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Cover Page Footnote

The authors would like to thank the stakeholder partners that contributed their time and experiences to this paper. All statements in this paper, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

So much more than a “pair of brown shoes”: Triumphs of patient and other stakeholder engagement in patient-centered outcomes research

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Abstract

This piece illustrates the “real world” experiences of patients and other stakeholder partners in research to help inform and inspire future patient-centered outcomes research (PCOR) efforts. The Patient-Centered Outcomes Research Institute (PCORI) was created in 2010 to fund research that helps patients, clinicians, and other healthcare stakeholders make informed health decisions. The first 50 funded PCORI Pilot Projects engaged patients, caregivers, parents, patient advocates, clinicians, and other non-traditional research stakeholders to serve in advisory and leadership positions on their research teams, many for the first time. In interviews with seven patients and other stakeholders, several lessons learned emerged, including how to build confidence over the course of a research project; how to offer translation and interpretation insights reflective of practical experience; how to understand the benefits and limitations to stakeholder participation; and how to positively influence the research process and study outcomes. By the completion of their Pilot Projects, the stakeholder partners profiled here considered themselves “empowered” research contributors. The authors are hopeful these stories will encourage more patients and other stakeholders to contribute their time and experiential learnings to improve the process, and results of, PCOR.

Keywords

Patient engagement, stakeholder engagement, patient-centered outcome research

The names in this piece have been changed to protect the identity of those quoted.

“Did you ever get the feeling that the world was a tuxedo and you were a pair of brown shoes?”, Patrick asked as he scanned the room. As a first time patient co-investigator on a two-year research study Patrick wanted to break the ice. He needed to acknowledge what it felt like to be the only one in a crowded setting without an advanced degree. From that moment forward, he felt more comfortable. He had set the stage. Now his new fellow research team members better understood what it was like to be in his shoes.

Patrick was one of more than a dozen patient co-investigators who helped lead the first funded research projects of the Patient-Centered Outcomes Research Institute (PCORI). Established by the Patient Protection and Affordable Care Act in 2010, PCORI funds research that helps patients, clinicians, and other healthcare stakeholders make informed health decisions.¹ In 2012, PCORI funded 50 Pilot Projects to support the collection of preliminary data on evidence-based methods and strategies to advance the field of patient-centered outcomes research (PCOR). At its core, PCOR seeks to answer the questions that matter most to patients and their caregivers.

Building upon decades of work in community-based participatory research (CBPR) including patient perspectives by design², and growing in part due to the creation of PCORI, a more vivid picture is emerging of stakeholder involvement in the research process. “Nothing about us; without us,” a phrase first championed by the disabilities movement³, has brought scores of individuals into the research enterprise to help ensure that the research questions being addressed directly reflect the needs of patients. It has been suggested that the improved relevancy of research can increase the use of evidence by decision-makers, thereby improving the chances that patients, caregivers, and other stakeholders benefit from improved health outcomes.⁴

Many Pilot Projects engaged patients, caregivers, parents, patient advocates, clinicians, and other non-traditional research stakeholders to serve in advisory and leadership positions on their teams. As a first time opportunity for many of these patients and other stakeholders (hereafter referred to as stakeholder partners), a subset of the engaged stakeholders embarked on an effort to capture the authentic experiences of other stakeholder partners for the benefit of future PCOR research efforts. Two of the stakeholder co-investigators opened a general call

among the identified stakeholder partners in the PCORI Pilot Projects Learning Network (PPPLN). PCORI established the PPPLN, managed by AcademyHealth, to facilitate knowledge synthesis and sharing across projects and disciplines, to foster new collaborations among researchers, and to accelerate methods for PCOR. This learning network served as a mechanism to connect and encourage shared learning among the disparate projects, and create greater awareness among stakeholder partners. All those who responded were interviewed. Acknowledging some self-selection bias in those stakeholder partners who volunteered their time, it should be stated upfront that the experiences shared do not necessarily reflect those of engaged stakeholders in other Pilot Projects.

These stakeholder partners had a unique opportunity for firsthand exposure to, and engagement in, the research process. As part of the PCORI funding, investigators were encouraged to include an Engagement Plan that outlined meaningful engagement of stakeholder partners in their research study. Since authentic engagement can take many shapes and forms, PCORI was not prescriptive in their review criteria, opening the door for truly creative and enlightened thinking about stakeholder partner inclusion. The burgeoning evidence base around active stakeholder engagement in research is beginning to document many tangible benefits, including enhanced research quality, improved recruitment and retention rates, and changes in the translation and dissemination of research findings to new communities.⁵

The seven stakeholder partners described here served in distinct capacities on their individual Pilot Projects. Four of seven partners served as stakeholder co-investigators, engaging in highly influential roles to help recruit human subjects, review and revise survey design, contribute to data analyses, and support translation and dissemination efforts. The other three stakeholder partners participated on stakeholder/patient advisory committees that functioned as standing authorities on patient and stakeholder engagement issues. While each experience was unique, these seven stakeholder partners collectively demonstrate that by contributing their time and sometimes deeply personal experiential learning—in truly embracing the research process—they made an impact, not only on the research proceedings and outcomes, but also on their own commitment to future research involvement.

