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# Briefing: Multi-Stakeholder Collaboration in Patient-Reported Outcomes Measurement

Statewide Quality Advisory Committee Meeting

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# Briefing: Multi-stakeholder Collaboration in Patient-Reported Outcomes Measurement

## I. About MHQP

## II. Highlights: Spring 2013 MHQP

### PRO Measurement Meeting

- Perspectives
- Issues & Challenges
- Opportunities for Collaboration

## III. Considerations

# About Massachusetts Health Quality Partners



- Established in 1995
- A broad based coalition of physicians, hospitals, health plans, purchasers, patient and public representatives, academics, and government agencies
- MHQP's mission: Drive measureable improvements in health care quality, patients' experiences of care, and use of resources in Massachusetts through patient and public engagement and broad-based collaboration among health care stakeholders

# Quality Measurement Landscape

Provider-Focused Measures

Patient-Centered Measures

## Clinical Quality – Process, Structural and Safety

Examples:

- Recommended care provided for pneumonia, heart failure, heart attack,
- Blood pressure control
- Computer Physician Order Entry (CPOE)
- Patient safety practices

## Outcomes

Examples

- Readmissions
- Mortality

## Patient Experience

Examples:

- Hospital stay
- Care at your doctor's office

## Care

### Coordination/Transitions

Examples:

- Medication reconciliation
- Discharge record – hospital to home or other care setting

## Patient-Reported Outcomes

Area/Examples:

- Health status (physical, social, emotional health – fatigue, pain scale, anxiety depression, social function at school or work )
- Functional status (ability to resume to desired activities of daily living post a hip or knee procedure)

Patient-reported data (questionnaires or surveys)

Chart/Claims-Based data

# Patient Reported Outcomes Measurement

## ***Working definition:***

Patients' feedback on their feelings about their physical, mental and social health or what they are able to do (functional status) as they are dealing with chronic diseases or conditions; or when they are undergoing a treatment or a procedure

## **Patient-Reported Outcomes Measurement**

Area/Examples:

- Health status (physical, social, emotional health – fatigue, pain scale, anxiety depression, social function at school or work )
- Functional status (ability to resume to desired activities of daily living post a surgical procedure)

## **Patient-Reported Outcomes Measure (PROMs)**

- Measure tool or instrument (survey) used to collect Patient Reported Outcomes data

***Critical Success Factor: Engaging the Patient***

# MHQP Multi-Stakeholder Collaboration in PRO Measurement - Spring 2013 Meeting

- To understand stakeholder perspectives, priorities and current experiences in PRO measurement
- To identify critical issues and challenges faced in advancing PRO measurement work
- To develop next steps and collaborative engagement in PRO measurement to:
  - Provide better care
  - Activate patients in improving their health
  - Align multi-stakeholder resources and objectives

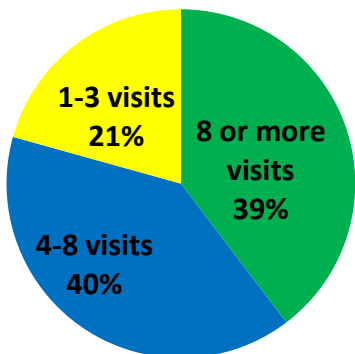
# Patient perspectives on patient-reported information

~75%-80% of patients reported that:

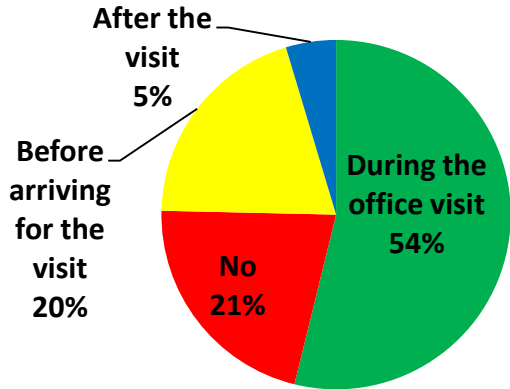
- Their providers understand their health concerns and goals for improving health
- Their providers ask the kind of questions that help them in understanding their physical, mental and emotional health
- They provide feedback to their provider through questionnaires
- They sometimes or never receive an explanation to the purpose or how the information they provide will be used

# Patients are currently providing feedback to their providers...

Approximately how many visits have you made to a health care provider in the last two years?

