Authentic Engagement Of Patients And Communities Can Transform Research, Practice, And Policy

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Abstract

The engagement of patients and the public is increasingly important in the design and conduct of research. Some researchers still cling to the outdated notion that laypeople cannot contribute meaningfully to science; for some, "community engagement" is another term for recruiting patients for trials. Authentic engagement encompasses far more, involving stakeholders as full partners in all phases of research, as research funders increasingly require. Such engagement, although challenging, can enhance the quality and impact of studies on many levels, from ensuring that data are relevant to users' needs to elevating the moral plane of research by showing respect to patients and vulnerable populations. We share examples from our work, including the engagement of patients in a study of cancer screening decisions and the engagement of inner-city residents in addressing social determinants of health. These engagement principles are of growing relevance to health systems and policy makers responsible for population health.

Engaging stakeholders—from patients to local residents and communities—is increasingly important in today's world.[1] The core concept is hardly new.[2] Politicians have always courted constituents and engaged the public to build their political base. Activists have always cultivated grassroots support and recognized that buy-in from community leaders was essential for progress. Similar principles are well established in public health, where field work has always occurred in the community and provided opportunities to give voice to marginalized populations.[3]

But a transformation around engagement is now occurring in medicine. It builds on a longstanding movement to promote patient-centered care, which seeks to empower patients as consumers; equip them to make more informed choices; and, if desired, exercise control

over their options.[4,5] In this issue of *Health Affairs*, Steven Findlay discusses one example of this movement: supplying patients with performance data to evaluate the quality of providers or treatment options.[6] Findlay reports that patients face challenges in making use of these data, but the successes and setbacks of this enterprise are features of a dynamic trend, bridging policy and technology to arm patients with better information tools.

The engagement movement is also taking hold in research. Increasingly, funders expect investigators to engage patients and the community; there is less lenience for "checking the box" on engagement by including a focus group or appointing a patient to an advisory committee but having no plan to take their input seriously. Some of the credit for this shift in expectations goes to the Patient-Centered Outcomes Research Institute (PCORI), a health research funder formed under the Affordable Care Act.[7,8] PCORI has cultivated a research culture that links funding to *authentic stakeholder engagement*, a term we use in this article to characterize the involvement of all relevant stakeholders in all phases of research. Authentic engagement includes stakeholders as full partners in setting research priorities; forming research questions; and shaping the design, funding, conduct, and dissemination of studies. It forms relationships built on trust and respect for partners, regardless of their training or experience in science or research.

In effect, PCORI and similar groups are bringing the long-standing principles of community-based participatory research[3] to health care. This strand of research, with its long tradition in public health and the social sciences, places communities squarely in the center of research design and conduct. When it is applied to health care, the goal is to give patients and other stakeholders a similar determinative role, but old habits die hard. The democratic community-based participatory style of research is alien to many academic medical centers and research laboratories, where concerns persist that laypeople cannot contribute meaningfully to science. Traditional researchers, and many mainstream funders, still cling to outdated notions of "community engagement" as another name for recruiting patients for trials.

Researchers with experience in authentic engagement understand that there are many challenges, such as greater time demands and sharing power with nontraditional partners, but engagement carries many benefits. First, it helps direct research toward questions that matter most to stakeholders. It creates a user-oriented research agenda that expands beyond scientists' intellectual interests to address the data needs of key change agents, be they clinicians, policy makers, patients, or parents. Second, because patients and other stakeholders know their lived world and language better than most investigators, engagement enhances study design by selecting outcomes that matter to end users and by choosing methodologies that optimize data collection and validity. Third, authentic engagement elicits buy-in, getting participants excited about implementation and dissemination. Fourth and foremost, it elevates the moral plane of research by showing respect to patients and vulnerable populations. Treating these stakeholders as coequal partners minimizes the potential for the research process to alienate patients and communities, which can fuel mistrust. We offer below two examples from our recent work.

