0	0.0	35	100	0	0.0	0	0.0	14	100	0	0.0
Montenegro	0	0.0	21	70.0	9	30.0	0	0.0	10	83.3	2	16.7
Netherlands	8	1.9	340	81.3	70	16.8	6	0.6	477	48.9	493	50.5
North Macedonia	0	0.0	56	71.8	22	28.2	0	0.0	18	28.6	45	71.4
Norway	0	0.0	124	92.5	10	7.5	1	0.5	178	81.7	39	17.9
Poland	0	0.0	900	94.8	49	5.2	0	0.0	503	79.2	132	20.8
Portugal	0	0.0	154	92.8	12	7.2	0	0.0	141	68.1	66	31.9
Romania	0	0.0	283	93.4	20	6.6	0	0.0	85	96.6	3	3.4
Russian Fed	65	2.8	1816	79.3	408	17.8	24	2.2	752	67.9	332	30.0
Serbia	0	0.0	129	86.0	21	14.0	0	0.0	24	63.2	14	36.8
Slovak Republic	0	0.0	123	96.9	4	3.2	0	0.0	122	79.2	32	20.8
Slovenia	0	0.0	52	92.9	4	7.1	0	0.0	35	68.6	16	31.4
Spain	0	0.0	910	87.8	126	12.2	0	0.0	795	58.4	566	41.6
Sweden	2	0.7	252	90.7	24	8.6	5	1.2	328	76.1	98	22.7
Switzerland	0	0.0	386	95.5	18	4.5	0	0.0	416	75.4	136	24.6
Türkiye	4	0.2	2002	90.9	197	8.9	12	2.3	441	82.6	81	15.2
Ukraine	1	0.3	245	73.1	89	26.6	0	0.0	77	59.7	52	40.3
United Kingdom	0	0.0	2890	71.4	1156	28.6	0	0.0	3433	56.5	2640	43.5
Total	87	0.4	19753	84.9	3431	14.7	79	0.3	18413	65.9	9459	33.8

Note: Information was missing for more than 10% of adults in Republic of Moldova. Belarus and Georgia have <5 adults seen in 2024 and are excluded from the table for adults.

Note: Oral proton pump inhibitors were reimbursed in most countries except in Bulgaria, Georgia, Kazakhstan, Lithuania and Serbia. In Armenia they were reimbursed for some outpatients. In Kosovo in 2024 there was no system for the reimbursement of medication PwCF cover the cost of the therapy themselves.

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Appendix 2 List of contributing centres and national registries

This is a list of the individual centres and the national registries, with their representatives, that contributed data to the ECFSPR in 2024. In turquoise: the name of the country representative in the ECFSPR Steering Group; underlined: the name of the database manager for the national registry; in italics: new participants with 2024 data.

Country	Centre/National Registry name	Contact
Albania	1 individual centre:	Irena Kasmi
	"Mother Thereza" Hospital Centre, Department of Paediatrics, Tirana	Irena Kasmi Evda Vevecka
	Regional Hospital Centre "Shefqet Ndroqi", Adults, Tirana	*Irma Tashi*
Armenia	2 individual centres:	Satenik Harutyunyan
	Yerevan State Medical University, Muratsan University Hospital, Cystic Fibrosis Centre, Yerevan Arabkir Medical Centre-Institute of Child and Adolescent Health, Yerevan	Satenik Harutyunyan Vachagan Baghdasaryan Aghavni Sararyan
Austria	14 individual centres:	Dorothea Appelt
	Medizinische Universität Graz, Universitätsklinik für Kinder- und Jugendheilkunde, Klinische Abteilung für Pädiatrische Pulmonologie und Allergologie und CF Zentrum für Kinder, Jugendliche und Erwachsene, Graz	Ernst Eber Maria Gaber Manfred Modl Doris Malle-Scheid
	Medizinische Univ. Graz, Abteilung für Pulmologie, Univ. Klinik für Innere Medizin, Graz	*Nikolaus Kneidinger* *Maria Hermann* *Holger Flick*
	Medizinische Universität Innsbruck, Zertifiziertes CF Zentrum für Kinder, Jugendliche und Erwachsene, Innsbruck	Dorothea Appelt Johannes Eder
	Klinikum Klagenfurt am Wörthersee, Abteilung für Kinder- und Jugendheilkunde, Pädiatrische Pulmologie/ Allergologie, Klagenfurt	Franz Hubert Wadlegger Marc Schlapschy
	Kepler Universitätsklinikum, Universitätsklinik für Kinder- und Jugendheilkunde, Linz	Claudia Hochpöchler
	Kepler Universitätsklinikum, Klinik für Lungenheilkunde/ Pneumologie, Linz	Katrin Scheich
	Kardinal Schwarzenberg Klinikum, Abteilung für Kinder- und Jugendmedizin, Schwarzach im Pongau	Josef Riedler Christoph Seelbach
	PEK Klinikum Steyr, Abteilung für Kinder- und Jugendheilkunde und Abteilung für Lungenheilkunde, Steyr	Alexander Ebner Margit Kallinger
	Medizinische Universität Wien, Allgemeines Krankenhaus Wien für Thoraxchirurgie, Vienna	Peter Jaksch Dagmar Liebhart
	Medizinische Universität, Allgemeines Krankenhaus Wien, Universitätsklinik für Kinder-und Jugendheilkunde, Klinische Abteilung für Pädiatrische Pneumologie, Allergologie und Endokrinologie, Zentrum für Cystische Fibrose, Vienna	Saskia Gruber Brigitte Mersi
	Klinik Ottakring, Abteilung für Kinder- und Jugendheilkunde mit Ambulanz, Vienna	Mehtap Schmidt Sophie Mandelburger
	Klinik Hietzing, Abteilung für Atmungs- und Lungenkrankheiten, Vienna	Andrea Lakatos–Krepcik
	Klinikum Wels-Grieskirchen, Abteilung für Kinder- und Jugendheilkunde, Wels	Vera Karin Bauer Magdalena Puschmann Andrea Viechtbauer

