



**PATIENT ENGAGEMENT IN RESEARCH:  
A TOOLKIT FOR PATIENT-FAMILY  
ADVISORY COUNCILS**

“  
AFTER ALL, WHO ARE  
YOU CREATING THE  
EVIDENCE-BASE FOR?  
”

--a patient in a focus group with Planetree

This toolkit is organized by the conceptual model of patient engagement in research. It follows the life cycle of research from deciding what topic areas should be prioritized to receive research funding, to developing a research question, designing a study, conducting research, disseminating and implementing results, and finally, evaluation.

## TABLE OF CONTENTS

- 04 How to Use This Toolkit
- 06 Overview Of Patient Engagement In Research
- 10 Setting Agendas and Determining Funding
- 12 Review, Design and Conduct of Research
- 14 Dissemination and Implementation
- 16 Evaluation of Results

## DOWNLOAD RESOURCES

- > [A Sample Agenda for the First Meeting of PFACs and Researchers](#)
- > [5 Questions PFACs Should Ask Researchers at Their Healthcare Organization](#)
- > [Barriers to Engagement in Research & Ways to Overcome Them](#)
- > [Promising Practices for Meaningful Consumer Engagement: Examples of Hospitals in Massachusetts](#)
- > [Stories of Patient & Family Advisors Collaborating on Research at Michigan Medicine](#)

# THE TOOLKIT

## **This toolkit is intended to support Patient-Family Advisory Councils (PFACs) engagement in research.**

In general, a PFAC is the formal name used to describe groups of healthcare consumers (patients, families, & staff members) working together as a team to improve healthcare in an organization. In the U.S., Massachusetts is currently the only state that has required PFACs since 2008. While it is difficult to get an exact count of the number of PFACs working in healthcare organizations in the U.S., what is clear is that the value of PFACs in hospitals, outpatient clinics, nursing homes, and other types of healthcare settings is growing.

PFACs look at patient and family experiences in healthcare organizations “through the patient’s eyes.” Collectively, they use their personal experiences and first-hand knowledge to improve how healthcare is delivered. Healthcare organizations nationwide are using PFACs as a foundational structure to engage patients and family members as partners in quality and process improvement, strategic planning, hiring and evaluation, staff training and more to promote community building and align the organization’s strategic priorities with what matters most to patients.

In addition to partnering with organizations to improve healthcare, consumers are also beginning to partner with scientists to ensure that research aligns with what matters most to patients and families.

In traditional research, patients were often limited to being research subjects in scientific studies. They had little or no input into what research topics were studied or funded. They had little or no input into how the studies were designed and conducted. And, they had little or no input into how the information was analyzed and shared with the world once the study was complete.

## **This way of doing research is changing.**

In 2010, Congress appointed the Patient-Centered Outcomes Research Institute (PCORI) to “improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions. Specifically, PCORI funds comparative clinical effectiveness research, or CER, as well as support work that will improve the methods used to conduct such studies. The goal of PCORI’s work is to determine which of the many healthcare options available to patients and those who care for them work best in particular circumstances. They do this by taking a particular approach to Comparative Effectiveness Research called Patient-Centered Outcomes Research, or PCOR, research that addresses the questions and concerns most relevant to patients, and we involve patients, caregivers, clinicians, and other healthcare stakeholders, along with researchers, throughout the process.” ([www.pcori.org](http://www.pcori.org)). PCORI describes this new method of patient engagement in research as “research done differently.”

Patient engagement in research means that scientists don’t conduct research “on, to, or about patients,” rather they partner “with” them. Ideally, this partnership would begin early in the research process, beginning with how research funding and priority areas are selected with patient and family input. Patient engagement in the research process would go on to include a partnership with researchers in developing a research topic, designing their study, conducting their study, sharing their study findings and results with others, and evaluating the quality and value of the information.

