Patient and Clinician Views on Comparative Effectiveness Research and Engagement in Research: A Panel Discussion on PCORI Survey Results

Patient-Centered Outcomes Research Institute

Introductions

Moderator and Presenters

- Lori Frank, PhD, Director of Engagement Research, PCORI

- Laura Forsythe, PhD, Program Officer, Engagement Research, PCORI

Panelists

- Marc Boutin, JD, Executive Vice President & Chief Operating Officer, National Health Council

- Barbara Doty, MD, FAAFP, Primary Care Physician and Board of Directors Member, American Academy of Family Physicians

- Susan Rawlins, RN, WHNP-BC, Director of Education, National Association of Nurse Practitioners in Women's Health (NPWH)

PCORI’s Mission and Vision

Mission

The Patient-Centered Outcomes Research Institute (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.

Vision

Patients and the public have the information they need to make decisions that reflect their desired health outcomes.

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Survey Purpose and Methods

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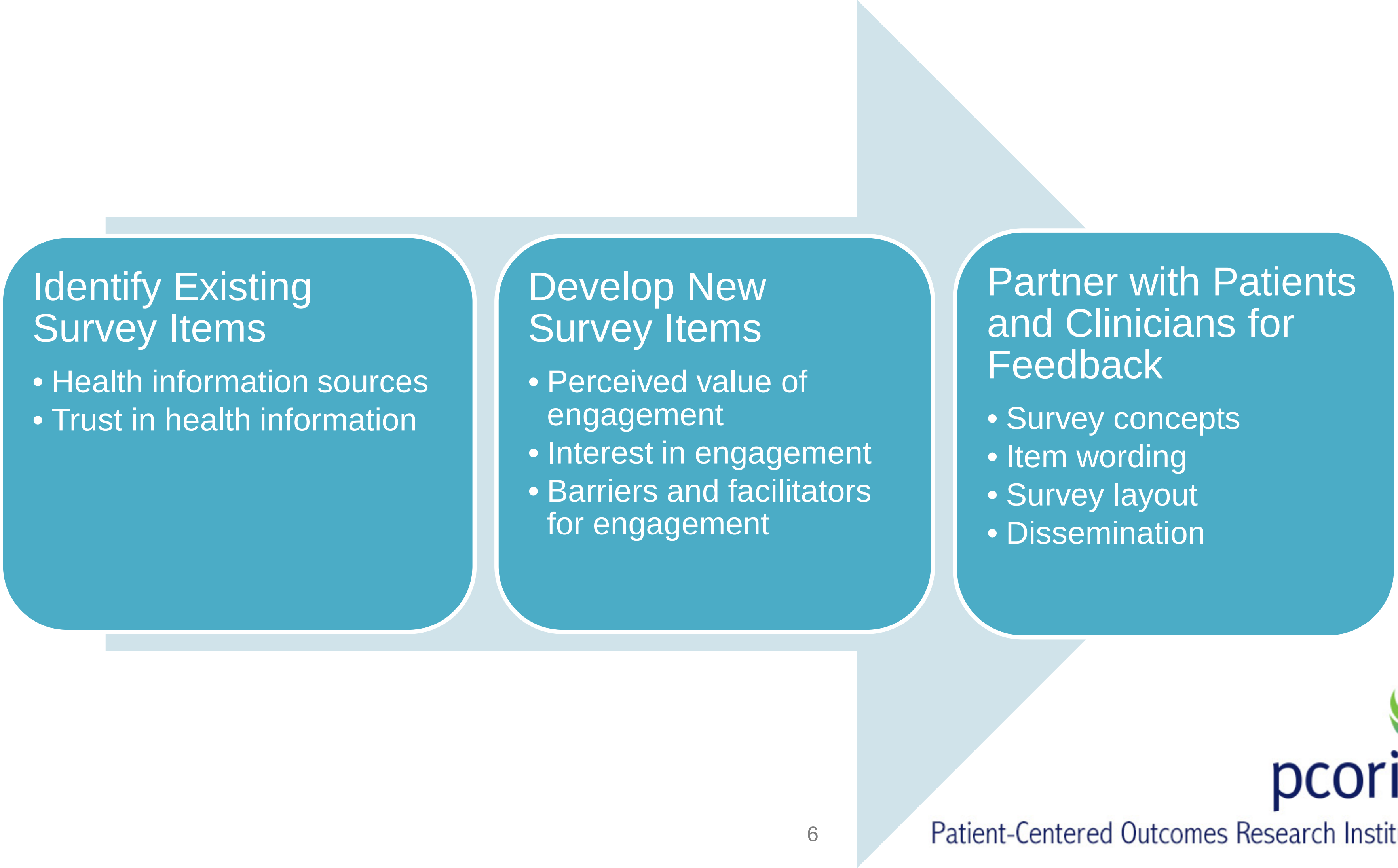
Purpose of the Survey

- Assess attitudes of chronic disease and rare disease **patients** toward
  - Health Research
  - Engagement in Research

- Assess attitudes of **primary care clinicians** toward
  - Health Research
  - Comparative Effectiveness Research (CER)
  - Engagement in Research

Methods: Survey Development



Identify Existing Survey Items

- Health information sources
- Trust in health information

Develop New Survey Items

- Perceived value of engagement
- Interest in engagement
- Barriers and facilitators for engagement

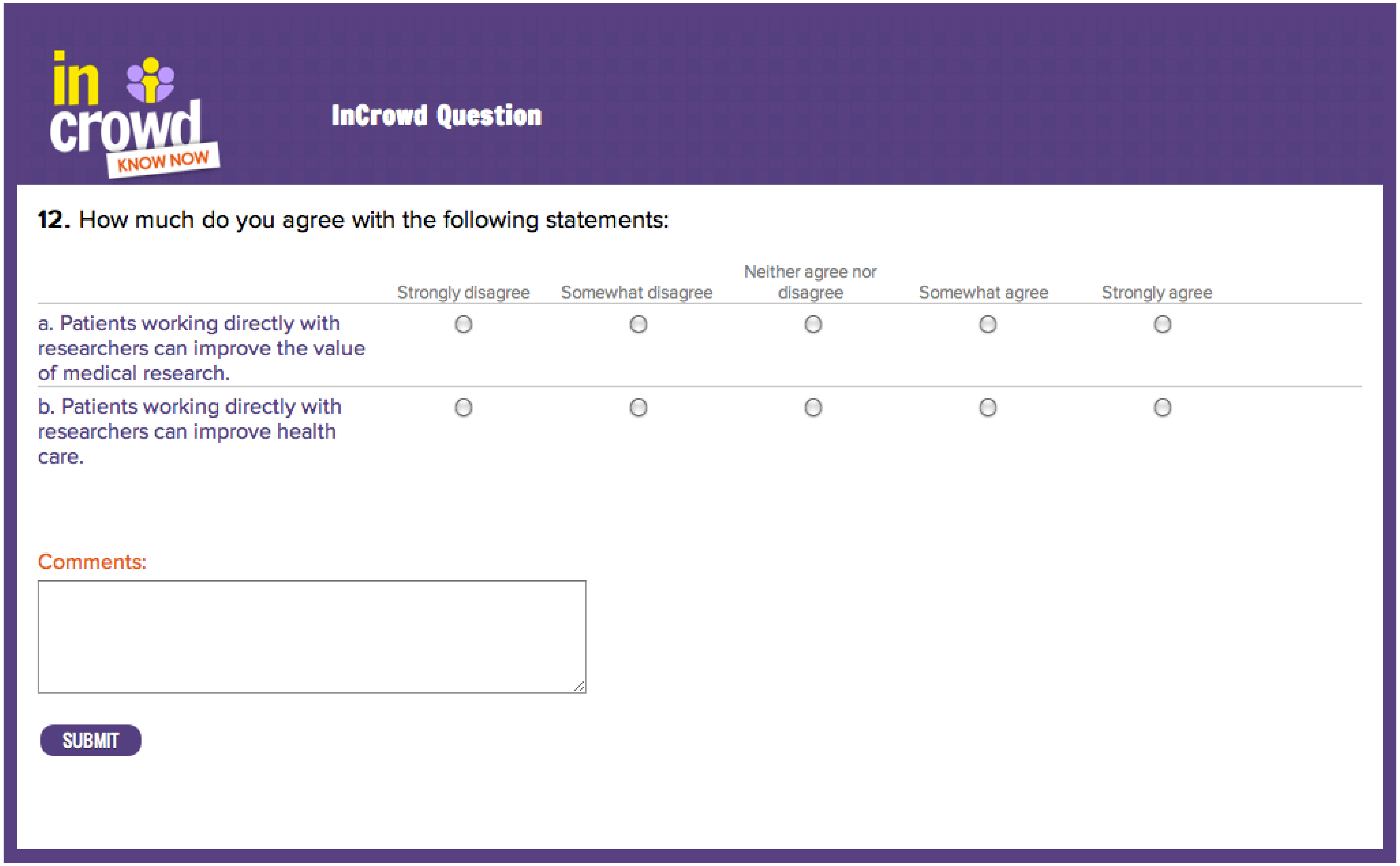
Partner with Patients and Clinicians for Feedback

- Survey concepts
- Item wording
- Survey layout
- Dissemination

Methods: Crowdsourced Survey

- Recruitment from existing opt-in panels based on pre-supplied profiled information
- Web-based survey
- Rapid data collection
- Limited generalizability

