



Identifying research targets by **M**erging **P**atient And **C**linician **T**reatment information

Module 2 Survey Results

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Module 2

Overview

- IMPACT Module 2 launched on December 4th, 2023.
- N=25 participants completed the survey that followed Module 2:
 - 19 patients/parents
 - 6 clinician/researchers
- Module 2 provided education about health research and how to be involved in patient centered outcomes research (PCOR).
- Module 2 used materials published by PCORI, which you can check out here: <https://www.pcori.org/engagement/research-fundamentals>
- The module was followed by a survey to assess patients and providers' previous experiences as partners in research. The results are summarized below.
- These responses were used to design the second section of the IMPACT Roadmap, "Partnership Principles for PCOR/CER in PFIC".

Module 2 Survey Results

The main points concerning partnerships that were shared in the survey by module participants:

1. Listening to patients is crucial to building partnerships.
2. Time constraints and logistical challenges (money, travel to research sites) are critical barriers to partnership identified by both patients and clinicians.
3. Providing sufficient and accessible information is a necessity (using lay language, explaining the research study, providing updates and results).



Here is a summary of the patients/caretaker responses to each of the survey questions:

Q1: Tell us about a time when you and your current PFIC clinical care provider were truly working as partners?

- When doctors or nurses listened to the patient regarding symptoms or personal needs.
- When doctors or nurses went the extra mile to get the patient better treatments or get them into a clinical trial.
- When doctors or nurses communicated frequently during times of emergency.
- Some did not experience this.

Q2: Tell us about a time that you and your current PFIC clinical care provider were NOT working well as partners - what went wrong?

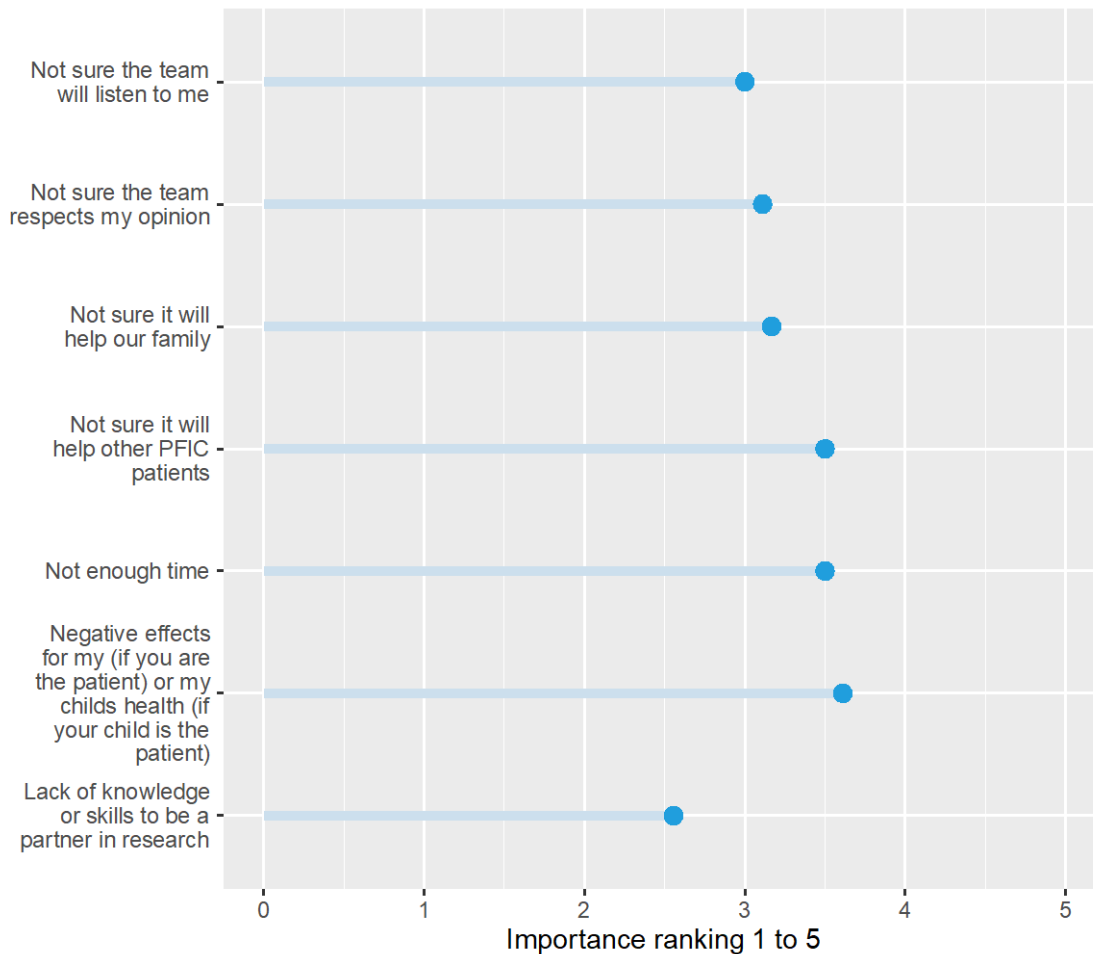
- Lack of listening.
- Limited communication, or breakdowns in communication.
- Lack of consideration for personal circumstances (ex. insurance, what medicines have already been taken, mental health, etc.).
- Some have not experienced this.

