

# Advisory Panel on Communication and Dissemination Research

---

October 1, 2015  
8:00 a.m. to 5:00 p.m. ET



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Welcome

## Jean Slutsky, PA, MSPH

Chief Engagement and Dissemination Officer  
Program Director, Communication and Dissemination Research,  
Patient-Centered Outcomes Research Institute

## Lauren McCormack, PhD, MSPH

Director, Center for Communication Science, RTI International  
Communication and Dissemination Research Panel Chair



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Housekeeping

---

- 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 or by emailing [advisorypanels@pcori.org](mailto:advisorypanels@pcori.org).
- Visit [www.pcori.org/events](http://www.pcori.org/events) for more information.
- Chair Statement on COI and Confidentiality



# Agenda

---

8:00 a.m. – Welcome, Introductions, Recap of May Meeting

8:30 a.m. – Patient/Caregiver Journey Mapping

9:15 a.m. – Outcomes and Behaviors of PCORI studies

10:15 a.m. – Break

10:30 a.m. – Clinician Perspective on Challenges with Engaging Patients

11:00 a.m. – Discussion of RTI/UNC Literature Review

12:00 p.m. – Lunch

12:45 p.m. – Patient Perspectives on Challenges with Engaging Physicians

1:15 p.m. – Review of Research Questions

2:00 p.m. – Outcome of Effective Communication and Dissemination

2:30 p.m. – Break

2:45 p.m. – Continue Discussion on Outcome of Effective Communication and Dissemination

3:30 p.m. – Framework of Communication and Dissemination

4:30 p.m. – Wrap-up and Next Steps



# Introductions

## **Danny van Leeuwen, MPH, RN, CPHQ**

Principal, Health Hats

Communication and Dissemination Research Panel Co-Chair



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Recap of May Meeting

**Michelle Henton, MA**

Program Associate, Communication and Dissemination Research



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Current CDR Priority Areas

---

1. **Communication strategies** to promote the use of health and healthcare CER evidence by patients and clinicians
2. **Dissemination strategies** to promote the use of health and healthcare CER evidence by patients and clinicians
3. **Explaining uncertain health and healthcare CER evidence** to patients and clinicians

## Results from discussion:

- There is a gap in what the research finds v. what the patient wants to know
- Consider moving research beyond the clinic setting and expanding to incorporate the community



# Challenges and Opportunities

## Results from discussion:

- How do we get all members of the healthcare team (patients, physicians, caregivers, researchers, payers, policy, etc.) involved in communication
- Mutual goal setting across the healthcare team; measuring both health and patient-reported outcomes
- Challenges in the evidence continuum:
  - Not enough studies with efficacious results are being disseminated into healthcare practice

### Evidence Continuum

Collect and systematically  
review the evidence

Communicate  
and translate

Diffuse and  
disseminate

Adopt and  
implement

Sustain, evaluate  
impact and adjust



# Moving the Field Forward

---

## Results from discussion:

- Targeting research areas of interest
- Need to receive more innovative applications
- Identifying what communication and dissemination research is already out there
- The importance of using frameworks in communication and dissemination research
- Implementation, adoption, and sustainability of efficacious study results



# Patient/Caregiver Journey Mapping

**Lauren McCormack, PhD, MSPH**

Director, Center for Communication Science, RTI International

**Danny van Leeuwen, MPH, RN, CPHQ**

Principal, Health Hats

[www.health-hats.com](http://www.health-hats.com)



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Discussion

---

Think about a time when you, a family member, or friend were a patient. Briefly describe your experience, especially related to engaging with clinicians/the healthcare team.



# Outcomes and Behaviors of PCORI Studies

**Bill Lawrence, MD, MS**

Senior Program Officer, Communication and Dissemination Research



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Current CDR Priority Areas

---

1. **Communication strategies** to promote the use of health and healthcare CER evidence by patients and clinicians
2. **Dissemination strategies** to promote the use of health and healthcare CER evidence by patients and clinicians
3. **Explaining uncertain health and healthcare CER evidence** to patients and clinicians



# Outcomes

---

- What outcomes do we need to evaluate in the context of CDR?
- What defines success in our program (so that we know to measure it)?



