Understanding the CF Patient Registry

What is the Patient Registry?
Insight CF Registry Research Project

Thank you for your interest in the Insight CF Registry Research Project. The goal of this training is to help you gain a broader understanding of the Patient Registry and the data gathered in the Patient Registry Annual Report. This will help you develop a research question to submit for the project through the form at www.cff.org/InsightCF.

This training covers:
• What the CF Patient Registry is and what kind of data it includes
• How data from the Patient Registry is used and interpreted
What is the Patient Registry?

For Insight CF, we invite questions on any and all topics. However, our current focus is on questions that can be answered using the data in the CF Foundation Patient Registry.

So what is the Patient Registry? The Registry is made up of information collected during care center visits from individuals with cystic fibrosis who have consented to share that data for research purposes.

Between 1986 and 2015, 45,000 people have contributed patient registry data. The Registry includes information from the vast majority of individuals with CF in the U.S. and contains a comprehensive list of factors associated with CF care.

For more information about the Registry please visit [www.cff.org/Our-Research/CF-Patient-Registry](http://www.cff.org/Our-Research/CF-Patient-Registry)
What Information Can You Find There?

The Cystic Fibrosis Foundation Patient Registry collects information at diagnosis, during clinic visits, during hospitalizations and annually, including:

• Diagnosis
• Treatments
• Care received
• Demographics
• Measurements and screening tests
• Other conditions and events
Information in the Patient Registry

**DIAGNOSIS**
- Age at diagnosis
- Method of diagnosis: newborn screening, respiratory and/or gastrointestinal symptoms, failure to thrive
- CFTR gene mutations
- Sweat test results

**CARE RECEIVED**
- Location of care: clinic, hospital or home
- Providers seen during clinic visit
- Reason for hospitalization: pulmonary exacerbation, transplant, gastrointestinal
- Length of hospital stay

**DEMOGRAPHICS**
- Age
- Sex
- Race
- Ethnicity
- Vital status
- State of residence
- Personal and parental education
- Employment status
- Marital status
- Smoking status
- Health insurance coverage

**TREATMENTS**
- Antibiotics
- Mucus thinners
- Bronchodilators
- Anti-inflammatory agents
- Airway clearance techniques
- Pancreatic enzymes
- Nutritional supplements
- CFTR modulators
- Growth hormone
- Insulin
- Oxygen

**OTHER CONDITIONS AND EVENTS**
- CF-related diabetes
- Asthma
- Sinus disease
- Gastroesophageal (acid) reflux disease (GERD)
- Liver disease
- Allergic bronchial pulmonary aspergillosis (ABPA)
- Osteoporosis
- Depression and anxiety
- Transplant: lung, liver, kidney

**MEASUREMENTS AND SCREENING TESTS**
- Height and weight
- Lung function
- Cultures: *Pseudomonas aeruginosa*, *Staphylococcus aureus*, *Burkholderia cepacia* complex, nontuberculous mycobacteria
- Pancreatic function
- Screenings: mental health, bone health, CF-related diabetes

Click here to download this information.
Using the Patient Registry’s Annual Data Report

Ask Questions That Can Be Answered With Registry Data
What is the Patient Registry Annual Data Report?

• Each year, Registry data is compiled anonymously and published in the Patient Registry Annual Data Report. Data from more than 28,000 people with CF are included in the Foundation's most recent reports.

• The Patient Registry reports provide the CF community with an annual snapshot of the care received and health outcomes within the CF Foundation Care Center Network.

• You can view the current report here.
How Do I Interpret the Annual Data Report?

Each style of chart contains a different type of information. Use the key below to help you when looking for different data points. Ask yourself what information you’re looking for, then look for the specific type of chart.

- **Outcomes differed by age**: combined data charts
- **Outcome differs across centers**: box-and-whisker charts
- **Percentage of the population**: pie chart
- **Population is distributed**: bar charts
- **How things have changed over time**: line charts

Information you want → Look for → Combined data charts → Box-and-whisker charts → pie chart → bar charts → line charts.
Combined Data Charts: How Outcomes Differ by Age

If you are interested in how outcomes differed by age, look for combined data charts.

The chart below suggests that more than 50 percent of children younger than age 10 have Medicaid as a form of their health insurance. Medicare use is relatively low overall, but increases as individuals age.
If you are interested in how an outcome differs across centers, look for the box-and-whisker charts.

The chart below shows the distribution of the percentage of eligible individuals taking dornase alfa (Pulmozyme®) at each center. More than half of the centers prescribe dornase alfa to 90 percent or more of their patients.
Pie Charts: Percentage of Population

If you are interested in the percentage of the population with an attribute, look for pie charts.

The chart below shows that 90 percent of infants with CF are born at full term.

![Pie Chart: Birth Characteristics of Infants Born and Diagnosed with CF in 2013]

- Full Term: 90.6%
- Preterm: 9.4%
Bar Charts: How Population is Distributed

If you want to see how the population is distributed, look for bar charts. The chart below shows that most infants receive a sweat test within two to three weeks of their positive newborn screening and 80 percent within six weeks.
Line Charts: How Things Have Changed Over Time

If you are interested in how things have changed over time, look for line charts.

The chart below shows that the percentage of individuals with depression and osteoporosis has increased over time.
Thank you!

We appreciate your time and interest in the Insight CF Registry Research Project.

To learn about how to format a research question and learn about the next steps, please go to www.cff.org/InsightCF.

For questions and feedback, please contact: insightcf@cff.org.