

# Advisory Panel on Improving Healthcare Systems

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May 27, 2015. 9:30 a.m. – 5:00 p.m. EST

May 28, 2015. 8:30 a.m. – 1:00 p.m. EST



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Welcome & Introductions

*Steven Clauser, PhD, MPA*

*Director, Improving Healthcare Systems*

# Housekeeping

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- Today's webinar is open to the public and is being recorded.
- Members of the public are invited to listen to this teleconference and view the webinar.
- Anyone may submit a comment through the webinar chat function, although no public comment period is scheduled.
- Visit [www.pcori.org/events](http://www.pcori.org/events) for more information.
- Chair Statement on COI and Confidentiality



# Panel Leadership

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- Doris Lotz, MD, MPH
  - IHS Advisory Panel Chair
- Michael Dueñas, OD
  - IHS Advisory Panel Co-Chair



# Advisory Panel Members

- **Jim Bellows, PhD, MPH \***  
*Senior Director, Care Management Institute, Kaiser Permanente*
- **Mary Blegen, RN, MA, PhD, FAAN**  
*Adjunct Professor, College of Nursing, University of Colorado at Denver*
- **David Bruhn, PharmD, MBA**  
*Health Outcomes Liaison, National Accounts, GlaxoSmithKline*
- **Daniel Cherkin, MS, PhD**  
*Director, Bastyr University Research Institute Senior Scientific Investigator, Group Health Research Institute*
- **Bonnie Clipper, DNP, RN, MA, MBA, FACHE, CENP \***  
*Vice President, Patient Care Services and Chief Nursing Officer, Medical Center of the Rockies*
- **Elizabeth Cox, MD, PhD**  
*Associate Professor, Departments of Pediatrics and Population Health Sciences, University of Wisconsin-Madison*
- **Timothy Daaleman, DO, MPH \***  
*Professor and Vice Chair, Family Medicine, University of North Carolina at Chapel Hill School of Medicine*
- **Lisa Freeman\***  
*Independent Patient Safety Advocate and Consultant*
- **John Galdo, PharmD, BCPS**  
*Clinical Pharmacy Educator, Barney's Pharmacy*
- **Ravi Govila, MD\***  
*Vice President, Medical Management and PPO, Blue Cross Blue Shield of Michigan*
- **Eve Kerr, MD, MPH**  
*Director, Ann Arbor Center for Clinical Management Research*
- **Joan Leon, BA**  
*Retired Health Consultant*
- **John Martin, MPH**  
*Senior Director, Research Operations, Premier Inc.*
- **Carolyn Petersen, MS, MBI \***  
*Senior Editor, MayoClinic.org*
- **Susan Salahshor, MPAS, PA-C**  
*Physician Assistant, Liver Transplant, Mayo Clinic in Florida*
- **Anne Sales, RN, PhD**  
*Professor, School of Nursing, University of Michigan*
- **Jamie Sullivan, MPH**  
*Director of Public Policy, COPD Foundation*
- **Leonard Weather Jr., MD, RPH**  
*Director, Omni Fertility and Laser Institute*

\* Indicates New Panel Members



# The Improving Healthcare Systems Program Staff



Steven Clauser, PhD, MPA  
Director



Penny Mohr, MA  
Sr. Program Officer



Beth Kosiak, PhD  
Program Officer



Neeraj Arora, PhD  
Sr. Program Officer



Els Houtssteller, PhD  
Sr. Program Officer



Michelle  
Johnston-Fleece, MPH  
Engagement Officer



Carly Parry, PhD, MSW  
Sr. Program Officer



Lauren Azar, MHA  
Sr. Program Associate



Alex Hartzman, MPH, MPA  
Program Associate



Andrea Hewitt, MPH  
Program Associate



Hannah Kampmeyer  
Senior Admin Assistant

# Introductions

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- What's your **name**?
- What **stakeholder group** do you represent and/or the organization do you represent?
- Say a little bit about your **passion** and **what made you interested in PCORI**.



# Today's Agenda & Meeting Objectives

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- **Day 1:**
  - IHS Program & PCORI Updates
  - Strategic Vision
  - Topic Refinement Breakout Session
    - Comparative Effectiveness of Different Models for Screening for Intimate Partner Violence (IPV)
  - PCORnet Presentation
- **Day 2:**
  - Topic Refinement Breakout Session
    - Comparative Effectiveness of Different Models of Palliative Care Delivery for Life Limiting Illnesses
  - Prioritization Process for Future Meetings



# IHS Program & PCORI Updates

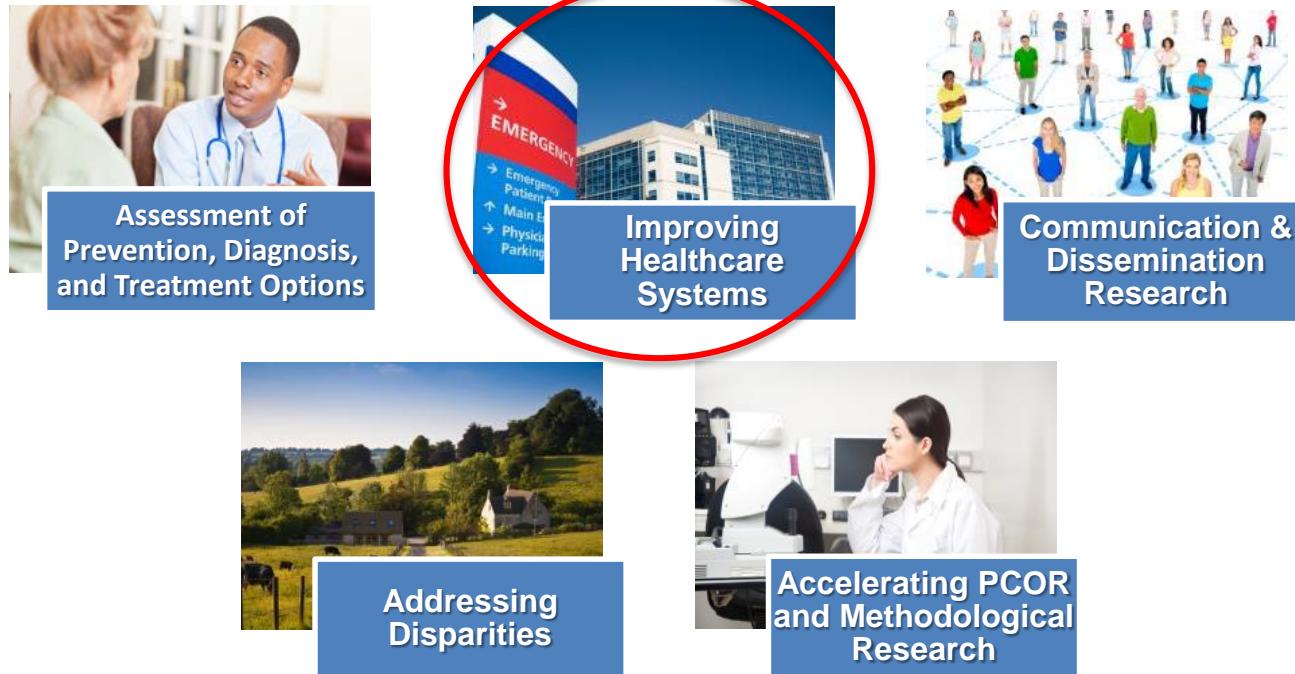
*Steven Clauser, PhD, MPA*

*Director, Improving Healthcare Systems*

# Overview of PCORI and IHS

## PCORI's 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.**



## IHS Goal Statement

To support studies of the comparative effectiveness of alternative features of healthcare systems that will **provide information of value to patients, their caregivers and clinicians, as well as to healthcare leaders, regarding which features of systems lead to better patient-centered outcomes.**

# Distinctive Components of IHS Studies

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- Adapt patient-centered outcomes research (PCOR) model beyond clinical treatment options to different levels of the healthcare system;
- Require inclusion of well-articulated comparators (ideally head-to-head comparisons);
- Focus on outcomes relevant to patients;
- Involve patients and other stakeholders in the entire research process; and
- Conduct research in real-life settings.



# The IHS Portfolio Overview

- 64 Projects; \$203 million funding; 22 States & D.C.

Funding Mechanism	N of Projects	Total Funding as of 5/13/15
Broad	59	\$123 million
Pragmatic	3	\$36 million
Targeted	2	\$45 million
<b>Total</b>	<b>64</b>	<b>\$203 million</b>

- **Broad:** Both small (\$1.5M, 3 year) and large (\$5M, 5 year) investigator-initiated studies; 2 cycles per year; competitive LOIs
- **Pragmatic:** \$10M, 5 year head-to-head comparisons in large, representative study populations and settings; PCORI, IOM, and AHRQ CER priorities; 2 cycles per year
- **Targeted:** Largest and require greatest specificity; range from \$5M - \$30M; often collaborations with other organizations; ad hoc funding

AP  
Priorities



# Our Funded Studies Database

- <http://www.pcori.org/research-results>

*Tips: Enter search terms to search the title, researchers, and abstracts. You may also filter by the categories listed below. Select desired terms from the drop-down lists and then click the GO button to view the results.*

Displaying 1 - 50 of 64

Search our awards

Enter a keyword

Primary Condition/Disease

All

Download the filtered data as an .xls

State

All

PCORI Research Priority Area

Improving Healthcare Systems

Award Type: Research

All

Award Type: Program

All

GO

RESET

Year Awarded	Project Title	Organization	State
2015	<a href="#">Comparative Effectiveness of State Psychotropic Oversight Systems for Children in Foster Care</a>	Rutgers The State University of New Jersey, New Brunswick	New Jersey
2015	<a href="#">Simplifying Survivorship Care Planning: Comparing the Efficacy and Patient-Centeredness of Three Care Delivery Models</a>	Johns Hopkins University	Maryland
2015	<a href="#">Integrating Online Weight Management with Primary Care Support: Patient-Centered Strategies for Addressing Overweight and Obesity in Primary Care</a>	Brigham and Women's Hospital	Massachusetts
2015	<a href="#">Putting Patients at the Center of Kidney Care Transitions</a>	Duke University	North Carolina

All public abstracts for PCORI-funded studies are available on our website and accessible through a searchable database (shown left)



