



Advancing the Science of Measuring What Matters to Patients:

A Qualitative Analysis to Identify **Patient-Driven Priorities** for Patient-Centred Measurement

Fuchsia Howard¹, Linda Warner¹, Lena Cuthbertson², Richard Sawatzky^{3,4}

¹School of Nursing, The University of British Columbia

²Office of Patient-Centred Measurement, British Columbia Ministry of Health

³School of Nursing, Trinity Western University

⁴Centre for Advancing Health Outcomes, Providence Health Care

We declare no conflicts of interest



Michael Smith
**Health
Research BC**
BC SUPPORT UNIT

Background & Study Aim



Our PCM Methods Cluster *sought to advance the science of PCM by considering how to transform the data from PROMs and PREMs into relevant information* for providers, decision makers, patients, and researchers, to foster action that would result in improved care, patient outcomes, resource utilization, and better quality of life



OUR STUDY AIM:

To identify *patient-driven* priorities for research on advancing the science of PCM.



Methods

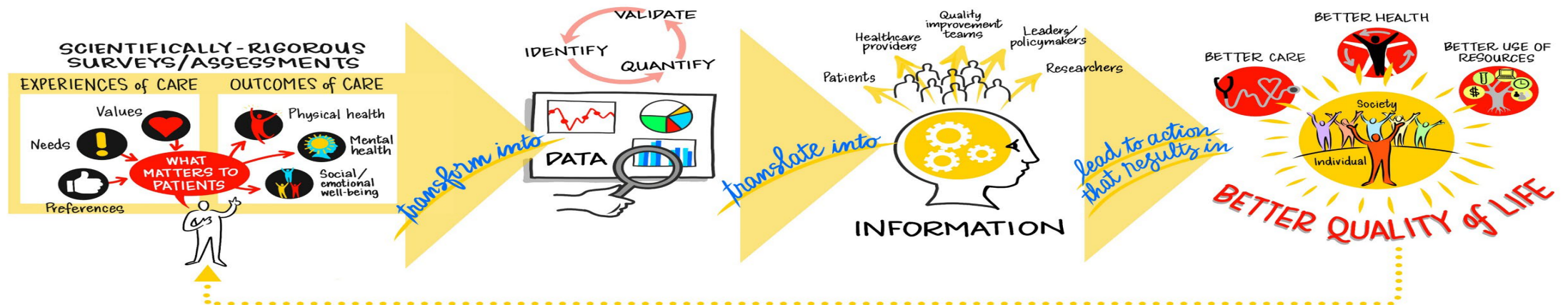
Data Collection: In-person focus groups across British Columbia, Canada during fall/winter 2018

Focus Group Guiding questions (semi-structured) based on PCM value chain (see schematic below)

Sample: 73 patients and family members (7 Focus Groups)

