

# **Listening to Patients, Caregivers, and Clinicians: Meeting Stakeholder Needs for Comparative Effectiveness Research - A PCORI Survey**

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**November 4, 2015**



# Welcome

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We welcome your questions and comments via the chat function on the right side of your screen



We welcome your comments via Twitter to @PCORI and #PCORI



An archive of this webinar will be posted to <http://www.pcori.org/events/2015/listening-patients-caregivers-and-clinicians-meeting-stakeholder-needs-comparative> following this event.



If we are unable to address your question during this time, please e-mail your question to us at [surveys@pcori.org](mailto:surveys@pcori.org)



# Introductions

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## Moderator:

- Lori Frank, PhD, PCORI Program Director, Evaluation and Analysis



## Presenters:

- Lauren Fayish, MPH, PCORI Program Associate, Evaluation and Analysis
- Thomas Workman, PhD, American Institutes for Research, Principal Investigator



## Discussant:

- Jean Slutsky, PA, MSPH, PCORI Chief Engagement and Dissemination Officer



# Introductions

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## Panelists:

- Pam Flores, Patient Representative
- Lisa Heral, RN, BA, CCRC, Caregiver Representative
- Lynn M. Olson, PhD, American Academy of Pediatrics



# Agenda

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- Introduction to PCORI
- Survey background and methods
- Key survey findings
- Implications for PCORI
- Panel Discussion



# Introduction to PCORI



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

# About PCORI

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- An independent research institute authorized by Congress in 2010
- Funds patient-centered comparative effectiveness research (PC-CER) that engages patients and other stakeholders throughout the research process
- Seeks answers to real-world questions about what works best for patients based on their circumstances and concerns



# PCORI - Our Mission

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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**.



# We Fund Patient-Centered Comparative Effectiveness Research

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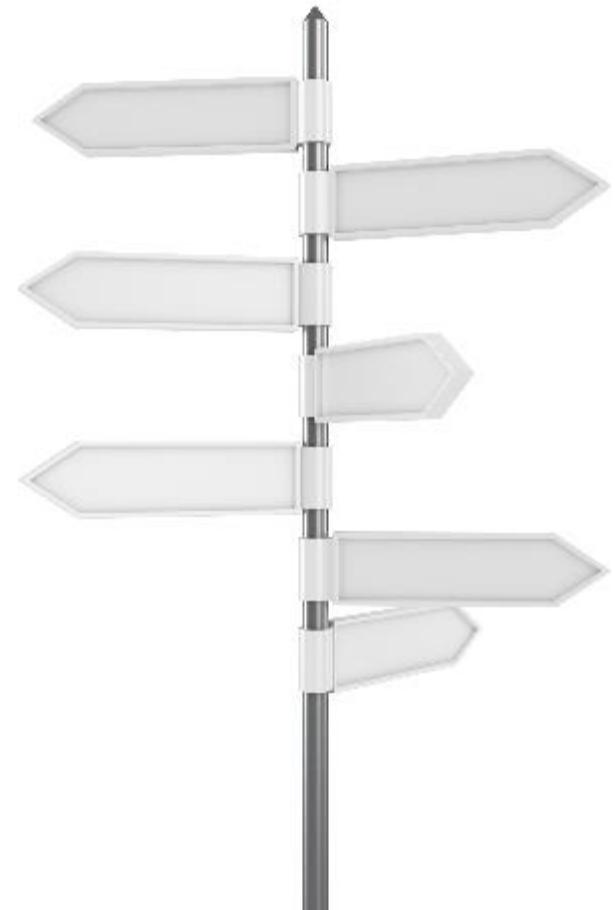
- Measures benefits in real-world populations
- Describes results in subgroups of people
- Generates and synthesizes evidence comparing benefits and harms of at least two different methods to prevent, diagnose, treat, and monitor a clinical condition or improve care delivery
- Helps consumers, clinicians, purchasers, and policy makers make informed decisions that will improve care for individuals and populations
- Informs a specific clinical or policy decision



# How is Our Work Different?

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- We fund research on which care options work, for whom, under which circumstances.
- We focus on answering questions most important to patients and those who care for them.
- We aim to produce evidence that can be easily applied in real-world settings.
- We engage patients, caregivers, clinicians, insurers, employers and other stakeholders throughout the research process.
- This makes it more likely we'll get the research questions right and that the study results will be useful and taken up in practice.



