Patient vs. Community Engagement: Emerging Issues

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Background: The value proposition of including patients at each step of the research process is that patient perspectives and preferences can have a positive impact on both the science and the outcomes of comparative effectiveness research. How to accomplish engagement and the extent to which approaches to community engagement inform strategies for effective patient engagement need to be examined to address conducting and accelerating comparative effectiveness research.

Objectives: To examine how various perspectives and diverse training lead investigators and patients to conflicting positions on how best to advance patient engagement.

Research Design: Qualitative methods were used to collect perspectives and models of engagement from a diverse group of patients, researchers and clinicians. The project culminated with a workshop involving these stakeholders. The workshop used a novel approach, combining World Café and Future Search techniques, to compare and contrast aspects of patient engagement and community engagement.

Subjects: Participants included patients, researchers, and clinicians.

Measures: Group and workshop discussions provided the consensus on topics related to patient and community engagement.

Results: Participants developed and refined a framework that compares and contrasts features associated with patient and community engagement.

Conclusions: Although patient and community engagement may share a similar approach to engagement based on trust and mutual benefit, there may be distinctive aspects that require a unique lexicon, strategies, tactics, and activities.

Key Words: patient engagement, community engagement, World Café, future search, lexicon

(Med Care 2018;56: S53–S57)

The basis for including patient perspectives and input in research reflects the Patient-Centered Outcomes Institute’s (PCORI’s) proposition that the inclusion of patients (a term used here to include community members and patient stakeholders who have a strong personal connection with a disease) enables a richer, more relevant scientific discovery process.3,4 Thanks in part to 2 current forces—the rapid pace and demand for health care to answer critical questions that matter to payers, providers, and patients; and the emergence of funding requirements from PCORI and other agencies—interest in the concepts of “patient engagement,” “stakeholder engagement,” and “community engagement” has increased. Each of these terms encompasses commonalities and differences that emerge from different practice, intellectual, and disciplinary traditions. Researchers, patients, communities, advocates, policy makers, funders, stakeholders, and evaluators need a consistently understood set of concepts and language for basic terms. They require a common language.3

The funding of a PCORNet clinical data research network, the “Greater Plains Collaborative” (GPC)4 gave rise to a collaborating group of approximately 15 faculty and staff from 10 academic medical center and health care system settings. Each site identified at least 1 person to serve on the GPC engagement committee with a core leadership team (1 patient and 2 academic leaders) hubbed at the grantee site, the University of Kansas Medical Center. The purpose for the committee was to assist the overall project and activate local engagement efforts on behalf of supporting GPC-related clinical trials and activities. The majority of individuals were not clinicians; they had a variety of academic degrees (MA, MPH, PhD, DrPH) and training (sociology, anthropology, public health, etc.). The GPC did not provide criteria regarding the skills, background, experience or training desired for the individuals selected.
Many of the partnering institutions opted to enlist a member of their National Institutes of Health Clinical and Translational Science Award community engagement key function area to serve on the GPC engagement committee. This could have served as a common bond; however, these individuals had diverse academic training and different levels of experience working with patients (vs. working in community settings). This, in retrospect, contributed to misunderstandings from the beginning.

The GPC engagement core leadership team detected differences in approach and willingness to engage patients at the participating sites. This problem continued over months interspersed with emails communications and individual telephone calls, resulting in very little progress. For example, while engaging patients was explicitly part of each site’s scope of work, some of the engagement committee members argued that they needed a clearer set of expectations of what a patient partner would be involved in doing before they would extend an invitation and ask a volunteer to participate. Friction extended as those with greater patient engagement experience argued two points. First, that to act as a gate-keeper and a priori decide what was in the best interest of a patient volunteer did not promote patient self-determination and independence; second, that the point of collaboration was to co-design and develop shared expectations, roles and responsibilities, so their presence was essential to progress. Community engagement experienced committee members explained that they had nurtured relationships and worked hard to develop trust with community organizations and community members over many years. To jeopardize that trust by encouraging involvement with yet-to-be-established professional relationships was something that was considered too risky. These tensions did not resolve and they effectively stalled development of a representative Patient Advisory Council. In response, the GPC lead engagement core team (K.S.K., C.J., and L.S.A.) initiated a real-time, collaboratively constructed activity to articulate differences contributing to tension in an effort to reveal the underlying biases that were generating roadblocks.

