



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

## **PFIC IMPACT: December Focus Group Discussion Summary**

### **Overview**

We held our eighth PFIC IMPACT Focus Group meeting on December 18<sup>th</sup>, 2024!

- Attendees: 10 patients & parents + 2 clinicians & researchers
- Our goal for the meeting was to review what we've done so far in IMPACT and discuss how we can use the Treatment Experience App (TEA) to identify our final list of PC-CER targets in and set us up for our next steps after the project ends in July 2025!
- We also reviewed preliminary data from the TEA, filled out the TEA survey, and brainstormed strategies to boost community participation in the TEA.

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### **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 (PC-CER). PC-CER studies compare two or more treatments based on outcomes important to patients, like itch reduction, family quality of life, and/or financial burden. One of PFIC Network's main goals in IMPACT is to develop a comprehensive list of treatments questions and outcomes to target with future PC-CER studies. To do this, we built the IMPACT Treatment Experience App ([TEA](#)), which gathers and displays patient experiences with different treatments.

### **Discussion Summary**

To ensure our final list of PC-CER targets truly represents the needs and preferences of the PFIC community, it is critical that we continue to gather as much input as possible through the TEA. During the December focus group, members brainstormed strategies for communicating about the TEA to encourage more participation:

### **Distinguishing the TEA from the Registry**

Focus Group members highlighted the importance of distinguishing between the TEA and the Patient Registry in PFIC Network communications. Both are unique, complimentary data collection tools co-created by PFIC patients and clinicians:

- The PFIC Network Patient Registry collects data on the impact of PFIC and various treatments over time.
- The IMPACT Treatment Experience App (TEA) captures patients' feedback on how important it was to them receive certain treatments. In addition, a



summary of the data that participants enter in the TEA is displayed in the TEA, so you can also use it to browse other patients' experiences with treatments. We will hopefully pair data from both these tools for a future PC-CER study.

### **Clarifying the TEA's Data Collection Approach**

Members asked questions about the TEA, revealing important information to share with the broader PFIC community about the tool:

- "Can I see if I have already completed the TEA survey for a treatment?"  
Unfortunately, the TEA cannot show users whether they have already shared their experiences for treatments because it does not collect any personal identifiers - but, not to worry! Our goal is to gather as much information about treatment experiences as possible. If you complete the TEA survey for the same treatment more than once, you might include new information which is still very valuable!
- "Does the TEA collect medical records?"  
The TEA does not collect medical records primarily because its mission is to capture patients' firsthand experiences, which are often overlooked or absent in standard medical documentation.

### **Motivating Participation in the TEA**

In our discussion, we explored ways to increase participation in the TEA, so we can gather more patient insights and finalize our PC-CER targets. Members suggested the following strategies for PFIC Network and the broader PFIC community:

- Encourage physicians or nurses to share the TEA with their other PFIC patients.
- Offer a ready-made message template for families to share with providers.
- Encourage patients and families to invite their PFIC peers to complete the TEA.
- Provide raffle drawing incentives for those who participate.
- Dedicate time at the PFIC Family & Scientific Conference for filling out the TEA.
- Launch campaigns reminding people to *revisit* the TEA if they have started a new medication or if an existing treatment has stopped working.
- Invite participants in the PFIC Network Patient Registry to complete the TEA.
- Allow community members the option of having a PFIC Network staff member enter responses in the TEA on their behalf.
- Post brief video testimonials about the TEA from community members.

### **December Focus Group Wrap-Up**

- PFIC Network and the IMPACT project team will use focus group members' feedback to create communications and motivate participation in the TEA.



- During our next focus group in February, we will discuss our final list of targets for PFIC PC-CER. This list will be generated using data from the TEA and IMPACT Module 5 results.



*Even if you already shared some of your treatment experiences, please visit the [PFIC IMPACT Treatment Experience App \(TEA\)](#) and share your treatment experiences in the TEA survey. The treatment experiences you enter into the TEA are super important to get a better picture of what is most important to research!*

### **Don't miss it! Next IMPACT activities...**

- **Our next focus group will take place on Thursday, February 20<sup>th</sup> at 6pm ET.**
  - It will be hosted as a virtual Zoom meeting and will last 90 minutes. Participants will receive a \$90 gift card as thanks for their time and input.
  - We hope to see you there! If you would like to participate, [register here](#).
- **Our last IMPACT Module (Module 6) will go live on Monday, March 24<sup>th</sup>!**
  - Look out for emails from Melissa with an invitation!
  - If you haven't already, we encourage you to take [Modules 1-5](#).

Please contact us anytime with feedback, questions, or concerns: [melissa@pfic.org](mailto:melissa@pfic.org)