Methods: Instrument Example



InCrowd Question

12. How much do you agree with the following statements:

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
a. Patients working directly with researchers can improve the value of medical research.	○	○	○	○	○
b. Patients working directly with researchers can improve health care.	○	○	○	○	○

Comments:

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Survey Respondents

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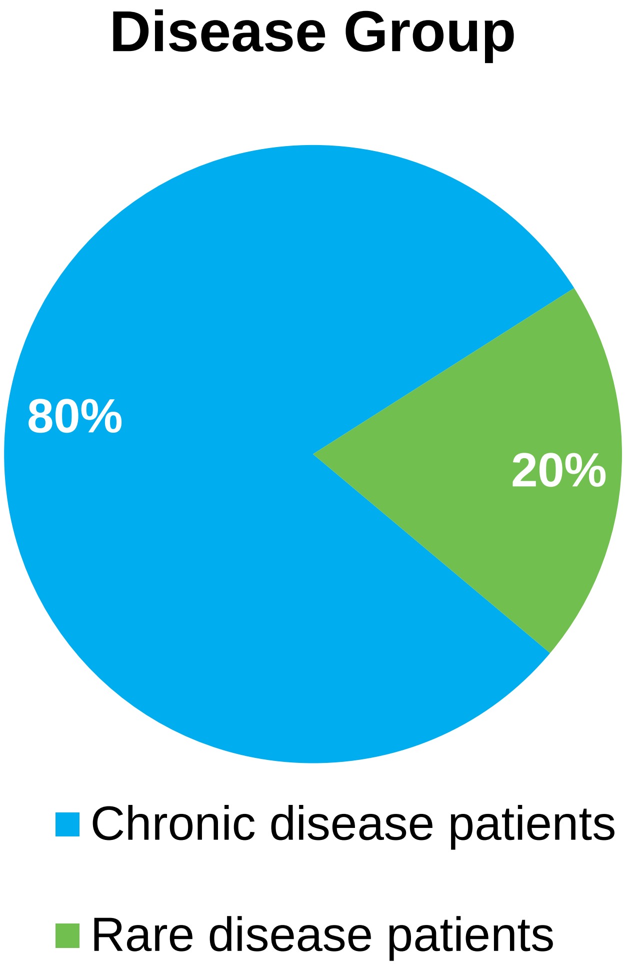
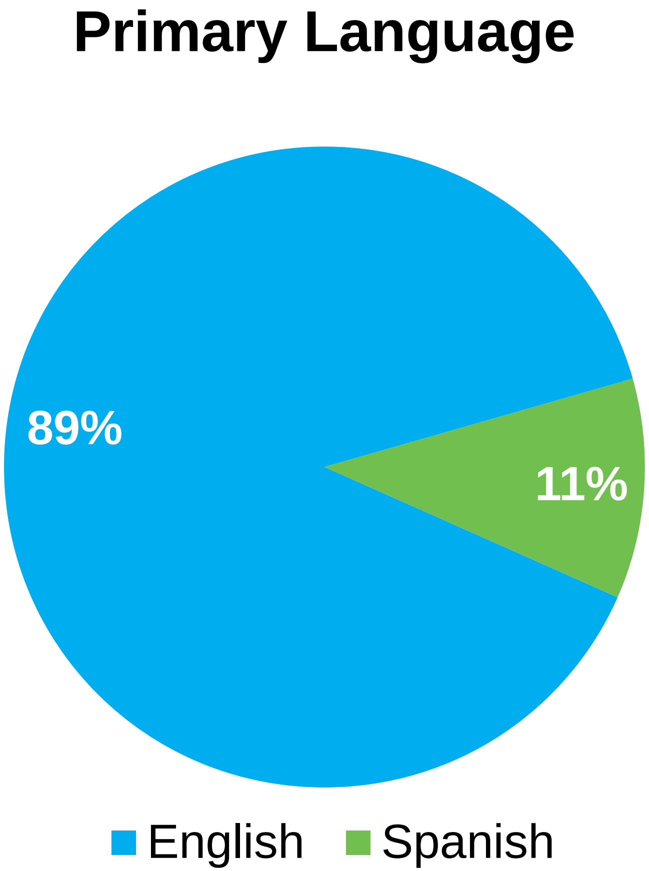
Respondents: Patients (N=900)





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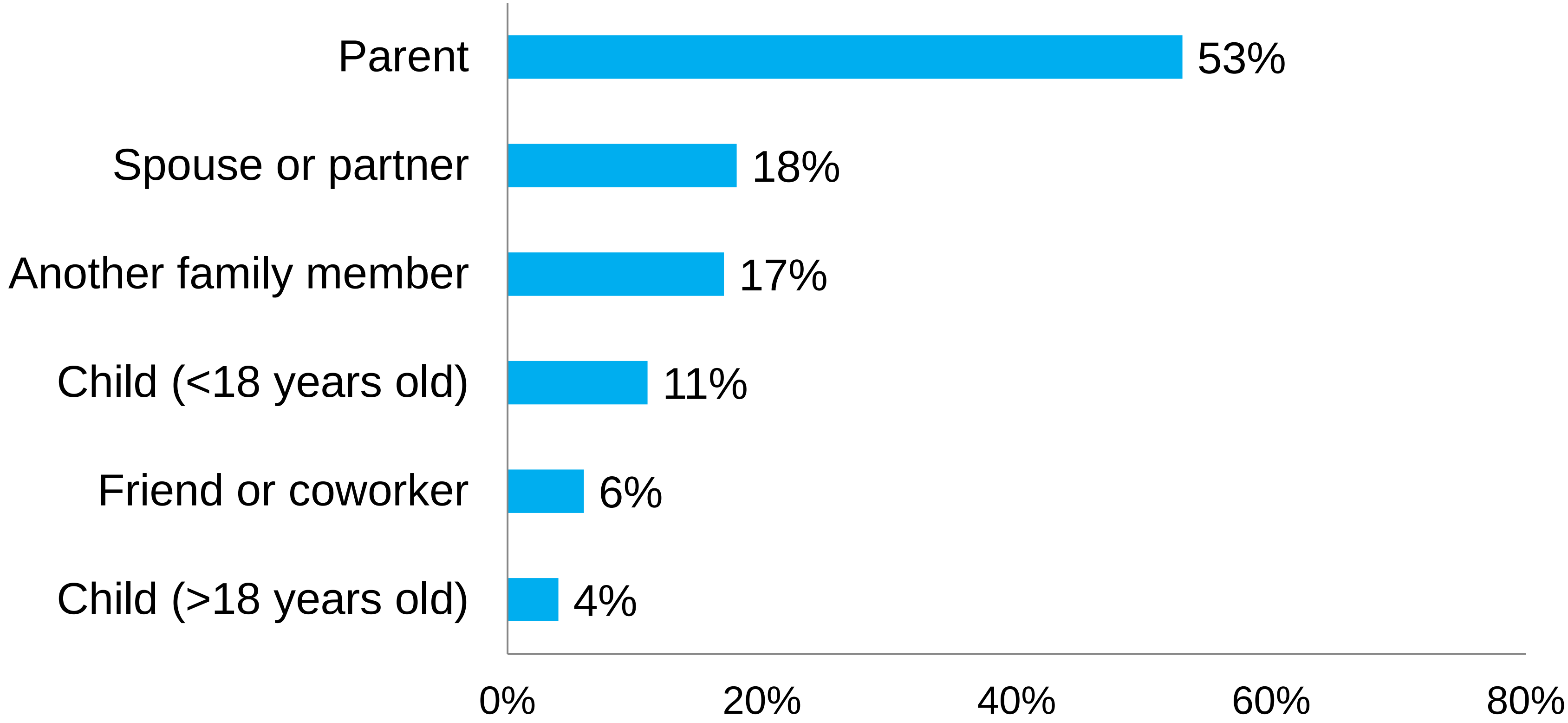
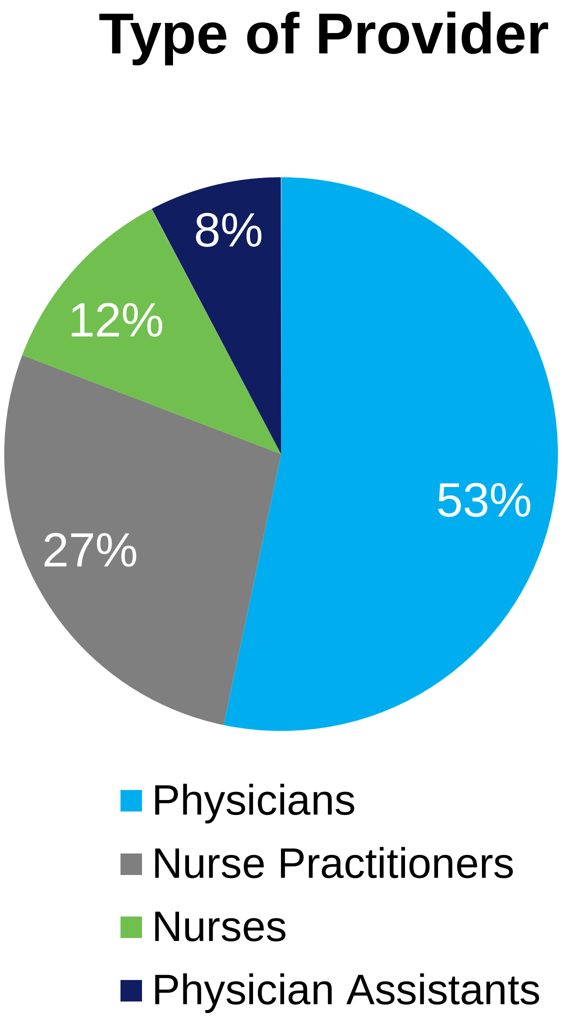
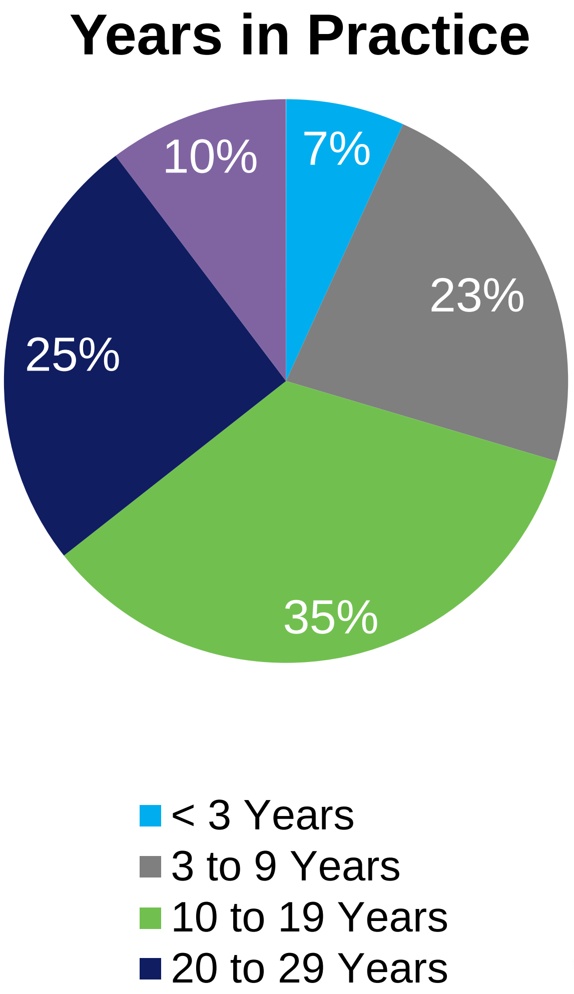
Respondents: Caregivers (N=100)

