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**PLANETREE PCORI ENGAGEMENT AWARD#2421
FOCUS GROUP PROTOCOL DEVELOPED BY PFAC**

Focus Group Agenda:

- Welcome & Introductions

FACILITATOR CHECKLIST:

- Share project summary below
- Share one-page handout created by patient partner that explains the project
- Share one-page definition of PCOR from PCORI
- Obtain informed consent and signatures
- Obtain demographic survey
- Distribute gift cards (note the # of participants & gift cards)
- Write down the # of participants _____ and # of gift cards given_____
- Turn recorder on

PROJECT SUMMARY: Thank you for agreeing to participate in this important project funded by the Patient-Centered Outcomes Research Institute (PCORI) Engagement Award program. Our project is focused on building our knowledge of how Patient Family Advisory Councils (PFACs) engage with patient-centered outcomes research (PCOR). To do that, we are conducting focus groups with PFACs around the country so that we can understand where there are gaps in accessing usable, understandable information about patient-centered outcomes research and how that information supports the work of PFACs. The one-page handout that I've shared with you describes the ways that you can participate over the course of this two year project. As it says on your informed consent form, we need to audio record the focus groups so that we can remember what is said. The focus groups are anonymous. We will not identify you by your comments or how much or little your council engages with research. We would like to collect some basic demographic information from you so that we can describe the characteristics of PFAC members. If you would please complete the one page survey that would be very helpful. Again, this information will only be presented as averages and will not identify you in any way. As it says in your informed consent, your participation in this project is voluntary. You can stop participating at any time.

The focus group will last between 60 and 90 minutes. The questions that we will use during the focus group were created by a PFAC and are designed to help us accomplish the aims of the project.

If everyone is ready, I will start the recording now.



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Focus Group Questions for PFAC:

- 1) This is your time to brag as a PFAC. What would you say are your most important accomplishments as a council?
- 2) What are some projects that are on your agenda in the coming year? (*Probing Question: How do you decide what projects you will work on?*)
- 3) For this project, we are interested in how PFACs engage with something called, patient-centered outcomes research. Have you heard of patient-centered outcomes research? (*Probing Question: What is your understanding or awareness of patient-centered outcomes research? Please describe.*)
- 4) I've shared a handout that has the working definition of Patient-Centered Outcomes Research for you to read. I will paraphrase it now:

Patient-Centered Outcomes Research Definition:

Patient-Centered Outcomes Research (PCOR) is focused on helping patients and families make informed decisions about their healthcare and improve experiences and health outcomes that matter most to patients.

Based on this definition, how relevant do you think patient-centered outcomes research is to your role as a PFAC and the work that you do at this organization? (Please describe.)

- 5) Is this or another type of research available to your council?
- 6) How often, and in what ways, do you use research results or findings to inform or guide the work of this council? (*Probing Question: Do you use research to decide what topics you are interested in as a council? Inform the decisions you make? Inform the advising you provide to the organization?*)

- 7) For this project, we are also interested in how PFACs engage 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.

Based on this definition, how would you describe this PFAC's current level of engagement in research? (*Probing Questions: Have you ever been asked to be part of the research process? This includes, developing a research topic or question, conducting research, and/or sharing the results or findings of the project. (Please describe). What do you know about this organization's participation in research? Is there an opportunity for PFAC members to partner with staff on research projects?*)

- 8) Would you or your PFAC be interested in engaging in research? Why or why not?
- 9) How would engaging in research benefit your PFAC? (Please describe).
- 10) In your opinion, what type of support would you or your PFAC need to engage in research? (*Probing Questions: partnerships with staff; access to researchers; training; on-site library access, etc.*)
- 11) What challenges or barriers might limit you or your PFAC's ability to engage in research? (*Probing Questions: fears about personal qualifications, language/jargon, access, time, format of research findings, etc.*)
- 12) Can you describe an instance when your PFAC worked on a quality improvement project or issue that would have benefited from the use of research findings? (Please describe).
- 13) Thinking about what we have discussed, what type of information would you want included in a guide developed for PFACs by PFACs about engaging in research? Specifically, what type of information or tools would help you participate in research design- that is, deciding what topics to research, conducting research, or dissemination- that is, sharing the findings with the public?

THANK YOU: Thank you again for your participation today. The information you provided will help us better understand where there are gaps in accessing usable, understandable information about patient-centered outcomes research and how that information supports the work of PFACs.



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WRAP UP & NEXT STEPS: Our goal is to conduct focus groups with 20 PFACs by the end of August. The information we learn from the focus groups will help us develop a guide for PFACs to engage with research. This guide will be available for free through Planetree's website beginning in October 2017 (during patient-centered care awareness month). We hope to share a first draft of this manual with you in November 2016. Once you receive a copy of the manual, we would like to invite your PFAC to participate in a virtual call to share your feedback and questions on the draft. We will schedule a time that works best for you sometime between November 2016 & January 2017). You will receive a \$35 gift card for participating in the one-hour call.



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BACKGROUND INFORMATION ABOUT PROJECT

Title of Project: *Building Knowledge of How Patient-Family Advisory Councils (PFACs) Engage with Patient Centered Outcomes Research (PCOR)*

Background: Today, partnerships with patients and family are at the forefront of healthcare quality improvement efforts. Accrediting bodies are incorporating standards on how organizations partner with healthcare consumers. Legislation has been enacted, in some states, requiring hospitals to have patient and family advisory councils (PFACs) and established institutions, like the Institute of Medicine, CMS, the American Hospital Association and others have embraced partnerships with patients as core to their improvement agendas. 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. Despite this increasing engagement with PFACs, 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.

