

A Novel Stakeholder Engagement Approach for Patient Centered Outcomes Research

Katherine K. Kim¹, Dmitry Khodyakov², Kate Marie¹, Howard Taras³, Daniella Meeker⁴, Hugo Campos⁵, Lucila Ohno-Machado³
¹University of California Davis, ²RAND, ³University of California San Diego, ⁴University of Southern California, ⁵Patient Co-Investigator

Background

The engagement of patients and other stakeholders is a critical element in the design of patient-centered outcomes research (PCOR) studies. However, methodology for scalable engagement in research management particularly activities such as operationalization of principles and setting of priorities is not well-developed.

Study Design

PCORI engagement principles were applied to the development of network policies and determination of research priorities in three conditions:

- Weight management/obesity, Heart failure, Kawasaki disease

Objectives:

- Operationalize a comprehensive stakeholder engagement program
 - Utilize PCORI Engagement Framework (See Fig 1)
- Enable meaningful participation in creation of stakeholder-engaged research vision
 - Stakeholder advisory boards involved in planning and development the governance activities and refining policies.
- Assess engagement strategies at scale
 - Stakeholder research prioritization expert panels that set research priorities using an online, modified Delphi method, a deliberative, iterative approach to attaining consensus with discussion and statistical feedback (See Fig.2)
 - Assessment will be conducted in future

