Stakeholders' Perspectives on Stakeholder-engaged Research (SER)

Strategies to Operationalize Patient-centered Outcomes Research Principles for SER

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Background: US federal funding agencies increasingly incentivize stakeholder-engaged research which represents a paradigm shift toward incorporating a range of stakeholders in research design, conduct, and dissemination.

Objectives: We use qualitative methods to capture experience-based recommendations on how to operationalize 4 Patient-Centered Outcomes Research (PCOR) principles in stakeholder-engaged research, specifically: (1) reciprocal relationships; (2) colearning; (3) partnership; and (4) trust, transparency, and honesty.

Research Design: We conducted semistructured interviews with members of a stakeholder panel who participated in a 2-year comparative effectiveness study of cholesterol screening and treatment among young adults.

Sample: Participants included 8 young adults and parent panelists and 11 professional panelists (clinicians, researchers, policy developers, and disseminators).

Measures: The interview guide included questions about the 4 PCOR principles and queried preferred strategies to attain them. Interview transcripts were analyzed using an a priori and emergent coding structure.

Results: Participants provided strategies to promote the 4 PCOR principles. Although some stakeholder-identified strategies were complementary, others conflicted due to (1) competing ideologies identified among the principles, and (2) distinct stakeholder preferences. Illustrative of competing ideologies, participants simultaneously preferred receiving relevant articles before calls (to facilitate colearning) but also minimal outside reading (to achieve partnership). Illustrative of distinct stakeholder preferences, young adult and parent panelists generally preferred calls to occur on weekends/evenings, whereas professional panelists preferred mid-week work hours.

Conclusions: Our exploratory study provides stakeholder-identified strategies to achieve the 4 PCOR principles, and demonstrates the need to identify, acknowledge, and address potentially conflicting strategies due to the potential for competing ideologies or variation in stakeholder preferences.

Key Words: stakeholder engagement, patient engagement, patient-centered outcomes research, comparative effectiveness research

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US federal agencies increasingly incentivize the involvement of stakeholders as partners in research, referred to as stakeholder-engaged research (SER).[1–3] The Patient-Centered Outcomes Research Institute (PCORI), the National Institute of Health, and the Agency for Healthcare Research and Quality promote stakeholder engagement comparative effectiveness, implementation of evidence-based practices, and dissemination studies,[4–6] and the US Departments of Defense and Veterans Affairs are committing new resources to SER.[7,8] SER represents a paradigm shift toward incorporating a range of stakeholders in research design, conduct, and dissemination,[3,9] based on the belief that engagement of those who are responsible for or affected by the health care issues "improve uptake of the evidence and improve the likelihood that patients will achieve the health outcomes that they desire."[9]

SER may be conducted through sustained collaborative community-academic partnerships, patient advocacy groups within academic institutions, convening of stakeholder advisory panels for specific studies, or stakeholder involvement for discrete aspects of the research process.[2,10–14] The theory of SER rests on the assumptions that engagement with stakeholders can meaningfully inform all components of research, including agenda setting, proposal development,

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study design, data collection, analyses and interpretation, and dissemination, thereby helping to align research activities with societal needs.[15] To elicit stakeholder preferences, priorities, and values, SER draws upon existing methods and approaches that elicit perspectives both individually (eg, interviews, surveys, and ranking techniques) and through group interactions (focus groups, deliberative discussions, citizens' juries, town meetings, Delphi methods, and conferences/symposia).[2,9,13,16] SER has been applied to a range of areas including cancer,[17] diabetes care,[18] and cerebral palsy.[19]

Although SER shares similarities with community-based participatory research and participatory action research,[2] SER is also distinct in its articulation of taxonomies and principles specific to patient-centered outcomes research (PCOR). First, SER engages end-users of research beyond community members and patients, to family members, providers, purchasers, payers, policy makers, product makers, and principal investigators and, while active social change may result, it is not a requirement as is the case in participatory action research.[12,20] Second, both peer-reviewed literature and published methodology standards introduce core principles that distinguish SER in PCOR.[21,22] Prior research places importance on ongoing stakeholder engagement across the research process with adequate stakeholder preparation and skilled facilitation allowing for expression of diverse viewpoints.[21,22] To provide a foundation for defining and evaluating stakeholder engagement efforts, PCORI codified themes from these varied approaches into a stakeholder engagement rubric that highlights 4 principles: reciprocal relationships, colearning, partnership, and trust, transparency, and honesty.[20] Nevertheless, there remains a lack of consensus on approaches to operationalize these principless across stakeholder engagement.[13,15] In this paper, we aim to advance methodology of SER by presenting stakeholder perspectives on operationalizing the 4 core principles of SER articulated by PCORI.

METHODS

Given the limited literature on SER principles and strategies, we used semistructured interviews to explore how members of a heterogenous stakeholder panel (hereafter, "panelists"), who had participated in 1 PCORI-funded comparative effectiveness study on cholesterol screening and treatment, operationalized each of the 4 principles.

Study Sample

After completing the study, the research team contacted each panelist over 3 months (April–June 2015) by email or phone to elicit experience-based preferences and recommendations for operationalizing the PCOR principles. The study sample included young adults (n = 5), parents (n = 3), clinicians (n = 6), researchers (n = 3), payers (n = 1), and policy developers and/or disseminators (n = 1). For the adolescent and parent samples, respectively, panelists were reflective of clinical risk factors associated with high cholesterol, including familial hypercholesterolemia (adolescent, n = 1; parent, n = 1), other cardiovascular risk (ie, obesity; adolescent, n = 2, parent, n = 1), and no known cardiovascular risk (adolescent, n = 3; parent, n = 1). All panelists but 1 young adult participated during the 3-month window for study recruitment and is not included in our sample. Participants completed an informed consent to participate in this study and received $50 for participation in the interview. The study received review and approval from the Tufts University Health Sciences Campus Institutional Review Board.