# The IHS Portfolio – Targeted Funding

- Targeted funding initiatives are the most resource intensive
  - Require greatest specificity
  - Take most time for development
    - Expert workgroups
    - Iterative review with Board Subcommittee
    - Review and approval by the Board of Governors

Funded Targeted Topics	Total Funding Allocated
STRIDE / Falls Injury Prevention (Administered by NIA)	\$30 million
Effectiveness of Transitional Care*	\$15 million

Targeted Topics Under Development	Total Funding Allocated
Hepatitis C Virus	\$50 million total (joint effort-PCORI)
Integration of Mental Health and Primary Care*	N/A (joint effort-external)
Multiple Sclerosis	N/A (joint effort-PCORI)
Chronic Back Pain for Musculoskeletal Disease*	N/A (June expert workgroup)

\* Topics prioritized by the IHS Advisory Panel

# The STRIDE Study



STRategies to  
Reduce  
Injuries and  
Develop confidence in  
Elders

- PCORI-National Institute of Aging research partnership
  - \$30 million / 5-year award made June 1, 2014
- Multisite cluster randomized clinical trial
  - 6,000 diverse, community-dwelling participants age 75+
  - 10 systems / 86 local practices across 15 states
- Status Update:
  - Pilot complete
  - Main trial scheduled to launch June 2015



# Project ACHIEVE

(Achieving Patient-Centered Care and Optimized Health In Care Transitions by Evaluating the Value of Evidence)

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- \$15 million/3 year award; Project started January 1, 2015
  - Retrospective/Prospective observational cohort study
  - Aims to identify forms of transitional care that produce the best patient-centered results for different patients in different healthcare contexts.
    - 6-year retrospective data analysis to select a subset of TC clusters for the prospective study;
    - Prospective cohort analysis will compare patients and caregivers exposed to pre-defined clusters of TC services versus matched cohorts exposed to little or no TC services (40 hospitals; 12,000 patients)
- Status Update:
  - First interim progress report complete and on time
  - Protocol submitted for review by external methods committee
  - First face-to-face meeting June 11-12, 2015
  - Developing an Evidence to Action Network



# The IHS Portfolio – Pragmatic Clinical Studies

IHS has funded 3 studies in 2 cycles thus far:

1. **“Early Supported Discharge for Improving Functional Outcomes After Stroke”**  
– PI: Pamela Duncan, PhD, PT at Wake Forest University
2. **“A Pragmatic Trial to Improve Colony Stimulating Factor Use in Cancer”** – PI: Scott Ramsey, MD, PhD at Fred Hutchinson Cancer Research Center
3. **“Integrating Patient-Centered Exercise Coaching into Primary Care to Reduce Fragility Fracture”** – PI: Christopher Sciamanna, MD at Penn State U Hershey Medical Center

## Improving Healthcare Systems Priority Topics Included in Most Recent PFA

Topic	Date Prioritized
Integration of Mental Health and Primary Care	April 2013
Perinatal Care	April 2013
Discharge from the NICU	January 2015
Prevention of Dental Caries	January 2015
Chronic nonspecific, musculoskeletal pain	May 2014
Pharmacy Integration	January 2015
Suicide Prevention	January 2015



# Insurance Features Updates

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- Two topics discussed at Oct. 2014 meeting:
  - Enrollee Support for Patients in High-Deductible Health Plans
  - Comparison of Accountable Care Organizations (ACOs) for Improving Patient-Centered Care
- Multi-stakeholder workgroups held January 8-9, 2014
  - Meeting summaries and a list of attendees is available on our website
  - Ongoing discussions with AHRQ
  - Continuing to receive proposals through our broad funding announcement



# Status of Other Prioritized Topics

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- April 2013 Meeting
  - Patient-Empowering Care Management
    - Working with the John A. Hartford Foundation on a jointly funded project to develop the CaRe-Align model of empowering care for older adults with multiple chronic conditions
- May / October 2014 Meetings
  - Linkages Between Providers and Community
    - Incorporated as part of other initiatives (e.g., ACO topic and Falls project). No further action planned.
  - Patient Engagement in Quality Improvement Projects
    - Focus of PCORnet Health Systems pilot projects



# Future Directions and Considerations

**GAO Highlights**

March 2015

**COMPARATIVE EFFECTIVENESS**

**Initial Assessment of the Patient-Centered Outcomes Research Institute**

**Highlights of GAO-15-301, a report to congressional committees**

**Why GAO Did This Study**

In 2010, PPACA authorized the establishment of PCORI as a federally funded, nonprofit corporation to improve the quality and relevance of CER. PCORI, which began operation in 2010, is required to identify research priorities, establish a research project agenda, fund research consistent with its research agenda, and disseminate research results, among other things. To fund PCORI, PPACA established the Patient-Centered Outcomes Research Trust Fund, through which the institute is expected to receive an estimate of \$3.5 billion from fiscal year 2010 through 2019.

PPACA mandated that GAO review PCORI's activities by 2015 and 2018. This report assesses (1) the extent to which PCORI establishes priorities and processes for funding and disseminating comparative clinical effectiveness research consistent with its legislative requirements; (2) the status of PCORI's efforts to fund comparative clinical effectiveness research; (3) PCORI's plans, if any, to evaluate effectiveness of its work; GAO reviewed relevant legislative requirements and PCORI documentation, including funding data, and interviewed PCORI officials. GAO also interviewed relevant stakeholders, including health policy experts and PCORI contractors. PCORI provided technical comments, which GAO incorporated as appropriate.

**What GAO Found**

The Patient-Centered Outcomes Research Institute (PCORI) has established priorities and processes for funding comparative clinical effectiveness research (CER)—which is research that evaluates and compares health outcomes and the clinical effectiveness, risks, and benefits of two or more medical treatments, services, or items such as health care interventions—and is developing dissemination plans, consistent with the legislative requirements of the Patient Protection and Affordable Care Act (PPACA). In 2012, PCORI established five broad research priorities: (1) assessment of prevention, diagnosis, and treatment options; (2) improving health care systems; (3) researching communication and dissemination strategies; (4) comparing interventions to reduce health disparities; and (5) accelerating patient-centered outcomes research and methodological research. PCORI has developed a research agenda with the first priority priority would be addressed. PCORI has established a multi-step research funding process designed to assess and select contract applications for funding. Funded contracts are monitored by PCORI staff. Per legislative requirement, PCORI is developing a peer review assessment process to review final reports submitted by contract awardees and is in the process of developing a plan for the dissemination of funded research potentially beginning in 2015, in coordination with the Agency for Healthcare Research and Quality.

PCORI has started awarding contracts for research and plane to award additional contracts through 2019. As of October 2014, PCORI has awarded 360 contracts to fund research projects, committing a total of \$670.8 million to them. PCORI expects to commit about \$2.6 billion to research contracts, out of \$3.5 billion in total estimated spending. Approximately \$105 million in commitments to date are for PCORNet, a data research network aimed at improving the capacity for and speed of conducting CER. PCORI officials stated that they expect to spend a total of \$271 million on PCORNet through fiscal year 2019. PCORI officials stated that limited amounts of data will be available through PCORNet for researchers to use after September 2015 with the amount of available data increasing over time.

PCORI has established an evaluation plan and is developing efforts to measure outcomes. PCORI has developed initial plans for evaluating the institute's efforts against its three strategic goals, which are to increase information, speed implementation, and influence research. To do so, PCORI has developed primary outcome measures for assessing PCORI's progress related to these strategic goals. In its strategic plan, PCORI notes that these are meant to be long-term measures because research typically requires several years to complete and address your strategic goals and to demonstrate impact. Therefore, since 2013, PCORI has been using early and intermediate process and output measures—such as the number of people accessing or referencing PCORI information—as a way to monitor its progress toward its strategic goals. PCORI anticipates having some early results related to its primary outcome measures starting in 2017 after the first CER studies are completed and their findings released, although full evaluation of the results of these outcome measures will not be possible until around 2020.

View GAO-15-301. For more information, contact Kathleen M. King at (202) 512-7114 or [King@gao.gov](mailto:King@gao.gov).

United States Government Accountability Office

GAO's initial assessment of PCORI found that PCORI has met its mandate to establish research priorities and a research agenda as well as processes to seek proposals for and fund useful comparative effectiveness research (CER) studies! Moving forward, we will continue to:

- Evaluate and build upon existing portfolio to identify and strategically manage clusters of research projects
- Fund research through the Broad, Targeted and Pragmatics PFAs with a greater proportion of larger, potentially more impactful studies
- Fund key targeted initiatives, with increasing emphasis on selected Priority Topics
- Build partnerships with other agencies
- Work closely with our Board and Board subcommittees

[www.gao.gov/products/GAO-15-301](http://www.gao.gov/products/GAO-15-301)



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# How does this Influence the Advisory Panel's Work?