Contacts:
 PSCANNER.ucsd.edu
 kathykim@ucdavis.edu

The Engagement Approach

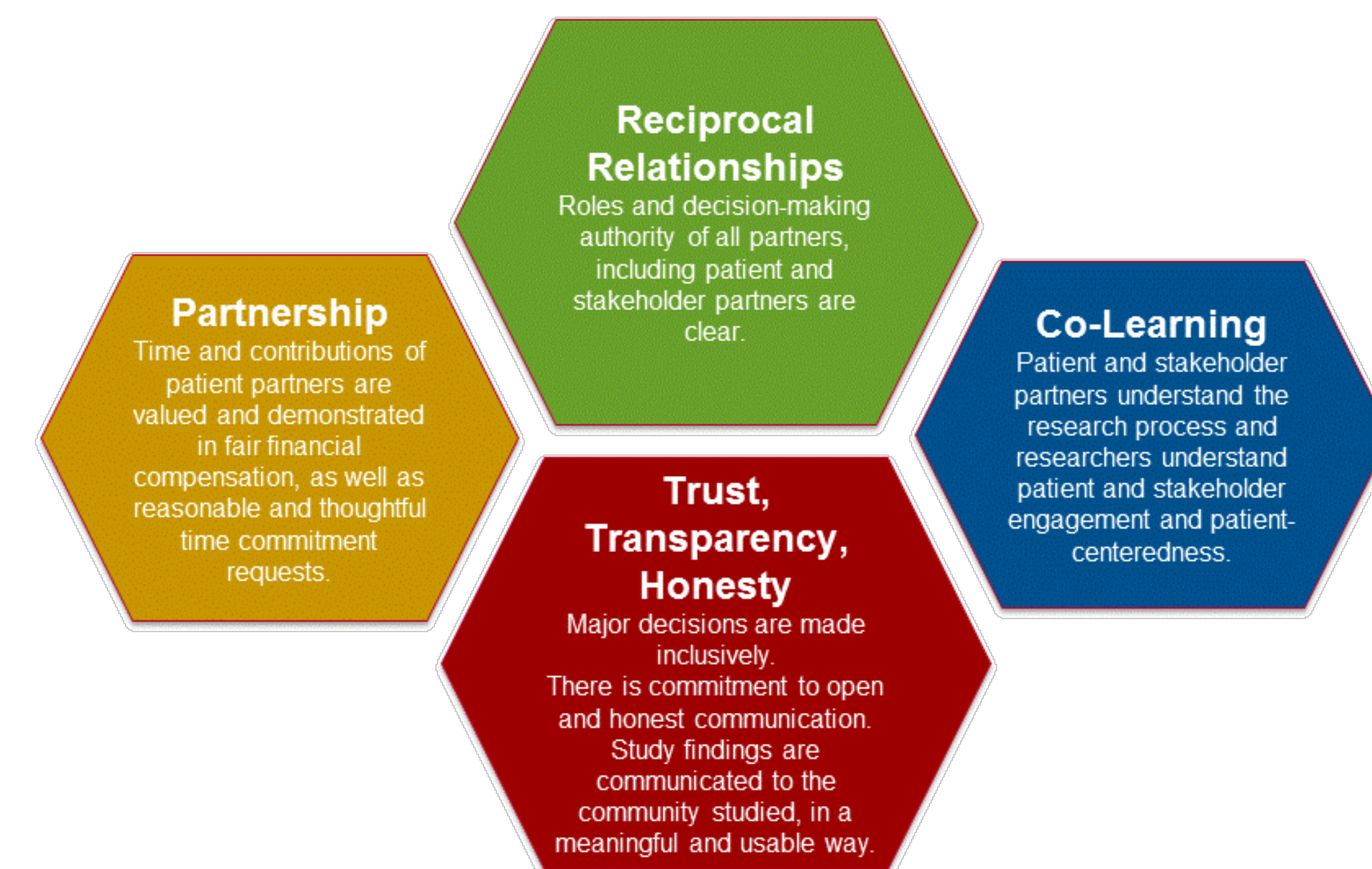


Fig. 1. PCORI Engagement Framework

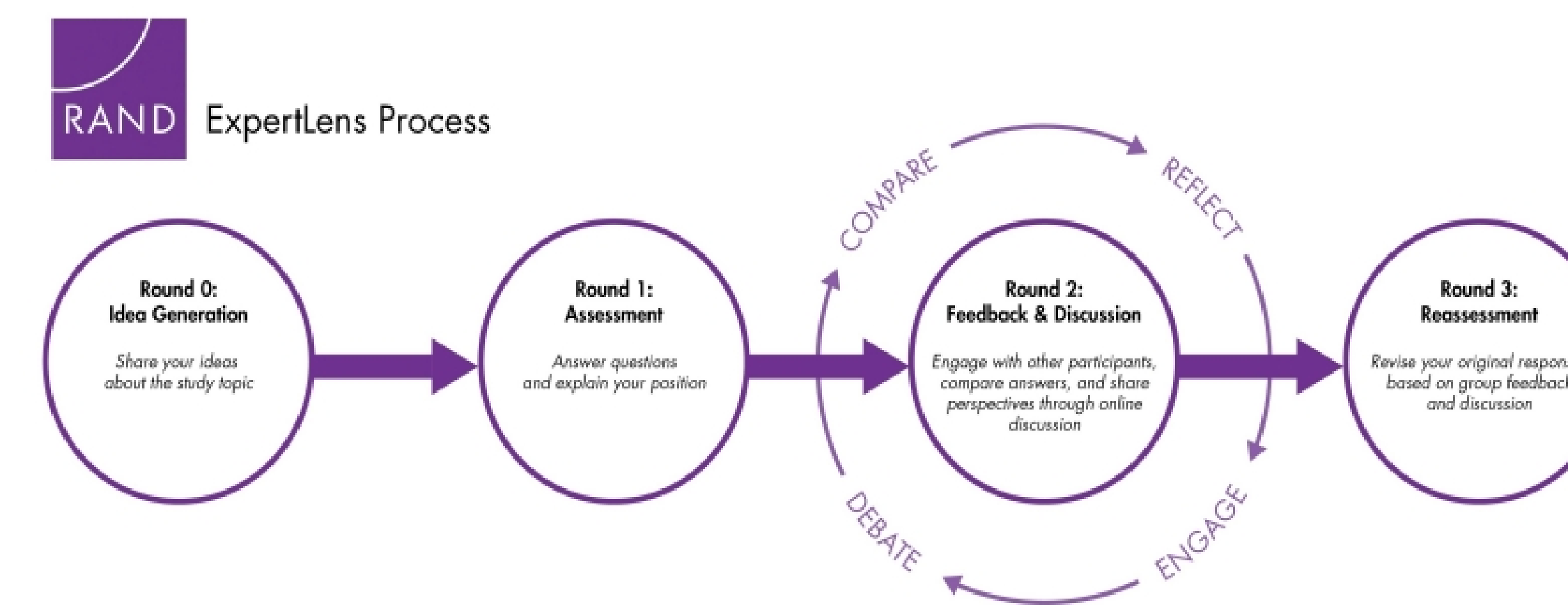


Fig 2. Online Modified Delphi & ExpertLens Software

Stakeholder Advisory Board Participation

- 20 patients/patient advocates, 26 clinicians
- Stakeholder Research Prioritization Panels
- 349 patients, clinicians and researchers
- Lessons learned regarding implementation
- High level of staffing support needed
- Challenges in reconciling diverse expectations for engagement
- Unmet need for rigorous evaluation



Fig 3. Operationalized Strategies Mapped to Engagement Framework

Setting

pSCANNER: patient-centered SCALable National Network for Effectiveness Research clinical data research network.

- 14 clinical sites
- 30 million patients

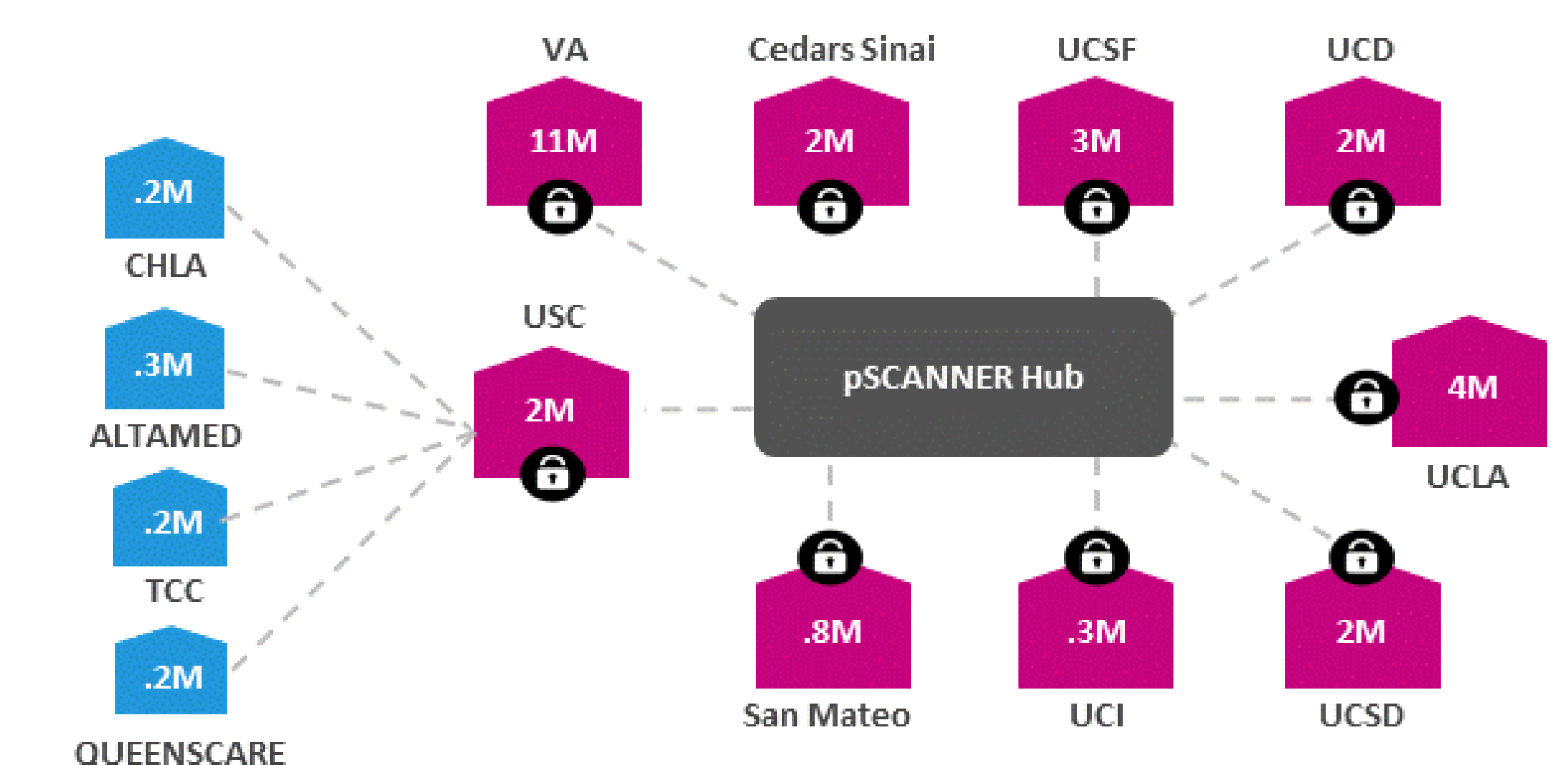


Fig. 4. pSCANNER Network

Conclusions

An efficient way to engage large numbers of representative stakeholders in research is a necessary first step to assure the public of trustworthy use of data networks for health research. This paper describes a comprehensive approach to engagement in PCOR research management that can inform ongoing development of rigorous methodologies.

Implications for Policy or Practice: This study provides insights on advantages, challenges, and lessons learned related to meaningful participation of patients, and interaction among diverse stakeholders who might not typically work together. These findings may be helpful for other researchers and practitioners interested in research networks and patient-centered outcomes research.

Acknowledgements

Funded by PCORI CDRN-1306-04819 (Ohno-Machado, PI)