# The CDR Portfolio

---

- 34 Studies as of last cycle
  - Focus on primary outcomes
    - “Most important”
    - Not necessarily powered for secondary outcomes
  - 29 with evaluable primary outcomes
    - 2 with outcomes TBD
    - 3 not applicable
  - 9 studies with multiple primary outcomes



# What outcomes Are Our Studies Using?

---

- Themes:
  - Condition specific symptoms or function – 4 studies
  - HRQOL (overall or domain specific) – 2 studies
  - Utilization as proxy for disease severity – 1 study
  - Health knowledge or skills – 2 studies
  - Patient decision making measures – 5 studies
  - Shared decision making – 5 studies
  - Health behavior – 7 studies
  - Self-management/self-efficacy – 4 studies
  - Adherence – 3 studies
  - Quality of care/medical errors – 3 studies
  - Patient experience with care – 1 study
  - Risk communication effectiveness – 1 study



# Break

10:15-10:30



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Clinician Perspective on Challenges with Engaging Patients

**Lauren McCormack, PhD, MSPH**

Director, Center for Communication Science, RTI International



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Discussion of RTI/UNC Evidence-based Practice Center and Systematic Review of the Literature on Communication and Dissemination

**Lauren McCormack, PhD, MSPH**

Director, Center for Communication Science, RTI International



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Overview: Communication and Dissemination Strategies

To Facilitate the Use of Health-Related Evidence

Lauren McCormack, PhD, MSPH



Communication and Dissemination Strategies To Facilitate the Use of Health-Related Evidence. November 2013. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/research/findings/evidence-based-reports/commstrattt.html>

# Purpose of the Review

## Communication

Addressed comparative effectiveness of communicating evidence in various contents and formats that increase the likelihood target audiences will understand and use information