# Who Are Our Stakeholders?



# Survey Background and Methods

# Background

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In late 2014, PCORI conducted surveys of four stakeholder groups:



# Survey Objectives

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- To understand attitudes toward CER
- To understand the use of health information in decision-making
- To understand awareness of and attitudes toward engagement in research



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- To evaluate the potential for engagement in research to enhance the uptake of research results in clinical practice



# Survey Objectives

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- To understand the use of health information in decision-making
- To understand awareness of and attitudes toward engagement in research
- To evaluate the potential for engagement in research to enhance the uptake of research results in clinical practice
- To inform methods to facilitate use of CER and the engagement of patients and stakeholders in research



# Survey Development

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- Partnership with American Institutes for Research (AIR)
- Guided by an overarching multi-stakeholder advisory panel and four survey-specific working groups
- Survey development included literature review and cognitive testing
- Surveys fielded September 2014 – January 2015



# Sample Recruitment

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Sample	Methods for Recruitment
<b>Rare Conditions</b>	Convenience samples of patients and caregivers obtained through Genetic Alliance liaising with relevant advocacy organizations to survey their members
<b>Chronic Conditions</b>	Nationally representative samples of patients and caregivers obtained via probability-based online panels (GfK Knowledge Panel®)
<b>Clinicians</b>	Nationally representative sample of primary and specialty physicians, physician assistants, and nurse practitioners drawn from the American Medical Association MasterFile



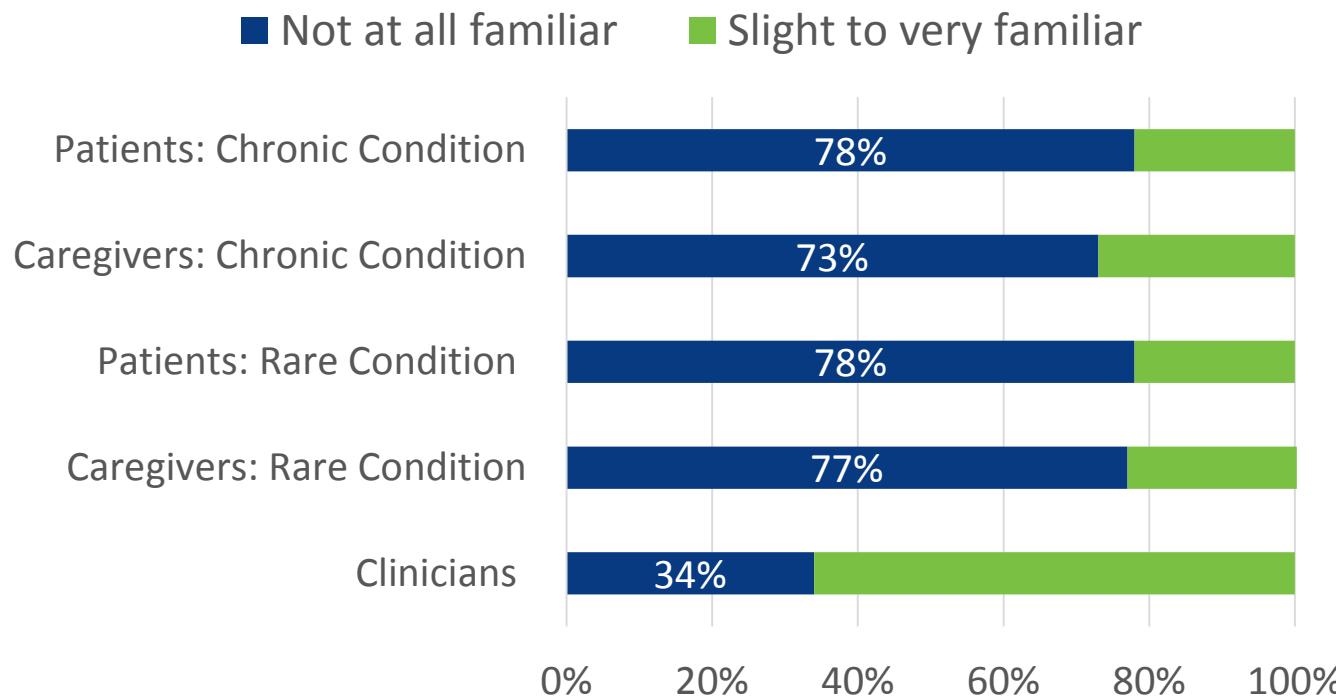
# Sample Characteristics

Sample	Patients	Caregivers
<b>Rare Conditions</b>  <i>N=560 patients, 609 caregivers</i>	Top Conditions <ul style="list-style-type: none"><li>• Transverse Myelitis (26%)</li><li>• Pemphigus (20%)</li></ul>	41% caring for a child under age of 18  Top Conditions <ul style="list-style-type: none"><li>• Gangliosidosis-1 (16%)</li><li>• GLUT1 deficiency (16%)</li></ul>
<b>Chronic Conditions</b>  <i>N=762 patients, 776 caregivers, findings weighted</i>	Top Conditions <ul style="list-style-type: none"><li>• High blood pressure (18%)</li><li>• Diabetes (11%)</li></ul>	29% caring for a spouse or partner  Top Conditions <ul style="list-style-type: none"><li>• Diabetes (15%)</li><li>• Chronic Pain (8%)</li></ul>
<b>Clinicians</b>  <i>N=638, findings weighted</i>	<p><i>Provider Type:</i> Physician (62%), Nurse Practitioner (24%), Physician Assistant (14%)</p> <p><i>Practice Setting:</i> Urban (45%), rural or small town (21%)</p>	