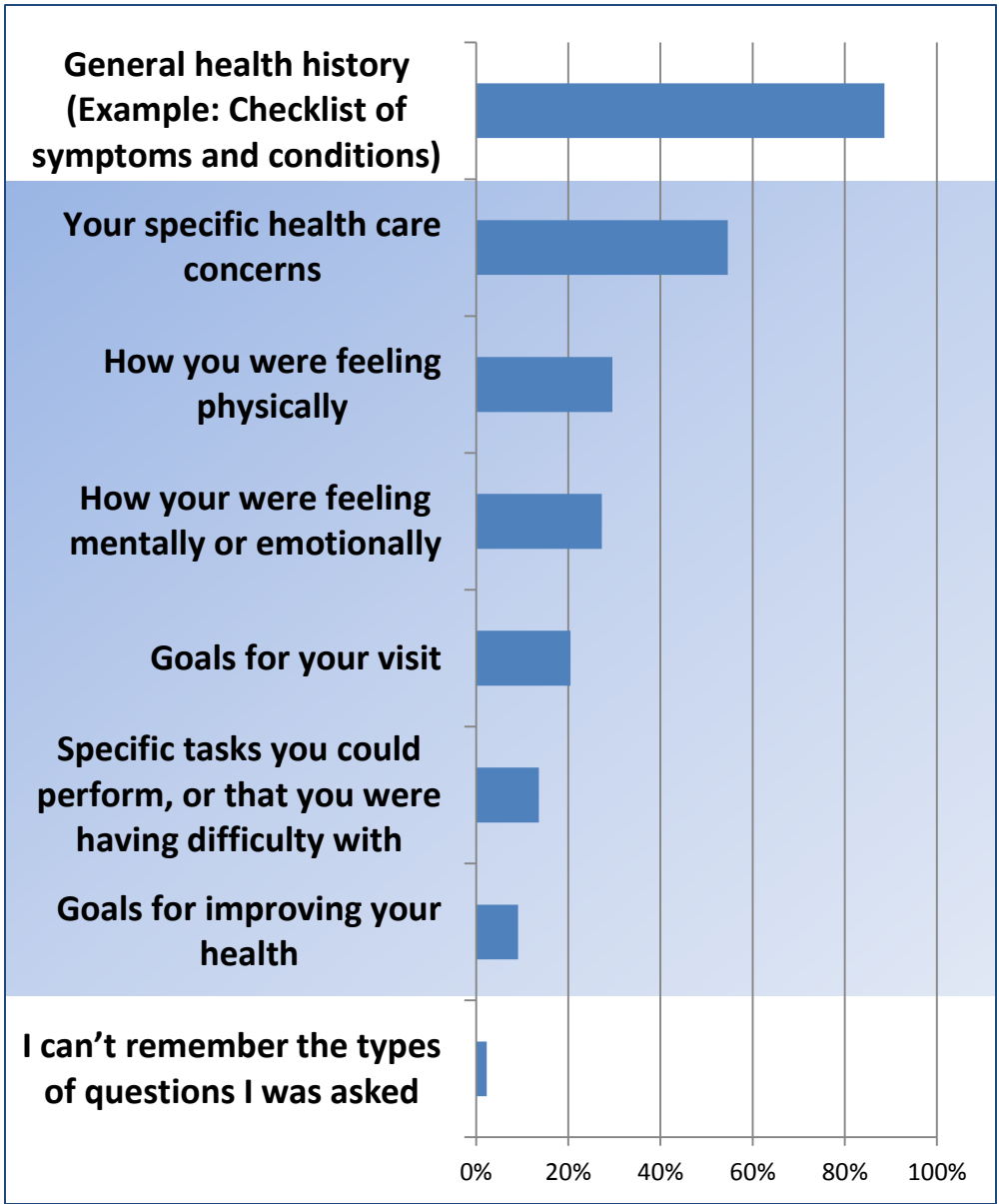


For these visits, have you ever been given a questionnaire about your health?



