



At-A-Glance report 2019

Cystic Fibrosis in Europe - Facts and Figures 2019

The European Cystic Fibrosis Society Patient Registry (European CF Registry) is happy to present this report with key information about how cystic fibrosis (CF) affects people with CF and their families throughout Europe.

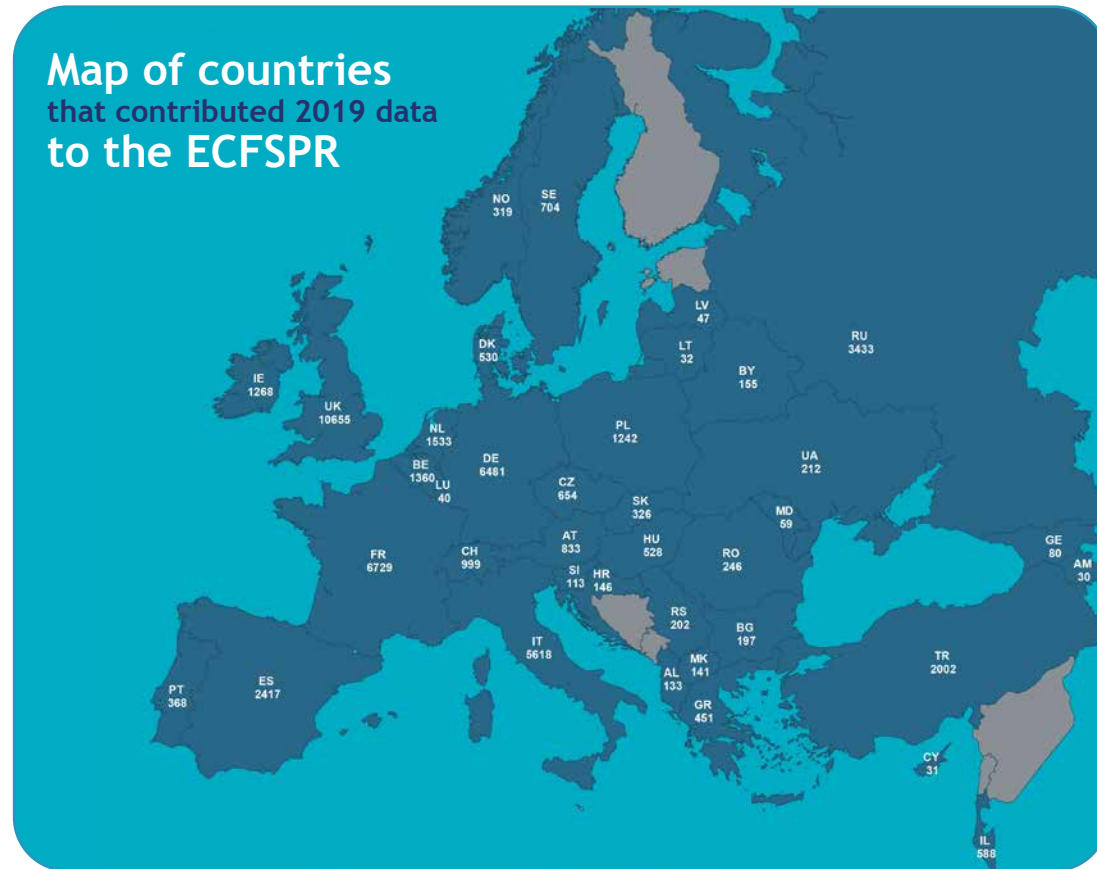
The European CF Registry collects, measures and compares data of people with CF living in Europe and neighbouring countries who agree to be in the Registry. The information is important to better understand CF, encourage new European standards of care and treatment, conduct research, and inform public health planning.

If you want to know more about the European CF Registry visit our website www.ecfs.eu/ecfspr.

For more in-depth information see the full report here: www.ecfs.eu/sites/default/files/general-content-images/working-groups/ecfs-patient-registry/ECFSPR_Report_2019_v1_23Dec2021.pdf.

