

Advisory Panel on Communication and Dissemination Research

May 28, 2015
8:30 AM to 5:00 PM 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



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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.
- Visit www.pcori.org/events for more information.
- Chair Statement on COI and Confidentiality

Wireless access:

- Select the “WestinMeetingNetwork” network
- Launch your internet browser
- Enter access code – **PCOR2015**

Agenda

8:30 AM – Welcome

8:35 AM – Introductions

9:00 AM – Roles and Expectations of CDR Advisory Panel

9:30 AM – Overview of CDR Program

10:15 AM – Break

10:30 AM – Discussion of Topic #1 – Current CDR Priority Areas

12:00 PM – Lunch

1:00 PM – Discussion of Topic #2 – Challenges and Opportunities of the Current CDR Priority Areas

2:30 PM – Break

2:45 PM – Discussion of Topic #3 – Moving the Field Forward

4:30 PM – Wrap-up and Next Steps



Introductions

Sarah Chew, BA

Program Assistant, Communication and Dissemination Research



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Roles and Expectations of CDR Advisory Panel

Michelle Henton, MA

Program Associate, Communication and Dissemination Research



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Advisory Panels - Background

- PCORI is authorized by Congress to appoint permanent or ad hoc advisory panels, as determined appropriate
- **PCORI Advisory Panelists provide recommendations to PCORI's Board of Governors, Methodology Committee, and staff to help:**
 - **plan, develop, implement, improve, and refine our research agenda**
 - **determine the best approaches for patient engagement**
 - **and/or prioritize research topics**
- Panelists must be willing and able to travel to Washington, DC, between 2 and 4 times a year to attend advisory panel meetings
 - Throughout the course of their service, panelists may also need to attend meetings by teleconference
- The Board of Governors will select a chairperson to facilitate panel activities (including setting meeting dates) in conjunction with PCORI's designated staff leader



Highlights from Advisory Panel Training

- **Vision:** Patients and the public have information they can use to make decisions that reflect their desired health outcomes
- **Mission:** PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community



Highlights from Advisory Panel Training

- **Goals**
 - Substantially increase the quantity, quality, and timeliness of useful, trustworthy information available to support health decisions
 - Speed the implementation and use of patient-centered outcomes research evidence
 - Influence clinical and health care research funded by others to be more patient-centered
- **Strategic Imperatives:** Engagement, Methods, Research, Dissemination, Infrastructure
- **Core Values:** Usefulness, Transparency, Patient-centeredness, Inclusiveness, Evidence



Highlights from Advisory Panel Training

- Comparative Effectiveness Research (CER)
 - Compares at least two approaches, both of which are viable alternatives
 - Compares two or more clinical strategies that each have **established efficacy**
 - Studies the benefits and harms of interventions and strategies delivered in real-world clinical settings
 - Is based on health outcomes that are meaningful to the patient population under study and are likely to guide the decisions regarding care made by patients, caregivers, and providers



Highlights from Advisory Panel Training

- All panels consist of members who are clinicians, patients, experts in science/health services research, integrative health and primary prevention, and appropriate experts from industry
- All panel charters and members have been reviewed and approved by PCORI's Board of Governors
- Panel members are randomly assigned to 1-, 2-, and 3-year terms
- Panel charters will remain in effect for one year beginning on the day of the first meeting
 - The charter is subject to review, reauthorization, amendment, or termination by the Board of Governors or its designee



Highlights from Advisory Panel Training

- Keys to being a successful panelist include
 1. Offering your unique perspective
 2. Become familiar with the Engagement Rubric
 3. Be prepared
 4. Speak up as early and often as you can
 5. Network with fellow panelists