Serve as the primary decision-maker for…



Respondents: Primary Care Clinicians (N=750)





Clinician Views on CER

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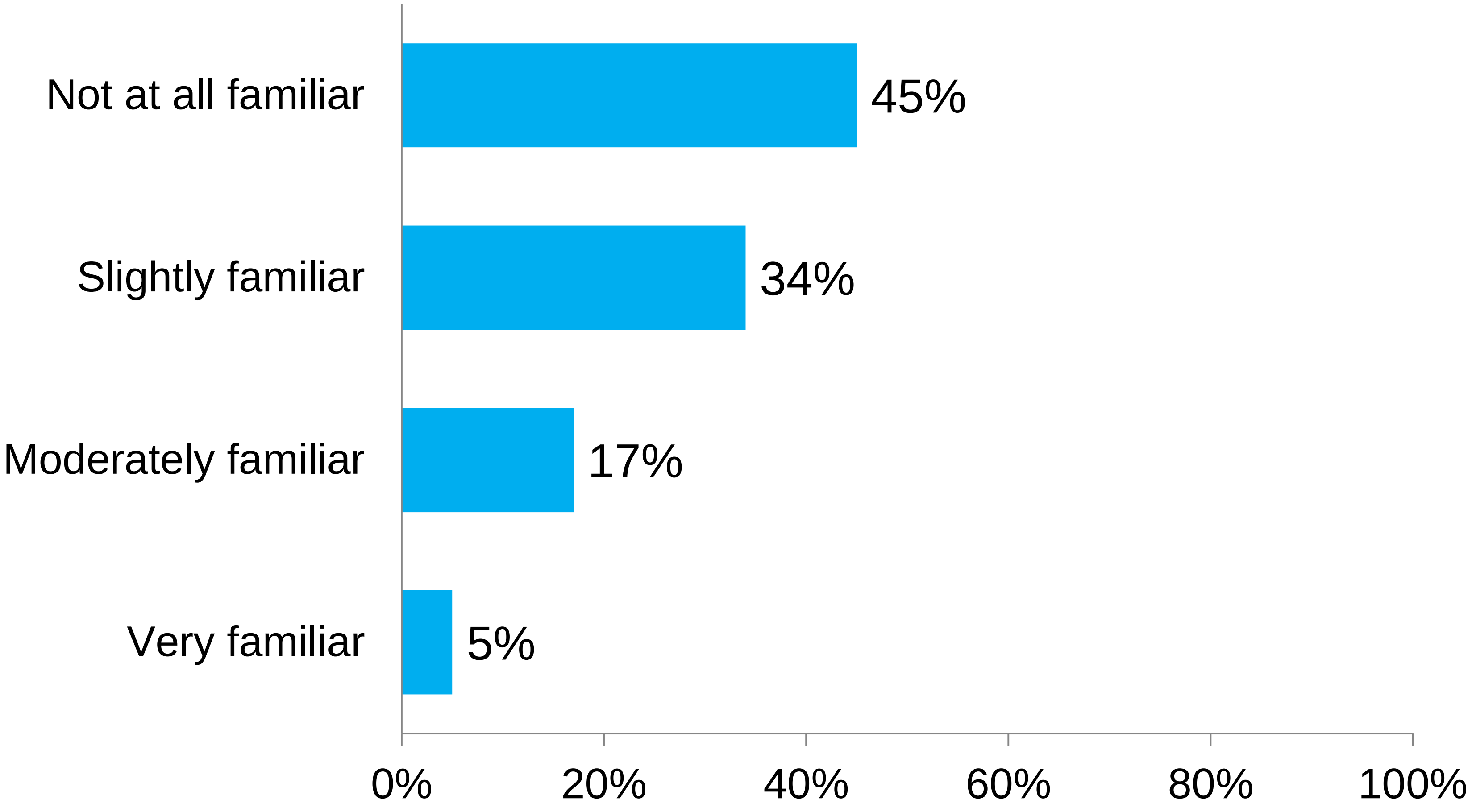
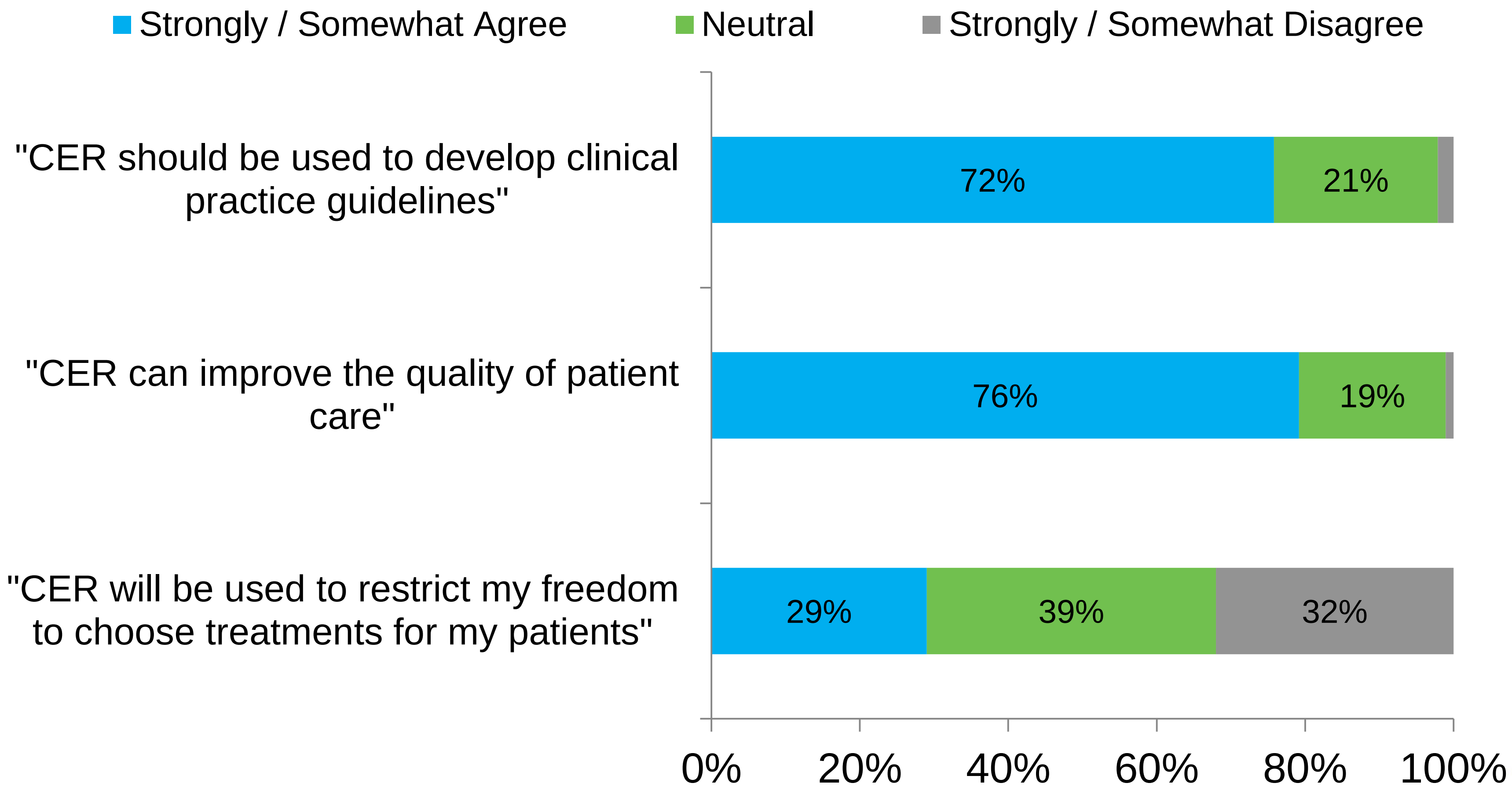
Primary Care Clinicians Report Low Familiarity with CER