December 2021

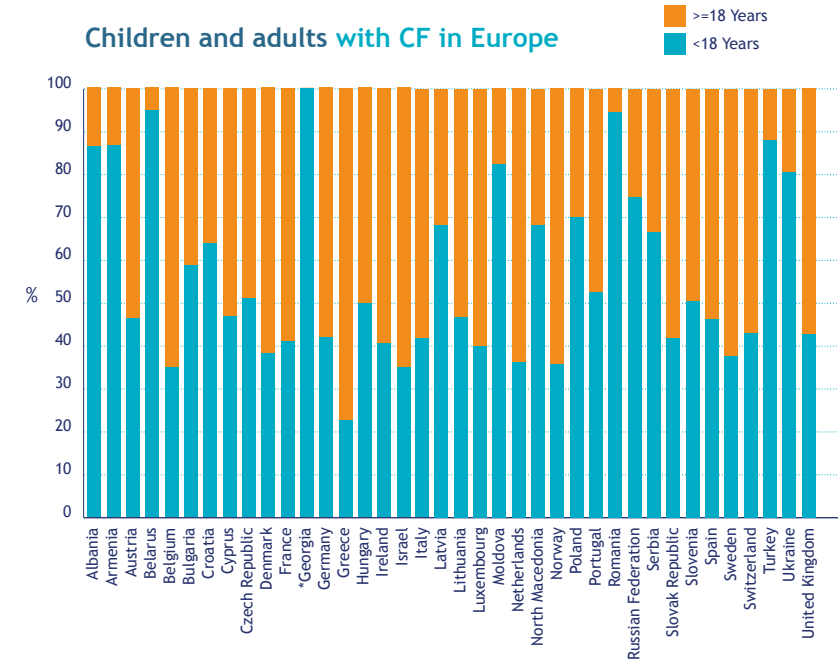
Map of countries that contributed 2019 data to the ECFSPR



Proportion children-adults

- The proportion children-adults varies between the countries.
- For some countries only a few individual centres sent data to the European CF Registry

