

## Engaging PFACs in Research: What, Why, & A Roadmap

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### What We Learned

**PFACs are aware of PCOR and find it relevant to their work as a council. First-hand experience, not PCOR, informs PFACs' understanding, decision making, and recommendations to the healthcare organizations they advise.**

#### Aim

The purpose of this project is to build our knowledge of how PFACs receive and make use of PCOR and to co-develop a tool that will support their awareness and use of PCOR in the future.

#### Actions Taken

Focus Groups with 20 PFACs around the country in: behavioral health, addiction rehab, outpatient surgery, community hospitals, acute care hospitals (including VA and pediatric specialty), & academic medical centers.

Sample Characteristics : n = 212  
(63% female; 7% African-American, 88% white); avg. age = 56 (range 22-87 years)

Education	4% high school-technical 19% some college 37% college degree 40% graduate degree
Member of PFAC	27% less than a year 23% 1-2 years 15% 2-3 years 35% 3+ years

“**AFTER ALL, WHO ARE YOU CREATING THE EVIDENCE-BASE FOR?**”  
--a patient in a focus group with Planetree

“RESEARCH DONE DIFFERENTLY”

### Summary of Results

#### Factors that Promote Engagement with PCOR

- Assigning PFAC members official roles within organization provides access to research journal subscriptions (ie.- email/network access)
- Access to on-site library; librarian services
- Interaction with researchers at organization
- Meaningful involvement with research department at organization; research topic development; conduct of research; sharing results
- Processes requiring presenters to share relevant research findings/literature on any topic put forth to PFAC for feedback

#### Barriers to Engagement with PCOR

- Limited access to research (journal subscriptions limited to institutions/orgs., limited full text articles publically available, rental/purchasing costs for consumers).
- Lack of consumer friendly language:
  - (a) published research organized into categories by medicalized jargon, not consumer-friendly search terms;
  - (b) published research articles have jargon and complex statistical analyses;
  - (c) articles and IRB materials not written to promote consumer understanding).
- Time (most PFAC members are un-paid volunteers).

### Sample of Engagement Roadmap



#### DISSEMINATION

In many ways, the true value of research is in sharing the findings about what was learned with the people who need it the most, in a timely manner. This creates the opportunity for the information gained from research projects to be used and applied in real-world settings and decisions. In this phase of the research process, PFACs can play a key role in getting the word out.

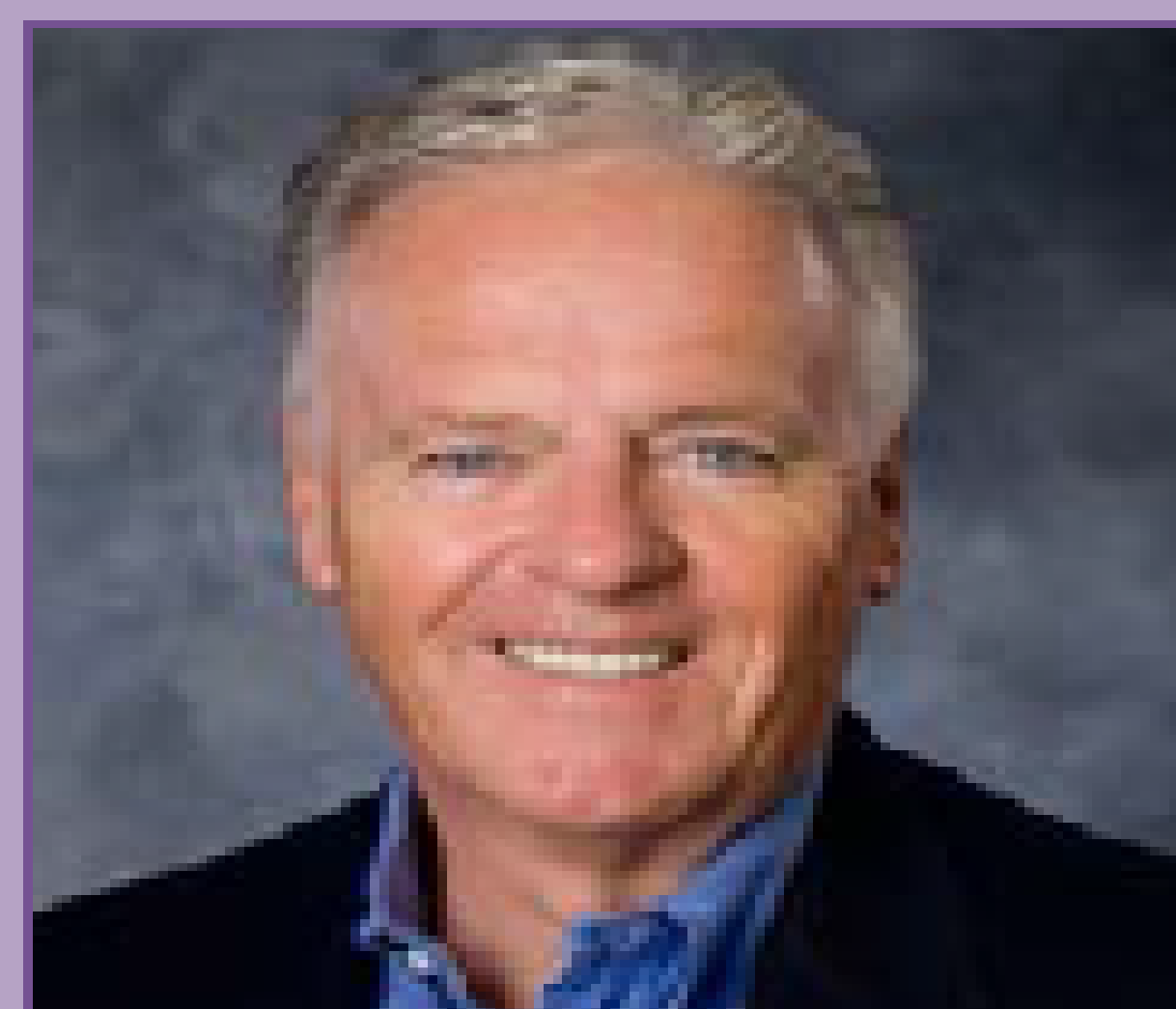
For example, recently, the [National Academy of Medicine \(NAM\)](#) asked a scientific advisory panel of experts to collect and summarize the evidence for patient and family engaged care (PFEC). As a result, a [discussion paper](#) is now publicly available with a comprehensive accounting of recent and reliable information to build support for PFEC all in [one place](#). The paper includes a framework and logic model for PFEC, which describes specific changes and steps that healthcare organizations need for PFEC to truly flourish in process and practice.

In response to the framework, authors of an editorial in the [BMJ](#) urged industry leaders and patient-family partners to [co-create a "to-do list"](#) for PFEC that goes beyond buzzwords, like patient-centered care, to the heart of true partnership with patients and families.

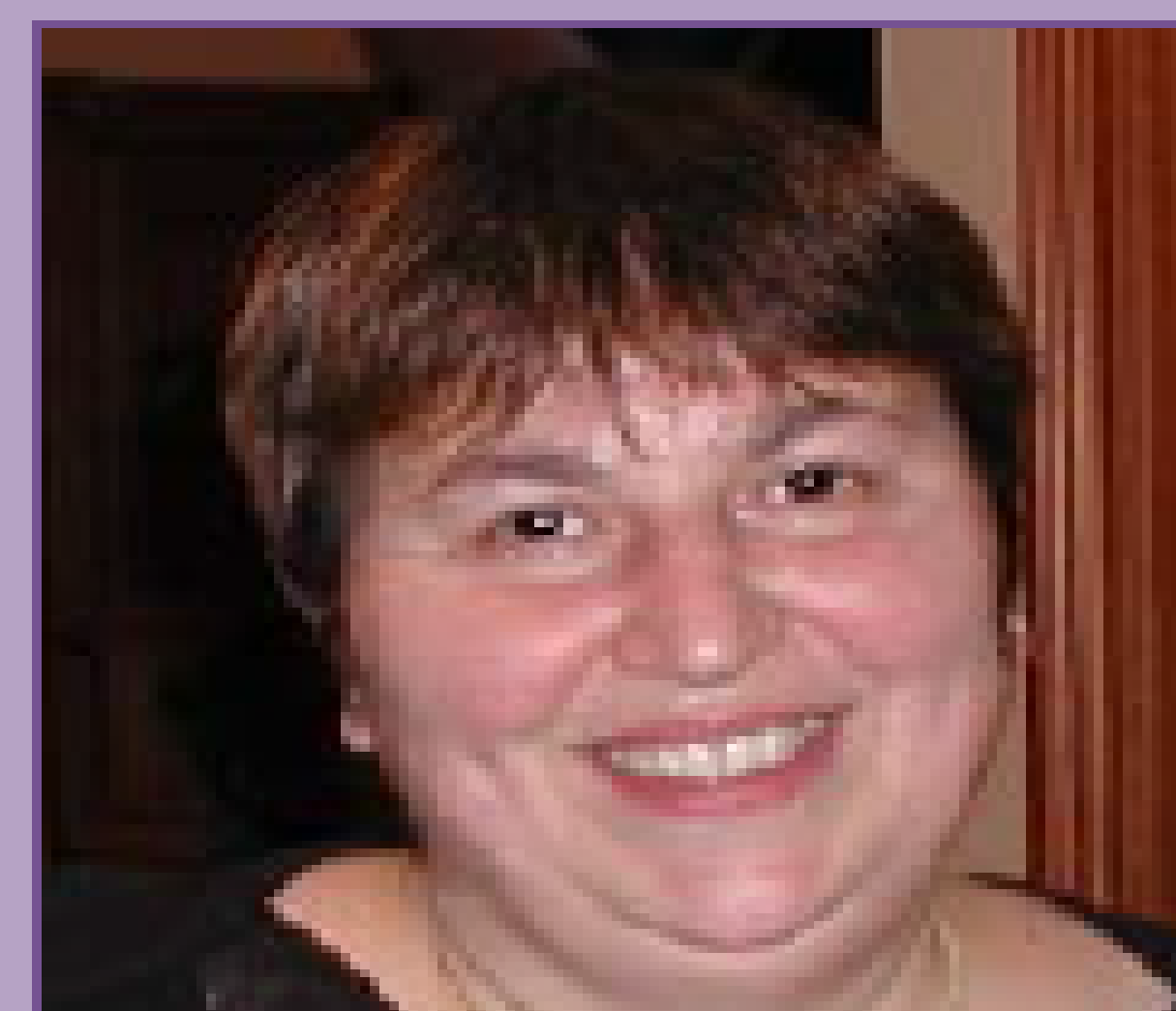
In response to this charge, members of [Planetree's International patient-family advisory council](#) decided that the first step in defining and accomplishing a "to-do list" for PFEC is to explain the concept of PFEC and distill the 38-page discussion paper into a consumer-friendly summary.

We reasoned that while the industry rallies and organizes itself around the concept of PFEC, the average consumer doesn't know what the term means and why it matters.

### PFAC'S HELP YOU GET THE WORD OUT!



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Read how: <http://bit.ly/2voJAtu>

Download the FREE PFAC Toolkit for Engagement in Research: [www.planetree.org/resources](http://www.planetree.org/resources)