



# Patient Engagement Advisory Panel

*September 21, 2013*  
*Washington, DC*

Patient-Centered Outcomes Research Institute

# Agenda for September 21

8:30-9:00 a.m.      Recap of Day 1

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9:00-10:30 a.m.      Discuss Framework for Engagement in  
Dissemination

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10:30-10:45 a.m.      **Break**

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10:45-12:00 p.m.      PCORI Topics for Discussion

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12:00 – 1:00 p.m.      Call for Topics

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1:00 p.m.      **Meeting Adjourned** *(Boxed Lunch Provided)*

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## Recap of Day 1

***Sue Sheridan, MIM, MBA***

*Director of Patient Engagement*

***Suzanne Schrandt, JD***

*Deputy Director of Patient  
Engagement*

***Charlotte W. Collins, JD***

*Chair*

***Darius Tandon, PhD***

*Co-Chair*

Patient-Centered Outcomes Research Institute

# Action Items from Day 1

- Rubric Discussion
- Engagement Strategic Plan
- Ambassadors Program
- Pipeline to Proposal Awards



# Framework for Engagement in Dissemination

***Orlando Gonzales, MPA***

*Chief of Staff for Engagement*

***Anne C. Beal, MD, MPH***

*Deputy Executive Director and Chief  
Officer for Engagement*

***Darius Tandon, PhD***

*Co-Chair*

Patient-Centered Outcomes Research Institute

**PCORI's Vision for  
Dissemination and Implementation  
of Clinical Comparative Effectiveness Research**

# The Case for Addressing the Implementation Gap

**Optimal Healthcare Delivery**

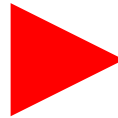
PCORI's *Blueprint for Dissemination and Implementation* Targets the Gap



Research + Practice

# Establishing a PCORI Action Plan for Dissemination to Promote Implementation

**DISSEMINATION**



**IMPLEMENTATION**

## PCORI's Action Plan for

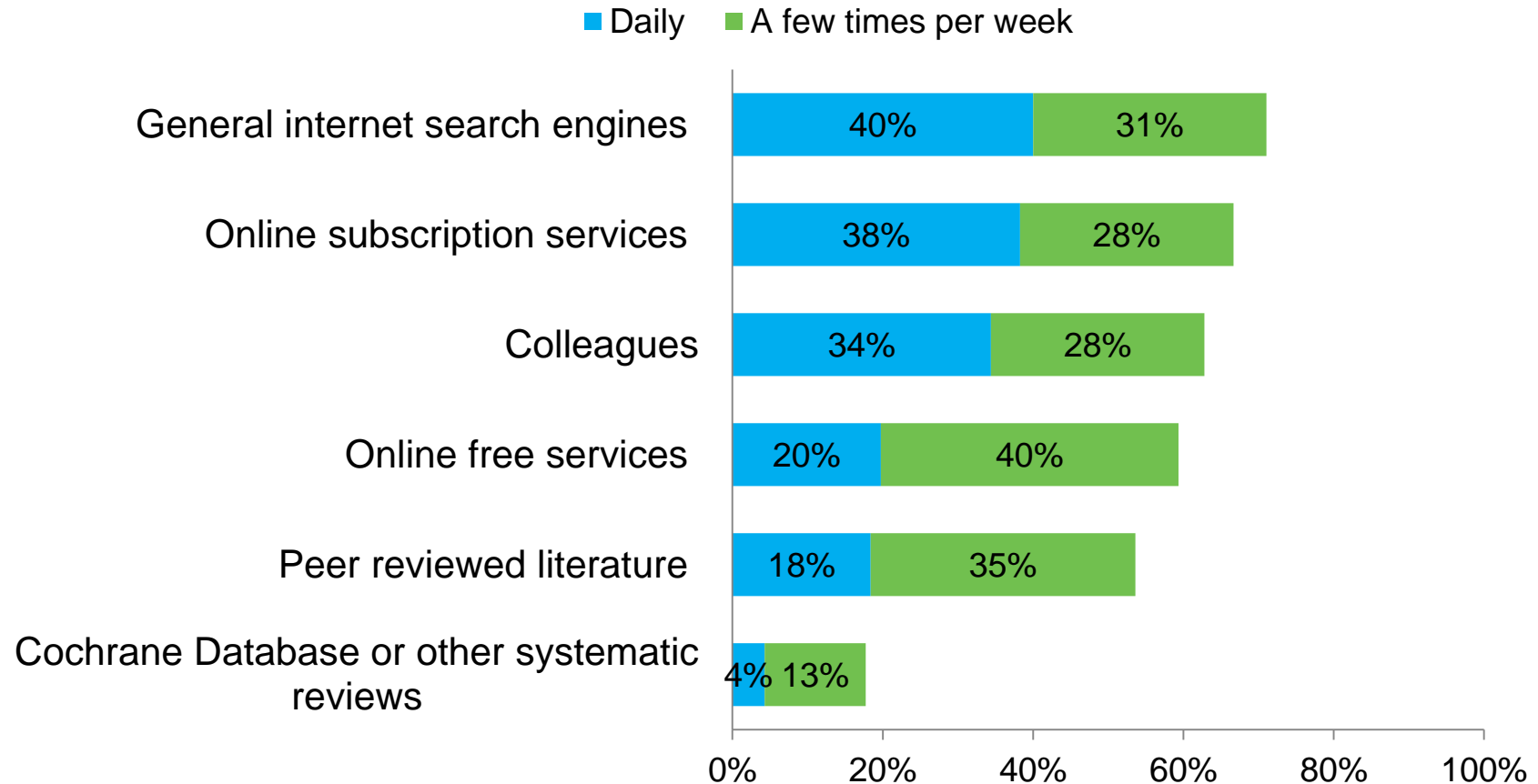
### Dissemination and Implementation is being established:

