Patient Priorities Care Research Agenda: Results of Multi-stakeholder Engagement

A White Paper

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March, 2018

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EXECUTIVE SUMMARY

Older adults with multiple conditions and complex health status often receive care that is fragmented, burdensome, of unclear benefit, and not always focused on what matters most to them. This fragmented, uncertain care can be frustrating for patients and caregivers, clinicians, health systems and payers, and there is general consensus that a new approach is needed. We propose a move to an approach in which primary and specialty healthcare is aligned based on patient goals and care preferences.[1-3]

Patient Priorities Care is patient health outcome goal and preference directed care for older adults with multiple chronic conditions (MCC) achieved through primary/specialty care alignment.[1-3] The Patient Priorities Care approach is designed to be imbedded in care delivery systems that have the needed infrastructure, relationships, and incentives such as Patient Centered Medical Homes (PCMHs), specialty neighborhoods, Accountable Care Organizations (ACOs), and integrated healthcare systems.

Problems Patient Priorities Care addresses:
Patient Priorities Care is designed to address many problems related to the healthcare that older adults with MCC receive. For example, older adults with MCC:

- **Vary in their health outcome priorities and care preferences.**[4,5] Individual disease guideline driven care often is not consistent with patients' outcome goals or care preferences.[6]
- **Receive numerous treatments that are of uncertain benefit, and potential harm**. Twenty percent of older adults receive guideline recommended medication that adversely affects coexisting condition.[7]
- **Receive care from providers that is disease-siloed, burdensome and fragmented.** Patients' multiple providers each focus on their own set of diseases and disease-specific outcomes, following evidence-based guidelines that may not apply to older adults with multiple, complex health conditions because the evidence that informed the guidelines was obtained in younger people or people with fewer diseases. Researchers defining and measuring the work required of patients and caregivers find that the patient workload can be as burdensome as the conditions themselves.[8-11] There is an increasing demand for a simpler, less burdensome and fragmented approach to the care of persons with MCC.[6,8,12-14]
- **See multiple providers, who themselves are unclear about who is accountable for a patient's care.** For example, in large integrated health care system, patients with Diabetes Mellitus co-managed in primary care and diabetes clinics had poorer blood pressure control than those managed in either clinic alone (more ≠ better).[15] Primary care providers, specialists, and patients often do not share understanding of each clinicians' roles and responsibilities which are usually not made explicit.[16]

Patient Priorities Care as a solution to the problem:
We propose that the best way to address the disconnect between what patients want from their healthcare and what they receive is for primary and specialty clinicians to align their care around achieving each patient's health priorities, defined as their health outcome goals within the context of their acceptable care preferences and burden. This approach will decrease both fragmentation and the receipt of unwanted care that is of unclear benefit.[1-3]

Methods Used to Develop Patient Priorities Care:
Patient Priorities Care was developed through a planning process that involved over 100 stakeholders, including patients, caregivers, clinicians, policymakers, researchers, payers, and healthcare system representatives over an 18 month period.[3] A major in-person "kick-off" meeting during the first four months of the planning phase resulted in six major areas to consider as a Patient Priorities Care archetype developed: patients' goals should drive care; clinicians must clarify their roles and responsibilities; health information technology is needed to support goals directed care; an interdisciplinary team must be part of this type of care; there must be appropriated quality metrics; a business plan is needed.[3]

Subsequently, three advisory groups (a patient-caregiver group; a primary and specialty clinician group; and a healthcare systems group) met by webinar twice a month for four months to develop major themes for Patient Priorities

Care. As planning proceeded, workgroups were formed from the advisory groups' members to "build –out" key components of the Patient Priorities Care model: a patient/caregiver engagement group, a goals elicitation group, and a primary/specialty care alignment group. We also solicited advice from experts regarding HIT, quality metrics, and business plan development, and had three smaller in person meetings to further explicate patient goals elicitation, primary and specialty communication, and workflow development. At the end of our planning process, patients, caregivers and clinicians who had not previously been involved in planning Patient Priorities Care provided feedback and advice for future implementation and dissemination.[3]

Results of the Patient Priorities Care Planning Process:
Patient Priorities Care is a care approach designed for older adults with multiple chronic conditions (MCC) who are the major users of health care. In the Patient Priorities Care approach, health outcome goals and care preferences are elicited from patients and caregivers by trained facilitators and transmitted through health IT (HIT) and other potential mechanisms to all the patients' providers, and to the patients and caregivers. Health outcome goals are personalized (not disease-centered) health outcomes that persons hope to achieve through their health care. Care preferences are the activities, behaviors, and "workload" involved in being a patient or caregiver that patients are able and willing to do and tolerate.[1-3]

Primary care clinicians and specialists decide upon their roles and responsibilities in the care of specific patients. Providers also communicate with patients and caregivers about clinical uncertainty, trade-offs between treatment benefits and adverse effects, and what is known about prognosis. The different providers then collaborate together and with patients and caregivers to translate disease specific care into care aligned with patients' health outcomes goals and care preferences. Patients, caregivers, and providers then choose care consistent with patients' goals and care preferences. Patient Priorities Care requires the patient and the provider – neither is sufficient, both are necessary. While Patient Priorities Care is focused on older adults with MCC, patient outcome goal and preference directed care is appropriate for the entire age and health spectrum.

The Patient Priorities Care approach requires health system infrastructure to implement, including an electronic medical record (EMR), care coordination and multidisciplinary healthcare teams, and population health management capability. During the planning process, healthcare system executives expressed support for aligned, goals directed care and felt that it was both the right thing to do, and could also provide a competitive edge. They also felt that eliciting patient goals and preferences could be done by existing clinical personnel. However, they noted innovation fatigue, need for initial investment in training clinicians in goals directed care, and competing demands for EMR and HIT upgrades.[1-3]

SECTION 1: PROBLEM

Older adults with multiple conditions, complex health needs, and functional limitations are the major consumers of health care. These patients face a health care system that is often fragmented and inefficient; leading to care that can be poor quality and high cost. Commonly cited causes of the fragmentation, high cost, and poor outcomes are a payment system based on volume not quality, a delivery system that is fragmented across providers and settings, and a lack of attention to what matters to patients.[1-3]

Demand is growing for a standard of care for all older adults with complex health needs (i.e., patients with MCC) in which all the providers caring for a complex patient integrate their care to address that patient's health outcome priorities, thus improving the quality of care and health outcomes while potentially lowering healthcare costs. To get to this standard of care, the confluence of evidence supports the need to realign the relationship between primary and specialty care, and to place the patient at the center of care.[1-3]

Older adults with multiple chronic conditions (MCC) generally share these characteristics:
- **They vary in their health outcome priorities and care preferences.**[4,5] Care that is driven by individual disease guidelines is often not consistent with patients' outcome goals or care preferences.[6]
- **They receive numerous treatments that are of uncertain benefit and potential harm.** Twenty percent of older adults receive guideline recommended medication that adversely affects coexisting condition(s).[7]
- **They receive care from providers that is focused on specific diseases, which can be burdensome and fragmented.** A patient's multiple providers tend to focus on their own areas of specialization, and on disease-specific outcomes. Evidence-based guidelines followed by the patient's clinicians may not apply to older adults with multiple, complex health conditions because evidence was obtained in younger people or people with fewer diseases. Researchers have found that the workload for patients can be as burdensome as the conditions themselves.[8-10] This burden is a result of fragmented care; the typical older adult sees two primary care and five specialists a year.[11] A primary care provider (PCP) whose practice consists of 30 percent Medicare patients with ≥ four chronic conditions must coordinate with 86 other providers in 36 practices. Patients with a greater number of conditions were more likely than other patients to use multiple hospitals, fragmenting care coordination across settings.[11] There is an increasing demand for a simpler, less burdensome and fragmented approach to the care of persons with MCC.[6, 8,14]
- **They see multiple providers, who themselves are unclear who is accountable for a patient's care.** For example, in large integrated health care systems, patients with diabetes mellitus co-managed in primary care and diabetes clinics had poorer blood pressure control than those managed in either clinic alone (more ≠ better).[15] Primary care clinicians, specialists, and patients often do not share understanding of each clinician's roles and responsibilities, which are usually not made explicit.[16]

The life and health care goals of patients are highly personal. For older adults, disease specific outcomes of care, such as lipid or glucose level, are not what are most important. Rather, patients want pain to be controlled so that they can walk to the store or to church, or want to experience less fatigue so they can care for or play with their grandchildren. Current care is not focused on what matters most to patients. Patient Priorities Care, that focuses on achieving patients' specific health outcome goals within the context of their care preferences (what they are able and willing to do to achieve these outcomes) is, by definition, the highest value care.[2]

Older adults with MCC represent approximately 15 percent of Medicare and 25-50 percent of dual Medicare-Medicaid eligible individuals. These patients are not necessarily facing their last few years of life; rather, they are patients for whom current disease-centered care is burdensome, fragmented, and of unclear benefit. While health care utilization by this population is growing rapidly and includes increasing numbers of office visits, emergency department (ED) visits, procedures and hospitalizations, these patients are also increasingly experiencing adverse consequences from disease-specific, guideline-adherent care. Complex patients may ultimately regret care decisions that were made without considering their goals and preferences. Due to the lack of evidence for many of treatments they receive, this

population is arguably most in need of an evolution from siloed, disease-centric care to shared decision-making based on their health outcome goals and preferences.

The development of Patient Priorities Care began with a planning phase jointly funded by The John A. Hartford Foundation (JAHF) and Patient Centered Research Outcomes Institute (PCORI).[3] This planning resulted in the development of a care archetype based on patient health outcome goals and care preference directed care for older adults with MCC achieved through alignment between primary and specialty care.[3] The Patient Priorities Care approach can be embedded in care delivery systems that have the necessary infrastructure, relationships, and incentives. Examples of such systems are patient-centered medical homes (PCMHs), specialty neighborhoods, accountable care organizations (ACOs), and integrated health systems. Patient Priorities Care is currently being piloted in order to produce preliminary evidence of the feasibility and effectiveness of patient the approach, combined with efforts to increase demand and stakeholder engagement in this new approach to the care of patients with MCC (see Section 3).

Section 2: Patient Priorities Care as a Solution to the Problem

What is Patient Priorities Care?