# Key Findings

# Familiarity with Comparative Effectiveness Research (CER)



**Few patients and caregivers are familiar with the term CER.  
One-third of clinicians are not at all familiar with CER.**



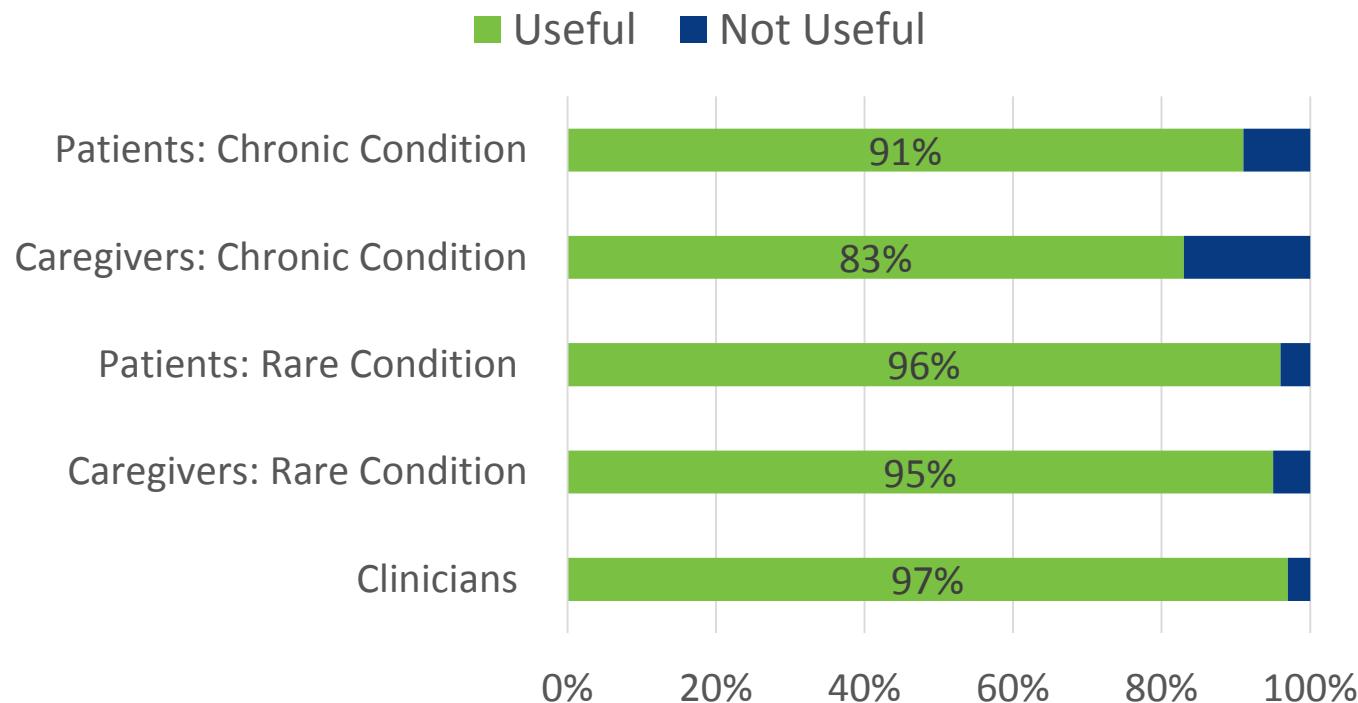
# What is CER?

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“ One type of medical research compares the possible benefits and harms of different diagnostic test and treatment options, or different ways to prevent problems caused by your condition, in order to inform your medical decisions. It might compare one treatment to another and ask which one is better for a health condition and why. This research is commonly called comparative effectiveness research (CER). ”



