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Researcher Perspectives on Data Needs

Discussion questions:

- Looking ahead, what are the main data needs?
- What are the implications of the (recently broadened) statutory scope for PCOR?
- What questions cannot be answered and who is not served by the current PCOR data infrastructure?
- What new data sources could be incorporated into the PCOR data infrastructure?
- What data capacity challenges is HHS best positioned to address in the context of its public mission, authorities, programs, and data resources?

Looking ahead, what are the main data needs?

- Common data model for patient-reported outcomes
- Common data elements for PROs
- Comparative effectiveness metrics across conditions
- Medical and non-medical cost data
 - Insurance deductibles
 - Co-payments
 - Caregiver expenses
 - Work productivity (absenteeism/presenteeism)

What are the implications of the (recently broadened) statutory scope for PCOR?

*“Research shall be designed, as appropriate, to take into account and capture the full range of clinical and patient- centered outcomes relevant to, and that meet the needs of, patients, clinicians, purchasers, and policy-makers in making informed health decisions. In addition to the relative health outcomes and clinical effectiveness, clinical and patient- centered outcomes shall include the **potential burdens and economic impacts of the utilization of medical treatments, items, and services on different stakeholders and decision-makers respectively. These potential burdens and economic impacts include **medical out-of-pocket costs**, including health plan benefit and formulary design, **non-medical costs to the patient and family**, including caregiving, effects on future costs of care, workplace productivity and absenteeism, and healthcare utilization.**”*

- Major opportunity to examine cost in context of effectiveness
- Potential for Inter-agency collaboration
 - AHRQ, NIH, CMS, and possibly even FDA
- Ingredients for learning health system approach across provider organizations

What questions cannot be answered and who is not served by the current PCOR data infrastructure?

- Currently cannot answer cross-cutting CER questions as related to patient reported outcomes

What new data sources could be incorporated into the PCOR data infrastructure?

Final Report

The PCORnet Patient reported Outcomes (PRO) Common Measures Working Group (CMWG)

October 1, 2014

Working group members

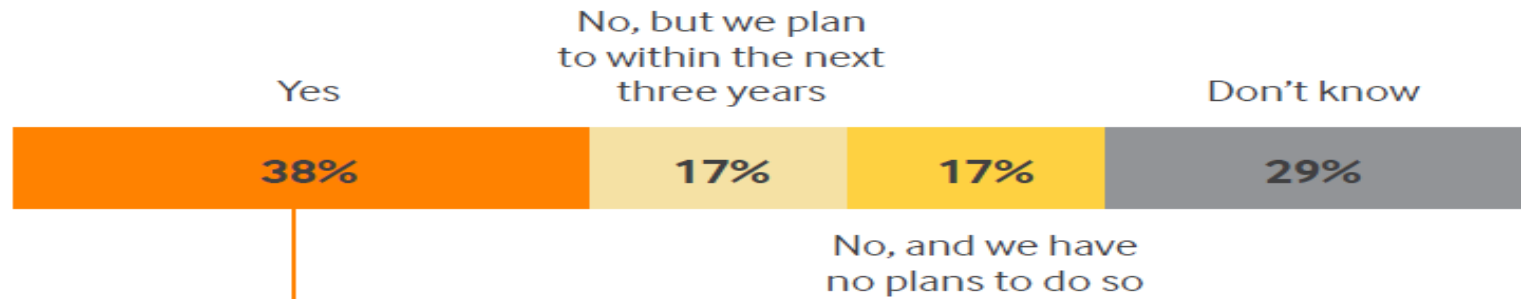
Working Group to Define Common Measures			
Partner	Name	Email	
C9_Chicago Area Patient Centered Outcomes Research Network (CAPriCORN)	David Cella	d-cella@northwestern.edu	Chair
C5_Kaiser Permanente & Strategic Partners Patient Outcomes Research To Advance Learning (PORTAL) Network	Reesa Laws	Reesa.Laws@kpchr.org	<i>Member</i>
P9_Mood Patient-Powered Research Network	Thilo Deckersbach	tdeckersbach@mgh.harvard.edu	<i>Member</i>
P3_CCFA Partners Patient Powered Research Network	Michael Kappelman	michael_kappelman@med.unc.edu	<i>Member</i>
P4_Arthritis patient Partnership with comparative Effectiveness Researchers (AR-PoWER PPRN)	James Henry Willig	jwillig@uab.edu	<i>Member</i>
P6_The COPD Patient Powered Research Network	Richard Mularski	Richard.A.Mularski@kpchr.org	Vice-Chair

PCOR Common Measures Working Group 2014 recommendations

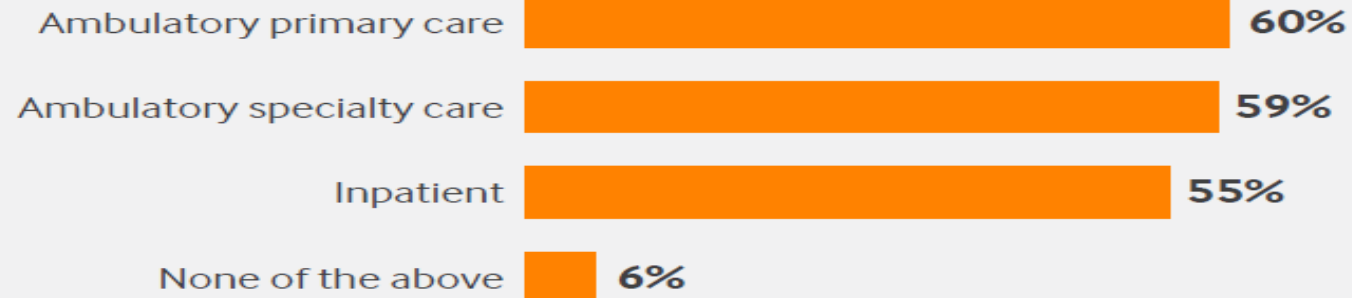
Nine Core Adult Questions	8 Core Pediatric Questions
General Health	General Health
Quality of Life	Quality of Life
Physical Function - 1	Pain Interference
Physical Function - 2	Fatigue
Depression	Stress
Fatigue	Depression
Sleep Disturbance	Peer Relationships
Social Roles & Activities	Family Relationships
Pain Interference	