Q3: Imagine yourself as a partner in a PFIC Network patient-centered outcomes research project. We don't want patient partner involvement to be just checking a box or a rubber stamp. What could the research team do to help you feel like a true partner in these discussions?

- Frequently updating participants regarding study results (via email or text).
- Explaining the study design and study results to patient partners in lay terms.
- Engaging patient partners and study participants in active Q&A discussions.
- Considering patient unmet needs and priorities when designing research questions.



Q4: Barriers patients and their families may face participating as a partner in designing and carrying out patient-centered research (rated by importance):



Q5: Are there any other barriers that you can think of?

- Time
- Logistics
- Burden of disease

Q6: What could we do to overcome these barriers?

- Engaging in active and focused discussion with patient partners.
- Sending information about the research study and collaboration expectations in advance.
- Organizing meetings so they are short, efficient, and output-driven.
- Scheduling meetings in alignment with patient availability.
- Ensuring that study endpoints are relevant for patients.



Q7: What do you think that families or patients could gain by participating in a PFIC Network patient-centered outcomes research project?

- Feeling connected to the community
- Feeling empowered by helping others
- Learning more about new developments in research
- Learning from other patients' experiences

Q8: What unique challenges will our child and family-focused projects face?

- Time
- Scheduling meetings around kids' activities (e.g. school)
- Communicating with children about their experiences can be difficult and subjective.

Q9&10:

Based on this module, to do research that is truly meaningful to PFIC patients and their families, IMPACT <i>must</i> ...	Based on this module, to do research that is truly meaningful to PFIC patients and their families, IMPACT <i>should not</i> ...
<ul style="list-style-type: none"> - Keep sharing outputs/results. - Look at different age groups and subtypes. - Include patients as part of the team. 	<ul style="list-style-type: none"> - Become too demanding in terms of time. - Not provide updates on results. - Neglect participants' ideas. - Make it too clinical.



Here is a summary of the clinicians/researcher responses to each of the survey questions:

Q1: In your clinical work with PFIC patients, how do you form effective partnerships with patients and families?

- Discuss realistic treatment goals.
- Understand the impact of PFIC on daily life.
- Take time to listen (but this is often limited), use lay language, and emphasize the importance of shared decision making.

Q2: What are the biggest barriers to forming partnerships with patients and families that you face during clinical care?

- Patient's expectations regarding treatment options.
- The challenge of providing complete information due to many unknowns and the uniqueness of treatment journeys.
- Lack of effective treatments.
- Time constraints.

Q3: We don't want patient/parent involvement to be just checking a box or a rubber stamp in PFIC Networks future PCOR projects. How can we make sure that they are true partners in this work?