Engagement Of Patients In Practice-Based Research

We conducted a two-year study, funded by PCORI, to explore how patients approach decisions about cancer screening. The intervention took advantage of a portal used by 72,000 patients to identify people facing decisions about breast, colorectal, and prostate cancer screening. An online module asked them seventeen questions about their stage of readiness for screening, primary concerns, and preferred approach to making the decision. Respondents were given the option to forward their preferences to their clinician's electronic medical record. Subsequently, postencounter surveys were administered to patients and their clinicians after their next office visit to evaluate (along with audiorecordings of selected visits) how well patients' concerns were addressed in the encounter.

The module did not go live until the second year of the study. The entire first year was devoted to engaging patients and other stakeholders in the formative work, helping design the study and construct the questions that would appear on the portal when it went live. Patient engagement included ten focus groups eliciting general themes of concern about cancer screening, online discussions and two in-person meetings involving a working group of forty-six patients evaluating drafts, cognitive testing of wording involving thirteen patients, usability testing of prototypes involving seven patients, and a fourteen-member patient advisory board that met monthly for oversight throughout the project. Clinician engagement included a fourteen-member working group that also met monthly throughout the study to plan the intervention and its implementation. Our investigation illustrates the different types of engagement that can aid a study. There is a place for human subjects research that enrolls patients or the public for lay input on specific issues, as this study did through focus groups, cognitive testing, and usability testing. But projects can also benefit from long-term collaboration with stakeholders who serve as research partners, as this study did through online discussion and advisory boards.

A question that hangs over PCORI-style engagement is whether this effort substantively changes the course of research. We found that it did. During the design phase (year 1) we received 772 comments on the questions to be fielded in the decision module; the questions underwent 23 revisions. As detailed in the online Appendix,[9] patients provided 46.1 percent of the comments—more than the core research team (35.5 percent). Through this process, patients challenged overall project objectives, identified problematic wording, and added important topics. By helping reword questions, they contributed to improved readability for a lay audience, simplified the module by removing thirteen questions and four transition statements, increased sensitivity to issues that concern patients, and provided creative suggestions for administering questions in an interactive online format. Clinicians' input resulted in the development of customized work flows for implementation in busy primary care practices. Our experience was that the study owed much of its success to the guidance received from stakeholders, which is detailed in the Appendix.[9]

Engagement Of The Community In Health Equity Research

In 2011 our community engagement program at the Center on Society and Health initiated Engaging Richmond, a community-academic partnership with residents of an economically

disadvantaged neighborhood in Richmond, Virginia.[10] The partnership engages the community in research to explore the social and environmental factors that influence health in local communities, sets priorities, and develops targeted action strategies to bring evidence to policy makers and change agents.

To establish the groundwork for authentic engagement, we invested time in building relationships and trust with existing community-based coalitions and organizations. Residents joined the partnership as co-investigators and collaborated on community needs assessments that focused on health inequities and the social and economic conditions that affect their health and well-being. They were engaged as full partners in all aspects of the research, from developing research questions to collecting and analyzing data and developing action plans. Residents developed a sense of ownership over the research and a commitment for moving from research to action, and they ultimately developed a vetting procedure for funding opportunities. The partnership emphasized power sharing, and community members took on leadership roles.

Since 2011 our research program has been guided by the priorities outlined by the community in its needs assessment. Together with residents, we have studied the consequences of firearms violence, parental engagement in programs for youth, early childhood education, public housing redevelopment, and childhood asthma. Team members have undergone qualitative research training and have employed focus groups, in-depth interviews, and participatory photography (also known as photovoice, in which residents used visual images and critical dialogue to describe community needs and strengths).[11]

Residents have helped with concept mapping and pathway modeling to incorporate their perspectives into complex causal models. In several projects, team members and other community stakeholders collaborated to build pathway models—drawing on their lived experience to design diagrams that elucidate potential causal factors contributing to health outcomes. Their early work featured a pathway model linking food assistance to health outcomes in a health impact assessment for the US Congress,[12] and another focused on the health implications of education.[13] With funding from PCORI's methodology program, we are now testing the stakeholder engagement in question development (SEED) method,[14] in which patients and stakeholders in urban and rural settings are designing pathway models for health outcomes and prioritizing questions for future research, which will be disseminated in 2016 to research funders and other target audiences.