PROMs Usage Is Limited but Growing

Does your organization use a Patient-Reported Outcome Measures (PROMs) system?



In which of the following clinical care settings does your organization use PROMs?

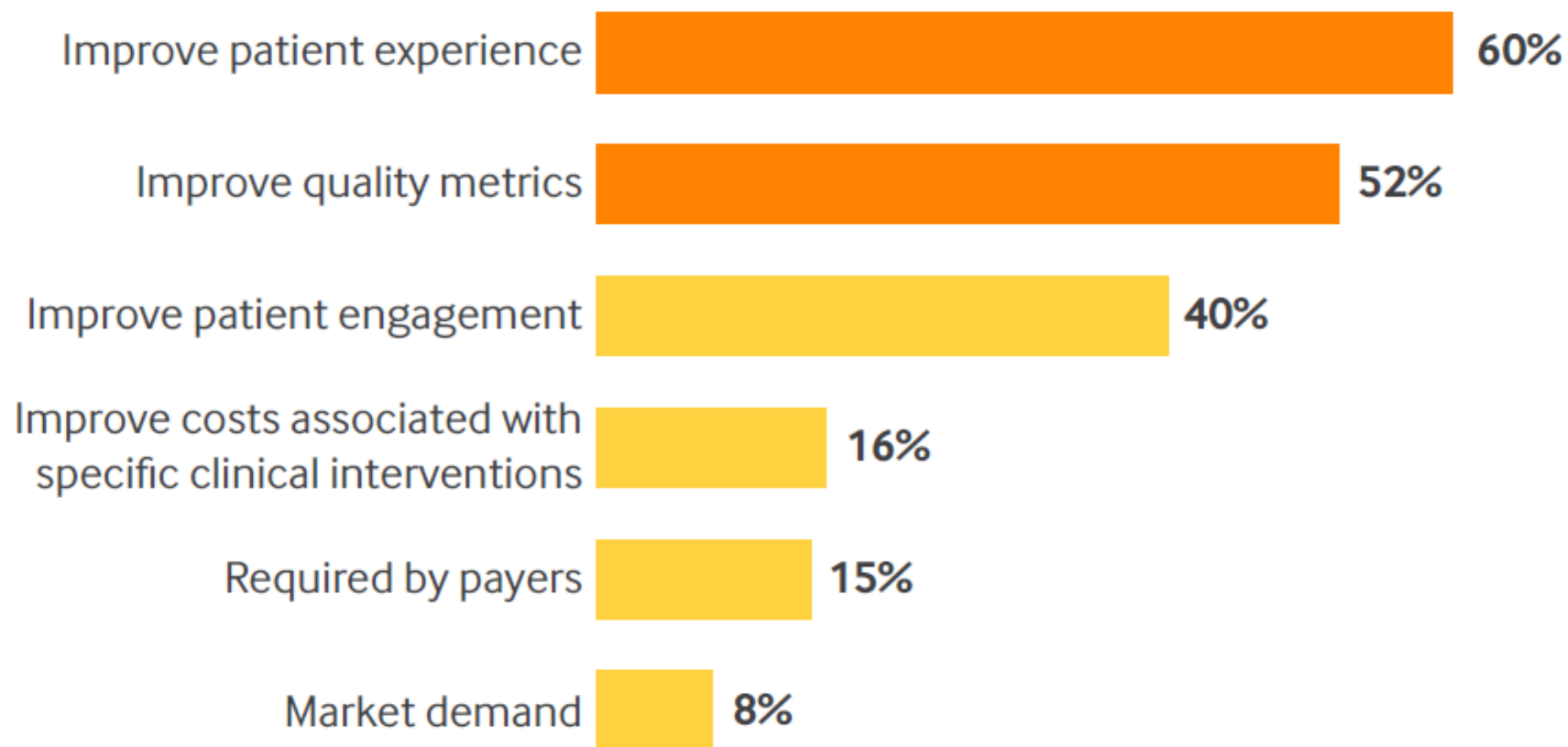


Base: 235 (multiple responses) among those using PROMs systems

Even those who collect PROMs capture information on fewer than 50% of patients, often excluding underrepresented minorities and patients with lower educational level.

Better Patient Experience and Quality Are the Top Reasons to Collect and Use PROMs

What are the top two reasons for health care organizations to collect and use Patient-Reported Outcome Measures (PROMs)?



What data capacity challenges is HHS best positioned to address in the context of its public mission, authorities, programs, and data resources?

- Promote technologies to capture patient-provided data, including PROs
- Promote patient activation and engagement
- Endorse health care quality initiatives and PRO Performance Measures
- Fund the Mandates

Thank you