Patient Perspectives Survey  
n=58

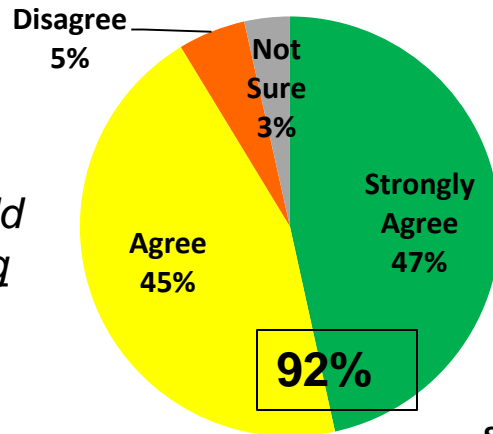
## Types of Questions:



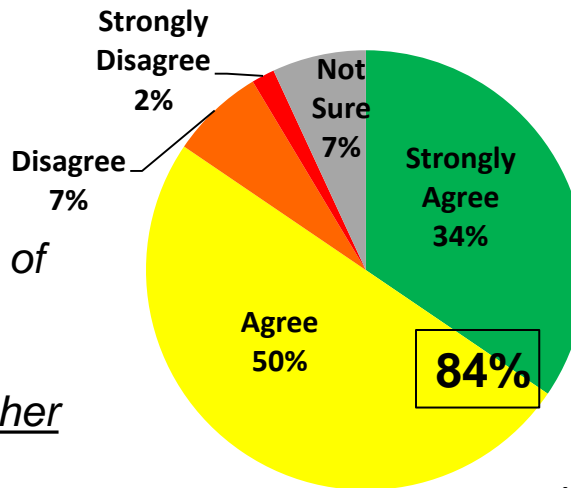


# Patients Report PROs could be helpful in improving health...

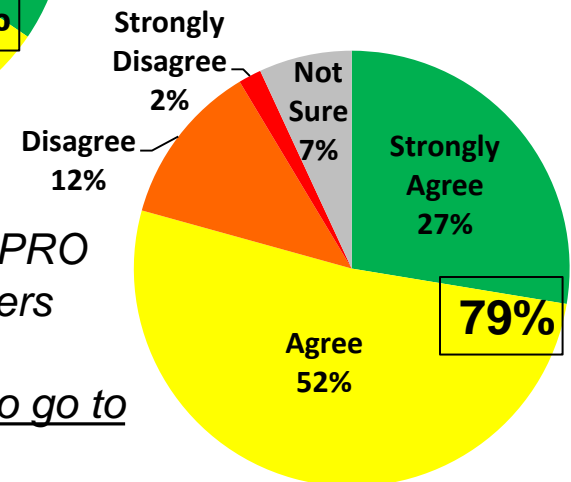
*Discussing results from my PRO questionnaire could be helpful in taking action with my provider toward improving my own health*



*A summary of PRO questionnaire results of patients could help a provider improve the health of all of his or her patients.*



*Comparing total or combined PRO results across different providers could be helpful to patients in making decisions about who to go to for care*



# Meeting participants/organizations shared their interest, priorities and activities in PRO measurement

## Populations and Conditions/Areas of Interest

- Adults, children and seniors
- Conditions and procedures
  - Depression, Pain management (multiple conditions), Asthma, Diabetes, Cancer, Heart Disease, Arthritis/joint disease, rare conditions in children
  - Knee and hip replacement, CABG, Bariatric surgery
  - Multiple-conditions, less focus on disease category

## Organizational priority for ~70% of participants

- About half are actively collecting data
- Other half are planning in the next 6-12 mths

# Types of Patient Reported Outcomes Measures or Instruments (PROMs)

## Survey tools in-use or under consideration:

- SF-12
- PROMIS-10
- PHQ-9 (Mental Health)
- Barthel Index (Activities of daily living)
- Seattle Angina Questionnaire
- Medicare Health Outcomes Survey (HOS)

Many others to consider.....

## Additional considerations:

- Short-forms, profiles, computer adaptive testing
- Specific areas/domains within physical, mental and social health, functioning)
- Proxies, culture and language

# Lots of other measures to consider...

## Patient-Reported Outcomes Measures/Instruments (PROMS)

### ***PROMs under consideration or in use by respondents:***

- SF-12
- Barthel Index (activities of daily living)
- PHQ-9 Depression
- PROMIS -10
- Medicare Health Outcomes Survey (VR-12, IADL, Pain)
- Sexual Health in Men (SHIM)
- Multiple Sclerosis Rating Scale
- Dermatology Life Quality Index (DLQI)
- Seattle Angina Questionnaire (SAQ)
- ALS Functional Rating Scale (ALSFRS)
- International Prostate Symptom Score (IPSS)
- Modified Rankin Scale (mRS) (stroke or other neurological disability)

### ***Many others to consider... national and international***

- SF-36
- Nottingham Health Profile
- Health Utilities Index (HUI®)
- Quality of Well Being Self-Administered (QWB-SA) Scale
- EuroQol (EQ-5D)
- PedsQL™ 4.0 Measurement Model
- Adult Asthma Quality of Life Questionnaire (AQLQ)
- Migraine Specific Quality of Life (MSQOL)
- Ankylosing Spondylitis Quality of Life questionnaire (ASQoL)
- Western Ontario and McMaster Universities Arthritis Index (WOMAC)
- Quality of Life in Epilepsy Inventory (QOLIE-89 and QOLIE-31)
- Kidney Disease Quality of Life instrument (KDQOL)
- Hip dysfunction and Osteoarthritis Outcome Score (HOOS)
- National Eye Institute Visual Functioning Questionnaire (NEI VFQ-25)
- Visual Function Index-14 (VF-14), post cataract surgery
- Knee injury and Osteoarthritis Outcome Score (KOOS)

*Meeting Participant Survey  
n=18*

# Key themes and issues...

- PRO measurement is early in its adoption and use in clinical practice
  - ▣ Many goals and priorities for PRO measurement
  - ▣ Patient engagement is critical
- Incorporating PRO into practice is a major culture change for patients and providers
  - ▣ Activation of patient involvement in their care, physician buy-in
  - ▣ Patient-provider relationship
  - ▣ Practice work-flow
- Measurement concerns: Who? What? How? Then what?
  - ▣ Measure validity in research versus practice
  - ▣ Limited experiences in collection, unclear standards
- Cost: Time, \$ and ROI
  - ▣ Survey fatigue, practice staff resources, collection/technology

# Challenges/Needs

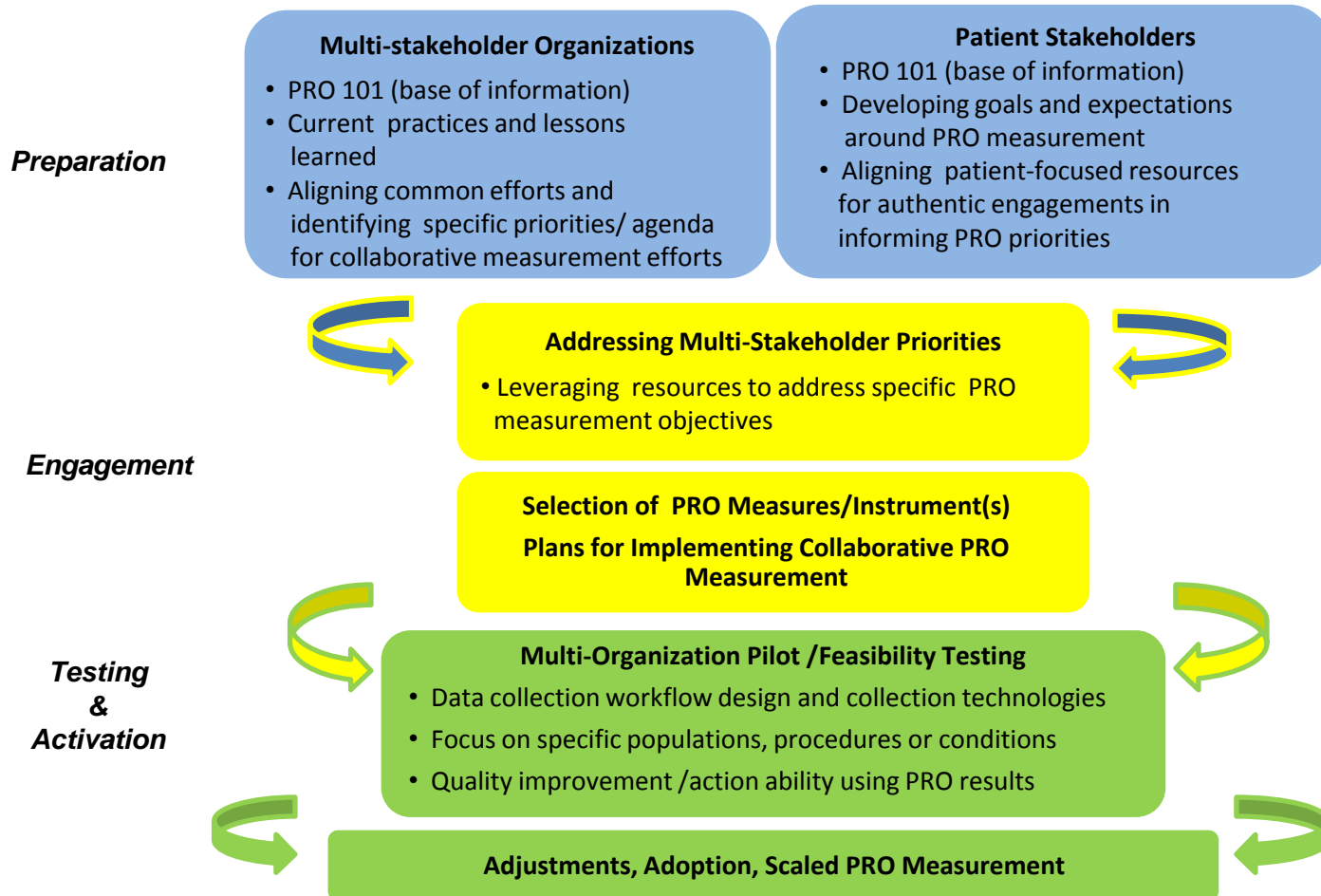
- Understanding and setting provider, patient and other stakeholder priorities or expectations with PRO measurement
- Identifying meaningful and actionable measures
  - ▣ Face validity (in practice)
  - ▣ Interventions, patient care plans
- Implementing best practices for collection
  - ▣ Work flow design, mechanisms/technologies for data capture, frequency in collection
- Funding and participation by multi-stakeholders

# Multi-stakeholder Opportunities for Collaboration

- Conduct further understanding of the PRO landscape, active measurement activity and best practices
- Align and leverage patient resources to incorporate authentic patient engagement and involvement in PRO measurement
- Engage multi-stakeholders including patients in the selection of PRO measure(s)
- Pilot test:
  - Feasibility of measure/instruments
  - Data collection work flow design or technologies
  - Communication and dissemination of results
  - Action plans, interventions by providers and patients

# Draft MHQP Roadmap – Multi-stakeholder Engagement in Advancing PRO Measurement

## PRO Measurement Roadmap: Multi-Stakeholder Engagement in Advancing PRO Measurement





# Considerations...

- What are the SQAC priorities and objectives around PRO measurement?
- How can MHQP's commitment to PRO measurement support the SQAC and overall PRO measurement objectives?
- What role can/will the SQAC play as part of the MHQP PROM Roadmap for Massachusetts?

# Questions or more information?

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