## **Why focus on PFAC engagement in research?**

Patient engagement in research doesn’t just apply to PFACs. Any patient, family member, consumer, and/or caregiver that is interested in a topic or project can be engaged as a stakeholder in the research process. For this specific project, we chose to focus on PFAC engagement in research because more and more healthcare organizations are relying on PFACs to inform how they do business, including the conduct of research. As a group, PFACs represent the voices of healthcare consumers. They can help researchers frame their research questions from the perspective of what matters most to patients and families. They can ensure that the way the research is conducted includes patient partners in the process. They can also ensure that research findings are shared in a way that allows consumers to easily access and understand the information to make health decisions that are important to them.

An additional reason to focus on PFACs is that the organization of PFACs often aligns with the process of research. That is, research usually takes time and a dedicated team to accomplish it. Many PFACs tend to have regular meetings and ways to regularly communicate among their members and with organizational leaders, including researchers, for sustained periods of time. PFAC members are dedicated to improving patient and family experiences and typically commit to their role on the council for a certain period of time. Not only can PFACs guide researchers in how they approach, conduct, and share research in a way that aligns with what matters most to consumers, they are also likely to be able to repeatedly engage in research over the course of a project. These factors make PFACs a very important group to consider for engaging in research. A final reason to focus on PFACs is that as healthcare organizations rely on PFACs to advise them and guide the decisions, it is important to understand how PFACs access and use research findings to inform the recommendations they make.

## **Currently, we don’t know enough about how PFACs engage in research.**

Despite increasing engagement with PFACs in healthcare organizations, little is known about how these groups receive or make use of patient-centered outcomes research (PCOR) to inform their understanding, decision making, and recommendations to the healthcare organizations they advise.

## **As a solution to this problem, this toolkit has been co-created with patient partners and Patient-Family Advisory Councils from each region of the United States.**

Without these partners, this toolkit would not have been possible. Our partners have been engaged from the beginning stages of this project, when it was just an idea. With their help, we were able to describe the topic we were interested in, develop a central question and the ways we could get answers to that question. Next, we wrote a description of our project, determined how we would accomplish it, explained why it was important, and how we would share the information with others. This written plan was then used to apply for a Patient-Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI- [www.pcori.org](http://www.pcori.org)). With PCORI funding support, we completed our project together and now we are sharing the results with the world. In traditional research language- the steps of the research process we just described are also known as: setting agendas and determining funding; review, design and conduct of research; disseminating and implementing results; and finally, evaluation.

Because this tool has been co-developed by PFACs for PFACs- we have made every effort to use consumer-friendly language. That means that while some PFAC members may have a background in research- we want to make sure that this toolkit meets the needs of members who don’t.

## **This toolkit is a free resource for you to use and share – and we hope you will!**

The value of this toolkit is in people using it. We encourage you to share it with others. Tweet about it! Email it to a friend! Post a link to it on your website! Share it with your local nursing home, hospital, university, or state healthcare association! Tag, you’re it! Pass it along!

# PATIENT-CENTERED OUTCOMES RESEARCH DEFINED

Patient-Centered Outcomes Research (PCOR) helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in accessing the value of health care options

|   |   |   |  |
|---|---|---|--|
| <i>"Given my personal characteristics, conditions and preferences, what should I expect will happen to me?"</i> | <i>"What are my options and the potential benefits and harms of these options?"</i> | <i>"What can I do to improve the outcomes that are the most important to me?"</i> | <i>"How can clinicians and the care delivery systems they work in help me make the best decisions about my health and healthcare "</i> |
|---|---|---|--|

## Let's start by defining what we mean when we say, "patient engagement in research"

According to the Patient-Centered Outcomes Research Institute, "engagement in research," is defined as, "meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to sharing the results or findings with the public."



For this project, we asked 20 PFACs around the country to tell us about their engagement in research.

We conducted focus groups, a type of group interview, with PFACs from a variety of organizations including: behavioral health hospitals, addiction-rehabilitation communities, outpatient surgery centers, community-based hospitals, acute care hospitals & academic medical centers.

All together we interviewed 212 people. PFAC members ranged in age from 22 to 87 years old with an average age of 56 years. The majority of PFAC members were white (88%). More than half of the PFAC members were female (63%). We also asked PFAC members about their education level and how long they had been members of the PFAC.

|   |   |
|---|---|
| <b>Education Level of PFAC</b>          | 4% high school-technical<br>19% some college<br>37% college degree<br>40% graduate degree |
| <b>Number of Years as a PFAC Member</b> | 27% less than a year<br>23% 1-2 years<br>15% 2-3 years<br>35% 3+ years                    |

Over half of the PFAC members we interviewed had a college education or higher. Fifty percent (50%) of participants had been part of their PFAC for two or more years.