Country	Centre/National Registry name	Contact
Austria (cont.)	Klinikum Wels-Grieskirchen, Abteilung für Lungenkrankheiten, Wels	Alexander Leitner Thomas Tempelmayer
Belarus	1 individual centre:	Sviatlana Keegan
	Belarusian Republic Children's Centre of Pulmonology and Cystic Fibrosis, Pulmonary Department, 3rd City Children's Clinical Hospital, Minsk`	Vladimir Bobrovnichiy Sviatlana Keegan Katsiaryna Chyrkun
Bulgaria	2 individual centres:	Guergana Petrova
	Alexandrovska University Hospital, Paediatric Clinic, Sofia	Guergana Petrova
	University Hospital St. Marina, 2nd Paediatric Clinic, Varna	Miglena Georgieva Margarita Nikolova
Bosnia and Herzegovina	*2 individual centres:*	*Amina Selimovic* *Olivera Ljuboja*
	The Federation of Bosnia and Herzegovina, University Clinical Centre of Sarajevo, Paediatric Clinic, Department of Pulmonology, Sarajevo	*Amina Selimovic* *Ahmed Mulać*
	The Republika Srpska, University Clinical Centre, Banja Luka	*Olivera Ljuboja* *Jelena Milijkovic*
Croatia	1 individual centre:	Duska Tješić-Drinković Andrea Vukić Dugac
	University Hospital Centre Zagreb, Cystic Fibrosis Centre – Paediatrics and Adults, on behalf of the Croatian people with CF Database, Zagreb	Duska Tješić-Drinković Andrea Vukić Dugac Ivan Bambir
Cyprus	1 individual centre:	Panayiotis Yiallouros
	Medical School, University of Cyprus, children and adults, Nicosia	Panayiotis Yiallouros Panayiotis Kouis Pinelopi Anagnostopoulou
Czech Republic	Cystic Fibrosis Registry of the Czech Republic	Pavel Drevinek Alena Bilkova Milan Macek Marek Turnovec
Denmark	Cystic Fibrosis Registry Denmark	Hanne Vebert Olesen Tacjana Pressler Line Krosgaard
Estonia	4 individual centres:	Maire Vasar
	North Estonia Medical Centre, Internal Medicine, Clinical Department of Pulmonology, Tallin	Liina Viks
	Tallin Children's Hospital, Paediatric Allergology and Pulmonology Unit, Tallin	Silvi Plado
	Lung Clinic of Tartu University Hospital	Viktoria Ivanova
	Children's Clinic of Tartu University Hospital, Tartu	Maire Vasar Anneli Viidebaum
Finland	Cystic Fibrosis in Finland	Varpu Elenius Katriina Pihlajamaa Aleksi Kemppainen
France	Registre Français de la Mucoviscidose	Antoine Bessou Alexandre Lafourcade
Georgia	2 individual centres:	Dodo Agladze
	LTD, Medical Genetics and Laboratory Diagnostic Centre, Tbilisi	Dodo Agladze

Country	Centre/National Registry name	Contact
Georgia (cont.)	*Clinic "Diacor", Department of Internal Medicine / National Centre for Lung Fibrosis and Sarcoidosis, Tblisi,*	*Lika Sigua*
Germany	German Cystic Fibrosis Registry	Lutz Naehrlich Julia Wosniok
Greece	Cystic Fibrosis Registry of Greece	Elpis Hatziagorou John Tsanakas Maria Davis Panagiota Mitrou Kostas Mathioudakis
Hungary	Cystic Fibrosis Registry of Hungary	Andrea Párniczky Géza Marsal
Iceland	1 individual centre:	Helga Elidottir
	Children´s Medical Centre Landspitali – The National University Hospital of Iceland, Reykjavik	Helga Elidottir Olafur Baldursson
Ireland	Cystic Fibrosis Registry of Ireland	Godfrey Fletcher Laura Kirwan
Israel	6 individual centres:	Meir Mei-Zahav
	Soroka University Medical Centre, Ben Gurion University of the Negev, Beer Sheva	Inbal Golan-Tripto
	Carmel Medical Centre, Haifa	Galit Livnat
	Ruth Rappaport Children's Hospital, Rambam Medical Centre, Haifa	Michal Gur
	Hadassah Medical Centre, Mount Scopus, Jerusalem	Malena Cohen-Cymberknoh
	Schneider Children's Medical Centre of Israel, Petah Tikva	Meir Mei-Zahav
	Safra Children's Hospital, Sheba Medical Centre, Ramat Gan	Ori Efrati
	Beilinson Hospital, Rabin Medical Centre, Petah Tikva	Moshe Heching
Italy	Italian Cystic Fibrosis Registry	Fabio Majo Marco Salvatore Annalisa Amato Gianluca Ferrari
Kazakhstan	1 individual centre:	Elena Amelina
	Multidisciplinary City Hospital No. 1, Astana	Irina Mukatova Elena Amelina
Kosovo	*1 individual centre:*	*Vlora Nimani*
	Pediatric Clinic, Pulmonology Department, University Clinical Centre of Kosovo (department for both children and adults)	*Vlora Nimani*
Kyrgyzstan	*2 individual centres:*	*Talant Sooronbaev*
	National Centre of Cardiology and Internal Medicine, M. Mirrakhimov, Bishkek and National Centre of Maternity and Childhood Care, Bishkek	*Talant Sooronbaev* *Elivira Isaeva* *Alymbek Sharshembiyev* *Maamed Mademilov* *Ainura Abdraeva*
Latvia	1 individual centre:	Elina Aleksejeva
	Rīga Stradiņš University, Children's Clinical University Hospital, Department of Pneumology, Riga	Elina Aleksejeva Dita Gaidule-Logina