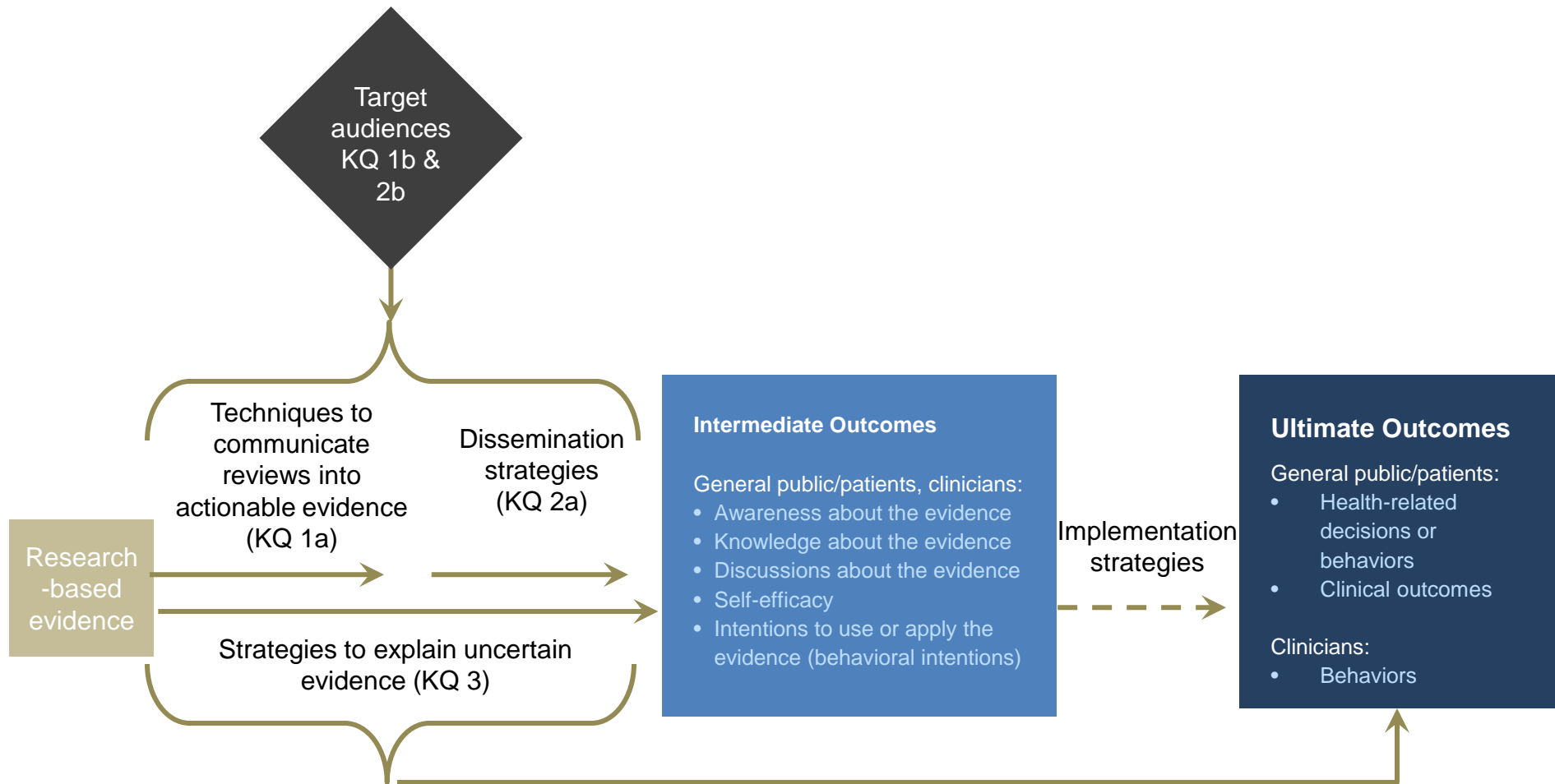
## Dissemination

Examined comparative effectiveness of variety of approaches for disseminating evidence from those who develop it and those who are expected to use it

## Uncertainty

Examined the comparative effectiveness of various ways of communicating uncertainty associated with health-related health-related evidence to different target audiences, including evidence translators, health educators, patients, and clinicians

# Analytic Framework



Note: KQ = Key Question



# Evidence-based Practice Center Systematic Review Methods

Systematically searched, reviewed and synthesized scientific evidence from MEDLINE®, the Cochrane Library, Conchrane Central Trials Registry, PsycINFO®, and the Web of Science

- Communication and Dissemination: published 1/1/2000 to 3/15/2013
  - Head to head comparisons only
- Uncertainty: published 1/1/1966 to 3/15/2013
  - Comparisons with usual care included established for EPC

Used standard EPC methods for dual review of abstracts and full text articles to determine inclusion

Reviewed evidence abstraction for completeness and accuracy

Two reviewers independently rated the risk of bias of studies.

Team jointly discussed and graded the overall body of literature and graded strength of evidence on guidance established for EPC

# Communication Strategies

## Communication Strategies

Tailoring  
the  
message

Targeting  
the  
message to  
audience  
segments

Using  
narratives

Framing  
the  
message



# Communication Strategy 1: Tailoring the Message

Communication designed for an individual based on information from the individual

## **Example approaches:**

- Using a computerized database of messages that can be combined in response to answers to preprogrammed questions asked of an individual.
- Applying an electronic algorithm to design messages based on individual input regarding a limited number of questions.
- Trying to direct messages to individuals' status on key theoretical determinants of the behavior of interest.
- Incorporating recognizable aspects of participants to convey (implicitly or explicitly) that the messages are designed specifically for them.
- Providing messages to participants about their psychological or behavioral states.

# Communication Strategy 2: Targeting the message to audience segments

Communication designed for subgroups based on group membership or characteristics such as age, sex, race, cultural background, language, and other “psychographic” characteristics (e.g., a person’s attitudes about a particular subject matter)

## **Example approaches:**

- Manipulating language, visuals, music, or choice of behavior topic in ways that make the message more interesting, relevant, or appealing to specific subgroups

# Communication Strategy 3: Using Narratives

Communication delivered in the form of a story, testimonial, or entertainment education

## **Example approaches:**

- Invoking personal stories, case studies, anecdotes, testimonials, experiential sharing
- Using entertainment education or photo novellas or graphic novels.

# Communication Strategy 4: Framing the Message



- Negative (loss) frame: “With drug X, you have a 5% chance of dying” vs. “With drug X, you have a 95% chance of surviving.”

# Results: Communication Strategies

9

articles met inclusion criteria

## Multiple strategies used at one time

Framing versus narratives: Loss-framed messages used in conjunction with narratives were more persuasive than:

1. loss-framed messages in conjunction with statistical information alone or
2. gain-framed messages in conjunction with either narratives or statistical information (1 trial; insufficient SOE).