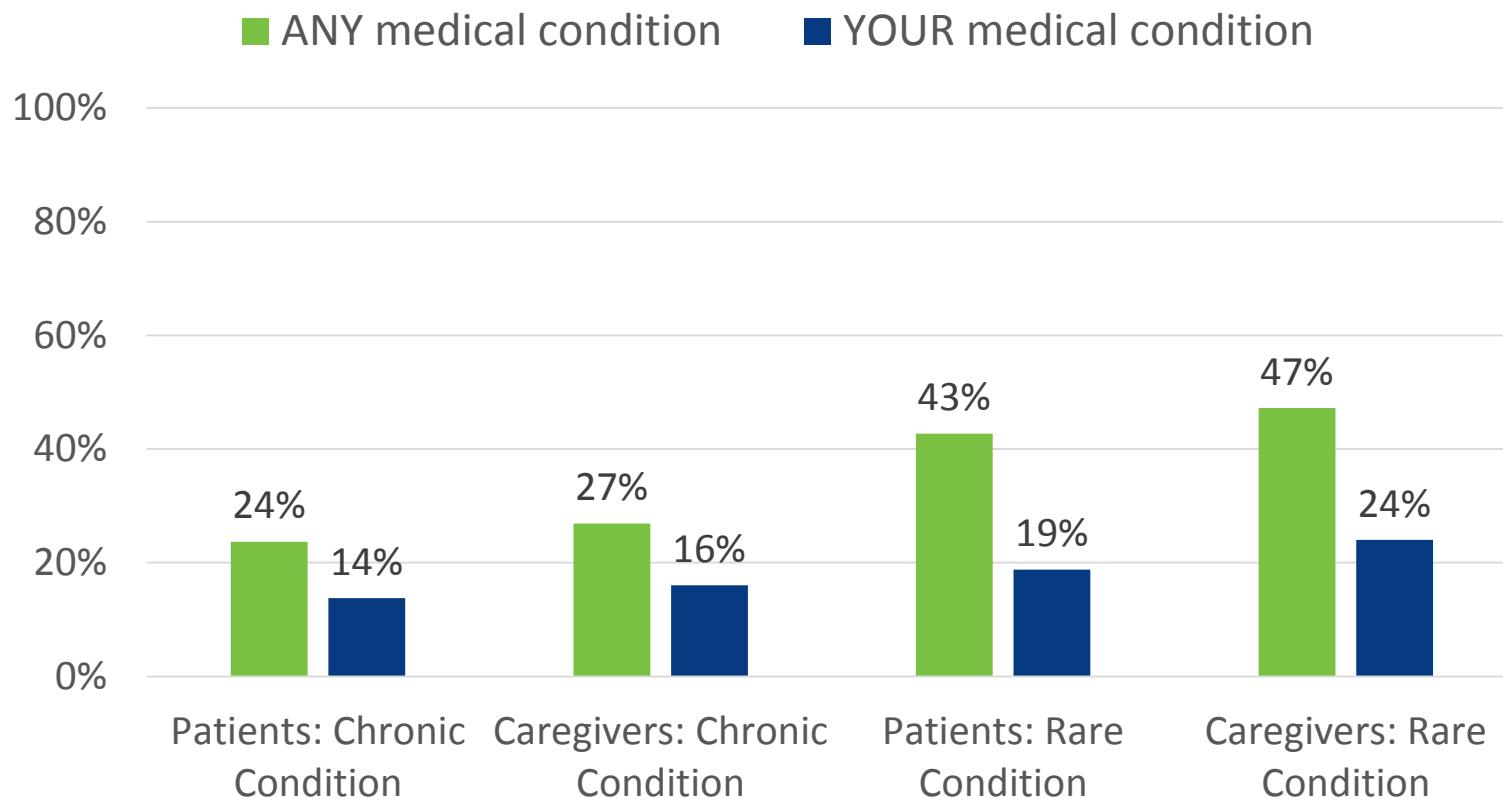
# Usefulness of CER for Making Treatment Decisions



**When the concept is explained, nearly all patients, caregivers, and clinicians believe that CER is useful for making treatment decisions.**