Country	Centre/National Registry name	Contact
Lithuania	2 individual centres:	Kęstutis Malakauskas
	Hospital of Lithuanian University of Health Sciences Kauno Klinikos, Adult Cystic Fibrosis Centre, Kaunas	Kęstutis Malakauskas Virginija Kalinauskaitė-Žukauskė
	Hospital of Lithuanian University of Health Sciences Kauno Klinikos, Centre of Paediatric Chronic Respiratory Diseases, Kaunas	Valdonė Misevičienė
Luxembourg	1 individual centre:	Anna-Maria Charatsi
	Centre Hospitalier de Luxembourg, Department of Paediatrics and Department of Pulmonology, Luxembourg	Anna-Maria Charatsi Michael Sieren
Rep. of North Macedonia	2 individual centres:	Tatjana Jakovska-Maretti Valentina Cvejovska Cholakovska
	Centre for Cystic Fibrosis - Children and Adults, University Clinic for Respiratory Diseases in Children-Kozle, Skopje	Tatjana Jakovska-Maretti Ivana Arnaudova Danevska
	University Children's Hospital, Centre for Cystic Fibrosis, Skopje	Valentina Cvejovska Cholakovska Andrijana Andreevska
Rep. of Moldova	1 individual centre:	Christina Tomacinschii
	Outpatient Centre for Cystic Fibrosis and Other Rare Diseases, Chisinau	Christina Tomacinschii Oxana Turcu
Montenegro	*1 individual centre:*	*Tomo Plamenach*
	Institute for Children's Diseases, Clinical Centre of Montenegro, Podgorica	*Tomo Plamenach*
Netherlands	Dutch Cystic Fibrosis Registry	Domenique Zomer Renate Kos
Norway	Norwegian Cystic Fibrosis Patient Registry	Egil Bakkeheim Magnhild Louise Pollestad Kolsgaard
Poland	19 individual centres:	Łukasz Woźniacki
	2nd Department of Lung Diseases and Tuberculosis, Medical University of Bialystok, Bialystok	Łukasz Minarowski
	Voivodeship Children's Hospital, Dept. of Paediatric Pneumology and Allergology, Bydgoszcz	Radoslawa Staszak–Kowalska Mikolaj Kowalski
	Cystic Fibrosis Centre, Polanki Paediatric Hospital, Gdansk	Maria Trawinska-Bartnicka Ewa Sapiejka Anna Steinert-Dymecki
	Centrum Medyczne Karpacz, Children/Adults' Hospital, Karpacz	Grzegorz Gaszczyk Monika Rams
	John Paul II Upper Silesian Child Health Centre, The Independent Public Clinical Hospital no. 6 of the Medical University of Silesian in Katowice, Katowice	Urszula Grzybowska-Chlebowczyk Bozena Kordys-Darmolinska
	Paediatric Clinic Holy Cross Paediatric Centre, Provincial Integrated Hospital in Kielce, Kielce	Elżbieta Kołodziej Maciej Szczukocki
	St. Louis Regional Specialised Children's Hospital, Krakow	Stanislaw Stepniewski Daria Dziecichowicz-Latala
	The University Hospital in Krakow, Pulmonology and Allergology Clinical Department, Krakow	Krysztof Sladek Iwona Gross-Sondej

Country	Centre/National Registry name	Contact
Poland (cont.)	Barlicki Hospital, Medical University of Lodz, Department of General and Oncological Pulmonology, Lodz	Małgorzata Pietrusinska
	Wojewódzkie Wielospecjalistyczne centrum Onkologii i Traumatologii im. M. Kopernika w Lodzi, Ośrodek Pediatryczny im. J. Korczak, Lodz	Agnieszka Brzozowska Agnieszka Koniarek-Maniecka Katarzyna Kapszewicz
	Cystic Fibrosis Centre for Adults, Independent Hospital No. 4, Lublin	Irena Węgrzyn-Szkutnik Adam Krusiński
	University Hospital of Lords Transfiguration, Dept. of Pulmonology, Allergology and Pulmonary Oncology, Poznan	Szczepan Cofta Daria Springer Hanna Winiarska
	Karol Jonscher University Hospital of Poznan University of Medical Sciences, Poznan	Irena Wojsyk-Banaszak Agnieszka Korytowska-Niklas
	Institute of Tuberculosis and Lung Diseases, Rabka-Zdrój Branch, Dept. of Pneumology and Cystic Fibrosis, Rabka Zdroj	Henryk Mazurek Andrzej Pogorzelski Lidia Pawlik
	Provincial Clinical Hospital no. 2, St. Queen Jadwiga, Dept of Allergology and Cystic Fibrosis, St Jadwigi Krolowej in Rzeszów, Rzeszów	Marta Rachel
	Szczecin Hospital “Zdroje” Dep. Of Pediatrics, Allergology and Pulmonology, Szczecin	Pawel Gonerko Pawel Fabisiak
	Lubuski Institute of Pulmonary Medicine, Adult Cystic Fibrosis Treatment Centre, Torzym	Michal Karolak Agnieszka Szklarska
	Dziekanow Paediatric Hospital, Cystic Fibrosis Centre, Institute of Mother and Child, Warsaw	Dorota Sands Łukasz Woźniacki
	Institute of Tuberculosis and Lung Diseases, Adult CF Centre, Warsaw	Wojciech Skorupa Sylwia Ziernik
Portugal	Cystic Fibrosis Registry of Portugal	Luisa Pereira
Romania	10 individual centres:	Liviu Pop
	Regional Cystic Fibrosis Centre, Clinical Emergency Children's Hospital of Brasov, Brasov	Laura Larisa Dracea
	Clinical Children’s Hospital “Grigore Alexandrescu”, Bucharest	Simona Mosescu
		Livia Brezeanu
	Emergency Hospital for Children Marie Curie” – Paediatrics 3, Bucharest	Maria Iulia Brustan Ioana Gradinaru
	Institute of Pneumology "Marius Nasta", Adult Centre, Bucharest	Cristi Popa
	Mother & Child Health Institute, Bucharest	Iustina Stan Valentina Comanici
	Sf. Apostol Andrei County Emergency Clinical Hospital, Department. of Paediatrics, Regional CF Centre, Constanta	Cristina Andrei
	Regional Cystic Fibrosis Centre Cluj, Clinical Emergency Hospital for Children of Cluj-Napoca, Cluj-Napoca	Radu Sorin Șerban Szabo Csilla-Enikő
	Regional Cystic Fibrosis Centre, “Sf. Maria” Children Emergency Hospital Iasi, Iasi	Dana-Teodora Anton-Paduraru
	National Cystic Fibrosis Centre- County Emergency Clinical Hospital "Pius Branzeu" Timisoara	Liviu Pop Ioana Ciuca
	Pulmonology Clinic, Adult CF Centre, Clinical Hospital of Infectious Diseases and Pulmonology "Victor Babes" University of Medicine and Pharmacy Timisoara,	Camelia Corina Pescaru Adelina Maritescu