METHODS

To illuminate why the GPC engagement team was so stymied, 2 members of the GPC core engagement team (a researcher/K.S.K. and the lead patient advocate for the GPC/C.J.) drafted a “compare and contrast” table to identify similarities and differences that had been discussed and that had been argued to be essential for effectively engaging patients and engaging communities. The table was used as the basis for a stepwise discussion aimed at articulating similarities and differences that perhaps were contributing to the conflict. An online, real-time approach using GoToMeeting enabled everyone to wordsmith, revise and adjust perspective, tone and language in the table together. This process served to develop a lexicon (or to identify a need for one) and it forged a way to respectfully engage in a conversation about issues or aspects of engagement that had eluded group consensus. Finally, the discussion of the table elements could deconstruct the tension into specific topic areas where agreements could be reached and where differences could be aired. The group could collectively struggle, both online as a group and in follow-up phone and email conversations, to determine whether differences of opinion, fact, approach or nuances were important and how to preserve and present them.

Following the development and expansion of the table, the group planned to bring the discussion to a broader audience at the North American Primary Care Research Group meeting as a workshop. The GPC lead engagement core team wrote an abstract, sought feedback from the group and invited co-presenters. The abstract was accepted and a subcommittee of the GPC engagement team met by conference call (with follow-up emails) to plan the workshop. To encourage multi-stakeholder discussion, the workshop leveraged the presence of patient participants who were involved in the North American Primary Care Research Group (NAPCRG) Patient and Clinician Engagement (PaCE) project5 and were attending the NAPCRG meeting that year and specifically reached out to invite them to participate. In addition, 2 group communication formats, World Café6 and Future Search7 were blended to introduce a novel method for pairwise and group discussion at the workshop. The pairwise discussion format of Future Search was blended with a World Café table topical approach as follows. Six tables of 8 participants were instructed to sit next to individuals whom they did not know or collaborate with to ensure all sectors were blended (eg, nonclinician researcher, clinician researcher, patient/caregiver, community) at each table. There was highly energized, nonstop conversation over the course of 1 hour, with pairwise 3-minute conversations (first with the person to the right of a designated scribe; then to the left of the scribe) focused on 6 of the initial 10 domains identified during the GPC compare and contrast table activity. Following the paired conversations, the group convened first as a table of 8, then as a whole to discuss their reactions to the exercise and to suggest ways to blend nuances, highlight similarities or better distinguish differences among the domains discussed.

RESULTS

Table 1 presents the summary table derived from the GPC engagement leaders’ discussion (which includes both patient perspectives and academic leader perspectives) and the NAPCRG workshop (which included patients, clinicians, researchers, caregivers, and others). The original table included 10 topics which expanded to 12 after discussions and the workshop. Each of the 12 characteristics of engagement that emerged from GPC conversations and the workshop compare and contrast various dimensions of engagement (Table 1).

Patient and Community Member Perspectives

Patients shared that they are unfamiliar with research and research principles, so it is a novel experience to be involved with a researcher or research team. They are eager to initiate a dialog with those formally trained in research and to offer their related or relevant “lived experience” expertise.8 Patients said that they typically have a personal connection to the condition or disease in question and where they usually are in a receiving role in the health care encounter. This may be different if they are approached to participate in research as a community member because of their residency, their faith community or where they work. As a community member, they
**TABLE 1. Comparing and Contrasting Patient and Community Engagement by Common Characteristics**

| Characteristic | Patient Engagement | Community Engagement |
|----------------|--------------------|----------------------|
| **Source of common Interest** | Often begins with health issue or disease experience | Often begins with health resource deficit or social justice issue that impacts health and/or health care access |
| | Establishing and sharing values | Establishing and sharing values |
| | Altruism and willingness to participate in research on behalf of one’s self or family | Interest may be directed at collective community impact; for the “greater good” even if research topic is not of personal relevance |
| | Personal; sometimes driven by caregiving relationship for another | May or may not have a personal stake, but individuals see the relevance to the collective community |
| | Commitment based on experience of medical care and/or treatment; commitment also may be mediated by relationship to the recruiting physician or clinical team | Commitment based on condition(s), infrastructure, public health concerns, organizational mission; commitment may be mediated by recognizing the community service of the researcher/research team |
| **Durability** | May not be enduring relationship; can/may end with the end of the research project but may persist | Often endures over years of trust-building and ongoing collaboration |
| **History** | Duration may be discontinuous or episodic | Duration tends to be continuous |
| | Not engaged as a participant in the process or formulation of research | Not consulted but rather “studied”; not engaged in the process or formulation of research |