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- Need greater precision by the Advisory Panel
  - Clear articulation of specific CER questions that can be answered with PCORI-funded research
  - Provide recommendations for research that's focused on specific interventions, populations, settings, etc.
  - Focus on topics and questions that PCORI can impact with its research
  - New processes will help with these efforts
- Greater involvement of the Board of Governors and Board sub-committee on topics



# Discussion

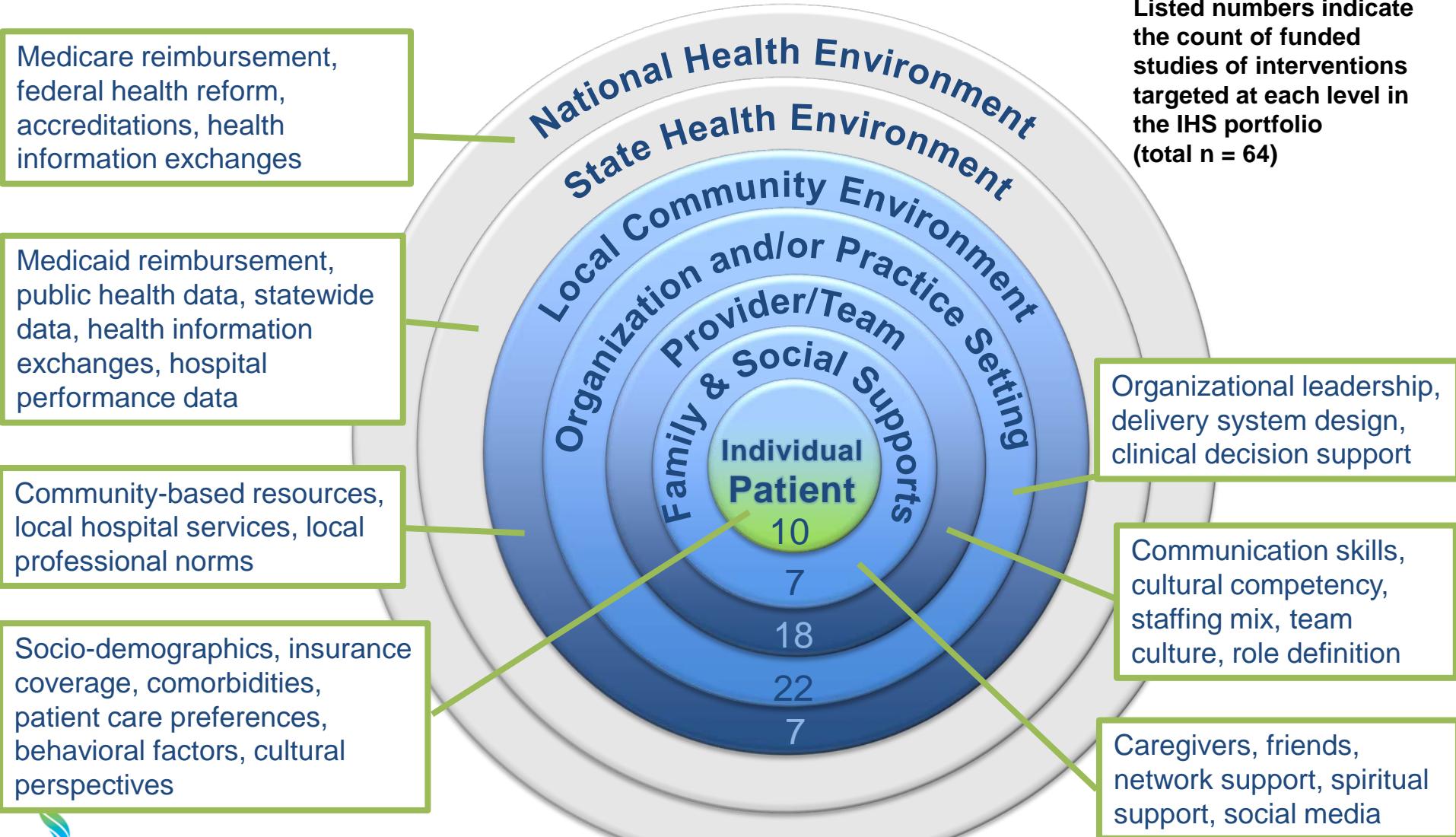
# Strategic Framework

**Lauren Azar, MHA**

*Senior Program Associate, Improving Healthcare Systems, PCORI*

# The Healthcare System

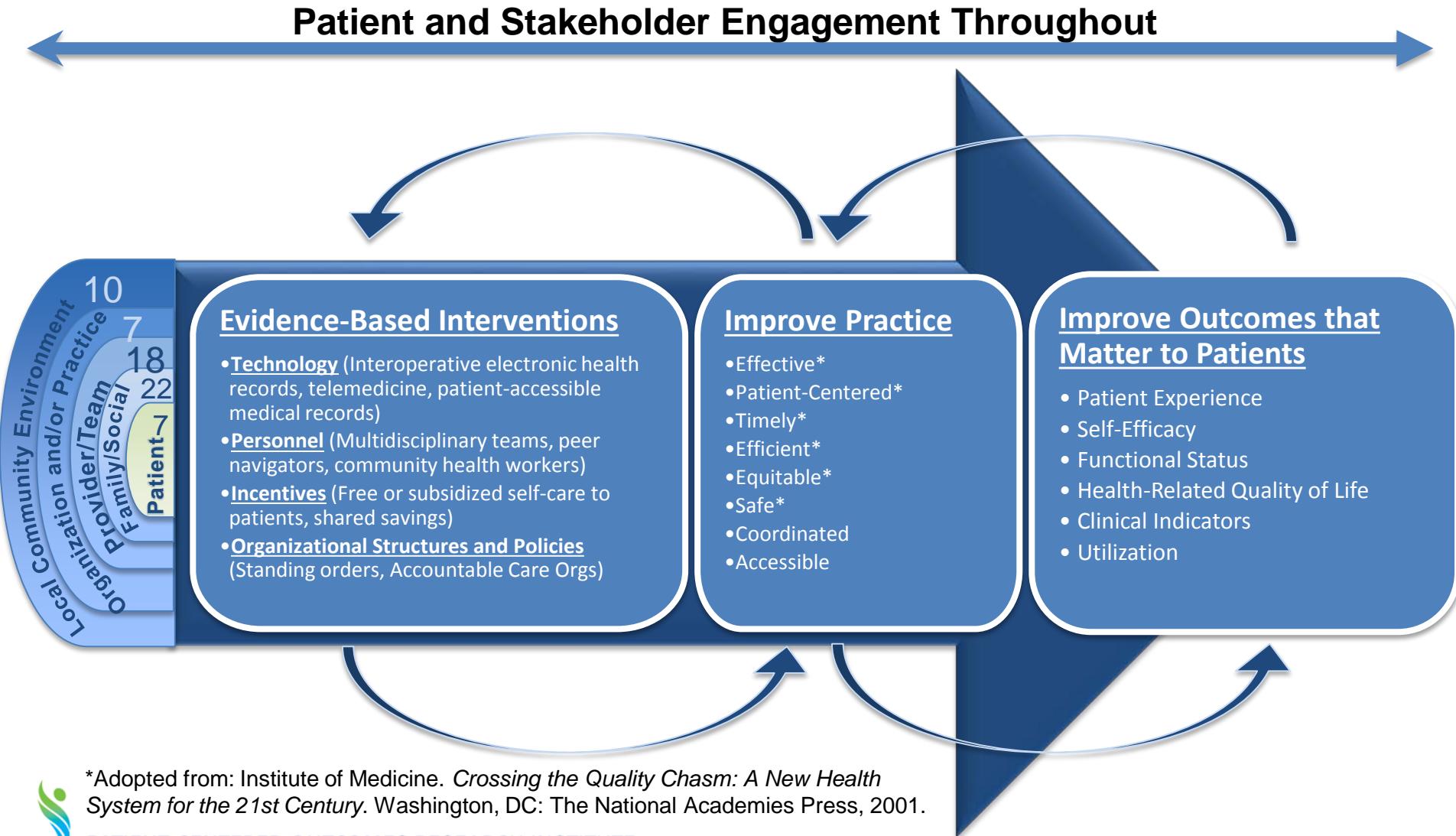
Figure adapted from: Taplin, SH; Clauser, S., et al. (2012). Introduction: Understanding and Influencing Multilevel Factors across the Cancer Care Continuum. *Journal of the National Cancer Institute*, 44, 2-10.



# Studies Comparing Interventions by System Level

System Level	# of Studies in the IHS Portfolio	Examples of Comparisons in the IHS Portfolio
Individual Patient	10	Compares the use of an electronic asthma medication tracker to standard primary care (no tracker) for children with asthma and their parents and caregivers
Family and Social Supports	7	Compares the use of advance planning tools for access to community-based and in-home services for the frail elderly and their caregivers to an electronic educational intervention of available services and programs
Provider/Team	18	Compares nursing home staff team-based training and palliative care delivery using an adapted National Quality Forum protocol to a standard nursing home palliative care protocol
Organization and/or Practice Setting	22	Compares elements of Patient-Centered Medical Home (e.g., addition of a primary care physician in the context of regularly scheduled dialysis sessions and health promoters to help support patients and their caregivers) to traditional team-based specialty care for end-stage renal disease patients
Local Community Environment	7	Compares an emergency department to home community health worker that links patients with community-based social-support (e.g., home-delivered meals) and medical follow-up, to care transition programs using written and verbal discharge instructions alone.

# IHS Strategic Framework



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# Vision for the Future

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- This is a continuously evolving framework
  - Continue to update with funded projects
  - Goal is to ensure a balanced portfolio
  - Aiming for a realistic structure for evaluating our work that encompasses the most critical aspects of our research and accounts for critical issues facing patients and other stakeholders in the real world



# Discussion

# Lunch Break

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12:15 p.m. – 1:00 p.m. EST



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# Objectives of Breakout Sessions & Formulating CER Questions

*Penny Mohr, MA*

*Senior Program Officer, Improving Healthcare Systems*

# Break-Out Session Format

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- Today's Topic: "Comparative Effectiveness of Different Models for Screening for Intimate Partner Violence (IPV)"
- Tomorrow's Topic: "Comparative Effectiveness of Different Models of Palliative Care Delivery for Life Limiting Illnesses"

## Sequence of Events:

1. Topic presentation to full panel based on topic brief
2. Disburse to assigned break-out group
  - Three break-out groups organized by stakeholder (see assignments)
  - Facilitators and note takers assigned; Will need to identify the report back presenter
  - Reference hand-outs: Topic briefs, sample CER questions, guides
3. Note taker will help presenter put together report back slides
4. Panel will reconvene; 3 presenters report back for each of their groups; followed by discussion facilitated by PCORI staff



# Break-Out Session Objectives

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- Recommend whether the topic is well suited for PCORI to fund
  - Consider the prioritization criteria, and where the topic might be weak
- Consider what specific populations/subpopulations would be important to study
- Recommend what interventions should be compared or tested
- Identify specific CER questions and rank them
  - Hand-outs with example CER questions provided
- List key stakeholder groups we should involve in the topic development process moving forward



# How to Write a Research Question



**PEOPLE:** the group of people to be studied

**OPTIONS:** the choices or options that should be compared

**OUTCOMES:** what good and bad things a patient can expect from each option to help them make a decision



# What Research Questions are Within PCORI's Mandate?

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- PCORI funds studies that compare the benefits and harms of two or more approaches to care.
- Cost-effectiveness: PCORI will consider the measurement of factors that may differentially affect patients' adherence to the alternatives such as out-of-pocket costs, but it cannot fund studies related to cost-effectiveness or the costs of treatments or interventions.
- Disease processes and causes: PCORI cannot fund studies that focus on risk factors, origins, or mechanisms of disease.



