



1. Background Information

Principal Investigator: Annette Totten

Project Title: A cluster-randomized trial comparing team-based versus primary care clinician-focused advance care planning in practice-based research networks

Contract ID Number: PLC-1609-36277

Groups Engaged (check all that apply):

- Patients/Consumers
- Family Caregivers
- Patients/Caregivers/Advocacy Organizations
- Community-Based Organizations
- Clinicians
- Clinics/Hospitals/Health System Representatives
- Purchasers
- Payers
- Life Sciences Industries
- Policy Makers
- Training Institutions
- Subject Matter Experts
- Other, please specify: [Click or tap here to enter text.](#)

2. Purpose Statement and Goals

Meaningful engagement among diverse partners is a core element of the Meta-LARC ACP (advance care planning) project.

Engagement assures we focus on what matters most to patients and families, collaborate effectively with all partners, successfully implement the Serious Illness Care Program, and promote the value of ACP.

Engagement helps us achieve our purpose: to make ACP routine in primary care practice so patients with serious illnesses get care they want and care that supports what is important to them and their families.

Table 1 lists the four key goals for engagement in this project. For each goal, there are corresponding key activities and an overview of the approach to monitoring and measurement.

This section overlaps with Section 8, which includes more specific details about our approach to measurement and how we will use quality improvement approaches to assess our engagement activities and continue working towards the goals.

Table 1. Engagement Goals

	Goal For Engagement	Key activities to achieve the goal	How to Measure
1	<p><i>Developing ACP Adaptation</i></p> <p>To guide the project in creating training, tools, and ACP workflows for the practices that use language and tone that is respectful of patients and families and that involves them in ACP appropriately</p>	<ul style="list-style-type: none"> Collect feedback from Patient and Family Advisors (PFAs) and other partners on the training materials through surveys, participation in workgroup(s) and/or discussions at key Research Project Partnership (RPP) meetings. Feedback focuses on ensuring the program and materials are a) sensitive to language and tone and b) likely to resonate with a wide range of patients. Involve PFAs and ultimately Patient Family Advisory Councils (PFAC) in the development of patient facing materials 	<ul style="list-style-type: none"> Documentation and description of ideas generated by Patient and Family Advisors (PFA) and other partners Count and description of PFA-/partner-generated ideas that resulted in changes to the materials as well as the overall approach embodied in the research questions, plan for implementation, or dissemination activities
2	<p><i>Focusing on Important Outcomes</i></p> <p>To ensure the project is answering questions and measuring outcomes that matters to patients and their families</p>	<ul style="list-style-type: none"> Develop strong patient, family and community ties by including these partners in key decision-making steps (meetings, surveys) Create flexible and transparent processes that invite PFAs to contribute meaningfully throughout the study Implement numerous mechanisms to capture ideas, thoughts, suggestions from early stages through decision-making on various topics (e.g. training delivery, outcomes measurement, inclusion/exclusion criteria) Promote collaboration among team members by inviting PFAs to participate in PBRN Operations Group 	<ul style="list-style-type: none"> List of specific activities that invite PFAs and other partners participation Number of partners who actually joined the activity Number of times the activity was held and number of times PFAs and other partners were able to participate Summary of comments received on protocols, measures, and standard operating procedures

	Goal For Engagement	Key activities to achieve the goal	How to Measure
		meetings, ensure that they build relationships with other partners and are supported in sharing their ideas, and that their ideas are heard and integrated into approaches throughout the project	
3	<p><i>Implementing SICP</i> To appropriately guide the project in implementing the Serious Illness Care Program (SICP)</p> <p>To assure the implementation is successful and potentially replicable in real-life primary care settings and that the implementation considers what patient need to prepare for initial and follow-up conversations</p>	<ul style="list-style-type: none"> • Collect feedback and host discussions with clinicians/administrators at participating practices and external stakeholders to ensure spread and replication of our version of SICP is feasible • Ensure representation from clinicians and administrators from community and academic family practices (both participating and other in PBRNs) in partner discussions to provide critical perspectives • Provide support to clinics to engage their patient population, often through a PFAC, to provide insight during implementation of the study to increase success 	<ul style="list-style-type: none"> • Whether the research process was positively affected by the partners • Specific examples of how the content (ACP implementation and measurement) of the research project was impacted • Number of patients who agree to participate in ACP and enroll in the study
4	<p><i>Integration of ACP in Primary Care</i> To enable patients and families to make informed decisions about their health care by making conversations about serious illnesses, patient values and preferences, and ACP a routine part of primary care</p>	<ul style="list-style-type: none"> • Enhance study recruitment and retention strategies in order to increase scalability of the intervention • Develop strong relationships with patient, family, clinician, and primary care practice partners to increase comfort with SICP and ACP conversations • Explore ways of engaging patients, families and primary care clinicians and practices in this conversation outside study parameters (ongoing communication) 	<ul style="list-style-type: none"> • Number of participating primary care clinics having PFACs prior to study enrollment • How PFACs support clinics in the research study implementation • Number of new PFACs that were created at participating primary care clinics • Creation of documentation in patient's medical record that allow ACP activities to be tracked and billed for ACP conversations (indicators of sustainability)

Table 2 identifies project goals related to each engagement group involved in the project. The goals highlight the particular expertise embodied by each group, and the role that group plays in strengthening the project.

Table 2. Partner goals

Partner	Goals
<ul style="list-style-type: none"> - PFAs - PFACs - Family/Care Partners 	<p>To meaningfully influence the approach and implementation of ACP in clinics by:</p> <ul style="list-style-type: none"> • Bringing personal experiences to the team and project tasks • Helping medical professionals understand what people are going through and the understanding that ACP is another aspect of the care partnership • Improving overall ACP as it is happening • Identifying gaps/misconceptions/misinterpretations in care that patients face in ACP • Giving real feedback (not theoretical) based on personal medical experiences and experiences as a caregiver or legal guardian • Incorporating the patient perspective from planning through dissemination (e.g. feedback, brainstorming, input) • Achieving a positive patient experiences with ACP • Enabling patients and families to make informed decisions around ACP and make patients and families more comfortable with having these conversations • Improving serious illness care and ensure that care is consistent with goals and preferences of patients and families • Ensuring that those with a lived experience with serious illness care provide real world perspectives that inform/influence the experience of care for others • Contributing value by helping those patients and families facing serious illness for the first time • Measuring outcomes that are meaningful to patients and families
<ul style="list-style-type: none"> - Clinicians - Primary Care Practices 	<ul style="list-style-type: none"> • Developing skills/confidence/comfort with having these conversations with patients and families • Creating reliable and valid tools for ACP, serious illness care planning and end of life communication in primary care • Expanding knowledge and improving current processes on ACP in primary care • Responding effectively to patient and family questions/concerns • Measuring outcomes that are meaningful to clinicians and their patients • Improving trust and relationships with patients, families, and communities, especially in end of life care
<p>External Stakeholder Partners</p>	<ul style="list-style-type: none"> • Understanding their role as community partners in supporting conversations around serious illnesses and ACP in primary care • Learning about effective/evidence-based models of ACP identified in the study and identifying community dissemination opportunities • Supporting primary care physicians (community and academic), patients and families addressing serious illness by understanding their needs and linking to community resources • Developing strong patient/community partnerships to support future research • Increasing awareness of ACP • Making conversations around serious illnesses and ACP a routine part of primary care

	<ul style="list-style-type: none"> Understanding determinants of successful implementation of ACP across borders in primary care practices Creating reliable and valid tools for ACP and serious illness care planning
Subject Matter Experts	<ul style="list-style-type: none"> Increasing knowledge and skills in ACP in primary care teams and improving current ACP Incorporating evidence into practice (current tools, study outcomes) Bringing attention to gaps in partner involvement and participation and addressing concerns in a timely manner
Training Institutions (PBRN Academic Entities)	<ul style="list-style-type: none"> Developing skills and tools for engagement that can be used in the future for other studies Creating reliable and valid tools for ACP and serious illness care

3. Partner Roster, Bios, and Roles

This is a large, complex project. The overall structure is that the RPP fulfills the role of the study advisory committee, described further in Section 4. It is the hub of a five-component patient, family, and partner engagement structure. There have already been changes in participation within these components and we anticipate changes throughout the project. We will update our directory and member lists to reflect the most current participants as part of our regular progress reports. The biographies provided are current as of May 31, 2018. Bios are provided in alphabetical order, below Table 3, for all the PFAs and other partners whose bios were not included as key personnel in the proposal.

