



The European Cystic Fibrosis Society Patient Registry: a useful tool for people with Cystic Fibrosis.

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The European Cystic Fibrosis Society Patient Registry (ECFSPR)

Collects, measures and compares data of people with cystic fibrosis (CF) living in Europe and neighbouring countries who agree to be in the Registry. The information is used to improve the health and wellbeing of people with CF; it helps to understand the disease better, develop new European standards of care, conduct research and inform public health-planning.

Objective

We describe how to bring data collected and analysed by the ECFSPR closer to people with CF and their families, and how benchmarking can be used as a tool to improve CF care in Europe.

Methods

In a joint project with the European federation of CF patient associations, the ECFSPR has developed an At-a-glance report with key-information of CF in Europe presented in infographics. The information refers to the ECFSPR Annual Data Reports with more detailed information.

The infographics approach will also be employed in two other projects in the pipeline:

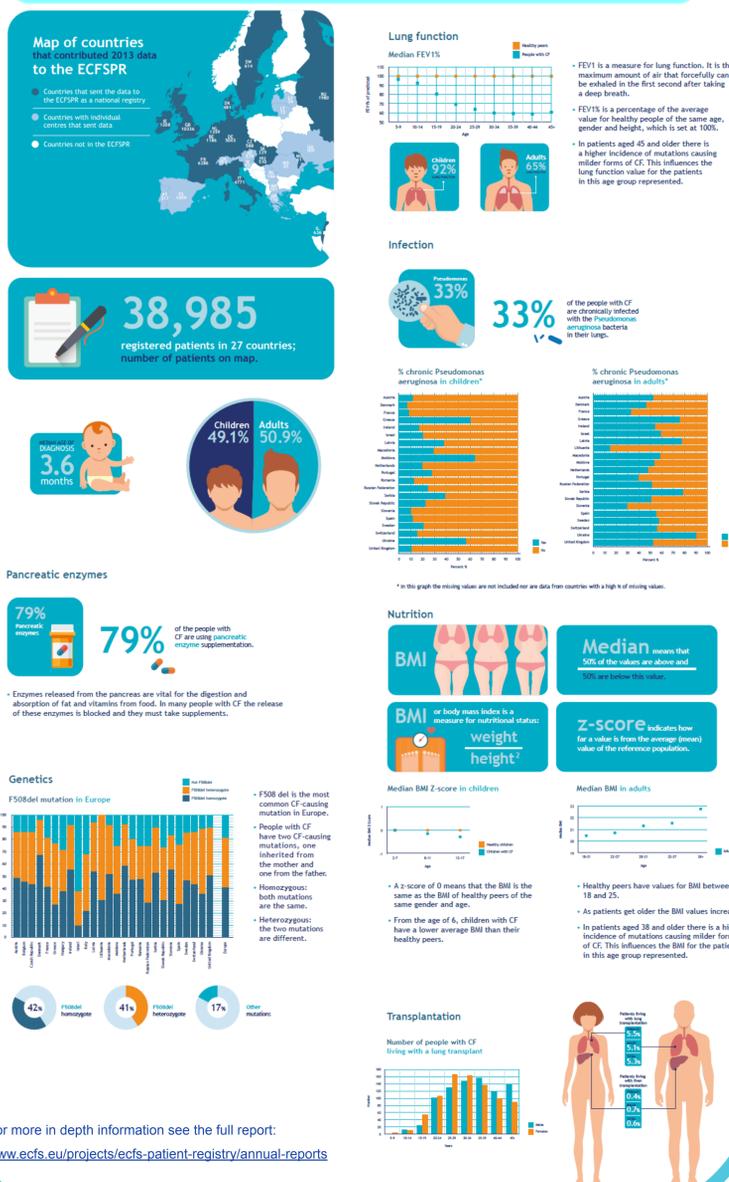
- A poster for distribution in CF clinics that highlights how the European CF registry is relevant to patients and the importance of patient involvement;
- Social media, as a channel to bring ECFSPR data and people with CF together.

In a separate project a group of clinicians has developed a benchmarking system to monitor the quality of CF care. The system is included as an add-on to the online data-collection platform ECFSTracker, and can be used by all participating centres and national registries in the ECFSPR.

At-a-glance Report

Cystic Fibrosis in Europe – Facts and Figures 2013

A report with key information about how cystic fibrosis (CF) affects people with CF and their families throughout Europe.

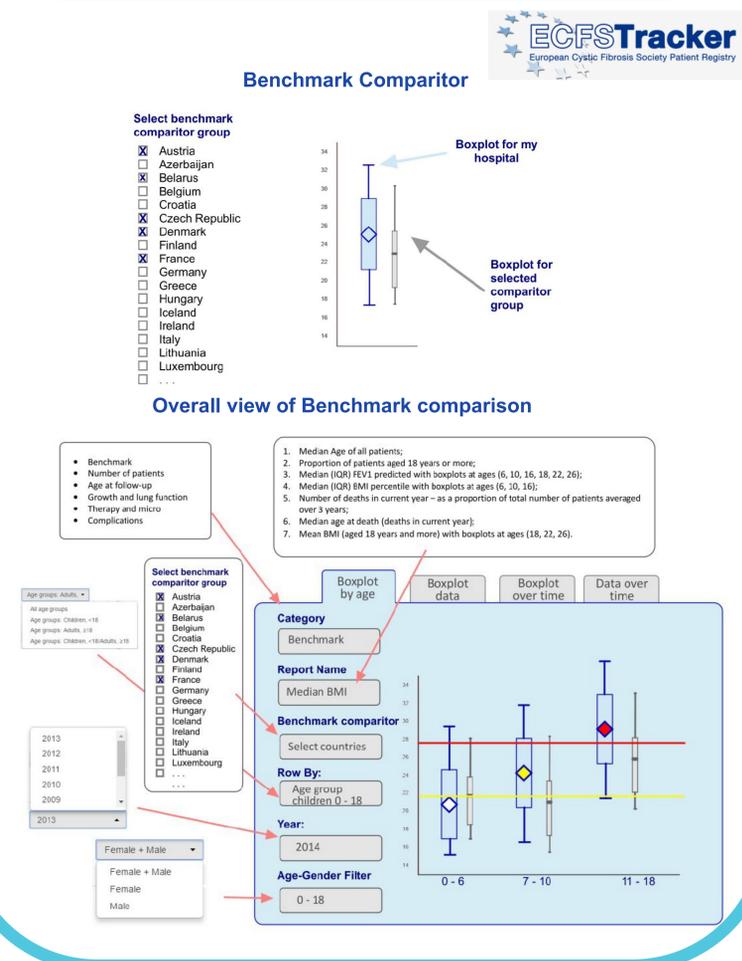


For more in depth information see the full report:
www.ecfs.eu/projects/ecfs-patient-registry/annual-reports

Benchmarking

Allows the cross-comparison of indicators of quality of care, the benchmarks, i.e. between a single centre and its own country / other countries, between a country and other countries.

Agreements will be made between individual centres in a country to allow comparison between them.



Conclusion:

The At-a-glance data report is an efficient visual medium that can be used to present and explain data to the patients who are the key to every registry. The benchmarking module in ECFSTracker will be a valuable addition to help identify areas for improvement in CF care.

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