# Collaborative Break-Out Discussion

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- Focus: Provide targeted input without scientific jargon
- Participate: Encourage exchange of ideas among diverse perspectives
- Be respectful: Disagree with ideas, not people
- Ask for help when you need it: PCORI staff will be present at each break-out session



# Questions / Discussion



# Topic Presentation:

## *Screening for Intimate Partner Violence (IPV)*

*Presenter:*

*Dan Cherkin, MS, PhD*

*Senior Scientific Investigator, Group Health  
Research Institute*



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# Screening for Intimate Partner Violence

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- Compare the effectiveness of health system approaches that aim to increase *identification of and improve outcomes for* patients directly affected by intimate partner violence.



# Screening for Intimate Partner Violence

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- Introduction to the Topic
- Patient-Centeredness and Impact/Burden of the Condition
- Evidence Gaps and Ongoing Research
- Potential Research Questions
- PCORI Funding on this Topic



# Introduction to the Topic

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- Intimate partner violence (IPV) is harm that occurs between current or former romantic partners/spouses. IPV can take the form of physical, sexual, or psychological abuse.
- Screening is any range of methods that aims for all patients in a healthcare setting to be asked about having experienced or currently experiencing IPV.
- The effectiveness of IPV screen is debated
  - Routine screening has been recommend by a 2011 IOM report and 2012 US Preventive Services Task Force and many associations have endorsed/provided limited guidelines
  - Research has found limited support for the effectiveness of universal screening by itself



# Patient-Centeredness and Impact/Burden

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## Patient-Centeredness:

- Direct relevance to patients experiencing IPV
- Screening leads to a 133% increase in the rate of IPV identification

## Impact/Burden of IPV:

- 27% of men and over 30% of women experience physical IPV
- Leading cause of injuries for women ages 15-44 and one of the leading causes of homicides for pregnant women
- Victims experience a wide range of medical problems as well as other health consequences such as substance abuse and mental health problems
- Large financial impact on the health system



# Ongoing Research and Evidence Gaps

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- There have been 10 RCTs on this area with only 3 of the 10 completed in the US. There is one major ongoing study.
- Insufficient evidence to justify universal screening for all women entering healthcare setting
  - Do not know which subgroups, at which stage, may benefit from screening
- Research suggest screening with more intensive interventions may be effective with certain high risk female populations
- New research is needed on:
  - What circumstances IPV screening is to be done
  - Effectiveness of screening plus a comprehensive intervention
  - Differences in outcomes for universal vs. targeted screening



# Potential Research Questions

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- What is the comparative effectiveness of conducting universal IPV screening compared to targeted screening in acute care, primary care, obstetrics/gynecology offices or all setting?
- For separate samples of men and women, what is the comparative effectiveness of (a) IPV screening only, (b) IPV screening followed by a comprehensive intervention, (c) IPV screening followed by a brief intervention, or (d) a control group receiving no screening/no interventions for improving patient-centered outcomes for IPV victims?
- What is the comparative effectiveness of a brief intervention targeting women that seeks to reduce IPV and problem drinking vs. a brief intervention focused on IPV only?
- What is the comparative effectiveness of alternative interventions (e.g., advocacy, risk assessment, patient decision aid) to reduce mental health consequences of intimate partner violence (depression, sleep disorders, and anxiety) among patients experiencing intimate partner violence?



# PCORI Funding on this Topic

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- PCORI has no studies funded related to IPV as of May 2015



# Breakout Session

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1:40 p.m. – 2:45 p.m. EST



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# Break

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2:45 p.m. – 3:00 p.m. EST



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# Report Back / Discussion

## Next Steps:

*Comparative Effectiveness of Different Models  
for Screening for Intimate Partner Violence (IPV)*

# PCORnet Presentation

*Sarah Green, MPH*

*Associate Director, CER Methods and Infrastructure*

# PCORnet: A Novel, Patient-Centered Infrastructure for CER

*Sarah Greene, MPH, Associate Director*

*CER Methods and Infrastructure Program, PCORI*

*Improving Health Systems Advisory Panel – May 27, 2015*



# Overview

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- Impetus, Opportunity, Challenge
- PCORnet Vision and Composition
- What Will Success Look Like?
- Projects Underway & On Deck

# The impetus: our national clinical research system is well-intentioned but flawed...

- ➊ High percentage of decisions not supported by evidence\*
- ➋ Health outcomes and disparities are not improving
- ➌ Current system is great **except:**
  - Too slow, too expensive, and not reliable
  - Doesn't answer questions that matter most to patients
  - Unattractive, burdensome to clinicians and administrators
  - *Has yet to harness immense potential of health data*

# The opportunity: a reusable infrastructure for comparative effectiveness research

- Clinical trial coordinating centers & large research networks are often established for one purpose or one funding cycle
- New trial or new condition typically begets construction of a new infrastructure
- Persistent inefficiencies in the current research process, from regulatory and operational to recruitment and data collection
- By blending capabilities of healthcare systems and patient-driven organizations in support of a sustainable national ecosystem for research, PCORnet can serve as a more efficient and effective platform for clinical CER

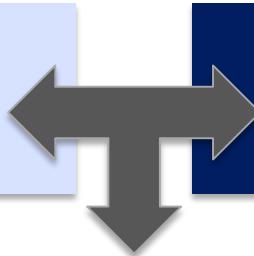
# The challenge: healthcare data

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“One great strength of prospective research remains the fact that data needs can be identified in advance and collected according to rigorous, pre-specified, and validated standards. Routinely collected patient data rarely meets such standards. **Most patient data has been collected to serve immediate clinical and business needs, not for research purposes.** Often there is significant variation in the categorization of data, the structure of reported data, and also the methods of soliciting and recording data.

**Vision for PCORnet is that it will enable rapid, large-scale, patient-centered clinical research in real-world care delivery systems and communities**

**PCORI is about  
*Research*  
Done Differently**



**PCORnet is about  
*Research Infrastructure*  
Done Differently**

Engaging patients and stakeholders is the cornerstone

# Composition: A Network of Networks



## 11 Clinical Data Research Networks (CDRNs)

System-based networks, such as integrated delivery systems, academic medical centers, federally qualified health centers,



## 18 Patient-Powered Research Networks (PPRNs)

Patients with a condition in common form a research network, often in collaboration with academic researchers



## Coordinating Center

Provides technical and logistical assistance under the direction of a steering committee and PCORI program staff



# PCORnet Facts & Figures

## 29 networks + Coordinating Center

- 11 Clinical Data Research Networks
- 18 Patient-Powered Research Networks

} Complementary and synergistic capabilities in the 2 types of networks

## 155 involved organizations across the US

## 3000+ collaborators/contributors

## Multiple millions of patients cared for in the participating systems

## Phase I = March 1, 2014 – September 30, 2015

## Phase II = October 1, 2015 – September 30, 2018

## PCORI investing **≈\$275M** to build this infrastructure

## Among the 18 PPRNs, 9 are focused on rare conditions

# 75 Participating Health Systems in 11 CDRNs...

Lead Organization (Network name)	Partnered Health Systems
Patient Outcomes Research To Advance Learning (“PORTAL”)	<ol style="list-style-type: none"><li>1. Denver Health</li><li>2. Group Health Cooperative</li><li>3. Group Health Research Institute</li><li>4. HealthPartners Research Foundation</li><li>5. KP Center for Effectiveness &amp; Safety Research</li><li>6. KP Colorado (Institute for Health Research)</li><li>7. KP Georgia (Center for Health Research)</li><li>8. KP Hawaii (Center for Health Research)</li><li>9. KP Mid-Atlantic States (Mid-Atlantic Permanente Research Institute)</li><li>10. KP Northern California (Division of Research)</li><li>11. KP Northwest (Center for Health Research)</li><li>12. KP Southern California (Department of Research &amp; Evaluation)</li></ol>
PaTH: Towards a Learning Health System in the Mid-Atlantic Region (“PaTH”)	<ol style="list-style-type: none"><li>1. University of Pittsburgh/UPMC and UPMC Health Plan</li><li>2. Penn State College of Medicine/Hershey Medical Center</li><li>3. Temple University School of Medicine/Temple Health</li><li>4. Johns Hopkins Univ/Johns Hopkins Health System &amp; Johns Hopkins Health Care</li></ol>
Children’s Hospital of Philadelphia (“PEDSNet”)	<ol style="list-style-type: none"><li>1. Children’s Hospital of Philadelphia</li><li>2. Cincinnati Children’s Hospital Medical Center</li><li>3. Children’s Hospital Colorado</li><li>4. Nemours Children’s Health System</li><li>5. Nationwide Children’s Hospital</li><li>6. St. Louis Children’s Hospital</li><li>7. Seattle Children’s Hospital</li><li>8. Boston Children’s Hospital</li></ol>

# 75 Participating Health Systems in 11 CDRNs...

Lead Organization (Network name)	Partnered Health Systems
Harvard Medical School ("SCILHS")	<ol style="list-style-type: none"><li>1. Boston Children's Hospital</li><li>2. Partners (Mass General and Brigham and Women's Hospital)</li><li>3. Wake Forest Baptist University Medical Center</li><li>4. Cincinnati Children's Hospital</li><li>5. University of Texas Health Science Center</li><li>6. Columbia University</li><li>7. Morehouse School of Medicine</li><li>8. University of Mississippi Medical Center</li></ol>
Vanderbilt University ("Mid-South CDRN")	<ol style="list-style-type: none"><li>1. Vanderbilt Health System</li><li>2. Vanderbilt Healthcare Affiliated Network (VHAN)</li><li>3. Greenway Medical Technologies</li></ol>
University of California San Diego ("pSCANNER")	<ol style="list-style-type: none"><li>1. University of California Research eXchange (UC-ReX) network</li><li>2. VA Informatics and Computing Infrastructure (VINCI)</li><li>3. UC San Diego (UCSD),</li><li>4. VA Tennessee Valley Healthcare System</li></ol>
University of Kansas Medical Center ("Great Plains Collaborative")	<ol style="list-style-type: none"><li>1. University of Kansas Medical Center</li><li>2. Children's Mercy Hospital</li><li>3. University of Wisconsin-Madison</li><li>4. Medical College of Wisconsin</li><li>5. Marshfield Clinic</li><li>6. University of Health Sciences at San Antonio</li><li>7. University of Texas Southwestern Medical Center</li><li>8. University of Iowa Healthcare</li><li>9. University of Minnesota</li><li>10. University of Nebraska</li></ol>