Patient Priorities Care is based on the idea that the best way to address the disconnect between what patients want from their healthcare and the care they receive is for primary and specialty clinicians to align care around achieving patients' priorities, defined as patients' health outcome goals within the context of their care preferences and the burdens they find acceptable. This approach will decrease both fragmentation and the receipt of unwanted care of unclear benefit.[1-3]

The Patient Priorities Care approach has several new and innovative features. It focuses on older adults with MCC who are not at the end of life, although it is appropriate for patients throughout their lifespans. Patient Priorities Care calls on patients to determine what they want from their current health care. This process is not necessarily their future health care, although the future would also be addressed within the Patient Priorities Care paradigm. It places a premium on patient and caregiver engagement, goals development, preference articulation and communication of goals.[1-3]

Most importantly, Patient Priorities Care explicitly brings clinician participation to patients' goals directed and preference based care. Clinicians are charged with defining their roles and responsibilities, communicating patients' goals and preferences among themselves and with patients and caregivers, translating disease-specific care into priorities directed care, and aligning and then delivering this care to focus on patients' goals and preferences.[1-3]

Patient Priorities Care is both distinct from and builds upon several other important care support interventions. It is not care management, which helps patients navigate fragmented, complex and burdensome care but does not get at the root causes of the fragmentation and complexity. It is different from primary and specialty care coordination, which helps with communication and management of complex, fragmented disease-specific care, but does not align all this care with patient priorities. Unlike advance care planning, Patient Priorities Care does not focus primarily on those who are at the end of life. Patient Priorities Care is firmly rooted in the present and the issues surrounding current, fragmented, burdensome healthcare. During the planning phase, four guiding principles and two core components, described below, were constructed to clearly communicate the essence of Patient Priorities Care and to guide the work moving forward.

Guiding Principles for Patient Priorities Care

- **Patient outcome goals and care preferences drive care and communication.** The focus of healthcare decision-making delivery changes from diseased based care to patient priority based care. Clinicians align their care within the context of patients' outcome goals and care preferences. Patients' goals and preferences are shared in all communications, and patients and caregivers participate in all care decisions.[2]

- **Roles and responsibilities are agreed to and collective accountability is established.** Specific responsibilities for a patient's care are assigned to the primary care or specialist clinician most qualified and available to deliver those aspects of care. All members of the team, including patients and caregivers, are willing and able to carry out the roles and responsibilities for decision-making and care, which are determined by the patient's conditions, outcome goals and care preferences. Accountability is assigned and agreed upon for all processes and outcomes of care. All clinicians agree upon what they are accountable for in the care of each patient.[2]

- **Anticipatory guidance is provided; expectations, tradeoffs, and uncertainty are acknowledged.** Clinicians prepare patients for anticipated developments and/or possible situational crises. Knowledge of what might happen helps patients and caregivers understand the need for establishing goals and preferences to prepare them for informed decision-making when acute or chronic care choices arise. Care decisions and likely outcomes that are unknown or uncertain, of which there are many for older adults with MCC, are acknowledged and communicated.[2]

- **Information and care is integrated and shared.** All clinicians work from the same plan based on patient's actionable and achievable health outcome goals and what patients are willing to do to achieve them. Care includes sharing information with all clinicians, and with patients and/or caregivers. Comprehension of information shared is confirmed.[2]

Core Components of Patient Priorities Care

- **Patient's health outcome goals and care preferences are elicited, documented, and transmitted:**
  a. Patients and caregivers are invited and encouraged to identify and communicate their health outcome goals, as well as their treatment and care preferences.
  b. Patient health outcome goals and care preferences are documented and incorporated into health records.
  c. Patient's health outcome goals and care preferences are transmitted to all clinicians, and updated and transmitted regularly, or as needed.
  d. These outcome goals and care preferences then guide interactions among patients, caregivers and providers, as well as the selection of care options.[2]

- **Primary care and specialty clinicians provide care aligned with patient's outcome goals within the context of their care preferences:**
  a. Primary care, specialists, patients, and caregivers agree to roles and responsibilities.
    i. Key roles and responsibilities can be as a consultant vs. a co-manager of the patient's multiple problems vs. the primary point of contact for the patient, assuming the major role in their care.
    ii. Usually one provider, often the primary care provider, will be the designated primary point of contact and "quarterback."
    iii. Primary care and specialty clinicians must also agree on patients' health outcome goals and care preference-based information flow.
  b. Primary care clinicians, specialists, patients and caregivers translate health outcome goals and care preferences into care options and engage in health outcome goals and care preferences-based shared decision-making and care.[2]

Definitions of Key Terms Used in Patient Priorities Care

Health outcome goals are personalized, patient-centered (not disease-centered) outcomes that persons hope to achieve through their health care.[17,18] To inform care, these goals must be specific, measurable, and actionable (e.g. pain controlled sufficiently to allow five hours of sleep most nights; ability to walk at least one block; cognitive and physical capacity to care for grandchildren). Health outcome goals are distinct from behavioral goals such as stopping smoking or losing weight, and from disease management goals such as improving HbA1c or blood pressure.[1]

Care preferences refer to what people are able and willing to do and to tolerate when selecting or undergoing specific treatments, diagnostic evaluations, or procedures.[19-23] They are the activities, behaviors and "workload" involved in being a patient or caregiver (e.g. adhering to medications; following dietary recommendations; sticking with exercise regimens; attending health care visits; keeping appointments; self-monitoring and management tasks and coping with adverse effects, burden and discomfort of treatments).[2, 22]

Together, patients' health outcome goals and care preferences are termed patients' priorities.

Link between outcome goals and care preferences. The care preferences represent the investment or cost in terms of activities, tasks, time, inconvenience, discomfort, money etc. that the patient and caregivers are willing and able to devote to achieving the health outcome goals. Both pieces are necessary to arrive at care decisions for older adults with MCC.[2]

Target Population for Patient Priorities Care

Patient Priorities Care requires the involvement of both the patient and the provider(s). The target patient population is older adults with MCC who are the major users of health care; they account for 80 percent of Medicare utilization and are overrepresented in Medicaid and in the VA system.[24,25] Once goals and preferences are elicited from patients, primary care providers and specialists collaborate to translate goals into care options. Patients, caregivers, and providers then choose care consistent with patients' goals and care preferences. While Patient Priorities Care is focused on older adults with MCC, patient outcome goal and preference directed care is appropriate for the entire age and health spectrum.

How the Patient Priorities Care Approach Affects Patients: An Example

The experience of an older patient with MCC, described in the example below, illustrates how current disease-specific care can be translated into care that is focused on patient goals and preferences, and demonstrates how goals directed care would be less burdensome and fragmented.

Medical History
Mr. Alvarez, an 81-year-old man with chronic obstructive pulmonary disease, coronary artery disease, heart failure with a left ventricular ejection fraction of about 30%, and type 2 diabetes.

Medications
Carvedilol 6.25 mg twice daily, Lisinopril 20 mg daily, Spironolactone 25 mg daily, Furosemide 40 mg daily, Metformin 1000 mg twice daily, Aspirin mg 81 daily, Atorvastatin mg 40 daily, and Ezetemibe 10 mg daily, Doxepin, Albuterol, Tiotropium, Omeprazole, and a Multivitamin.

Social history
He is widowed and lives alone. His only child is a daughter who lives in the same town and he has a 5-year-old grandson. He does not smoke or drink alcohol and is a retired accountant.

Patient Perspective
Mr. Alvarez has been cared for by his cardiologist for 15 years as his heart failure has worsened. He also sees a primary care provider and pulmonologist. He remains independent in his basic activities of daily living and is cognitively intact. He complains of insomnia, fatigue, dyspnea with one flight of stairs, postural lightheadedness, and poor appetite. He met with an APRN member of the health care team who is trained in helping patients understand their health priorities, particularly when they are facing tradeoffs and uncertainty. He feels that he has had a good life and life prolongation is not a priority. He would not want to prolong his life if his function worsened from its current state which he realizes is very likely to happen over the next year or two. His cardiologist has told him that he should consider getting a defibrillator as it may prevent him from dying of an arrhythmia and his pulmonologist would like him to try outpatient pulmonary rehabilitation to improve his exercise capacity. He is not sure either one of these recommendations are aligned with what he has discussed with the nurse about his values and health priorities.

Refined Patient Health Priorities
1. Health Outcome Goals:
    a. To be able to climb 2 flights to get to his daughter's apartment and walk 2 blocks to the store without having to stop because of shortness of breath
    b. To be able to sleep at least 5 hours a night without walking up and to feel rested enough during the day that doesn't fall asleep.
2. Care preferences:
    a. Fewer medications, avoiding medication adverse effects now more important than reducing risk of future health events

b. No major surgery or procedures to prolong life and only if quick improvement in symptoms or function could be expected afterwards

Values underlying these priorities
1. Daughter and grandson are his most important connections. He really enjoys coming to her house 2 days a week in the afternoons to help keep an eye on his grandson
2. He maintains some of his IADLs including shopping and cooking, and he wants to be able to walk to the store and go shopping.
3. He hasn't been able to do some of his hobbies during the day because he too tired and sleepy many mornings.

Existing Evidence for the Patient Priorities Care Approach

Although Patient Priorities Care represents a new approach to care for patients with MCC, there is substantial evidence to support components of the Patient Priorities Care approach. In addition, Patient Priorities Care builds upon several care models for adults with MCC that have evidence of efficacy and value. Some of this evidence and these care models are described below.

Patient engagement and activation have been shown to improve health outcomes. Patient engagement in self-management and care decisions improves care quality and patient and family/caregiver satisfaction even with advanced illness.[26,27] Person-centered care that focuses on what matters most to the person has been shown to improve patient activation, which in turn, improves health outcomes.[26,27] When health professionals, patients and caregivers partner, measurable improvements in the quality and safety of care result, including increases in informed care choices and reductions in medical errors. Literature has also shown that engaged patients have better outcomes including better management of chronic diseases and overall improved functioning.[28]

Several studies have demonstrated that patient goal elicitation is feasible in clinical practice.[24,25] The elicitation of specific, measurable, actionable outcome goals improves patient satisfaction and outcomes.[24,25,29] Similarly, shared decision-making helps clinicians understand patients' preferences about treatments and outcomes.[20]

Interventions for persons with MCC are not as well supported. A recent systematic review found modest and mixed evidence of various interventions aimed at improving physical, psychosocial, patient satisfaction, and health care utilization outcomes in persons with MCC.[30] In ten trials, case management and care coordination were not effective nor were patient-oriented behavioral interventions when they were not linked to health care delivery and/or did not involve clinicians. Organizational (health system) interventions targeting areas where patients have difficulties, e.g. medication management, were more likely to be effective. Authors of the Cochrane Review highlighted the lack of a clear theoretical framework guiding interventions for MCC. They also noted that results suggested the need for interventions integrated into the health system and focused on areas that are difficult for patients.[30] Findings from this systematic review informed the Patient Priorities Care approach, which includes a clear framework, is integrated into health systems, and focuses on what matters most to patients.

