ROADMAP 201 Warm-up:
Zoom Chat: How to Formulate PSC Research Questions

PSC is a complicated disease with lots of medical and scientific jargon and complex concepts that are challenging to understand. Through the ROADMAP Research series, we can learn together and build a common language to discuss research needs for PSC. Our PSC voices will enhance research and drug development.

During the ROADMAP Research 201 session on September 29th, four fantastic PSC researchers will present an overview of important PSC research areas. Then we'll all have an opportunity in breakout rooms to ask questions and share our ideas for important areas to study in our quest for treatments and a cure for PSC.

In preparation for the Research 201 webinar, Dr. Ruth-Anne Pai, Director of Research Strategy, will open a casual discussion on how to formulate research questions during a **Zoom Chat on September 23rd at 6pm Mountain Time. Please join us: https://links.pscpartners.org/ZoomChat.**

The process of collecting our thoughts and forming a question can be difficult, but with some practice we can ensure that our voices and needs drive important scientific research for PSC. Below is a quick FAQ and glossary of terms to get us started.

1. What is a research question?

As kids, we observed lots of interesting things in the world around us, but usually were offered few answers. Our own curiosity and research led to an improved understanding of the world, and the same is true for our explanation of PSC. Some answers are identified through the scientific process. A person asks a question, finds that they could design and perform an experiment to address the problem, analyzes the data, and comes to a conclusion about their findings.

In every instance, we would not learn anything if we didn't begin with a question. Oftentimes, answering one research question leads to many new questions to ask and address. No question is too basic, silly, or unimportant.

2. What are the steps to forming a research question?

Once we are diagnosed with PSC, we begin noticing new things about our bodies and asking new questions. Some questions come to mind easily, but most start with an observation. For example, we may notice that we itch more frequently, and we visit our doctors, asking them what could be causing the problem and whether it's related to PSC.

These observations lead to research questions and scientific research leads to a better understanding of how PSC can cause itching. Now, we can always further refine our understanding of PSC itch by asking additional questions and performing more scientific research.

3. What can I do to let PSC Partners and researchers know which questions are important to me?

PSC affects many different aspects of our lives. In addition to the physical, emotional, and social issues that a PSC diagnosis may cause, the need to develop new relationships with physicians and coordinate care raises many questions and concerns. In sharing our experiences, needs, and questions with each other, clinicians, and the research community, we can identify important research questions to prioritize in scientific research.

Here is one example of a question brought to researchers' attention by our fantastic community: "Why is it that some people experience itch for the first time with recurrent PSC after transplant?" Having identified this as an important unanswered question, we can address this need through scientific research.

4. What are the important terms used when discussing research questions?

- **Data**: pieces of information collected during research projects or experiments.
    - The data we collect may be numbers (like bilirubin levels) or values (like pruritus severity and frequency). Altogether, these data begin to paint a picture and when analyzed carefully, may provide clues to support or reject a hypothesis.

- **Hypothesis**: an educated guess or prediction about what the answer to a research question will be.
    - Through research, we perform experiments and collect data that may support our hypothesis. Alternatively, we may decide that the data do not support our initial hypothesis. In this case, we may revise or reject our original hypothesis.

- **Conclusion**: a final decision summarizing the data findings and implications of a research project or experiment.
    - Sometimes our conclusion includes an answer to our original research question. However, research doesn't always lead to a definitive answer to our questions, and oftentimes the conclusion will acknowledge that more work is needed to address the research question. In addition, a conclusion may be revised based on additional or new data. For example, new recommendations may be given for cancer screening in PSC.

- **Mechanism**: an explanation of how various processes work together to produce an end result.
    - In research, and in PSC, we refer to disease mechanisms to explain how our bile ducts become damaged, for example. We'll examine mechanisms more in depth in the Research 301, when we begin discussing how genetics, bile, the microbiome, and immune system are interconnected in the development and progression of PSC.

- **Statistics**: a discipline dedicated to the methods involved in collecting, organizing, analyzing, and interpreting data
    - Statistics is an important component of PSC research. For example, we use statistics to concretely determine whether a difference we see in our data is valid and repeatable. Statistics helps us come to an informed and accurate conclusion about what our data mean and whether our hypothesis is correct.

- **Future directions**: next steps to research after coming to a conclusion from our initial research project or experiment

    - After asking a research question, designing and performing an experiment, analyzing our data, and using statistics, we draw a conclusion about our hypothesis. Oftentimes, our conclusion is that we don't yet have enough data or evidence to answer the research question. In that case, the future direction may be to further interrogate the question in additional experiments and in new ways. As scientists, our hope is that this rigorous progress will eventually result in an answer to our question, leading to new and exciting questions to address in future directions for research.

Remember, your input is crucial to this process -- from the identification of important research questions to the development of future directions for research.

Our PSC voices matter!