Primary Care Clinicians Report High Perceived Value of CER



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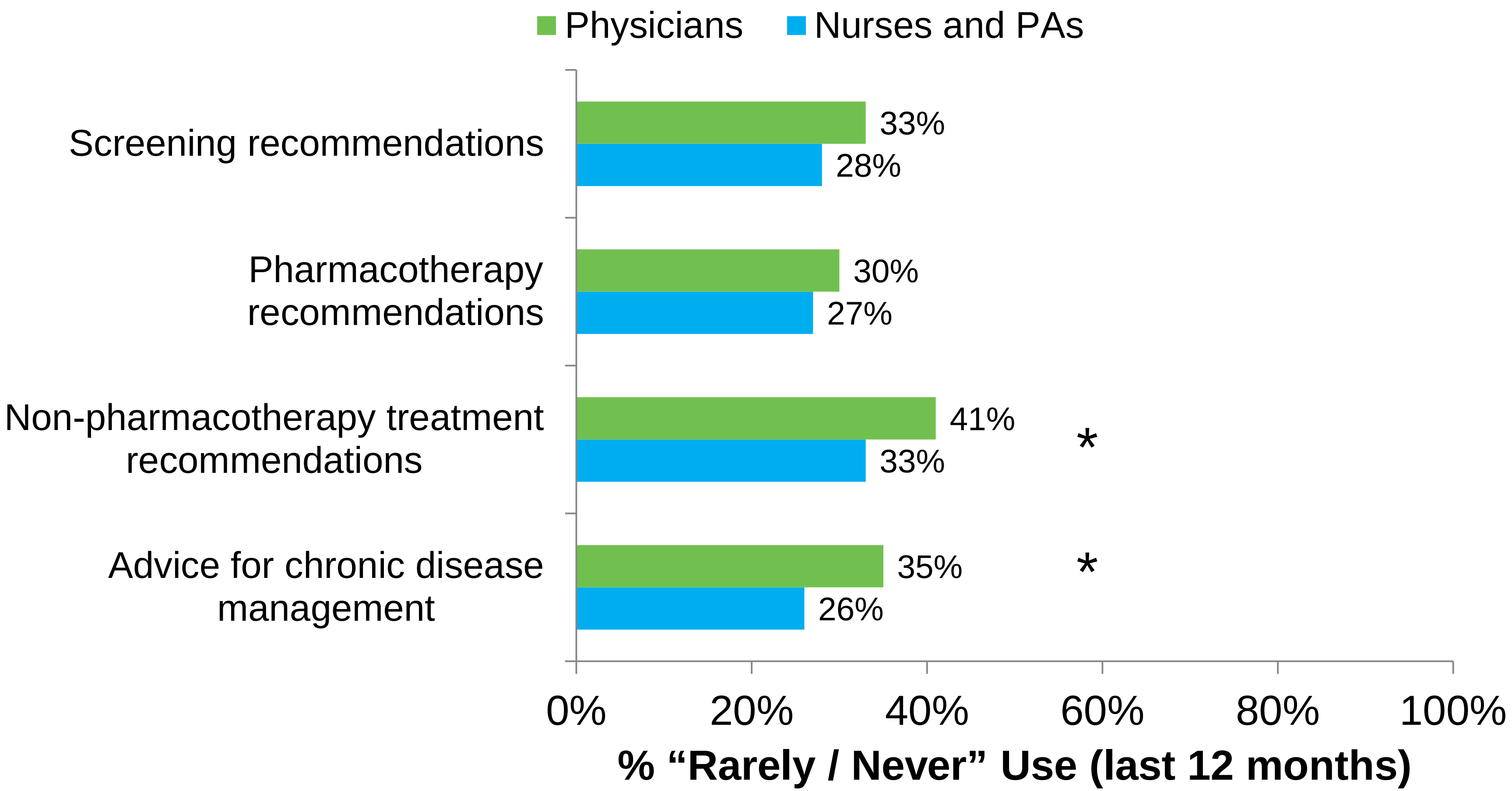
Primary Care Clinicians Report Infrequent Use of CER to Provide Information to Patients



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Patient and Clinician Views on Health Information and Research

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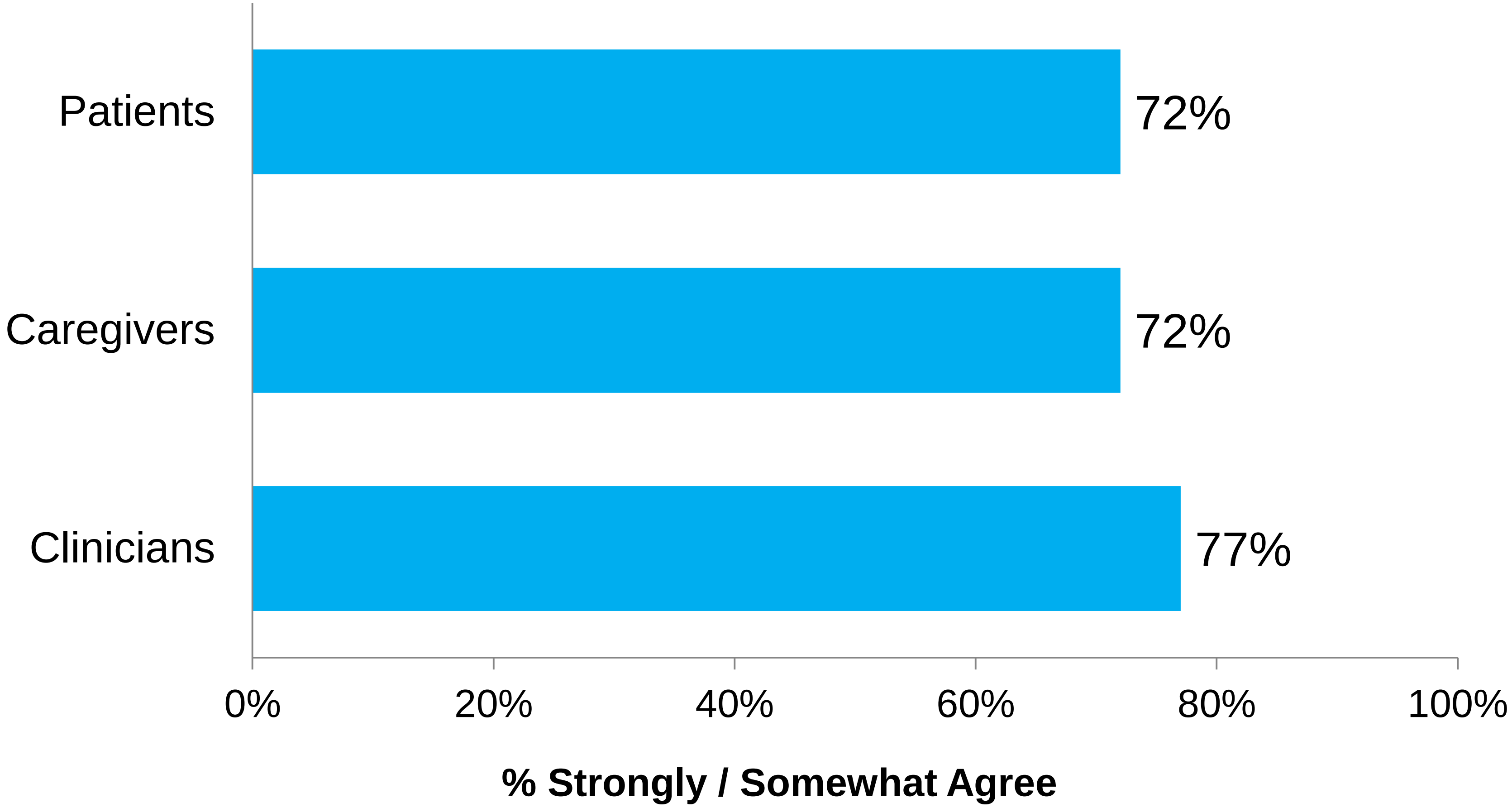
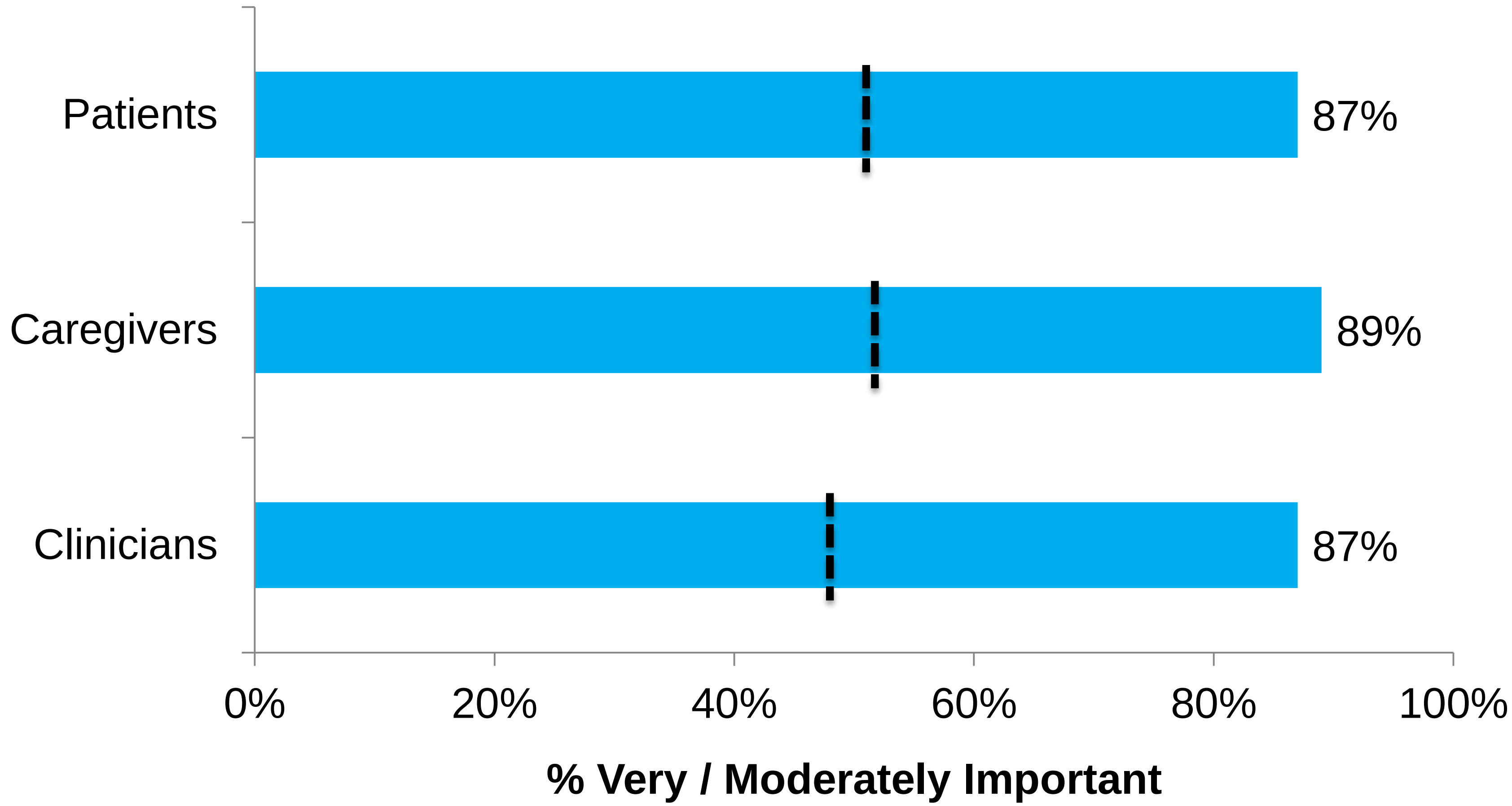
Patients, Caregivers, and Clinicians Agree that Research Helps Patients Make Better Treatment Decisions



