

Community-based Palliative Care Delivery for Adult Patients with Advanced Illnesses and their Caregivers

PCORI Applicant Town Hall Session



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

July 13, 2016

Agenda

I. Welcome and Introductions

II. Background

III. PFA Overview

IV. Applicant Resources

V. Questions

Submitting Questions:



Submit questions via the chat function in Meeting Bridge.



Ask a question via phone (an operator will standby to take your questions).



Welcome to the Town Hall!



Jean Slutsky, PA, MSPH

Chief Engagement and
Dissemination Officer

Program Director,
Communication and
Dissemination Research Program



Steven Clauser, PhD, MPA

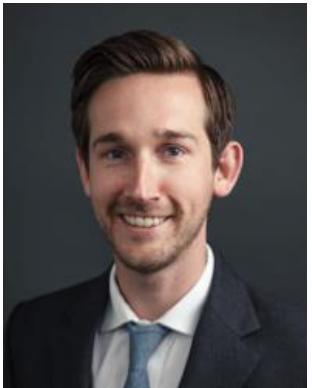
Program Director,
Improving Healthcare Systems

Introductions



Neeraj Arora, MS, PhD

Senior Program Officer,
Improving Healthcare
Systems Program



Chris Gayer, PhD

Program Officer,
Communication and
Dissemination Research
Program

Our Mission

- PCORI helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from **research guided by patients, caregivers and the broader health care community.**



Overview

- **Advanced, serious illnesses result in significant patient and caregiver burden in terms of physical and psychological symptoms and declining quality of life (QOL)** (Kelley and Morrison, 2015; IOM 2014)
- **Palliative care makes a difference**
 - Systematic reviews show that patients with advanced illnesses who receive palliative care services report clinically meaningful improvements in QOL, lower symptom burden, lower caregiver distress, and reduced hospitalizations (Dy et al., 2012; ICER, 2016; Gomez et al., 2013)
- **Core components of palliative care include:** (IOM, 2014; NCP, 2013)
 - Systematic assessment and management of patient symptoms
 - Psychosocial support for patients and caregivers
 - Advance care planning
 - Coordination among different clinicians to facilitate goal concordant care
- **Palliative care is more than hospice**
 - Hospice is a setting for delivering palliative care to individuals nearing death



Stakeholder Perspectives

- **Patients and caregivers:** Access to palliative care services is typically limited to inpatient hospitals or end-of-life hospice settings; patients and caregivers need palliative care where they live – in their community (CAPC, 2015)
- **Clinicians:** Limited workforce of palliative care specialists results in significant strain on meeting the needs of patients and caregivers in the community; community-based clinicians feel underprepared to communicate about and deliver palliative care (CAPC, 2015, Kamal et al., 2013)
- **Health systems and payers:** Several approaches to delivering community-based palliative care are emerging; decision makers need comparative information on the most **effective and efficient** ways of organizing and delivering palliative care in the community (ICER, 2016)
- **A 2014 WHO resolution** urges member states to integrate evidence-based palliative care services across all levels of care, **with emphasis on primary care, community and home-based care** (WHO, 2014)



PCORI Multi-stakeholder Workgroup

- 112 questions were submitted by 82 participants
- Two workshop breakouts discussed the following broad questions/categories:
 - ***Communication, Education, and Decision Making***
 - Clinician training and education
 - Patient and caregiver support and education
 - Shared decision making
 - Approaches to advanced care planning
 - Family communication
 - ***Models of Palliative Care Delivery***
 - Timing of palliative care delivery
 - Integrated vs. consultative models
 - Setting of palliative care delivery
 - Models of care focused on caregivers
 - Leveraging technology to deliver palliative care



Stakeholder Category	Count
patients	31
clinicians	16
hospitals/systems	3
industry	3
payers	2
researchers	27



Targeted PFA Goal

The goal of the proposed targeted PFA is to generate evidence to:

- Support **care planning over time** that is consistent with the goals and preferences of patients with advanced illnesses and their caregivers, and
- Support the **delivery of coordinated, community-based palliative care** that effectively implements those care plans



Question #1:

Advance Care Planning (ACP)



Question 1: Advance Care Planning

- *What is the comparative effectiveness of different patient and caregiver-directed, clinician-directed, and combination approaches to facilitating advance care planning conversations between adult patients living with advanced illnesses, their caregivers, and clinicians on patient-centered and other outcomes over time?*



Question 1: Advance Care Planning

Population:

- Geographically and racially/ethnically diverse **patients** living at home with any serious advanced illness who experience a high symptom burden and/or functional limitations, their **caregivers**, and/or **clinicians** providing health care to patients with advanced illness.
- Conditions may include but are not limited to:
 - Advanced heart failure
 - COPD
 - Advanced kidney disease
 - Advanced neurodegenerative diseases
 - Advanced cancers
 - Combinations of the above