- To guide the organization in disseminating the research findings of funded research conducted in the national program areas
- To speed implementation by actively facilitating how PCORI's research findings can be used by healthcare decision makers
- To evaluate how the effect of the dissemination of such findings reduces practice variation and disparities in health care



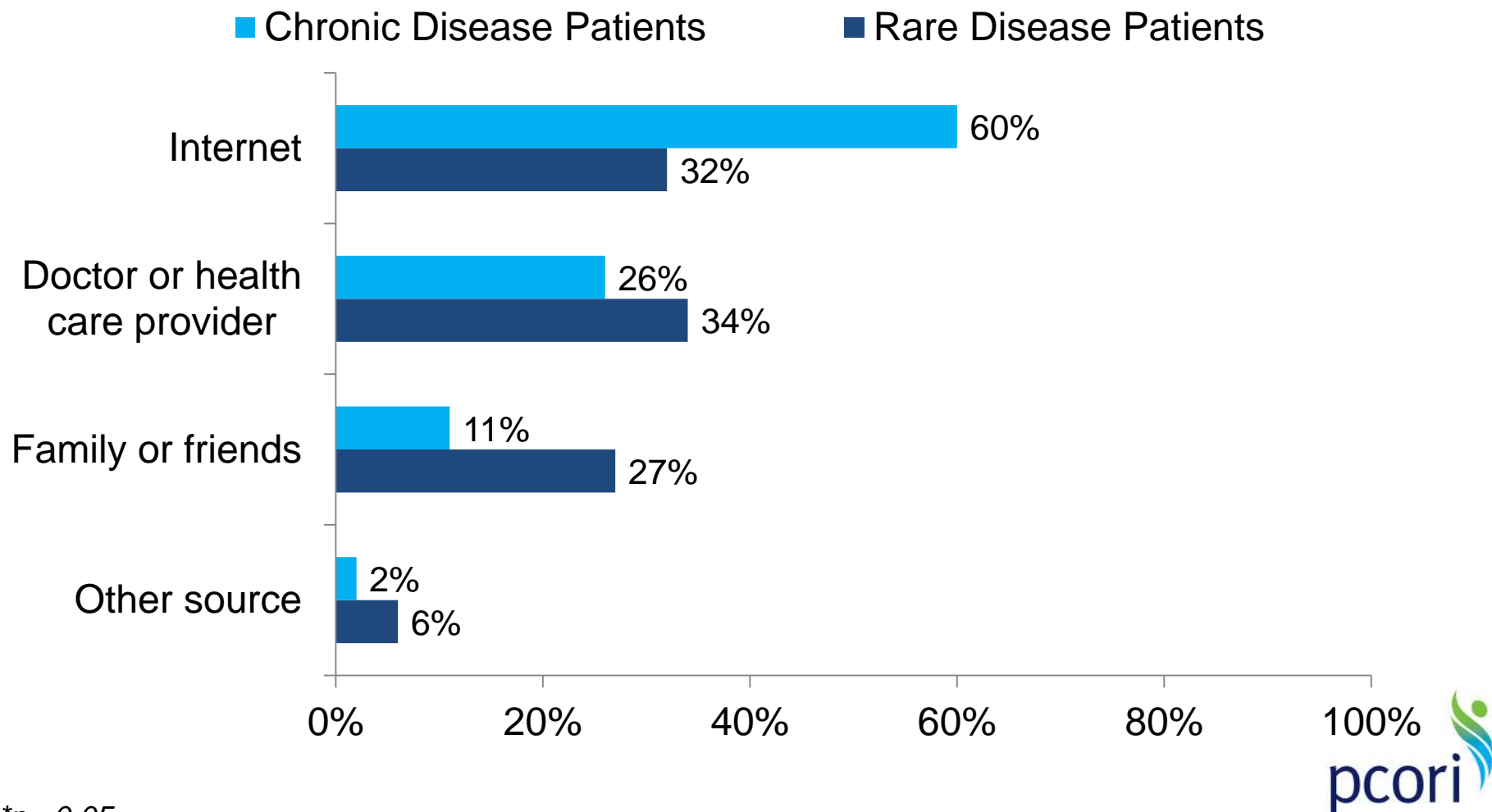
# *Clinicians frequently use general Internet searches and colleagues to obtain information to diagnose and treat patients*

How often do you use the following sources to obtain information to diagnose, treat and care for patients?



