

Learning From Others

Lessons for Improving Collaborations Between Stakeholders and Researchers

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Among other events (eg, 2013 Institute of Medicine Report),¹ the creation of the Patient-Centered Outcomes Research Institute (PCORI) has led to increased levels of engagement among researchers, patients, caregivers, and clinicians. While a number of scientists were regularly engaging patients and clinicians in their work before PCORI's emergence, the PCORI framework of stakeholder engaged research accelerated the rate of researchers collaborating with patients, caregivers, and clinicians to develop their research questions and study protocols, and to execute studies. The impact has been so significant that researchers are engaging stakeholders even for work that is not funded by PCORI, demonstrating the benefit researchers have derived from broadening the research team.

However, bringing together these stakeholder groups requires careful thought and attention to ensure that all voices are heard and that all participants feel valued and respected. Not all research teams with a diverse set of experts have succeeded in this endeavor. As Boyer and colleagues² note, there has been little described about how to best incorporate multiple stakeholders into successful research programs.³ PCORI has established impactful training programs for patient and caregiver scientists and has a number of mechanisms to aid in the training of researchers in how to engage patients, caregivers, clinicians, and even national stakeholders into their programs of research. Offerings from PCORI include, among others, blogs, webinars, in person training at PCORI annual meetings, an engagement rubric, and methodology standards (<https://primeinc.org/pcori/rubric>). However, we do not know the reach of these offerings nor how they impact researchers' practices in engaging patients, caregivers, and clinicians.

Researchers interested in developing their skills in forming strong teams, including both stakeholders and researchers, can benefit from observing and learning from researchers who have gone before them in these collaborations. In this issue of *Medical Care*, we learn valuable lessons from investigators who have developed successful collaborations with patient, caregiver, and clinical stakeholders, and from those who have been confronted with challenges.

Nowell and colleagues⁴ highlight the importance of engaging with patients in the inquiry of how patients perceived their involvement with ArthritisPower. The study team first attempted to conduct their own evaluation, which was, by their own account, only moderately successful. In contrast, months later their patient leader successfully conducted an evaluation of other patients' feelings and perceptions of their involvement with ArthritisPower. The authors believed that the patient-led engagement survey was more fruitful, which could be due to the use of open-ended questions and patients feeling more comfortable opening up to another patient rather than one of the study investigators. Relatedly, the investigators also stressed the importance of regular evaluations to ensure that the principles of reciprocal relationship, colearning, honesty, and trust are maintained.

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The author declares no conflict of interest.

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ISSN: 0025-7079/18/5610-00S9

Regular evaluation of stakeholder-researcher engagement is also vital to address problems quickly to improve both the science and the stakeholder experience.

Nowell and colleagues reported several other important lessons. First, patients preferred to receive study updates by emails rather than participate in conference calls that were primarily summaries of the work that had been accomplished. Instead, they wanted the calls to be devoted to decision-making and working through key issues that needed addressing by the research team. Often times researchers use these meetings for updates to keep patients in the loop. However, at least in this experience, patients wanted the updates in written format so that their time could be spent contributing to the project. In addition, the patient team yearned for connection with each other outside team meetings. Thus, the principal investigators of the project developed a private Facebook page for the patient team members to communicate with each other about both the governance work they were collaborating on, and to talk with each other about their experiences living with arthritis. This innovative and kind change likely improved the patients' involvement in the project and provided the researchers an opportunity to reciprocate to the patient collaborators.

Another important lesson imparted by Nowell and colleagues was the acknowledgment that as patient collaborators became more enmeshed in the team and developed research expertise, their representation as a typical patient decreased. Thus, they described their process of maintaining patient study teams that were diverse in terms of their research experience, as well as their diversity in other domains (eg, diagnosis, race and ethnicity, sociodemographic characteristics). Furthermore, they established a second, larger group with whom they would interact with less frequently but who were available for consultation as needed. Relatedly, Kimminau et al⁵ highlight the differences between community engagement and patient engagement, particularly in terms of community members often feeling comfortable representing a collective experience, whereas patient experiences are intensely personal and thus not perceived by patients as generalizable. Both of these papers address the important point that it is critical to have a diverse research team. Specifically, the patient collaborators should reflect a combination of "expert patients" who have gained substantial experience in working with research teams, have wide networks they can learn from, and who have unique perspectives from working with researchers for significant periods of time, as well as patients who are new to research and bring a fresh perspective. Too often researchers are collaborating predominantly with white, wealthy, highly educated patients, and this work could be vastly improved upon by including a more diverse group of patient and caregiver collaborators.

Kimminau and colleagues⁵ raised the important issue of inclusion of patient stakeholders when the study is conducted

across multiple sites. In their experience, academic researchers across sites differed in their willingness and protocols for engaging patients. This is a significant challenge that needs addressing, as many of these types of studies require multiple sites. Moreover, an advantage of having multiple sites is that you can get more diverse patient representation which ultimately improves the quality of the science. Developing protocols for sites to agree upon before grant submission may help alleviate this problem.

Finally, Boyer and colleagues² described their use of multiple methods to engage stakeholders including surveys, community studios, and the incorporation of patient stakeholders on an oversight committee and an advisory council. It is crucial that we differentiate how to involve patients as study participants (eg, large surveys) versus those who are part of the study team. All participation is valuable and can illuminate key issues.

This issue of *Medical Care* is especially beneficial in that it provides key lessons regarding what methods succeed, and which fail, at engaging patients and caregivers as collaborators (or as citizen scientists). We still have much to learn and teach one another on how best to respect and learn from stakeholders and how to improve collaboration and adherence to engagement principles. PCORI has much to offer scientists in this way and it is critical that they continue to reach out to scientists, particularly early career scientists, to help them learn these skills. PCORI could disseminate the training they currently conduct at their annual meeting to other appropriate conferences. It would be helpful to understand how their training improves researchers' ability to assemble successful teams of patient, caregiver, and clinical stakeholders and researchers. PCORI has significantly changed the way we conduct science and thereby has improved the quality of our science. They can continue to advance this work by helping researchers better utilize the expertise of patients, caregivers, and clinicians.

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