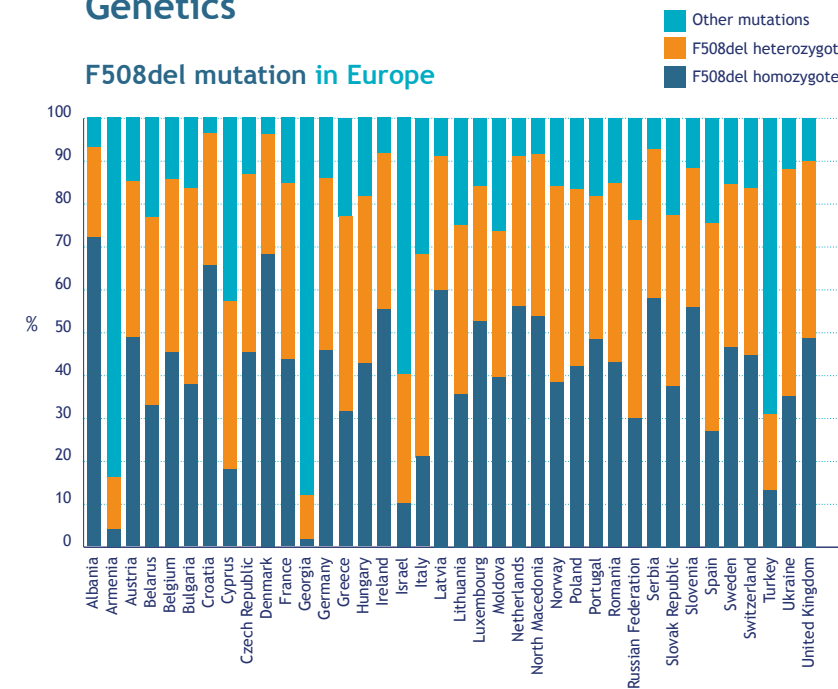
Children and adults with CF in Europe



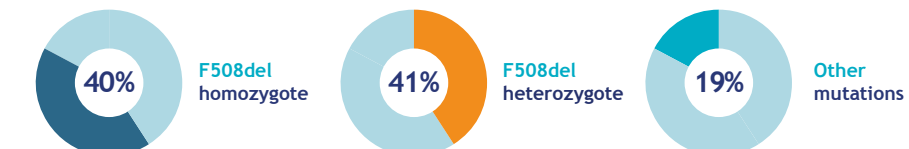
*For Georgia no adult patients were reported.

Genetics

F508del mutation in Europe



- F508del is the most common CF-causing mutation in Europe.
- People with CF have two CF-causing mutations, one inherited from the mother and one from the father.
- Homozygous:** both mutations are the same.
- Heterozygous:** the two mutations are different.



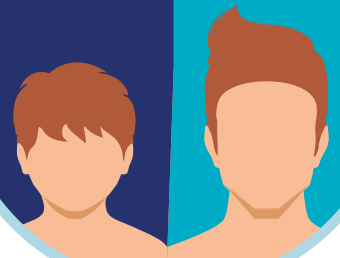
50,902

registered patients in 38 countries
number of patients on map

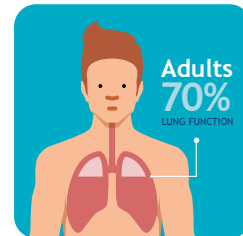
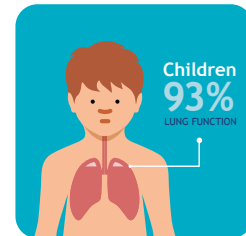
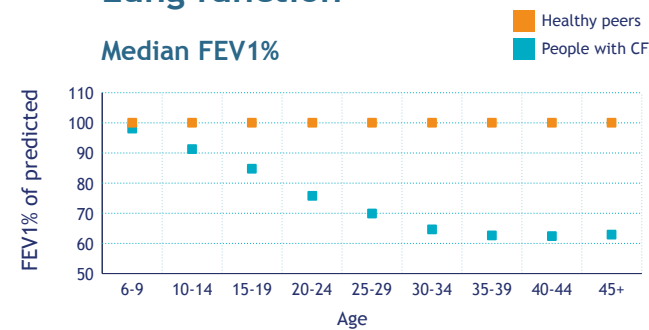
MEDIAN AGE AT
DIAGNOSIS
3.7
months



Children
48.6%
Adults
52.4%

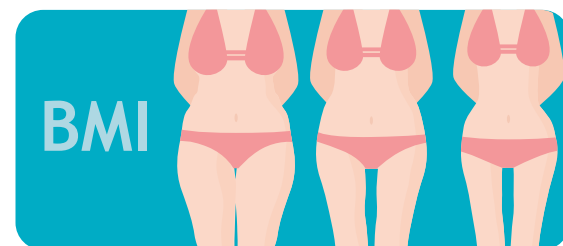


Lung function



- FEV1 is a measure for lung function. It is the maximum amount of air that can be forcefully exhaled in the first second after taking a deep breath.
- FEV1% is a percentage of the average value for healthy people of the same age, gender and height, which is set at 100%.
- In people with CF aged 45 and older there is a higher incidence of mutations causing milder forms of CF. This influences the lung function value for the people with CF in this age group.

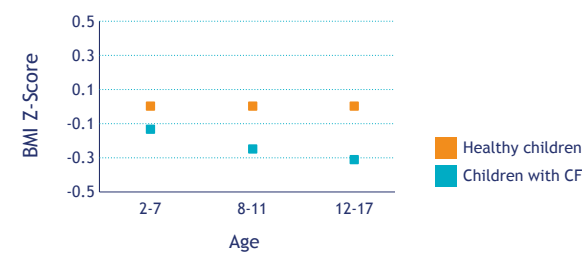
Nutrition



Median means that 50% of the values are above and 50% are below this value.