Overview of Communication and Dissemination Research Program

Jean Slutsky, PA, MSPH

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



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CDR Team



Jean Slutsky
Chief Engagement and
Dissemination Officer



Bridget Gaglio
Program Officer



Chris Gayer
Program Officer



 **Michelle Henton**
Program Associate

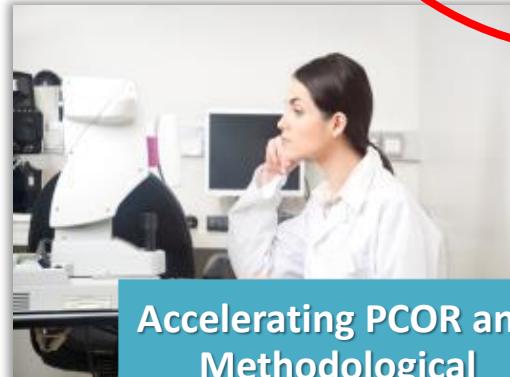
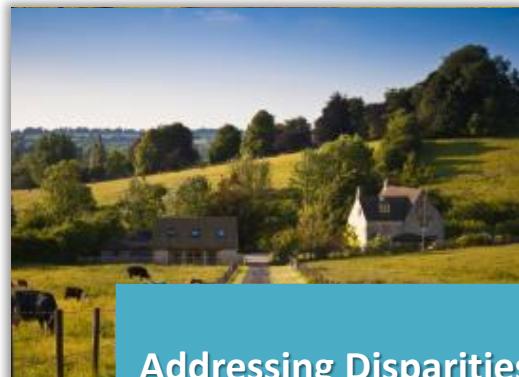


Sarah Chew
Program Assistant



Bill Lawrence
Senior Program Officer

The Research We Fund Is Guided by Our National Priorities for Research



Portfolio Overview



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Importance of CDR

Producing information is not enough.....

- Clear communication approaches and active dissemination of findings to all audiences, in easy to understand formats, are critical to increasing the awareness, consideration, adoption, and use of the data by patients, caregivers, and healthcare providers
- In other words, information itself is of little use unless:
 - It reaches those who need it
 - It is clear and comprehensible



Background

- Patients, caregivers, and clinicians need to be equipped with the best available information for making informed decisions.
- Knowledge about how to optimally communicate and facilitate the effective use of evidence, information, and tools by patients, caregivers, and providers is lacking in many areas
- Strategies are needed to make existing patient-centered outcomes research information available to patients and providers and to make the dissemination and implementation of this knowledge feasible in various contexts



CDR Funding Objective

The CDR program seeks to fund....

- Comparative effectiveness research
 - that involves the direct comparison of effective health communication and dissemination interventions or strategies that engage patients, caregivers, and providers
 - in the context of real-world clinical-care settings and situations
 - to enable patients and caregivers to make the best possible decisions in choosing among available options for care and treatment.



