EDITORIAL AND COMMENT

Farming, Ranching, Research: Patient Engagement on the High Plains

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Twelve years ago my husband and I were happily content with the challenges and rewards of tending our fourth-generation dryland wheat farm. I was also teaching English reading at the local community college. Then we were asked to be part of a rural healthcare research team—to participate not as study subjects but as community-based researchers. At that time, the concept of engaging patients in the research continuum and as co-researchers was considered experimental and, by some hardcore scientists, a bit quaint. Twelve years ago, I knew little about patient engagement and nothing about medical research. If asked, I would have said I was an engaged patient, informed about my own health. I stayed abreast of research as it was presented in the popular media. I maintained an active relationship with my primary care provider, and I felt empowered to ask hard questions, advocate for myself or my family, and demand some control over my health care decisions and actions. But, bottom line, I was and am a patient; I am not a researcher. Yet, here I am, commenting on today's research on patient engagement.

Engaging patients as co-researchers—co-creators, co-investigators, partner advisors—is crucial to the successful translation of medical discoveries into everyday clinical practice.¹ When I first had an opportunity to ask questions that matter to my community, to ensure that the participatory research process met the needs and personality of my small town, to improve the health of my community, I was a bit skeptical...and intrigued. I joined the Community Advisory Council of the High Plains Research Network (HPRN C.A.C.), created to complement the practice-engaged research of our university-based research network. The HPRN was collaborating with doctors' offices and clinicians in rural and frontier Colorado, but something was missing. Research was happening, but the questions were not relevant to primary care practice or their patients, and the answers were not aligned with the way we in the community lived our daily lives. The

missing piece was the patient voice and the real-life context that it brought to the research. Without this context, the research lacked local relevance and was, consequently, low impact. This is where I entered the world of patient-engaged research. For the past 12 years, I, along with a group of about 18 other community members, have straddled the fence between the university research world and our everyday lives in rural eastern Colorado.

The High Plains Research Network is not alone. Patient, stakeholder, community member, and practice engagement has taken off and is now the norm in many academic settings. The National Institutes of Health's Clinical Translational Science Awards encourage and support patient-engaged participatory research. The Patient-Centered Outcomes Research Institute (PCORI) requires active patient and stakeholder engagement in the research it funds. Patient engagement is a broad continuum of activities and participation, from fully engaged community-based participatory research (CBPR) to the less engaged individual patient representative sitting at an annual board meeting. While there is a robust body of literature on CBPR,^{2,3} less has been studied and disseminated on the rest of patient engagement. The two terms are not interchangeable. CBPR is one type of patient engagement. Patient and stakeholder engagement in patient-centered outcomes research (PCOR) falls along a broad continuum of engagement and participation.⁴ Common key elements are found across the continuum; however, the rest of patient engagement includes a wider variety of methods, locations, and research topics.

The work of Forsythe and colleagues signals an important milestone in the progress toward more genuine patient-engaged research. They studied the first group of PCORI pilot awardees, measuring patient engagement efforts actually occurring in the projects.⁵ They gathered data on the level of engagement, length and nature of engagement, facilitators and barriers to engagement, and how engagement impacted the research. This report provides an early understanding of the range of patient engagement strategies, activities, and lessons in PCOR. Their report is a starting point for patient engagement in the PCORI research portfolio and confirms key tenets that the HPRN C.A.C have found critical for success.

Several key components of patient engagement are described. First, patients and other stakeholders can and should be engaged early and often. Successful engagement is not a

one-time focus group or community meeting. Successful engagement leads to a meaningful long-term collaborative relationship. The HPRN C.A.C. and its research partners spend a significant amount of time together choosing research topics, learning about medical conditions and treatments, developing and conducting research projects, and presenting our findings. This long-term, enduring relationship requires continuous care and feeding. The bi-directional relationship is not just about getting acquainted. It is about trust and mutual respect. The research team trusts the community members' expertise and experiences. The community/patient partners trust the research team's skills, the application of their input, and that engagement will continue with integrity.

Second, successful patient engagement requires skilled facilitators and resources. Patients may not naturally know their role and the usefulness of their contributions. Attention to both a short-term agenda and long-term strategy is needed. The research team's role is to keep track of the work, discussions, outcomes, and finances. After all, patients and stakeholders have regular jobs and lives.

Third, the importance of communication should not be underestimated. Communication will take place in multiple ways. Members of the HPRN C.A.C. come from all walks of life. Some are comfortable with email while others respond to phone calls. Some demand texting or tweeting. Communication takes place in multiple modes, and our facilitators must be skilled in adapting to these needs: patient and community needs.

Fourth, time is a constant point of tension in the HPRN C.A.C., and is described by Forsythe et al. When the community gets excited about a research project, it is hard to abide by restrictions of the research timeline. On the other hand, patients don't live and work within the research world, and sometimes the patient response is slow. Patients must be informed of looming deadlines, not just arbitrary timelines. Patient engagement requires additional time for the research team in terms of travel out to the community, additional communication, and the back and forth required for engaged research conversation.

Finally, the ability to share power and leadership is crucial. Tokenism, described as the occasional request for advice, solicitation of help with subject recruitment on an IRB-approved study protocol, or review by one patient representative, will not make our research patient-centered. When patient partners are engaged as co-researchers, they have a say in the research question, the processes, and the interventions, not to mention the outcomes. For example, the HPRN C.A.C. dramatically changed the trajectory of a recent project on mental health. Despite interest from a research partner in focusing on the impact of depression on older rural males, the C.A.C. demanded an approach that could impact the mental health of the whole community. The C.A.C. chose to explore how the

community could impact any individual's mental health status and facilitate healing and access to services and support. Imagine these blurry power lines. When power sharing is genuine, locally relevant actionable messages become the driver.

Does patient engagement really matter? The three of us have done research together for the past 12 years: patient and community member, primary care provider, and researcher. Patients and community stakeholders have changed the approach of the High Plains Research Network and our academic partners. Patients choose the topics that matter to them. We learn about the topic; we share our expertise. The research blends scientific rigor and local relevance. The result? More people in eastern Colorado have been tested to prevent colon cancer, more use inhaled controller medications for asthma, and behavioral health is not just a 60-minute visit at the psychologist's office. Patients and researchers are co-investigators on grants and research awards, present together at local and national meetings, and co-author newspaper articles and peer-reviewed manuscripts—and sometimes write editorials, because patient engagement has made a difference in our communities.

Community and patient engagement is a long-term commitment: we encourage you to give it a try. Start by finding some people, meet with them regularly, listen to them, hang out at their place, and invite them to hang out at your academic office. Listen again. Change your work and ideas based on their input. Join the best science you know with the best community knowledge they have in order to produce something better than you could do without them.

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