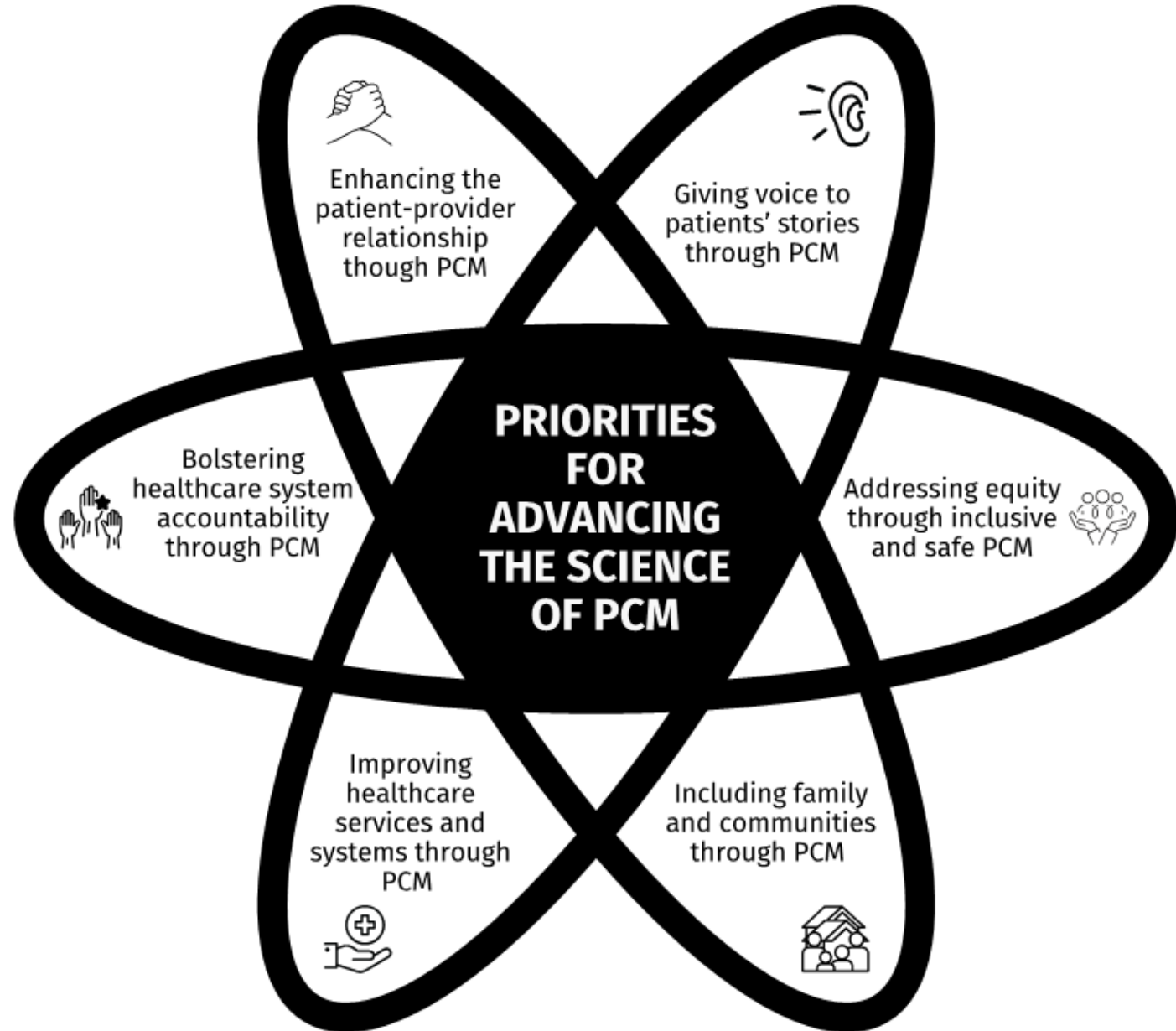
- Mean age of 59 years (range 21-88)
- 73% female
- 69% reported greater than a high school education
- 54% married
- 70% White

Data Analysis: inductive qualitative and constant comparative methods



Findings

The patients highlighted intersecting priorities for research on advancing the science of PCM that would help transform care