## During our focus groups, PFAC members described a variety of barriers that prevent them from engaging in research and some suggestions to overcome them.

- Not knowing if the organization has a research department or researchers, more generally.
- Invite the research department to your next PFAC meeting.
- Ask that all research proposals provide evidence of incorporating patient and family voices.
- Ask that all research proposals be reviewed by the PFAC.

---

- Limited access to research. Specifically, PFAC members described how research journal subscriptions are limited to institutions and organizations with only a limited amount of full text articles publicly available. The rental and/or purchasing costs for consumers was a barrier.
- See if your organization can provide institutional email addresses for PFAC members. In some cases, this gave PFAC members full access to research publications through the organizational subscription. If one exists, invite the medical librarian to your next PFAC meeting.
- Ask staff representatives and PFAC organizers to provide copies of the most recent research evidence for topics of interest to your PFAC.

---

- Published research articles have jargon and complex statistical analyses that are not easy for the average consumer to understand and apply to their healthcare decisions.
- Ask your clinician or provider to help you understand how the information applies to you and your healthcare decisions.
- Ask the medical librarian or a researcher to help you decode the information.
- Some research funding agencies, such as PCORI, and research publishers require that authors include summaries of research findings that are written in consumer-friendly language. If you find that information you are interested in is not easily understood by the average person, consider emailing the author, editor, or publishing organization to ask that jargon-free summaries or key take-away points for patients and families be included as standard practice.



**BARRIER**



**SUGGESTION**

## BARRIER

## SUGGESTION

-  When researchers come to our PFAC meetings, we tend to let them do all the talking since they are the “experts.”

Remember, no one understands the patient experience more than YOU. Patients and families have expert knowledge about their experiences, bodies, and disease/condition management that researchers need to know.

-  To level the playing field, try removing organizational name tags. Stick to first names only when you do introductions. That is, don't ask people to include their role. Begin your meeting with a general question and discussion about the topic. For example, if funding is available for diabetes research, ask the meeting participants to weigh in on the question: “What questions should research on diabetes answer for patients and families?” If your PFAC is focused on a specific disease, such as diabetes, ask participants, “What are the answers we need most from research on diabetes?”

-  When PFAC members participate in a research project, they are required to complete ethics training as part of the Institutional Review Board requirements for members of the research team. However, training materials are not written to promote consumer understanding.

-  Try using the CIRTification Program, developed by Emily E. Anderson, PhD. “CIRTification is a human research protection training program designed specifically for community research partners who do not have prior background or experience with research or familiarity with research ethics. Copies of all CIRTification materials are freely available for download from the [University of Illinois at Chicago \(UIC\)](http://www.go.uic.edu/CIRTification), Center for Clinical and Translational Science, Community Engagement and Research Core: [www.go.uic.edu/CIRTification](http://www.go.uic.edu/CIRTification)”

-  PFAC members lack confidence that they know enough about research to participate on a research team.

When patients and family members partner with researchers on a research project, all parties need an orientation process to understand the project, their roles on the project, their value to the project, communication preferences, and expectations for a successful partnership.

-  Try The Toolkit on Patient Partner Engagement in Research (TOPPER) created by Betty Kaiser, PhD, RN and Gay Thomas, MA of the University of Wisconsin – Madison School of Nursing and Elizabeth Cox, MD, PhD and Gwen Jacobsohn, PhD of the University of Wisconsin – Madison Department of Pediatrics, available at <http://www.hipxchange.org/TOPPER>. This toolkit contains the complete set of orientation materials used to prepare two parent advisory boards for their work on a research study “Family-Centered Tailoring of Pediatric Diabetes Self-Management Resources,” funded by the Patient-Centered Outcomes Research Institute.