CDR Funding Priorities

Focus on 3 three key 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



Communication and Dissemination Research

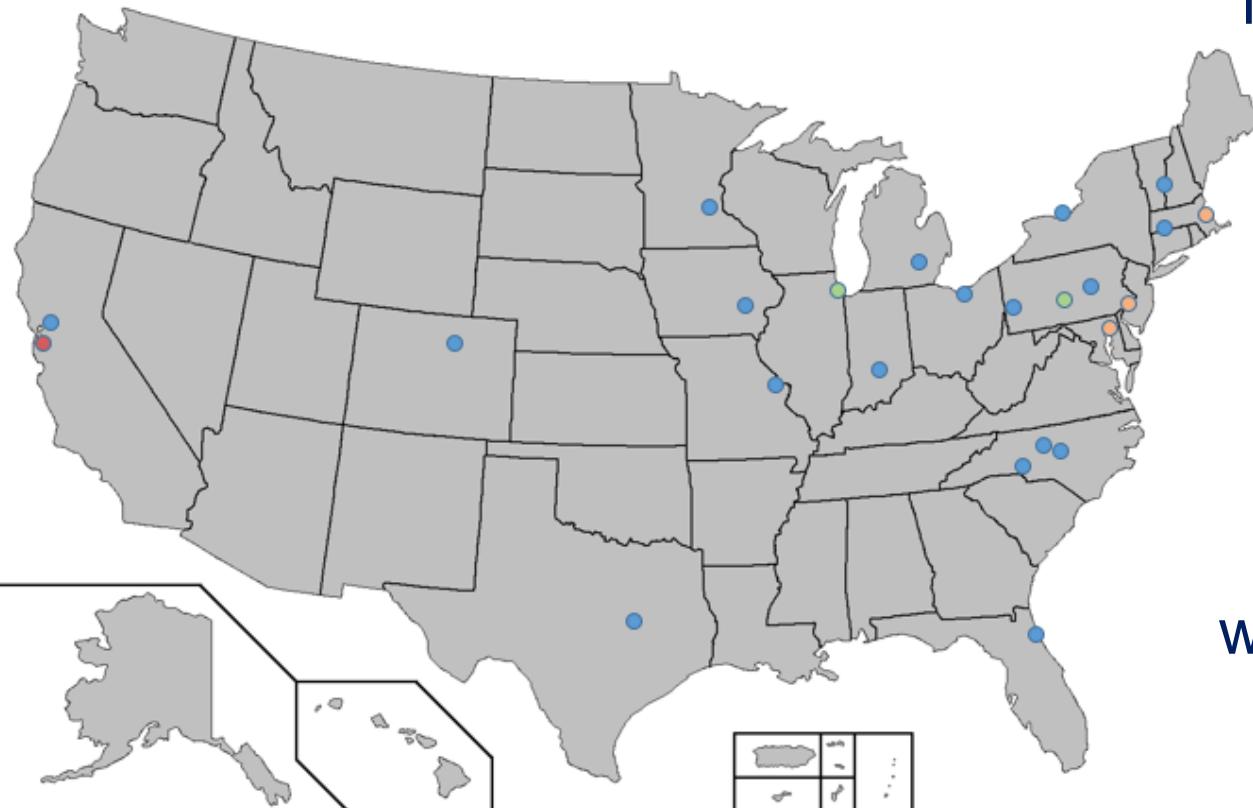
Available Funds: Up To \$8 Million