There is early evidence that cross-disease, universal, health outcomes can be mapped onto disease-specific outcomes and cover the domains of patient outcome goals, supporting their use in research and practice involving individuals with MCC.[31-33] Finally, as noted briefly and discussed in more detail below, health care systems meeting National Center for Quality Assurance (NCQA) patient centered medical homes (PCMH), specialty medical homes, and medical neighborhood standards, have the infrastructure that makes primary and specialty alignment and patient-centered care feasible. However, even when PCMH, specialty medical homes, and medical neighborhoods are implemented, they still focus on siloed and disease-specific care, rather than patient goals directed care, which may explain mixed results of studies that have investigated costs and outcomes.[34]

Patient Priorities Care Builds on Existing Models

Patient Priorities Care also builds on several different models and innovations for complex, older patients. Most of these health care innovations have focused on specific conditions/diseases (e.g., dementia, cancer, heart failure), treatment options for single conditions (e.g., shared decision-making), advanced disease or end-of-life treatment (palliative care, Program for All Inclusive Care of the Elderly) or on specific aspects of health care (e.g., hospital care; transitions of care). Patient centered medical homes and accountable care organizations are models that focus on improving coordination of care. However, this care remains largely disease-centered.

Currently, no known approach addresses the issue of fragmented, burdensome, and unwanted care for older adults with MCC who are not yet in the last few years of life. The Patient Priorities Care approach addresses this gap by building on previous innovations, many of which were supported by The John A. Hartford Foundation (JAHF). For example, the Care Transitions Intervention highlighted the importance of patient activation; the Center to Advance Palliative Care (CAPC), a model for improving health care for people facing serious illness, spotlighted the need to elicit and address each individual's health goals and care preferences; Guided Care, a model in which a nurse works with patients, physicians and others to provide coordinated, patient-centered care, the GRACE Program (Geriatric Resources for Assessment and Care of Elders), and the Program for All Inclusive Care of the Elderly (PACE) all showed that integrated team care of complex older adults could improve outcomes. These innovative models provide a foundation on which to build an approach to care that focuses on achieving the health outcomes most wanted by older adults with MCC.

SECTION 3: Building the Research Agenda

The aim of this two-year Patient Centered Outcomes Research Institute (PCORI) funded project: *"A Research Agenda for Translating Disease Specific Care to Patient Goals-Directed Care for People with Multiple Chronic Conditions,"* is to organize multiple stakeholders, particularly patients, caregivers and researchers, but also clinicians, policy makers, healthcare system representatives and payers, to develop a research agenda and network for Patient Priorities Care. The ultimate aim of this research agenda is to ready Patient Priorities Care for patient centered outcomes research (PCOR) and comparative effectiveness research (CER).

Five important stakeholder organizations, The Patient and Family Centered Care Partners (PFCCpartners), the American College of Cardiology (ACC), the American College of Physicians (ACP), the American Geriatrics Society (AGS), and the JAHF, are partnering with the research team that is developing Patient Priorities Care approach with the goal of convening patients, caregivers, clinicians, researchers and other stakeholders, to investigate, articulate, and develop a way to address the array of research questions associated with aligned, patient priorities aligned care, particularly how to translate disease specific care into care directed by the goals and preferences of patients. This project is currently being carried out through series of workshops, webinars and conferences over 2 years with the following objectives:

1) *Objective 1:* Design a research agenda in patient centered outcomes research (PCOR) and comparative effectiveness research (CER) around developing and implementing goals-directed care that focuses specifically on translating disease specific care into aligned patient health outcome goals-directed care. We will begin with cardiovascular care, reviewing the current evidence that is applicable to aligned, goals-directed care, and developing a research agenda for primary specialty alignment around goals-directed care that will also inform such research for other specialties.

2) *Objective 2:* Bring a new specialty, general surgery, into the Patient Priorities Care initiative. Develop a research agenda around the steps needed for general surgeons to align care around patient health outcomes goals. This will be "proof of concept" about the research needed to develop aligned, goals-directed care for multiple specialties.

3) *Objective 3:* Identify and build a collaborative research network in aligned Patient Priorities Care that involves patients, caregivers, providers and other stakeholders in order to maintain momentum and turn research questions into feasible and fundable PCOR/CER studies.

Building the Research Agenda: The Team

The Lead, Co-Leads and Planning Committee for this award are as follows:

Co-Investigators		
Name	**Title**	**Role**
Caroline Blaum, MD, MS	Project Lead	Dr. Caroline Blaum is a practicing geriatrician and palliative care physician who has conducted extensive research and led numerous clinical interventions and health care redesign projects for complex patients, particularly frail elders and patients with multiple comorbidities and geriatric conditions. Most recently, she was one of the leaders of the planning process that developed the Carealign care model that proposes to align primary and specialty care of patients with multiple chronic conditions with patient health outcome goals and care preferences. This planning process was co-funded by the JAHF and PCORI from

		1/2014 to 7/2105. Currently, she is Co-PI, with Dr. Mary Tinetti at Yale, of the JAHF funded pilot study of the Carealign model on subcontract from Yale University. She will lead this project, overseeing all activities and assuring that deliverables, milestones and outcomes of the project are achieved.
Libby Hoy	Project Co-Lead	Libby Hoy is the mother of three sons living with mitochondrial disease. She has 20+ years of experience navigating the health care system. In 2010, Ms. Hoy founded PFCCpartners to create a community of patients, families, providers and health care organizations committed to the shared learning of Patient & Family Centered Care practice. She has served as an Advisor to Patient Centered Outcomes Research Institute (PCORI), Partnership for Patients, Institute of Medicine (IOM), National Quality Forum (NQF) and as Faculty for the Institute for Healthcare Improvement (IHI). Ms. Hoy and the PFCCpartners work to develop the infrastructure and capacity for healthcare systems to engage patients and families in all aspects of clinical care. She will be co-lead on all aspects of the project, and will assure strong patient and caregiver input in all areas.
Michael W. Rich, MD	Project Co-Lead	Dr. Rich is a Professor of Medicine and Cardiology at the Washington University School of Medicine, and Director of the Cardiac Rapid Evaluation Unit at Barnes-Jewish Hospital in St. Louis. Dr. Rich's primary research focus has been the prevention and treatment of cardiovascular disease in the aging population. He has participated in numerous investigator-initiated and multi-center clinical trials involving elderly cardiac patients, and he has published extensively on heart failure disease management, coronary heart disease, atrial fibrillation, and cardiovascular risk reduction in the elderly. He is an internationally recognized expert in geriatric cardiovascular disease, and he is past president of the Society of Geriatric Cardiology. Dr. Rich is extremely interested in patients with MCC along with their cardiovascular diseases, and will provide cardiology expertise to efforts to develop a research agenda to turn disease specific cardiovascular care to patient goals-directed care. In addition, Dr. Rich has extensive experience in using planning processes and conferences to develop research agendas which is the core of this project.
Planning Committee		
Name	**Title**	**Role**
Amy Berman, RN	Senior Program Office at the Hartford Foundation (JAHF)	Ms. Berman is a crucial advisor as an expert in helping develop and evaluate innovative, cost-effective models of care for older adults.
Aanand Naik, MD	Associate Professor, Department of Medicine, Section of Health Services Research, Baylor College of Medicine	Dr. Naik is a geriatrician and will provide expert opinion in patient-centeredness and improving outcomes in older adults with multi-morbid conditions. He is also a VA researcher.

Eileen Sullivan-Marx, PhD, RN, FAAN	Dean and Erline Perkins McGriff Professor at NYU School of Nursing	Dr. Sullivan-Marx is a recognized leader in the care of older adults, developing health policy and improving functional outcomes. She will provide critical input and a nursing perspective. She was on the Steering Committee for the Carealign Planning Project.
Janet Austin, PhD	Patient and Caregiver Representative	Ms. Austin was vital to the development of the Carealign approach. She is both a patient and caregiver and has extensive networks around chronic pain issues. She will continue to represent the patient and caregiver perspective in this project.
John Dodson, MD, MPH	Assistant Professor, Department of Medicine NYUSOM Assistant Professor, Department of Population Health NYUSOM Director, Geriatric Cardiology Program NYU Langone Medical Center	Dr. Dodson is a cardiologist whose research aims to address some of our current gaps in knowledge in order to achieve better decision-making and more patient-centered care for older adults with cardiovascular disease. He will be extremely helpful in informing the agenda for goal directed care in cardiology.
Lillian Min, MD, MSHS	Assistant Professor, Internal Medicine University of Michigan Medical School	Dr. Min is a geriatrician and expert in hypertension. She will be instrumental in helping develop a research agenda to move from disease to patient goal specific care for older complex patients. She is a VA researcher.
Mary Tinetti, MD	Gladys Phillips Crofoot Professor of Medicine (Geriatrics) and Professor in the Institute for Social and Policy Studies, of Epidemiology (Chronic Diseases) and of Investigative Medicine; Section Chief, Geriatrics	Dr. Tinetti is a geriatrician and researcher in geriatrics. She served as PI of the JAHF funded Carealign planning project which developed the Carealign approach. She is currently the PI of the JAHF pilot to test implementation of the Carealign approach in a large primary care practice in Connecticut.
Nancy Lundebjerg, MPA	Chief Executive Officer for AGS	As long term COO and now CEO of AGS, Ms. Lundebjerg will provide vital expertise and networking resources for this project. She is very involved in healthcare policy for people with MCC.
Phil Posner, Ph.D.	Patient Representative	Dr. Posner is a patient representative and was crucial to the development of the Carealign approach. He will continue to represent the patient perspective in this project.
Rob Schreiber, M.D.	Hebrew Rehabilitation Center- Boston, Chief Medical Officer Harvard Medical School, Instructor in Medicine	Dr. Schreiber is a geriatrician, researcher and expert in post-acute care, chronic disease self-management, patient and caregiver activation and transitions of care. He will provide expertise in the development of this research network and agenda.
Project Coordinators		
Name	**Title**	**Role**
Rosie Ferris, MPH	Senior Research	Rosie is a senior research coordinator at NYUSOM. She

	Coordinator in the Department of Geriatric Medicine and Palliative Care at NYU School of Medicine	will be vital in the coordination of both virtual and in-person meetings. She will be responsible for project communication and communication with project funders in regards to reports and deliverables. She will also be vital as she will be responsible for both writing and producing all deliverables for the project.
Stephen Hoy	Director of Strategy and Programs for PFCCpartners	Stephen will be essential in coordinating meetings and handling the logistics of meetings that take place. He will also be vital in managing the social media presence for the project.