Framing versus targeting: loss-framed message used in combination with non-targeting was most persuasive relative to any other combination of framing and targeting (2 trials; insufficient SOE)

- Results held only in the short term for one of the trials
- targeting was done on different factors across the trials

# Goals for Dissemination

## Goals for Dissemination

Increase  
reach to a  
variety of  
audiences

Increase  
motivation  
to use an  
supply  
information

Increase  
ability to  
use and  
apply  
evidence

Multicomponent



# Dissemination Strategy 1: Increase Reach

Distributing evidence widely to many audiences and across many settings to increase the reach of information

## Example approaches:

- Postal
- Electronic and digital media
- Social media
- Mass media
- Interpersonal verbal group or individual outreach

# Dissemination Strategy 2: Increase Motivation

Increasing interest in the evidence through champions (also known as “cheerleaders”), opinion/thought leaders, or social networks

## Example approaches:

- Champions (cheerleaders): People who take ownership of the evidence and visibly promotes it within their own organization or across other settings.
- Opinion or thought leaders (frequently has an endorsing or persuasive element): Recognized experts who lend their name to dissemination efforts to endorse the idea being disseminated and to establish credibility.
- Social networks: A network of individuals who have a common perspective, relationships, or similar connection

# **Dissemination Strategy 3:**

## **Increase Ability to Use and Apply Evidence**

Providing additional resources about the evidence, such as how it can be incorporated into current practice or specific suggestions for change, to enhance a traditional dissemination strategy

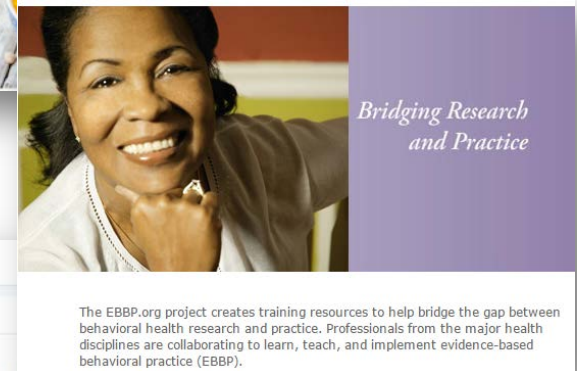
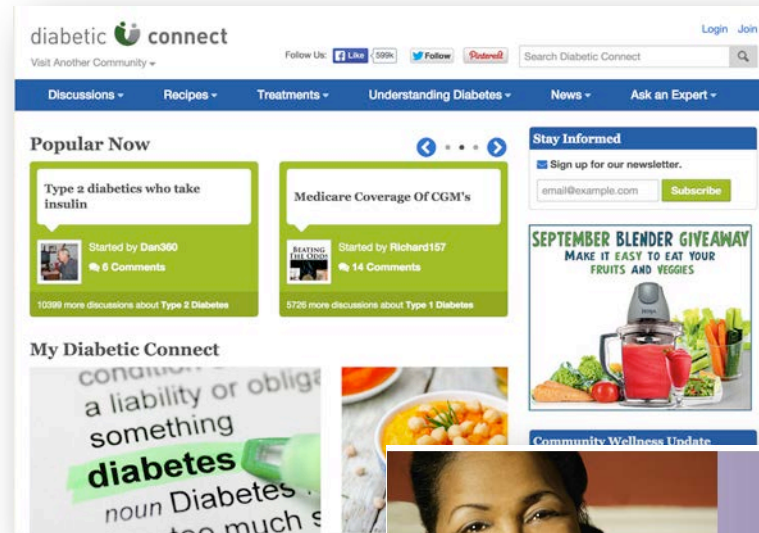
### **Example approaches:**

- Provision of supporting “how-to” materials: Includes physical materials that a health care practice might use to apply evidence in their activities.
- Supporting materials do not include brochures, counseling resources, or resources that originate from the practice.
- Skill training, capacity building, and problem solving: Training in any skill that would allow appropriate use of evidence (to overcome barriers).

# Dissemination Strategy 4: Multicomponent Dissemination Strategies

It is common practice to combine multiple dissemination strategies to address a combination of reach, motivation, or ability goals

A multicomponent approach uses several dissemination strategies in concurrent combination or in sequence to increase the reach of evidence, enhance the end users' motivation to adopt and use or apply evidence.