# 75 Participating Health Systems in 11 CDRNs...

Network name Lead Organization/PI	Partnered Health Systems
NYC-CDRN Weill Medical College	<ol style="list-style-type: none"><li>1. New York-Presbyterian Hospital</li><li>2. Weill Cornell Medical College</li><li>3. Columbia University Medical School</li><li>4. Montefiore Medical Center</li><li>5. NYU Langone Medical Center</li><li>6. Mount Sinai Health System</li><li>7. Clinical Directors Network (FQHC)</li></ol>
Chicago Community Trust (“CAPriCORN”)	<ol style="list-style-type: none"><li>1. Loyola University</li><li>2. Northwestern Medicine</li><li>3. Northshore University Health System</li><li>4. University of Chicago</li><li>5. University of Illinois Hospital &amp; Health Sciences System</li><li>6. Cook County Health and Hospital System</li><li>7. Alliance of Chicago’s Federally Qualified Health Centers</li><li>8. Hines VA</li><li>9. Jesse Brown VA</li><li>10. Lurie Children’s Hospital</li><li>11. Children’s Hospital of University of Illinois</li><li>12. Comer Children’s Hospital</li></ol>
Accelerating Data Value Across a National Community Health Center Network (“ADVANCE”)	<ol style="list-style-type: none"><li>1. OCHIN</li><li>2. Health Choice Network</li><li>3. Fenway Clinic</li></ol>
Louisiana Public Health Institute (“Louisiana Clinical Data Research Network – LACDRN”)	<ol style="list-style-type: none"><li>1. Greater New Orleans Health Information Exchange</li><li>2. Louisiana State University</li><li>3. Louisiana Public Health Institute</li><li>4. Tulane University</li></ol>

# 80 Different Organizations Involved in 18 PPRNs...

Organization	PI	Condition	Population Size
Duke University	Laura Schanberg	Juvenile Rheumatic Disease	9000
ALD Connect, Inc	Florian Eichler	Adrenoleukodystrophy	3000
Phelan-McDermid Syndrome Foundation	Megan O'Boyle	Phelan-McDermid Syndrome	737
Immune Deficiency Foundation	Kathleen Sullivan	Primary Immunodeficiency Diseases	1250
University of Pennsylvania	Peter Merkel	Vasculitis	500 (Pilot)
Parent Project Muscular Dystrophy	Holly Peay	Duchenne and Becker muscular dystrophy	4000
Arbor Research Collaborative for Health	Bruce Robinson	Primary Nephrotic Syndrome (Focal Segmental Glomerulosclerosis [FSGS], Minimal Change Disease [MCD], and Membranous Nephropathy [MN]) Multiple Sclerosis	1250
Epilepsy Foundation	Janice Beulow	Aicardi Syndrome, Lennox-Gastaut Syndrome, Phelan-McDermid Syndrome, Hypothalamic Hamartoma, Dravet Syndrome, and Tuberous Sclerosis	1500
Genetic Alliance, Inc	Sharon Terry	Alström syndrome , Dyskeratosis congenital, Gaucher disease, Hepatitis, Inflammatory breast cancer, Joubert syndrome, Klinefelter syndrome and associated conditions, Metachromatic leukodystrophy, Pseudoxanthoma elasticum (PXE), Psoriasis	50- 50,000

# 80 Different Organizations Involved in 18 PPRNs...

Organization	PI	Condition	Population Size
University of California, San Francisco	Mark Pletcher	Cardiovascular Health	100,000
Cincinnati Children's Hospital Medical Center	Peter Margolis	Pediatric Crohn's Disease and Ulcerative Colitis	15,000
Crohn's & Colitis Foundation of America	R. Balfour Sartor	Inflammatory Bowel Disease (Crohn's disease and ulcerative colitis)	30,000
Global Healthy Living Foundation	Seth Ginsberg	Arthritis (rheumatoid arthritis, spondyloarthritis), musculoskeletal disorders (osteoporosis), and inflammatory conditions (psoriasis)	50,000
American Sleep Apnea Association	Susan Redline	Sleep Apnea	50,000
COPD Foundation	Richard Mularski	COPD	50,000
Accelerated Cure Project for Multiple Sclerosis	Robert McBurney	Multiple Sclerosis	20,000
University of South Florida	Rebecca Sutphen	Hereditary Breast and Ovarian Cancer (HBOC)	17,000
Massachusetts General Hospital	Andrew Nierenberg	Major Depressive Disorder, Bipolar Disorder	50,000

# CDRN Spotlight: Greater Plains Collaborative (GPC)

## Engagement

Pioneers Research Registry, developed in collaboration w/community members, has >18,000 participants and offers opportunity for community members to sign up to be contacted about research in which they may be interested by completing a brief health history. It will serve as a rich resource for GPC activities.

## Potential Impact

Brings together a diverse population of 6 million people across 1300 miles covering 7 states with a combined area of 679,159 square miles, including patients in rural and underserved minority areas

GPC builds on strong research programs, existing community engagement and informatics infrastructures, and data warehouses developed through the NIH Clinical and Translational Science Award initiative

*Russell Waitman, PhD  
University of Kansas Medical Center*

*CER Methods and Infrastructure,  
awarded December 2013*

# PPRN Spotlight: Community Engaged Network for All (CENA)

## Engagement

Leaders and affected individuals from each condition community convene to oversee CENA

## Potential Impact

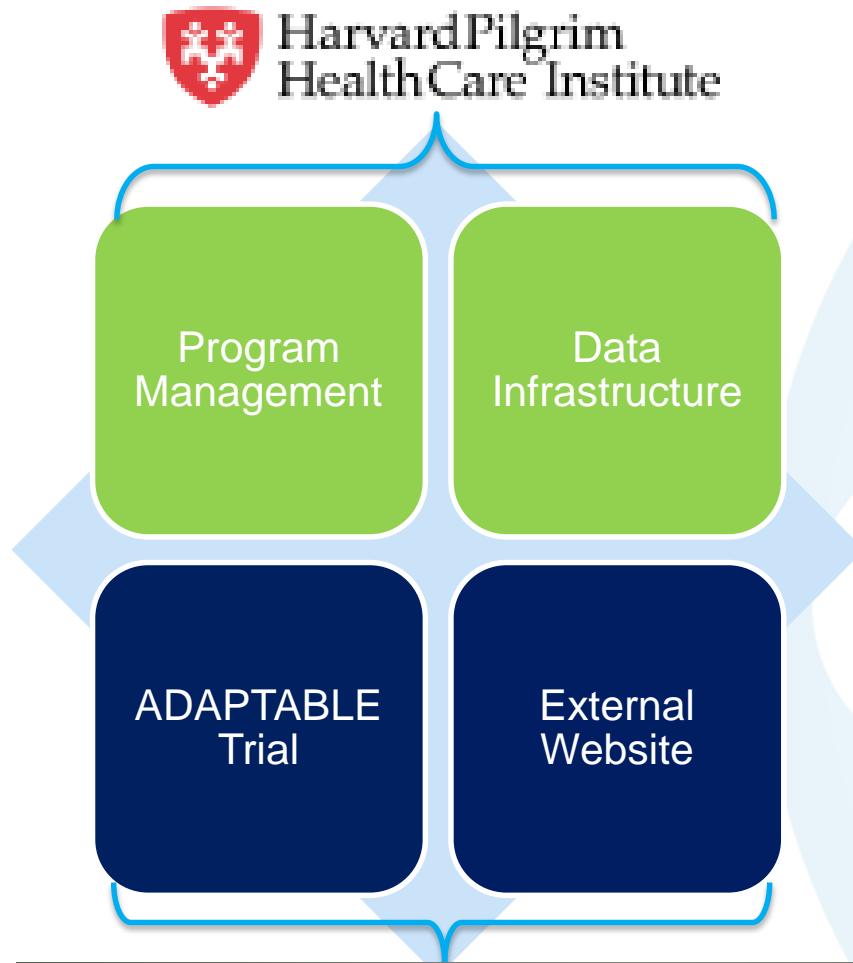
Could change practice by shifting research culture from one where academic researchers reach out to participants, to one where participants lead

Through participant-led governance models and cost-effective data capture from participants using the PEER platform, ten Disease Advocacy Organizations (DAOs) will launch or update online registries for each disease condition and invite additional participants to engage in participant-centric research.

*Sharon Terry, MA,  
Genetic Alliance, Inc.*

*CER Methods and Infrastructure  
Awarded December 2013*

# Coordinating Center, co-led by Harvard and Duke, supports PCORnet



# PCORnet Steering Committee

- Each Clinical Data Research Network (n=11)
- Each Patient Powered Research Network (n=18)
- Patient representative
- HHS agencies (*potential funders, data suppliers*)
  - NIH
  - FDA
  - AHRQ
  - CDC
  - CMS
  - ONC
  - ASPE
- Pharmaceutical / device manufacturers
- PCORI and Coordinating Center

**Purposeful composition of the Steering Committee to help ensure that PCORnet influences research funded or conducted by others**

# Hallmarks of Success at 18 Months

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1. Highly **engaged** patients, clinicians, health systems, researchers and other partners
2. A **collaborative community** supported by robust governance
3. Analysis-ready **standardized data** with strong privacy protections
4. Oversight that **protects patients**, supports the timely conduct of research, and builds trust in the research enterprise
5. Research that is **sustainably integrated** into care settings and with communities of patients

Most PCORnet networks came together as new partnerships, with relatively little collaboration together before being funded through PCORnet—we are simultaneously building the **infrastructure AND culture**



# Proving the Concept with New Large-scale Research Projects

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Guiding principle of PCORnet: make research easier

- Analysis-ready data in standard format, with harmonized definitions, built-in quality checks
- Reusable analysis tools (“Library” of analytic queries)
- Efficient clinical trial enrollment and follow up
- Simple, pragmatic studies integrated into routine care
- Administrative simplicity
- Patient involvement
- Common Data Model that includes Common PRO measures

Initial PCORnet projects will help assess end-to-end functionality: design, implementation, analysis, reporting