Total Direct Cost : \$1.5 million

Maximum Project Period: 3 years



Current Portfolio



Number of Projects:
35

Amount Awarded:
\$60.7 million

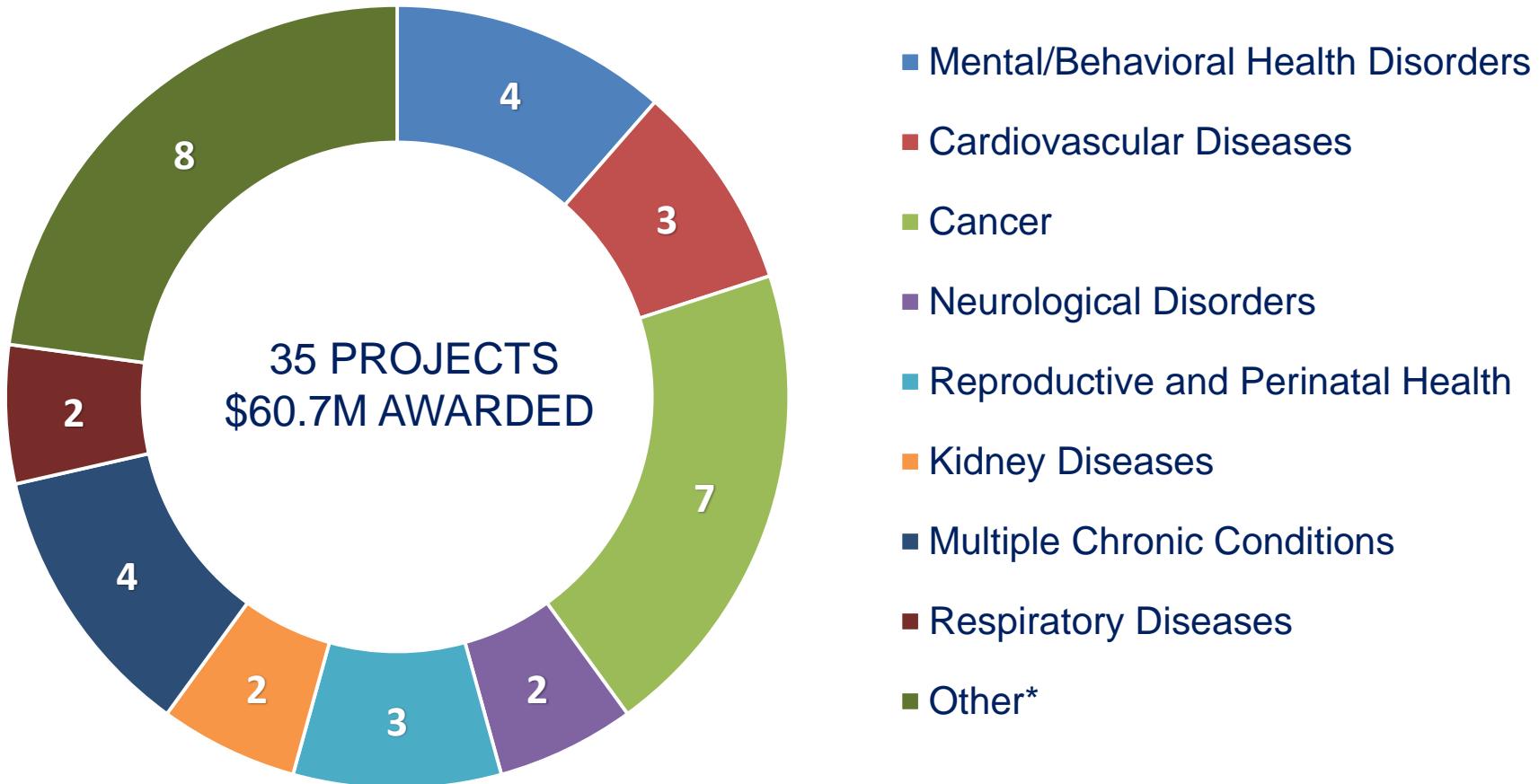
Number of states
where we are funding
research:

17

- =1 studies
- =2 studies
- =3 studies
- =4 studies



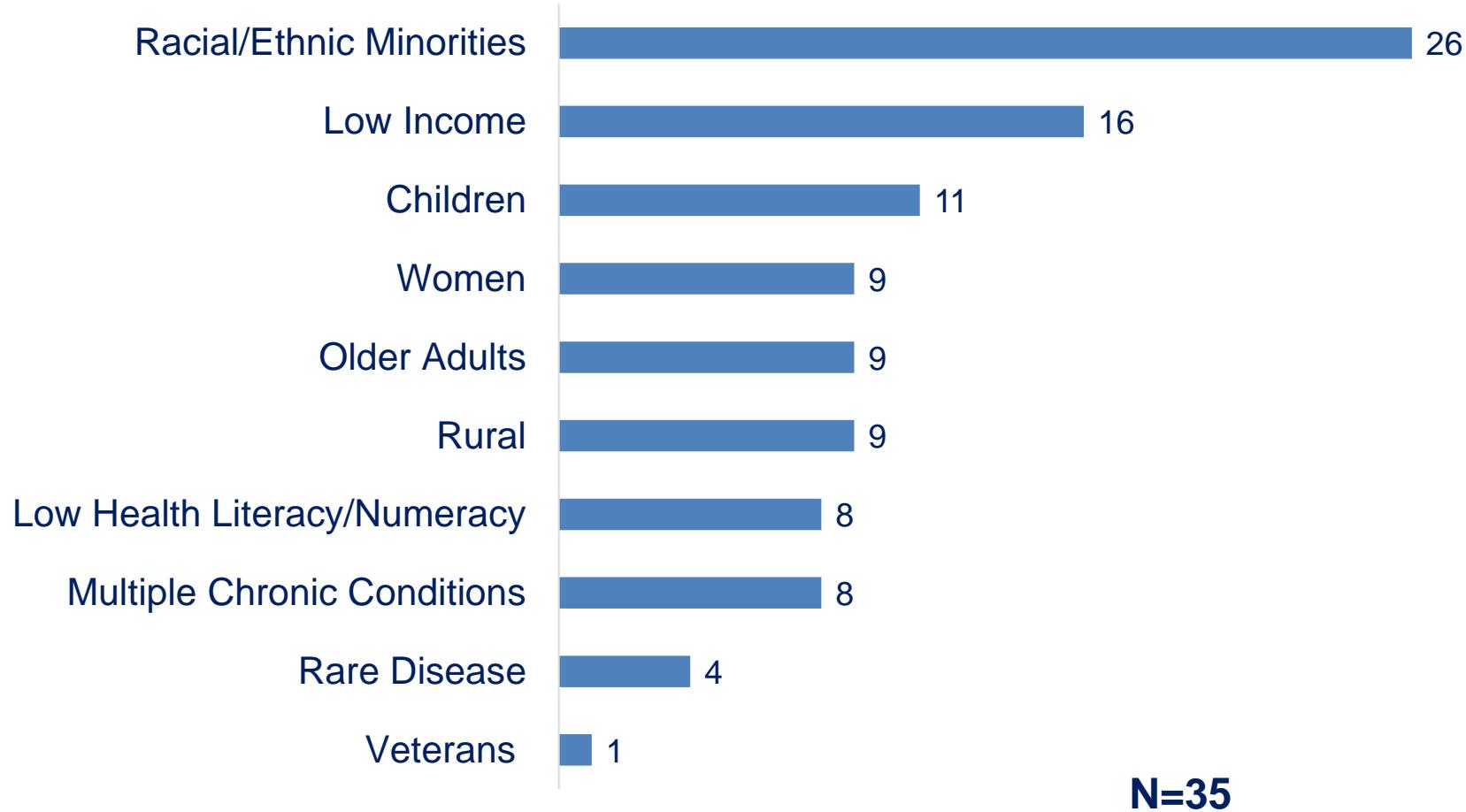
Portfolio by Disease/Condition



* Other includes: Diabetes (1), CT Scan Radiation Dose (1), Rare Genetic Disorders (1), etc.



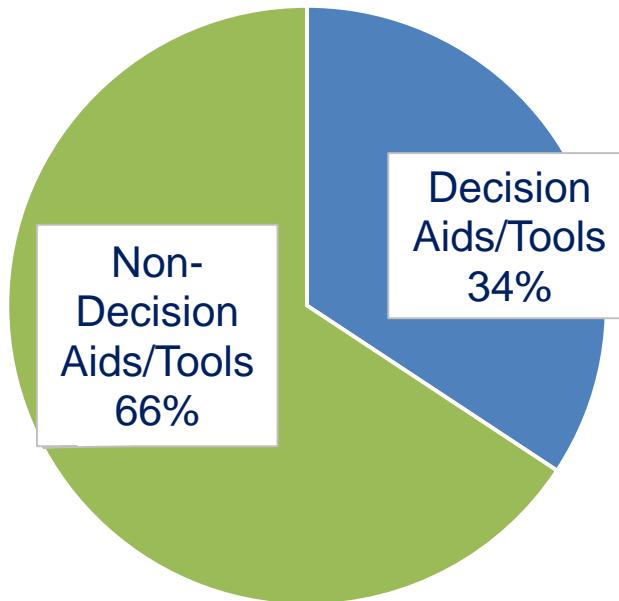
Portfolio by PCORI Priority Populations*



*Not mutually exclusive



Decision Aids in CDR Portfolio



Tools that help patients understand:

- evidence about clinical management options
- their preferences about clinical outcomes
- so as to engage in shared decision making for making choices among those options