# Results: Dissemination

42

articles reporting on 38 studies

## Disseminating evidence to clinicians

- Ability strategies are not more effective than reach strategies (4 trials; low SOE)
- Multicomponent strategies appear more effective than one strategy alone for affecting clinician behaviors (7 trials; moderate SOE) and clinical outcomes (6 trials; low SOE)

## Disseminating evidence to patients

- Evidence is inconsistent for determining benefit of dissemination approaches focused on changing health-related decisions and behaviors (12 trials; insufficient SOE)
- Evidence is insufficient for determining benefit of dissemination approaches focused on changing clinical outcomes (2 trials; 1 low SOE, 1 insufficient SOE due to 1 trial in each category) or knowledge outcomes (3 trials; insufficient SOE due to inconsistent findings or 1 trial in a category)

## Disseminating evidence to patients and clinicians

- Evidence is inconsistent for determining benefit of dissemination approaches for health related decisions and behaviors (6 trials; insufficient SOE) or clinical outcomes (1 trial in each category; insufficient SOE)

# Uncertainty Concepts Addressed in the Review

<b>Overall strength of evidence</b>	Degree of confidence that the estimates of effects are correct and represent the true effect. When overall strength of evidence is insufficient or low, uncertainty is high.
<b>Risk of bias</b>	Degree to which individual studies are protected from systematic errors or bias. When risk of bias is high, the quality of evidence is poor, leading to uncertainty.
<b>Consistency</b>	Degree to which studies present findings similar in direction of effect, magnitude of effect, or both. Evidence lacking consistency includes studies with greatly differing or conflicting effect estimates.
<b>Precision</b>	Degree of random error surrounding an effect estimate with respect to a given outcome. Studies express dispersion around a point estimate of risk, such as a confidence interval, which indicates the reproducibility of the estimate.
<b>Directness</b>	Degree to which the evidence either directly links the interventions to the outcome of interest or directly makes the comparison of interest. When evidence indirectly links interventions to the outcomes most of interest, evidence is uncertain.
<b>Net benefit</b>	Balance or tradeoffs in benefits and harms for prevention or treatment services. When the balance of benefit and harm is too close to call or when evidence is lacking, the appropriate course of action with regard to prevention or treatment is uncertain.
<b>Applicability</b>	Whether a study intervention is expected to have the same effect in populations and settings where it was not studied but might be applied.
<b>Overall strength of recommendation</b>	The overall judgment of policymakers that evidence should be applied in particular populations and settings

# Results: Uncertainty

10

articles reporting on 9 studies

## Communicating precision

**Mixed effects** of presenting numeric risks as point estimates vs 95% CIs, depending on the studies outcome, width of the CI and presence or absence of comparative information about average population risk (2 studies; insufficient SOE)

## Communicating directness

**Compared to usual care**, choice of cholesterol medication with direct evidence of benefit was better for patients receiving nonnumeric advice or factual information encouraging consumers to choose the drug with direct evidence (1 study; low SOE).



## Results: Uncertainty (cont.)

### Communicating net benefit

- **Choice of a heartburn medication** that was more likely to have net benefit was better for consumers receiving nonnumeric advice or factual information encouraging consumers to choose the drug with greater net benefit than for patients receiving usual care (1 study; low SOE)
- **In cancer screening tests**, additional nonnumeric information about benefits had little effect on refusals. More nonnumeric information on harms significantly increased test refusals and significantly decreased decision satisfaction. (1 study; low SOE)
- **Compared with usual care**, giving men prostate cancer screening information alone or framed in the context of information about other, more beneficial screening service significantly increased prostate cancer knowledge (low SOE)
- **Giving prostate cancer screening information** alone versus framed in the broader context of more beneficial services had differential effects on patient involvement and screening (2 studies; insufficient SOE)

### Communicating strength of recommendations

**Only single small study** examined the effects of different ways of wording recommendations to convey strong or weak recommendations for care; this precludes definitive conclusions (1 study; insufficient SOE)

# Lunch

12:00-12:45



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Patient Perspectives on Challenges with Engaging Physicians

**Danny van Leeuwen, MPH, RN, CPHQ**

Principal, Health Hats

[www.health-hats.com](http://www.health-hats.com)



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Review of Research Questions

**Chris Gayer, PhD**

Program Officer, Communication and Dissemination Research



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Research Prioritization

## Topic genesis

Investigator initiated

Program initiated

Patient/stakeholder initiated



## Topic endpoint

Broad funding announcements (PFA)

Targeted funding announcements (tPFA)

Pragmatic Clinical Studies (PCS)

**Today's goal: Focus on the *what*, not on the *how*....**

- Are there opportunities for CDR that are not currently being presented/outlined in the broad PFA?