“ DO NOTHING ABOUT ME, WITHOUT ME. ”

### MEET PATIENT AND FAMILY PARTNERS AT MICHIGAN MEDICINE BY MARIE ABRAHAM, MA, [INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE](#)

Michigan Medicine (formerly the University of Michigan Health System) began inviting patients and families to partner with them over twelve years ago. This came about after the wife of a critically injured patient chronicled the details of her husband's care over his 11 week hospitalization. She wrote as a way to help her remember important information about his care but she also wrote about her observations of how the experience could be improved. She shared her journal with senior leadership. They saw it as a valuable teaching tool for clinicians and staff and invited her to join the Patient Safety Committee becoming their first patient and family advisor.

Now, twelve years later, Michigan Medicine has over 400 patient and family advisors who serve on various onsite patient and family advisory councils, committees, and task forces. They also have over 800 e-advisors (advisors who work remotely) who review materials, share feedback, and respond to surveys. Given their reputation as one of the nation's leading research institutes, it is not surprising that patient and family advisors are asked to collaborate on research projects at Michigan Medicine.

[Click here to meet some of the PFAC Advisors](#)

**1** SETTING AGENDAS & DETERMINING FUNDING PRIORITIES

## SETTING AGENDAS AND DETERMINING FUNDING

Researchers have identified a need for patient and family involvement in setting research agendas and determining funding priorities.

**2** REVIEW, DESIGN & CONDUCT OF RESEARCH

For example, in a [paper](#) published by [The Journal of the American Medical Association \(JAMA\)](#) which explored medical research funding trends from 1994 to 2012, researchers concluded that research funding in the United States under funds chronic diseases that are most burdensome and expensive for patients and families. Additional studies indicate that the majority of current research is focused on areas that do not align with the top research priorities identified by patients and families.

**3** DISSEMINATION & IMPLEMENTATION OF RESULTS

In an effort to bridge the gap between the research being conducted and the priorities of patients and families, [The Patient-Centered Outcomes Research Institute \(PCORI\)](#) has set out to change the way that research agendas and funding priorities are determined to better align with information that matters most to patients and families. That is, PCORI wants to set agendas and prioritize funding for research that answers questions to support “real world” experiences and healthcare decision making dilemmas in the daily lives of patients and families and do it in way that is transparent and inclusive.

**4** EVALUATION

# ENGAGE

### GET IN THE GAME.

Have a voice at the table. PFACs can submit patient-centered research questions directly to The Patient-Centered Outcomes Research Institute (PCORI) here: <http://www.pcori.org/get-involved/suggest-patient-centered-research-question> to help set agendas and prioritize funding.

Read more about patient engagement in the research development process in clinical trials here: <http://bit.ly/2eKJUM7>

# NOT SURE HOW TO WRITE A RESEARCH QUESTION?

CONSIDER USING THIS STEP-BY-STEP PROCESS PROVIDED BY PCORI.

## STILL NOT SURE HOW TO PARTNER WITH RESEARCHERS?

Get Tools & Resources from Institute for Patient and Family-Centered Care <http://bit.ly/2gmPkgI>



A **Toolbox** for Creating Sustainable Partnerships with Patients and Families in Research

# GAINING PERSPECTIVE THROUGH THE EYES OF PATIENTS

When developing a research topic about a certain health condition, perspective taking is key to understanding what matters most to patients and families living with that condition.

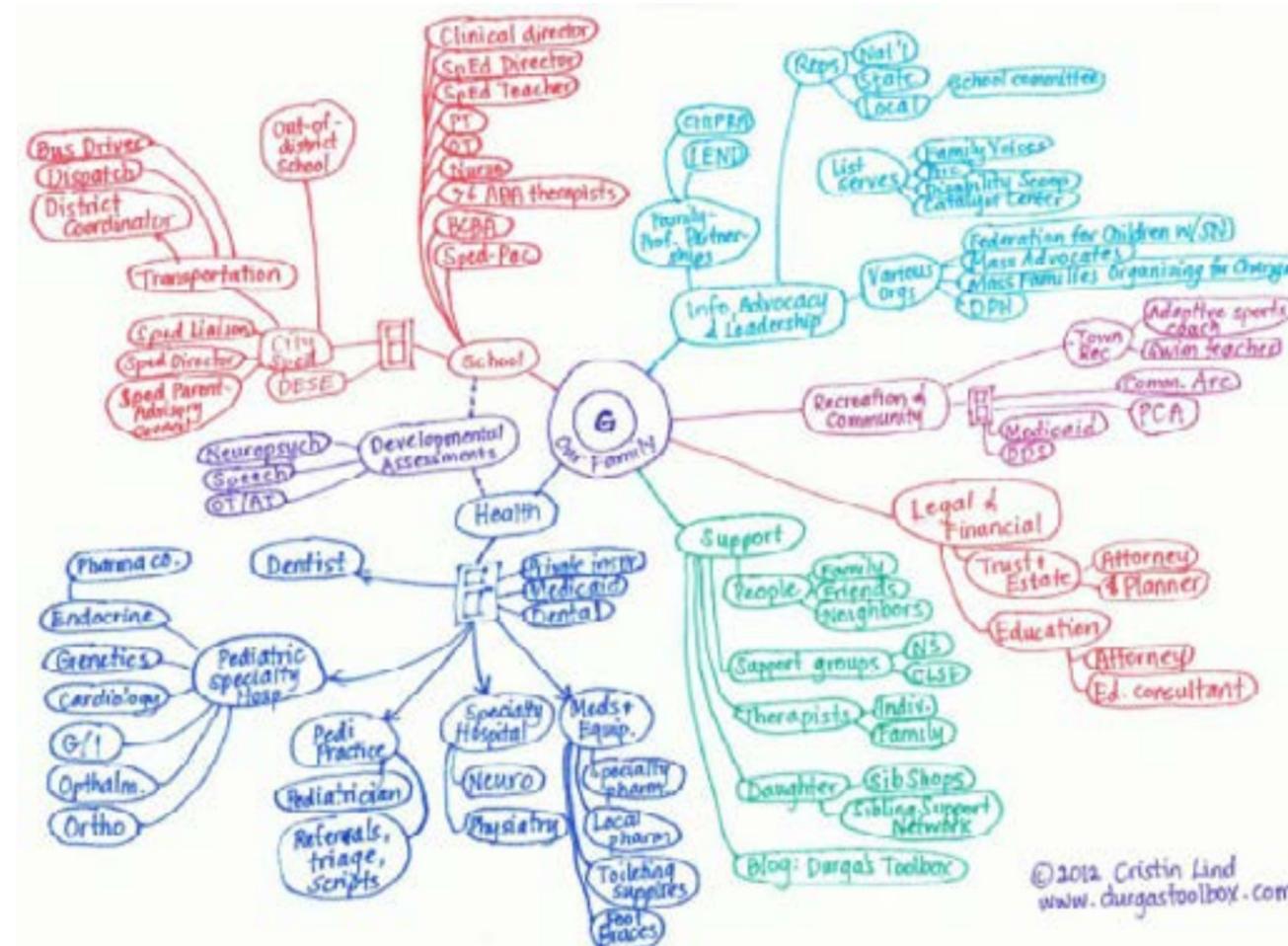
Some organizations have PFACs that are dedicated to certain healthcare conditions. Members of these PFACs are generally focused on one condition and use their lived experience with the condition to improve the services and experiences of others. When researchers at their organization want to study a condition, such as diabetes, they might engage the PFAC by asking the members to describe what is important to them.

For example, a researcher may ask patients and families **“Based on your experience of living with diabetes, what questions should research about diabetes answer?”**

Asking patients and family members to spend some time reflecting on their answers to that question and then visually sharing what a “day in the life” of living with a healthcare condition is like, helps researchers to take on the perspective of patients and family members. That is, researchers get to walk in the patients’ shoes by getting a glimpse into daily life. Sharing information visually using drawings, photos, and graphics are some of the methods being used to help share this type of information. The perspective gained from this activity can inform what questions researchers ask, how they conduct their research, and how they share what they find.

- 1 SETTING AGENDAS & DETERMINING FUNDING PRIORITIES
- 2 REVIEW, DESIGN & CONDUCT OF RESEARCH
- 3 DISSEMINATION & IMPLEMENTATION OF RESULTS
- 4 EVALUATION

# GABE'S CARE MAP



# ENGAGE

- Distribute disposal cameras or take pictures with your cell phones to visually tell the story of what life is like living with a certain health condition, such as diabetes.
- Ask patient and family partners to share their perspectives by taking pictures of what is important to them. This can include photo experiences of their: daily routines, goals, joys, hopes, problems, challenges, and worries that relate to living with their disease or condition.
- Come together as a group with the research team to share photos and the stories gathered. What can researchers learn about the experience of living with a condition, such as diabetes, from these photographs? How does it shape the research questions and design of their research study?
- If your organization doesn't have a PFAC focused on specific conditions, that's okay! You could adapt this activity by inviting patients and family members living with diabetes to complete a visual diary. When you come together, co-facilitate the session with the research team.

Using visual materials, such as drawings, art, photos, videos, and more, can improve communication and perspective taking between researchers and patients. For example, when Cristin Lind, a mother of a child with special needs, needed to communicate the complexities of caring for her son, she drew a picture at her dining room table. The drawing above represents **“Gabe's Care Map.”**

Gabe, Cristin's son, is represented by the letter "G" in the circle in the center. The color-coded ovals represent all the areas of care that are necessary to coordinate to help Gabe live his best life. Sharing the care map with others helped them to see what a day-in-the-life was really like for Gabe and his family. Cristin's care map is a visual tool that is also being used by teams of patients and researchers to better understand what questions researchers ask and whether the proposed research on a given topic would make a difference in the daily lives of patients and families. In other words, how would research on a particular topic effect my care map? How would the information gained from the research study make a difference in the daily lives of patients and families? The care map can also improve the design and conduct of research studies. For example, the care map creates a better understanding of how much time patients have to participate in research studies and in what ways.

To learn more about care mapping, visit Cristin's website: <https://durgastoolbox.com/caremapping/> and watch a video about using care mapping and engagement in research here: [http://www.healthaffairs.org/events/2013\\_02\\_06\\_patient\\_engagement/](http://www.healthaffairs.org/events/2013_02_06_patient_engagement/)

1 SETTING AGENDAS & DETERMINING FUNDING PRIORITIES

2 REVIEW, DESIGN & CONDUCT OF RESEARCH

3 DISSEMINATION & IMPLEMENTATION OF RESULTS

4 EVALUATION

## 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.

PFEC centers on the idea of partnering with consumers to ["continuously integrate patient and family perspectives and involvement—at the point of care, in health care system design, and in defining outcomes that matter most."](#) To that end, we contend that a "to-do list" designed to build and sustain this partnership, should begin with an invitation to patients and families to engage. What follows is an explanation of PFEC and an invitation to patients and families to engage in their healthcare written by consumers, for consumers. This project is an example of how PFACs can be involved in not only the translation of research for use in the "real-world," but the dissemination phase as well. [The letter is available for download here.](#)

When researchers design a research study, they plan in advance for the dissemination and implementation phase. That is, researchers need to think about and describe the ways in which they will share the findings from their study before the study even begins. In planning for dissemination of research findings, PFACs play a key role in three ways.

This framework encourages research teams to consider which stakeholder groups need to be included in the engagement of the overall research project and the dissemination and implementation phases.

## IMPLEMENTATION

Implementation refers to the phase of the research process in which research findings are used or "put into practice." That is, now that you have shared your research findings, you want people to engage with the information. This "engagement" can take on many forms depending on the type of research study is involved (ie.- a randomized controlled clinical

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



**RICHARD HANKE, Ed.D., SPHR,**  
Planetree International Patient-Family  
Advisory Council



**LISA FREEMAN**  
Planetree International Patient-Family  
Advisory Council & Executive Director,  
Connecticut Center for Patient Safety



**RICHARD ZORZA**  
Planetree International  
Patient-Family Advisory Council  
Johns Hopkins Oncology Patient  
and Family Council