# Demonstration Projects in Development

- **ADAPTABLE** – an RCT comparing two doses of Aspirin in Patients with heart disease (secondary prevention)
- **CER in the Weight Cohort** –two large observational studies under development (bariatric surgery outcomes; antibiotic exposure in children and weight gain)
- **Rapid-Cycle Research** with health systems and health plans – multi-system comparative research on systems improvement
- **PPRN Demonstration Projects** – up to eight single PPRN studies, and one multi-PPRN studies

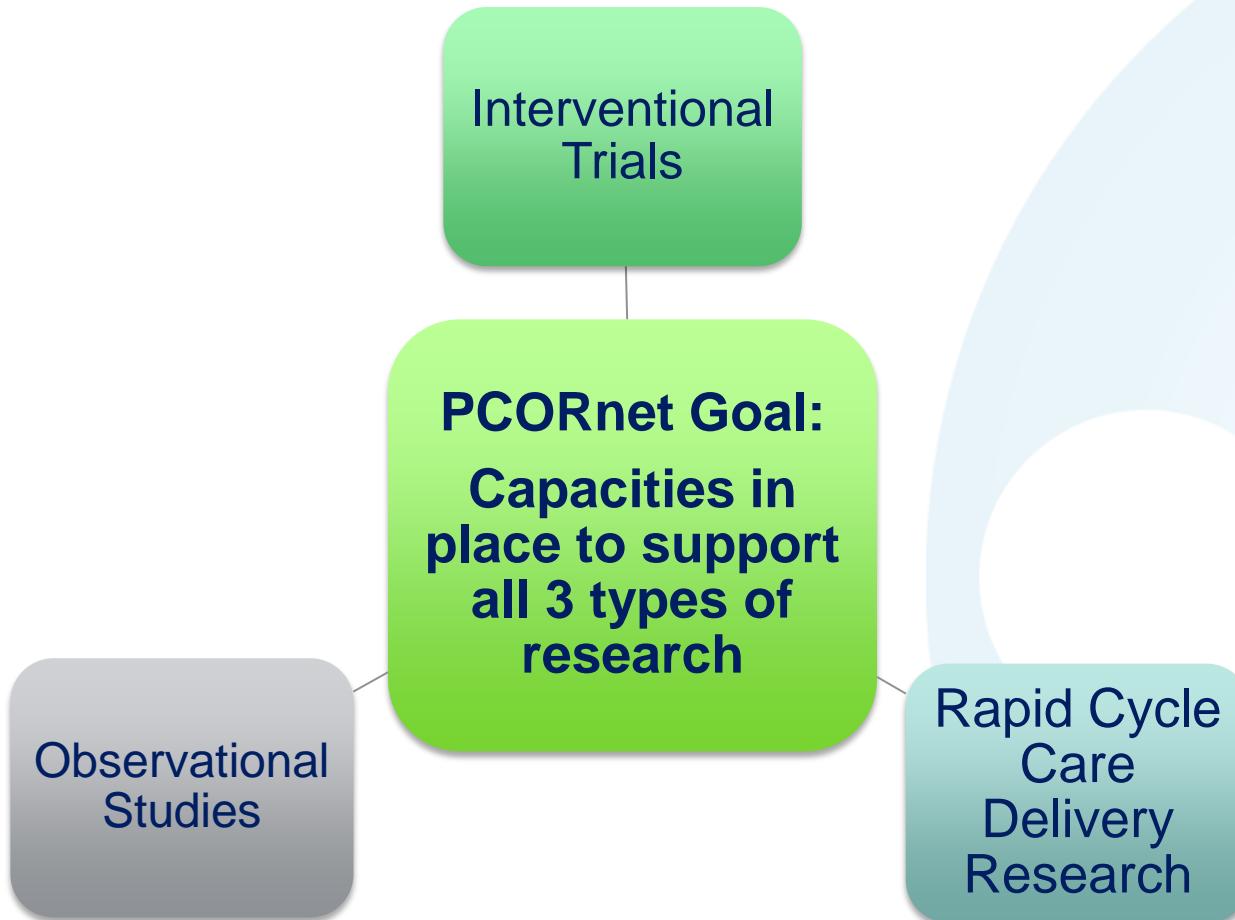
Awarded  
May 2015

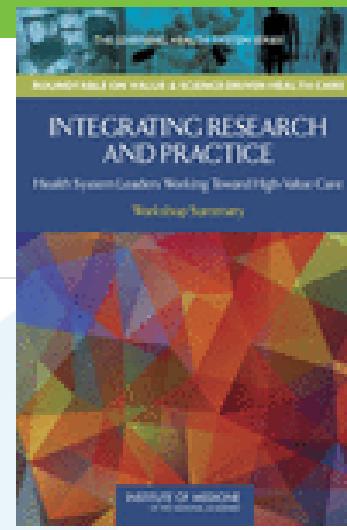
Applications  
due today!

CDRNs  
developing  
topics

PFA under  
development

# PCORnet Infrastructure and a “Research Triple Aim”





# Integration of Research & Practice

- PCORI – IOM meeting held on June 20, 2014
- 29 health systems leaders (most from PCORnet health systems: KP, Vanderbilt, UIC, UPMC, NYU)
- System leaders not keen on either embedded clinical trials or large observational studies
- But excited by prospect of closer ties with PCORnet researchers and data; a focus on research on system performance, and on opportunities for iterative data analyses and rapid-cycle turnaround of data

# Development Process for Health Systems Demonstration Project

 **Step 1:** PCORI will provide support to PCORnet sites to engage health systems leaders to work jointly to identify and prioritize a set of data-driven research activities of high interest to systems and/or clinicians within the systems; this will be supported by the PCORnet Coordinating Center's Health Systems Interaction and Sustainability Task Force

- Total costs not to exceed \$1 million over 1 year

 **Step 2:** PCORI will encourage submission of proposals of high priority to health systems for up to five one-year studies. These studies will be awarded through a limited PFA.

- Total costs not to exceed \$4 million.

# Guiding Principles for Identifying Health System Research Demonstration Projects

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- Project must be of interest and add value for two or more PCORnet health systems
- Project must leverage data resources (PCORnet Common Data Model) with or without additional health system data
- Topics should be rated as priority by CEOs/system leaders, and their input should be included in the PFA responses
- Topics must involve iterative review and discussion between researchers and health systems leaders
- Initial projects may be descriptive projects or they may evaluate utility of data sources for addressing specific questions of health systems leaders.

# **NEXT-D: Collaboration with CDC on Diabetes Research Initiative**

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- ➊ Natural Experiments in Translation – for Diabetes (NEXT-D)
- ➋ The NEXT-D study aims to understand how population-targeted policies affect prevention behaviors and diabetes outcomes (e.g., quantity and quality of care used, morbidity)
- ➌ PCORI will fund up to 3 CDRNs to participate in CDC's NEXT-D initiative, who also must have submitted a proposal to the CDC NEXT-D FOA
  - Applicants to CDC will submit a supplemental response to PCORI's limited PFA targeting our additional requirements: patient-centeredness, methodology standards, engagement
- ➍ Unique cross-agency collaboration

# Coming Into View – A National Resource

- Able to conduct large observational studies affordably using a common data model, distributed querying, sharing of data when needed
- Able to conduct clinical trials affordably through improved contracting, IRB coordination, engagement of clinicians and sites, and identification, recruitment, consenting and follow-up of subjects.
- Openness to data linkage with other databases, (e.g., registries, CMS) for funded studies
- Openness to collaboration with outside investigators across a wide range of topics

# Summary and Take-Away Points

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- PCORnet has made great strides in first 15 months toward building an infrastructure to support CER, and...
- ...We have a ways to go to test and fine-tune the overall capabilities – demonstration projects will help prove the concept
- Uniting of patients, researchers, and other stakeholders makes for a complex mix of the norms, mores, and ways of working—creation of culture and infrastructure at once
- Health Systems Demo Projects and NEXT-D will be jointly overseen by the PCORnet and IHS programs
- We will welcome the opportunity to share our progress with you periodically, or go deeper on a particular area

# Thank You!



[www.pcornet.org](http://www.pcornet.org)  
@PCORnetwork  
sgreene@pcori.org

# Recap of the Day

*Michael Dueñas, OD*

*Doris Lotz, MD, MPH*

# Next Steps & Closing Remarks

*Steve Clauser, PhD, MPA  
Director, Improving Healthcare Systems*

# Next Steps

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- This evening we will have a dinner at 6 p.m. (EST) for all panelists. We hope all of you can join!



# Adjourn

**Thank you for your participation!**

**Our meeting tomorrow will begin  
at 8:30 am EST**

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**www.pcori.org**



# Advisory Panel on Improving Healthcare Systems

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May 28, 2015

8:30 a.m. – 1:00 p.m. EST



# Housekeeping

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- Today's webinar is open to the public and is being recorded.
- Members of the public are invited to listen to this teleconference and view the webinar.
- Anyone may submit a comment through the webinar chat function, although no public comment period is scheduled.
- Visit [www.pcori.org/events](http://www.pcori.org/events) for more information.
- Statement on COI and Confidentiality



# Today's Agenda & Meeting Objectives

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- **Day 2:**
  - Topic Refinement Breakout Session
    - Comparative Effectiveness of Different Models of Palliative Care Delivery for Life Limiting Illnesses
  - Prioritization Process for Future Meetings
  - Working Lunch
    - Discuss potential future CER topics



# Topic Presentation:

## *Models of Palliative Care Delivery for Life Limiting Illnesses: Addressing Supportive Care Needs of Patients and Families*

*Timothy P. Daaleman, DO, MPH*  
*University of North Carolina at Chapel Hill*



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# Models of Palliative Care Delivery

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- Purpose: compare the effectiveness of different models of palliative care delivery for patients with life limiting illnesses on patient and family-centered outcomes.



