Identifying research targets by **M**erging **Pa**tient And **C**linician **T**reatment information

PFIC IMPACT: Module 6 Results Summary

Overview

IMPACT Module 6 was launched on March 24th, 2025.

- N=21 participants completed the learning and feedback sections in Module 6
  - 16 patients/parents
  - 5 clinician/researchers
- Module 6 introduced the role and importance of multi-stakeholder research teams in patient-centered comparative clinical effectiveness research (CER).
- The module was followed by a survey to collect input on participating in such teams for PFIC, which informed the development of guidelines for building effective PFIC-specific multistakeholder research teams.

Background

Project IMPACT, inspired by discussions at PFIC Network's 2022 Conference, aims to make treatment decisions easier and more informed. This can be done through patient-centered Comparative Effectiveness Research (CER). Patient-centered CER studies compare two or more treatments based on outcomes important to patients, like itch reduction, family quality of life, and/or financial burden. It also requires patients and other stakeholders to be actively involved as partners at every stage of the research process, including serving on research teams.

Key Takeaways

Responses to Module 6 revealed strong interest across stakeholder groups (patients, caregivers, clinicians, researchers) in joining multi-stakeholder research teams.

- **Willingness to Participate**
  - Roughly one-third wanted to be heavily involved (e.g., as co-investigators), while others preferred advisory or occasional input roles.

- **Preferred Areas of Contribution**
  - Patient and parent participants were most interested in contributing to:
    - Establishing a research agenda
    - Discussing study results
    - Disseminating findings to the community

- **Motivating Factors**
    - Key reasons participants were motivated to join multistakeholder research teams included:
        - Ensuring PFIC research reflects patient priorities
        - Gaining insights from patient and caregiver perspectives
        - Making a meaningful impact

- **Support needs**
    - Participants selected the following as the most important types of support needed to ensure that all stakeholders can work together as equal partners on research teams:
        - Flexible participation options
        - Clear expectations and structured tasks
        - Guidance on best practices for patient engagement in research
        - Training on research terminology and processes

- **Concerns**
    - Patients & caregivers expressed concern about:
        - Being tokenized or not taken seriously
        - Time constraints
        - Relevance of their unique perspective to the research project
        - Accessibility (e.g., language, time zones)
        - Ensuring meaningful inclusion of the child patient perspective

- **Success Factors**
    - Participants across roles emphasized the following key qualities for successful multistakeholder research teams:
        - Clear communication and transparency
        - Respect for diverse perspectives
        - Flexibility in participation
        - Recognition and appreciation for contributions

Please contact us anytime with feedback, questions, or concerns: melissa@pfic.org