- In early cycles, several CDR projects focused significant effort towards the development, validation, and pilot-testing of decision aids and tools
- Focus on head to head comparisons of demonstrated interventions, strategies, and tools
- **The development, testing, and validation of individual decision aids/tools is considered non responsive to the CDR funding announcement**



Patient-Centeredness vs. Patient Engagement

- **Patient-Centeredness** is a component of what PCORI is looking for in research applications.
 - Does the project aim to answer questions or examine outcomes that matter to patients within the context of patient preferences?
 - Research questions and outcomes should reflect what is important to patients and caregivers
- **Patient engagement** is about having patients as partners in research as opposed to merely subjects.
 - Active engagement between scientists, patients, and stakeholders
 - Community, patient, and caregiver involvement already in existence or a well-thought out plan



Patient and Stakeholder Engagement

- Participating in formulation of research questions
- Defining essential characteristics of the study participants, comparators, and outcomes
- Monitoring study conduct and progress
- Drafting a plan for disseminating research results



The Engagement Rubric



Planning the Study



Conducting the Study



Disseminating the Study Results



PCOR Engagement Principles



We Also Work to Improve Research Methodology

In any study, methods matter. That's why we've developed methodology standards that patient-centered CER should follow, at a minimum.

Methodology Standards: 11 Broad Categories

- Formulating Research Questions
- Patient-Centeredness
- Data Integrity and Rigorous Analyses
- Preventing/Handling Missing Data
- Heterogeneity of Treatment Effects
- Data Networks
- Data Registries
- Adaptive and Bayesian Trial Designs
- Causal Inference
- Studies of Diagnostic Tests
- Systematic Reviews



How Are Applications Reviewed?

Applications are reviewed against five criteria:

- Impact of the condition on the health of individuals/populations
- Potential for the study to improve healthcare and outcomes
- Technical merit
- Patient-centeredness
- Patient and stakeholder engagement

- Applications are reviewed by a panel of two scientists, one patient, and one other stakeholder.
- PCORI's Board of Governors makes funding decisions based on merit review and staff recommendations.



Questions?

Break

10:15-10:30



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Discussion Topic #1 – Current Communication and Dissemination Research Priority Areas

Chris Gayer, PhD

Program Officer, Communication and Dissemination Research



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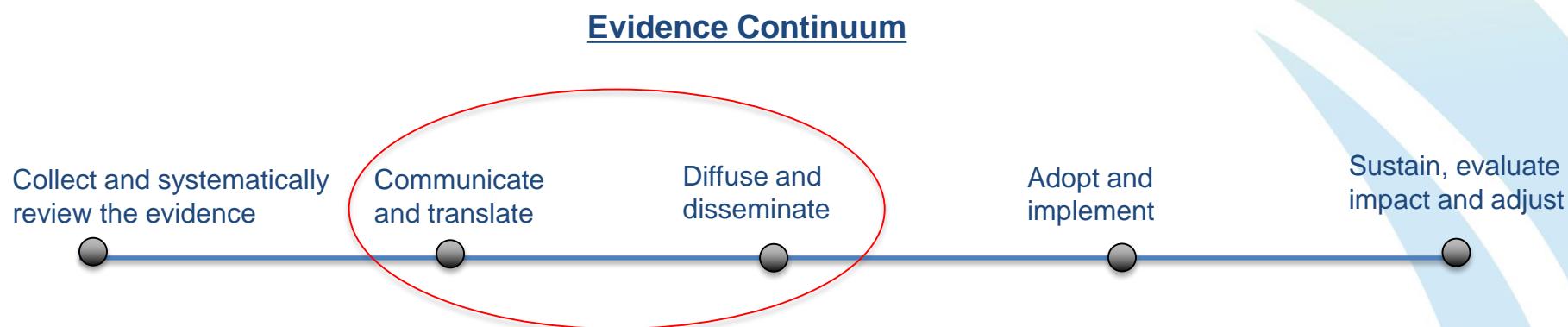
Current CDR Funding Priorities

