How to Form a Research Question

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 develop a research question to submit for the project through the form at www.cff.org/InsightCF.

**This training covers:**
- The process of scientific research
- How to come up with ideas for research
- How to turn an idea into a research question
How Does the Research Process Work?

Form a Research Question
- Specifies the knowledge to be gained from the research study
- Addresses information missing from previous research

Design the Study
- Outlines the protocol and procedures for the study
- Describes the analytic techniques to allow valid interpretations of the results

Implement the Study
- Collect data
- Conduct data analysis

Disseminate Results
- Shares the study findings, acknowledging the study’s strengths and limitations
- Findings may lead to further questions continuing the cycle

Ultimately, Insight CF will include all phases of research. We are starting with research questions.
Formulating a Research Question

How Do I Come Up With a Research Idea?

Research ideas are all around us. They are the things you wonder as you live your life with CF:

- Consider times when you needed to make a decision and wanted more information to help you make that decision.
- Consider information you heard or read and wondered if it was accurate.
- Consider differences between people you know with CF and wondered why their CF was different.

I wonder…
Turning Your Idea Into a Research Question

Not all ideas or questions are research questions. Research questions:
• Involve the comparison of two groups of people
• Have an answer that is a measure of the magnitude of the difference between the two groups of people

Here is an example of the difference between a regular question and a research question:

**How many people with CF have CF-related diabetes (CFRD)?**

**Do individuals with CFRD have worse lung function than those without CFRD?**
A Research Question Has Four Elements

1. **WHAT** are the groups of people that will be compared?
2. **HOW** would I measure differences between these groups?
3. **WHO** will be included in the study?
4. **WHY** is this important?
The first thing we must establish for our research question is **what** are the groups of people that will be compared? Most any group of people can be compared with another group. It is important that these two groups of people are **different in at least one obvious way**.

**Examples of groups to compare:**

- Males and females
- Individuals diagnosed with CF in the first year of life compared to individuals diagnosed after their first birthday
- Infants with meconium ileus at birth compared to infants without meconium ileus
- Children who are underweight for their age compared to children with average weight for their age
- Adults aged 18 – 24 in college compared to those not in college
- Individuals who cultured positive for nontuberculous mycobacteria compare to those with a negative culture
- Individuals taking an antibiotic compared to those not taking that antibiotic
How?

The second component is **how** to measure the difference you suggest we measure. This tells us how we know if there is a difference between the two groups of people.

**Examples could include comparing two groups to examine differences in the:**

- Average FEV$_1$% predicted
- Average number of centimeters that children grew
- Percentage of individuals who develop a new infection with *Burkholderia cepacia*
- Percentage of individuals who received a feeding tube
- Percentage of individuals who screen positive for anxiety
- Percentage of individuals who survived
- Percentage of women who report pregnancies
Who?

Depending on the study, it may not make sense to include the entire Registry population. Once you have selected your two distinct groups, you may consider narrowing who belongs in those groups based on the following factors. You may narrow the population in your groups based on:

- **Time:** You may want to examine an effect in the recent past, or you may want to examine populations before or after an event in the history of CF care. For example, research could study groups before or after there was universal newborn screening or before or after a CF medication became available.

- **Age:** Some studies may relate only to infants, adolescents or adults. For studies that examine lung function, research must start with children age 6, because lung function measurements are not recorded beforehand.

- **Sex:** You may want to include only males or females for biological, psychological or sociological reasons.

- **Individuals who already have the outcome:** For example, if your study is measuring the number of people who need transplants then you would need to exclude individuals who already had a transplant from the study.
Why?

On the question submission form, you are asked, “Why is this study important to you, and why do you think it is important for the wider CF community?”

This is your opportunity to build your case for the importance of your questions to the CF community.

**Points to consider:**

- What are the implications to the CF community of not having this question answered?
- How many people in the CF community would benefit from an answer?
- What is the potential impact of knowing the answer to your research question?
Example Research Questions

WHO? Among individuals with an FEV\(_1\)% predicted less than 40%,

WHAT? do those referred for transplant differ from those not referred with regard to

HOW? type of health insurance and distance from their home to a transplant center?

HOW? Does the percentage of individuals with *Pseudomonas aeruginosa* infections differ

WHO? between children aged 6 to 18

WHAT? living in the northeastern, southern, midwestern and western regions of the U.S.?
Thank you!

We appreciate your time and interest in the Insight CF Registry Research Project, and look forward to receiving your research questions. To see how the submitted questions will be reviewed and learn about the next steps, please go to [www.cff.org/InsightCF](http://www.cff.org/InsightCF).

For questions and feedback, please contact: [insightcf@cff.org](mailto:insightcf@cff.org).