## ***Patients use the Internet as first source of health information***

The most recent time you looked for information about health or medical topics, where did you go **first**?

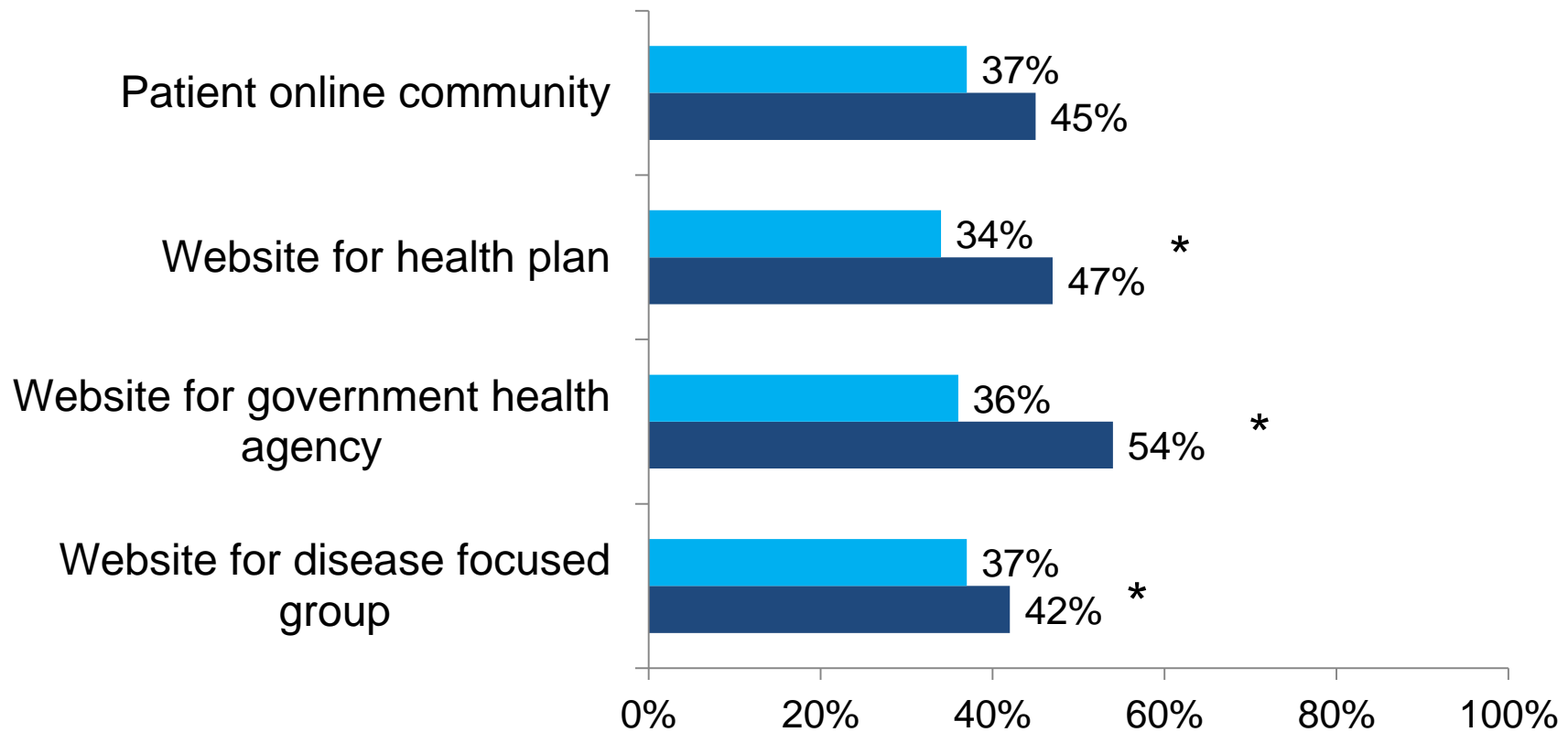


\* $p < 0.05$

## Patients use a variety of Internet sources

In the past 12 months, which of the following internet sources have you used to get information about health or medical topics?

