Advisory Panel on Communication and Dissemination Research Meeting Summary

Overview

On October 1, 2015, the PCORI Advisory Panel on Communication and Dissemination Research (CDR) convened in Washington, DC.

The CDR advisory panel is made up of 21 representatives of patients, caregivers, patient advocates, clinicians, researchers, industry, and policy makers. The panel was joined by PCORI and CDR staff. The meeting was open to the public via webinar, and slides and meeting materials were posted to the website in advance.

This was the second meeting of the year for the panelists. After brief introductions from Jean Slutsky, Chief Engagement and Dissemination Officer and Program Director of the CDR program, PCORI staff gave a recap of the May meeting and went over the agenda for the day. The purpose of this meeting was to continue the conversation started during the spring meeting by identifying the communication and dissemination challenges with clinicians and patients, elaborating on the CDR portfolio, discussing the priorities and outcomes that are important to CDR, and building a framework to help guide CDR at PCORI.

Related Information

- About This Advisory Panel
- Meeting Details and Materials

The Patient-Centered Outcomes Research Institute (PCORI) is an independent organization created to help people make informed healthcare decisions.

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Patient-Caregiver Journey Mapping

Journey mapping[1] is a tool often used by companies that helps them see what their customers want and the ways of going about meeting their needs. A patient journey map summarizes the experiences a patient has had over time. For this discussion, panelists were asked the following:

> *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.*

Panelists focused their discussion specifically on their experiences in finding health and healthcare information and in providing understandable information, both for themselves and for others. While technology such as phone apps and health-related websites exist to help find information, the available information is not always evidence-based or reliable. Additionally, the health information is often on a population level and not tailored to the individual. The discussion concluded with the summary that as either a patient or clinician, a lot of important health information is buried deep in medical journals, or if information is widely available, it may not be evidence-based, and often patients do not know what is reliable and what is not. Overall, communication and dissemination efforts should emphasize health and healthcare information that is evidence-based and relevant to the consumer.

Discussion of RTI, International/University of North Carolina Literature Review

After a brief discussion of the priority areas and outcomes of the current CDR portfolio by Bill Lawrence, MD, MS, Senior Program Officer of the CDR program, Lauren McCormack, PhD, MSPH, Chair of the CDR panel, discussed a literature review she and her colleagues at RTI International conducted[2]. For this review, the team did a systematic search of the three CDR priority areas: communication, dissemination, and explaining uncertainty. For communication and dissemination, articles that were published between January 2000 and March 15, 2013 were analyzed. Only those studies that were head-to-head comparisons were included for analysis. A search was also done for explaining uncertainty between January 1966 and March 15, 2013. Comparisons with usual care were included (see the full analytical framework below).

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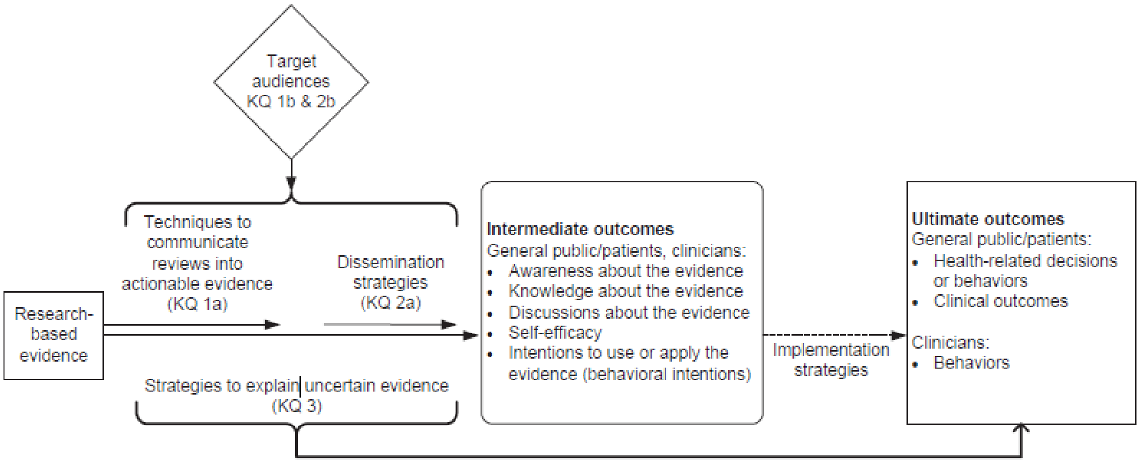
[1] More about journey mapping can be found at http://www.healthcodesign.org.nz/03_explore_b.html

[2] Full report and executive summary can be found at http://www.ahrq.gov/research/findings/evidence-based-reports/commstrattp.html

Figure 1: Analytic framework for communicating and disseminating strategies and explaining uncertainty



Note: KQ = Key Question.