Country	Centre/National Registry name	Contact
Russian Federation	Cystic Fibrosis Registry of the Russian Federation	Elena Kondratyeva Marina Starinova Olga Kondratenko Yulia Gorinova Stanislav Krasovsky Diana Sergienko Yulia Melyanovskaya
Serbia	2 individual centres:	Milan Rodić
	National Centre for Cystic Fibrosis, Mother and Child Health Institute of Serbia "Dr Vukan Čupić", Belgrade	Milan Rodić Aleksandar Sovtić
	Institute for Child and Youth Health Care of Vojvodina, Department of Pulmonology, Novi Sad	*Milena Bjelica*
Slovakia	6 individual centres:	Hana Kayserova Nina Bliznakova
	Children's CF Centre, DFN Banská Bystrica, Banská Bystrica	Branko Takáč Ivana Gondová
	Centrum Cystickej Fibrozy Pre Dospelych FNSP FDR, Banská Bystrica	Eva Bérešova
	Centrum Cystickej Fibrozy Pre Dospelych, Klinika Pneumologie l.SZU a Univerzitna Nemocnica, Bratislava	Marta Hajkova
	Klinika detskej Pneumologie SZU UN Bratislava, Pracovisko Podunajské Biskupice, Bratislava	Hana Kayserova Nina Bližňáková
	CF Adult centre, University Hospital L Pasteura, Košice	Lenka Kopčová
Slovenia	Centrum Cystickej Fibrozy Detí, Detská Fakultná Nemocnica Košice, Košice	Anna Fetekeova Zuzana Hribíková
	3 individual centres:	Uroš Krivec
	University Clinic of Pulmonary and Allergic Diseases, Golnik	Matjaž Fležar Julij Šelb
	University Medical Centre Ljubljana, Department of Pulmonology and Allergy, Ljubljana	Barbara Salobir Maja Badinovac
	University Medical Centre Ljubljana, University Children`s Hospital, Department of Paediatric Pulmonology, Ljubljana	Uroš Krivec Jasna Rodman Berlot
Spain	26 individual centres:	M. Dolores Pastor Vivero
	Parc Taulí Hospital Universitario, Hospital de Sabadell, Unitat de Pneumologia Pediátrica i Unitat de Fibrosi Quística, Sabadell, Barcelona	Oscar Asensio de la Cruz Miguel Garcia Gonzàlez Xavier Pomares Amigó Concepción Montón Soler
	Hospital Sant Joan de Déu, Unitat de Pneumologia Pediàtrica i Fibrosi Quística, Barcelona	Maria Cols i Roig Jordi Costa i Colomer
	Hospital Universitari Vall d'Hebron, Unidad de Fibrosis Quística del Adulto, Barcelona	Antonio Alvarez Fernández Jordi Carnicero Rabadan Eva Polverino
	Hospital Universitari Vall d'Hebron, Unidad Fibrosis Quística y Neumología Pediátrica, Barcelona	Silvia Gartner Sandra Rovira Amigo
	Hospital Universitario Cruces, Unidad de Fibrosis Quística, Bizkaia	M. Dolores Pastor Vivero Ainhoa Gómez Bonilla Beatriz Gómez Crespo
	Hospital Universitario Reina Sofia, Unidad de Alergia y Neumología Pediátricas y UGC Neumología, Facultad de Medicina e Instituto Maimónides de Investigación Biomédica de Córdoba (IMIBIC), Córdoba	Javier Torres Borrego José Manuel Vaquero Barrios Marina Calvo
	Complejo Hospitalario Universitario Insular Materno Infantil, Las Palmas de Gran Canaria	Antonio José Aguilar Fernández