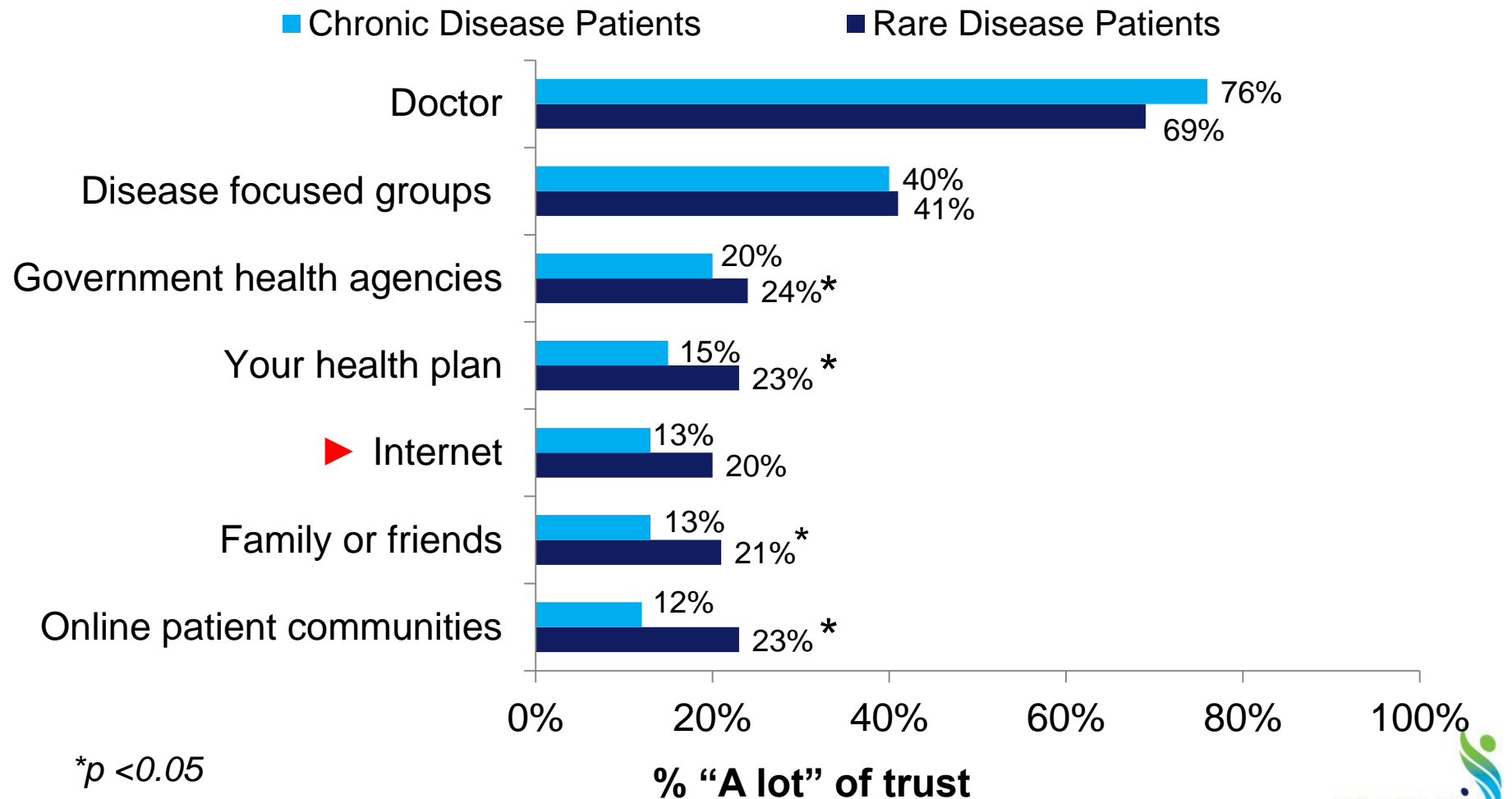
■ Chronic Disease Patients      ■ Rare Disease Patients



\* $p < 0.05$

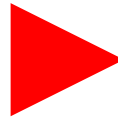
# Patients' trust in Internet is low compared to other sources

How much do you trust information about health or medical topics from each of the following?



# Potential Mechanisms for Dissemination to Promote Implementation

**DISSEMINATION**



**IMPLEMENTATION**

- Engage major patient organizations
- Establish partnerships with specialty organizations;
- Build working relationships with health plans;
- Develop partnerships with health systems;
- Connect thru the National Patient-Centered Clinical Research Network;
- Publish findings in key journals; and
- Explore use of web services, social media, apps, etc.