Question 1: Advance Care Planning

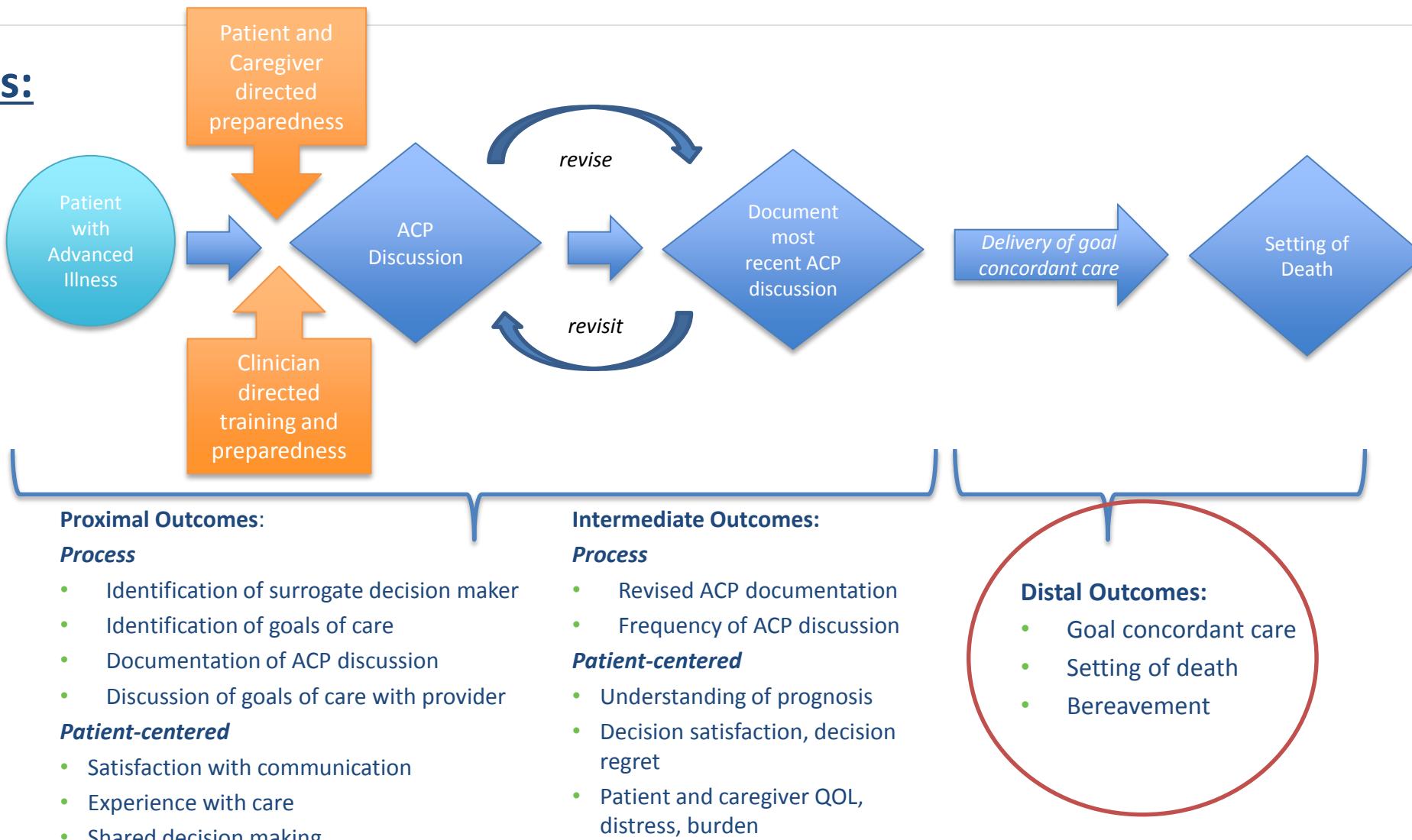
Interventions and Comparators:

- Two or more efficacious and/or widely used programs and/or interventions designed to facilitate advance care planning conversations **and** documentation of goals of care **over time.**
 - Approaches directed at patients and caregivers
 - Approaches to support clinicians in delivering ACP
 - Combined approaches



Question 1: Advance Care Planning

Outcomes:



Question 1: Advance Care Planning

Timing:

- Up to 5 years

Setting:

- Community-based settings such as hospital-based clinics, solo or group physician practices, and the patient's home.
- In-patient institutionalized settings such as nursing homes and hospices are not included under this announcement.