Country	Centre/National Registry name	Contact
Spain (cont.)	Hospital Universitario La Paz, Unidad de Fibrosis Quística Adultos, Servicio de Neumología, Madrid	Concha Prados
	Hospital Universitario La Paz, Sección de Neumología Pediátrica, Unidad de Fibrosis Quística Pediátrica, Madrid	Marta Ruiz de Valbuena Máiz, Cristina de Manuel Gómez
	Hospital Universitario La Princesa, Neumología Adultos, Madrid	Rosa María Girón Rosa Mar Gómez-Punter
	Hospital Niño Jesús, Sección de Neumología Pediátrica, Unidad de Fibrosis Quística, Madrid	Alejandro López Neyra Verónica Sanz Santiago
	Hospital Universitario Ramón y Cajal, Unidad de Fibrosis Quística, Madrid	Luis Máiz Carro Saioa Vicente Santamaria Enrique Blitz Castro Rosa Maria Nieto Royo Ana Morales Tirado
	Hospital Universitario 12 de Octubre, Unidad de Fibrosis Quística Pediátrica, Madrid	Carmen Luna Paredes Enrique Salcedo Lobato
	Hospital Universitario 12 de Octubre, Unidad de Fibrosis Quística Adultos, Madrid	Layla Diab Cáceres
	Hospital Regional Universitario de Málaga, Unidad Fibrosis Quística Adultos de Andalucía Oriental, Málaga	Casilda Olveira Fuster Gabriel María Olveira Fuster
	Hospital Regional Universitario de Málaga, Unidad de Fibrosis Quística Pediátrica, Málaga	Estela Pèrez-Ruiz Pilar Caro-Aguilera Juan Carlos Ramos Díaz
	Hospital Clínico Universitario Virgen de la Arrixaca, Unidad de Fibrosis Quística, Murcia	Pedro Mondéjar-López Silvia Lorca Mayor
	Hospital Universitario Central de Asturias, Unidad de Fibrosis Quística, Oviedo	José Ramón Gutiérrez Martínez David González Jimenez Marta Garcia Clemente
	Hospital Universitario Son Espases, Servicio de Neumología y Servicio de Pediatría, Unidad de Neumología y Alergia Pediátrica, Palma de Mallorca	Alexandre Palou-Rotger Catalina Bover-Bauza Joan Figuerola Mulet Leticia Rubia de Azevedo
	Hospital Universitario Virgen del Rocío, Unidad de Fibrosis Quística, Sevilla	Isabel Delgado Pecellín Esther Quintana Gallego Laura Carrasco Hernández
	Hospital Universitario Nuestra Señora de Candelaria, Santa Cruz de Tenerife, Tenerife	Alicia Callejón Orlando Mesa Medina Jesus Rodríguez González
	Hospital Clínico Universitario de Valencia, Unidad de Neumología Infantil y Fibrosis Quística Pediátrica, Valencia	Silvia Castillo Corullón
	Hospital Universitario y Politécnico La Fe, Unidad de Trasplante Pulmonar y Fibrosis Quística, Valencia	Amparo Solé Jover Carmen Inés Perez Munoz
	Hospital Álvaro Cunqueiro, Servicio de Neumología y Servicio de Pediatría, Vigo	Cristina Ramos Hernández María Jesús Rodríguez Sáez Aida del Campo García
	Hospital Universitario Miguel Servet, Unidad de Neumología Pediátrica y Fibrosis Quística, Zaragoza	Carlos Martín de Vicente
	Hospital Universitario Miguel Servet, Unidad de Neumología Pediátrica y Fibrosis Quística, Zaragoza	*Inés Herrero Labarga*

Country	Centre/National Registry name	Contact
Sweden	Cystic Fibrosis Registry of Sweden	Christina Krantz Anders Lindblad
Switzerland	19 individual centres:	Andreas Jung
	Kinderspital Aarau, Kantonsspital Aarau AG, Abteilung pädiatrische Pneumologie, Allergologie und Immunologie, Aarau	Dominik Müller-Suter
	Kantonsspital Aarau AG, Klinik für Pneumologie und Schlafmedizin, Aarau	Gabriele Mauro Tini Lydia Eisenmann
	Universitätsspital Basel, Klinik für Pneumologie, Adulte Cystische Fibrose, Basel	Kathleen Jahn
	UKBB Universitäts-Kinderspital beider Basel, Abteilung Intensivmedizin & Pneumologie, Basel	Daniel Trachsel Anja Jochmann Jakob Usemann
	Inselspital Bern, Universitätsklinik für Pneumologie, Adulte Cystische Fibrose, Bern	Dagmar Lin Michaela Semmler
	Lindenhofspital Quartier Bleu, Bern	Bernhard Schwizer Iris Schmid
	Universitätsklinik für Kinderheilkunde, Zentrum für Cystische Fibrose und Pulmonologie, Inselspital, Bern	Philipp Latzin
	Hôpitaux Universitaires de Genève, Département de la Femme, de l'Enfant et de l'Adolescent, Unité de Pneumologie Pédiatrique, Genève	Anne Mornand Nadège Gabent
	Hôpitaux Universitaires de Genève, Département de Médecine, Service de Pneumologie, Consultation de Mucoviscidose Adulte, Genève	Jérôme Plojoux Valerie Durand
	Centre Hospitalier Universitaire Vaudois (CHUV), Département femme-mère-enfant, Service de pédiatrie, Unité de pneumologie et mucoviscidose pédiatrique, Lausanne	Isabelle Rochat Laurence Mioranza
	Consultation de Mucoviscidose Adulte et de CFTR-related Disorders, Service de Pneumologie, Département de Médecine, Centre Hospitalier Universitaire Vaudois (CHUV), Lausanne	Angela Koutsokera Marie-France Derkenne Isabelle Huart Bellavere
	Luzerner Kantonsspital, Zentrum für Zystische Fibrose für Kinder und Jugendliche, Luzern	Nicolas Regamey Michael Hitzler Lucia Eichhorn Sonja Ettlin
	Luzerner Kantonsspital, Abteilung für Pneumologie, Zentrum für Cystische Fibrose für Erwachsene, Luzern	Christian Murer Gabriele Riedener Luzia Rytz
	Hôpital Neuchâtelois – Pourtales, Consultation de Mucoviscidose Adulte, Neuchâtel	Jean Marc Fellrath Sidikka Ozturk-Beungies
	Children's Hospital of Eastern Switzerland, Division of Paediatric Pulmonology & CF Centre, St Gallen	Jürg Barben Andreas Jung Katharina Hartog Christine Baumgartner
	Kantonsspital St. Gallen, Lungenzentrum, Zentrum für Cystische Fibrose für Erwachsene, St. Gallen	Anna-Lena Walter Martin Brutsche Rebekka Kleiner
	Kantonsspital St. Gallen, Lungenzentrum, Zentrum für Cystische Fibrose für Erwachsene, St. Gallen	Anna-Lena Walter Martin Brutsche Rebekka Kleiner
	Kantonsspital Winterthur, Klinik für Pneumologie und Klinik für Innere Medizin, Adulte Cystische Fibrose, Winterthur	Markus Hofer
	Universitäts-Kinderspital Zürich, Abteilung für Pneumologie, Zürich	Andreas Jung Alexander Möller Eugènie Collaud Rachel Kusche Djamila Laban