Table 3. Research Project Partnership (RPP) Roster

Oregon Rural Practice-based Research Network (ORPRN)		
Angela (Angie) Combe, MS	Engagement Manager, Facilitator	[email address]
Annette Totten, PhD	Co-Principal Investigator	[email address]
David (Dave) Dorr, MD	Co-Investigator	[email address]
Jodi Lapidus, PhD	Statistician	[email address]
Katrina Murphy	Research Assistant	[email address]
Katrina Ramsey, MPH	Biostatistician	[email address]
Kristen Dillon, MD	Clinician Representative	[email address]
LeAnn Michaels	Project Manager	[email address]
Lyle (LJ) Fagnan	Co-Investigator	[email address]
Seiko Izumi, PhD, RN	Co-Investigator	[email address]
Sonya Howk, MPA:HA	Coordinator	[email address]
Susan Lowe	Patient Family Advisor	[email address]
Quebec Practice-Based Research Network of Laval University (QPBRN)		
France Légaré, BSc Arch, MD, MSc, PhD, CCFP, FCFP	Co-Principal Investigator	[email address]
Jean-Sébastien Paquette	Clinical Director	[email address]
Patrick Archambault, MD, MSc, FRCPC	Co-Investigator, Clinician Representative	[email address]
Priscille-Nice Sanon	Patient Family Advisor	[email address]



Patient-Centered Outcomes Research Institute Engagement Plan

Sabrina Guay-Belanger, MSc, PhD	Coordinator	[email address]
University of Toronto Practice Based Research Network (UTOPIAN)		
Ivanka Pribramska, PhD	Coordinator	[email address]
Judy Katz	Patient Family Advisor	[email address]
Kirsten Wentlandt, MD	Clinician Representative	[email address]
Michelle Greiver, MD	Co-Investigator	[email address]
Rabiya Siddiqui	Facilitator	[email address]
Sharon Strauss, MD, FRCPC, MSc, HBSc	Consultant	[email address]
Iowa Research Network (IRENE)		
Barcey Levy, PhD, MD	Co-Investigator	[email address]
Gail Drey-Provin	Patient Family Advisor	[email address]
Jeanette Daly, RN, PhD	Coordinator	[email address]
Keith Provin	Patient Family Advisor	[email address]
Maresi Berry-Stoelzle, PhD, MD	Co-Investigator	[email address]
Megan Schmidt	Facilitator	[email address]
Olga Petrova	Patient Family Advisor	[email address]
Peter Kim, MPH	Medical Student	[email address]
State Networks of Colorado Ambulatory Practices & Partners (SNOCAP)		
Cat Halliwell	Facilitator	[email address]
Donald (Don) Nease, Jr. MD	Co-Investigator	[email address]
Ken Dailey	Patient Family Advisor	[email address]
Mary Fisher, MPH	Coordinator	[email address]
Matthew Simpson, MD, MPH	Co-Investigator	[email address]
Wisconsin Research & Education Network (WREN)		
Amanda Hoffmann, MPH	Research Coordinator	[email address]
David Hahn, MD, MS	Co-Investigator	[email address]
Deb Constien	Patient Family Advisory	[email address]
Dominic Dharam, MPH	Coordinator/Facilitator	[email address]
Lisa Sampson, MBA	Coordinator	[email address]
Duke, Primary Care Research Consortium (PCRC)		
Azalea Kim, MD	Investigator	[email address]
Dr. B. Angeloe (Angel) Burch Sr.	Patient Family Advisor	[email address]
Beth Mancuso-Mills	Facilitator	[email address]
Jared Lowe, MD	Investigator	[email address]
Kathleen (Kathy) Chmielewski, CMA(AAMA), CCRP	Coordinator	[email address]
Rowena Dolor, MD, MHS	Co-Investigator	[email address]
At-Large Representatives		
Ghislaine Rouly	Patient Family Advisor - CA	[email address]
Jacqueline Alikhaani	Patient Family Advisor - US	[email address]
James (Jim) Pantelas	Patient Family Advisor - US	[email address]
Kathy Kastner	Patient Family Advisor - CA	[email address]
Megan Rich, MD	Clinician - US	[email address]
Institute for Patient- and Family-Centered Care (IPFCC)		
Deborah Dokken	Consultant/Patient Family Advisor	[email address]
Mary Minniti, CPHQ	Consultant	[email address]

Oregon Rural Practice-based Research Network (ORPRN)

Name: Angela (Angie) Combe, MS

Project Role: Engagement Manager, Facilitator, member of RPP, member of Cross PBRN (XPBRN), member of Engagement Group, coordinator of PCP-PFAC Partner Group, PBRN PFA liaison

Affiliation: Oregon Rural Practice-based Research Network (ORPRN)



PERSONAL STATEMENT

Angela is a Practice Enhancement Research Coordinator serving the Eastern Oregon region. She holds a Master of Science in Community Health Education and a Bachelor's degree in Nutrition/Dietetics, both from the University of New Mexico. Prior to joining ORPRN, Angela worked as Faculty for the Extension Services of Oregon State University and Washington State University. Her research and professional experiences working with youth, adults, and families have assisted in her continual development to plan, implement, and evaluate comprehensive nutrition, health promotion and prevention programs. Angela grew up in Portland and has called rural La Grande home for the last 13 years. In her personal time, she enjoys running, gardening, and exploring Oregon's northeast corner with her husband.

Name: Katrina Ramsey, MPH

Project Role: Biostatistician

Affiliation: Oregon Rural Practice-based Research Network (ORPRN)



PERSONAL STATEMENT

I joined ORPRN as a biostatistician in 2012. Previously, I studied English and German literature and taught high school in Poland. I discovered epidemiology and biostatistics at OHSU, where I received my MPH, and spent ten years with the Northwest Portland Area Indian Health Board supporting community-initiated public health efforts. Outside of work, I love to read and go for walks with my husband and kids.

Name: LeAnn Michaels

Project Role: Program Manager, member of RPP, coordinator of Office Hours, member of XPBRN, member of Executive Committee, member of Engagement Group, and member of Measurement Workgroup

Affiliation: Oregon Rural Practice-based Research Network (ORPRN)



PERSONAL STATEMENT

LeAnn has worked at ORPRN since 2008, first as the Manager and currently as the Meta-LARC Program Manager. She served as the Administrative and Research Coordinator for the Meta-LARC project and helped Dr. Fagnan launch this consortium. Within ORPRN, she has

participated in studies focused on a wide array of primary care topics, including care transitions, care management, cardiovascular health and shared decision-making. She holds a Bachelor's degree in nutrition from North Dakota State University. Prior to ORPRN, she worked in digestive health research and in clinical trials. She enjoys music, reading, taking outings with her family and, according to her children, she enjoys doing the laundry.