For communication (KQ1), nine articles met the inclusion criteria. Multiple communication strategies were used at one time, which included tailoring the message, targeting the message to audience segments, using narratives, and framing the message. Forty-two articles reporting on 38 studies were found for dissemination (KQ2). Dissemination goals include increasing reach to a variety of audiences, increasing motivation to use and supply information, increasing ability to use and apply evidence, and using multicomponent strategies. The results from the dissemination search found that multicomponent strategies appear more effective than one strategy alone for affecting clinician behaviors, and evidence is inconsistent for determining benefit of dissemination approaches for health-related decisions and behaviors in both patients and clinicians. Uncertainty (KQ3) includes concepts like risk of bias, precision, directness, applicability, and overall strength of the recommendation. Ten articles reporting on nine studies were found. Two of the studies addressed communicating precision, which found mixed effects of presenting numeric risks, and communicating directness compared to usual care, which found that receiving direct evidence of benefit was better for patients receiving non-numeric advice or factual information when it came to choosing cholesterol medication.

Clinician and Patient Perspectives

Clinician Perspective

Lauren McCormack led the clinicians in a discussion on the challenges of engaging with patients when it comes to making decisions about their care. The main concern clinicians had was the uncertainty about where patients get their health and healthcare information. There is no central repository of health information, and no easy way to determine if published information is evidence-based. The other concern discussed was the lack of time a clinician has to address all of the patients’ concerns and to understand all of the patients' issues that occur outside of a clinic visit. Relatedly, there was an emphasis on using a team care approach when it comes to patient health and creating a "feedback loop" to know how a person is doing between visits.

Patient Perspective

Danny van Leeuwen, MPH, RN, CPHQ, Co-Chair of the CDR panel, led the patients/caregivers/advocates in a discussion of their perspectives. The patient/caregiver/advocate perspective was described as a "life full of –ologists and –ists," meaning a patient may have many appointments and conversations with a variety of physicians. At times, it is hard to have those conversations, both because they are not easily understood and they may be exhausting. Patients often look to peers for their support and information; those who have had lived experiences, either in person or online. The key for patients is balancing having a normal life and managing health.

Review of Research Questions

Chris Gayer, PhD, Program Officer for the CDR program, discussed the path of research prioritization, the current areas of interest from the CDR PFA, and the areas of interest identified by CDR staff and the CDR advisory panelists. The main points of interest from this discussion included:

- The emphasis on funding projects that study dissemination strategies
- Mutual goal setting by the patients and clinicians, including physicians, nurse practitioners, physician assistants, and other health professionals on the care team
- Creating a flow of information
- Patient adherence and working with the healthcare team

Outcome of Effective Communication and Dissemination

For the discussion of outcomes of effective communication and dissemination, the panel broke into four groups. Panelists discussed what they felt were some of the barriers and the important outcomes to effective communication and dissemination research.

Group #1:

- Addressing provider satisfaction and burnout
- Looking at systems level outcomes and removing ineffective interventions and/or interventions with low utilization
- Caregiver satisfaction with provider communication
- Targeting clinicians and increasing patient-centered physicians
- Principal Investigators (PIs) should have plans to disseminate efficacious findings

Group #2:

- Mutual goal setting by patient and provider that meets the needs of the patient
- The provider needs to have an understanding of the patient's social situation, which is often left out of the clinic visit discussion
- Successful communication of when a treatment is not necessary
- Provider guidance for helping patients access information, since not all information is evidence-based or from a reliable source

Group #3:

- Two main questions: How do patients and clinicians define value? How do they navigate the lifecycle of a disease?
- Patient preference and determining a successful intervention
    - Understanding how the patient's life is changing with and outside of the disease
    - Incorporating appropriate care coordination and understanding how behavior changes based on management
- Goal alignment across the entire healthcare team

Group #4:

- Guideline adherence for physicians
- Using the electronic health record (EHR) to increase dissemination efforts in hospital systems
- Encouraging dissemination and allowing PIs to be innovative in their dissemination approach
- Addressing the burden on physicians and the healthcare team

The recurring themes throughout the discussion addressed the need for patient, caregiver, and physician satisfaction. Patients and caregivers need to understand what the physician is saying, but the physician needs to address the patient's cultural, communication, and care needs, as well as address the psychosocial issues that might be hindering behaviors like adherence.

Framework for Communication and Dissemination Research

The day concluded with a discussion of the future development of a framework for communication and dissemination research. Bridget Gaglio, PhD, Program Officer for the CDR Program, led the discussion with the panelists to begin conceptualizing a framework to help identify the concepts that were discussed throughout the day, how they were defined, and how they could work together. This framework will be created and modified in subsequent meetings.

Next Steps

The panel will meet again on April 13, 2016.