Interview Procedures

Semistructured individual or group telephone interviews lasted 30–90 minutes (averaging 45 min), depending on the number of participants. The interviews were conducted by a researcher (T.I.M.) who had observed and presented to the panel, but not assumed the role of leader or moderator. We initially planned to conduct group interviews to capture dynamic interplay of the distinct preferences between panelists, but ultimately used some individual interviews due to scheduling challenges. Because individual interviews may offer less opportunity for participants to consider their perspective in relation to that of others, the researcher provided additional probes on previously reported themes to understand heterogeneity of preferences among the diverse sample. All interviews were recorded digitally and transcribed by a professional transcription service.

Measures

Before the interview, participants were emailed a 2-page information sheet that defined each of the PCOR principles. The interviewer confirmed that this information sheet was available to each participant and then provided a series of closed-ended and open-ended questions about their perspectives on each principle and what structures and/or processes would prevent or facilitate attainment. See Appendix 1 for definitions offered for each PCOR principle and interview questions.

Data Analysis

After reviewing transcripts for accuracy and completeness, a researcher (T.I.M.) independently coded the transcripts at a general level to condense the data into analyzable units.[25] Segments of text ranging from a phrase to several paragraphs were then assigned codes based on a priori (ie, colearning, reciprocal relationships, partnerships, etc.) or emergent themes (eg, reiterating and reinforcing roles). The same text may have been assigned >1 code. Through an interdisciplinary team review of the preliminary codebook, the final list of codes consisted of themes for each of the 4 principles regarding how stakeholders operationalized these concepts and then strategies to achieve these principles. For each code used, the research team developed a definition and illustrative quote. One researcher (T.I.M.) then independently coded each transcript and recorded memos to identify both methodological considerations for interpretation of the collected data as well as conceptual and substantive insights of the data. After coding each transcript in hard copy, the researcher then entered these codes into Dedoose, a mixed methods software program[26] generated tables of collated data for each code, further refined and systematically applied the coding structure, and then explored coding co-occurrences. He then provided tables of

assembled quotes to the interdisciplinary team who reviewed these collaboratively to facilitate interpretation of coded data. In the presented results, we use italics to identify thematic codes that emerged from this process; for each italicized code, the findings are illustrated using quotes provided in Tables 1–4.

RESULTS

Figure 1 provides a conceptual framework for the relationship between the stakeholder-identified strategies to promote the 4 PCOR principles. As illustrated in this figure, the strategies may be synergistic in attaining 1 or multiple principles (as demonstrated in arrows connecting each of the quadrants). At the same time, quadrants are separate as our data suggest that some strategies may be distinct or in conflict with the other principles. We first turn to strategies that promote each principle and then to the relationships between identified strategies, whether synergistic or in conflict.

Reciprocal Relationships

Operationalizing the Concept of "Reciprocal Relationships"

Study respondents identified 2 characteristics of the stakeholder advisory panel that were important to development of reciprocal relationships: (1) complementary expertise, and (2) recognition of shifting stakeholder roles across the research process. First, participants emphasized the importance of ensuring that stakeholders offered *complementary expertise* or perspectives that would otherwise

TABLE 1. Operationalizing and Strategies for Stakeholder-engaged Research: Reciprocal Relationship

Domain	Illustrative Quote	Respondent
A. Reciprocal relationship		
Ai. Operationalizing reciprocal relationships		
Complementary expertise	"I … thought our role as being kind of an advisor to you guys, 'cause it's not like you need to know the content, but sometimes when you're developing whatever tool you're developing, you can't see the forest for the trees … Another professional that could say, "Wait a minute, this doesn't make sense," or, "It does," similarly I think that our patient and family stakeholders also had a great deal to contribute in terms of what emphasis or direction they should take, because they knew what was important to them."	Professional panelist
Recognition of shifting stakeholder roles across the research process		
New roles because of stakeholders' multiple identities	"That's an important point that I might have been invited onto the panel in one role, but made a contribution in more than one role …. I have this memory of having developed a [committee that required technical expertise], and come to find out that the parent on the committee was a [professional with that technical expertise]. She was there, and she was a parent. But she in fact had more expertise than anyone else in the group about the work we were doing."	Professional panelist
Value of holding multiple roles	"I think my role was double-fold. Because I have some scientific expertise in the area, I'm a clinician, and a parent, I thought my role was, on some of the calls, to give more scientific expertise and other calls to sort of bridge or reflect what I was hearing from the parents and from the parent and other stakeholders … I think the first one, the scientific expertise, is wearing my researcher hat and the second one is wearing more my clinician hat."	Professional panelist
New roles because of stakeholders' emerging interests	"I think I found my role throughout the study, I think it would have been best to say, we want you guys to focus on these points and give us feedback. Again, I really loved the openness and I didn't feel like this was a part time job or a research assistant position. I really like how open it was. It's a balance of telling us really what to focus on and having the autonomy of putting our input where we really wanted to show what we were more interested in or stuff that we really wanted to highlight throughout the study."	Parent panelist
New roles due to stakeholder's perceptions of study's needs	"My role was to provide the payer's perspective around screening and medical management. I think as the initiative unfolded there was probably less of a role as a health plan would influence cholesterol screening and decision making around that. I don't think for this particular initiative there was a whole lot for me to contribute, but I think it's important to include a health plan as a stakeholder."	Professional panelist
Aii. Strategies for reciprocal relationships		
Report roles and rules of governance	"For me [the governance structure for this kind of study] comes as second nature, but I'm sure for the parents and the adolescents it doesn't. Maybe it would have been helpful the layout beginning the structure of a typical scientific venture and the governance and maybe a shared document or whatever helps."	Professional panelist
Reiterate and reinforce roles of panelists	"I think for me probably in the beginning and this just might have been because I was busy and not paying attention as much. I didn't quite understand the extent of all the different people that were going to be involved. It took me a little bit to just kind of figure out who was who and what they were doing and what the components were. I don't know that that's fixable other than by reinforcing it a couple of times from the beginning."	Parent panelist
	"I mean, I think in terms of the reciprocal relationships, one of the things that was done that I think was really helpful was the introduction, the pictures, the sort of understanding who's who, introducing people in a way that was first names, not hierarchically based. I think those things all helped to, to allow people to feel that they had a contribution to make regardless of what their title or position is."	Young adult panelist
Renegotiate roles	"I think that our patient and family stakeholders had a great deal to contribute in terms of what emphasis or direction [patient and family stakeholders] should take, because they know what was important to them."	Professional panelist