# Exposure to Research Comparing Possible Benefits and Harms



**Few patients and caregivers have read or heard about CER for their health condition.**



# Top Sources of CER Information for Patients and Caregivers

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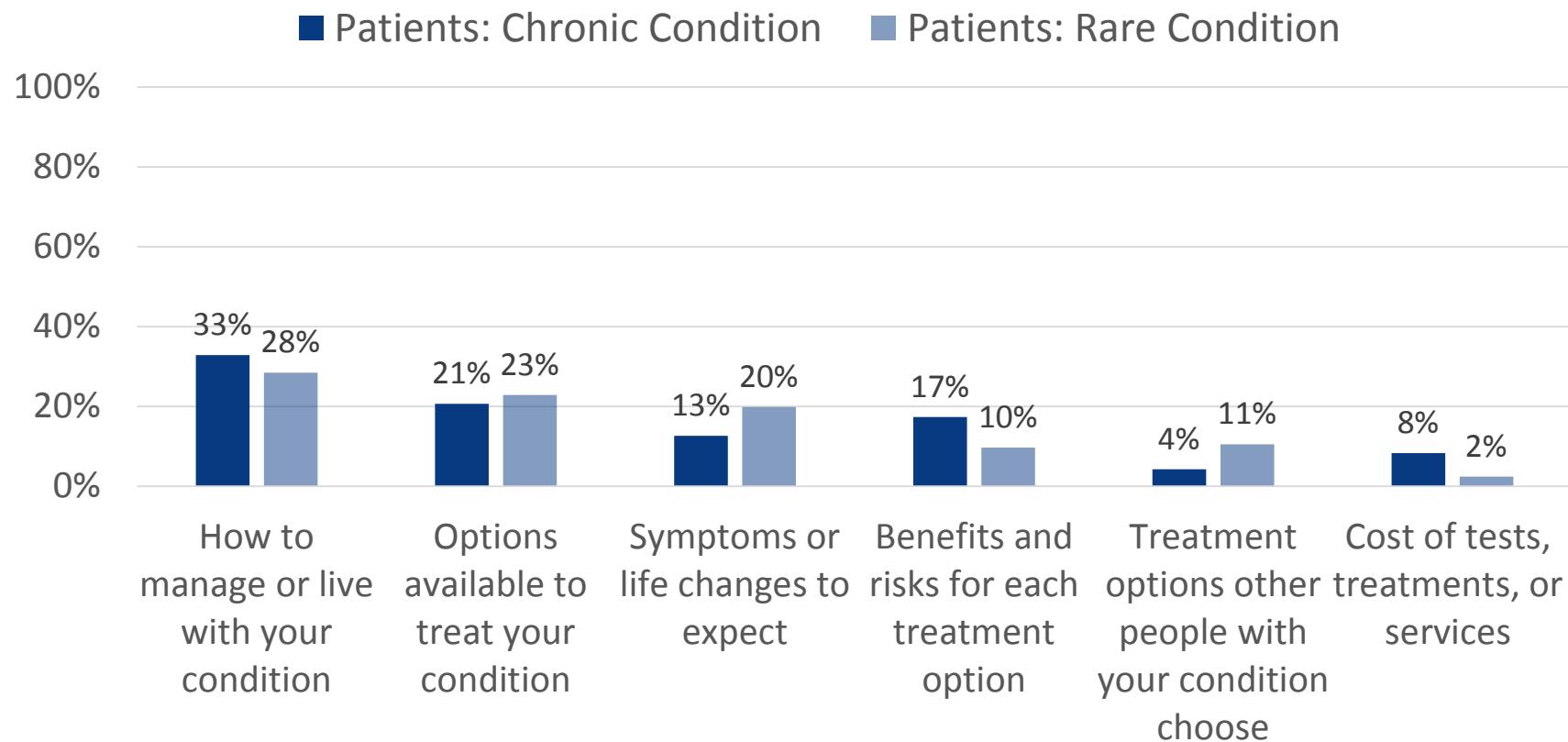
Of those who have read or heard about CER for their condition in the past 12 months:

Chronic Condition	
Patients	Caregivers
Healthcare Professional (72%)	Healthcare Professional (63%)
Website (30%)	Website (39%)

Rare Condition	
Patients	Caregivers
Online Health Communities (61%)	Healthcare Professional (66%)
Healthcare Professional (54%)	Online Health Communities (63%)



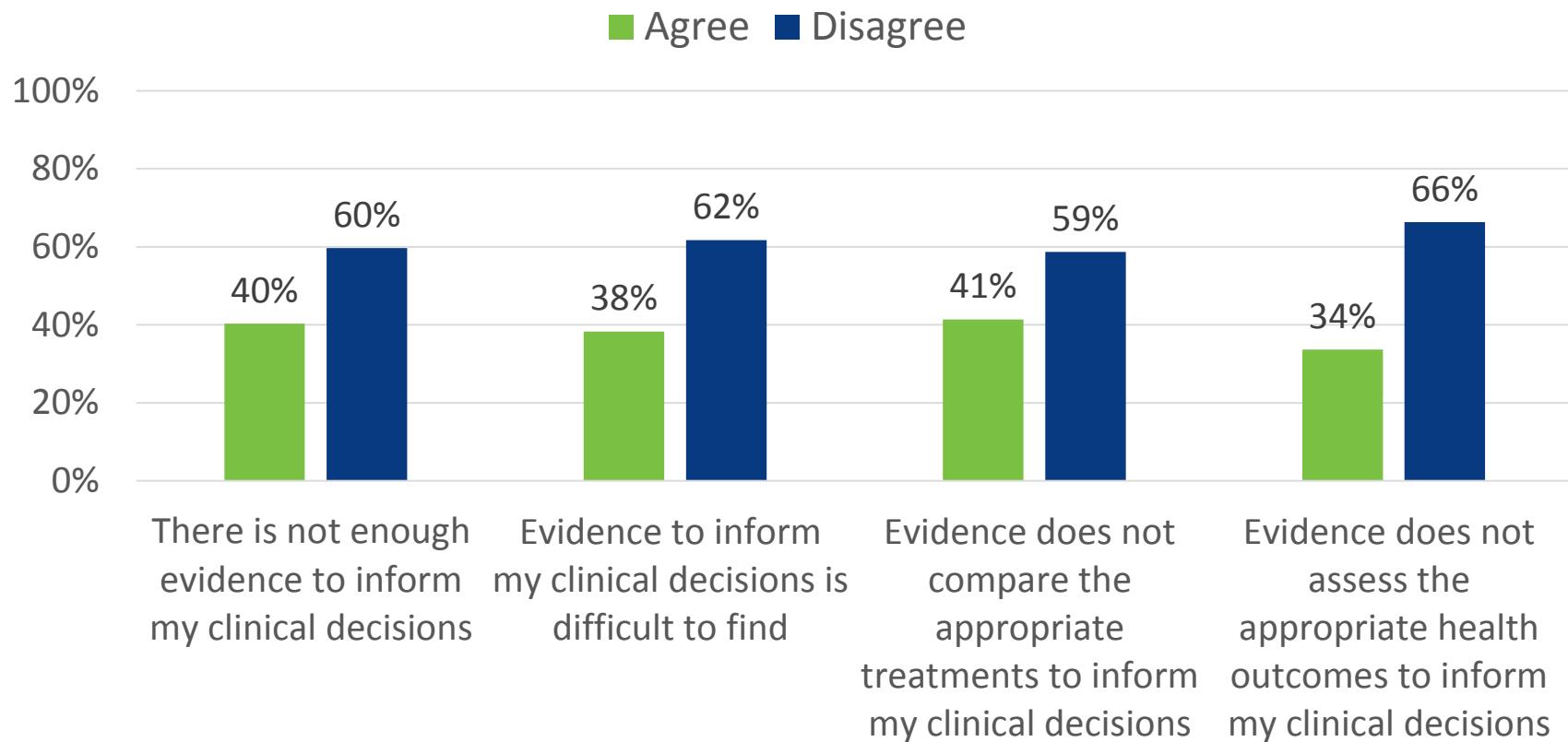
# What Patients Most Want to Know From Health Information



**Patients and caregivers seek health information to understand treatment options and manage the condition.**



# Clinician Use of Research Evidence



**Over 1/3 of clinicians believe that research evidence is not adequate.**



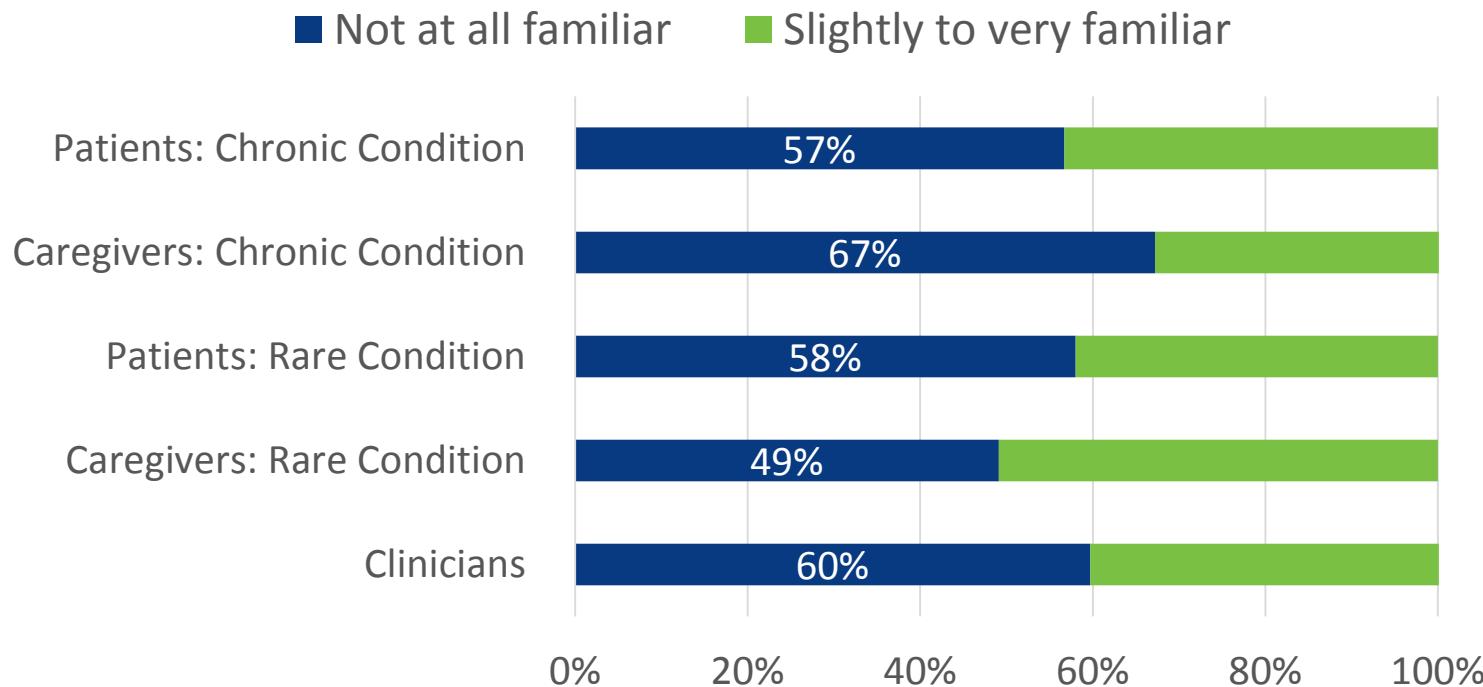
# Summary: CER and Health Information Needs

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- Patients, caregivers, and clinicians have limited familiarity with the term CER but expect CER findings to be useful for decision-making
- Few patients or caregivers have read or heard about CER for their condition, but if they have, clinicians and online health communities are top sources of information
- Patients and caregivers seek health information to understand treatment options and manage their condition
- Many clinicians are dissatisfied with the availability of research evidence to inform clinical decision making



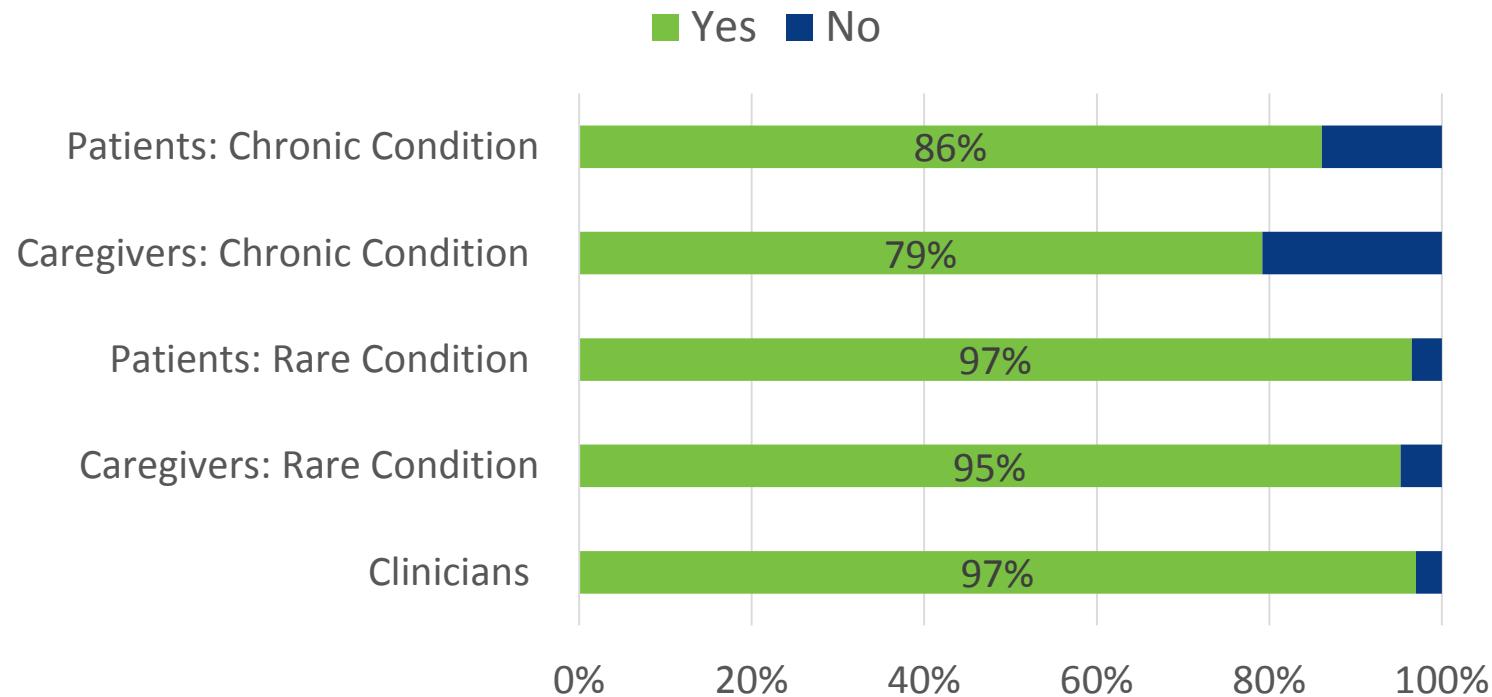
# Familiarity with Engagement in Research



**Many patients, caregivers, or clinicians are unfamiliar with studies where patients partner with the research team to decide what research is done and how it is done.**