Country	Centre/National Registry name	Contact
	Universitätsspital Zürich, Klinik für Pneumologie, Adultes CF Zentrum, Zürich	Macé Schuurmans Carolin Steinack Thomas Kurowski
Türkiye	Cystic Fibrosis Registry of Türkiye	Deniz Doğru Ersöz
	Cystic Fibrosis Registry of Türkiye, Ankara	Deniz Doğru Ersöz
	Marmara University, Faculty of Medicine, Division of Paediatric Pulmonology, Istanbul	Bülent Karadağ Yasemin Gökdemir Ela Erdem Eralp Burcu Uzunoğlu
	Medipol University, Faculty of Medicine, Division of Paediatric Pulmonology, Istanbul	Sedat Öktem Gözde Cavildak Karaaslan
	Medeniyet University, Faculty of Medicine, Division of Paediatric Pulmonology, Istanbul	Saniye Girit Sinem Can Oksay Yadigar Öztürk
	Koç University, Faculty of Medicine, Division of Paediatric Pulmonology, Istanbul	Zeynep Seda Uyan Erdem Gönüllü
Ukraine	18 individual centres:	Halyna Makukh
	KNP ”City Multidisciplinary Hospital of Mother and Child - Prof. Rudnev”, Dnipro	Olga Lacinska-Prykhodko Anastasiia Fialkovska
	Ivano-Frankivsk Regional Children’s Clinical Hospital of Ivano-Frankivsk Regional Council, Department of Pulmonology, Ivano-Frankivsk	Sirun Makian Olha Fedynska
	Municipal non-profit enterprise «Khmelnytskyi Regional Children’s Hospital» of Khmelnytskyi Regional Council, Khmelnytskyi	Liliya Brukhnova Olga Yevchuk
	Regional Clinical Children’s Hospital of the Kirovohrad Region, Kropyvnytskyi	Yuriy Chornyi Vasyl Khoroshchak
	Municipal Non-Profit Enterprise "Kyiv Regional Children's Hospital", Boyarka, Kyiv	Anna Mykytiuk
	Okhmatdyt Specialised Children's Hospital, Centre for Orphan Diseases & Gene Therapy, Kyiv	Yuliia Ostapyshena
	Volyn Regional Children's Hospital, Paediatric Department and Volyn Regional Clinical Hospital, Pulmonology Department, Lutsk	Miroslava Melnyk Oleh Yakovenko
	Cystic Fibrosis Centre of Western Ukrainian Specialised Children’s Medical Centre, Lviv	Lyudmyla Bober Halyna Makukh
	Municipal non-profit enterprise «Regional Children’s Hospital» of the Transcarpathian Regional Council, Mukachevo	Khrystyna Petrychko Elizaveta Birov
	Mykolaiv Children’s Regional Clinical Hospital, Mykolaiv	Nataliya Lesnycha Olexandr Plytkin
	Volyn Regional Children's Hospital, Paediatric Department and Volyn Regional Clinical Hospital, Pulmonology Department, Lutsk	Miroslava Melnyk Oleh Yakovenko
	Cystic Fibrosis Centre of Western Ukrainian Specialised Children’s Medical Centre, Lviv	Lyudmyla Bober Halyna Makukh
	Municipal non-profit enterprise «Regional Children’s Hospital» of the Transcarpathian Regional Council, Mukachevo	Khrystyna Petrychko Elizaveta Birov
	Mykolaiv Children’s Regional Clinical Hospital, Mykolaiv	Nataliya Lesnycha Olexandr Plytkin
	Odesa Regional Children’s Clinical Hospital, Department of Specialised Care for Older Children, Odesa	Iryna Holovenko Pavlo Heorhiiev
	Odesa Regional Clinical Hospital, Odesa	Iryna Gonta Yuri Gulchencko
	Regional Centre of Medical Genetics, Poltava	Olena Tul
	Regional Specialized Dispensary Cystic Fibrosis Centre, Rivne	Oksana Yarmoiyuk
	Communal non-commercial enterprise Sumy Regional Council «Regional Children’s Clinical Hospital», Sumy	Olga Kolomiets Ihor Zmyslya

Country	Centre/National Registry name	Contact
Ukraine (cont.)	Ternopil Regional Children's Hospital, II Children's Department / I. Horbachevsky Ternopil National Medical University of the Ministry of Health of Ukraine, Department of Children's Diseases with Children's Surgery, Ternopil	Iryna Shostak Oksana Boyarchuk Lesia Dobrovolska
	Communal non-profit enterprise «Vinnytsia Regional Children's Clinical Hospital Vinnytsia Regional Council», Department of Paediatrics #2, Vinnytsia	Valeriia Demianyshyna Oksana Moravska
	Municipal non-profit enterprise «Zaporizhzhya Regional Clinical Children's Hospital» Zaporizhzhya Regional Council, Pulmonary Department, Zaporizhzhya	Tetyana Okul Irina Kolman
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Appendix 3 Inclusion criteria and technical notes

People with CF: inclusion criteria
The ECFSPR registers people diagnosed with CF in accordance with agreed definitions:

- Two sweat tests value > 59 mmol/L chloride: CF diagnosis accepted.
- One sweat test value > 59 mmol/L chloride and DNA Analysis/Genotyping – two identified disease-causing CF variants: CF diagnosis accepted.