# AHRQ and PCORI's Role in Dissemination and Implementation

Success for PCORI *and* AHRQ = **Impact** on practice and patient outcomes

## Authorizing Legislation

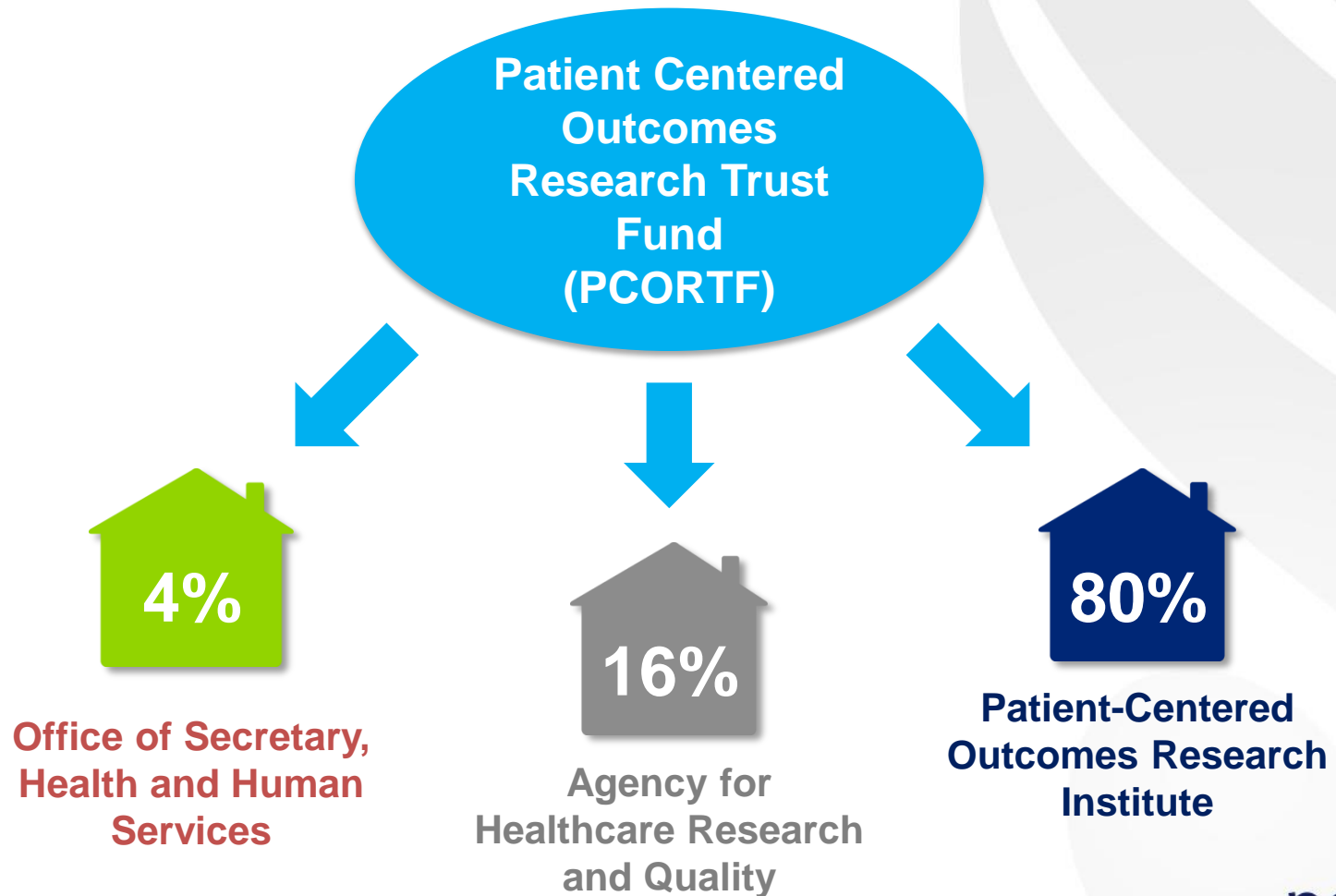
### Agency for Healthcare Research and Quality (AHRQ)

- AHRQ shall disseminate the research findings that are published by PCORI Sec. 937(a)(1)
- Create informational tools that organize and disseminate research findings for physicians, health care providers, patients, payers, and policy makers Sec. 937(a)(1)
- Develop a publicly available resource database that collects and contains government-funded evidence and research Sec. 937(a)(1)

### Patient-Centered Outcomes Research Institute (PCORI)

- The purpose of the Institute is to assist patients, clinicians, purchasers, and policy-makers in making informed health decisions by advancing the quality and relevance of evidence...**and the dissemination of research findings** with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services, and items described in subsection (a)(2)(B).