Name: Susan Lowe

Project Role: Patient Family Advisor, member of RPP, member of Training & SICIP Adaptation Workgroup

Affiliation: Oregon Rural Practice-based Research Network (ORPRN)



PERSONAL STATEMENT

Susan has lived in The Dalles, Oregon for most of her life. She has 2 sons, Doug and Dylan. She worked for the Area Agency on Aging for 24 years and The Dalles Meals on Wheels for 9 years. Susan is a patient representative on the Community Advisory Council as well as the Clinical Advisory Panel for our local CCO/Health Council. She serves as a patient representative and Co-chair of the Patient and Clinician Engagement (PACE) group for the North American Primary Care Research Group.

Quebec Practice-Based Research Network of Laval University (QPBRN)

Name: Jean-Sébastien Paquette

Project Role: Clinician Representative, member of RPP, member of XPBRN

Affiliation: Quebec Practice-Based Research Network (QPBRN)



PERSONAL STATEMENT

I am a family doctor and a researcher working in a family practice teaching unit (Saint-Charles-Borromée). I am the father of three adorable children. My passions are research, astronomy, Walt Disney World and music (DJ Style and Jazz). I discovered the ACP, thanks to the team of France Légaré who made me know the subject and introduced me to the project research team.

Name: Priscille-Nice Sanon

Project Role: Patient Family Advisor, member of RPP

Affiliation: Quebec Practice-Based Research Network (QPBRN)



PERSONAL STATEMENT

Priscille-Nice Sanon is a patient partner affiliated with the Quebec PBRN. She has battled with sickle cell disease and Graves' disease. She is also the patient co-supervisor for the local SPOR SUPPORT Unit affiliated with Laval University in Québec. She was implicated in research project and also a member on board of director for scientific conferences (local and international).

Name: Sabrina Guay-Belanger, MSc, PhD

Project Role: Research Coordinator, member of RPP, member of XPBRN, member of Executive Committee, member of Training & SICP Adaptation Workgroup

Affiliation: Quebec Practice-Based Research Network (QPBRN)



PERSONAL STATEMENT

Sabrina holds a Bachelor's degree and a Master degree in Pharmacology. She also holds a PhD in Molecular Medicine. She is the Quebec PBRN coordinator, and also the Meta-LARC ACP project coordinator in Canada. She has a strong interest for doing research that direct impact on the quality of care and patients' life, and this is the reason why she joined this research team. She loves music, reading, and spending time with friends and family.

University of Toronto Practice Based Research Network (UTOPIAN)

Name: Ivanka Pribramska, PhD

Project Role: Research Coordinator, member of RPP, member of XPBRN, member of Training & SICP Adaptation Workgroup, member of Measurement Workgroup, coordinator of PCP-PFAC Partner Group

Affiliation: University of Toronto Practice Based Research Network (UTOPIAN)



PERSONAL STATEMENT

Ivanka joined University of Toronto Practice-Based Research Network (UTOPIAN) in 2014 as the PRBN's Operations Manager. She holds a PhD degree in Information Science from Charles University in Prague. Prior to joining UTOPIAN, she worked at University College London, Institute of Child Health as an Information Officer. She enjoys supporting primary care researchers in their endeavors during work hours and reading/ baking/ hiking after hours.

Name: Judy Katz

Project Role: Patient Family Advisor, member of RPP

Affiliation: University of Toronto Practice Based Research Network (UTOPIAN)



PERSONAL STATEMENT

I have lived through the decline of both of my parents. They made it abundantly clear how long and how much medical intervention they wanted, and at what point they wanted to cease treatments and just be comfortable. They had a strong belief in quality as opposed to quantity of life. Their example showed me how important it is for patients to convey their desires to their families and care givers. Any decisions that had to be made were taken out of our hands so that we were not conflicted, and my parents ultimately received the care they wanted. I feel strongly that it is important to find the best way for other patients to also follow this example.

Name: Kirsten Wentlandt, MD

**Project Role: Clinician Representative, member of RPP, member of XPBRN,
member of Training & SICP Adaptation Workgroup**

Affiliation: University of Toronto Practice Based Research Network (UTOPIAN)



PERSONAL STATEMENT

Kirsten Wentlandt graduated with her PhD in Physiology and Neurosciences before finishing her MD at Queen's University. She then returned to the University of Toronto to complete her residency in Family Medicine, fellowship in Palliative Care and a Masters in Health Sciences

(Health Administration). She joined UHN after graduating in 2011 as a Palliative Care physician and as the Medical Affairs Lead in Physician Leadership and Development. She currently divides her time between provision of clinical services, teaching, research development and in her administrative roles for UHN's Medical Affairs portfolio, Cancer Care Ontario and the Toronto Central LHIN's Palliative Care Council. Dr Wentlandt's research interests are varied, utilizing concepts and ideas that have come through her experiences in both her clinical and corporate teachings. Quality patient care, patient satisfaction, barriers to care, quality improvement targeting physicians and their leaders are all topics she has explored.

Iowa Research Network (IRENE)

Name: Jeanette Daly, RN, PhD

Project Role: Research Coordinator, member of RPP, member of XPBRN

Affiliation: Iowa Research Network (IRENE)



PERSONAL STATEMENT

Jeanette M. Daly, RN, PhD is an Associate Research Scientist in the Department of Family Medicine, University of Iowa. She is the Associate Director for the Iowa Research Network, a practice-based research network in which she has conducted research (diabetes management, colorectal cancer screening, management of Methicillin-resistant Staphylococcus aureus, and elder abuse) since its inception in 2001. She has been a co-investigator on funded grants working with colorectal cancer screening using five different manual fecal immunochemical tests (FIT) and one automated FIT.

Name: Megan Schmidt

Project Role: Research Assistant, Facilitator

Affiliation: Iowa Research Network (IRENE)



PERSONAL STATEMENT

Megan Schmidt is a Research Assistant in the Department of Family Medicine, University of Iowa. She holds a Master of Education degree from University of South Carolina and a Bachelor

of Arts degree in Elementary Education from Wartburg College. Prior to joining the team at University of Iowa, Megan worked as Program and Volunteer Coordinator in a local non-profit and she also taught in the United States, China, and Colombia. Megan's interest in the advanced care planning project is twofold. As an educator, she is interested in the training aspect of the project. In addition, her uncle was diagnosed with a glioblastoma in the spring of 2016, so end-of-life care has been an ongoing discussion among family members for the past few years. In her free time, she enjoys reading and traveling.

Name: Peter Kim

Project Role: Medical Student, member of RPP

Affiliation: Iowa Research Network (IRENE)



PERSONAL STATEMENT

Peter Kim, MPH, is a medical student at the University of Iowa Carver College of Medicine who recently joined the Iowa Research Network (IRENE) to work with Drs. Levy, Daly, and Berry-Stöelzle for a year. He plans to pursue family medicine for residency after graduation. His experience with the palliative care team and hospice during his family medicine rotation in Cedar Rapids, IA, led him to appreciate the importance of advance care planning in primary care.