## Current Areas of Interest from CDR PFA:

Compares strategies that increase knowledge on how to communicate complex information to patients and caregivers

Compares and identifies best practices of dissemination and translation techniques to facilitate shared decision making in everyday practice

Identifies and compares practices that increase understanding of the tension between strongly held beliefs and contrary evidence, and of their impact on the shared decision-making process

Compares strategies meant to generate conversations between patients and providers about what is appropriate and necessary treatment (e.g., Choosing Wisely<sup>10</sup>) based on patients' preferences and conditions

Compares strategies for conveying uncertainty associated with health and healthcare evidence that increase the likelihood that patients and caregivers will understand the information, incorporate it into decision making, and evaluate personal trade-offs

Identifies and compares promising practices that address contextual factors and their impact on patient-centered communication

Compares the effectiveness of health literacy- and numeracy-sensitive health communication strategies that relay risks and benefits of health decisions so that individuals can make sound healthcare decisions

Compares strategies and methods that optimize communication between the patient, family/caregiver, and the healthcare team (e.g., role of family member/caregiver in patient-provider, patient-caregiver, and healthcare team interactions)

Compares innovative approaches for using existing electronic clinical data and other electronic modalities (e.g., EHRs) from the healthcare system or from a network of systems to enhance clinical decision making by patients and providers



## Areas of interest identified by staff and advisory panel

Shared decision making in acute/emergency settings

CER of ways to reach clinicians about treatment gaps - more effective way to influence practice and change practice behavior based on evidence

Sharing genetic test results

Models of how to scale up evidence-based interventions in health services improvement

CER of dissemination and translation techniques to facilitate the use of CER by patients, clinicians, payers, and others (IOM 100)

Communication and dissemination across the healthcare continuum

Family planning (CDC Healthy People 2020 goal)

Identifying effective approaches to dissemination to clinicians as evidenced by improved patient behavior and clinical outcomes.

Choosing Wisely - Comparison of interventions for reducing unnecessary care (overutilization)

Testing strategies for communicating to patients, including patients with lower health literacy, concepts related to over-detection, over-diagnosis, and over-treatment

CER of patient decision support tools on informing diagnostic and treatment decisions (e.g., treatment choice, knowledge acquisition, treatment-preference concordance, decisional conflict) for surgical and nonsurgical procedures- especially in patients with limited English-language proficiency, limited education, hearing or visual impairments, or mental health problems (IOM 100)

CER of different approaches to implementing shared decision making

Communication of information to those with low literacy and numeracy

Study of newer health system models (i.e., health homes, integrated care models, Accountable Care Organizations (ACOs)) that promote comprehensive care management and care coordination for people with multiple or chronic health conditions

Adherence – medication and self-management



# PICO(T)

---

**Populations/People/Patient/Problem**

**Intervention**

**Comparison**

**Outcomes**

**Timing and Settings**

**Are there opportunities for CDR that are not currently being presented/outlined in the broad PFA?**



# Outcome of Effective Communication and Dissemination

## Small Group Discussions



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Break

2:30-2:45



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Continued: Outcome of Effective Communication and Dissemination

Large Group Discussion



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# Framework for Communication and Dissemination

**Bridget Gaglio, PhD, MPH**

Program Officer, Communication and Dissemination Research



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# What Is a Conceptual Framework?

---

- Graphical or narrative representation
- Way of linking all key constructs or variables
- Showing presumed relationships among them
- Presumptions of relationships based on literature, expectations based on prior and personal experiences, theory, and methods
- Can include multiple levels