Does Engagement Matter?

Although authentic engagement can be challenging and requires ongoing effort, it can vitalize research. As the SEED project illustrates, engagement can change the very questions researchers take up and can reorient the research agenda to reflect user needs. Engaged stakeholders can contribute to deeper understanding of the data. For example, members of a minority community can share valuable insights into culturally specific language and subtext. In one of our studies, our findings were informed by residents of an inner-city neighborhood, who collaboratively coded focus-group data and identified themes that the academic partners may have overlooked (see the Appendix).[9]

Stakeholder engagement can help move evidence into action. For example, Engaging Richmond has partnered with local coalitions, funders, policy makers, and other academic researchers who are invested in addressing community priorities. Residents meet with local stakeholders, explaining their priorities and demonstrating the value of research by providing evidence to drive and inform action. Common themes in these partnerships are their focus on dissemination and implementation of solutions, the development of novel interventions, and the use of a community lens to explore complexity in hard-to-reach populations.

The impact in the community has been tangible. In the priority area of behavioral health, Engaging Richmond has developed and disseminated a resource guide on mental health programs and services, provided mental health first aid training to more than 200 community residents and service providers, hosted more than 150 residents at a community event on mental health and stigma, and helped train more than 100 residents and service providers on promoting resilience to psychological and emotional trauma. Engaged residents of Richmond are now working with policy makers, such as staff in the mayor's office, leading to concrete action to address community priorities. For example, building upon our public housing research, local officials are pursuing a pilot program to provide wraparound services for residents who are being relocated by redevelopment work. Additionally, the housing developer has submitted an application to provide permanent supportive housing for residents with disabilities, serious mental illnesses, or substance abuse disorders—a decision that the developer attributes to the research evidence presented in collaboration with residents and local service providers.

The energy surrounding these engagement experiences has attracted the interest of faculty at our institution, Virginia Commonwealth University, and colleagues elsewhere. Clinical investigators on campus and at other institutions are interested in our practice-based research network and our methods for engaging patients. Local researchers have approached Engaging Richmond for help on tailoring and testing community-based interventions, identifying barriers and facilitators to service use, and disseminating research findings to target audiences. As part of a study on the impact of firearm violence,[15] the Urban Institute funded Engaging Richmond to conduct qualitative research and a photovoice project with victims and perpetrators.[16] Our center is now working with colleagues in San Diego, California, to engage community stakeholders on the use of big data to address behavioral health priorities.[17]

The change in thinking about patient and stakeholder engagement has implications across sectors. Researchers must think less about how to engage patients or residents in their research but instead how to make their research more relevant to practices and the community.[18] They must listen to their stakeholders—whether they are patients, clinicians, experts, or the community at large—and they must return to their stakeholders to present the results of their research (see Appendix).[9] With these changes, patients and residents can begin to see how they benefit from research; authentic engagement promotes agency and empowerment, which is an especially important benefit for historically disenfranchised populations.

Conclusion

Finally, progress in engaging stakeholders has implications for policy makers, especially for health systems and public health agencies that are increasingly accountable for population health outcomes.[19] Now more than ever, meaningful change in the determinants of health requires the engagement of stakeholders across sectors who share aligned incentives to achieve common goals—a strategy known as collective impact.[20] Working together, these stakeholders can hope to achieve greater impact than they could achieve on their own.[21] The long-term relationships and collaboration on which such engagement depends—whether for research, practice, or social action—requires infrastructure and an investment of resources to maintain those relationships. In the end, all parties can benefit by joining hands, and the door to these possibilities opens with authentic engagement.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

NOTES

1. Woolf SH, Purnell JQ, Simon SM, Zimmerman EB, Camberos GJ, Haley A, et al. Translating evidence into population health improvement: strategies and barriers. Annu Rev Public Health. 2015; 36:463–82. [PubMed: 25581146]

2. World Health Organization. The Ottawa Charter for Health Promotion [Internet]. Geneva: WHO; 1986 Nov 21. [cited 2016 Feb 29]. Available from: http://www.who.int/healthpromotion/conferences/previous/ottawa/en/

3. Minkler, M.; Wallerstein, N., editors. Community-based participatory research for health: from process to outcomes. 2. San Francisco (CA): Jossey-Bass; 2008 Oct.