State Networks of Colorado Ambulatory Practices & Partners (SNOCAP)

Wisconsin Research & Education Network (WREN)

Name: Amanda Hoffmann, MPH

Project Role: Research Coordinator, member of XPBRN

Affiliation: Wisconsin Research & Education Network (WREN)



PERSONAL STATEMENT

Amanda Hoffmann, MPH is a Regional Research Coordinator (RRC) with the Wisconsin Research and Education Network (WREN). As an RRC, she operationalizes and manages a variety of practice-based and translational research projects in diverse primary care settings throughout Wisconsin. Additionally, she facilitates primary care clinics in evaluating and improving their quality of care. She holds a Master of Public Health degree with a concentration in Community Health Sciences from the University of Illinois-Chicago and a Bachelor of Science degree in Biological Sciences from Marquette University in Milwaukee, WI. Some of her research interests include: community health, community capacity building/community engagement, and health promotion/disease prevention.

Name: Deb Constien

Project Role: Patient Family Advisor, member of RPP, member of Training & SICP Adaptation Workgroup

Affiliation: Wisconsin Research & Education Network (WREN)



PERSONAL STATEMENT

Deb Constien lives in Sun Prairie with her husband of 24 years and 18 year old son Jacob. Deb was diagnosed with Rheumatoid Arthritis at the young age of 13. She graduated from Mount Mary College in 1993 with a double major in Dietetics and Biology. Deb serves as the Board Chair in Madison Wisconsin, for the Arthritis Foundation and Advocacy Chair for the Madison Leadership Board. Also for the Arthritis Foundation, Deb serves on the National Walk Committee, Platinum Ambassador Taskforce, National Advocacy Committee and started the Wisconsin Advocacy Committee. She leads an Arthritis Support Network in the Madison area. She also is on the Patient Council for the Global Healthy Living Foundation, Patient Partners in Research for GHLF, and a Representative for IFAA- International Foundation of AutoImmune AutoInflammatory Arthritis. She is a member of the Leadership Board Committee for WREN- Wisconsin Research and Education Network.

Duke, Primary Care Research Consortium (PCRC)

Name: Jared Lowe

Project Role: Investigator, Medical Student, Resident, member of RPP, member of Training & SICP Adaptation Workgroup

Affiliation: Duke, Primary Care Research Consortium (PCRC)



PERSONAL STATEMENT

I am currently an internal medicine resident at Duke University Hospital and will complete my Palliative Medicine fellowship at Duke in the 2018-2019 academic year. After that, I will serve as the Duke Hospital Chief Resident from 2019-2020. My related work includes implementing a course for medical residents on communication skills for advance care planning (ACP), as well as managing a primary-care based pilot of ACP delivery that leverages a predictive tool to identify patients likely to benefit, appointments with designated Patient Navigators, and integration with the electronic health record. I am interested in developing population health-based approaches to improve the integration of palliative care across the spectrum of care.

At-Large Representatives

Name: Ghislaine Rouly

Project Role: Patient Family Advisor – Canada At-Large, member of RPP

Affiliation: Quebec Practice-Based Research Network (QPBRN)



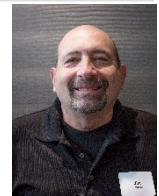
PERSONAL STATEMENT

Ghislaine Rouly is the President of Friends of the Patient at the University of Montreal's Hospital Center (CHUM) and a patient partner with the Center of Excellence on Partnership with Patients and the Public (CEPPP). Besides also sitting on two committees for the Medical Aid in Dying, she cares for a loved one with a serious illness and holds further expertise in palliative care.

Name: James (Jim) Pantelas

Project Role: Patient Family Advisor - USA At-Large, member of RPP, member of XPBRN Workgroup

Affiliation: PCORI, Congressionally Directed Medical Research Program, and Michigan Institute for Clinical & Health Research



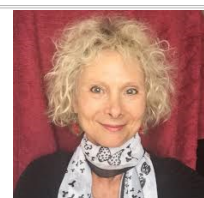
PERSONAL STATEMENT

I am a 12 year, late stage lung cancer survivor, the father of three young daughters (ages 8, 9 and 12), and a veteran. Prior to my diagnosis I was the owner of an information technology consulting and staffing firm. Since that diagnosis I have become active in a variety of roles in research and healthcare settings. I am also involved in peer review for PCORI (on multiple boards), CDMRP (Congressionally Directed Medical Research Program) Lung Cancer Research Program, and for MICH-R (Michigan Institute for Clinical & Health Research). I am a member of the leadership panel for Free to Breathe, a non-profit lung cancer support and research organization, and represent the patient perspective in their research funding efforts. The issues that drive me are ones associated with my personal experiences as a lung cancer survivor, and as the father of a 12-year-old with significant disabilities resultant from a severe brain bleed at the age of 21 days. My own diagnosis led to an early and very much unplanned retirement, so most of my last 12 years have been spent in patient and research advocacy roles. As someone who has lived with a life-threatening disease for the past 12 years, I have faced the issues associated with advance planning and directives, as well as with the ever-evolving nature of these directives as the disease progresses. I have experienced the conversations that are required firsthand, and, because of my ongoing involvement as a patient advocate in the lung cancer world.

Name: Kathy Kastner

Project Role: Patient Family Advisor – Canada At-Large, member of RPP, member of Training & SICP Adaptation Workgroup

Affiliation: University of Toronto Practice Based Research Network (UTOPIAN)



PERSONAL STATEMENT

The communication spectrum is my passion, specifically as relates to health with a focus on end of life. By spectrum, I mean verbal/nonverbal; tone and delivery; listening and hearing; context and confidence; one-on-one and within one's community. I have been immersed in identifying gaps in patient-facing health communication from the time I was in a pre-natal class and was overwhelmed by jargon and assumptions (that 'we expectant parents' had sufficient basic knowledge). This led to developing television networks for patient education, broadcasting in hospitals across North America including, in the U.S., Johns Hopkins, NY Presbyterian, UCLA, and several VA's. Alas, not in Oregon. This wound down around the time my father-in-law was diagnosed with CHF, and my attention turned to his 'winding down' advance care planning trajectory. When I realized how little I knew about what to expect, towards meaningful planning, I set about learning - finding my End of Life 101 first via palliative and hospice health care professionals on social media who welcomed me as a 'knowledge translator'. This expanded to include attending and tweeting from conferences, meeting and learning 'in real life' conversations, and being provided to links to resources and end of life blogs. What I learned (and continue to learn) prompted blogging that became BestEndings.com. As for my father-in-law, he is 97, with all his wits about him while his body is failing. I have collaborated with WestPark Health Center (Complex Continuing Care) on the Palliative and Supportive Care Steering Committee, the Toronto International Summit on Leadership Education for Physicians as part of the group exploring 'Emotional Intelligence', serving as a public member for the College of Occupational Therapists of Ontario, Women's College Hospital Partnership, and finally as a PCORI patient ambassador.

Institute for Patient- and Family-Centered Care (IPFCC)

Name: Deborah Dokken

Project Role: Patient Family Representative/Engagement Consultant, member of RPP, member of Engagement Group, member of Training & SICP Adaptation Workgroup

Affiliation: Institute for Patient- and Family-Centered Care (IPFCC)



PERSONAL STATEMENT

Deborah's involvement in health care grew out of personal experiences – the loss of two infants due to prematurity, her husband's long battle with a rare abdominal cancer, and the care of elderly parents. She is now on the staff of the Institute for Patient- and Family-Centered Care (IPFCC). Previously, she was a co-investigator and the Associate Director of the Initiative for Pediatric Palliative Care (IPPC), a national project focused on improving care for children with life-threatening conditions and their families. Deborah has been a member of committees of the IOM, the FDA, and NIH and has also served on a hospital PFAC and a pediatric ethics committee. She is the author of several articles related to family-centered health care and is co-editor of Pediatric Nursing journal's "Family Matters" section. Since downsizing from her home

of 20+ years, Deborah enjoys urban, apartment living and exploring good food and wine!