Building the Research Agenda: Planning Phase (January-November 2016)

Since the beginning of this project in January 2016, we have engaged in 30+ meetings with our Project Co-Leads, Planning Committee and other stakeholders including virtual and two in person meetings composed of members from both groups. At the beginning of this award, we developed a **Charter** that outlines the mission, vision, scope, structure and definition of common terms to aid in the process of forming a multi-stakeholder research agenda:

I.   **Mission**: We are committed to creating a research agenda for patient priority aligned care facilitated by a research community inclusive of multiple stakeholders.

II.   **Vision**: To change the culture of healthcare for older adults with multiple chronic conditions (MCC) so that care is aligned with their health outcome goals and priorities.

III. **Scope of the Community**: A community of diverse stakeholders including researchers, patients, families, policy makers, caregivers, clinicians, payers, funders and other stakeholders representing and/or caring for older adults with MCC.

IV.   **Community Structure**
    1. Interactive technology platform to host collaborative space.
    2. Continuous community development, recruitment, encouragement, and gratitude for participation.
    3. Partnerships with a broad range of stakeholders, building on the existing networks of the Planning Committee.
    4. Collaborative community interactions including the guidance of the researchers to translate research priorities into a comprehensive research agenda.

V.   **Community Stakeholder Agreements**
    1. Commit to respectful collaboration with all stakeholders in the community.
    2. Actively inform the co-design of the research agenda.
    3. Focus on the translation of disease specific care into patient priority aligned care.

VI.   **Contributions:**
    1. *Co-Investigator Team*: Identify and invite stakeholders to participate in meetings and dialogue about patient priority directed care, cultivate overall plan for development of research community and agenda, develop online community, coordinate and host in person meetings and maintain focus on the mission of this award across all community and research agenda development activities.
    2. *Planning Committee Team*: Participate in 2-4 in person meetings, monthly planning meetings (virtual) and supplementary calls as needed to identify existing networks from area of expertise to contribute to the broader Stakeholder Community and contribute intellectually to development of research agenda.
    3. *Stakeholder Community*: Utilize web based portal to suggest research questions, react to others' ideas and identify the research needs of older adults with MCC and possibly attend an in person event to co-design the research agenda.
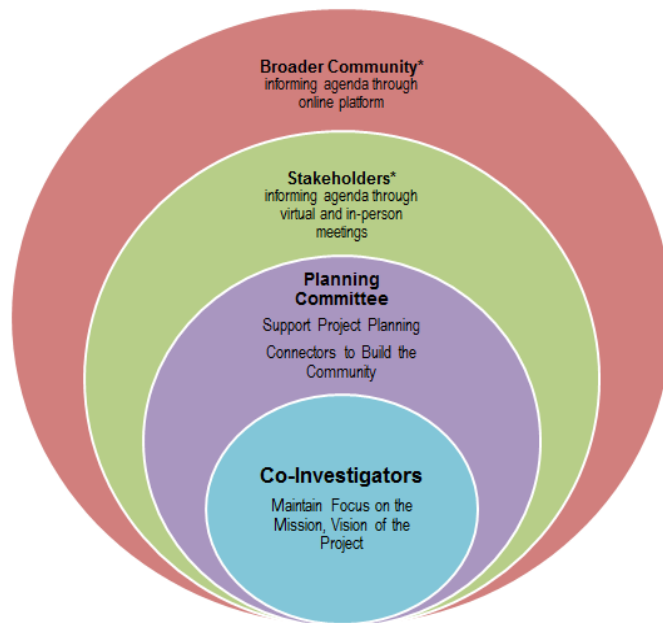
VII. **Guiding Definitions**

1. **Patient Priorities Care** is based on patient identified health outcome goals which are rooted in a person's values, culture and preferences, and form the basis for the alignment of primary and specialty care.
2. **Stakeholder Engagement** is the meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results. We believe that such engagement can influence research to be more patient centered, useful, and trustworthy and ultimately lead to greater use and uptake of research results by the patient and broader healthcare community (based on PCORI Definition).
3. **Patient Directed Health Outcome Goals** are high priority health outcomes that a person hopes to achieve with their health care team. To inform care, these health outcome goals must be specific, measurable, and actionable (e.g. pain controlled sufficiently to allow five hours of sleep most nights; able to walk at least one block). Health outcome goals are distinct from behavioral goals such as stopping smoking or losing weight and from disease goals such as improving HbA1c or blood pressure. These goals are formed within the context of each patient's culture, values and belief structure.
4. **Care Preferences** are the activities, behaviors and care workload involved in being a patient or caregiver that is reasonable for a patient to take on in the context of their lives, which is influenced by the culture, values and beliefs of the individual.

As part of this guiding document, we developed a circular graphic representing the structure (below) of the award and how patient, caregivers and others stakeholder groups can contribute and inform the research agenda.

During these calls, with the expertise of our stakeholders, we developed a preliminary agenda for our large stakeholder meeting to be held in November. We also held an in-person meeting in May, 2016 in Long Beach, CA with the Co-Leads and some members of the Planning Committee to continue to work on and finalize the agenda for the larger conference to be held in November, 2016 to formulate the research agenda for Patient Priorities Care.

Objective 1: Patient Priorities Care Research Agenda Meeting

The Fall Research Agenda Meeting occurred on November 1st and 2nd, 2016 at Heart House in Washington, DC and was co-hosted with the American College of Cardiology (ACC) with collaborators including PFCCpartners, Washington University in St. Louis, American College of Physicians (ACP), American Geriatric Society (AGS) and the John A Hartford Foundation (JAHF). The meeting was a great success. We had 62 attendees, including patients, caregivers, researchers, providers, health care system representatives, healthcare quality experts, payers and other key stakeholders. This two day meeting was composed of six sessions consisting of panels, short talks, break out groups and large group discussion. The agenda and participants are as follows:

Broader Community*
informing agenda through online platform

Stakeholders*
informing agenda through virtual and in-person meetings

Planning Committee
Support Project Planning
Connectors to Build the Community

Co-Investigators
Maintain Focus on the Mission, Vision of the Project

*Includes researchers, patients, families, policy makers, caregivers, clinicians and other stakeholders.

Patient Priority Care Research Agenda Meeting: Tuesday, November 1st, 2016 (Day 1) Overall Facilitator: Wendy Nickel		
Time	**Agenda Item**	**Presenter(s)**
10:00am-10:10am	**Breakfast and seating**	
10:10am-10:40am	**Opening Remarks and Introduction** • Introductions • Background, Goals and Deliverables of meeting • Statement from PFCCpartners	Caroline Blaum Gary Oftedahl Stephen Hoy
10:40am-11:00am	**Keynote**	Amy Berman
Session 1: Changing the Provider/Patient Relationship for Patient Priority Care Session Facilitator: Gary Oftedahl		
11:00am-11:30am	**Panel Discussion:** How could the clinician, patient, caregiver, family relationship support Patient Priority Care?	**Moderator**: Gary Oftedahl **Patient/Caregiver Perspective:** Phil Posner **Primary Care Perspective:** Jonathan Rosen **Specialist (Cardiologist) Perspective:** Nannette Wenger
11:30am-12:00pm	**Breakout Groups** *(See Instructions for Breakout Group Session 1)*	
12:00pm-12:30pm	**Report Out and Large Group Discussion**	**Moderator**: Gary Oftedahl Small Group Reporters
12:30pm-1:00pm	**Lunch**	
Session 2: Tradeoffs, Uncertainty and Treatment Complexity for Patients and Providers Session Facilitator: Marcus Escobedo		
1:00pm-1:15pm	**Short Talk:** Multiple Chronic Conditions Guiding Principles, and Introduction to Session Topic	Cynthia Boyd
1:15pm-2:00pm	**Scenario Panel 360 View and Large Group Discussion:** Patient Priority Care decision-making	**Moderator:** Marcus Escobedo **Primary Care (Geriatrics) Perspective:** Mary Tinetti

		Specialist (Cardiologist) Perspective: Mat Maurer **Caregiver Perspective:** Nancy Lundebjerg **Patient Perspective:** Richard Zorza **Goals Facilitator:** Lauren Vo
2:00pm-2:40pm	**Breakout Groups** *(See Session 2 Instructions for Breakout Group)*	
2:40pm-2:50pm	**Break**	
2:50pm-3:30pm	**Report Out and Large Group Discussion**	**Moderator:** Marcus Escobedo Small Group Reporters
3:30pm-3:45pm	**Break**	
Session 3: The "How": Environment, Process and Tools *Session Facilitator: Tara Bristol Rouse*		
3:45pm-4:15pm	**Short Talks**: Overview of current environment, processes and tools and discussion of where we need to go	**Patient and Caregiver Process:** Wendy Nickel **Training and other Processes:** Aanand Naik **Decision Aids:** Dan Matlock
4:15pm-4:30pm	**Short Panel Discussion**	**Moderator:** Tara Bristol Rouse **Panelists:** Wendy Nickel Aanand Naik Dan Matlock
4:30pm-5:00pm	**Breakout Groups** *(See Session 3 Instructions for Breakout Groups)*	
5:00pm-5:30pm	**Report Out and Large Group Discussion**	**Moderator:** Tara Bristol Rouse Small Group Reporters
5:30pm-6:00pm	**Reception (Heart House)**	
6:00pm-7:00pm	**Dinner (Heart House)**	

Patient Priority Care Research Agenda Meeting: Wednesday, November 2nd, 2016 (Day 2) Overall Facilitator: Wendy Nickel		
Time	**Agenda Item**	**Presenter(s)**
7:30am-8:00am	**Breakfast**	
8:00am-8:15am	**Recap from Day 1**	Mike Rich
Session 4: What outcomes matter? Session Facilitator: Rob Schreiber		
8:15am-8:20am	**Introduction to Session**	Rob Schreiber
8:20am-9:00am	**Short Talks**: Measuring processes and outcomes for Patient Priority Care	**Quality Metrics:** Erin Giovenetti **Process Measures:** Lillian Min **Measures That Matter:** Orla Sheehan **Creating the Business Case:** Tom Meehan
9:00am-9:30am	**Breakout Groups** *(See Session 4 Instructions for Breakout Group)*	
9:30am-10:00am	**Report Out and Large Group Discussion**	**Moderator:** Rob Schreiber
10:00am-10:15am	**Break**	
Session 5: Moving to Comparative Effectiveness Research (CER) Session Facilitator: Tara Bristol Rouse		
10:15am-11:00am	**Panel:** Moving ideas to CER	**Moderator**: Tara Bristol Rouse **Marcel Salive** of National Institutes on Aging (NIA, NIH) **Amy Berman** of The John A. Hartford Foundation (JAHF) **Richard Ricciardi** of the Agency

		for Healthcare Research and Quality (AHRQ) **Neeraj Arora** of Patient Centered Outcomes Research Institute (PCORI) **Susan Mende** of the Robert Wood Johnson Foundation (RWJ)
Session 6: Prioritizing the Research Agenda and Setting up the Research Network *Session Facilitator: Gary Oftedahl*		
11:00am-12:00pm	**Large Group Discussion:** Prioritizing the Research Agenda	**Moderator:** Gary Oftedahl Mike Rich
12:00pm-12:30pm	**Setting up a research network for Patient Priority Care, Closing Remarks and Next Steps** **Dots for Voting:** You will have 4 colored dots to vote on specific themes or questions you think are most important within each Session **Red-** Most important **Yellow-** 2nd most important **Blue-** 3rd most important **Green-** 4th most important	Caroline Blaum Stephen Hoy