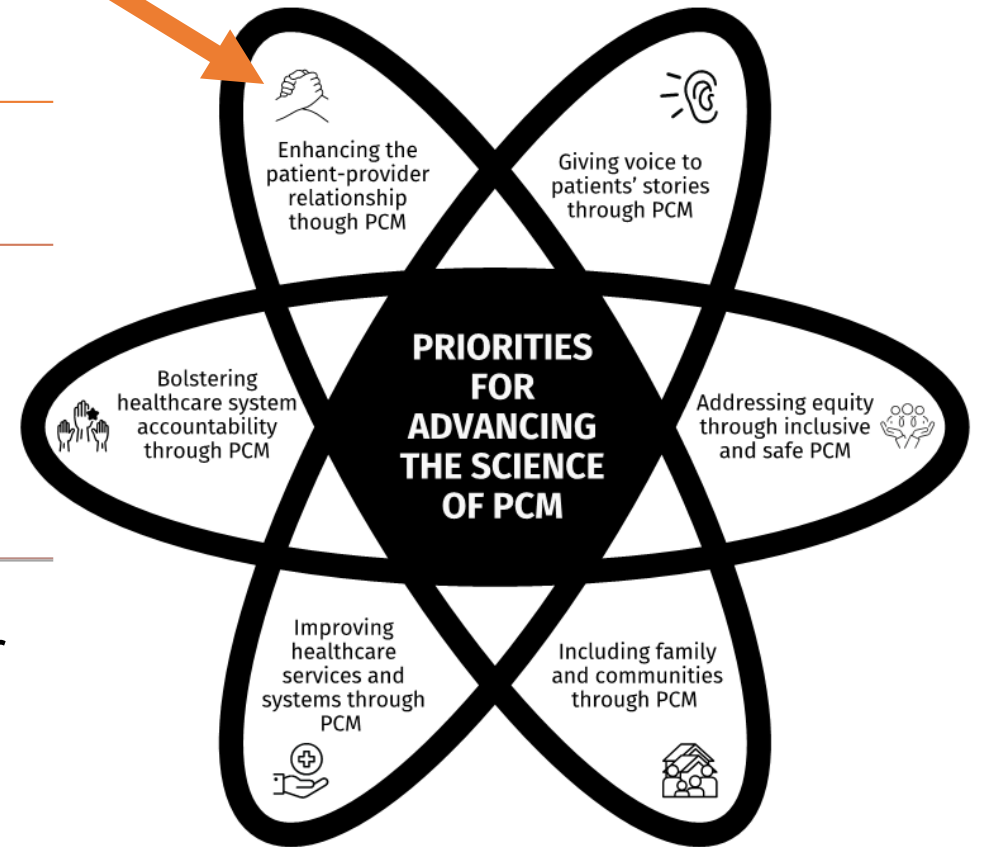


Enhancing the patient-provider relationship through PCM

Patients wanted PCM to strengthen trust, respect, and reciprocity in the patient-provider relationship.

PCM was framed as a potential mechanism by which a provider could be made aware of a patient's individual priorities, so that what matters most to the individual patient is addressed in all interactions.

Patients wanted PCM to be the impetus for helping their provider(s) genuinely hear their individual concerns and to engage in dialogue to build a respectful partnership.