Name: Mary Minniti, BS, CPHQ

Project Role: Patient Family Engagement Consultant, member of RPP, member of Engagement Group, member of NPFN Partner Group

Affiliation: Institute for Patient- and Family-Centered Care (IPFCC)



PERSONAL STATEMENT

Mary Minniti, CPHQ, is the Senior Policy and Program Specialist at the Institute for Patient- and Family-Centered Care (IPFCC). For the Advance Care Planning Research Project, she will guide and support robust patient and family engagement. Over the past 20 years, she has found meaningful ways to transform the health care experience in partnership with patient and family advisors and clinical improvement teams. She served as the Quality Director for a multi-specialty practice and supported transformational changes including piloting new care models including patient-centered medical home implementations and community wide collaboration to improve chronic care management. Mary served as a principal investigator for an AHRQ funded study entitled *Medication Management at Home: Patient-Identified Processes and Risks*. Patient and family advisors served as consultants to the project from conception to dissemination. Her passion is bringing patients and family members into conversations about health care transformation because of the positive and powerful impact it creates for all involved. Mary is a proud grandmother, an avid gardener, and dog lover.

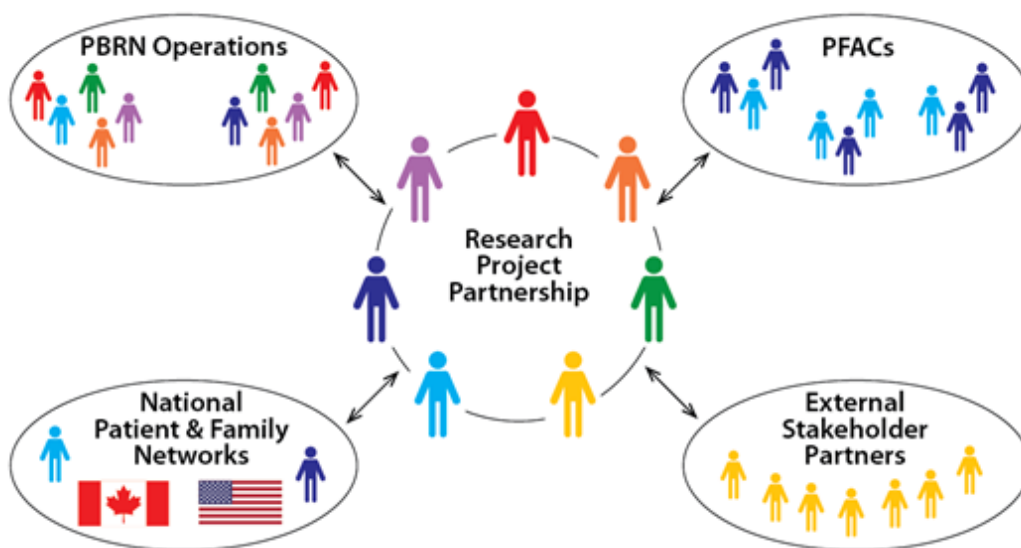
4. Engagement Structure

Overview

The interactions of the different partners and the Research Project Partnership (RPP) form the foundation for our engagement plan. The RPP fulfills the role of the study advisory committee. It is the hub of a five-component patient, family, and partner engagement structure. These five components are: 1) Research Project Partnership (RPP), accountable for all major study decisions; 2) PBRN Operations Groups are established by each of the seven Practice Based Research Networks (PBRNs) to facilitate and monitor PBRN-and practice-level activities, 3) patient family advisory councils (PFAC) from participating clinics that represent patients and families at the primary care practices, 4) national patient and family networks (NPFN) selected to connect the study to the larger perspective of patients beyond the study and 5) external stakeholder partners (ESP) including key organizations and individuals with expertise in ACP and related issues. These groups and their inter-relationships are represented in Figure 1 (page 16). The hub and spoke representation, with the RPP as the hub, represents the responsibility the RPP has to solicit, consider, and integrate the input and expertise from all partners. It is not

meant to imply that the groups may not interact directly or that there won't be other communication patterns. For example, the PFACs may have more frequent interactions with their PBRN than with the RPP directly, though we will create opportunities for PFACs to communicate directly with the RPP. This structure draws on the expertise and experience of the study team documented in the proposal and of the partners profiled in Section 3 of this Plan. Essential to the engagement are the meetings and activities described in Section 5.

Figure 1. Patient, Family and Partner Engagement Structure and Partnerships*



**Figures represent types of participants, not the number of members.
Color Key: dark blue=patients; light blue=families; orange=primary care clinicians; green and purple=primary care staff and administrators; yellow=external stakeholders; red=researchers (Investigators and staff)*

Key Components of our Engagement Structure

As the RPP is the foundation for engagement and the overall project, we are holding quarterly meetings of the RPP to assure that all the organizations meet and communicate in real time, with meetings occurring in person when feasible (2-3 times during the project) and via web other times. When in-person meetings are not possible, the Coordinating Centers will facilitate attendance by some team members at rotating PBRN locations (i.e., 2 team members attended the May 2018 RPP from IRENE in Iowa). Led by the co-PIs, these meetings are important to maintain project momentum, to communicate significant details about the project, to receive guidance on study progress, and to understand successes and challenges to the study. Between meetings, written updates will be sent to the RPP monthly. Additionally, we offer monthly Office Hours and other synchronous and asynchronous mechanisms so that interaction can occur between and among stakeholders. We want options that provided flexibility for participation and seeking input without creating an undue burden on partners. The initial



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structure will be modified as needed with input from the RPP to ensure that meaningful and timely engagement occurs across and throughout the difference project phases.

Both of the project PIs have significant engagement experience with different communities; the US PI (Annette) has worked with various partners including government agencies, professional organizations and providers; the Canadian PI (France) has extensive experience working with practices and with patient involvement including working with the Quebec Strategy for Patient-Oriented Research (SPOR) Network. Additionally, we have engaged The Institute for Patient- and Family-Centered Care (IPFCC) to consult on engagement, with a focus on developing the skills of the project team, including the PIs, CO-PIs, staff, PBRNs and participating practices. In order to efficiently divide tasks and make any decisions necessary between meetings we have established workgroups. There are three standing workgroups: Executive Committee, Cross-PBRN (XPBRN), and Engagement. These will meet for the entire length of the project. Ad hoc groups will have shorter timelines and be created to match the task associated with different phases. For example, initial ad hoc groups have been formed to create the ACP training, write the engagement plan, and identify approaches practices can use to identify patients appropriate for ACP. A data collection group will be formed soon, and later in the project groups may focus on other topics such as implementation challenges or dissemination. Each group will contain a varying mix of members, including partner representation. Additionally, each group will be supported by a staff member from the Joint Coordinating Center. These staff members have experience as practice facilitators and as PBRN managers and coordinators.