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

### The 7Ps Framework

| Category                | Description   |
|-------------------------|---|
| Patients and Public     | Current and potential consumers of patient-centered health care and population focused public health, their caregivers, families and patient and consumer advocacy organizations.   |
| Providers               | Individuals (e.g. nurses, physicians, mental health counselors, pharmacists, and other providers of care and support services) and organizations (e.g. hospitals, clinics, community health centers, community based organizations, pharmacies, EMS agencies, skilled nursing facilities, schools) that provide care to patients and populations. |
| Purchasers              | Employers, the self-insured, government and other entities responsible for underwriting the costs of health care.   |
| Payers                  | Insurers, Medicare and Medicaid, state insurance exchanges, individuals with deductibles, and others responsible for reimbursement for interventions and episodes of care.  |
| Policy Makers           | The White House, Department of Health and Human Services, Congress, states, professional associations, intermediaries, and other policy-making entities.  |
| Product Makers          | Drug and device manufacturers   |
| Principal Investigators | Other researchers and their funders   |

TOOL

Use this tool created by Tufts Clinical and Translational Science Institute to help you determine who needs information about your research project and why.

## DISSEMINATION

1. Help researchers determine what patient, family, consumer, civic, public and private organizations, healthcare payers, and government groups would most benefit from receiving information about their research and its findings.

2. Help researchers understand and define what it is about their research and its findings that these groups need to know.

### Key questions to ask are:

- + What information about the study do these groups need and why?
  - + How could each of these groups use information from this study?
3. Partner with researchers to determine the best ways for that information to reach those key audiences.
- + What do we know about how these groups learn or prefer to receive information?
  - + How can we match our information to these needs and preferences?
  - + What communication channels do these groups use?
  - + What is the best way to get our information to the people who need it most?

Identifying who needs the information gained from your research project, what information they need, and how they need that information fashioned in a way that they can understand is critical groundwork for the next phase in the research life cycle.

## IMPLEMENTATION

PFACs can translate research findings into a consumer-friendly summary to share with patient, family, and consumer groups about why they need the information and how to use it to inform healthcare related choices and decisions.

- + Share the study findings at scientific meetings and conferences demonstrating how the research findings can be used to further additional scientific inquiry and partnerships with patients and families on research teams.
- + Present the research findings to key groups, highlighting how the research meets an unmet need for patients and families and provides a “real-world” solution or application.
- + Ask questions, such as, “how can we help you, use this information?”



The evaluation phase of the research life cycle refers to the process by which groups describe and assess the overall impact, including the value, quality, and rigor of research.

Historically, patients and families have been left out of the evaluation process. For example, current models to assess the strength, quality, and relevancy of scientific evidence give low marks to qualitative research and top marks to randomized controlled trials and quantitative study designs that are currently published in ways that is difficult for the average person to understand and use in making healthcare decisions.

While there are examples in the literature describing how traditional models to evaluate research aren't perfect, they nevertheless, remain the standard.

There is increasing momentum to engage patients and families, not only in the research process, but as evaluators of research. [Planetree \(@Planetree\)](#) is working with its PFAC to create an evaluation tool that is understandable, accessible, and supportive of patients and family members in finding research, evaluating it, and putting it to use.

In this phase of the research life cycle, engage by becoming members of online communities for research journals. In addition to using social media to increase patient participation and awareness of recently published research findings, these online communities are part of a growing movement to support “research done differently,” by engaging everyone in the research process, rather than just scientists and professional researchers.

For example, the [Stanford Medicine X and Symplur announce an Everyone Included™](#) social media research challenge is focused on building collaborations to improve healthcare by supporting project teams and ideas that include everyone, not just researchers.

Last year, in 2016- radiologist, Dr. Ruth Carlos, deputy editor of the Journal of the [American College of Radiology \(#JACR\)](#) won the [Everyone Included™](#) Research Challenge for her team's work in engaging patients and families in the journal's online Twitter community ([@JACRJournal](#)). Using this community, researchers and patients were able to not only connect online, but to have meaningful conversations about topics in radiology that mattered most to patient participants and their families.

“  
RESEARCH  
DONE  
DIFFERENTLY  
”

## PROMISING PRACTICES FOR MEANINGFUL CONSUMER ENGAGEMENT: EXAMPLES OF HOSPITALS IN MASSACHUSETTS

In 2010, the state of Massachusetts enacted legislation requiring all hospitals create and maintain Patient and Family Advisory Councils (PFACs). According to research conducted in 2016, out of 111 hospitals, about 10% of PFACs in Massachusetts are engaged in research activities, with about half engaged in study planning and design and about one-quarter around implementation.