# PCORTF Distribution



# 3 Goals: PCORI's Blueprint for a Dissemination and Implementation Action Plan

1. Gather opinions from experts on what PCORI's blueprint should encompass
2. Identify gaps where there is a need to develop new knowledge on best practices for dissemination & implementation
3. Grow consensus behind an approach to our work in dissemination and implementation

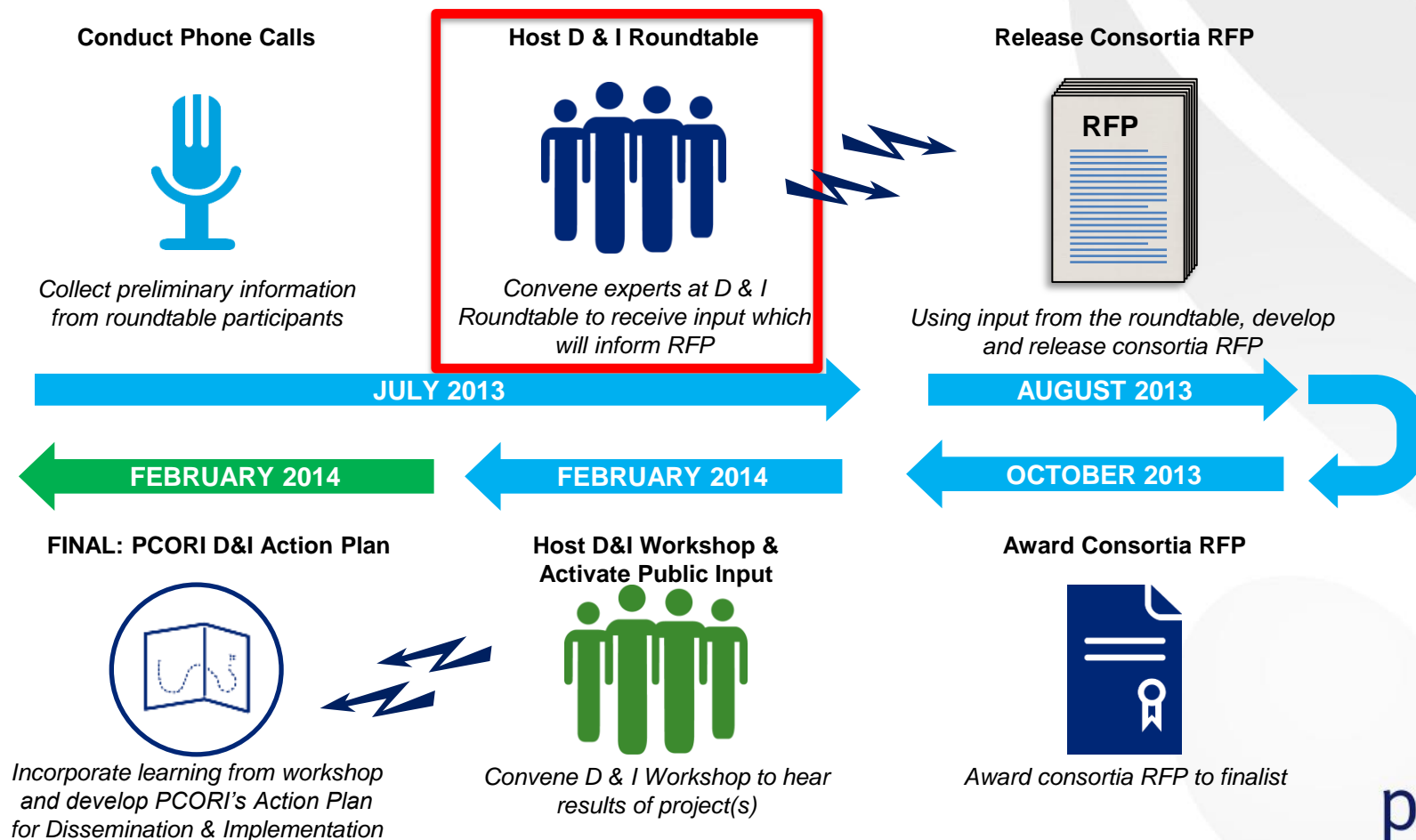


# Items PCORI Will Explore at a Later Date

- Peer-review
- Public comment
- Aspects of scholarly publishing
- The requirement that we make our research results available to clinicians, patients and the general public within 90 days “after the conduct or receipt of research findings”

# Developing the PCORI Dissemination and Implementation Action Plan

## Process for Developing PCORI's Action Plan for Dissemination and Implementation



# **Overview of the Roundtable and Opportunity for the Patient Engagement Advisory Panel to Provide Input**

# Overview of the Roundtable Agenda

## Establishing PCORI's Action Plan for Dissemination and Implementation

1

Welcome and Introductions

2

Brian Mittman - Overview of D&I Frameworks

3

Jean Slutsky - Overview of AHRQ's D&I Efforts

Break

4

Roundtable Discussion - Part 1

5

Roundtable Discussion - Part 2

Break

6

Public Comment Period

7

Next Steps and Adjourn



# 28 Roundtable Participants



# Discussion Questions: Share Experience

1

Given your personal experience in dissemination and implementation, what are the lessons learned, barriers, and successful facilitators in dissemination and implementation?

2

What strategies can PCORI use to build on or complement AHRQ's current work in dissemination and implementation?

3

What key elements would you like to see in PCORI's blueprint to help your organization with implementing research findings?

# Discussion Questions: Help Formulate RFP

4

What is the best approach to develop a framework for implementing results of comparative effectiveness research (CER)?