$^{*}p < 0.05$

Patients, Caregivers, and Clinicians Value Research That Measures Things Patients Care About



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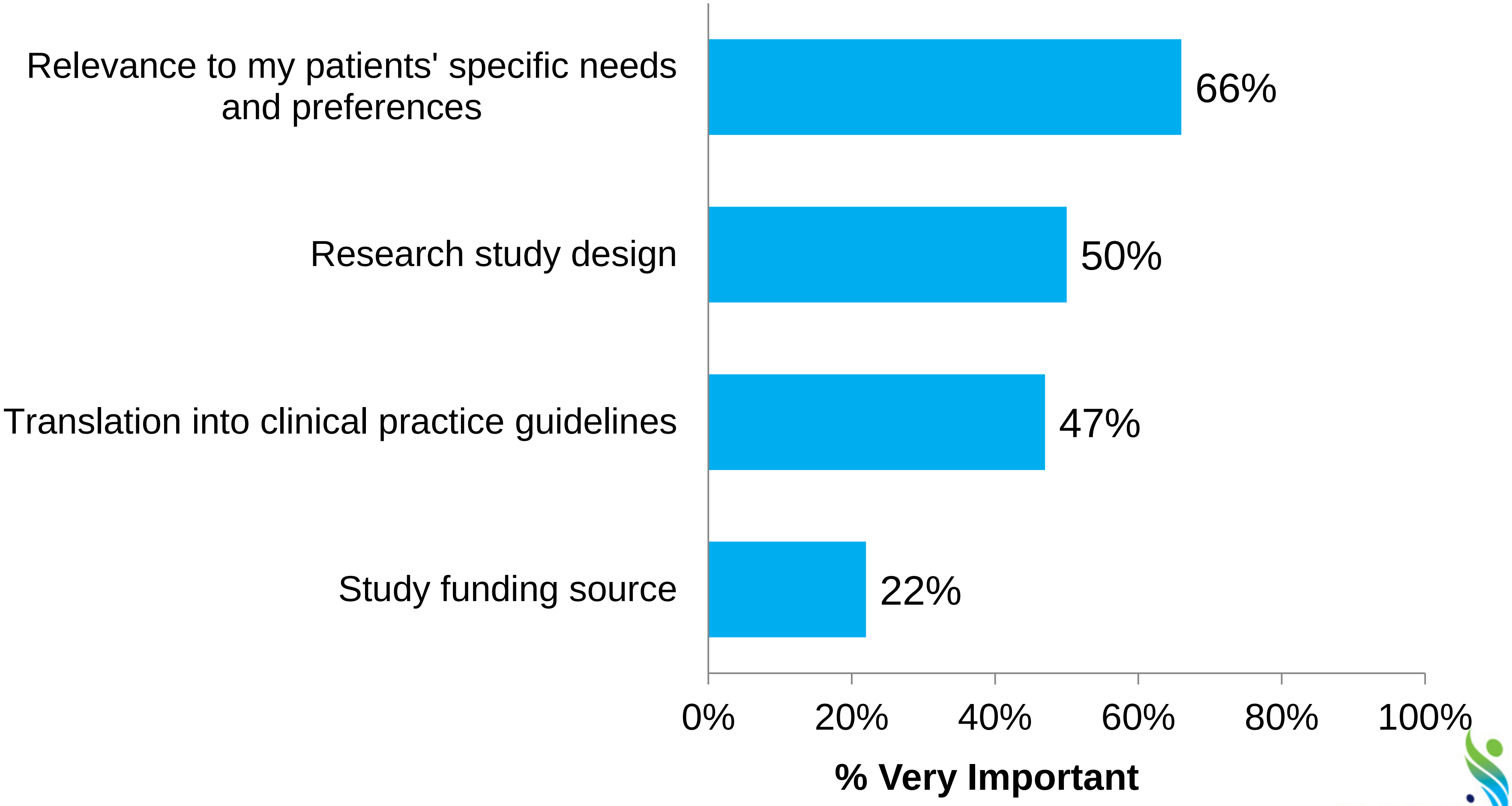
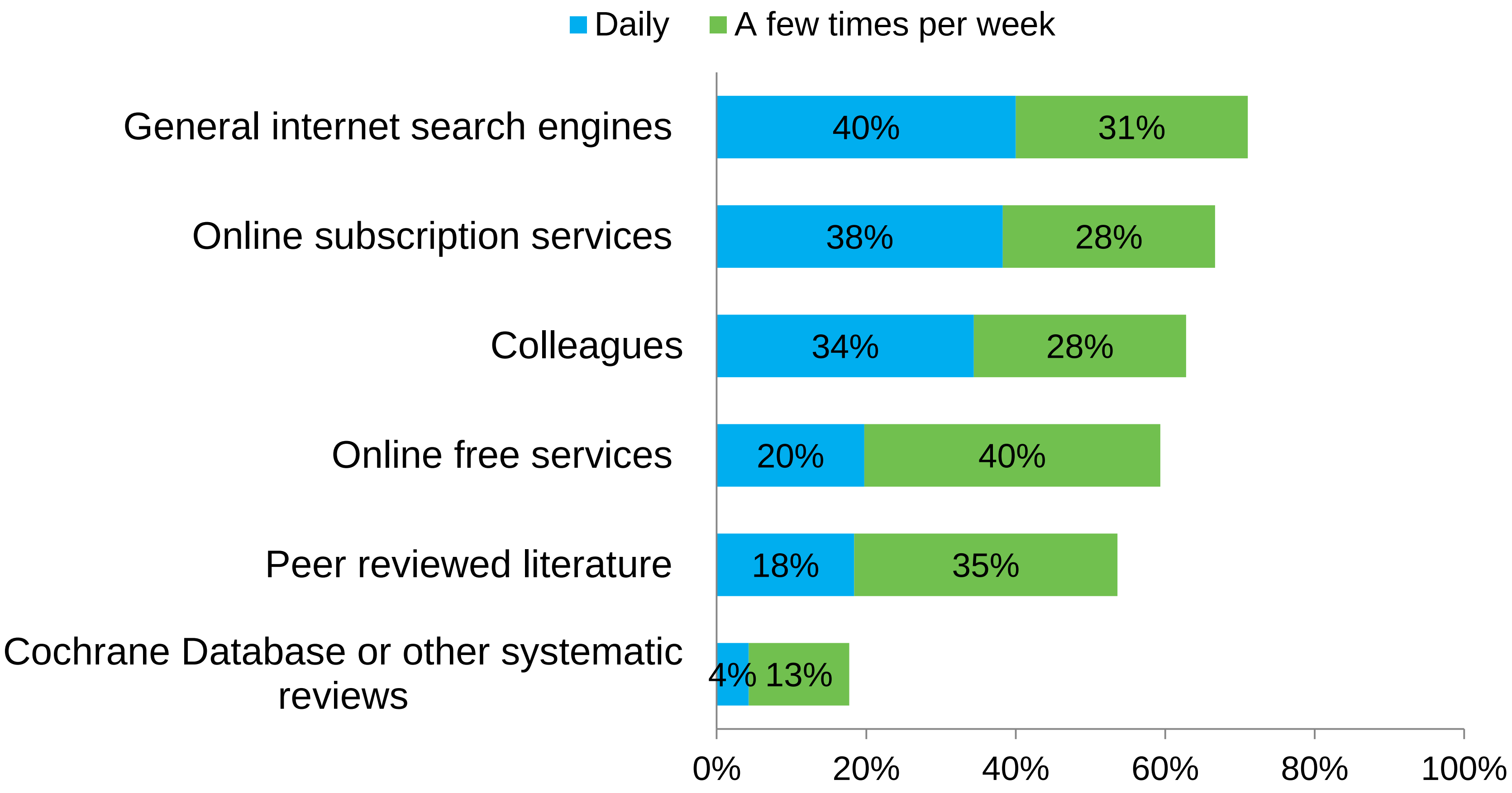
Research for Clinical Decisions: Relevance to Patients' Needs is Important to Clinicians