# Models of Palliative Care Delivery

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- Introduction to the Topic
- Patient-Centeredness and Impact/Burden of the Condition
- Evidence Gaps and Ongoing Research
- Potential Research Questions
- PCORI Funding on this Topic



# Introduction to the Topic

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- **Definition:** Palliative care (PC) is *an approach to care* that targets improving quality of life of patients and their families by addressing problems associated with life-threatening illness; it is a broad *spectrum of care at any point in the illness trajectory*.
- **Palliative Care is provided in multiple ways:**
  - Settings include: hospitals, nursing homes, long-term acute care facilities, the patient's home, hospice, or outpatient clinics
  - Providers include:
    - Primary care physicians and specialty providers (e.g., oncologists, pulmonologists, cardiologists)
    - Palliative care specialists from social work, chaplaincy, nursing, palliative medicine, hospice, etc.



# Introduction to the Topic

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## Patient-Centeredness:

- Palliative care focuses on reducing burden of illness to patients, families/caregivers, relieving suffering, improving quality of life
- Patients and caregivers play important roles in managing symptoms and side effects of treatments between healthcare visits

- Evidence Base to Date:

- Numerous palliative care interventions have demonstrated ***efficacy*** on several patient-centered outcomes, work is needed to understand:
  - Relative benefits and harms of comparing different PC approaches
  - Timing, Target Populations, and Care Models
    - When to initiate palliative care, which patients, how to best integrate and coordinate this care, what are effects on caregiver burden, and how to determine symptom assessment and monitor care quality



# Impact/Burden

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## Impact/Burden:

- Population-Level → an aging US population will have a greater proportion of individuals likely to be diagnosed with chronic, life limiting illnesses
  - Increased illness burden is associated with symptoms, compromised functional status, and reduced quality of life
- Patient-Level → with life-threatening illness are likely to suffer from multiple chronic conditions
- Family/caregivers → also suffer profound physical and emotional consequences (e.g. caregiver burden, lowered quality of life)



# Ongoing Research and Evidence Gaps

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- **Palliative Care (PC)** systematic reviews (3) and a state-of-practice review showed:
  - PC trials that improved continuity of PC services did not include head-to-head comparisons of different care models
  - No study compared integrative vs consultative approaches to PC delivery
  - Few published studies used rigorous scientific methods
  - Wide variety of index diseases, populations, interventions, outcomes
    - → difficulty in comparing results
- Clinical practice guidelines are consensus-based (e.g., National Quality Forum, National Consensus Project, IOM); limited information to inform evidence-based guidelines and drive systems-level change



# 5 Potential Research Questions

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## 1. Timing of palliative care delivery:

- What is the comparative effectiveness of models involving palliative care specialists ***early in the disease course versus at key points*** based on changes in symptom burden on improving patient functioning and quality of life, reducing caregiving burden, and avoiding hospital and emergency department visits?

## 2. Coordination of palliative care:

- What is the comparative effectiveness of ***fully integrated palliative care models versus different modalities of consultative approaches*** (in person vs. virtual) on patient and family centered outcomes across life limiting illnesses?
  - Does the relative impact of different palliative care approaches depend upon variation in the trajectory of symptom burden and life expectancy associated with a life limiting illness?

## 3. Caregiver burden:

- What is the comparative effectiveness of ***different approaches for facilitating caregiver preparedness and self-care*** ability across the trajectory of life limiting illnesses on caregiver functioning and quality of life?



# 5 Potential Research Questions

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## 4. Caregiver burden:

- What is the comparative effectiveness of multicomponent interventions that include systematic assessment of caregiver burden and education **tools tailored** to caregivers' risk profile versus **untailored** caregiver education interventions versus usual care on caregiver functioning and quality of life?

## 5. Symptom assessment & monitoring:

- What is the comparative effectiveness of real time, in home assessment/monitoring of patients' symptom burden using **technology-supported interventions** such as patient portals and mhealth applications versus **clinic-based assessment** of patient symptoms on patients' functioning and quality of life during the course of a life limiting illness?



# PCORI Funding on this Topic

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- PCORI has funded 16 studies in palliative or end-of-life care (2/2015 analysis)
  - 4 are IHS studies of *palliative care approaches* in highly specific populations and settings
  - 2 are IHS oncology studies include a palliative care or goal of treatment aspect
  - 10 are studies of *decision aids*, patient/caregiver-provider communication or other decision-making aides that include goals of care, informed consent for high-intensity treatments, and other important aspects of decision-making for patients with life-threatening illnesses



# Breakout Session

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8:50 a.m. – 9:50 a.m. EST



# Break

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9:50 a.m. – 10:00 a.m. EST



# Report Back / Discussion



## Next Steps:

*Comparative Effectiveness of Different Models of  
Palliative Care Delivery for Life Limiting Illnesses*