Meeting Participants:

Name:	Title/Affiliation
Richard M. Allman, MD	Chief Consultant, Geriatrics & Extended Care Service, U.S. Department of Veterans Affairs
Katherine Alteneder, JD	Coordinator, Self-Represented Litigation Network
Neeraj Arora, MS, PhD	Senior Program Officer, Improving Health Systems Team, Patient Centered Outcomes Research Institute
Michael Barr, MD, MBA	Executive Vice President, Quality Measurement and Research Group, National Committee for Quality Assurance
Amy Berman, RN	Senior Program Officer, The John A. Hartford Foundation
Arlene Bierman, MD, MS	Director, Center for Evidence and Practice Improvement, Agency for Healthcare Research and Quality
Cherie C. Binns, RN	Registered Nurse, Clinical Systems Consulting
Caroline Blaum, MD, MS	Diane and Arthur Belfer Professor of Geriatrics; Director, Director Division of Geriatric Medicine and Palliative Care, NYU School of Medicine
Kelli Bohannon	Associate Director, American College of Cardiology
Cynthia Boyd, MD	Associate Professor of Medicine, Division of Geriatric Medicine and Gerontology, Johns Hopkins University School of Medicine
Tara Bristol Rouse	Faculty, Patient and Family Centered Care Partners
Victoria Dickson, PhD, CRNP	Associate Professor, Rory Meyers College of Nursing, NYU

Lilian Dindo, PhD	Assistant Professor, Menninger Department of Psychiatry and Behavioral Sciences, Baylor College of Medicine
John Dodson, MD, MPH	Assistant Professor of Medicine and Population Health; Director, Geriatric Cardiology Program; Leon H. Charney Division of Cardiology; New York University School of Medicine
Marcus Escobedo, MPA	Senior Program Officer, John A. Hartford Foundation
Jessica Esterson, MPH	Project Director, Yale Geriatrics, Yale School of Medicine
Rosie Ferris, MPH	Senior Research Coordinator, Division of Geriatric Medicine and Palliative Care, NYU School of Medicine
Peter Fielding	Consultant
Daniel Forman, MD	Professor of Medicine, University of Pittsburgh
Erin Giovannetti, MD	Research Scientist, National Committee for Quality Assurance
Marian Grant, DNP, RN	Director of Policy and Professional Engagement, (NP), The Coalition to Transform Advanced Care
Jerry Gurwitz, MD	Executive Director, Meyers Primary Care Institute
Linda Hamilton	Patient/Caregiver Representative AU Health
Gene Harkless, DNSc, APRN	Associate Professor, Chair of Department of Nursing, University of New Hampshire
Maureen Henry, JD	Research Scientist, National Committee for Quality Assurance
Kizzy Hernandez-Bigos, BA	Patient Priority Facilitator, ProHealth Physicians
Mary Herold, RN	Clinical Risk Manager, MedStar Georgetown University Hospital
Stephen Hoy	Director of Strategy and Programs, PFCCpartners
Kathleen Kelly, MPA	Executive Director, Family Caregiver Alliance and the National Alliance on Caregiving
Hibah Khan, MPA	Administrative Coordinator, Division of Geriatric Medicine and Palliative Care, NYU School of Medicine
Ben Kligler, MD, MPH	National Director for Integrative Health, Veterans Health Administration
Yasmeen Long, MA	Program Officer, Eugene Washington PCORI Engagement Awards, Patient-Centered Outcomes Research Institute
Nancy Lundebjerg, MPA	Chief Executive Officer, American Geriatrics Society
Dan Matlock, MD, MPH	Associate Professor, Medicine-Geriatrics, University of Colorado
Mathew Maurer, MD	Professor of Clinical Medicine, Columbia University
Tom Meehan, MD, MPH	Executive Director, Connecticut Center for Primary Care
Susan Mende, BSN, MPH	Senior Program Officer, Robert Wood Johnson Foundation
Lillian Min, MD, MSHS	Associate Professor, Geriatric Medicine, University of Michigan
Brittany Morrongiello	Program Coordinator, Division of Geriatric Medicine and Palliative Care, NYU School of Medicine
Christine Mulvey	Project Manager, ProHealth Physicians & Connecticut Center for Primary Care
Aanand Naik, MD	Associate Professor of Medicine and Health Policy, Houston Center for Innovations in Quality, Safety, and Effectiveness
Wendy Nickel, MPH	Director, Center for Patient Partnership in Healthcare, American College of Physicians
Gary Oftedahl, MD	Collaborator, Oftedahl Consulting, Inc.
Lyn Paget	Managing Partner, Health Policy Partners
Philip Posner, PhD	Ambassador, Patient-Centered Ooutcomes Research Institute
Richard Ricciardi, PhD, MS	Director, Division of Practice Improvement, Agency for Healthcare Research and Quality

Mike Rich, MD	Professor of Medicine, Washington University in St. Louis
Jonathan Rosen, MD	Family Practitioner, Family Medical Group, Bristol, CT; Primary Care Clinical Champion, Patient Priority Care
Marcel Salive, MD, MPH	Program Officer, Division of Geriatrics and Clinical Gerontology, National Institute on Aging/NIH
Robert Schreiber, MD	Medical Director, Evidence-based Programs, Hebrew SeniorLife, Healthy Living Center of Excellence
Orla Sheehan, MD, PhD	Research Associate, Center on Aging and Health, Division of Geriatrics and Gerontology, Johns Hopkins University
Elizabeth Sheley	Medical Writer
Rani Snyder, MPA	Program Director, The John A. Hartford Foundation, Inc.
Michael Steinman, MD	Professor, School of Medicine, University of California, San Francisco
Eileen Sullivan-Marx, PhD, RN	Dean & Erine Perkins McGriff Professor, Rory Meyers College of Nursing, NYU
Mary Tinetti, MD	Gladys Philips Crofoot Professor of Medicine and Public Health; Chief, Yale Geriatrics, Yale School of Medicine
Janice Tufte	Consulter, Hassanah Consulting
Lauren Vo, APRN	Patient Priority Facilitator and APRN, ProHealth Physicians
Nanette Wenger, MD	Professor of Medicine (Cardiology) Emeritus, Emory University School of Medicine
Yasmin Yusuf, MHA	Administrator, MedStar Georgetown University Hospital
Joan Zorza, Esq	Partner, Zorza Associates
Richard Zorza, Esq	Founder, Zorza Associates

Objective 1: Patient Priorities Care Meeting #1: Research Agenda Meeting Findings

This meeting generated a vast amount of material regarding a potential research agenda for Patient Priorities Care. At the end of the second day, all meeting attendees were given 24 votes (6 per each of the 4 sessions) to establish what they felt the most important questions were out of which 113 research questions/themes were generated. Below, these themes are ordered from most votes to least votes all Sessions combined:

# of Votes	Theme/Question
48	How do you utilize the EMR to support care based on patient priorities and preferences? In order to support Patient Priority Care, do you need requirements from national organizations (ex. AAMC, NQF)?
45	Does Patient Priority Care affect utilization of healthcare (i.e perceived burden, ED visits, medications, etc.)?
36	What are the pragmatic structures/incentives/processes/payment systems to facilitate patient priority care?
35	What is most effective for eliciting goals and preferences: Peers, Clinician or Peer Mentored by clinician?
31	Who is the best person to have the priority care discussion?
30	How do we measure goals and preferences? (and concordance with goals and preferences)
29	What us the best way to document and transmit goals by patient or caregiver? (there needs to be buy-in from everyone involved)
28	What are the core elements of Patient Priority Care that should be present in every health system?
28	How do we measure appropriate deintensification?
27	How do we communicate tradeoffs between current health and burden vs. future health and burden in an unbiased way?
27	What are useful tools for eliciting patient's priorities?
26	What is the best way to collect initial information (patient, family) through provider (MD, non-MD,

	technology)?
26	Is there an unintended consequence of providing Patient Priority Care because it could focus on patients that have the education and resources to become engaged?
23	How do we incorporate Patient Priority Care into medical education (Medical students, residents and practicing physicians)?
22	What are the mandatory skills (or, best mechanisms) that both patients and clinicians need to facilitate goals of care conversation?
22	How do we avoid creating measures that penalize a clinical team that tries to maintain function/outcomes in frail populations?
20	How do we get patients ready for Patient Priority Care?
20	Is there a role for "uncertainty" decision aids?
20	What percent of patients have a care plan that includes goals and preferences?
20	How do you build individualized measurement into systems of care?
17	How can we reconfigure the system to support Patient Priority Care? (Incentives, metrics, insurance)
17	What decision support is needed for linking treatment recommendation to patient priorities? How can tools/technology help? What degree of uncertainty is acceptable for this? Does "level of evidence" measures need to adapt?
17	Can we "turn-off" traditional measures (AC, BP) as we "turn-on" patient priority measures?
16	What are the ways to improve access to this care? Telemedicine, hot visits, "hotspot" team
15	Are there general balance questions that reflect attainment of goals vs. reducing/adjusting treatment burden? (measuring benefit vs. harm)
14	How do clinicians define patient centered care? Is there mismatch between what patients/families/caregivers and clinicians define as patient centered care?
14	How do social determinants of health drive decision-making?
14	What level of training does the goals facilitator need? Can we compare roles?
14	How would Patient Priority Care work or be implemented with different types of patients? (e.g. Cognition, mental illness, trauma, health literacy, SES, cultural norms, religion)
12	How do we identify appropriate patients for Patient Priority Care? Are there key subsets?
12	Who is the right person to have the discussion about decision-making?
12	At what point do you start communicating and educating people about Patient Priority Care? (ex. Public education before entering healthcare system)
12	What is the best strategy for integrating the care team around the patients' health priorities?
12	What is the most effective tool for shared decision making with the least amount of burden to patient/provider?
12	How to measure the slowing of functional and health decline?
11	What specific technology intervention can support communication of current care preferences? (Similar to ACP)
11	What is the value of proposition of Patient Priority Care? (incentives for health systems, administrators)
11	Can you align patient priorities with performance measures?
11	Do we need better "patient experience measures" for encouraging Patient Priority Care (goal attainment, active management, etc.)?
10	How to understand patient cultural norms of what aging looks like?
10	How can we scale up Patient Priority Care?
10	How do you open up the dialogue in general population about Patient Priority Care? Is social Media valuable for promoting this? How do you help people recognize that this is a problem that should be addressed?
9	How do we address clinicians facing burnout, time crunch?
9	How much evidence does the healthcare system need to support the culture change of Patient Priority