Clinicians Frequently Use General Internet Searches and Colleagues to Obtain Information to Diagnose and Treat Patients



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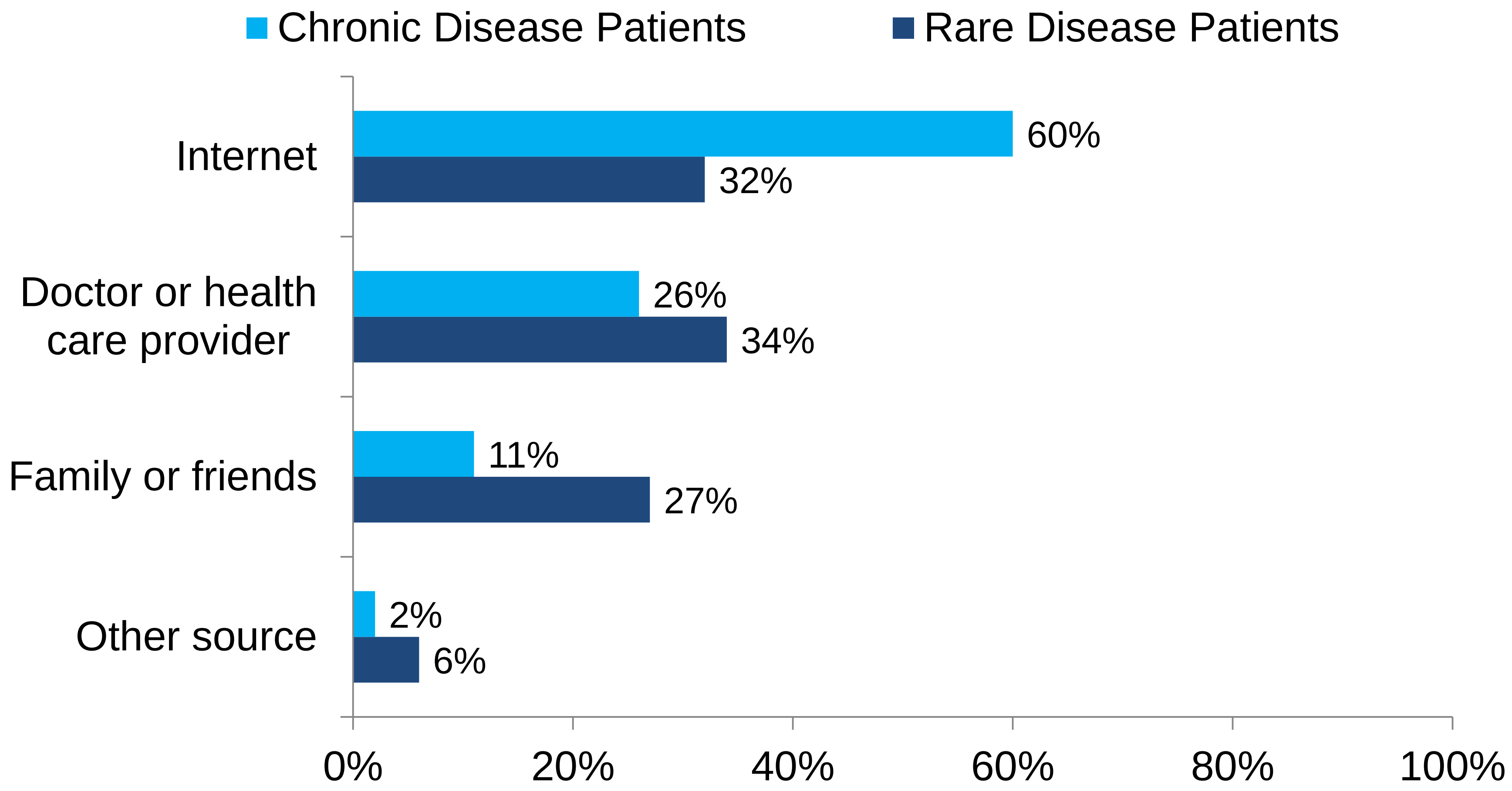
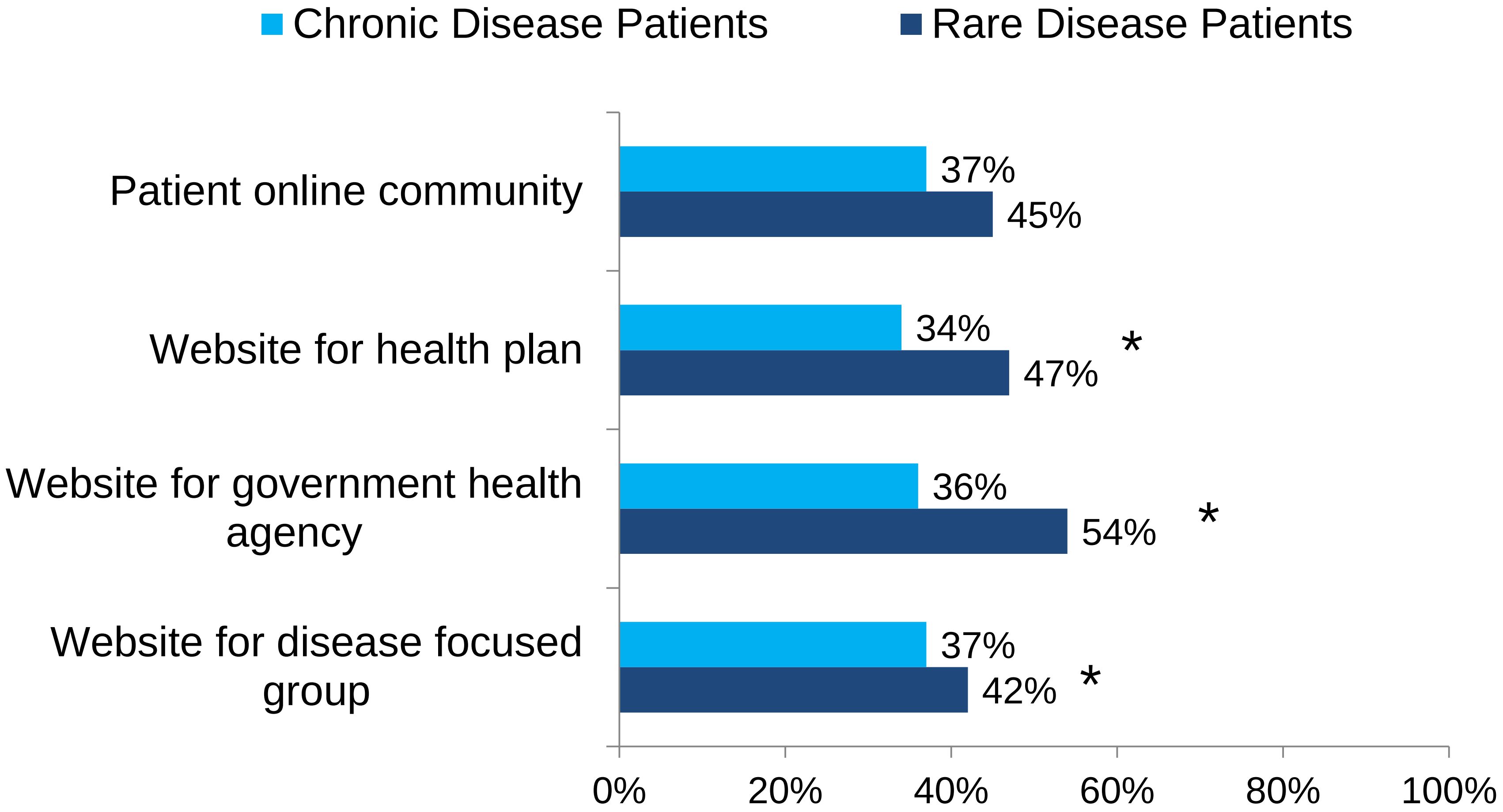
Patients Use Internet as First Source of Health Information