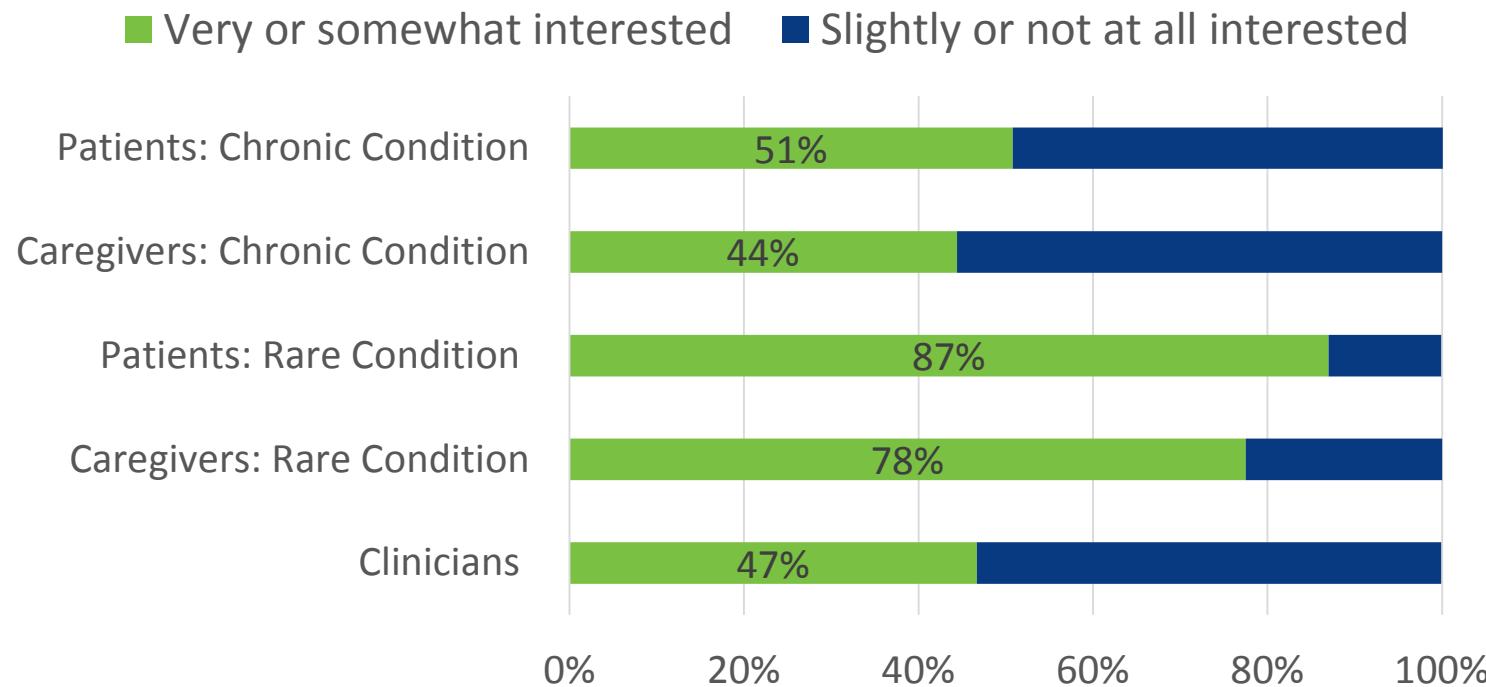
# Belief that Research Engagement would Improve Value of Research



**Patients, caregivers, and clinicians expressed the belief that their engagement would improve the value of research.**



# Interest in Research Engagement



**Interest in engagement in research was highest among patients and caregivers managing a rare condition.**



# Interest in Specific Roles for Research Engagement: Patients and Caregivers

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- Helping researchers understand what information they need
- Helping researchers make findings easy to understand
- Helping researchers get results out



# Clinician Views: Areas of Interest for Partnering with Researchers

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**Very or Somewhat Interested:**

- Helping decide which interventions to compare 60%
- Identifying key implications of study findings for clinical practice 56%
- Communicating findings to other clinicians 55%
- Helping determine how to collect data 52%
- Helping researchers analyze the data 34%

\*Item asked of a subset of clinicians (N=337)



# Top factors for Determining whether to Partner with Researchers: Patients and Caregivers

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- Belief that participation can result in meaningful findings
- Feeling respected by the researchers
- Having an interest in the research
- Having meetings at a time that doesn't interfere with other commitments
- Receiving information about research and how it is conducted
- Working for a team or organization that you know and trust



# Top Factors for Determining whether to Partner with Researchers: Clinicians (% “Very Important”)

## Important Facilitators

- Helping patients receive better care (75%)
- Contributing to scientific knowledge (57%)
- Making studies more meaningful to patients (56%)

## Important Barrier

- Lack of time (67%)

\*Item asked of a subset of clinicians (N=337)



# Summary: Views on Research Engagement

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- Familiarity with research engagement is limited but interest is high
- Making research more meaningful to patients is an important motivator for patients, caregivers, and clinicians
- Respect and trust in partnerships are important for patients and caregivers
- Clinicians endorse time as a top barrier to engaging in research.



# Implications for PCORI

**Jean Slutsky, PA, MSPH**

PCORI's Chief Engagement and Dissemination Officer  
and Program Director for Communication and  
Dissemination Research



# Panel Discussion



**Pam Flores**  
Patient  
Representative



**Lisa Heral**  
Caregiver  
Representative

**Lynn Olson**  
American Academy  
of Pediatrics



# Healthcare Stakeholder Views Webinar Series

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- **Listening to Researchers: Meeting Stakeholder Needs for Comparative Effectiveness Research - A PCORI Survey**

Wednesday, November 18, 2015

11:00 am – 12:00 pm ET

<http://www.pcori.org/events/2015/listening-researchers-meeting-stakeholder-needs-comparative-effectiveness-research-pcori>



# Thank you!

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- Acknowledgements
  - Patient, Caregiver, and Clinician survey respondents
  - Webinar panelists
- Stay current with email alerts at <http://www.pcori.org/home/signup> and follow us on Twitter @PCORI
- Please send questions or comments to:

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