Sweat value ≤ 59 mmol/L chloride:
If the sweat value is less than or equal to 59 mmol/L chloride or not reported, then at least 2 of these must be fulfilled:
DNA Analysis/Genotyping: two identified disease-causing CF variants;
Transepithelial (Nasal) Potential Difference or Intestinal Current Measurement: result consistent with a diagnosis of CF;
Clinical Presentation: typical features of CF.

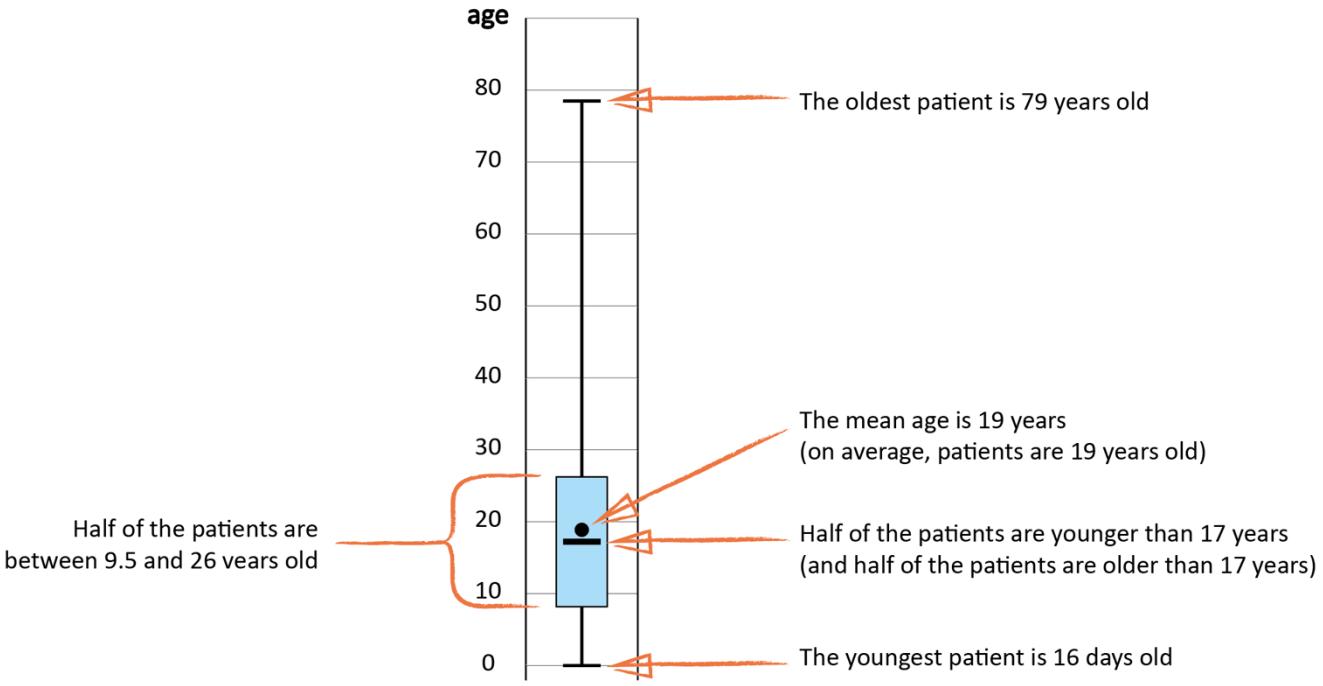
Diagnosis reversal:
If the CF diagnosis was reversed during the year, one of the options must be true:
DNA Analysis: unable to identify two disease causing CF variants;
Transepithelial (Nasal) Potential Difference and/or Intestinal Current Measurement: result not consistent with a diagnosis of CF;
Repeated normal values from sweat tests and confirmed by the clinical team.

References:
1) ECFS best practice guidelines: the 2018 revision
2) European Cystic Fibrosis Society Standards of Care: Best Practice guidelines (2013)

Data manipulation
To ensure that data are anonymous, the ECFS collects only year and month of birth and the day of birth is set to the 15th of the month.
For prenatal diagnoses, we set age at diagnosis equal to 0.
We checked for outliers and, whenever possible, we corrected the values according to the instructions of the national registries / individual centres. If, after the data quality controls, aberrant values were still present in the database, we set them to missing.
Software used for data management and statistical analyses: SAS software, Version 9.4. Copyright, SAS Institute Inc. SAS and all other SAS Institute Inc. product or service names are registered trademarks or trademarks of SAS Institute Inc., Cary, NC, USA.

Explanation of statistical terms
Max: maximum. It is the highest value.
Mean: it is the average value of a set of measurements. For example, if the mean age at diagnosis is 3 years, it means that, on average, the people are diagnosed when they are 3 years old.
Median: the value that separates the set of measurements in two halves, so that 50% of measurements are below the median value and the other 50% of measurements are above the median value. For example, if median age at diagnosis is 5 months, it means that half of the people are diagnosed before 5 months of age, and the other half of the people are diagnosed after 5 months of age.
Min: minimum. It is the lowest value.
N: the number of people in a group for whom the information is not missing.
N miss: number of missing values. It is the number of people for whom the information is missing.
Quartiles: the 25th percentile, the median (the 50th percentile) and the 75th percentile are collectively called quartiles, because they divide the set of measurements into quarters.
25th pctl: 25th percentile, also called first quartile. It is the value that separates the set of measurements in two parts, so that one quarter (25%) of the measurements is below it and the other three quarters are above it. For example, if

the 25th percentile for age at diagnosis is 1 month, it means that a quarter of the people were diagnosed before they were a month old, and the other three quarters were diagnosed after they were a month old.
50th pctl: 50th percentile, also called second quartile or median (please refer to definition of Median).
75th pctl: 75th percentile, also called third quartile. It is the value that separates the set of measurements in two parts, so that three quarters (75%) are below it and the other quarter is above it. For example, if the 75th percentile for age at diagnosis is 3 years, it means that three quarters of the people are diagnosed before they were 3 years old, and the remaining quarter was diagnosed after they reached 3 years of age.