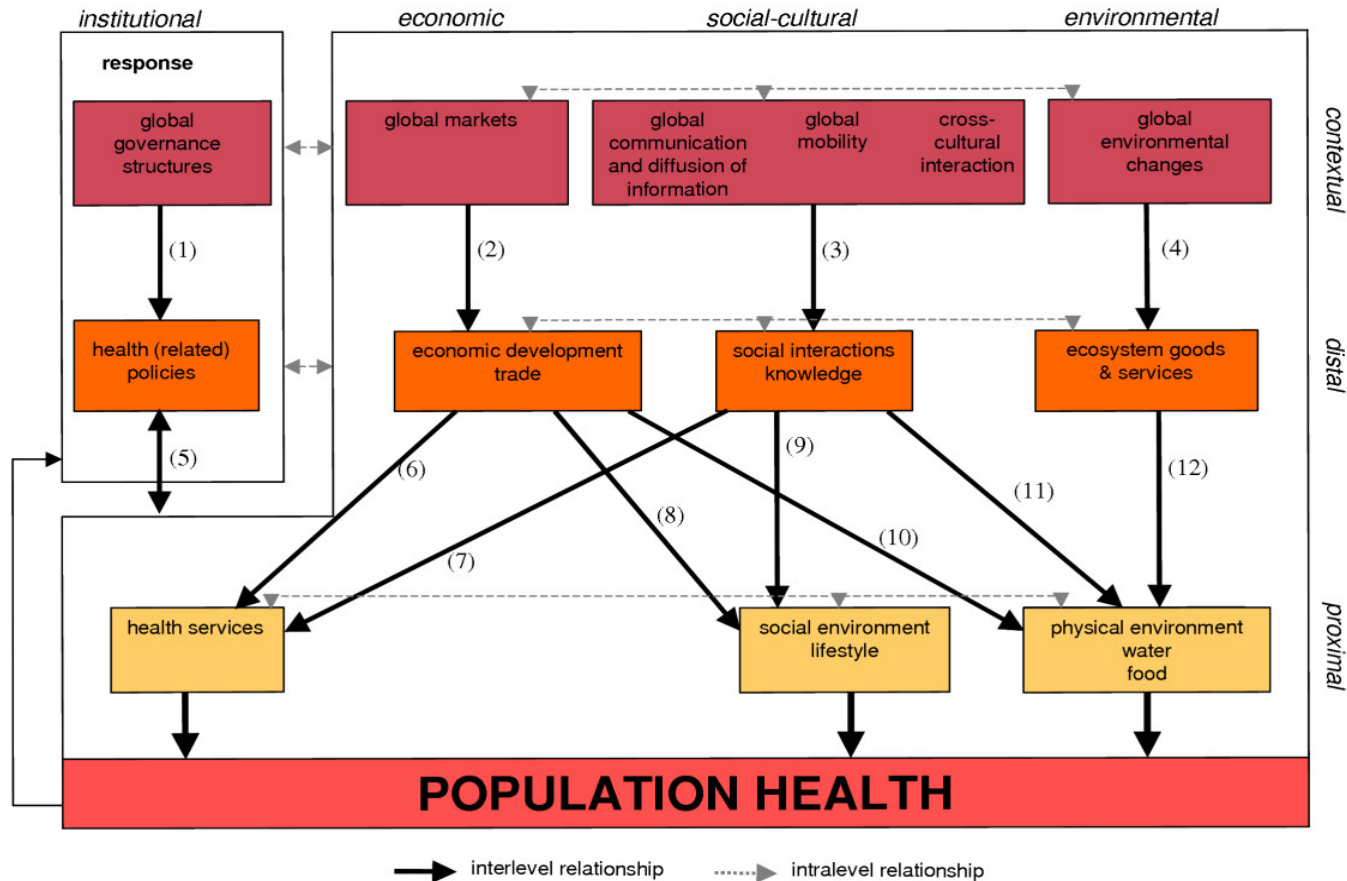
# Conceptual Framework: An Evolving Guide

---

- Development of a conceptual framework is a process through which one identifies the questions and lines of inquiry that matter most to them, develop appropriate strategies for pursuing those questions, and monitoring and reflecting on the learnings as the results unfold.
- Serves to summarize and integrate knowledge and generate hypotheses.
- Situating specific questions and strategies for exploring them within the wider universe of what is already known about a given topic or question.
- Allows one to make reasonable and defensible choices about how one might explore topics or themes
- Use of memos/notes to document changes over time.



# Example of a Conceptual Framework



Conceptual model for globalization and population health.



# Exercise – Creating a Framework for CDR

---

- Identify set of concepts – done over course of today's meeting.
- How are these concepts related? What connections do you see among them? Which connections are important?
- Only include concepts that will be operationally defined and measured.
- Start with the endpoint.
- Brainstorm different ways of putting the concepts together. Don't get locked into your first idea.
- When at a stopping point, write a narrative/memo of what the framework says at that point in time.
- Revisit at each future advisory panel meeting.



# Wrap-up and Next Steps



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE