UNIVERSITY *of* MARYLAND
SCHOOL OF PHARMACY

The **PATIENTS** Program
at the University of Maryland
School of Pharmacy

10-Step: Mapping and Resourcing Patient and Stakeholder Engagement in PCOR

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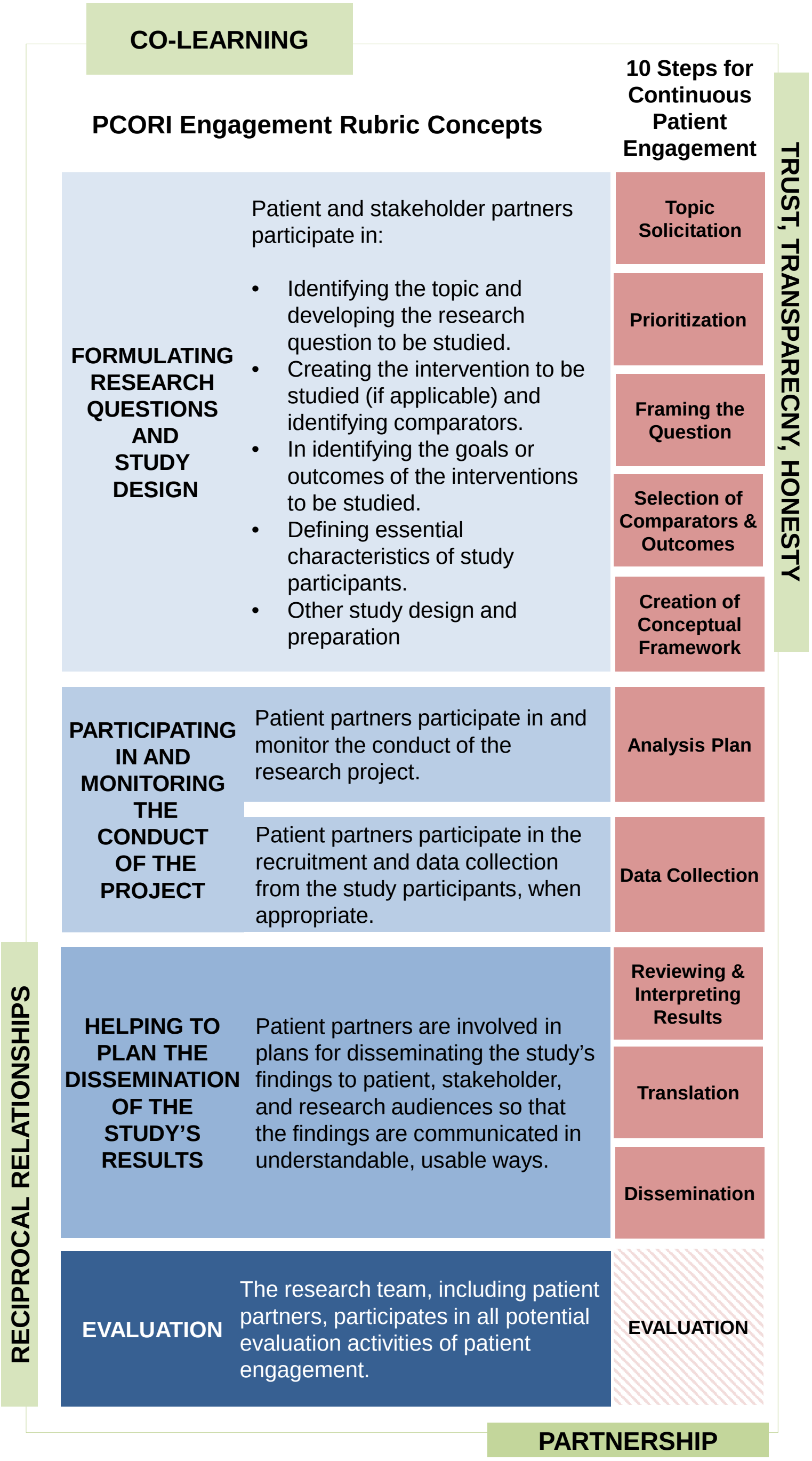
Background

- Patients' voices are critical to designing, conducting, and disseminating the results of Comparative Effectiveness Research (CER)/Patient-Centered Outcomes Research (PCOR) studies.
- There is limited guidance on when to use a particular method of patient engagement for a research step and the estimate of time and resources required to have authentic engagement from stakeholders.