	Care?
9	Do the currently available forms of big data include the data that informs decision-making and care delivery?
9	Can we test an abbreviated facilitation method (mechanisms, home, telehealth, care giver presence)?
8	How can we teach clinicians & their teams to recognize when there are conflicting decision makers (such as patients versus outspoken family) and provide them with tools to do the right thing?
8	Is this information about goals & preferences portable? How is it documented?
8	How do we create a patient-reporting method to capture measures of service vs. measures of outcomes of Patient Priority Care?
7	How can we adapt the Patient Passport for Patient Priority Care?
7	How to assess person's tolerance for uncertainty? And is there a way to increase tolerance?
7	Is there a business case that can be built around patient-reported outcomes vs. utilization outcomes?
6	How do we diagnose initial level of patient readiness for PPC? What about patients with depression and mild cognitive impairment?
6	How to promote transparency of uncertainty from the care team to patient/family?
6	What type of training does a Patient Priority Care facilitator need?
6	How do we market and disseminate this process? (Patients, funders, providers, etc.)
6	Can we measure caregiver burden/care receiver burden?
6	What is the best way to measure quality of life?
5	How do we address conflict between patient and caregiver?
5	What is the capacity of the system to absorb what is required for true Patient Priority Care? What resources are required?
5	What are research methodologies that can incorporate complexity, tradeoffs and uncertainty?
4	What skills do clinicians need to participate in Patient Priority Care?
4	How do we communicate tradeoffs?
4	How do priorities and attainment of priorities link to measure?
4	How do we define roles for patient, provider, and caregiver?
4	Are there differences between patient groups (culture, ethnicity, age) and who they would prefer to see for goal elicitation?
4	What measures should not be used?
4	How for social determinants of health?
4	How do we create a set of quality metrics specific to older, multimorbid adults?
3	Can patients with cognitive impairment participate in Patient Priority Care? How do we meaningfully engage them?
3	What is the division of labor among the healthcare team? We need to rethink/expand roles (this is a broader research agenda)
3	How do we incorporate what we know about human biases in interpreting risk in day to day decision making?
3	Who are right people and settings for patient priority elicitation conversations?
3	Does who facilitator is impact the goals that are elicited? Is there more buy-in depending on facilitator is?
3	What's the trigger to start Patient Priority Care? How often or what events would trigger re-evaluation of priorities?
3	What are the values and preferences of clinicians and health systems and how do they impact decisions?
3	Can goal attainment scaling be adapted for primary care?
3	How can goal attainment scales be structured to prevent gaming?
2	What are the ways to integrate EMPR? (broader: need to conduct human factors research)

2	Does increased time enhance communications or relationship building?
2	How can we acknowledge the patient/family perceptions of what is present care decisions and future care decisions?
2	How to tie treatments of multimorbid conditions to maintenance of mobility?
2	Are there unintended consequences of asking for preferences when resources aren't available?
2	How do we understand variability in how patients perceive burden?
2	How to evaluate the degree to which a patient wants certainty/uncertainty from clinicians?
2	What are the ethical issues related to tradeoffs? (ex. Benefits of a treatment outweigh the harm)
2	What's the best way to educate medical professionals about Patient Priority Care?
2	How do we improve the way we measure patient experience?
2	Should there be an individualized set of outcomes and process measures that patients and the care team agree on?
1	Active, Engaged Patients – Adapting what we know to MCC
1	How do you measure/change clinician's perceptions of patient attitudes toward medications?
1	What is the role of patient engagement and are there tactics/strategies that can be deployed to measure it?
1	Qualitative Research that helps us to understands the level of uncertainty among clinicians (and what do they weigh most)?
1	What does uncertainty mean to patients? Does Patient Priority Care reduce uncertainty?
1	Can disease specific evidence contribute to Patient Priority Care? How much do we need?
1	Who is the "quarterback" (primary point of contact)?
1	Do financial incentives promote patient engagement in Patient Priority Care?
1	How is something changed or altered based on presence of caregiver? What term besides "caregiver" can be used?
1	Is there a patient group that would get most benefit out of intensive interventions? Is there a patient group for whom online tools are adequate?
1	Can the values piece be done by peers/ with SMART goals and preferences done by person with more training?
1	Are there certain environments where this approach would be more successful?
1	Has there been measurable progress towards goals at follow-up?
1	How do we perform measures as patient ability to self-report diminishes?
1	Is there a case for building a longitudinal tracking methodology?
1	How do we adapt/validate pros for carious populations?
0	What facilitates the teams (sometimes across institutions) working together to drive Patient Priority Care?
0	Would it helpful to have big data that contained relevant information to Patient Priority Care?
0	How "SMART" (Specific, Measurable, Actionable, Realistic, Timebound) do smart goals need to be?
0	As goals are identified, how is information shared with family members? What are barriers?
0	How would peer coaches be accepted by the medical community?
0	How will you know/measure when there is cultural/system change?
0	Which measures of utilization are valid and meaningful?
0	Can objective measures (e.g. Gait speed) be adapted for primary care? Patient Priority Care?

Initial qualitative analysis using Atlas.ti qualitative software identified 5 major themes with subthemes. The first theme focused on aligning patient priorities with performance measures and whether existing, disease specific, measures can be adapted to support Patient Priorities Care. A subtheme of this was how to accurately measure patient and caregiver outcomes, such as slowing functional decline, reduced care burden, attaining health outcomes goals, and improved quality of life. The second theme involved research questions about how Patient Priorities Care would drive clinical

decision-making, a subtheme involved how PPC can be adapted to diverse patient types, such as those with cognitive impairment, poor health literacy, or with different cultural backgrounds. A third and significant theme generated by the group was who the appropriate "goals facilitator" is to elicit patient goals. In order for Patient Priorities Care to be scaled up, it is essential to look at the subtheme of what skills are needed by goals facilitators, but also patients and providers. Fourth, uncertainty in clinical decision-making was an overarching theme, how to assess it, be transparent in an unbiased way and measure and address differing levels of tolerance. Lastly, to develop and test tools to communicate and support care based on patient goals among the healthcare team. A subtheme is heath IT tools to support shared decision-making, and methods to enhance patient-caregiver and provider communication.

Objective 2: Patient Priorities Care Meeting #2: Surgery Research Agenda Meeting

The Patient Priorities Care Surgery Research Agenda Meeting occurred on July 20th, 2017 at NYU Langone Medical Center and was co-hosted with the American College of Surgery (ACS) with collaborators including PFCCpartners, Washington University in St. Louis, American College of Physicians (ACP), American Geriatric Society (AGS) and the John A Hartford Foundation (JAHF). We had 51 attendees, approximately half of whom attended our Cardiology meeting in Fall 2016. Many of the including patients, caregivers, researchers, providers, health care system representatives, healthcare quality experts, payers and other key stakeholders. This full day meeting was composed of four sessions consisting of short talks, panels, break out groups and large group discussions. The agenda and participants are as follows:

Patient Priorities Care Surgery Research Agenda Meeting

Thursday, July 20th 2017
NYU Langone Medical Center, 550 First Avenue, New York, NY 10016
Smilow Multi-Purpose Room (MPR)

Introductions, Background, Overview and Meeting Objectives

Time	Agenda Item	Presenter(s)

10:00am-10:30am	**Opening Remarks and Introduction**
	 • *Welcome and Introductions*
	 • *Background and Overview*
	     o *Patient Priorities Care*
	     o *Coalition for Quality in Geriatric Surgery*
	 • *Goals and Deliverables of meeting*
		Presenter(s):
		 Caroline Blaum
		 Libby Hoy
		 Ronnie Rosenthal

	Session 1: **Changing the Conversation: Moving from "Fix it" to Patient Priorities**	
10:30am-11:00am	**Short Talk:** *Changing the Patient/Surgeon Conversation, the Fix-It mentality and Mental Models*	**Presenter**: Gretchen Schwarze
11:00am-11:45am	**Breakout Groups**	**Breakout Group Facilitators:** Kizzy Hernandez-Bigos *(Group 1)* Stephen Hoy *(Group 2)*

		Lauren Vo *(Group 3)* Michael Mangold *(Group 4)*
11:45pm-12:15pm	**Report Out and Large Group Discussion**	**Moderator:** Gary Oftedahl Small Group Reporters
12:15pm-12:45pm	**Lunch** *Review Case Vignettes for Sessions 2 & 3*	

	Session 2: **Keeping Patient Priorities at the Center of** **Acute and Non-Acute Surgical Decision Making**	
12:45pm-1:15pm	**360° Panel based on Case Vignettes of Acute and Non-Acute Surgery**	**Panel:** Zara Cooper *(Moderator)* Anne Mosenthal *(Surgery perspective)* Lisa Freeman *(Family perspective)* Rob Schreiber *(PCP perspective)*
1:15pm-2:00pm	**Breakout Groups**	**Breakout Group Facilitators:** Kizzy Hernandez-Bigos *(Group 1)* Stephen Hoy *(Group 2)* Lauren Vo *(Group 3)* Michael Mangold *(Group 4)*
2:00pm-2:30pm	**Report Out and Large Group Discussion**	**Moderator:** Gary Oftedahl Small Group Reporters
2:30pm-2:45pm	**Break and Snack**	

	Session 3: **The Surgical Journey**	
2:45pm-3:15pm	**360° Panel based on Case Vignette**	**Panel:** Aanand Naik *(Moderator)* James Suliburk (*Surgery perspective*) Jon Rosen *(PCP perspective)* Libby Hoy *(Patient perspective)*
3:15pm-3:45pm	**Breakout Groups**	**Breakout Group Facilitators:** Kizzy Hernandez-Bigos *(Group 1)*

		Stephen Hoy *(Group 2)* Lauren Vo *(Group 3)* Michael Mangold *(Group 4)*
3:45pm-4:00pm	**Report Out and Large Group Discussion**	**Moderator:** Gary Oftedahl Small Group Reporters