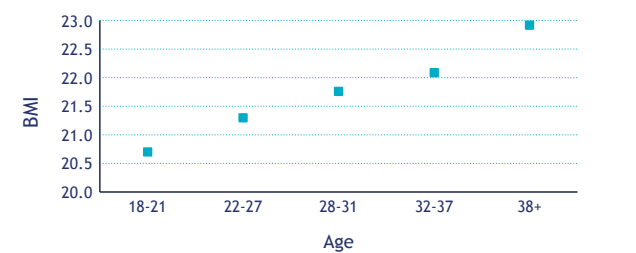
Z-score indicates how far a value is from the average (mean) value of the reference population.

Median BMI Z-score in children



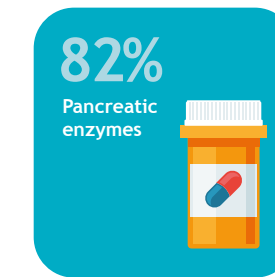
- A z-score of 0 means that the BMI is the same as the BMI of healthy children of the same gender and age.
- From the age of 2, children with CF have a lower average BMI than healthy children of a similar age.

Median BMI in adults



- Healthy peers have values for BMI between 18 and 25.
- As people with CF get older BMI increases.
- In adults with CF aged 38 and older there is a higher incidence of mutations causing milder forms of CF. This influences the BMI for the adults in this age group.