PCORI Engagement Rubric Concepts		10 Steps for Continuous Patient Engagement
FORMULATING RESEARCH QUESTIONS AND STUDY DESIGN	Patient and stakeholder partners participate in: • Identifying the topic and developing the research question to be studied. • Creating the intervention to be studied (if applicable) and identifying comparators. • In identifying the goals or outcomes of the interventions to be studied. • Defining essential characteristics of study participants. • Other study design and preparation	Topic Solicitation Prioritization Framing the Question Selection of Comparators & Outcomes Creation of Conceptual Framework
PARTICIPATING IN AND MONITORING THE CONDUCT OF THE PROJECT	Patient partners participate in and monitor the conduct of the research project.	Analysis Plan
	Patient partners participate in the recruitment and data collection from the study participants, when appropriate.	Data Collection
HELPING TO PLAN THE DISSEMINATION OF THE STUDY'S RESULTS	Patient partners are involved in plans for disseminating the study's findings to patient, stakeholder, and research audiences so that the findings are communicated in understandable, usable ways.	Reviewing & Interpreting Results Translation Dissemination
EVALUATION	The research team, including patient partners, participates in all potential evaluation activities of patient engagement.	EVALUATION

Objectives

Aim 1: To develop a Patient Engagement Translation Table (PETT) that maps patient-engagement methods to the 10-Step CER/PCOR Framework

Aim 2: Assess the resources and time required for planning and executing engagement activities for each patient engagement method and any special considerations regarding additional resources or time required for harder-to-engage sub-populations

Aim 3: Highlight patient engagement methods in the PETT that enhance engagement of under-represented patient groups

Aim 4: Develop a collaborative strategy for dissemination of the PETT with PCORI and other PCORI stakeholders