TABLE 2. Operationalizing and Strategies Principle for Stakeholder-engaged Research: Colearning

B. Colearning		
Bi. Operationalizing colearning		
Colearning about the research process	"For me [the scientific venture] comes as second nature, but I'm sure for the parents and the adolescents it doesn't."	Professional panelist
	"Because it's too different lens when you're a researcher implementing a study and where the actual participants … just to gauge what the researchers may not have thought about. I think they really did a phenomenal job in terms of gauging our perspective and what we thought about what they had proposed."	Young adult panelist
Colearning about patient-centeredness	"I like having the, some of the stakeholders who are professionals in on the same call as the stakeholders that were patients, because um, a lot of time when it comes to research, as investigators, we're kind of far removed from what the patient's perception is."	Professional panelist
Colearning about stakeholder engagement	"You know, it's interesting to me because I thought you did a good job of kind of diffusing … potential power gradients. I actually thought it was a bit of a learning experience, you know, I'm not sure the power gradients [in the stakeholder panel] are exactly as one would have guessed initially."	Professional panelist
Colearning about decision sciences	"Cause there's a lot of terminology, and then you know, you have a lot of different models, and you know, like, how you calculate the risk and things … I just think that the process is fascinating, you know, how you really, you know, everything is this scientific base. Yeah. With all the stats and things. Because sometimes, I mean, the decision making process could be very emotional, but then if you provide people with this scientific-based model, it might help a lot."	Parent panelist
Colearning about cholesterol screening and treatment	" … one of the positions we're speaking about, you know, there's only so much, so many minutes to see a patient, and so you have to you know, guard that, you know, if you add something in, something else is going to have to give."	Young adult panelist
Value of complementary expertise	" … I think the view of how, what participation in this project meant, might have evolved more for them, for the other stakeholders than the people involved in academics, you know, since we generally have a concept of how research works, and how you were basically taking information gathered from different groups, and using it to formulate different thought processes."	Professional panelist
	"I think we would tend to think that parents have power over teens, or clinicians have power over patients, but I actually think what came out of the discussion was that it's much more complicated than that … the different views, and trying to work together as a team to try and understand a disease dynamic and treatment, evaluation, and treatment dynamic, I think that was, for me, part of the learning process."	Professional panelist
Bii. Strategies for colearning		
Clarify objectives for colearning	"At the very beginning when [research team members] went through how we made medical decisions, what went into a decision, you know that kind of … helped to set my expectation was going to be from my input …. and how did we make medical decisions, and so I think that was a very good beginning, because that's what I had experience with, and that's what I could help with."	Young adult panelist
Build capacity of panelists to participate in research	"I got something for me coming into this, I really had a very limited … view on this whole subject, so I don't know if I can pinpoint one or three but everything that's sent out was really helpful and helped me get up to speed … "	Parent panelist
Use of stakeholder-specific meetings throughout the research process	"A lot goes on from month one to month two. It's hard to recap everything that was discussed in a conference call. Even if the following conference calls are not as long as the initial one I think having those 45 minutes, 50–45 minute follow-up calls would have been better. Even if having the main conference calls and the follow-ups could be, for example, geared towards us young adult stakeholders or adolescent stakeholders like we communicate with each other to see what everybody thought or if there were any follow-up on what we can bring to the next meeting. I think having a big, overall stakeholder call with follow-up conversation would have been very effective."	Young adult panelist
Ongoing communications through varied modalities to meet panelists' unique needs	" … would just for myself [the most effective methods to learn] would be the webinars and I think at least on the physician's side, it's just hard to give people another thing to read."	Professional panelist
	"If you have a chance to look at these articles please do. I think between stakeholder calls I think I would have had the time even to glance on those articles, even after the meeting or in between a conference call … Please review and help give us feedback if you have any."	Parent panelist
	"Did you guys think about any kind of listserv like thing in between? With sessions where people could, I mean, you could pose a question, and get feedback, and start an online, basically it's a conversation."	Young adult panelist
Independent activities to assist in building study-specific knowledge	"I am not an expert in cholesterol screening. I'm not an expert in decision-making models or reviews. I think it would have been more effective for me and possibly for other stakeholders if the research team had proposed us to read certain literature and to have a gauge with our feedback from what we've read ….Yeah, and another way to tie that in is to have the article available for the stakeholders and in the follow-up calls us adolescent stakeholders we discuss what we've read in the article and we make sure we have a list of points to discuss in the follow-up of overall stakeholder conference calls."	Young adult panelist

(*Continued*)

TABLE 2. Operationalizing and Strategies Principle for Stakeholder-engaged Research: Colearning (*continued*)

Create thematic and membership continuity across the research process	" … sort of coming back to the stakeholder engagement groups and revisiting things over and over again. Say, "What did we learn last time? What did we do? What are we learning this time."	Professional panelist
	"There was a certain sense that each call had a certain element of starting over again, and part of that was because the project was moving along, and there were different topics, so that it's understandable there but I think if we'd had more consistent kind of group interaction … instead of having a large group where you mix and match, and people come in and come out, trying to focus on having a group of smaller groups where all the stakeholders are represented, but you really try to build some group cohesiveness with more consistent participation."	Professional panelist

not be available to the research team. As 1 young adult panelist said, "I really like having a panel of your target audience [young adults] participating in this study to hit points where [the researchers] would have limitations." Second, participants emphasized that, in practice, reciprocal relationships required recognition that the roles of panelists might shift throughout the research process. Many respondents indicated that new roles arose because of the *stakeholder's multiple identities*. As 1 researcher who is also a parent said, "I might have been invited onto the panel in one role, but made a contribution in more than one role." Notably, *the value of holding multiple roles* was seen as an asset by multiple respondents. Participants also identified *new roles emerging because of (1) stakeholders' evolving interests* and *(2) stakeholder perceptions of the study's needs.*

Strategies to Promote Reciprocal Relationships: The 3 "R"s.

Report roles and rules of governance: Participants emphasized the need to *report roles and the rules of governance* at the outset of the research endeavor. One young adult stated the value of knowing the intended role she was to have at the outset of her participation, "it kind of gave me an overview of like, the type of things that I would be doing … and the input that you guys want from the younger adults … " A professional panelist suggested laying out the structure of a scientific venture and the governance through a shared document or other means (see Table 3, *reporting roles*). Panelists highlighted the value of reporting roles to mitigate the uncertainties that arise as stakeholders, especially young adults and parents, learn to participate in research studies.

Reiterate and reinforce the roles of panelists: Participants also emphasized the need to *reiterate and reinforce the roles of panelists* at each meeting. Multiple participants highlighted the benefit of a reoccurring introduction throughout the study that included first names and allowed people "to feel that they had a contribution to make regardless of what their title or position is," as stated by 1 female professional. Participants also emphasized the value of elaborating on the roles delineated at study out during the study, especially given the shifting tasks required of panelists.

Renegotiate roles: Stakeholders also emphasized the need to renegotiate their respective roles whether to accommodate a stakeholder's multiple identities, emerging interests, or study need (as described previously).

Colearning

Operationalizing Colearning

As stated by 1 professional panelist in response to the colearning prompt, "there was a lot of innovation on both sides and listening to people taking each other's viewpoints into account." Colearning occurred on a diverse array of topics that included: (1) the research process; (2) patient-centeredness; and (3) stakeholder engagement (as articulated in PCOR principles, see Table 2), as well as study-specific information about the methods (ie, *decision sciences*) and clinical topics (ie, *cholesterol screening and treatment*.) Participants emphasized the *value of complementary expertise* as part of colearning as well.

Strategies to Promote Colearning: The 3 "C"s.

Clarify objectives for colearning: Participants noted the importance of knowing what and how their respective expertise would be of assistance to the study; the value of this step was particularly emphasized for stakeholders with limited prior research experience. As 1 professional panelist stated,

"*I think the view of … what participation in this project meant, might have evolved more for the [parent and young adult stakeholders] than the people involved in academics … since we generally have a concept of how research works, and how you were basically taking information from different groups, and using it to formulate different thought processes.*"

This sentiment was echoed by young adults and parents who cited an emergent understanding of exactly how their perspectives and expertise would inform various aspects of the study and a need for clear understanding of the expertise that they brought and areas where capacity would be built; see illustrative quote in Table 3.

Build capacity of panelists: Respondents expressed that panelists arrived with varied types of expertise and experience with research and therefore required differential levels of capacity building to contribute to the study. Although the study provided several initial meetings focused on capacity building, recommendations included: (1) use of stakeholder-specific meetings throughout the research process in addition to full panel meetings (especially for parents and young adults); (2) ongoing communications through varied modalities to meet panelists' unique needs; and (3)

TABLE 3. Operationalizing and Strategies for Stakeholder-engaged Research: Partnership