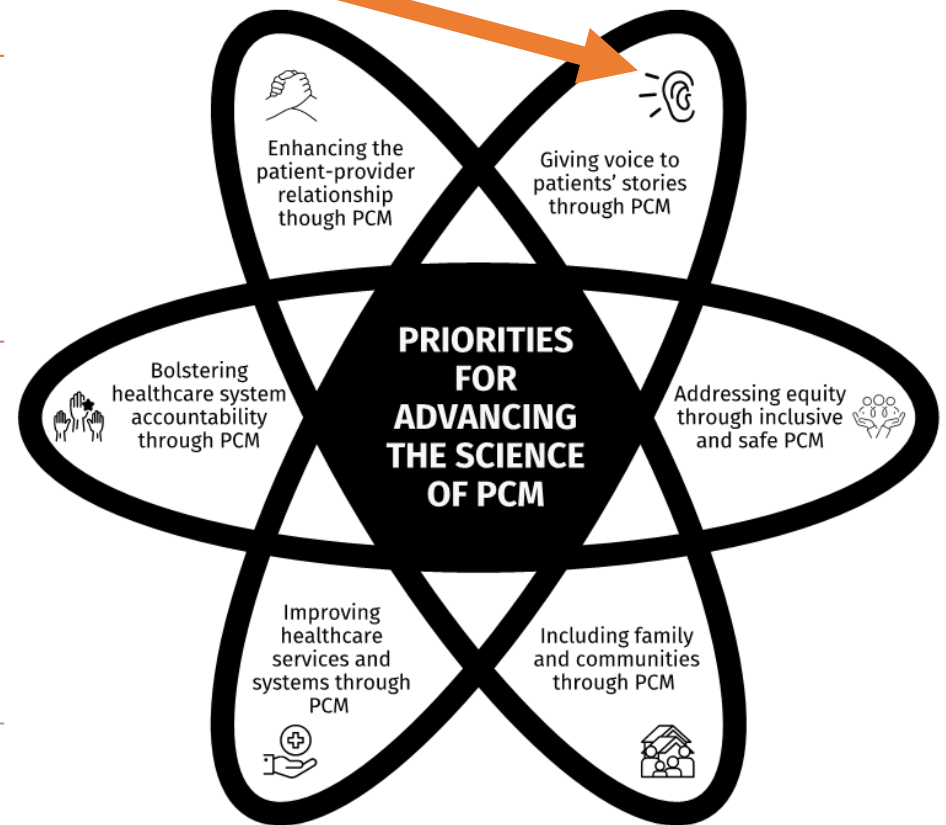


Giving voice to patients' stories through PCM

Patient perspectives, collected through PCM tools that complement clinician-reported data were framed as key to communicating patients' experiences and health status.

Patient stories, their narratives, their poems, the qualitative data, free-text comments collected through surveys and patient journey mapping were suggested as ways to “humanize” and contextualize, or illustrate, numerical data.

Patients did not want to be seen as “*just a data point,*” and believed their stories could help foster an appreciation of patients' experiences and enhancement of connection with providers and peers.



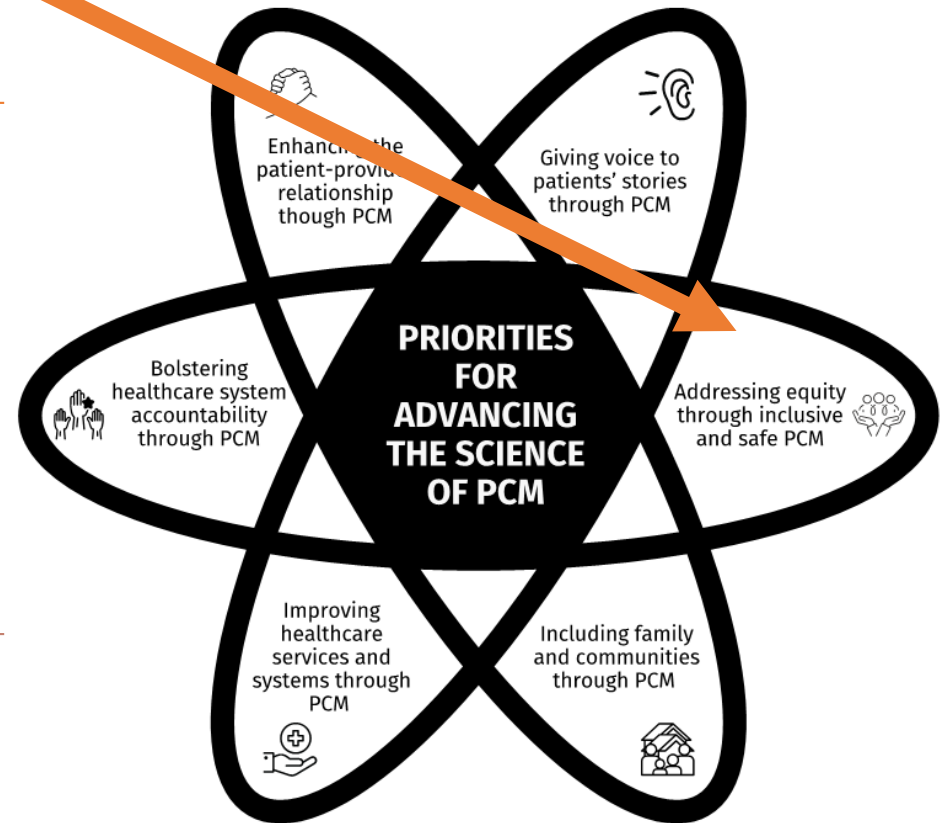
Addressing health equity through inclusive and safe PCM

Individual differences and social and structural influences create different health and healthcare experiences, which should be considered in PCM.

Integrating *inclusivity* into PCM

- Through accessible formatting and timing of assessments.
- Ensuring PCM is relevant and represents the diversity of individuals.

Ensuring *safety* throughout all aspects of PCM because of the potential to cause harm (i.e., difficult or distressing thoughts or emotions, disrespectful or unfair interactions with clinicians and healthcare organizations).



Including family and communities

PCM that includes family members, community members, and the broader community was endorsed out of recognition of the need for approaches and interventions at all levels.



Improving healthcare services and systems to better meet patient needs

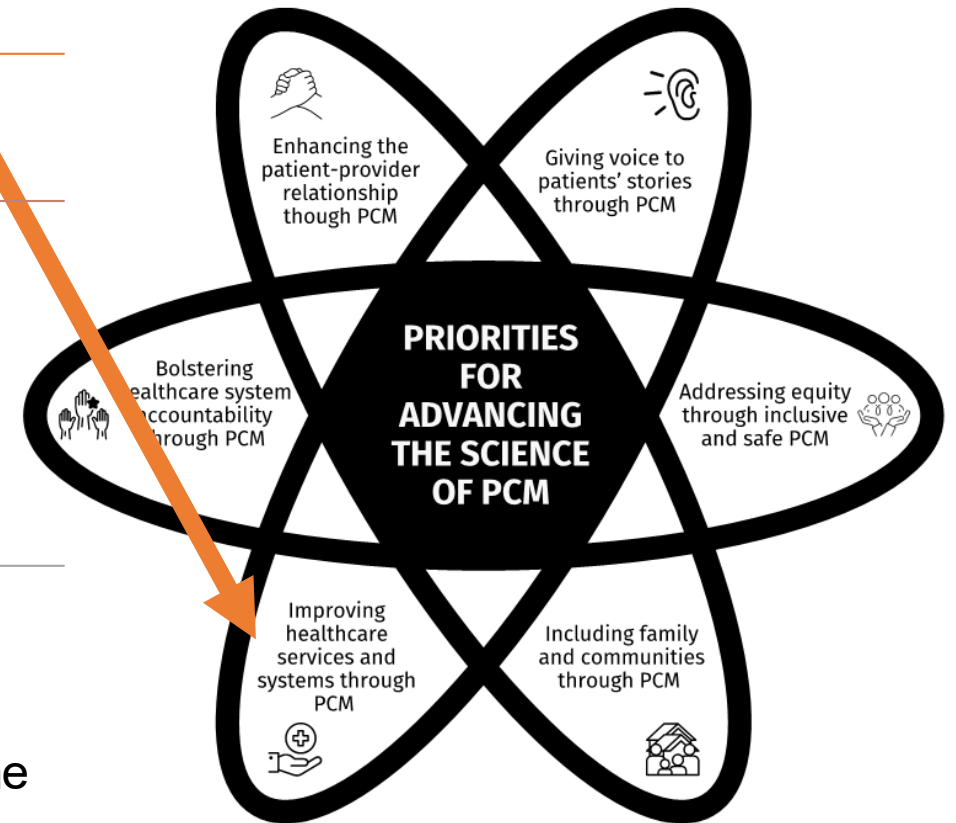
Patients advocated for PCM that promotes an effective and efficient healthcare system.