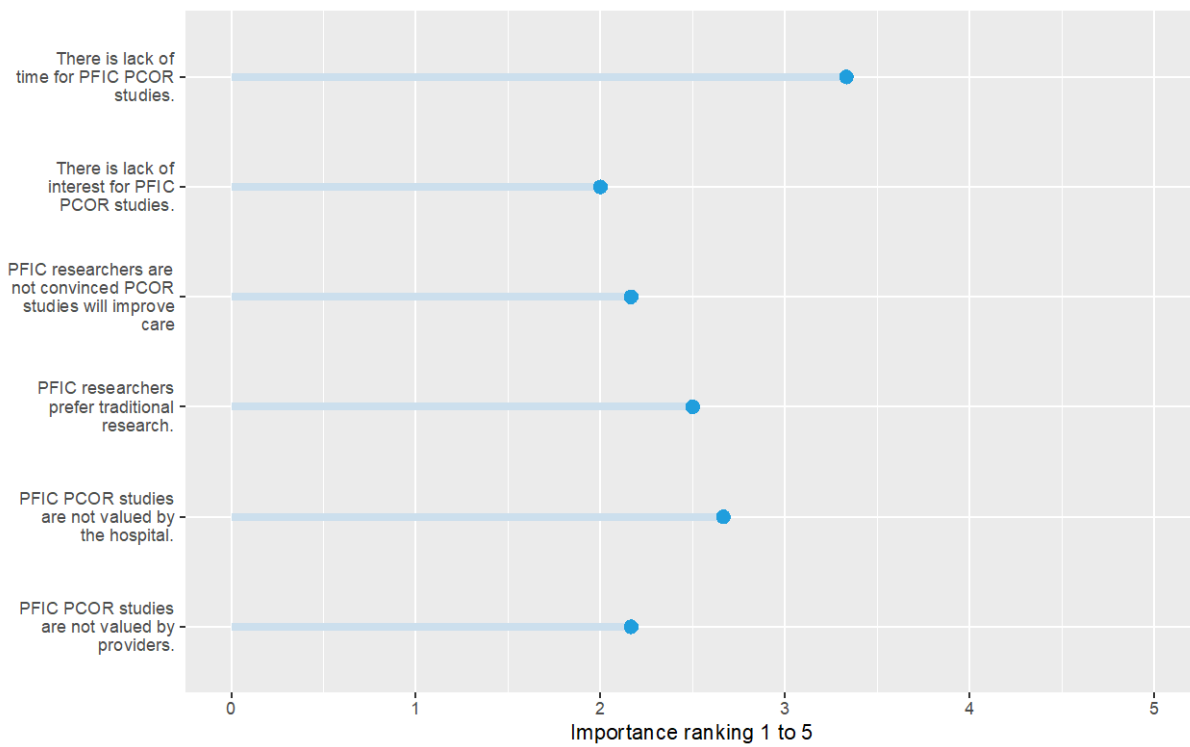
- Listen to and get to know each other.
- Understand what is feasible.
- Find a solution to the burden of travel to enhance possibility for all income groups to participate.
- Solicit patient critique to enhance discussion.
- Include a tangible benefit for patients to participate.

Q4: What do you think providers could gain by participating in PFIC Network's PCOR projects?

- Improved understanding of the disease and of care options.
- See the variability of treatment and treatment effects in patients from other care centers.
- Understand what outcomes are important to patients in their daily lives.
- Engaged population to work with.
- Academic credit.



Q5: Clinician/Researcher-Reported Barriers to PFIC PCOR (rated by importance):



Q6: Are there any other barriers that you can think of?

- Logistics (time and distance).
- Funding.
- Competition with other studies.

Q7: What could we do to overcome these barriers?

- Obtain sufficient funding (to deal with logistics, to compensate participants, to hire staff).
- Continued community education on the importance of PCOR, include successful examples of PCOR (look for transferrable aspects).

Q8: What unique challenges will our child and family-focused projects face?

- The need for child assent and parent consent.
- Age and educational level of child participants.
- Accounting for concerns of parents and child participants.
- Engaging parents with very ill children (those are important participants).



Q9&10:

<i>Based on this module, to do research that is truly meaningful to PFIC patients and their families, IMPACT must ...</i>	<i>Based on this module, to do research that is truly meaningful to PFIC patients and their families, IMPACT should not ...</i>
<ul style="list-style-type: none"> - Agree on primary and secondary outcomes. - Identify new symptoms at an early stage and collect patient story data. - Engage at the community level. 	<ul style="list-style-type: none"> - Ignore the desires of patients/parents. - Rely on data from high income patients only. - Get bogged down by multiple barriers.