

Centered Outcomes Research for Heart Failure and Kawasaki Disease: an Online Consensus Panel of Patients, Clinicians, and Researchers

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Background

Engagement of patients and clinicians is critical to generating evidence that is relevant to their concerns and values. There is meager understanding of optimal engagement for person-centered outcomes research (PCOR). High-touch methods such as in-person focus groups are not easily scaled to larger groups, while high-tech methods such as online surveys can be superficial. This study addresses this gap by assessing deep, high-tech engagement in a clinical data research network.

Study Design

We conducted a series of panels for heart failure (HF) and Kawasaki disease (KD) to set PCOR priorities, using online software and Delphi method, a deliberative and iterative approach to attaining consensus with discussion and statistical feedback. (See Fig. 1) Topics were rated using five criteria--informed decision making, collaboration, relevance, impact, innovation—applied to aspirational goals. Adult panelists with HF or KD (patients), clinicians, and researchers were recruited nationally via social media or network sites. Within condition, participants were randomized to either a single-stakeholder (patient or clinician) or mixed-stakeholder (patients, clinicians, and researchers) blinded panel. Participation was online, asynchronous, and took four hours over four-weeks. Analysis included rank-ordered topics (mean score), consensus (positive agreement) within panels, and comparisons across panels.

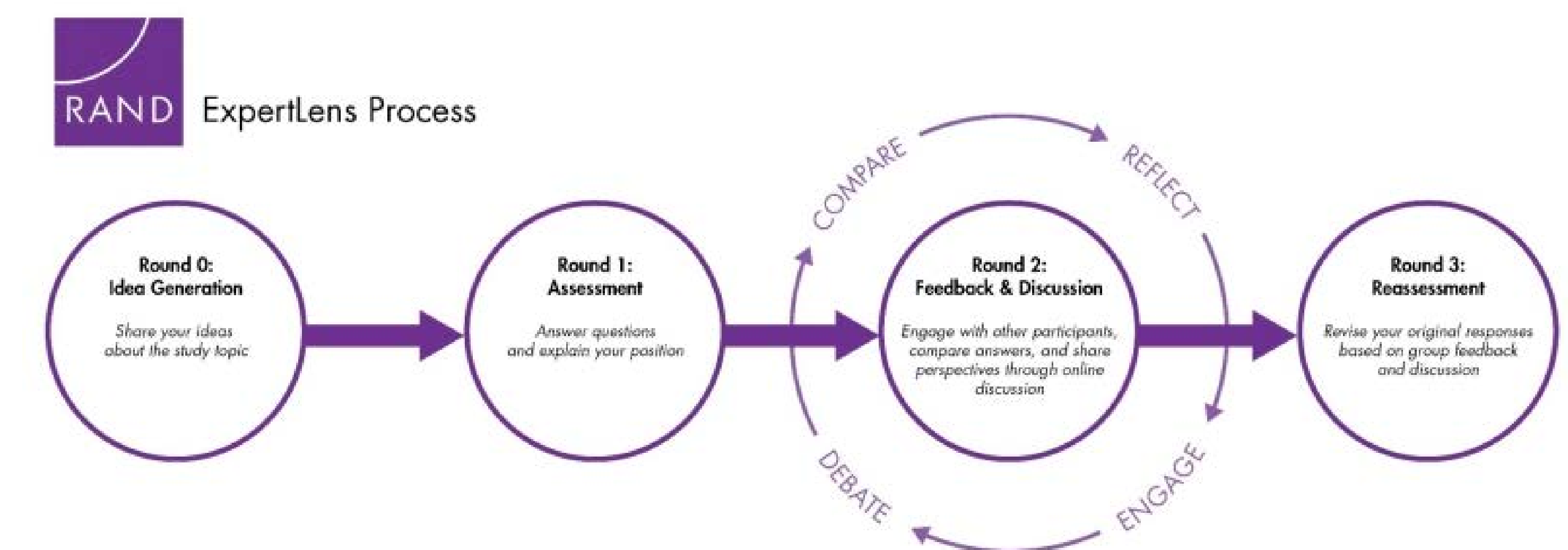


Fig. 1. Online Delphi Process

Results

228 panelists participated. Participants were assigned to only one panel. The heart failure patient-only panel achieved consensus on all topics. Other panels did not achieve consensus on any topics. There were significant differences in ratings between clinicians and patients on three to five criteria for every topic, and differences between mixed and patients on all but one topic 3: comparative effectiveness of telehealth and remote monitoring. There was a high level of agreement between patient-only and mixed panels, with significant differences in ratings between groups on three or more criteria for only one topic 1: comparative effectiveness of medications. Both panels achieved consensus on two topics 3: algorithms to identify cases from electronic health record data and 4: tools for awareness raising. In addition, the mixed panel achieved consensus on topic 1: medications and 2: early diagnostic tests.

	Rank ²			Mean ¹
	Clinician N = 30	Patient N = 30	Mixed N = 52	Overall N = 112
Heart Failure				
Aspirational Goal: to reduce unwarranted hospital readmissions for HF by 25% by 2020				
Topic 1: impact of care coordination on patient outcomes	1	1	2	7.33
Topic 2: balance between patient-centered outcomes and patient effort	2	2	3	7.24
Topic 3: comparative effectiveness of telehealth and remote monitoring	5	4	1	7.22
Topic 4: lifestyle change and symptom self-management strategies	3	4	5	7.14
Topic 5: predictors of deterioration	6	3	4	7.06
Topic 6: lifestyle change support strategies	4	6	6	7.02
Topic 7: patients' views on vitamins, supplements, and medications	7	7	7	5.75
Kawasaki disease				
Aspirational Goal: to reduce the percentage of new Kawasaki disease patients with permanent disability by one-quarter (from 7% to 5.25%) by 2020				
Topic 1: comparative effectiveness of medications for infants and children			1	7.83
Topic 2: tests for early detection of KD.			2	7.77
Topic 3: algorithms to identify possible cases from electronic health record data			3	7.14
Topic 4: tools for raising awareness among parents, caregivers, school staff and other non-clinicians			4	7.07
Topic 5: understand the long-term health challenges			5	7.04
Topic 6: education to reduce risk of cardiovascular damage			6	6.95
Topic 7: lifestyle change and symptom self-management strategies			7	6.36

¹ Rating on a score of 1= very unhelpful to 9=very helpful
² Rank by mean score within panel

Setting

pSCANNER: patient-centered SCAlable National Network for Effectiveness Research clinical data research network.
 • 14 clinical sites
 • 30 million patients

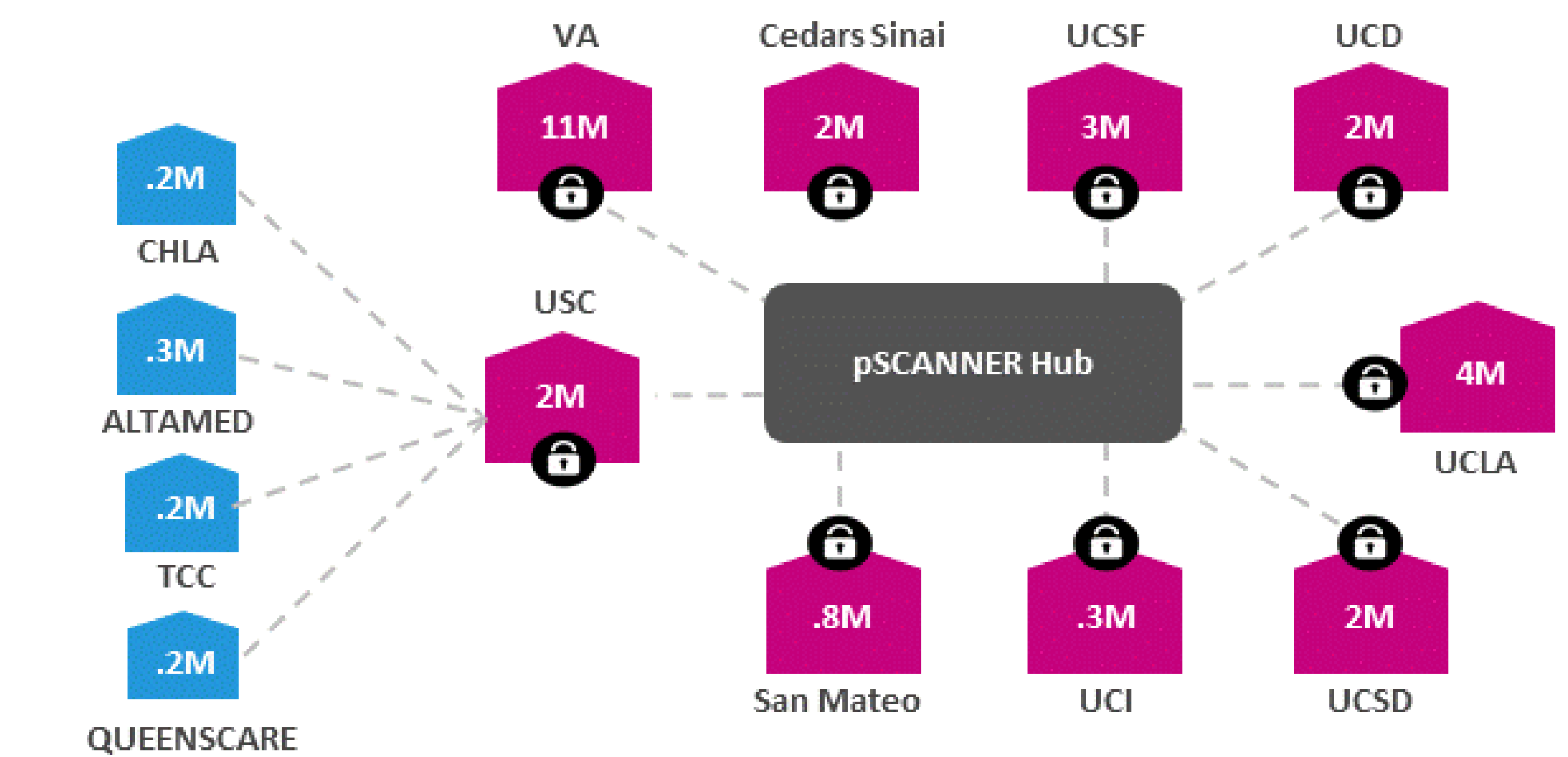


Fig. 2. pSCANNER Network

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.

We demonstrated that structured, high-tech engagement of stakeholders can yield rich contributions for PCOR. In this first of its kind study of substantial-scale stakeholder engagement in PCOR prioritization, results differed by health condition and stakeholder group.

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