4. Stewart, M.; Brown, JB.; Weston, WW.; McWhinney, IR.; McWilliam, CL.; Freeman, TR. Patient-centered medicine: transforming the clinical method. Thousand Oaks (CA): Sage Publications; 1986.

5. Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington (DC): National Academies Press; 2001.

6. Findlay SD. Consumer interest in provider ratings grows, and improved report cards and other steps could accelerate their use. Health Aff (Millwood). 2016; 35(4):xx–xx.

7. Frank L, Basch E, Selby JV. The PCORI perspective on patient-centered outcomes research. JAMA. 2014; 312(15):1513–4. [PubMed: 25167382]

8. Selby JV, Forsythe L, Sox HC. Stakeholder-driven comparative effectiveness research: an update from PCORI. JAMA. 2015; 314(21):2235–6. [PubMed: 26595059]

9.
To access the Appendix, click on the Appendix link in the box to the right of the article online.

10. Center on Society and Health. Engaging Richmond [Internet]. Richmond (VA): Virginia Commonwealth University; 2014 Nov 4. [cited 2016 Feb 29]. Available from: http://societyhealth.vcu.edu/work/the-projects/engaging-richmond.html

11. Wang C, Burris MA. Photovoice: concept, methodology, and use for participatory needs assessment. Health Educ Behav. 1997; 24(3):369–87. [PubMed: 9158980]

12. Woolf, SH.; Braveman, P.; Evans, BF. The health implications of reduced food stamp eligibility. Richmond (VA): Virginia Commonwealth University, Center on Human Needs; 2013 May.

13. Zimmerman, EB.; Woolf, SH.; Haley, A. Understanding the relationship between education and health: a review of the evidence and an examination of community perspectives. In: Kaplan, RM.; Spittel, ML.; David, DH., editors. Population health: behavioral and social science insights. Rockville (MD): Agency for Health-care Research and Quality; 2015 Jul. p. 347-84.Publication No. 15-0002

14. Center on Society and Health. The SEED method for stakeholder engagement [Internet]. Richmond (VA): Virginia Commonwealth University; 2014 Nov 1. [cited 2016 Feb 29]. Available from: http://societyhealth.vcu.edu/work/the-projects/the-seed-method-for-stakeholder-engagement.html

15. Bieler, S. Raising the voices of gun violence [Internet]. Washington (DC): Urban Institute; 2014. [cited 2016 Mar 7]. Available from: http://datatools.urban.org/Features/raising-the-voices-of-gun-violence/

16. Center on Society and Health. Photovoice: the cost of firearms violence [Internet]. Richmond (VA): Virginia Commonwealth University; [cited 2016 Feb 29]. Available from: http://www.societyhealth.vcu.edu/media/society-health/pdf/CSH-Firearms-Photovoice-OnePager.pdf

17. Center on Society and Health. San Diego big data demonstration project [Internet]. Richmond (VA): Virginia Commonwealth University; [cited 2016 Feb 29]. Available from: http://societyhealth.vcu.edu/work/the-projects/san-diego-big-data-demonstration-project.html

18. Build Healthy Places Network. Making the case for linking community development and health [Internet]. San Francisco (CA): BHP Network; 2015. [cited 2016 Feb 29]. Available from: http://www.buildhealthyplaces.org/resources/making-the-case-for-linking-community-development-and-health/

19. Eggleston EM, Finkelstein JA. Finding the role of health care in population health. JAMA. 2014; 311(8):797–8. [PubMed: 24457610]

20. Pastor M, Morello-Frosch R. Integrating public health and community development to tackle neighborhood distress and promote well-being. Health Aff (Millwood). 2014; 33(11):1890–6. [PubMed: 25367982]

21. Kania J, Kramer M. Collective impact. Stanford Social Innovation Rev. 2011; 9(1):36–41.