Key to the engagement structure is the consultative role of the IPFCC. IPFCC is facilitating the project team's ongoing development so the Coordinating Center team can implement and evaluate the patient and partner engagement plan. Specifically, IPFCC is providing coaching for the research team on effective engagement, and supporting outreach to national patient and family advisory groups. In the early phase of the project, IPFCC has assisted with recruitment of patient/ family partners to the RPP and PBRN Operations Groups and with recruiting two at large patient/family partners to the join the RPP (patient/family representatives not associated with a particular PBRN) through their extensive network. As an evaluation consultant, IPFCC will inform ongoing assessment designed to ensure engagement is authentic and meaningful to participants. The evaluation will be based on methods developed with funding from PCORI Engagement Award Initiative (IPFCC-1467). More information on the suite of tools can be found at <http://www.ipfcc.org/bestpractices/sustainable-partnerships/index.html>. IPFCC will advise on how to assess the PBRNs and provide support to ensure the partnerships with PFAs is meaningful and that both researchers and PFAs are provided the orientation and ongoing support to ensure successful integration of the voice of patients and families in all aspects of the research study.

5. Proposed Meeting and Key Activity Timeline

Table 4 provides the project meeting schedule, the frequency of meetings, the purpose of the group, and individuals who participate in each meeting. To orient to the meetings, we have provided a listed overview of this schedule.

Overview of Schedule

- Research Project Partnership (RPP) Meeting: First Monday of February, May, August, and November
- RPP Newsletter: First Tuesday of each month
- Office Hours: Friday following the first Tuesday of each month (may be replaced or augmented with other communication activities)
- Cross Practice-based Research Network Workgroup (XPBRN): First Monday of each month
- Executive Committee: Third Friday of the month (synchronous); other weeks update and discussion via (asynchronous) or subgroups
- Engagement Group: Second Monday of each month
- Primary Care Practice Patient and Family Advisory Council (PFAC): Monthly in years 2-4
- National Patient & Family Networks (NPFN): Twice a year
- External Stakeholder Partners (ESP): Twice a year

Table 4. Meta-LARC ACP Meeting schedule

Meeting/Activity	Frequency and Length	Setting/Method	Purpose	Attendees
Research Project Partnership (RPP) Meeting	2-hour quarterly entire project with up to annual in-person meeting (planned for year 1 and year 4 only)	Quarterly meetings on Zoom web conference platform; up to annual meetings in person to correspond with North American Primary Care Research Group annual fall meeting	Overall project guidance, including reviewing and approving protocols, consent forms, SICP materials, surveys, recruitment materials, outcomes, clinic workflow designs, data collection and analysis.	Totten, Légaré, Fagnan, Dorr, Izumi, Lapidus, Ramsey, Michaels, Combe, Howk, Murphy, Lowe, Archambault, Paquette, Guay-Belanger, Sanon, Dolor, Chmielewski, Kim, Lowe, Burch, Levy, Berry-Stöelzle, Daly, Petrova, Provin, Drey-Provin, Simpson, Fisher, Dailey, Greiver, Wentlandt, Pribramska, Straus, Siddiqui, Katz, Hahn, Sampson, Dharam, Constien, Rich, Alikhaani, Pantelas, Kastner, Rouly, Minniti, Dokken

Meeting/Activity	Frequency and Length	Setting/Method	Purpose	Attendees
RPP Newsletter	Circulated Tuesday prior to the first Friday of each month	E-mail attachment of newsletter to RPP members	Provide quick snapshot into project activities to inform project team, to identify areas to provide input, and to cue up conversation for Office Hours	All RPP members
Office Hours	1-hour meeting on first Friday of each month	Zoom web conference platform; unstructured meeting with no set agenda but monthly theme; ongoing Q&A curated	Opportunity to speak with the principal investigator, project manager and project team members to pose questions or offer input related to any aspect of the project	Staffed by Totten and Michaels, available for all RPP members
Standing Work Groups				
Cross Practice-based Research Network Workgroup (XPBRN)	Monthly during project lifetime	Zoom web conference platform	Set site eligibility criteria and plan for site recruitment; establish workflows for patient identification and documentation, patient recruitment; train practice facilitators; create Engagement Plan and Recruitment Plan	Fagnan, Dorr, Michaels, Murphy, Combe, Howk, Guay-Belanger, Paquette, Simpson, Fisher, Berry-Stöelzle, Wentlandt, Pribramska, Siddiqui, Dolor, Chmielewski, Kim, Hahn, Dharam, Sanon, Pantelas
Executive Committee/co-Investigators	Monthly synchronous; asynchronous off weeks	Zoom web conference platform	Ongoing oversight between RPP meetings	Totten, Fagnan, Dorr, Izumi, Ramsey, Michaels, Légaré, Guay-Belanger, Straus
Engagement Group	Monthly via Web; asynchronous work	Zoom web conference platform; email and shared documents	Review engagement activities, identify and address problems, conduct engagement	Totten, Minniti, Combe, Michaels, Dokken
Ad Hoc Work Groups				
Training and SICP Adaptation Workgroup (SICP)	Weekly to monthly during first 9 months of the project	Zoom web conference platform	Distinguish differences between study arms, adapt SICP materials for arms, create training materials and sample workflows	Izumi, Légaré, Archambault, Guay-Belanger, Pribramska, Lowe, Dokken, Burch, Constien, Kastner
Measurement	Bi-monthly from month 6-12	Zoom web conference platform	Define measurement for primary and secondary outcomes, select measurement tools, pilot test survey and	Totten, Dorr, Michaels, Greiver, Pribramska, Kim, Straus

Meeting/Activity	Frequency and Length	Setting/Method	Purpose	Attendees
			data collection instruments	
Partner Groups				
Primary Care Practice Patient and Family Advisory Councils (PFACs)	Up to monthly during clinic involvement, project years 2-4	Variable per participating practice, but primarily in-person meetings at clinic	Ensure patients and families are aware of participation and provide venue to pose questions, voice concerns, contribute to implementation planning at individual clinic, and learn about study progress.	Pending practice recruitment, but coordinated by: Combe, Fisher, Dharam, Siddiqui, Berry-Stöelzle, Chmielewski, Guay-Belanger
National Patient & Family Networks (NPFN)	Twice a year	Zoom web conference platform	Advise RPP on how to obtain input and share study progress and results to broad audience.	Totten, Minniti, Dokken, Boivin, , Srinivasan
External Stakeholder Partners (ESP)	Twice a year	Zoom web conference platform	Advise RPP on current practice advancements, policy issues and dissemination.	Totten, Straus, Tamblyn, Dillon, Bierman, Ganiats, Lesch, Block

6. Partner Preparation

Key to successful engagement is assuring that partners understand their role, the scope of their involvement and the range of engagement opportunities available. Equally important is that partners have the information and skills needed to engage and make meaningful contributions to the project.

Below we outline our approach to the preparation and ongoing support of our project partners.

Patient and Family Advisors (for the overall project) and Patient and Family Advisory Councils (for participating practices)

Preparation for the all partners, especially PFAs, is critically important. In order to fully participate, each individual needs to be oriented to the project, its scope and most importantly, how their feedback and input will guide and inform the research work. Engagement is complex in a large, multi-site project and it is easy to become overwhelmed. To avoid this, a number of initial methods were created to orient the partners to the project.



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Initial Orientation

Our initial orientation included an outreach email was sent welcoming them to the project and a face-to-face PFA orientation on November 19, 2017 in Montreal, before the first full RPP meeting. The Co-PIs, IPFCC staff, and key Meta-LARC staff were in attendance. Introductions, roles of PFAs, and the PCORI Engagement model were shared. The Co-PIs presented information about the study, solicited comments, and responded to questions. The PFAs identified their strengths and ways they hoped to have an impact on this research study. The PFAs also had the opportunity to interact and get to know one another prior to the full RPP meeting that afternoon.