C. Partnership		
Ci. Operationalizing partnership		
Recognize multiple stakeholder-identified motivations	" … it is all about making people feel valued. Who knows the best way to do that? Financial compensation is one, although was there any talk in the beginning about how people wanted to be recognized?"	Parent panelist
Value of stakeholder diversity	"I think the other thing that just rang true for me was, well, as an example, that [parent stakeholder member's name] said about cultural and language barriers that just, so many experience. I hadn't really thought of that."	Young adult panelist
Optimal not necessarily equal engagement	"I think [diversity of the stakeholder panel] is a challenge, because you had different stakeholders and everybody had their own area of expertise or experience. No matter what the topic is at any given meeting there are going to people who are gonna be less engaged just because of who they are."	Professional panelist
Reliance on individuals to represent heterogenous stakeholder constituencies	"There's always as you bring together quote/unquote stakeholders all of them had their own perspectives and experiences including the professional side and the lay person side. There's always a question of are your getting too driven by anecdotes, so that's what that person think and isn't true in application elsewhere to others."	Professional panelist
Cii. Strategies for partnership		
Communicate time commitment at study outset	"The only thing I can think of, and you can't always prognosticate, is, I don't remember when I agreed to participate in this if I really knew what the time commitment was … And obviously I've done pretty good, I've participated, but I wonder if you can, could have clarified more what the expectations so people could say not if they didn't think they had the time."	Professional panelist
Accommodate panelists' schedules		
Generate stakeholder-identified meeting times	"Well, I hate to say this, but I loved having calls at weird times like now 'cause I really don't have any time during the day … when I have calls during work, I'm just so disrupted. I miss half of them, I get paged in the middle, so as much as sometimes you know, it's hard to do in the evening, like tonight, I just decided to come home so I could actually take this call without being distracted … that is a good idea."	Professional panelist
Schedule multiple meeting times to review the same material	"[For the same meeting topic], I like how there was one in the evening, and one in the morning, and it was like, the evening times never changed, so I like kind of expected around like 6:00 or 7:00, so I kind of got used to that time, and I liked how there was a variety."	Parent panelist
Maximize time together		
Convening stakeholder-specific conversations off-line and reporting back to the group	… being able to follow-up on certain timing, everyone's very aware that we have an hour and a half time, and some conversations that tend to be more focused on maybe someone's viewpoint that would have helped … They would kind of take it off-line, and have some follow-up afterwards and had something that would have affected, or could have affected everybody, then did bring it back into the next meeting.	Parent panelist
Supply materials with adequate time for review	I think in terms of time contribution … I almost wish I had the material a little bit beforehand, rather than kind of the day of, or maybe the day before, the call.	Young adult panelist
Facilitate quality interactions		
Format of meetings	I actually think, and I know this would be difficult to do … there was one time where we all you know, met up together, and maybe had a meeting all together in a large conference room or something, then I feel like we'd all know each other by face … and maybe that trust would be there a little bit more, and it would help people … participate, maybe more so if they were maybe more reserved before.	Young adult panelist
	… I think that the convenience of like online, being able to get into the meetings, 'cause sometimes people can make any part of the meetings, and I think it was a really good common ground.	Parent panelist
Skilled facilitation	I've felt like it was extremely reasonable, and very interesting and as far as partnership, and everybody on this research team has been so nice, and so supportive, and kind of like school, there is no silly question, you know, and everybody's just been very supportive with everything that's, you know, that I have offered as information, so I think it's been um, it's been really nice doing this program with everybody … it's you know, it was just everything that is brought up is you know, dealt with very professionally, nicely, and so it just made things very comfortable, so it was easier to have the partnership.	Young adult panelist
Explicit identification of requested preparations	I think the only thing that I would say with the communication with emails is just trying to be very clear about, on like the subject line, of what you needed and what the topic was … if you get too many [emails], then people get less attentive to them. And I'm not sure if you guys could use calendar invites where it shows up automatically on your calendars … maybe on that has all the call-in numbers and what not.	Professional panelist
Compensate panelists equitably accounting for preferences	To me that is an equitable way of doing it, offering the same amount [to participants from each stakeholder group], but also it sounds like a generous amount. I would say it sounds fair.	Parent panelist
	[Given my role on the stakeholder panel], I felt uncomfortable accepting financial compensation …	Professional panelist

(*Continued*)

TABLE 3. Operationalizing and Strategies for Stakeholder-engaged Research: Partnership (*continued*)

	I:" … so to have a conversation [at the study outset] that explicitly says, 'How could we best recognize you in the context … of this process?'"	
	R:"'We want your ongoing contributions. It is really important for this engagement process. One of the ways to keep you engaged is to reflect your contributions … ' and that kind of thing. I don't what it is: birthday cards, Starbucks certificates …"	
Facilitate to acquire engagement among diverse panelists		
Format	"I think if we had met maybe once in person that that would have helped with the power differential, but I think that the panel always did a great job of, I felt that empowering me as a parent, helping decision making, but I …"	Parent panelist
	I think because it [stakeholder-specific calls] was in the beginning of the calls or the beginning of the research, so I thought it was very good starting out point comfort-wise	Parent panelist
Facilitation strategies	… and using first names, I think that was also very helpful [to address potential power differentials.]"	Parent panelist
	"Sufficient warnings to the academic and clinical people not to step on the patient and families, which sometimes we are want to do."	Professional panelist
Supporting materials	"I think that when you give the presentation, or give us the background information, you have the glossary, that's very helpful. But because for non-English speaker, you know, the medical term, or you know, that's another … set of language … we don't know, so it will be helpful, you know if you could create a glossary or you know, for a non-English speaker to translate the information, that would be helpful."	Parent panelist

independent activities to assist in building study-specific knowledge.

Create thematic and membership continuity across the research process: Both professional and young adult panelists cited the importance of ensuring thematic continuity to facilitate colearning; 1 young adult specifically noted the value of starting each meeting with a review of the decisions made at the previous one to review central concepts and explicitly build off the prior conversations. Panelists also emphasized the value of convening the same set of panelists to meet over time, as illustrated by the comments of 1 professional panelist who suggested routine participation of the same group of panelists over time "to build some group cohesiveness with more consistent participation."

Partnership

Operationalizing Partnership

Panelists indicated a preference for partnership to *recognize multiple stakeholder-identified motivations*. One professional panelist stated, "You know, the fact we're all stakeholders means that we all have skin in this game for different reasons … " The emphasis on customizing partnership to specific stakeholder needs and preferences was further elaborated upon by a parent who stated the need for time requests to acknowledge that "everyone has a different schedule and a different life."

Panelists frequently cited the *value of stakeholder diversity* as making the research "more interdisciplinary," expanding "a broader range of options," and adding "to the richness of the conversation." One young adult highlighted the overlap between colearning and stakeholder diversity:

"*I think the other thing that just rang true for me was, well, as an example, that [parent panelist's name] said about cultural and language barriers that just so many experience. I hadn't really thought of that.*"

Although respondents valued the diversity of the assembled panel, stakeholders noted 2 additional characteristics based on experiences. First, stakeholders expressed that *optimal engagement may not always equate to equal levels of engagement*, depending on the topic being reviewed and the expertise sought. Second, panelists noted the danger of *reliance on individuals to represent heterogenous stakeholder constituencies*. One panelist said, "There's always, as you bring together quote/unquote stakeholders, all of them had their own perspectives and experiences including the professional side and the lay person side. There's always a question of are your getting too driven by anecdotes, so that's what that person thinks and isn't true in application elsewhere to others."