Study design:

- RCT; Cluster RCT; Comparative observational/natural experiment studies; Mixed methods

Sample size:

- N= 750+ patient and caregiver dyads
- multiple follow-up data collection points



Question 1: Advance Care Planning

Total Direct Cost Per Project: \$6M per study

Maximum Project Period: 5 years



Question #2: **Community Based Models of** **Palliative Care Delivery**



Question #2: Models of Palliative Care Delivery

- *What is the comparative effectiveness of different established models of palliative care delivery in community settings on improving patient-centered and other outcomes among adult patients with advanced illnesses and their caregivers?*



Question #2: Models of Palliative Care Delivery

Population:

- Geographically and racially/ethnically diverse **patients** living at home with any serious advanced illness who experience a high symptom burden and/or functional limitations and their **caregivers**.
- Conditions may include but are not limited to:
 - Advanced heart failure
 - COPD
 - Advanced kidney disease
 - Advanced neurodegenerative diseases
 - Advanced cancers
 - Combinations of the above



Question 2: Models of Palliative Care Delivery

Interventions and Comparators:

- Two or more established palliative care models that vary on one or more of the following parameters:
 1. **Level of integration** between primary/subspecialty clinicians and palliative care specialists (e.g., consultative model, nurse-led case management model, co-management model);
 2. **Site of palliative care delivery** (outpatient clinic/doctor's office, home, or both);
 3. **Method of care delivery** (in-person visit, remote/telemedicine, or both).



Question 2: Models of Palliative Care Delivery

Outcomes:

- *Primary*: E.g., patient and caregiver QOL; patients' symptom burden; patient and caregiver distress, caregiver burden; receipt of goal concordant care
- *Secondary*: E.g., patient experiences of and satisfaction with care, perceptions of symptoms management; healthcare utilization (hospitalizations, emergency department visits); out of pocket costs/expenses



Question 2: Models of Palliative Care Delivery

Timing:

- Up to 5 years

Setting:

- Community-based settings such as hospital-based clinics, solo or group physician practices, and the patient's home.
- In-patient institutionalized settings such as nursing homes and hospices are not included under this announcement.

Study design:

- Cluster RCT; Alternative randomized trial designs or comparative observational/natural experiment studies may also be proposed.

Sample size:

- N = 1,000+ patients and their caregivers (total N =2,000)
- Multiple follow-up data collection points



Question 2: Models of Palliative Care Delivery

Total Direct Cost Per Project: \$10M per study

Maximum Project Period: 5 years



Key Dates

Online System Opens:	August 15, 2016
LOI Deadline:	September 14, 2016, by 5:00 p.m. (ET)
Application Deadline:	December 19, 2016, by 5:00 p.m. (ET)
Merit Review Dates:	March 2017
Awards Announced:	June 2017
Earliest Project Start Date:	August 2017



Helpful Hints

1. Must propose comparative effectiveness studies
 - Be sure to consider and describe how the research is comparative and why the comparisons are important to healthcare decision making
2. Consider how to demonstrate your proposed project's strengths related to PCORI's review criteria, including:
 - Impact of the condition to be studied on the health of individuals and populations
 - Potential for the study to improve health care and outcomes
 - Technical merit
 - Patient-centeredness
 - Patient and stakeholder engagement
3. Recognize that you must submit a Letter of Intent (LOI)
 - You must be invited, on the basis of the LOI, to submit an application
4. PCORI does not fund:
 - Research aimed at developing clinical practice guidelines
 - Cost-effectiveness analysis measuring dollar-cost per quality-adjusted life-year



Applicant Resources

Palliative Care Pre-announcement:

- <http://www.pcori.org/funding-opportunities/announcement/community-based-palliative-care-delivery-adult-patients-advanced>

Stakeholder workgroup meeting materials:

- <http://www.pcori.org/events/2016/prioritizing-comparative-effectiveness-research-questions-patient-centered-palliative>

May 23, Board of Governors Meeting Slides:

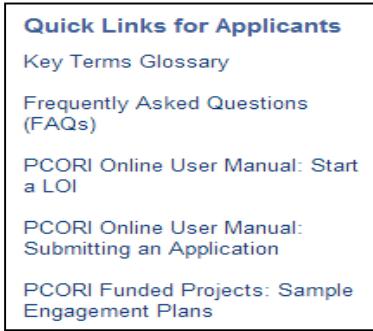
- <http://www.pcori.org/sites/default/files/PCORI-Board-Meeting-Presentation-Slides-052316.pdf>

PCORI Topic Brief: Patient-Centered Palliative Care Delivery for Adult Patients with Advanced Illnesses and Their Caregivers:

- <http://www.pcori.org/sites/default/files/PCORI-Palliative-Care-Stakeholder-Workshop-Topic-Brief-030716.pdf>



Applicant Resources: Where Can I Find Help?



Visit pcori.org/apply

- Application Guidelines
- FAQs
- PCORI Online User Manuals



For technical assistance

- PCORI Helpdesk: pfa@pcori.org



For programmatic assistance

- sciencequestions@pcori.org



Q&A



Ask a question via the chat function in Meeting Bridge.



Ask a question via phone (an operator will standby to take your questions).

If we are unable to address your question during this time, e-mail the Helpdesk at pfa@pcori.org.

