

History of

THE CANADIAN CF REGISTRY (CCFR)

WHEN DID THE CCFR BEGIN?

1973

Canadian CF clinics begin contributing data to the US CF Registry

1978

First joint US-Canada CF Registry Report is published

1984

Independent CCFR is established and managed by Cystic Fibrosis Canada

1988

Study using CCFR data supports high-fat diet that becomes global standard in CF care

1991

After the discovery of the CF gene in 1989, CCFR begins tracking genotype

2008

Electronic submission of data begins

2015

Updated web-based platform launches with improved functionality and features

2016

Study co-authored by Cystic Fibrosis Canada using CCFR data reveals benefit of newborn screening for CF in Canada

FUTURE PROJECTS

- Develop digital health tools to engage patients
- Support Clinical Trial Network

These combined efforts continue to translate into improved outcomes for people living with cystic fibrosis.

Cystic Fibrosis Canada would like to acknowledge the involvement and continued participation of CF patients who consent to having their data submitted, and the exceptional effort and contribution from CF clinic team members who collect and enter the data.

WHERE DOES THE DATA COME FROM?



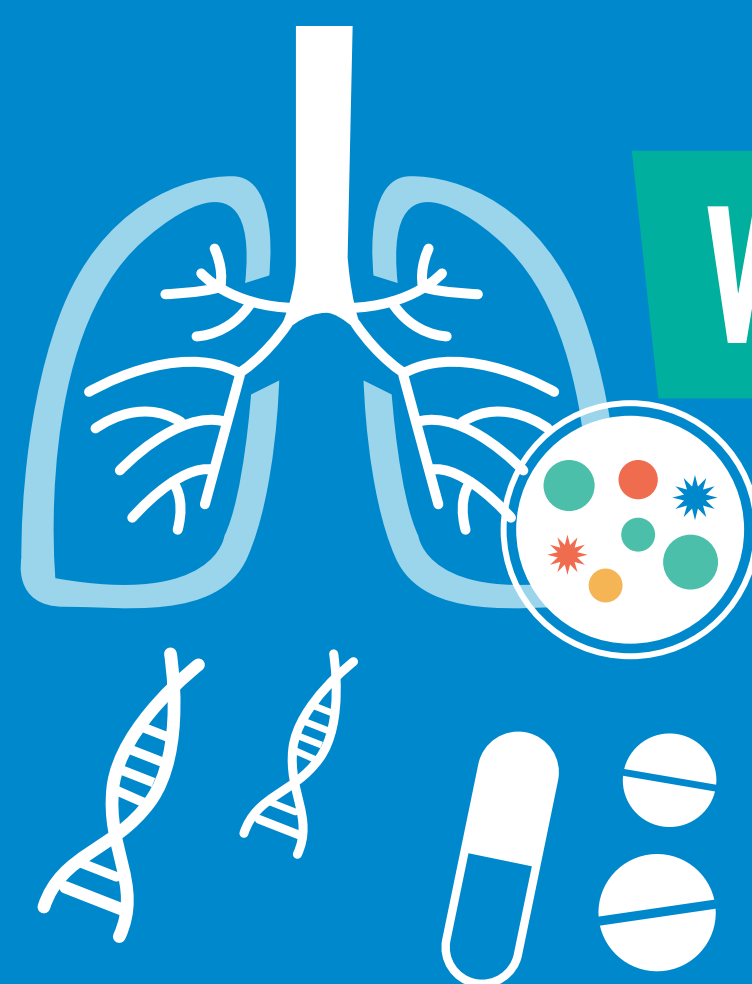
Participating CF patients who attend any of the 42 CF clinics across Canada are represented in the CCFR.

WHO ENTERS THE DATA?

CF clinic team members enter data into the secure online site. The system provides CF clinics with real-time access to health data on the CF population that they care for.



WHAT TYPE OF DATA IS COLLECTED?



Important clinical information is collected, including birthdate, genotype, lung function, height, weight, hospitalizations, medications, bacterial infections, and many more.

WHY DO WE COLLECT DATA?

To conduct **research** investigating differences in health outcomes within the population, benefits of newborn screening, survival post-transplant, among many others.



To **advocate** for more funding and resources in support of CF clinics.

To support **clinical care**, respond to emerging healthcare issues, monitor epidemiological trends and implement quality improvement initiatives.



To **educate**, promote awareness and increase knowledge about CF.