Strategies to Promote Partnership

Strategies identified by panelists for partnership included the need to: (1) *communicate time commitment at study outset*; (2) accommodate panelist's schedules; (3) maximize time together; (4) facilitate quality interactions; (5) *compensate panelists equitably accounting for preferences*; and (6) facilitate to acquire engagement among diver panelists. To accommodate panelists' schedules, participants highlighted 2 strategies, specifically (2a) *generate stakeholder-identified meeting times,* and (2b) *schedule multiple meeting times to review the same material.* To maximize time together, respondents noted *(3a.) convene stakeholder-specific conversations off-line and report back to the group* and *(3b) supply materials in advance for panelist review.* Respondents identified quality interactions being facilitated through the (4a) *format of meetings*, (4b) *skilled facilitation*, and (4c) *explicit identification of requested preparations* by panelists.

Panelists expressed preferences for the research team to *compensate panelists equitably accounting for preferences*. In addition, 1 professional panelist encouraged building in enhanced incentives to reward ongoing participation: "Because there's certainly ways people build an incentive; like if you participate in at least 80% of them, there's some kind of benefit stake." In 1 case, a professional panelist suggested that given his role, he did not feel comfortable accepting compensation.

Respondents also highlighted strategies to acquire full engagement among diverse panelists, including adjustments to

TABLE 4. Operationalizing and Strategies for Stakeholder-engaged Research: Trust, Transparency, and Honesty

D. Trust, transparency, and honesty		
Di. Operationalizing trust, transparency, and honesty		
Trust	"I think all group process are like this, especially when you're bringing people together who don't know each other, you know so I think over time, I got a sense that there was more comfort with speaking up and you know … it seems like there was less facilitation needed the more the project went on and the more people developed a comfort level with what was happening."	Professional panelist
Transparency	"I think in terms of transparency, I think everything was communicated to us during the stakeholder meetings. I really like when the researchers show the modeling decision system, the decision model system that they had in place. I really appreciate that during the … interviews some of the transcripts were made available to us during the panel and we had a chance to discuss and reflect how different or what are the different perspectives that we have on the interview … the only thing that I can think of is maybe having a short summary of the results that the researchers gained over the course of the study."	Young adult panelist
	"… the trustworthiness component comes back into play, how comfortable people are sharing based off of, 'Do you know these people, or you don't know these people, you feel like you know them because of how comfortable you are talking about everything.'"	Parent panelist
Honesty	"Everyone has been honest in terms of what the goals of the study is."	Young adult panelist
Dii. Strategies for trust, transparency, and honesty		
Generate ongoing communication		
Informal avenues	"I also think … after the calls, you guys would send email about, 'Any other thoughts that you have?' I think that's always good to include, just in any questions they had, I think that kind of builds a level of trust. And also it kind of forms a relationship between all the stakeholders and you guys."	Parent panelist
Formal avenues	" … the calls are typically every month, but like during those months, when they're like you know, in between two calls, maybe a short summary … almost like a newsletter format, just kind of a summary of what happened last month. Um, you know, kind of, advances that were made, I think that could be kind of cool."	Young adult panelist
Provide skillful facilitation		
Facilitation style	"Having been on a lot of conference calls, there's some where really your discussion is not encouraged, and they're kind of run by the leaders of the conference call, and so you're careful not to pitch in on certain ones, and I think maybe that's true for our nurses and patients, and so I think [the research team] did a good job of expecting everyone to speak, and that was very positive thing, I think, for us … I think [the research team] waited long enough and allowed there to be little bits of silence, and then … called on people that didn't speak up."	Professional panelist
Not lose sight of big picture in communicating with panel	"The transparency and honesty … is a little bit harder when you get into the deep mathematical thing. I did think they did a good job of coming back out and saying 'Here is the overall model; we're not going to show you what is underneath it.'"	Parent panelist
Provide conducive structure		
Face-to-face meetings	"Having a formal [in-person meeting] … and I know I'm in Missouri and everyone might be in different places, but I think initially even at the beginning, the midpoint, and then the at final stage. We would have created a personal bond. I think it would have made us more comfortable to share our perspectives to the panel."	Young adult panelist
Internet-based meetings, when face-to-face meetings are not possible	"If you can't have an in-person meeting in the beginning if everyone has access to someplace that has video conferencing, you could have had a virtual meeting … I mean, most of the professionals will have access to video conferencing, but many of the patients and families may not."	Professional panelist

(5a) *format*, (5b) *facilitation strategies*, and (5c) *supporting materials*. First, most young adult and parent stakeholders stated that stakeholder-specific meetings at the outset would build comfort within and across stakeholder groups. Second, panelists also emphasized facilitation strategies that helped to be responsive to the power gradients among diverse panelists (eg, creating space on the calls for patient and family perspectives to be heard and the use of first names for all panelists). Finally, panelists highlighted the need for additional resources, including a constantly updated glossary of terms to assist lay people and non-native English speakers in understanding the medical terminology associated with the study.

Trust, Transparency, and Honesty

Operationalizing Trust, Transparency, and Honesty

Stakeholders emphasized the need for proactive efforts to establish *trust,* with 1 participant stating that, "making an even playing field for all the different stakeholders probably are important factors in the sort of trust area." Stakeholders also emphasized the gradual nature of establishing trust, as 1 stakeholder explicitly called out, "I see the trust building over time, actually." Respondents specifically sought *transparency*, emphasizing clear communication about the process for decision-making and the decisions made in the research process, data, and final analyses. Finally, respondents highlighted the importance of *honesty* from the outset of the project with clear explication of goals and roles for stakeholders.

Strategies to Promote Trust, Transparency, and Honesty

Panelists provided strategies that emphasized the need for ongoing communication with panelists and specific attention to the facilitation and structure of the stakeholder panel.