**TABLE 1. Comparing and Contrasting Patient and Community Engagement by Common Characteristics (continued)**

| Characteristic | Patient Engagement | Community Engagement |
|----------------|--------------------|----------------------|
| **Involvement** | May not have substantial involvement or be engaged in the conduct of research beyond self | May have substantial involvement in the conduct of the research (ie, by providing entree and/or sponsorship to the researcher/research team) |
| **Orientation** | Medical/health care services-oriented | Medical/health care services/public health/health system-oriented |
| **Beliefs and values** | Project-specific goals must be consonant for patient participation | Establishment of explicit and shared beliefs is foundational to engagement process and impacts durability |
| **Stigma, misconceptions** | Stigma and misconceptions about a disease or condition may be barriers to engagement | Stigma and misconceptions about the community may be barriers to engagement |
| **Audience; reach** | Target audience may be narrowly defined to a group of patients, caregivers | Target audience may be narrowly or broadly defined to a group not necessarily inclusive of a disease or condition |
| **Role of nonresearch team “connectors”** | Frequently clinicians have a substantial role in patient engagement; they may recruit and/or be collaborators | Highly diverse group of connectors including organizational leaders, boards, faith leaders, community/neighborhood associations, teachers, public health department leaders, etc. |
| **Communication** | Critical to building trusted relationships, especially during the patient’s involvement and follow-up to share findings when study is complete | Critical to building trusted relationships and must be maintained with or without active study involvement |

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May or may not have a personal connection to the research topic, but they may have a community-wide perspective on the health issue or a community problem. For example, they may not use tobacco products, but they are aware of the levels of tobacco use in their community and understand its public health relevance. For most nonacademic participants, the distinction between being a patient and being a member of a community (or more often, a member of various communities) was thought to be arbitrary and relatively unimportant, and they stated that they could navigate and “wear different hats” depending on the situation.

Where patients are recruited to participate in research, the role of the patient may be a health care provider, a family member, or an individual with a shared experience. As such, the role of the patient may be more than that of a passive participant; they may also have a vested interest in the research being conducted. For example, they may be motivated by the potential to improve the health of their loved ones or the community as a whole.

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(Continued)
values, articulate and achieve health needs, and fulfill their responsibilities. However, these do not have to be competing priorities. Helping patients understand the different role a doctor can have as a researcher (vs. as a clinician) can establish a clearer perspective of their respective roles in research. Patients suggested that when recruitment occurs in the context of the delivery of health care services, discussions about respective roles could be enormously helpful.

**Group Perspectives**

Group discussion led to agreement that engagement with communities can be contrasted with patient engagement to reveal meaningful differences, but there was a lack of unanimity about how large those differences actually are. Developed from a long and rich history of action research, ethnography, constructivism and other social sciences, research that takes place in partnered, community settings (eg, with community members and/or organizations) generally represents a collective, shared interest in a topic. The topic may be a disease or health issue; or it may be an infrastructure feature, social determinant or environmental issue that is more loosely tied (or at least may be more indirectly tied) to health. The terms community engagement, community-engaged research, community-based research, community-informed research and community-based participatory research contribute to various interpretations and reflect different academic traditions that confound this discussion. A fundamental feature that distinguishes community engagement is that it depends on the interactions between academic (medical) centers/health services researchers and groups of people. Sometimes these groups are defined by and share a common geography, a common concern or a common health issue that bind them together as a collective. Individually, they may or may not be patients but collectively they may be organized as a nonprofit, community, advocacy or action organization with or without formal structure. When researchers work with the community, they connect with individuals—leaders and average citizens alike—who generally represent a collective voice and interest. In contrast, patient engagement may be very individualized and personal, as the engagement occurs because the person with a lived experience with a medical condition or disease; or is a caregiver for someone or a spokesperson for individuals with the condition or disease. But a community of patients is not the usual unit of engagement of interest for community engagement researchers. Rather, these researchers work with diverse communities who may loosely share common features and experiences. These individuals may be neighbors who similarly are affected by a condition (eg, living in a food desert), and they tend to seek, develop and have durable, long(er) lasting network ties.