Note: This is an example of how to read a boxplot. The numbers used in this figure are not real.

Appendix 4 Explanation of terms / Abbreviations

ABPA: allergic bronchopulmonary aspergillosis is an allergic lung disease characterised by an excessive response to the mould *Aspergillus fumigatus.*
BMI: body mass index, weight (kg) / [height (m)]^2.
Bronchodilator: medication that relaxes the muscles of the airways, used also for asthma.
CFRD: CF related diabetes.
CFTR: CF transmembrane conductance regulator. This is a protein at the cell surface that controls the salt and water balance across a cell. The gene that causes CF is the blueprint for the CFTR protein. Everyone has two copies of the gene for CFTR, but to be born with CF both CFTR genes must be affected by a CF-causing variant.
CFTR modulator therapy: Medication designed to correct the malfunctioning CFTR protein: different variants cause different defects in the structure of the protein and its functionality and the different CFTR modulators either correct or potentiate CFTR assembly or function; they can also be combined to become more efficient. CFTR modulator therapies work specifically for certain variant classes and those currently available are effective only in people with those variants. Not all known variants respond to CFTR modulator therapy.
Compassionate use: is a treatment option that allows the use of an unauthorised medicine for people with CF who have no alternative treatment options and no access to clinical trials.
Complex allele: To have CF you need two CFTR variants, one on each allele in chromosome 7 (where the CFTR-gene is located). If there is a variant on each allele they are considered to be in trans; if both variants are on the same allele they are in cis. Sometimes three (or even more variants) are found. It could be two variants in cis (and they are often known to be combined, e.g.F508 del with another variant) and one variant in trans. If there are two or more variants on the same allele it may be referred to as a complex allele.
DIOS: distal intestinal obstruction syndrome is a condition that is unique to people with CF. In DIOS, the intestines are blocked by thickened stool caused by sticky mucus and other mechanisms; this leads to reduced stool flow through the intestines and abdominal pain and may require emergency treatment.
FEV_1: the Forced Expiratory Volume of air in the first second of a forced exhaled breath.
FEV_1%: the FEV_1 as a percentage of the average value for healthy people of the same age, height, and sex.
Haemoptysis: coughing up blood. This happens frequently in small amounts in CF, so the complication we asked for is major bleeding (major meaning when the volume of expectorate is more than 250 ml over the course of the day).
Homozygous: CF is caused by variants of the CFTR gene, one on each allele. One is inherited from the mother and one from the father. If both variants are the same, the person is said to be homozygous for this variant.
Heterozygous: CF is caused by variants of the CFTR gene, one on each allele. One is inherited from the mother and one from the father. If these two variants are different the person is considered to be heterozygous.
ICM: Intestinal current measurement is a method to diagnose or exclude CF in difficult situations (e.g. unclear relevance of CFTR variants). CF is caused by abnormalities in the mechanism that carries salt into and out of cells. With ICM, the rate of salt transport is measured in tissue samples taken from the person (rectal biopsy) and measured against reference values of a healthy population. ICM can be carried out at any age.
LCI: Lung clearance index, measured by multiple breath washout (MBW); this is a test that measures non-homogeneity of lung ventilation. A tracer gas is inhaled, and the time to exhale a defined proportion of the gas is determined. MBW is very sensitive and particularly useful to measure lung function in children and people with milder forms of CF.
Macrolides: a type of antibiotic with anti-inflammatory properties. Azithromycin is a macrolide often used in people with CF who have chronic Pseudomonas aeruginosa lung infection.
Meconium ileus: small-bowel obstruction caused by unusual thick, sticky faeces (i.e. meconium, which is the first stool of newborn babies).
NaCl: sodium chloride. Here: inhaled hypertonic saline.
NIPPV: Non-invasive positive pressure ventilation; this refers to mechanical ventilation that helps people with CF with breathing difficulties. It is done with the help of a face mask and does not require the insertion of an artificial airway (tube). It can be one of two types: BiPaP (Bi-level positive air pressure) or CPaP (continuous positive air pressure).
NPD: Nasal Potential Difference; this is a method to diagnose or exclude CF in unclear cases and involves placing an electrode on the surface of the inside of the nose to measure the electrical potential difference across the nasal

epithelium. The NPD is a result of the transport of ions such as sodium and chloride in and out of the cells, a mechanism that is affected by defects in the CFTR protein.
Pancreatic insufficiency: the absence of pancreatic enzymes in the gut leading to malnutrition if not treated (in the ECFSPR pancreatic insufficiency is therefore defined as the use of pancreatic enzyme supplementation).
Pneumothorax: collapsed lung. In CF usually because of severe lung damage.
PPI: Proton Pump Inhibitors (medication that reduces the level of stomach acids).
PwCF: People with Cystic Fibrosis
rhDNase: recombinant human DNase (marketed as Pulmozyme®).
Steroids: are a group of medicines with strong anti-inflammatory properties. The type that are prescribed to people with CF are corticosteroids or glucocorticoids.
Z-score (or standardised scores): a way to compare results with a "normal" population, the reference population. Negative z-scores mean that the value is below the mean of values in the reference population, whereas positive z-scores mean that the value is above the mean. Z-score equal to 0 means that the value is equal to the mean of values in the reference population. For example, a z-score for weight of -2 means that the weight is 2 standard deviations below the mean of subjects of the same age and sex of the reference population. For example, if the z-score for BMI of a 10-year-old boy is -2, it means that the BMI for that boy is 2 standard deviations below the mean BMI of 10-year-old boys of the reference population.