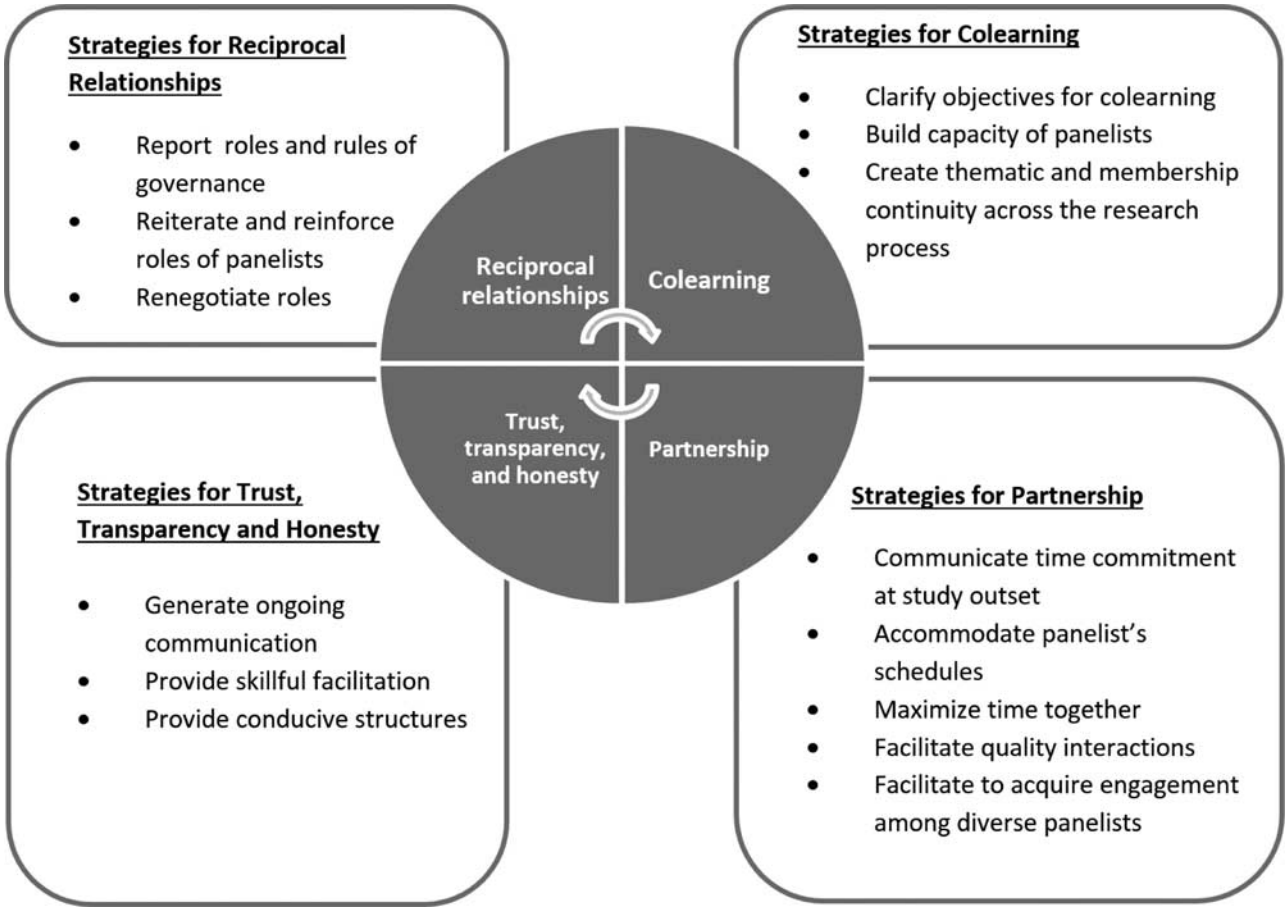

FIGURE 1. Framework for Stakeholder-Identified Strategies to Promote Patient-Centered Outcomes Research (PCOR) Principles.

Generate ongoing communication through formal and informal avenues: Panelists emphasized *ongoing communication*, including both *informal and formal avenues*, to establish trust and transparency with the research team. Suggested strategies included an (1) ongoing list of what the issue was that received stakeholder input, the stakeholder recommendation(s), and the study decision made, and (2) routinely distributed listserv or newsletter that would provide pertinent study updates including synopses of study-relevant news or publications.

Provide skillful facilitation: Respondents emphasized multiple approaches to the facilitation of the stakeholder panel that would help to ensure trust, transparency, and honesty. Stakeholders most frequently commented on the need for a *facilitation style* that created a "supportive context on the calls." A professional panelist highlighted that this may take explicit effort given professionalized norms. Panelists also cited the need for facilitation to *not lose sight of the big picture when communicating with the panel*.

Provide conducive structures: Respondents emphasized how the panel's structure can facilitate greater trust, transparency, and honesty including *face-to-face meetings* at least initially. Panelists generally preferred in-person meeting structure over internet-based meetings, but recognized the value of video conferencing given time and resource limitations in convening in-person meetings. Young adults and parent panelists also emphasized the value of being included in sessions covering technical topics as it allowed for them to stay informed.

Confronting the Conflicts in Stakeholder-endorsed Strategies and Perspectives

Although some stakeholder-identified strategies were complementary as noted above, others strategies were in conflict with one another due to the competing ideologies among the principles. We identified 3 areas where stakeholder-endorsed strategies conflicted with one another. First, conflicts emerged in strategies that emphasized brief, concise communications (to facilitate partnership) versus those that required more time to build capacity and promote transparency (to facilitate colearning and transparency). Second, conflicts emerged in strategies that emphasized preference to minimize communication (to generate partnership), while also articulating the desire for additional communication (to generate colearning and trust, transparency, and honesty) through newsletters. Third, conflicts existed in the preference to engage those with greatest expertise on a particular question (to promote reciprocal relationships and colearning),

while also ensuring involvement and equal engagement for the diverse membership (to promote partnership and trust, transparency, and honesty).