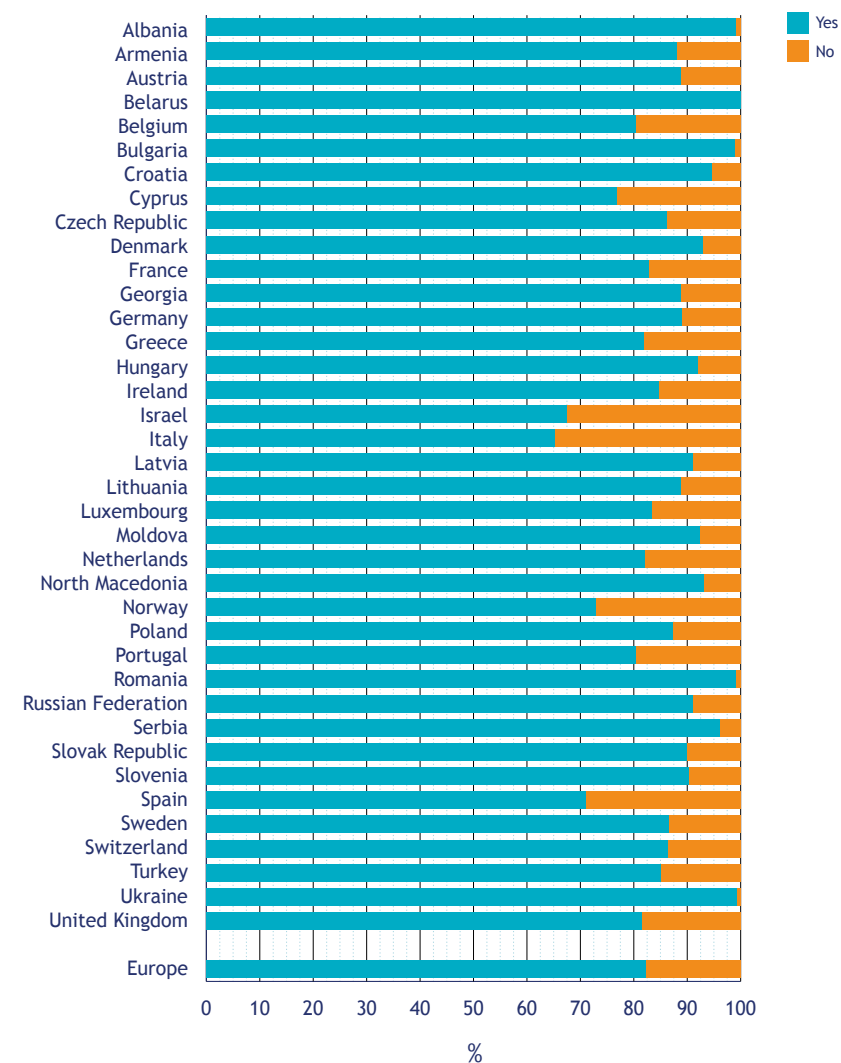
Pancreatic enzymes



82% of the people with CF use **pancreatic enzyme** supplements.*

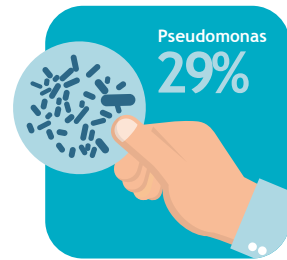
- Enzymes released from the pancreas are vital for the digestion and absorption of fat and vitamins from food. In many people with CF the release of these enzymes is blocked and they must take supplements.

% of people with CF who use pancreatic enzyme supplements



* Missing values are not included.

Infection

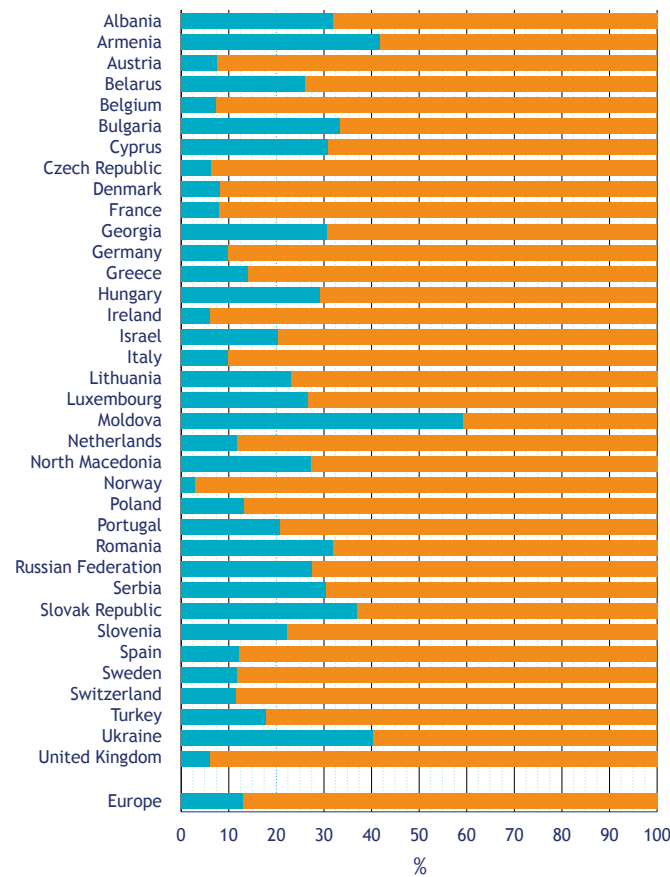


29%

of the people with CF are chronically infected with the *Pseudomonas aeruginosa* bacteria in their lungs.*