5

Which already existing frameworks would you recommend be reviewed for developing PCORI's blueprint for dissemination and implementation?

6

What would you include in the scope of work for the request for proposal (RFP)? What are the key abilities we should seek among applicants interested in developing a framework in response to the request for proposal (RFP)?



**Given your personal experience in dissemination and implementation, what are the lessons learned, barriers, and facilitators in successful spread and uptake?**





# What strategies can PCORI use to build on or complement AHRQ's current work in dissemination and implementation?





# What is the best approach to develop a framework for implementing results of comparative effectiveness research (CER)?



**Which already existing frameworks would you recommend be reviewed for developing PCORI's blueprint for dissemination and implementation?**



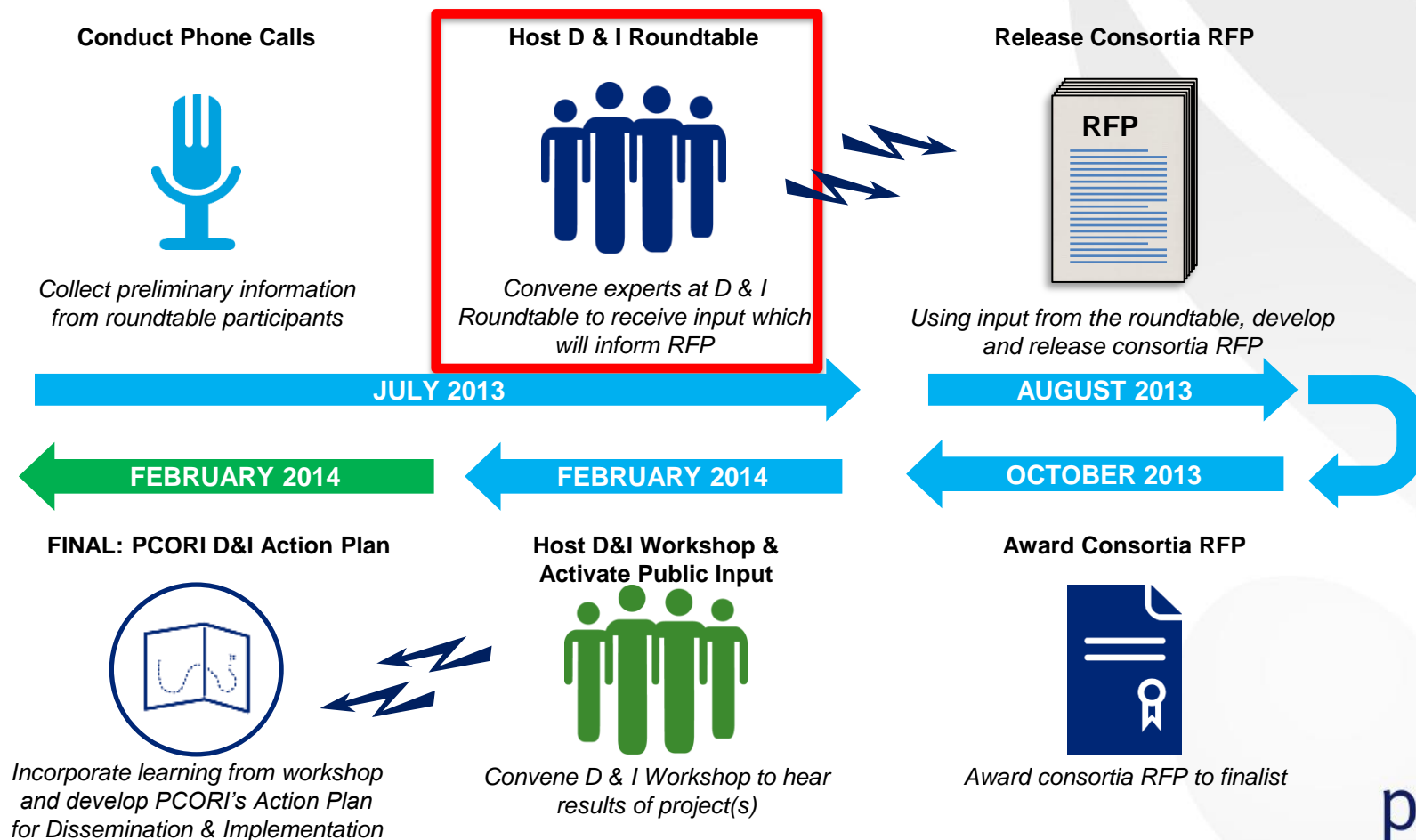
**What would you include in the scope of work for the request for proposal (RFP)? What are the key abilities we should seek among applicants interested in developing a framework in response to the request for proposal (RFP)?**