Session 4: **Prioritizing the Research Agenda**		
4:00pm-5:00pm	**Large Group Discussion, and All Session Voting and Closing Remarks**	**Presenters:** Gary Oftedahl Mike Rich Caroline Blaum Libby Hoy

Participants:

Name:	Title/Affiliation
Janet Austin, PhD	Patient and Caregiver
Amy Berman, BSN, LHD	Senior Program Officer, The John A. Hartford Foundation
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Joshua Chodosh, MD, MSHS, FACP	Michael L Freedman Professor of Geriatric Research Medicine; Director, Freedman Research Program on Aging and Cognition; Professor of Medicine and Population Health, NYU School of Medicine
JoAnn Coleman, DNP, ANP, ACNP, AOCN	Verification Committee and Education Committee Co-Chair, Sinai Center for Geriatric Surgery
Zara Cooper, MD, MSc	Associate Surgeon, Division of Trauma, Burns and Surgical Critical Care, Brigham and Women's Hospital; Assistant Professor of Surgery, Harvard Medical School
Ilene Corina	President, Pulse Center for Patient Safety and Education & Advocacy, Wantagh, NY
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Jessica Esterson, MPH	Project Director, Yale Geriatrics, Yale School of Medicine
Rosie Ferris, MPH	Senior Research Coordinator, Division of Geriatric Medicine and Palliative Care, NYU School of Medicine
Lisa Freeman	Executive Director, Connecticut Center for Patient Safety
Mary Geda, BSN, MSN, RN	Project Director, Yale University
Gene Harkless, DNSc, APRN	Associate Professor, Chair of Department of Nursing, University of New Hampshire
Katherine Harwood, MS	Geriatric Research Intern, NYU School of Medicine
Kizzy Hernandez-Bigos, BA	Patient Priorities Facilitator, ProHealth Physicians
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	Center; ACS/JAHF James C. Thompson Clinical Scholar in Residence; American College of Surgeons
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Gary Oftedahl, MD	Collaborator, Oftedahl Consulting, Inc.
Nicole Orr, MD, FACC	Assistant Professor (Cardiology), Tufts University School of Medicine; Post-Acute Cardiology Care
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Jennifer Ouellet, MD	Instructor Geriatric Medicine Clinical Educator Fellow, Yale University School of Medicine
Philip Posner, PhD	Ambassador, Patient-Centered Outcomes Research Institute
Mike Rich, MD	Professor of Medicine (Cardiology), Washington University in St. Louis
Jonathan Rosen, MD	Family Practitioner, Family Medical Group, Bristol, CT; Primary Care Clinical Champion, Patient Priority Care
Ronnie Rosenthal, MD	Professor of Surgery, Yale University; Surgeon-In-Chief, VA Connecticut Healthcare System
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Juliette Schlucter	Family Caregiver; Director of the Center for Child and Family Experience; NYU Langone Medical Center
Robert Schreiber, MD	Medical Director, Evidence-based Programs, Hebrew SeniorLife, Healthy Living Center of Excellence
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Eileen Sullivan-Marx, PhD, RN	Dean & Erine Perkins McGriff Professor, Rory Meyers College of Nursing, NYU
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Mary Tinetti, MD	Gladys Philips Crofoot Professor of Medicine and Public Health; Chief, Yale Geriatrics, Yale School of Medicine

Janice Tufte	Consulter, Hassanah Consulting
Lauren Vo, APRN	Patient Priorities Facilitator and APRN, ProHealth Physicians
Nanette Wenger, MD	Professor of Medicine (Cardiology) Emeritus, Emory University School of Medicine

Objective 2: Patient Priorities Care Meeting #2: Surgery Agenda Meeting Findings

This second large meeting to develop a research agenda for Patient Priorities Care generated 61 research questions. At the end of the day, all meeting attendees were given 12 votes (4 per each of the 3 sessions) to establish what they felt the most important questions. Below, these themes are ordered from most votes to least votes all Sessions combined:

# of Votes	Theme/Question
34	What materials/tools do patients and families need to engage?
33	Does patient identified best and worst outcomes inform decision to have surgery and care after surgery?
30	What are the fundamental elements of patient priorities have the biggest effect on decision making?
28	What is the "minimum" data set needed to make decisions? Who obtains it?
27	Does awareness and collection of patient priorities pre-op improve patient reported QOL at 90 days?
25	What is the cost effectiveness of incorporating patient priority care surgical decision making for the patient, surgeon and society?
24	What are the patient identified quality indicators of surgery?
24	What is the role of peer support teams in preparation for surgery? Multidisciplinary teams?
23	How do we align payment/incentives to support Patient Priorities Care?
21	How do we move from surgeon best/worst case to patient best worst case?
16	Do more with co-morbidities need more than one visit to prepare for surgery?
16	What are the outcomes that geriatric patients want communicated?
15	Would a care coordinator impact the alignment of patient priorities and outcomes?
14	Model of care for limited life expectancy patients
14	Identify expected outcomes for both the clinicians and the patients in common procedures?
13	Would patient-directed clinical support tools promote functional outcomes?
13	What frameworks can be made to prompt patient priorities and their effect?
13	Can people with lived experience inform surgeons of reality of the surgeries to improve patient communication?
12	What are the tools needed for surgeons to answer questions about functional outcomes and quality of life
12	What are the outcomes most important to each individual patient? A) how do we elicit b) how do we measure c) what if it is unrealistic?
11	How does patient priorities impact surgical utilization? And how do functional outcomes differ between groups?
11	What roles aside from the surgeons, can be empowered to begin the discussion about priorities, preferences and goals?
10	What is role of peer support in surgical decision making?
10	Does properly eliciting goals, preferences and priorities (upstream) help with difficult decisions?
10	Impact of imbedded geriatric worker?
10	Patient and profession education and tools. What are the tools and education that patients and caregivers need to be empowered enough to make effective decisions?
10	Research measures leading to clinical measures which are applicable to geriatric patients quality of life
9	Understanding clinical momentum and "hard stops." How to help?

8	Should the referral to the surgeon include the patient's primary goal to guide the conversation?
7	Do we need a improved way to do pre-operative functional assessment that helps patients decide?
7	How does informed evolve and get updated over time?
7	How can we structure processes, especially when things go wrong? (also coaching and anticipatory training)
6	What measures are in place to say the goals are being met even when the priorities may change?
6	How effective/accurate are surgeons in their predictions about how/if the surgery will improve goal attainment?
5	How do teams use priorities?
5	How do the priorities in the HER form the surgical encounter and the patient-surgeon interaction?
4	How is the information documented? A0 HER b) family/patient to carry? C) Shared between stakeholders?
4	What are the best practices if no directives/family present?
4	What are the best practices for patients to prepare for a surgery?
3	What events of care trigger substantial changes in goals?
3	What is the best time to have the conversation with persons with mild/moderate cognitive impairment to capitalize moment of lucidity?
3	Does the patient want surgeons to have those conversations?
3	What are the surgery specific questions that must always be asked one surgery is being considered?
3	How to standardize documentation, increase of access. How will patients understand legal documents?
3	What are the quality measures that include surgeon accountability for quality of life?
3	What are the measurable data we can use to support Patient Priorities Care conversations?
3	How to use narratives to empower patients and inform clinicians?
2	How best to support surrogate decision-maker in making difficult decisions in life or (QOL) limiting complications develop?
2	What is the impact of advanced care planning on clinical decision making? What matters most to patients?
2	Streamlining connection between stakeholders with complications arise?
2	Impact of burden of system on patient and caregiver
2	Are there standard processes of best practices to support individuals for both acute and elective surgery?
1	Do we need a template that goes through the surgical journey?
1	Does eliciting health priorities on a regular or customary basis help with larger decisions for surgery?
1	What effective education tools can prepare patients for conversation?
1	How to disseminate and implement best practices?
1	Informed consent
1	How to build evidence for ROI to change the business case?
0	How does surgeon function in continuity of care?
0	How to insure this information gets used?
0	What are the incentives for providers?

Analysis of these questions using Atlas.ti identified 10 main themes, which included the top 5 themes from the previous meeting focused on Cardiology. The main themes included:

1. **Tools/Education** (Needed for Patients/Families/Surgeons)
2. **Roles** (of Family/Caregivers, Patients, Surgeons, Teams, Peers and Coordinators)
3. **Best Practices** (Pre- and post-op, implementation and dissemination)
4. **EHR/Template** (referrals, documentation and informing Interaction)
5. **Business Case of PPC** (Payment/Incentives/Utilization/Cost Effectiveness)
6. **Quality of Life** (QOL)

7. **Patient Identified Quality Indicators and Outcomes**
8. **PPC for Different Patient Populations**
9. **Does PPC help with decision making?** (How about big, difficult decisions?)
10. **Data Set Needed**

Objectives 1 & 2: Meeting Comparative Analysis

Analysis revealed 6 of the highest density themes from each meeting are common to both the Cardiology and Surgery research agenda: 1) Education and tools needed to implement PPC, specifically the training and skills needed for patients, families, medical trainees and the care team, and tools to facilitate implementation; 2) The roles of stakeholders within PPC; a recurrent question involved who is the best person to elicit patient priorities and whether this can be an existing member of the care team to support seamless integration of PPC into usual care; 3) Whether existing quality metrics can be aligned with or adapted to support PPC, and how to measure patient and caregiver outcomes, such as slowing functional decline, reduced care burden and attaining health outcomes goals; 4) How PPC can be adapted for different groups including those with cognitive impairment, and people with diverse cultural, ethnic and socioeconomic backgrounds; 5) The data needed to support implementation and outcome measures for PPC, and whether existing and big data can be of assistance; and 6) research questions aimed at developing system-wide incentives, building a business case and scaling up. A research agenda for PPC was replicated in two separate research consensus conferences despite focus on different medical specialties. This supports the importance, accuracy, and translational nature of the research agenda our planning process elicited and suggests appropriate research will lead to a widespread foundation of evidence for implementation of PPC across multiple specialties.

Objective 3: Patient Priorities Care Research Consensus and Network Meetings

The Patient Priorities Care Research Agenda Network Meeting and Patient Priorities Care Research Agenda Consensus Meeting occurred on Monday, November 20th, and Tuesday, November 21st 2017 in Long Beach, CA and was co-hosted with collaborators including PFCCpartners and Washington University in St. Louis. We had 5 attendees on Day 1 and 10 attendees on Day 2. The group included two geriatricians, two cardiologists, 4 patient/caregivers and two staff.