The RPP meeting provided a general orientation to the project and introductions to the rest of team, and time for small groups to provide input on key areas: goal concordant care, clinic eligibility, and patient exclusion/inclusion criteria.

Information sharing and follow-up as of 5/31/18

Both the PCORI Engagement Model and the Phases of Research were reviewed and discussed during Montreal Orientation. A survey was sent to PFAs in early January 2018 and individual interviews were conducted to follow-up. This assessment served as a way to identify strengths and ongoing support needs for PFAs. The survey quantified the experience and training that each PFA had prior to this participation as well as any gaps in their knowledge about research in general and this study in particular. As new PFAs have joined the project, a welcome email has been sent out with a brief overview of the study, a request for biographical information and a link to the assessment survey.

Both PBRNs and PFAs have been referred to selected tools on the [IPFCC website](#) about engaging patients in research. The website and its content were funded by PCORI to support researchers in their efforts to partner more effectively with PFAs. Early in the formation of the RPP and onboarding of PFAs, we provided tools such as a description of the study, PFA frequently asked questions, commonly used acronyms, minutes and handouts from the Montreal meeting in November. Additionally all PFAs receive minutes and materials from each RPP meeting(s), a roster of RPP members containing contact information and biographies, a monthly project newsletter, and a calendar of important and upcoming meetings (e.g., Office Hours, quarterly RPP meetings, etc.) and project milestones.

Access to Study Staff

We have provided and plan to continue to use a variety of ways to invite participation and facilitate interactions among PFAs and the research team:

- An Engagement Team was introduced at the Montreal meeting that is comprised of Angela Combe, OHSU, and Mary Minniti and Deborah Dokken, IPFCC. PFAs are encouraged to contact any member of the team if they have questions or concerns.
-

- A monthly newsletter is sent out via email. It outlines opportunities for feedback and the status of key milestones in the project.
- Monthly Office Hours are held as follow-up to this communication. This time is available for partners to raise any questions, concerns or provide input on work underway.
- Alternative communication modes (e.g., blogs, bulletin boards) will be explored as potential ways for information exchange and engagement between RPP meetings.

Ongoing support and connection between PFAs and key engagement staff

PFAs have identified that regular contact between meetings, which provides for synchronous and asynchronous ways to be connected to other PFAs and key opportunities for early input, is valued. To address this need, the following mechanisms will be created:

- A secure on-line PFA workspace where documents, discussions, and resources can be stored. We are currently using Box and exploring other platforms (e.g. a project website)
- Updating the monthly newsletter format to clearly lay out what's coming up next for PFAs. It will describe how input will be solicited and how the input will influence the project direction and outcomes. At least once a quarter the newsletter will include a "Research Tip" for PFAs and highlight at least one PFA story.
- Targeted and integrated emails directly to PFAs for soliciting specific feedback on with timeframes and contact person for questions.
- Hosted calls for PFAs to meet other PFAs at all levels of the study to share experiences, questions and best practices.
- Connecting new PFAs with experienced PFAs to creating a "Learning Buddy" system.
- Periodic PFA evaluation of newly implemented processes to refine and improve their connections and meaningful participation in the research study.

Future plans for ongoing support

Our intention is to continue to monitor engagement and adapt our preparation and support as both the project enters different phases as individual needs change. At the six-month mark we surveyed PFAs and we will continue our practice of checking in with PFAs before quarterly RPP meetings and surveying them after quarterly RPP meetings. Our first six months have highlighted both successes and areas for improvement.

Specific areas for improvement

- **Timing of participation.** Some PFAs want to participate early in the process before documents are created or review multiple drafts. There are times when this will and will not be feasible and the expectations, opportunities and limitations need to be communicated more effectively.
- **Closing the loop.** PFAs want to know what that their input was considered and how it was used. This has not always been clear and we are working to develop better ways to track input and communicate this to the group.

- **Ways to maintain a connection between quarterly RPP meetings.** The space of three months between engagements and conversations is too long. Opportunities for interaction and learning among the PFAs is desired and could provide a way for PFAs assigned to workgroups to gather input/ideas from their peers. There is strong interest in a PFA “virtual” work space where questions can be raised and interactions can occur at different times (asynchronous) to respect the other demands on individual’s times, or documents and calls targeted to PFA, or pairing PFAs up in a ‘learning buddy’ system.
- **Involvement in workgroups.** Initial experiences of PFA participation in workgroups have been mixed. To improve workgroup performance, we will clarify roles and specify how PFA input can be obtained when work must be done outside of meetings. Efforts will be made to align expectations and provide basic information on each workgroup to help prepare PFAs. Each workgroup will follow a standard approach which includes providing the following written information to share as part of an orientation for PFAs to include:
 - Purpose of group
 - Timeline
 - Deliverable(s)

Preparing Clinic PFACs

- PBRNs will have the lead responsibility to support PFACs in their local area and ensure they are adequately oriented to the project and engaged meaningfully in influencing the research study at the local level.
- Meta-LARC will provide support and coaching to the PBRNs and clinics to promote the integration of patient and family voice occurs in the seven regions of the project. This could include development of materials and agendas for use with the PFACs, with input locally from each PBRN Operations Group. Virtual training or interaction may be considered (e.g. webinar) to help energize the local PFACs participation in the project.
- Input will be solicited from clinics to determine what support would be most useful to them in working with their PFACs on the research project. Materials and coaching will be provided as needed.

Other Stakeholders

In addition to PFAs and PFACs, there are other important stakeholders including the PBRNs, practices and external stakeholders. PBRN leadership has been included in the RPP from the beginning and primary care practices will be incorporated into project activities as identified. Representatives from selected national patient and family organization as well as professional organizations, government agencies, and research/primary care funding organizations will be recruited as external stakeholders and incorporated into the project during the second six months of the project. The purpose of these stakeholders is to consider the broader environment in which the project is situated as it pertains to dissemination and spread of ACP in general and the SICIP specifically.



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PBRN Orientation and Preparation

- PBRN leads participated in a webinar on involving PFAs in research.
- An assessment of PBRN strengths and opportunities for growth in the area of PFA engagement will occur through a survey and follow-up interviews with the seven lead PFA Coordinators from each PBRN.
- PBRNs will share learning, challenges and tips with each other related to their engagement efforts during XPBRN monthly meetings. Sharing of resources will be encouraged to promote effective engagement practices across sites.
- Each PBRN will be encouraged to have diverse representation on their Operations Group teams (e.g., geographic, ethnic, gender, etc.)
- Individual coaching/problem solving will be offered to PBRNs and clinics that are experiencing challenges or have achieved limited patient/family engagement.

National Patient and Family Organizations and other External Stakeholders Orientation and Preparation

- A webinar/remote meeting will be held with these stakeholders to orient them to the project and answer any questions. This will be scheduled in the second half of year 1. PFA representatives from the RPP will help develop the content.
- Input will be solicited from these stakeholders about how they would like to receive updates about the project.
- Stakeholders will be invited to a limited number of RPP or subgroup meetings as appropriate.
- Stakeholders will be invited to any presentations or discussions at professional meetings arranged by the project. If a broader input from specific stakeholders is needed (e.g. PFAs), members of these stakeholder groups will be asked to assist in distribution of surveys or outreach emails to their membership.