% chronic *Pseudomonas aeruginosa* in children*

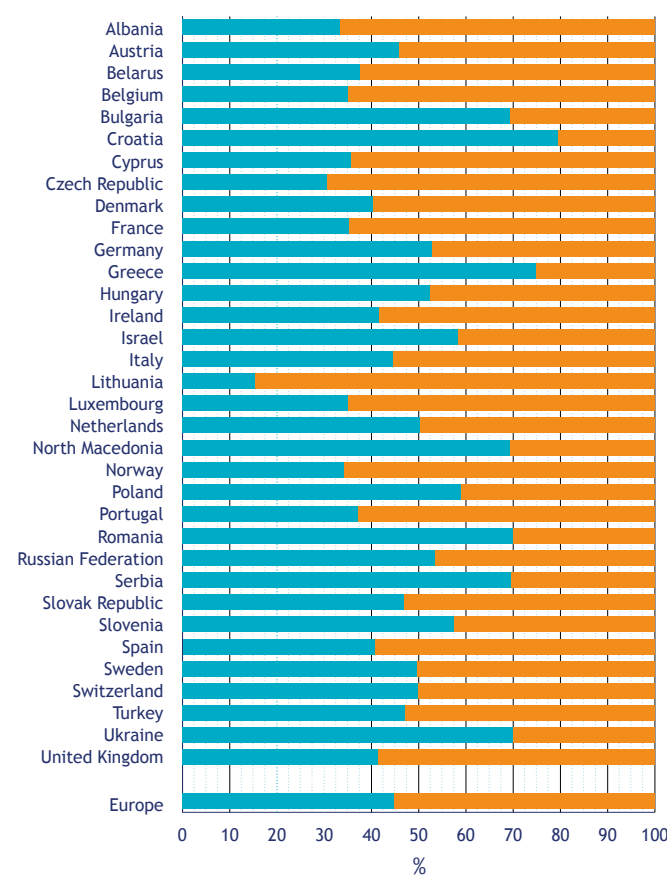
Yes
No



* Missing values are not included.

% chronic *Pseudomonas aeruginosa* in adults*

Yes
No



Armenia has fewer than 5 patients aged 18 years or more in 2019, and is excluded from this graph.

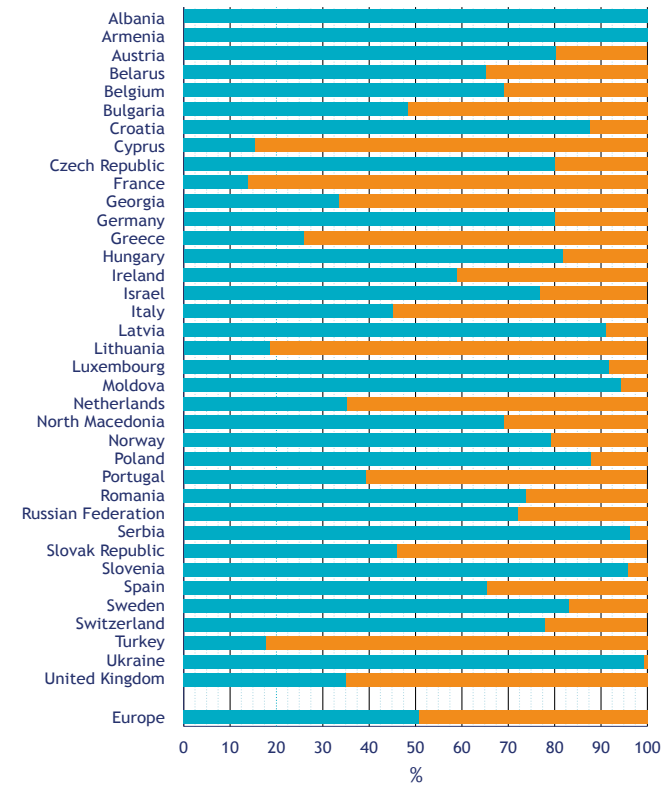
Georgia has 0% coverage for adults.

*Missing values are not included nor are data from countries with a high % of missing values.