# Future Meetings & Prioritization Process

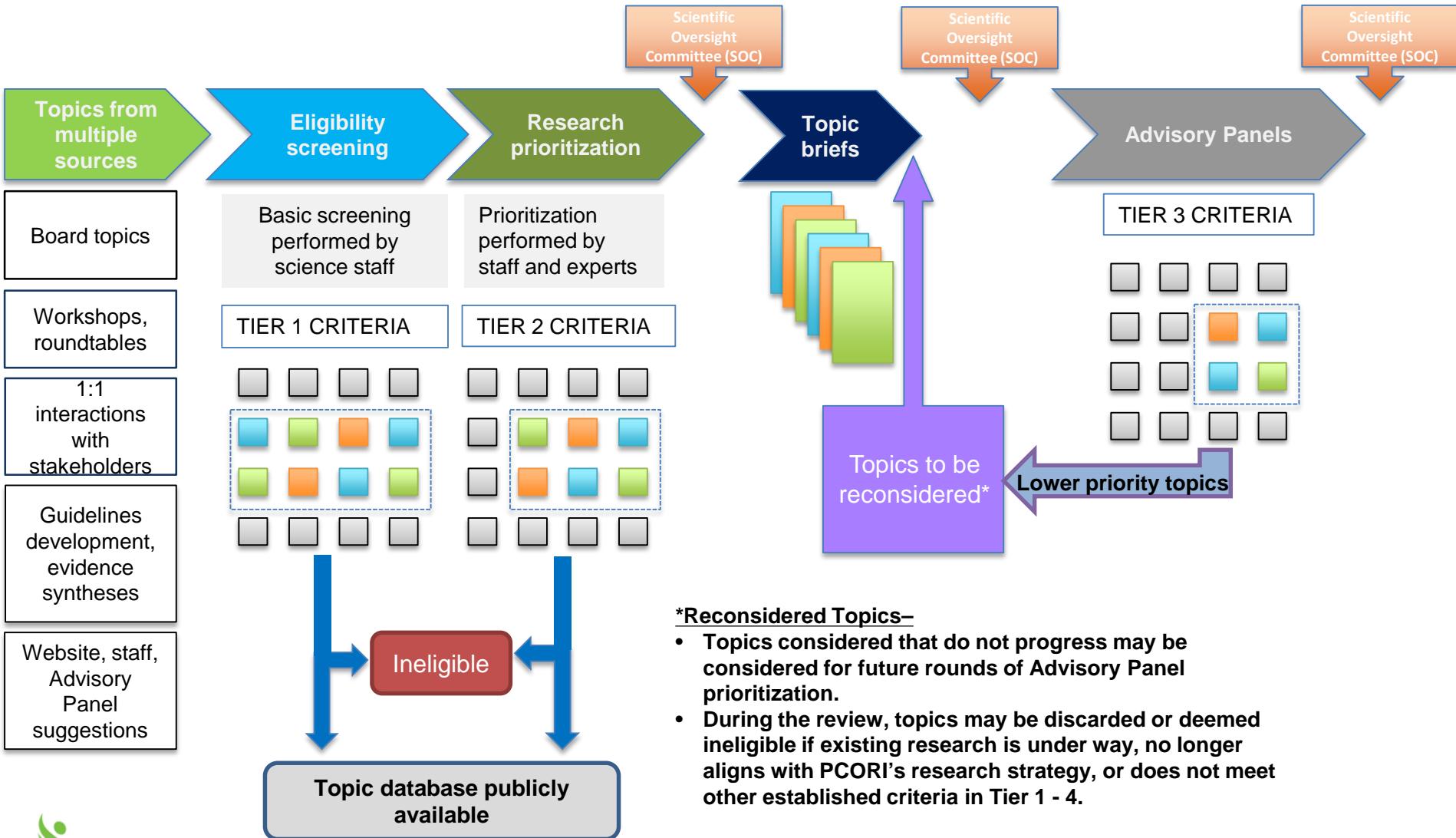
*Penny Mohr, MA*

*Senior Program Officer, Improving Healthcare Systems*

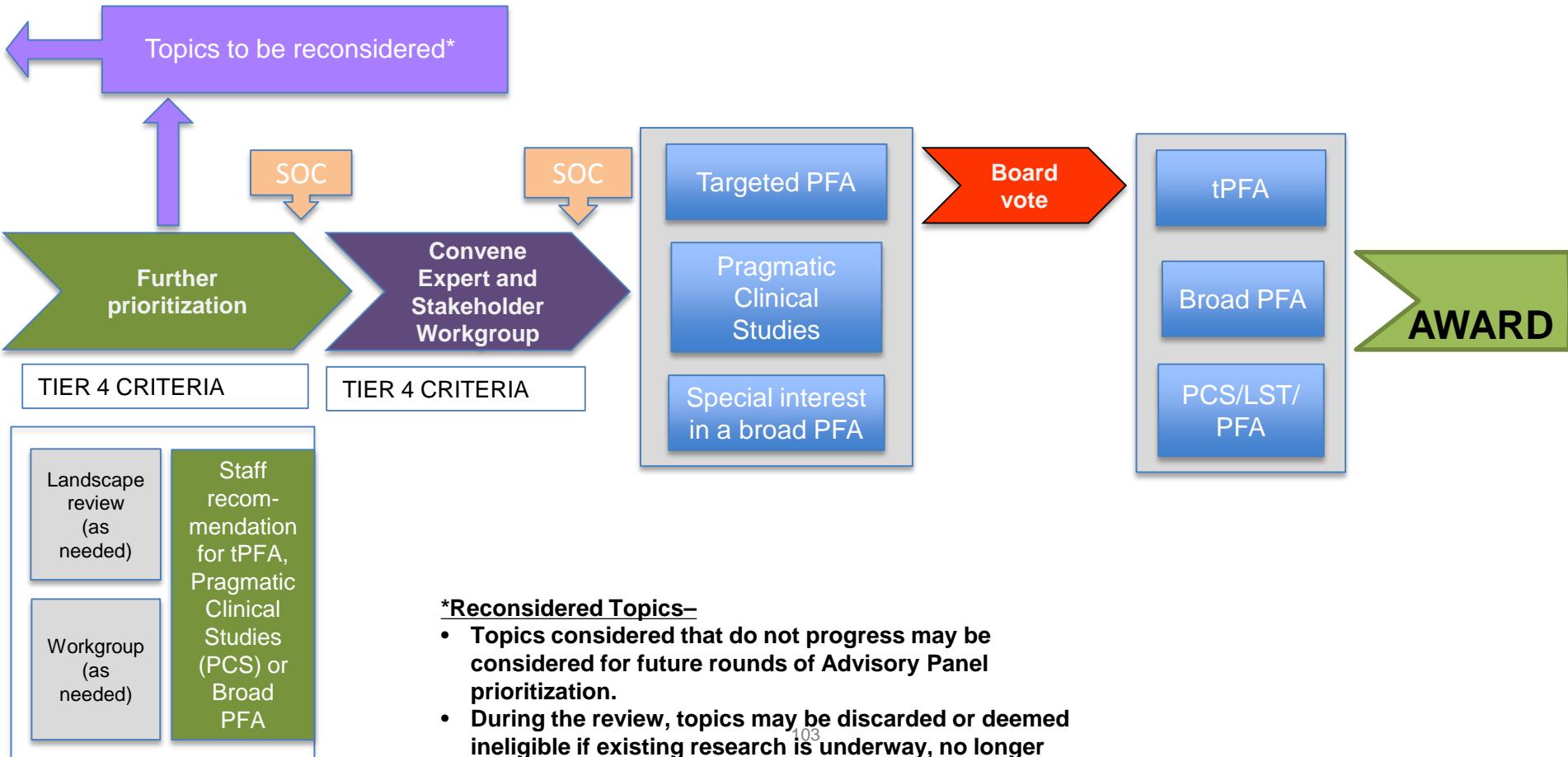


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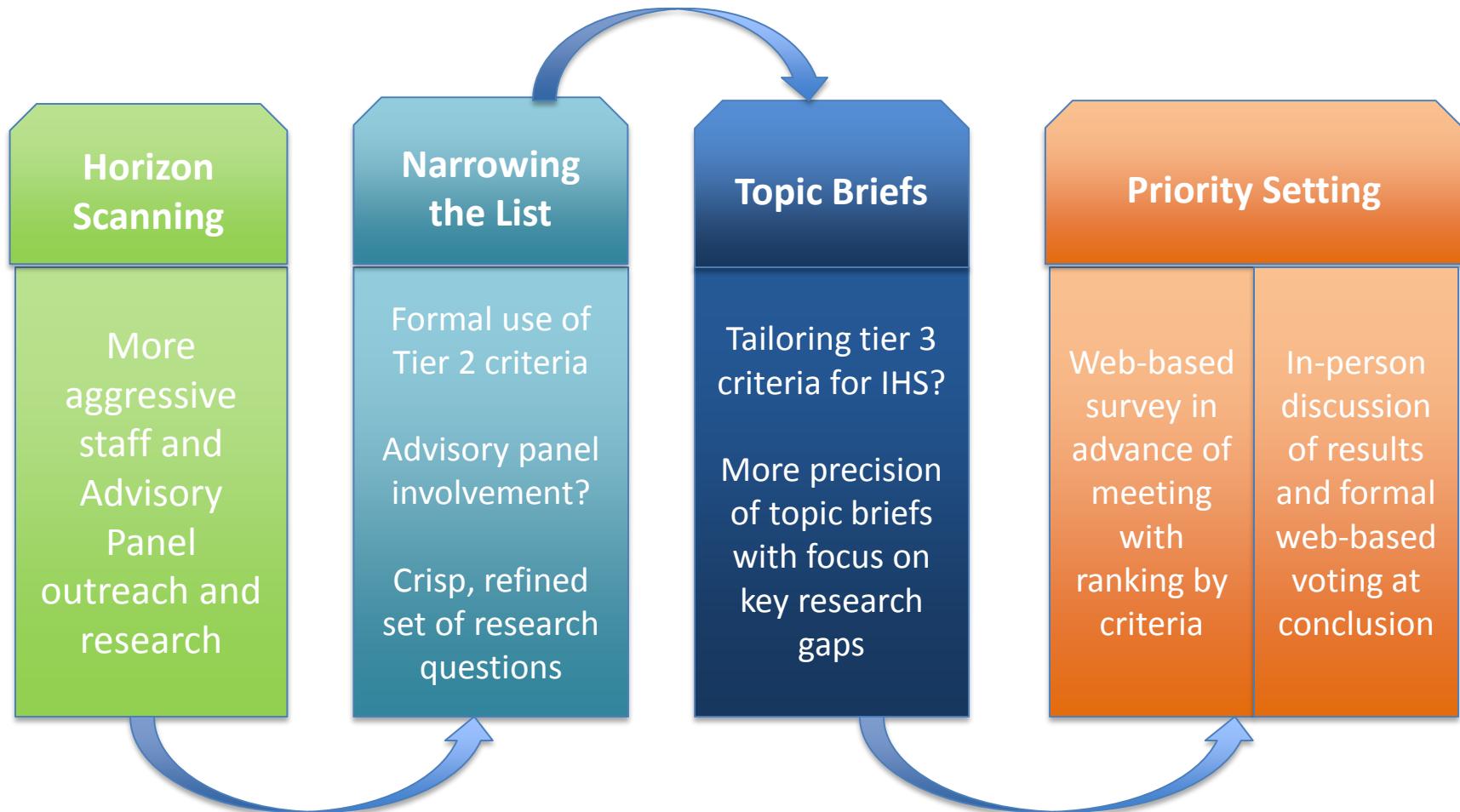
# PCORI Pathway for Topic Generation and Research Prioritization



# PCORI Pathway for Topic Generation and Research Prioritization



# Formalizing the Process



# Why Change?

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- To bring greater clarity and precision to the topic briefs and gain early buy-in from PCORI leadership
- To be more proactive in seeking input from a broad constituency focused on improving healthcare systems
- To include IHS-specific criteria that would improve the chances that our research findings are adopted and influence systems change
- To enable more discussion and consensus building among Advisory Panel members by using a formal modified-Delphi process



# Prioritization Process for Future Meetings

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## Sequence of Events:

1. Topic briefs sent to panelists ~2-3 weeks before pre-meeting prioritization survey is due
2. PCORI staff reports results of pre-meeting survey to panelists via email before the meeting
3. Panelists complete a second pre-meeting prioritization survey (if time permits)
4. PCORI staff distributes results before meeting or in hand-out form during the meeting
5. Presentation and discussion of the results for each of the highest ranked topics during meeting
6. Final prioritization of the top ranked topics during the meeting
  - Working to use more rigorous, formal methods
  - Have already done significant work to revise prioritization criteria



# Tier 3 Criteria Tailored for IHS

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**(1) Strongly Disagree; (2) Somewhat Disagree; (3) Neither Agree nor Disagree;  
(4) Somewhat Agree; (5) Strongly Agree**

- **Patient-Centeredness:** Patients and their family caregivers are likely to think evidence generated from the research question is relevant to them and their ability to make more informed decisions about their health care.
- **Impact on the Health of individuals and Populations:** Studies of this topic are likely to have a significant impact on the health of populations (in terms of prevalence, mortality, morbidity, individual suffering, and loss of productivity) and/or are likely to improve healthcare systems issues such as access to care, quality of care, and engagement in care.
- **Assessment of Current Options:** Research on this topic will address an important gap in the information available to patients and their caregivers, providers, and other key stakeholders.
- **Likelihood of Implementation in Practice:** Results from research on this topic have the potential to lead to meaningful improvement in the quality and provision of care.
- **Sustainability of Results:** New information on this topic is likely to remain current for several years. It is not likely to be rendered obsolete by new technologies or subsequent studies.



# Presentation of Data Example

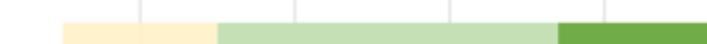
B. Displays the frequency of each ranked score for the criteria  
"overall importance" per question

Enrollee Support for High-Deductible Health Plans:  
Frequency of Overall Importance Score

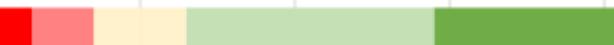
Comparison of PCOs between basic HDHP versus enhanced HDHP



For patients that are enrolled in high-deductible health plans, what is the difference in health outcomes for those that have "better pharmacy benefits" (exempt medications) vs. (nonexempt medications) paired with chronic disease management offered by employer vs. standard care?



What is the impact of clinical outcomes and utilization for employees that have an HRA vs. HSA account (controlling for the level of funding) and vs. no account associated with the high-deductible health plan?



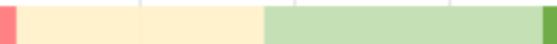
What are the most effective mechanisms (E-assistance, personal, or community partners) to inform consumers regarding coverage of preventive services (and those that are exempt from the deductible) under their plan?



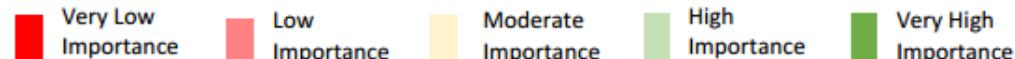
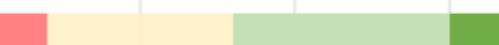
What is the difference in outcomes between having primary care visits in-house for free/low-cost covered by employer vs. out-of-house primary care visits covered by the employer vs. telemedicine vs. standard (out of house)?



What are the most effective mechanisms to inform consumers regarding services without first-dollar coverage, or which require out-of-pocket payment, under their plan?



Compare the PCO effect of social and financial incentive structures on the understanding of and engagement with high-deductible health plans.



# Discussion



# Lunch Break

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12:00 - 12:15 p.m. EST



# Working Lunch to Discuss Potential Topics for Future Prioritization

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12:15 – 1:00 p.m. EST



# Recap of the Day

*Michael Dueñas, OD*

*Doris Lotz, MD, MPH*



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# Next Steps & Closing Remarks

*Steve Clauser, PhD, MPA  
Director, Improving Healthcare Systems*



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# Adjourn

## Thank you for your participation!



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