*$p < 0.05$

Patients Use a Variety of Internet Sources (Last 12 Months)



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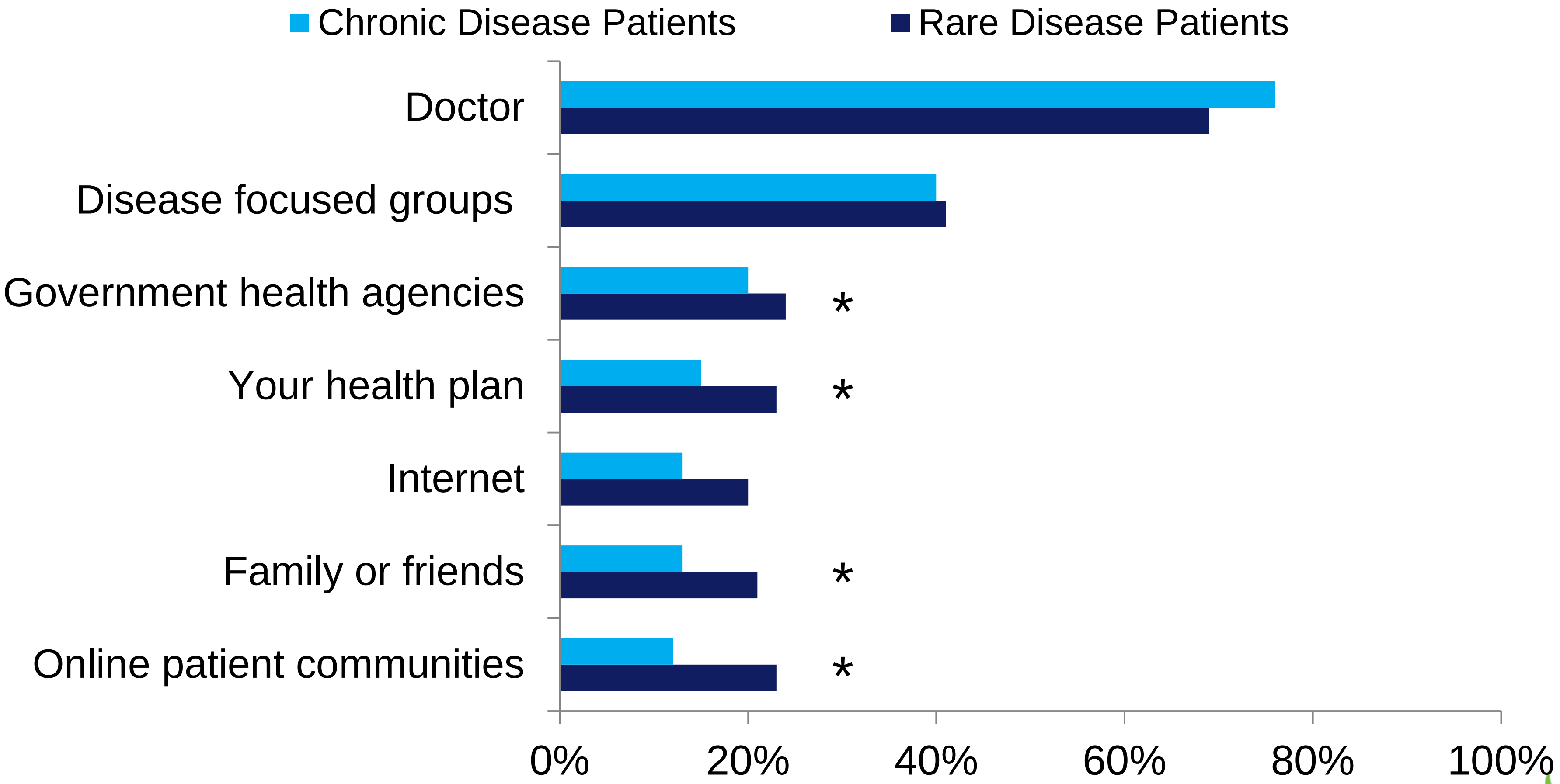
Patients’ Trust in Internet is Low Compared to Other Sources



% “A lot” of trust

*p <0.05

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Patient and Clinician Views on Engagement in Research

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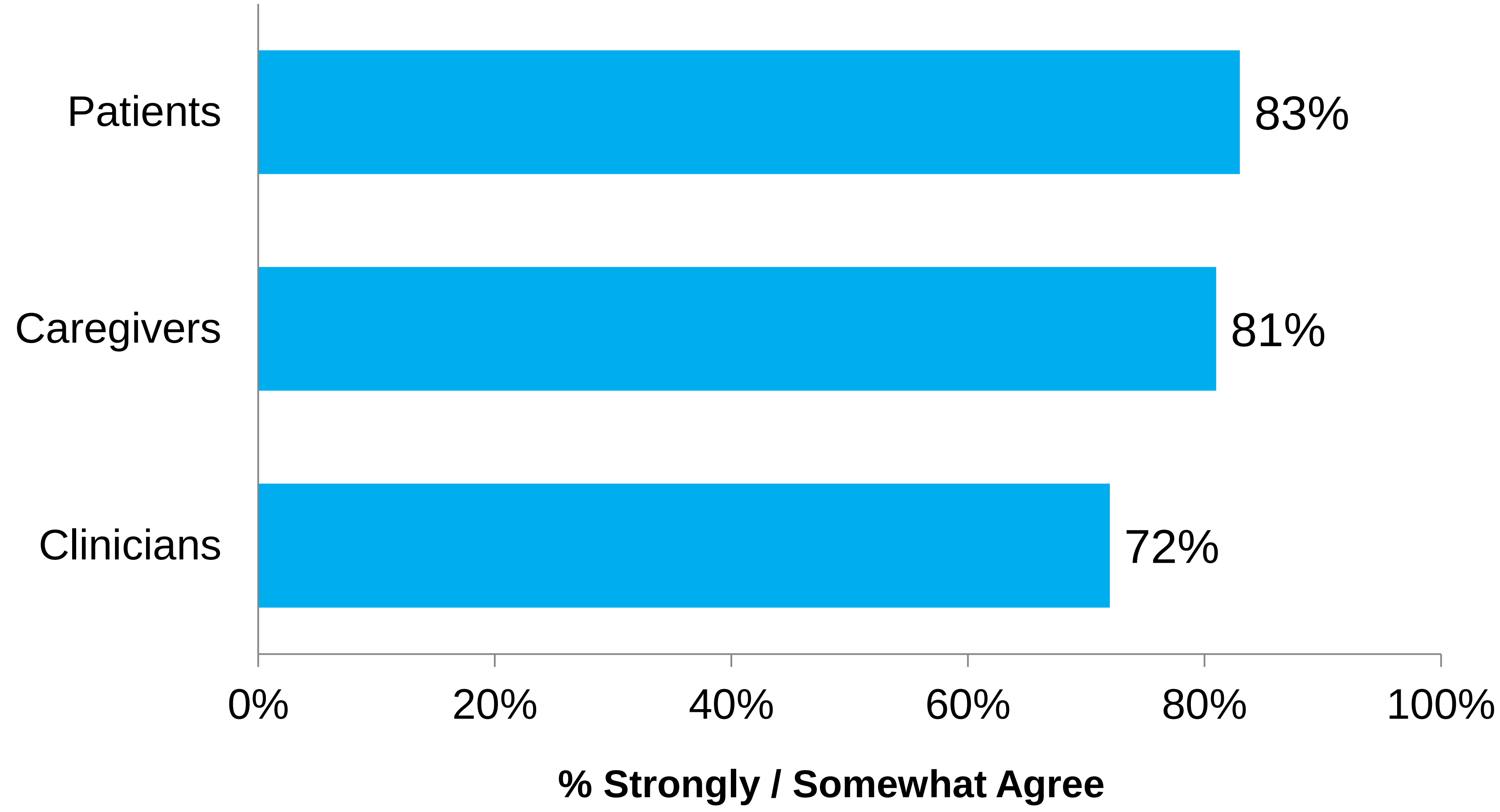
Respondents Agree that Working Directly With Researchers Can Improve the Value of Medical Research