Aspects of PCM that warranted investigation:

- The optimal timing, frequency, and location of patient reported assessments
- How a single assessment fits in a person's overall care journey

Patients collectively voiced a desire for patient-reported assessments that are:

- Integrated in a manner that works well for the patient and the provider
- Coordinated and communicated to enhance continuity of care
- Reduce rather than create bureaucracy



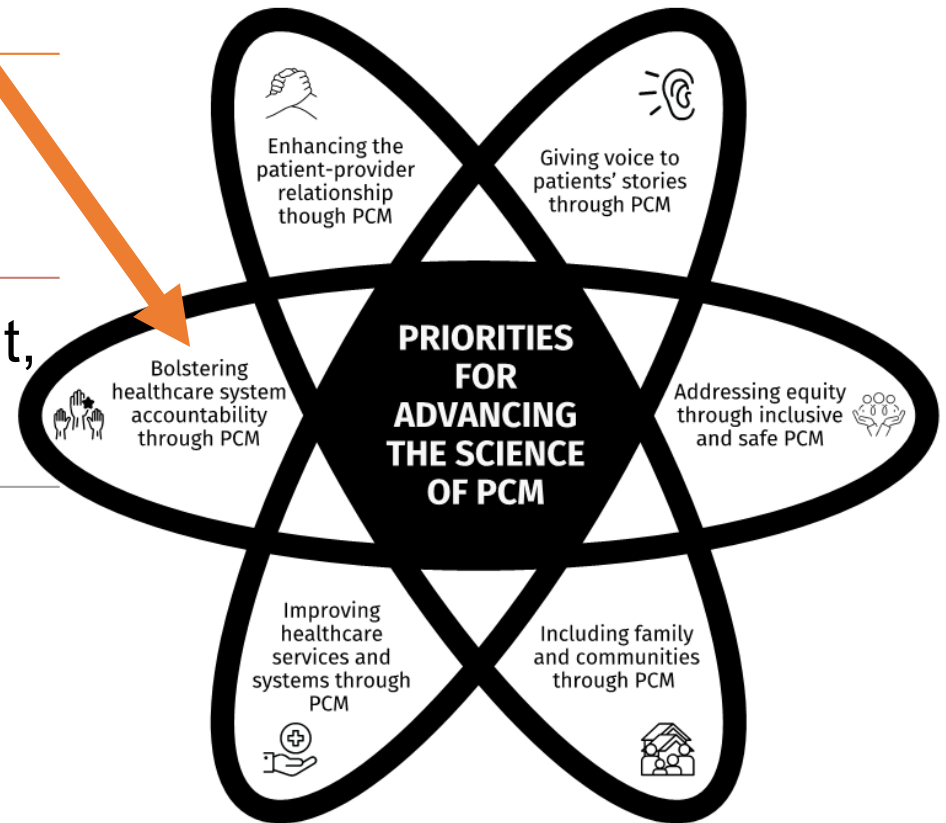
Bolstering healthcare system accountability

Patients raised questions about how PCM could bolster accountability and ensure that patient feedback is heard and acted upon

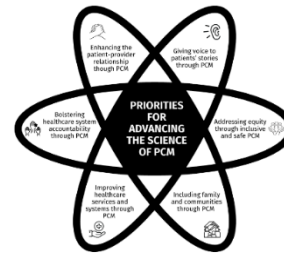
Patients articulated preferences for clear, transparent, and upfront communication

Aspects of PCM that appeared key to bolstering healthcare system accountability included:

- Taking action
- Making tangible changes based on the information
- Demonstrating to patients how PCM data led to action and changes



Our Conclusions



Patients suggested the prioritization of research wherein PCM could potentially transform an individual patient's care and the broader healthcare system.



The prioritization of research that focuses on the **function of PCM** contrasts with the proliferation of PROMs and PREMs research devoted to developing specific distal health or experience outcomes.



Thus, additional investigations are warranted to discern **how, for whom, and in which circumstances** PCM can be utilized to ensure that what matters to individual patients is prioritized in all healthcare encounters



These patient-driven priorities provide direction for future research efforts that could be positioned to make progress toward better health, better care, and better use of resources for individuals and for society.



For More Information & To Download Our Slides

Thank
you!

SCAN ME