7. Recruitment and Retention

Practice recruitment

As each PBRN seeks to recruit practices, flyers and materials will be developed. Our diverse partner panel, including PFAs and community clinicians, will provide input on the design and dissemination of these practice recruitment materials. ACP is an important, but difficult, topic to address in primary care practices, and partner involvement will help to ensure that recruitment materials for practices resonate with clinicians and administrators in real-world primary care practices.

Recruitment of practices by each PBRN will be monitored at the monthly Cross-PBRN Workgroup (XPBRN). This group is organized by the Coordinating Center and consists of PBRN



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directors, coordinators, site PIs as well as members of the RPP. If a particular PBRN is having difficulty with practice recruitment, additional support will be provided through the RPP, which includes PFAs and other partners.

Practice retention

Each PBRN Operations Group will assess and monitor local implementation of projects, and will identify issues to be shared with through the XPBRN meetings. In addition, each PBRN Operations Group will be encouraged to interface with local PFACs to maintain interest and engagement for individual practices to increase project retention.

Patient/participant recruitment and retention

In our cluster randomized study, participating primary care practices from each of the seven Meta-LARC PBRNs will provide ACP services to their patient panel. Practice team members and clinicians will be tasked with identifying appropriate patients and initiating conversations about the patient's values, preferences, goals, and expectations of health care. ACP conversations include potentially sensitive topics that will be discussed with individuals during times of serious illness. Input from patients and partners having lived experiences with serious illnesses will be crucial to the success of both the implementation of ACP and recruiting a subset of patients to enroll in the research study for one year.

To that end PFAs will provide input on patient- and care partner-facing ACP and study recruitment materials. PFA involvement will inform the conversations and dialogues that clinicians and primary care practice team members will have with eligible patients related to the research aspects of the project. Lastly, PFA input will inform the timing and structure of data collection by the research team as they work with enrolled patients. As many of the enrolled patients may experience worsening of their serious illness or death, we will rely heavily upon PFA input to ensure that our research team is approaching these patients and their family members with respect and dignity.

As enrolled practices seek to achieve recruitment targets for this study, we will monitor their ongoing progress and provide support to practices aiming to recruit patients. This will be monitored by individual PBRNs as part of their ongoing PBRN Operations Group meetings. Each PBRN Operations Group is joined by a PFA and at-large clinician, as those individuals exist within the PBRN and identified in Section 3. Those groups will seek to address local recruitment issues, and will identify themes to be shared and discussed with the XPBRN Workgroup. If practices need additional help and support, we will work with PFAs to assist practices with recruitment efforts. Furthermore, each PBRN, in working with practices for participant recruitment, will work with the PFACs of enrolled practices (when available) in order to support local project recruitment and retention.

8. Process and Outcomes Monitoring/Continuous Quality Improvement (CQI)

Our approach to process and outcomes monitoring is an extension of our approach to preparation and support described in Section 6 and it designed to support the purpose and goals listed in Section 2. We intend to continue to solicit feedback using quarterly post RPP meeting experience surveys of the PFAs and research team. These will vary in length and will be longer during the third quarter of every year to allow for additional questions. Quarterly surveys will be supplemented by annual feedback call sessions with PFAs. Additionally, IPFCC will continue to serve in an ombudsman role, providing a way for any team member to provide anonymous feedback.

Ongoing engagement capacity development and improvement will be facilitated using a systematic and formal approach to CQI. We will select and test changes using a variety of approaches and tools to create action plans. To formalize CQI, plans to monitor change will be tied to measures (either survey questions or process/activities measures described below) and these will be reviewed to evaluate and learn the effectiveness of the approach and capacity building to improvement.

Measuring engagement in research is a comparatively new endeavor, but there are an increasing number of resources available that provide both theoretical frameworks and practical guidance.¹⁻⁶ We plan to repeat items we used during the first six months of the project, augmenting these with measures of engagement being developed by others and tested across different types of engagement activities.

Examples of the questions we have used to date in phone and email follow-ups are included at the end of this section. Going forward, we plan to expand these with questions and/or tools other researchers and projects are using, refining as they become available. Two specific examples recently identified and that we plan to incorporate into our future work are: 1) The Patient Engagement Evaluation Tool (PEET).⁷ This tool has been used to evaluate engagement in guideline development and systematic reviews. It is built on a framework⁸ that defines effective engagement in terms of six domains (respect, trust, legitimacy, fairness, competence, and accountability) and 2) items developed by Goodman *et al.*⁸ designed to align with 11 engagement principles for comparative effectiveness research. These principles categorize activities such as “seek and use the input of community partners” and “facilitate collaborative, equitable partnerships.”

Table 5. Correspondence of Measures of Engagement and Goals

Measures of engagement	Overall	Goal 1	Goal 2	Goal 3	Goal 4
Number of PFAs that participated in the research project; number of hours involved	X				
Retention of PFAs in the project, reasons for leaving	X				
Survey items that asks for feedback on if the experience of participating in the various teams/meetings was meaningful, whether they felt valued, what contribution they felt they made		X			
Survey items about how closely the participation matched the PFAs original goals in participating	X				
List of specific activities that invited PFAs participation		X	X	X	
Number of PFAs who actually joined the activity		X	X	X	
Number of times the activity was held					
Documentation and description of ideas generated by Patient Family Advisors (PFA) and other partners		X		X	X
Summary of comments received on protocols, measures, and standard operating procedures			X	X	
Number and description of PFA-generated ideas that resulted in changes to the research topic, questions, plan, implementation, or dissemination activities		X	X	X	X
Whether the research process was positively affected by the partnership	X				
How many clinics had PFACs and how they involved them in the research study implementation					X
Documentation of new PFACs that were created as part of this research project					X
Find documentation in subject's medical record that advance care planning has been initiated					X
Find documentation that the subject's insurance has been billed for advance care planning conversations					X
Description of the PBRN mechanisms for patient/family engagement				X	

In addition to asking partners to report on their experiences, we will be documenting and describing processes and activities as part of our ongoing monitoring. Table 5 (page 33) expands on the Section 2 overarching goals and displays how the corresponding process measures align with engagement and goals.

This combination of regular surveys of partners and monitoring, with a focus on CQI, will help us create the capacity for effective engagement in this project. We will share with our partners and others our engagement evaluation outcomes to inform future work, create opportunities, and contribute overall to the field of engagement.

Examples of Engagement Evaluation questions: Questions used in assessments to date

PFAs have been asked to rate the extent to which they agree with questions:

- I felt prepared to partner with the researchers
- I felt supported by the researchers to speak up



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- The researchers listened to and took my perspective and ideas seriously
- I felt that my contributions were valued by the researchers
- The researchers were willing to make changes based on my input
- I believe the research project was improved because of my participation
- I felt that I participated in this project to the best of my ability
- I would partner with researchers in the future

In the last RPP meeting, I felt I was:

- Fully engaged in the discussion
- Able to share my perspectives with the group
- Respected by other group members
- Respected by the facilitators
- Contributing to a worthwhile endeavor
- What worked well at the last RPP meeting?
- What would you change for our next RPP meeting?

Researchers similarly have been asked the extent to which they agree the following statements reflect their experience:

- I felt prepared to partner with PFAs/PFAC
- I was able to elicit the perspective and input of the PFAs/PFAC
- I made changes based on the information I received from PFAs/PFAC
- The project was improved because of the partnership
- I would partner with PFAs and PFACs in the future

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