Based on your expertise in the communication and dissemination arena:

1. *What are your thoughts on the three priorities?*
2. *Are there targeted areas, questions, or topics within the existing priorities that we should be focusing on?*

Organizing the CDR Funding Priorities

- **Communication and Dissemination Strategies To Facilitate the Use of Health-Related Evidence**
 - *“The lack of comparative research evidence to inform communication and dissemination of evidence, including uncertain evidence, impedes timely clinician, patient, and policymaker awareness, uptake, and use of evidence to improve the quality of care.”*



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/commstrattp.html>

CDR Funding Priorities

Focus on 3 three key 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



Key Area #1: Communication Strategies

What is the comparative effectiveness of communication strategies to promote the use of health and health care evidence for patients and clinicians?

- Strategies used to communicate evidence so that target audiences can better understand it; the strategies are meant to increase the probability that recipients pay attention to the messages conveyed
- Focus on making evidence interpretable, persuasive, and actionable
- (e.g. – evidence summaries, decision aids, mobile apps, training modules, websites, etc.)



Key Area #2: Dissemination Strategies

What is the comparative effectiveness of dissemination strategies to promote the use of health and health care evidence for patients and clinicians?

- The active and targeted distribution of information or interventions via determined channels using planned strategies to a specific public health or clinical practice audience.
- (e.g. – mass/social/digital media, thought leader summits, social networks, organizational champions, toolkits, skill training, etc.)

Key Area #3: Explaining Uncertainty

What is the comparative effectiveness of different ways of explaining uncertain health and health care evidence to patients and clinicians?

- Strategies used to communicate uncertain evidence so that target audiences can better understand it; the strategies are meant to increase the probability that recipients pay attention to the messages conveyed

Discussion

Based on your expertise in the communication and dissemination arena:

1. *What are your thoughts on the three priorities?*
2. *Are there targeted areas, questions, or topics within the existing priorities that we should be focusing on?*

Up next.....

- Challenges and Opportunities of the Current CDR Priority Areas



Lunch

12:00-1:00



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Discussion Topic #2 – Challenges and Opportunities of the Current CDR Priority Areas

Bill Lawrence, MD, MS

Senior Program Officer, Communication and Dissemination Research



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The CDR program is interested in funding research projects!

- Comparative Effectiveness Research
 - Directly comparing interventions or strategies – either proven efficacious (preferably) or in wide use
 - Helping people make decisions about care options
 - Can be focused on patients, clinicians, caregivers (even better if all 3!)
 - In our priority areas of
 - Communication strategies
 - Dissemination strategies
 - Explaining uncertain health and healthcare CER evidence

CER vs. Development

- CER
 - A decision point is identified for which a choice is available among (communication, dissemination, uncertain evidence) interventions
 - Established interventions compared head-to-head
 - Real-world settings
 - Patient-centered outcomes collected

CER vs. Development (2)

- Development
 - Availability of other interventions not clear
 - New intervention is developed and tested as part of research project
 - Setting often limited
 - +/- Patient-centered outcomes
- Our challenge – Encouraging applications for quality research in CER rather than development

CER vs. “CER”

- CER, vs.
- “CER” of My Intervention
 - Alternative approaches not clear
 - Typically (closer to) efficacy study of one specific intervention vs. “usual care”

Challenges and Opportunities

- Challenges
 - Conveying to the field our interest in CER specifically?
- Opportunities
 - To spread the word on our interests
 - Are there groups interested in these areas that we are not reaching?
 - Others?

Break

2:30-2:45



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Discussion Topic #3 – Moving the Field Forward

Bridget Gaglio, PhD, MPH

Program Officer, Communication and Dissemination Research



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Wrap-up and Next Steps

Wrap-up and Next Steps

- Wrapping up the day
- Selecting a chair/co-chair
- Choosing the next Advisory Panel meeting time
- Communication preferences



Thank You

CDR Team

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