Conflicts in the stakeholder-identified strategies also emerged due to the preferences of different stakeholder groups. For example, young adult and parent panelists generally preferred calls to occur on weekends/evenings, whereas professional panelists preferred mid-week work hours. Two professional panelists preferred to meet routinely over the course of the study to optimize continuity and colearning and suggested setting the same time every month. Although this suggestion was favorable to the parent and professionals, the young adults in academic programs preferred to revisit the time within the context of each semester's demands.

DISCUSSION

With emergence of new funding mechanisms and methodological standards for SER,[1,4,5] considerable opportunity exists for conducting research that incorporates the perspective and priorities of diverse populations with vested interests. In this paper, we provide a series of stakeholder-identified strategies that operationalize the 4 PCOR principles. Although these were frequently complementary and even reinforcing, our findings also suggest that both the ideologies of the PCOR principles and the differences in stakeholder preferences, at times, resulted in conflicting strategies for achieving PCOR principles.

Prior work in stakeholder engagement suggests the need for plans to manage disruptive or dominating stakeholders and for resolving conflicts that may arise.[13] Conflicts have been previously identified in aligning stakeholder availability with the research process, whether due to availability or the need for some stakeholders (eg, federal partners) to acquire permission before participation.[12] Our findings suggest the need to plan for potential conflicts in preferences between panelists from different stakeholder groups as well as the need to resolve conflicts that may emerge in actualizing the PCOR principles. Consistent with the tenants of SER, researchers might engage the stakeholders, themselves, in how to resolve these challenges. For example, researchers might facilitate conversation with stakeholders to consider potential solutions, associated trade-offs, and ultimately arrive at a shared understanding of how the process will proceed. Researchers might also turn to conflict resolution approaches in which parties accept the conflict, recognize ways out of it, and engage in some tacit or explicit coordination.[27] With recent approaches to conflict resolution seeking to focus on the basic issues and structure of the conflict (rather than simply managing the conflict),[27] significant opportunities exist for application to resolve the conflicts identified in this study.

Our study has some limitations. First, we are reporting findings of a single 20-member panel from a 2-year comparative effectiveness study, limiting generalizability. However, we believe our findings hold important implications for future studies that may encounter comparable variation in the interest and perspectives across diverse panel memberships. Furthermore, we achieved thematic saturation in strategies articulated across stakeholder groups generally, but did not reach saturation sufficient to attribute themes to the particular subpopulations represented by group members (eg, race/ethnicity, sex). Given the variation in preferences between group memberships, future studies might aggregate across stakeholder panels to facilitate analyses specific to subpopulations that may have unique perspectives, preferences, and values.[16]

Our study respondents also noted the challenge for a stakeholder panel to represent the heterogeneity of lived experiences and interests that might characterize any stakeholder group. Our findings suggest the need to consider generalizability when constructing a stakeholder panel. Consistent with prior recommendations to engage advocacy or interest groups for acquiring perspectives from a larger catchment,[12] multiple panelists expressed concerns around the ability to capture the heterogeneity of stakeholder experiences and perspectives. Further research should consider the validity of methods to leverage the insights of individuals while concurrently employing methods (eg, surveys) that can capture the heterogeneity of any 1 group.

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APPENDIX

TABLE 1. Patient-Centered Outcomes Research (PCOR) Principles for Stakeholder-engaged Research (SER)

PCOR Principle for SER	Definition	Primary Interview Questions
Reciprocal relationships	"This principle is demonstrated when the roles and decision-making authority of all research partners, including the patient and other stakeholder partners, are defined collaboratively and clearly stated."[28(p3)]	How did you understand what your role was over the course of this study? How did you understand decisions would be made? What strategies, if any, supported that the roles and decision-making authority of all research partners were collaborative? Clearly defined? What else could have helped improve the roles and decision-making authority were collaborative? Clearly defined?
Colearning	"This principle is demonstrated when the goal is not to turn patients or other stakeholder partners into researchers, but to help them understand the research process; likewise, the research team will learn about patient-centeredness and patient/other stakeholder engagement, and will incorporate patient and other stakeholder partners into the research process."[28(p3)]	What types of new information did you learn over the course of this study? *Probe:* Clinical topic (ie, cholesterol screening and treatment); Medical decision-making: uncertainty, information, values, and preferences regarding outcomes; Study questions, design, procedures; Methods: semistructured interviews, decision analysis; the funding agency (PCORI and its priorities) What strategies, if any, supported colearning? *Probe:* What materials (webinars, information sheets, articles) worked best for you to learn? What materials were least effective? What else could have helped to improve colearning?
Partnership	"This principle is demonstrated when time and contributions of patient and other stakeholder partners are valued and demonstrated in fair financial compensation, as well as in reasonable and thoughtful requests for time commitment by patient and other stakeholder partners. When projects include priority populations, the research team is committed to diversity across all project activities and demonstrates cultural competency, including disability accommodations, when appropriate."[28(p3)]	What do you consider "fair financial compensation?" What strategies, if any, supported "fair financial compensation?" What else could have been done to facilitate "fair financial compensation?" What do you consider "reasonable and thoughtful requests for time commitments? What strategies, if any, supported "reasonable and thoughtful requests for time commitments?" What else could have been done to facilitate "reasonable and thoughtful requests for time commitments?"
Trust, transparency, and honesty	"These principles are demonstrated when major decisions are made inclusively and information is shared readily with all research partners. Patients, other stakeholders, and researchers are committed to open and honest communication with one another."[28(p3)]	What do you consider as indicators of inclusive decision-making? What strategies, if any, supported the process of making major decisions in an inclusive manner? What else could have been done to facilitate inclusive decision-making? What do you consider as indicators of "open and honest communication?" What strategies, if any, supported the process of "open and honest communication?" What else could have been done to facilitate "open and honest communication?"

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