Click here to to read examples: <http://bit.ly/1Hj3nKl>

CASE STUDY

## WE COULD NOT HAVE DONE IT WITHOUT YOU

Planetree would like to thank the following partners and Patient-Family Advisory Councils for their involvement and support of this project. Without YOU, this project would not have been possible. Thank you!

### PARTNERS

Healthcare for All  
Institute for Healthcare Improvement  
Institute for Patient- and Family-Centered Care  
Margo Michaels, LLC  
National Quality Forum  
People Make Place

### PATIENT-FAMILY ADVISORY COUNCILS

The Johns Hopkins Hospital (Baltimore, Maryland)  
Vanderbilt University Medical Center (Nashville, Tennessee)  
Maury Regional Medical Center (Columbia, Tennessee)  
Fauquier Health Hospital (Warrenton, Virginia)  
Carolinas Medical Center-Mercy (Charlotte, North Carolina)  
Bellevue Hospital Center (New York, New York)  
Northport Veterans Affairs Medical Center (Northport, New York)  
New York Presbyterian-Westchester Division (White Plains, New York)  
Northern Westchester Hospital (Mount Kisco, New York)  
Brattleboro Retreat (Brattleboro, Vermont)  
Longmont United Hospital (Longmont, Colorado)  
Enloe Medical Center (Chico, California)  
University of Washington Medical Center (Seattle, Washington)  
Griffin Hospital (Derby, Connecticut)  
Stamford Hospital (Stamford, Connecticut)  
Planetree (virtual, worldwide)  
Boston Children's Hospital (Boston, Massachusetts)  
Brigham & Women's Hospital (Boston, Massachusetts)  
Amita St. Alexius Medical Center (Hoffman Estates, Illinois)  
Laser Spine Institute (Tampa, Florida)

To all the Patient-Family Advisory Council Members around the world, THANK YOU for all you do to improve healthcare!

### FINANCIAL SUPPORT

This project by Planetree ([www.planetree.org](http://www.planetree.org)) was supported by funding from a Eugene Washington PCORI Engagement Award from the Patient Centered Outcomes Research Institute (PCORI). Read more about the project here: [bit.ly/1n23v9d](http://bit.ly/1n23v9d)

# ABOUT US

## PLANETREE

Planetree International is a mission based not-for-profit organization that partners with healthcare organizations around the world and across the care continuum to transform how care is delivered. Powered by over 50,000 focus groups with patients, families, and staff, *and* over 35 years of experience working with healthcare organizations, Planetree is uniquely positioned to represent the patient voice and advance how professional caregivers engage with patients and families. Guided by a foundation in patient centered care, Planetree informs policy at a national level, aligns strategies at a system level, guides implementation of care delivery practices at an organizational level, and facilitates compassionate human interactions at a deeply personal level. Our philosophical conviction that patient centered care is the “right thing to do” is supported by a structured process that enables sustainable change. ([www.planetree.org](http://www.planetree.org))

## PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

The Patient-Centered Outcomes Research Institute (PCORI), is an independent nonprofit, nongovernmental organization located in Washington, DC, authorized by Congress in 2010.

“Our mandate is to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions. Specifically, we fund comparative clinical effectiveness research, or CER, as well as support work that will improve the methods used to conduct such studies.

The goal of our work is to determine which of the many healthcare options available to patients and those who care for them work best in particular circumstances. We do this by taking a particular approach to CER called Patient-Centered Outcomes Research, or PCOR, research that addresses the questions and concerns most relevant to patients, and we involve patients, caregivers, clinicians, and other healthcare stakeholders, along with researchers, throughout the process.” ([www.pcori.org](http://www.pcori.org))

# THANK YOU

We welcome your thoughts and comments on how you use this toolkit. Please share your stories with us! You can send us an email: [jharrison@planetree.org](mailto:jharrison@planetree.org) or tell us on [Twitter @Planetree](https://twitter.com/Planetree)