**Group Perspectives**

Durability of relationship is highlighted as a difference between patient engagement and community engagement. While some patients may have ongoing or recurring relationships with investigators and research teams, most do not. This may be due to changes in their health or a single, episodic involvement in a research project.

In both the case of patient engagement and community engagement, funding instability and discontinuity sometime interrupts engagement, but its impact is felt most acutely in community engaged setting. Disturbances can tax the relationship building and relationship maintenance essential for engagement and may be detrimental to maintaining contact and trust.

**CONCLUSIONS**

There is precedence for seeing engagement along a continuum that includes time-bounded and time-dependent activities like building trust and personal relationships. Whether this continuum holds for both patient and community engagement is less clear. Effective approaches to patient engagement have not been well defined as compared to community engagement in a health care research setting. This may be due to greater clarity and acknowledgment that social assets are crucial to facilitate collaboration in community settings. The recognition that social capital and networking are reinforcing and yield cumulative benefit for conducting research distinguishes community research endeavors. In health care settings with patients, researchers have been slower to adopt and adapt engagement approaches largely because they have not had a need to do so and still be successful accruing patients to clinical trial/study participation. Clinically based research leverages engagement as a feature of the delivery of health care, and therefore, needs to depend less on initiating novel relationships outside of the clinic setting. The expectations of funders to encourage the inclusion of patient perspectives, joint decision making and collaboration throughout the research process will spur innovation in incorporating community engagement strategies into the clinic and other health care delivery settings.

This project has a number of limitations that influence the generalizability of findings. The participants represent an opportunistic sample that may be weighted toward individuals who had a pre-existing interest in the engagement experience. Both among the Greater Plains Collaborative PCORnet project participants and those attending the NAPCRG workshop, patient and community members may have a level of understanding not generally shared by the general population. Likewise, the academic partner and researcher participants are a group of stakeholders who have thought about and experienced the challenges of engaged research perhaps to a greater degree than others. Albeit with limitations, the collective efforts of 78 participants culminated in a set of recommendations to advance the field of engagement and to inform CER and PCOR. As a result of a collective agreement on the 12 dimensions of engagement (Table 1), the groups provide the following recommendations to encourage meaningful engagement.

1. The field of team science is expanding with new models, measures and methods that require operationalizing cross-disciplinary and cross-sector partnerships. Team science holds the potential to accelerate research by combining specialized expertise, approaches, and research methods across disciplinary boundaries. However, when disciplinary approaches and values differ and when language is used differently by scholars, stakeholders, patients and communities, clashes reveal stubbornness and dogmatism that interfere with the engagement process. Clarity of purpose and effective communication coupled with shared common language must be priorities.

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*Kimminau et al. Medical Care • Volume 56, Number 10 Suppl 1, October 2018*

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(2) The GPC participants and the NAPCRG workshop participants suggest continued expansion of engagement rubrics to account for novel approaches and the codification of a lexicon for training and team science collaboration. For example, the terms we use for participants who come from other fields than research—terms like research collaborator, citizen leader, research participant, study participant, patient representative, community stakeholder, and patient advocate—need further definition to achieve shared understanding. These terms will proliferate in the literature and if left undefined, will lead to further misunderstandings among participants.

(3) Greater attention is needed regarding the complexity of trust. Although there was unanimous agreement that trust is essential to engagement, there is a lack of a fully articulated and widely accepted approach for how to develop, gain and maintain trust in different research relationships. This is an area ripe for methodological innovation and one that would profit from multistakeholder collaboration.

We all benefit from recognizing the overlap, complementarity and uniqueness of establishing relationships with patients and with communities to accomplish patient-centered outcomes research. The wisdom of many of the patients who informed this work is that engagement is difficult, it is personal and it can be enormously enriching. Their advice is to pause to learn from others, listen actively, and to leave disciplinary silos and academic arrogance behind. Instead, we should seek to find common ground and collaborate as a team to accomplish patient-centered research that improves health and health care for individuals and communities.

ACKNOWLEDGMENT

The authors gratefully acknowledge the North American Primary Care Research Group (NAPCRG) Participatory Research Special Interest Group, members of the Greater Plains Collaborative Community Engagement Core and the 50 NAPCRG workshop (October 25, 2015) participants who added rich content and context for this brief report.

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