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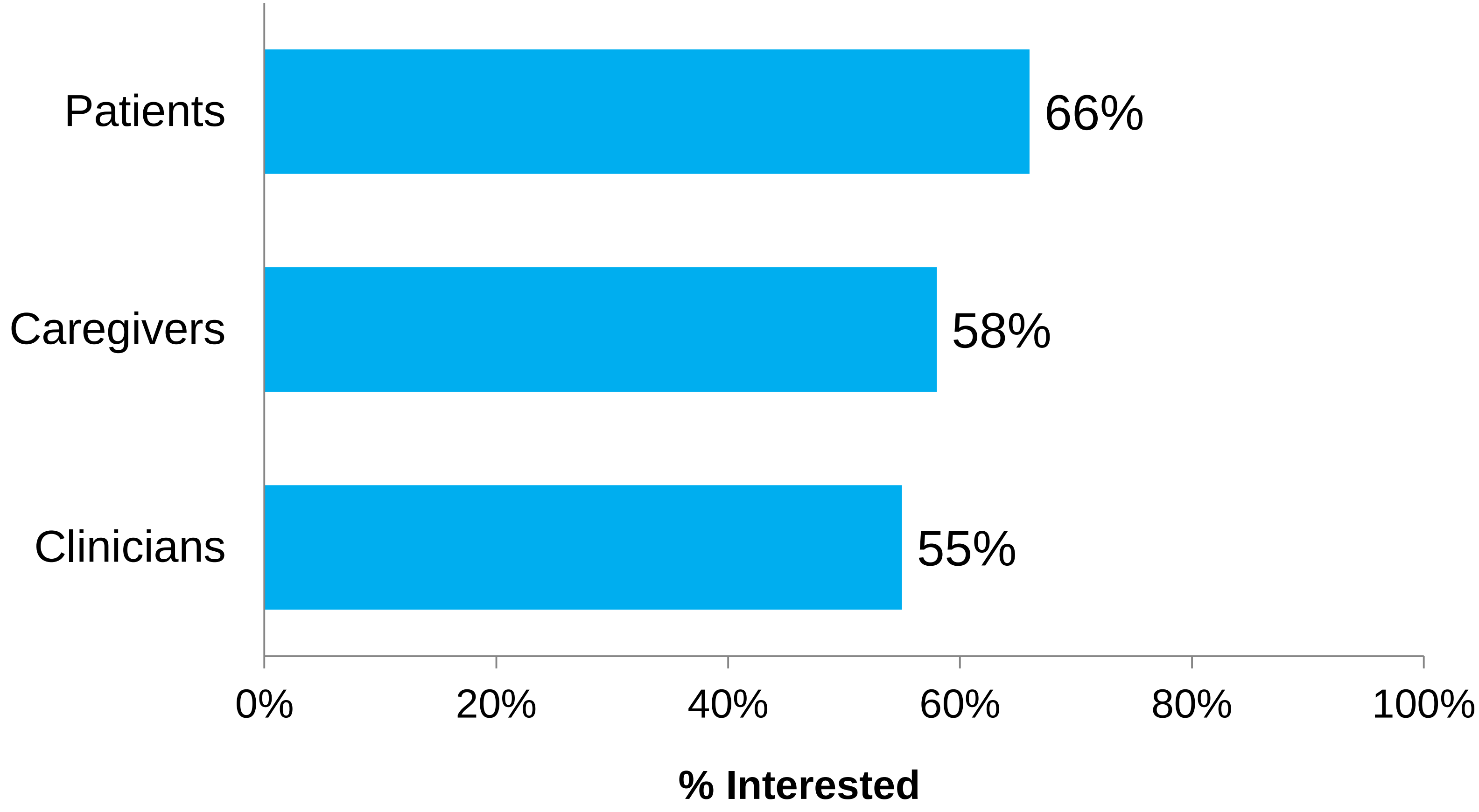
Patients, Caregivers, and Clinicians are Interested in Engaging in Research

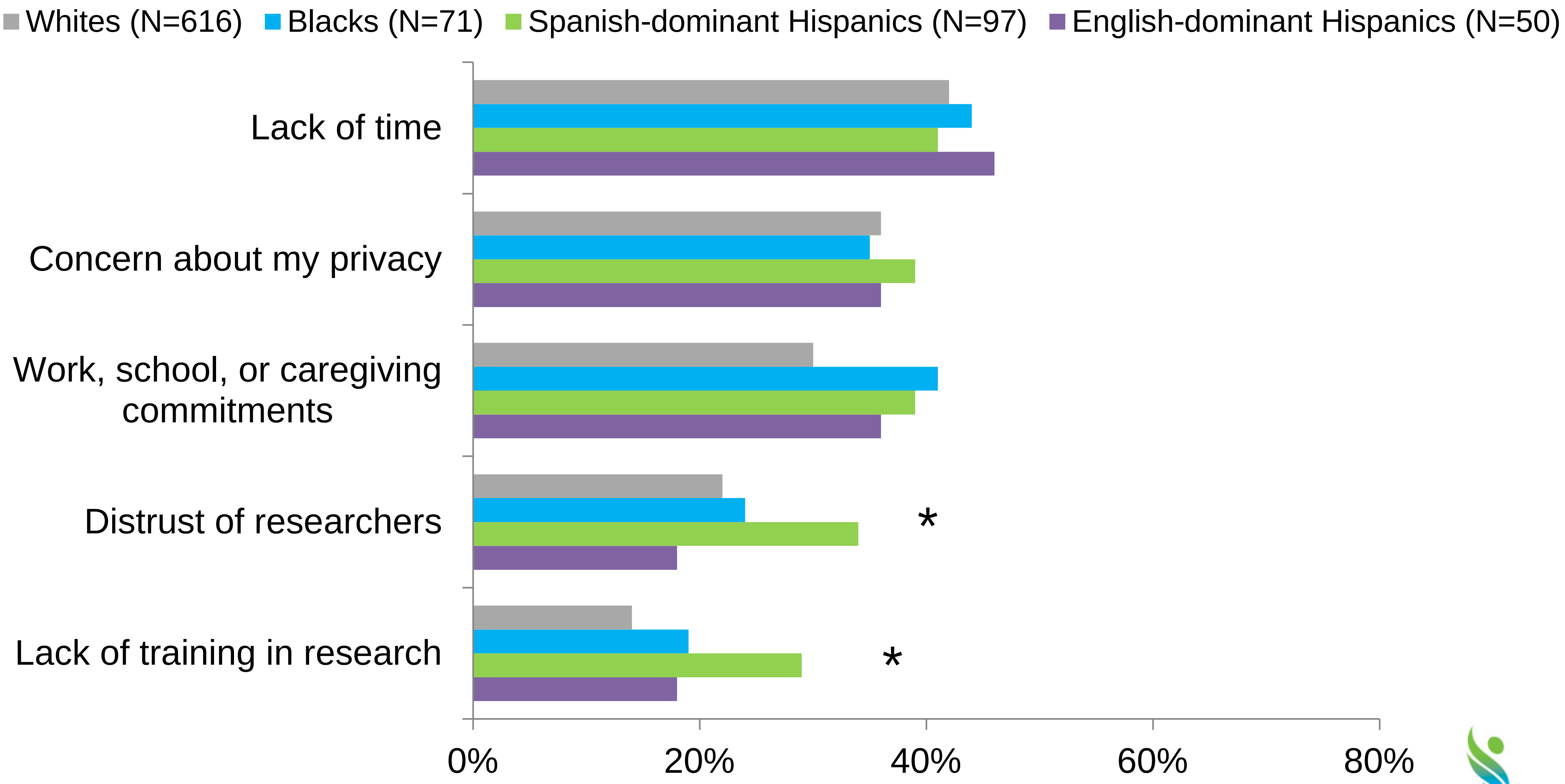


$^*p<0.001$

Barriers and Facilitators of Engagement

	Barriers	Facilitators
Patients	• Lack of time (43%) • Concerns about privacy (36%) • Work, school or caregiving commitments (33%)	• Helping others with their medical condition (68%) • Learning about their health (63%) • Helping the next generation (57%) • Getting paid (56%) • Making research more meaningful to patients (49%)
Clinicians	• Lack of time (79%) • Lack of payment (47%) • Lack of research training (35%)	• Helping patients receive better care (79%) • Getting paid (78%) • Contributing to scientific knowledge (61%) • Making research more meaningful for patients (61%) • Improving professional satisfaction (52%) • Helping researchers decide what to study (43%)

Barriers to Research Engagement Differ by Race/Ethnicity



*p ≤0.05

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Strengths and Limitations

- **Strengths**
  - Exploration of understudied topic areas
  - Inclusiveness of understudied populations: Spanish speakers, rare disease patients
  - Ecological validity

- **Limitations**
  - Generalizability
  - Self-reported data
  - New survey items testing complex constructs

Conclusions

- Health research is valued by patients and clinicians
- Clinicians expressed low familiarity with CER but high perceived value
- Use of CER is relatively low in this primary care clinician sample
- Limited CER evidence base in places clinicians seek information may explain limited use of CER

Conclusions

- Most patients, clinicians, and caregivers believe engagement can improve the value of health research
- Many patients, clinicians and caregivers are interested in engaging in research themselves
- Strategies to facilitate both patient and clinician engagement:
  - Establish link between engagement and patient care
  - Financial compensation
  - Minimize time burden

Implications for PCORI's work

- Expand the evidence base for CER questions of high importance to patients and clinicians
- Explore ways to get good CER data into the health information channels that patients and clinicians use
  - Plan for dissemination based on an understanding of patterns of health information use and understand differences by patient and provider type
- Raise awareness of the role of CER information in clinical and health decision-making
- Address barriers to research partnerships involving patients and involving primary care clinicians

Panel Discussion

- What factors might account for low familiarity with CER among primary care clinicians? What can PCORI do to increase familiarity?
- To what do you attribute limited use of CER in clinical decisions? What are the implications for PCORI?
- What are the consequences of engaging both patients and clinicians in research?
- How can time and financial barriers to engaging in research best be addressed? Which engagement facilitators should PCORI work to strengthen?

Thank you!

- Acknowledgements
  - Patient, caregiver, and clinician partners
  - PCORI Board of Governors
  - InCrowd researchers: Diane Hayes, Sue Levine
  - Panelists
- Please send questions or comments to:

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