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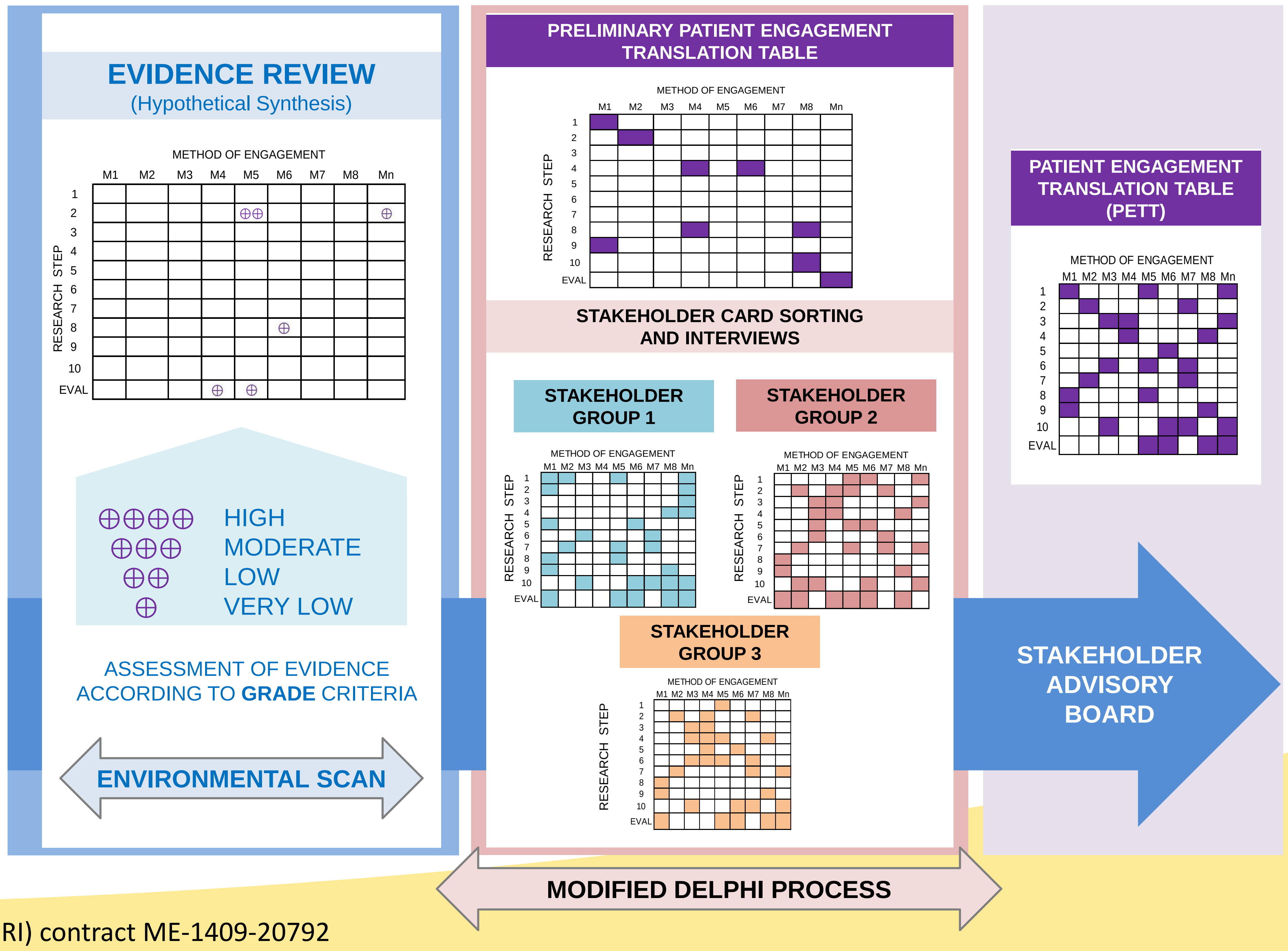
Methods

The study was conducted in two phases:

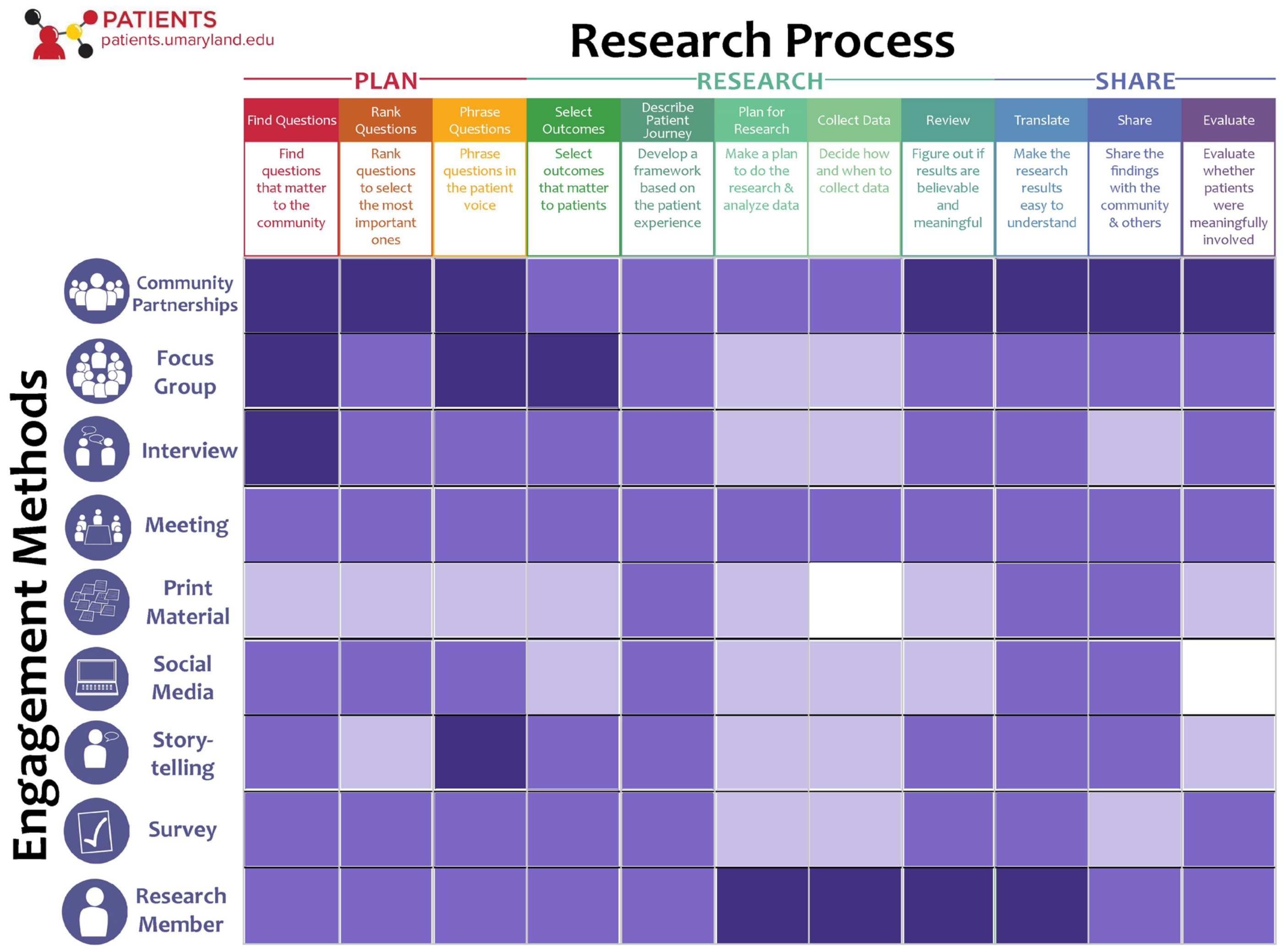
1. The environmental scan included systematic searches for information on patient engagement methods in peer-reviewed literature, gray literature, and key guidance documents;
2. Once we gathered evidence-based methods of engagement, we conducted interviews and focus groups with patients, other stakeholders and PCOR researchers. We included a card-mapping activity to identify methods corresponding to each stage of the 10-Step framework as well as evaluation.

Following PRISMA guidelines, we initially identified 8,394 records through database searching, of which only 165 articles were eligible for quantitative synthesis.

In Phase II, we identified 50 patients, 56 stakeholders (including clinicians and payers), and 50 researchers to participate in a one-hour focus group or interview. Patients and stakeholders included community leaders, clinicians, payers, English as a second language speakers, and vision-impaired participants.



Results



The shading is coded from darkest to lightest: most meaningful to not meaningful engagement methods throughout each step of the research process.

Conclusions

- Community partnerships are most meaningful in the planning and sharing stages of the research continuum.
- Stakeholders as research members is most meaningful when conducting the research.
- Engagement promotes transparency between researcher and community, across all methods.
- Flexibility in scheduling and availability of the research team is important for patient engagement.
- Selecting familiar locations for in-person activities increases community engagement.
- Use a combination of methods: by showing the diversity within the study, community members are more likely to believe the results and conclusions drawn.
- Pre- and continuous engagement takes resources:
  - Lay a framework for partnership before data collection
  - Provide resources/support for community before working on a study
  - Build a network of people engaged over time
  - Maintain a continuous presence in the community