Purpose: To address the current knowledge gap about how Patient-Family Advisory Councils (PFACs) understand, are aware of, receive, and/or make use of PCOR to inform their understanding, decision making, and recommendations to the healthcare organizations they advise.

The **Specific Aims** of this project are:

- 1) To describe understanding, awareness, relevance, and use of PCOR by PFACs.
- 2) To determine factors that may promote and/or limit engagement with PCOR by PFACs (ie.- training of PFAC members, availability of journal subscriptions, access to on-site healthcare consumer library, etc).
- 3) To develop a comprehensive engagement and education manual for PFACs about PCOR.
- 4) To disseminate the manual for PFACs about PCOR to stakeholder groups during Patient-Centered Awareness Month, October 2017

Dissemination Partners for the Manual are:

- National Quality Forum (NQF)
- Institute for Healthcare Improvement (IHI)



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Participating PFACs:

Twenty Patient-Family Advisory Councils from the following organizations have agreed to participate in this engagement project:

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

Description of PFAC Involvement:

The goal of this project is to develop an education manual for PFACs -co-developed with PFACs- about how to engage with research. The manual will be free, publically available, and launched during Patient-Centered Care Awareness Month in October 2017.

The 20 PFAC patient partners that have agreed to participate will be consistently engaged throughout the course of the project in several ways.

- 1) First, PFACs will participate in 90-120 minute focus groups. The purpose of the focus group is to understand how PFACs use research in their role and any barriers or facilitators to engaging with research. The focus groups are anonymous. PFAC members will receive a \$50 gift card for participating. At the end of the focus group, PFAC members will receive a one-page handout that explains the project, ways to stay involved throughout the project, and the goal of the project (to co-develop an education manual for PFACs about PCOR).



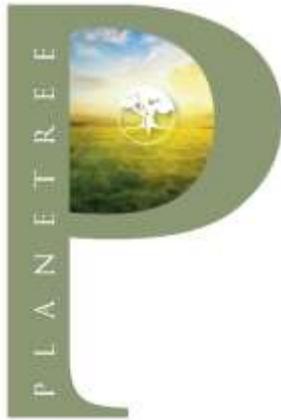
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- 2) Second, PFACs will be invited to join a virtual project community on www.MyPlanetree.org. This website, which is password protected and by invitation only, is an internal social media platform, managed by Planetree. The virtual project community will promote interaction through posts of questions and answers, project updates, and materials. This dynamic web platform also allows PFACs to communicate and post questions to other PFACs involved in the project.
- 3) Third, throughout the project, PFACs will be invited to virtual “check-in” question and answer sessions with the Project Lead, Dr. Jill Harrison. These virtual meetings will be held five times throughout the project on two different days/times to accommodate a variety of schedules and maximize participation. Using Zoom conference technology, participants can join as a group or individually via computer or dial in, toll-free, using a telephone. These on-going “check-in” meetings create consistency in the PFAC members’ voices informing the project, remaining engaged, clarifying information, talking about what we have learned so far, and asking questions. The virtual “check-in” sessions are noted in the project timeline. Check-in sessions will also be recorded and uploaded to the www.MyPlanetree.org virtual project community, where they can be downloaded and listened to at a later time by PFAC partners as members of the community.
- 4) Fourth, PFAC partners will provide feedback on drafts of the manual in a one-hour virtual working meeting to take place between August 2016 and February 2017. Participants will receive a \$35 gift card.
- 5) Fifth, PFAC partners are invited to participate in dissemination planning for the manual to take place between February 2017 and July 2017. Participants will receive a \$35 gift card.

ABOUT PCORI:

This project and the other projects approved for funding by the PCORI Engagement Award Program were selected through a highly competitive review process in which applications were assessed for their ability to meet PCORI’s engagement goals and objectives, as well as program criteria. For more information about PCORI’s funding to support engagement efforts, visit <http://www.pcori.org/content/eugene-washington-pcori-engagement-awards/>.

PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and healthcare decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work.

**ABOUT PLANETREE:**

After a negative experience as a patient in a California teaching hospital where she received in-patient medical care for several months in 1978, Angelica Thieriot, Planetree's founder, approached a group of hospital executives to partner with them on redesigning the care delivery from the patient's perspective. Nearly forty years later, Planetree, an international non-profit organization, has partnered with patients, families and staff in over 700+ healthcare organizations across the continuum of care in 16 different countries.

With an organizational mission to personalize, demystify, and humanize the healthcare experience, Planetree has written an award winning 3-volume series, Putting Patients First, as well as the widely disseminated practical Field Guides that address the continuum of care, including: the Patient-Centered Care Improvement Guide interactive workbook and manuscript with more than 106,242 downloads and 2 million+ page views since October 2008 and the Long-Term Care Improvement Guide interactive workbook and manuscript with 31,528 downloads and 664,827 page views since October 2010. As a recognized authority in the field of patient-centered care, Planetree engages international stakeholders to collaborate in transforming healthcare from the patients' perspective – including representatives of hospitals, continuing care, and behavioral health as well as industry experts such as The Joint Commission, World Health Organization, ISQua, Institute for Healthcare Improvement, American Hospital Association, and the National Quality Forum. Planetree Designation®, an award which honors patient-centered organizations, is recognized as a Quality Check by the Joint Commission, the accrediting body of healthcare organizations in the U.S. Currently, there are 72 Planetree Designated® Sites Worldwide and over 700 healthcare organizations following the Planetree model of patient-centered care.

Website: www.planetree.org

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