# Next Steps

# Developing the PCORI Dissemination and Implementation Action Plan

## Process for Developing PCORI's Action Plan for Dissemination and Implementation



**Thank you!**



## **Appendix: Roundtable Participants**



## Panelists

**Craig Acomb**, *Institute for Clinical Systems Improvement*

**Hilda Bastian**, *National Center for Biotechnology Information*

**Kathleen Blake**, *American Medical Association*



**Barbara Edson**, *American Hospital Association*

**Kevin Fahey**, *America's Health Insurance Plans*

**Tejal Gandhi**, *National Patient Safety Foundation*



**Don Goldmann**, *Institute for Health Improvement*

**Jennifer Graff**, *National Pharmaceutical Council*

**Matthew Holland**, *WebMD*





**Gail Hunt**, *National Alliance  
for Caregiving*  
**Bob Jesse**, *US Department  
of Veterans Affairs*  
**Norm Kahn**, *Council of  
Medical Specialty Societies*

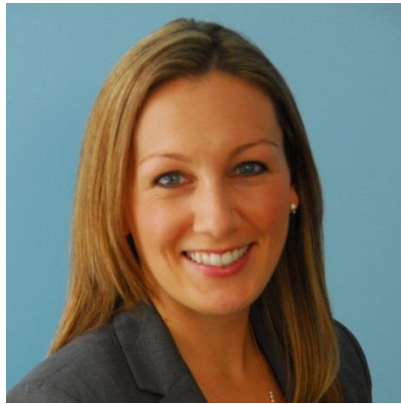
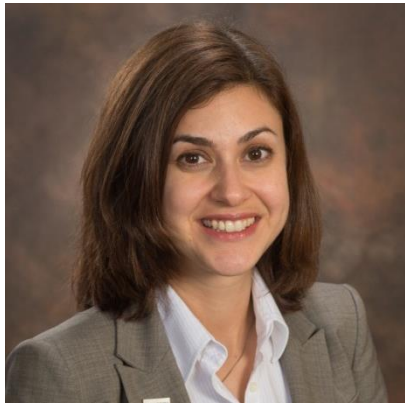


**Christine Laine**, *American  
College of Physicians and  
International Committee of  
Medical Journal Editors*  
**Sharon Levine**, *Kaiser  
Permanente*  
**Sarah Lock**, *AARP*



**Renee Mentnech**, *Centers  
for Medicare and Medicaid  
Services*  
**Brian Mittman**, *US  
Department of Veterans  
Affairs*  
**Doris Peter**, *Consumer  
Reports*





**Michelle Proser**, *National Association of Community Health Centers*

**Pamela Rich**, *National Business Group on Health*

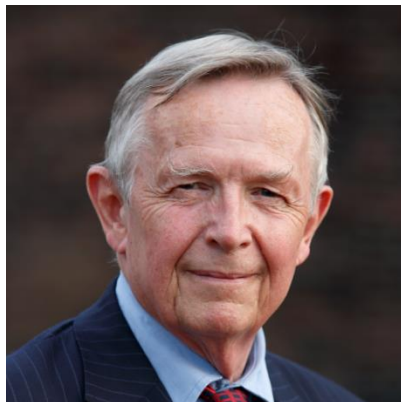
**Kate Ryan**, *Consumers United for Evidence-based Healthcare and National Women's Health Network*



**Bruce Seeman**, *Agency for Healthcare Research and Quality*

**Lisa Simpson**, *AcademyHealth*

**Jamie Skipper**, *US Department of Health and Human Services/Office of the National Coordinator*



**Jean Slutsky**, *Agency for Healthcare Research and Quality*

**Roger Snow**, *Medicaid Medical Directors Learning Network*

**Darius Tandon**, *Johns Hopkins University*





**Daniel Wolfson, ABIM  
Foundation**



**PCORI Staff**

**Ayodola Anise**, Senior  
Program Associate

**Anne Beal**, *Deputy  
Executive Director and Chief  
Officer for Engagement*

**Orlando Gonzales**, *Chief of  
Staff for Engagement*



**Joe Selby**, *Executive  
Director*

# 15 Minute Break

*We will reconvene at 10:45 am*



## PCORI Topics for Discussion

**Moderators:**

**Sue Sheridan, MIM, MBA**

*Director of Patient Engagement*

**Suzanne Schrandt, JD**

*Deputy Director of Patient  
Engagement*

Patient-Centered Outcomes Research Institute



## Panelist Topics for Discussion

### Moderators:

**Sue Sheridan, MIM, MBA**

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# Developing CER Usability Criteria

 Presenter: Marc Boutin

# AHRQ Advisory Panel Framework for Stakeholder Engagement

 Presenter: Perry Cohen



## NEXT STEPS

Patient-Centered Outcomes Research Institute

# PEAP Next Steps

- Next face to face meeting will be held on January 13-14 (Monday/Tuesday)
- Share revised rubric

# Thank you!

*Please pick up a boxed lunch before your depart.*

*Safe travels!*