Inhalation Treatment

% of people with CF who use hypertonic saline*

Yes
No

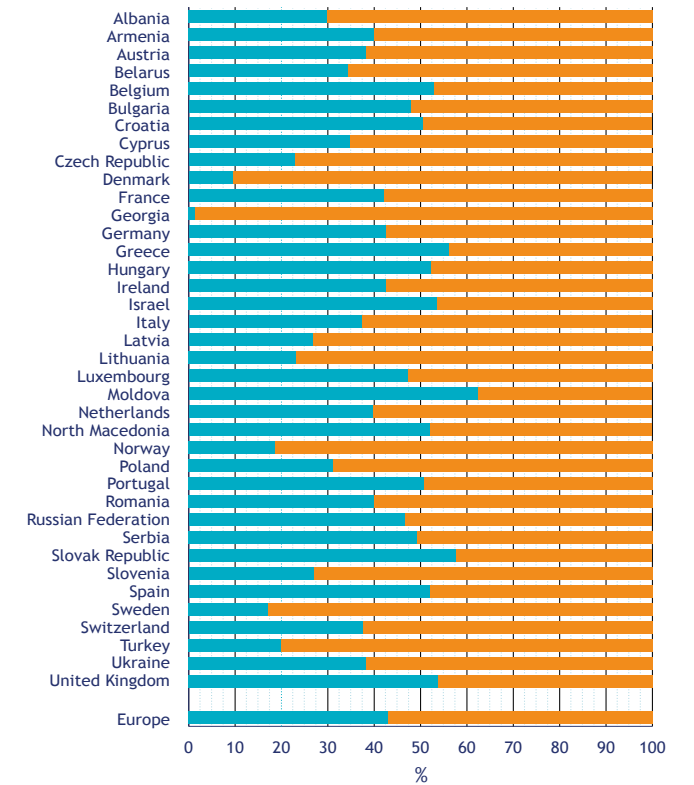


Hypertonic saline is prescribed to clear thick mucus from the lungs.

* Missing values are not included nor are data from countries with a high % of missing values.

% of people with CF who use inhaled antibiotics*

Yes
No

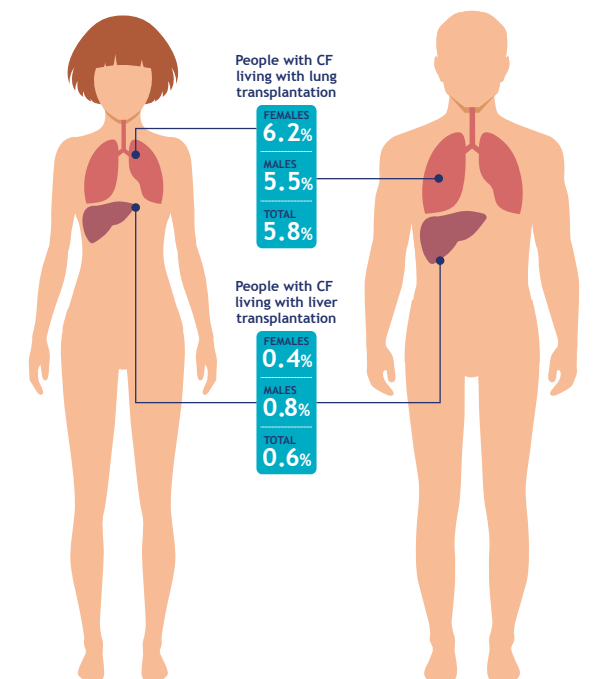
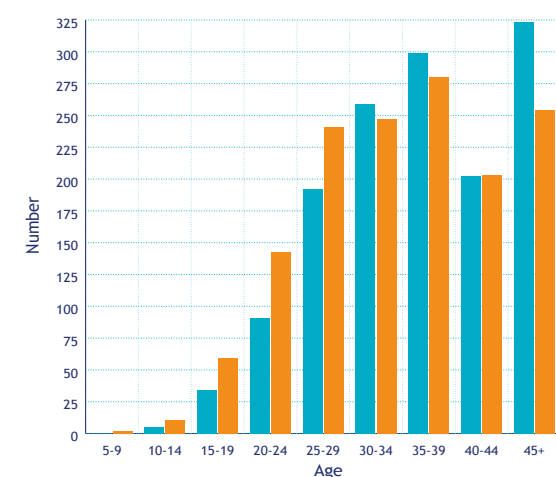


Inhaled antibiotics are prescribed to treat CF-specific bacterial infections, such as chronic *Pseudomonas aeruginosa*.

Transplantation

Number of people with CF living with a lung transplant

Male
Female



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