Patient Priorities Care Research Agenda Network Meeting **Monday, November 20th** **2:00pm-6:00pm PST** *PFCCpartners, 5199 E. Pacific Coast Highway, Suite 306, Long Beach, CA 90804* **Day 1: Sustaining the Network**		
Time	**Agenda Item**	**Presenter(s)**
2:00pm-2:30pm	Goals of Day 1 and 2 discussion, and level setting	Caroline Blaum Libby Hoy
2:30pm-4:00pm	Webinar Outline and Compilation	Caroline Blaum Libby Hoy
4:00pm-4:15pm	Break	

4:15pm-5:30pm	Strategies to maintain an engaged network: brainstorming and documented plan	Caroline Blaum Libby Hoy
5:30pm-6:00pm	Day 2 Planning	

Participants

Name:	Title/Affiliation:
Caroline Blaum, MD, MS	Diane and Arthur Belfer Professor of Geriatrics; Director, Director Division of Geriatric Medicine and Palliative Care, NYU School of Medicine
Rosie Ferris, MPH	Senior Research Coordinator, Division of Geriatric Medicine and Palliative Care, NYU School of Medicine
Libby Hoy	Founder & CEO, PFCCpartners
Stephen Hoy	Chief Operating Officer (COO), PFCCpartners
Hibah Khan, MPA	Administrative Coordinator, Division of Geriatric Medicine and Palliative Care, NYU School of Medicine

Patient Priorities Care Research Agenda Consensus **Patient Priorities Care Research Agenda Consensus Meeting** **Tuesday, November 21st, 2017** **8:00am-4:00pm PST** ***Hyatt Centric in "The Club Room", 285 Bay St, Long Beach, CA 90802***		
8:00am-8:30am	Breakfast	
8:30am-9:00am	Overview and Meeting Objectives	Caroline Blaum Mike Rich Libby Hoy
9:00am-10:00am	Defining the Research Agenda o *Selection of top themes* o *Selection of most important research questions within each theme, and combine if needed* *Suggestion of 5 themes, and 5 questions within each theme*	Working Group
10:00am-10:15am	Break and Snack	
10:15am-11:30am	Finalize selection of themes and research questions for Planning Group *Insert into PowerPoint presentation for web-conference*	Working Group

11:30am-12:30pm	Web Conference with Planning Group	Working Group and Planning Committee
12:30pm-1:00pm	Lunch	
1:00pm-2:30pm	Finalize research questions and formulate consensus statement o *Reword/edit selected research questions to make them clear and actionable*	Working Group
2:30pm-2:45pm	Break and Snack	
2:45pm-4:00pm	Next steps and publications	Working Group

Participants:

Name:	Title/Affiliation:
Janet Austin	Patient/Caregiver Advocate
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Rosie Ferris, MPH	Senior Research Coordinator, Division of Geriatric Medicine and Palliative Care, NYU School of Medicine
Libby Hoy	Founder & CEO, PFCCpartners
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Daniel Matlock, MD	Associate Professor, Medicine-Geriatrics, University of Colorado
Mike Rich, MD	Professor of Medicine (Cardiology), Washington University in St. Louis
Janice Tufte	Consulter, Hassanah Consulting
Nanette Wenger, MD	Professor of Medicine (Cardiology) Emeritus, Emory University School of Medicine

Objective 3: Patient Priorities Care Research Consensus Findings and Network Plan

Network

The major outcome of our first day networking meeting was a Webinar to inform stakeholders of the findings of our two large meetings in November 2016 and July 2017, as well as the consensus we would reach on Day 2 (November 21st). The Webinar took place on Thursday, January 11th from 3:00-4:00pm EST (2:00-3:00pm CST; 12:00-1:00pm PST). The Webinar started with presentation by PI Dr. Caroline Blaum which included background information on Patient Priorities Care, the PCORI award and findings to date. We had 56 attendees and a robust discussion following the presentation. All participants were added to the Patient Priorities Care stakeholder listerv that will receive updates on the research agenda, and project overall as it progresses.

Consensus Meeting

The consensus meeting resulted in the following six main themes that came out of the two year PCORI engagement award, ordered in terms of importance. The research questions found below are still be finalized to ensure they are comprehensive, representative of the findings overall and actionable and will be included in a paper that is forthcoming.

1. **Measures**
   a. How do we create measures to assess individual priorities and goals?
   b. Can we develop measures that over time improve care for individualized patients?
   c. How do you measure the health outcomes defined as important by the patient?
   d. Was the process of patient priorities care completed? Was it effective in reaching established goals?
   e. What are better patient experience measures? If these measures are achieved with patient priorities care, have we improved care?
2. **Training education, tools and skills**
   a. Develop and test a tool for eliciting patient preferences utilizing standard methods
   b. Develop and test strategies for translating patient priorities into clinical practice through shared decision-making and continuing on an ongoing basis.
   c. What strategies are most effective for providers to use in communicating the precepts of and strategies for ensuring alignment of care with patient-centered goals?
   d. What is the effect of Patient Priorities Care on clinical practice from the perspective of providers, health systems, and payers?
   e. Develop and test tool(s) for assessing patient satisfaction and concordance of care with individual patient preferences
   f. Building on current methods for functional assessment develop and test a standardized tool that could be readily incorporated into routine care and utilized to inform care decisions
   g. Does using a case-based approach to communicate possible outcomes prior to procedures (or other interventions) lead to improved patient understanding and more informed decisions?
   h. Evaluate current methods for assessing outcomes and prognosis in older patients with multiple chronic conditions, and assess whether incorporation of such information into discussions with patients and caregivers facilitates shared decision-making
   i. How frequently should the patient priorities template be updated (and what is the best way to do this) in order to ensure ongoing alignment of care with current priorities
   j. What communication strategies are most effective for communicating medical tradeoffs (Risks vs. benefits)?
3. **Business case**
   a. How does Patient Priorities Care effect utilization of healthcare (i.e perceived burden, ED visits, medications, etc.)?
   b. What is the value of incorporating patient priorities care decision making for the patient, physician, health care system, and society?
      i. Patient: Is the Patient Priorities Care process actually achieving what patients want it to?
      ii. Provider: is patient priorities care enhancing providers' ability to improve patient outcomes. Is Patient Priorities Care burdensome to providers?
      iii. Health care system: What is the return on investment for the health care system to create the business case for patient priorities care?
      iv. Society: What is the cost effectiveness of patient priorities care?
   c. How do we encourage all stakeholders to adopt patient priorities care?
      i. What are the optimal methods of marketing and promoting Patient Priorities Care? (to patients, funders, providers, etc.)
      ii. What resources are required of various stakeholders to adopt patient priorities care?
4. **Patient Groups**
   a. What unintended consequences arise from patient priority elicitation when resources are limited or unavailable? (Resources: Procedures, lifestyle; Consequences: adverse health outcomes, patient dissatisfaction, community effects and public policy)
   b. Do the goals generated by patient priorities care elicitation differ by patient age, gender, ethnicity, health literacy, language etc.? Also, do they differ depending on who does the elicitation of goals? (Do they understand the concept? Etc.; once we know the gaps in information, how do tailor goal elicitation, information and education to these populations?
   c. Should the patient priorities care goal elicitation process be triggered by an event (eg hospitalization) or should this be a routine ascertainment?

    d. Do patients, families and caregivers perceive patient centered care differently than their healthcare providers? What questions are perceived as patient centered by the patient, family and caregivers vs. healthcare providers? How do you reconcile when there are differences between any of these groups?

5. **Roles**
    a. Is a peer group, nurse practitioner, social worker, app or physician more effective in eliciting goals and preferences? Effective could mean impactful, easy to elicit, different content, increased buy, degree to which care informs care decisions.
    b. What structures and processes would be needed for a team to effectively be a quarterback for care?
    c. What are some methodologies to effectively engage family caregivers? If family caregivers are engaged what effect does that have on outcomes?
    d. How do explicit role descriptions of the team impact outcomes?
    e. What competencies do patients or family caregivers need to effectively coordinate care? How does that impact outcomes?

6. **Electronic Medical Record (EMR)**
    a. Can Patient Priorities Care be provided (or modified) for settings without EMR/HER?
    b. What is the best way to document and communicate goals by patients or caregivers?
       i. What is the optimal template for both patients and providers?
       ii. Who is the person in charge of the template?
       iii. How do you integrate the template into the EMR?
       iv. Is the template generalizable outside of an EMR?
    c. What is needed for linking treatment recommendation to patient priorities?
       i. How can tools/technology help?

SECTION 4: Other Current Activities in Patient Priorities Care

The initial Planning Phase described in the Executive Summary evolved into three other simultaneous and overlapping initiatives to train, test, generate evidence for, and disseminate Patient Priorities Care. In addition to PCORI, these initiatives are funded by The John A. Hartford Foundation (JAHF), Gordon & Betty Moore Foundation, and Robert Wood Johnson Foundation:

1. **Pilot** Patient Priorities Care in a health care system with supportive infrastructure (PCMH, ACO). This process has two stages. First, develop technical assistance for processes needed to implement Patient Priorities Care, including training facilitators to work with patients and caregivers to elicit health outcome goals, developing appropriate workflows and HIT capability, and preparing clinicians to translate disease-specific goals into outcomes-goal aligned care. Second, implement Patient Priorities Care within a health care system. This approach is currently piloting this approach in a primary care organization in CT.

2. **Scaling up** to develop ways to prepare patients, caregivers and clinicians for Patient Priorities Care has received funding. Working with the American College of Physicians, web based tutorials are being developed, including case scenarios, videos, and interactive training.

3. **Increasing awareness** and demand through a comprehensive communications strategy. A professional communications firm has been recruited to heighten awareness and build demand for this type of care as well as influence policy at a national level. As part of this work, we have launched a website and have an active Twitter presence.

These efforts are informed and supported by the findings of this PCORI Eugene Washington Award reported in this White Paper to develop a research agenda to support Patient Priorities Care.

SECTION 5: Next Steps

The research agenda generated through this Engagement Award forms the basis upon which we, and our collaborators, are developing studies and publications. Specifically, planned activities include:

1. Reporting our research agenda findings in peer reviewed literature.
2. Developing technical support that includes materials for training patients, clinicians who work with patients to identify their priorities, and providers who care for patients with MCC. Technical support will include: Training materials, information about clinical workflow to incorporate patient priorities care into routine clinical care, and tips and strategies for collaborative learning by clinicians to teach them to re-orient clinical decision-making from disease-specific decision-making to clinical decision-making aligned with patients' priorities.
3. Testing and dissemination of Patient Priorities Care by partnering with specialty organizations to prepare providers to use principles of Patient Priorities Care for their patients with MCCs.
4. Partnering with and supporting stakeholders (patients and caregivers, clinicians and health systems) who want to implement and evaluate Patient Priorities Care.

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