Many different dimensions surfaced in the interviews, including first time learning about the research process: how to build confidence over the course of the project; how to offer translation and interpretation insights reflective of practical experience; how to understand

the benefits and limitations to stakeholder-specific participation; and how to positively impact the research process and outcomes. This piece serves to document the variety of ways these stakeholder partners contributed to the research process and study outcomes and to specifically highlight how the Pilot Project research teams benefitted from stakeholder partner inclusion.

The Importance of Early Engagement

Including a non-traditional research partner in the early stages of research, particularly in the agenda setting and development process, is an opportunity to not only enhance the patient-centered nature of the project⁶, but to build greater comprehension of the project goals by all team members. Carol was recruited to serve on her project’s patient advisory committee early in the process. Although she didn’t know the principal investigator (PI) personally, she was connected with a colleague of the PI. Reflecting back on the process, Carol observed, “It was useful to be included at the early stages so I could get my mind around how [the research tool] works. When it came time to actually test it in the community and hold the focus groups, the tool was very familiar.” As a lead facilitator for several of the project’s focus groups, Carol believes that her inclusion upfront improved downstream efficiency by empowering her to communicate more effectively and with greater confidence in her knowledge of the tool.

Patients also bring a distinct understanding of the disease or condition being studied, and therefore may also enhance the applicability of the design in question. Charles, a co-investigator on his Pilot Project, felt included from the project’s onset, “I believe I’ve been an integral part of the research from the time I submitted suggested revisions to the first draft of the proposal. I helped ensure that the questions in consideration really affected patients and caregivers.”

First Time Experiences

For all seven stakeholder partners, this was their first time working on PCOR. None of the co-investigators had previously served in a leadership capacity in research. And though many of the stakeholder partners described themselves as familiar with healthcare, and to a lesser extent with research, none of the stakeholder partners knew what to expect from the process. Each learned, in their own way, the importance of defining their role and discussing strategies to maximize the effectiveness of their engagement throughout the research process.

As a first time experience, some stakeholder partners were reluctant to participate fully—unsure about how

their opinions would be solicited and their experiences applied by the research team. Samantha’s involvement stemmed from her previous work with a national disease foundation. Her daughter was diagnosed with a chronic condition several years prior, and she took a proactive role in learning as much as she could to support her daughter. When the Pilot Project PI needed someone with this perspective to help guide the research, she approached the national foundation that was looking for someone to serve on its patient advisory committee. “I was introduced as the ‘patient advocate,’ on my project, and I really thought I would just be there in name. I wasn’t aware of PCORI or their mission specifically. Then I got on these conference calls—and I would listen—but hold back. But then they would stop and ask, ‘Samantha, where are we going? Is this the right direction? What do you think?’ And I was like, ‘Wow, I better pay attention!’ I was surprised by that.”

For Samantha, the opportunity to observe and participate in the research process firsthand was an eye-opening one that demonstrated the value of PCOR. She gained insights she would never have obtained had she not committed her time to the project. She reflected, “Often people can never see the whole picture, but when [all the members of the research team] met up we could see how it all came together. I had no idea that [the researchers] could boil down all this information from physician and patient interviews into a scripted, well-written document. I learned a ton through this project. It opened my eyes. This is something big. This is important. [PCOR] can bring all the necessary people to the table. And together, we can really accomplish the task at hand.”

Eve is a mother and caregiver of a child with a neurodevelopmental disorder. Though she has had experience in the healthcare setting advocating on her son’s behalf, serving as a co-investigator on a research study was not something she had sought out. Before she felt comfortable truly embracing her new role, Eve needed to ask questions. Getting thoughtful answers from the PI helped enhance her own capacity to contribute. “I was not familiar with a lot of the terminology that was being used. The principal investigator took the time to explain it all to me so that when I gave my input it was meaningful because I truly understood the process.”

The process of “getting comfortable” takes longer for some stakeholders. As this was a new experience for many of the stakeholder partners and PIs both, each party learned along the way. A common first time experience was not having a clear delineation of roles and responsibilities at the onset. Marian, who came to the health field through an initial health scare when her

daughter was a toddler, was serving on a family advisory council for a hospital. When she was asked to participate as a co-investigator on a research study, she assented, due to her strong desire to give back to the healthcare community. She has since learned a number of tactics to put stakeholder partners at ease. Marian advised, “It’s helpful to set the rules ahead of time. For instance, clearly state that [stakeholder partners] should raise their hand if they’re confused. I went to another meeting yesterday where participants could raise cards that said ‘acronym’ or ‘time out’ when they needed to interrupt; that was a great strategy.”

Feeling like a Valued Member of the Team

All seven stakeholder partners were asked to contribute in various ways, gaining confidence throughout the process and proactively engaging in co-learning. They participated in many meetings—some in-person, but most by phone—and had access to all research team members. They were also empowered to ask questions. Carol found that, “[The research team members] were very happy to answer my questions; and sometimes apologetic for having used [confusing] words. I never felt that I was being bothersome by asking.”

Charles accepted the co-investigator role on his project because of his previous experience with the PI. Despite his comfort level given their existing relationship, it still took time to learn about the other researchers before he felt he had proven his worth to the team. Charles recalled, “I was a bit hesitant to speak up at the first meeting. After one of my comments, one of the researchers said, ‘That’s a really good point.’ And later during that meeting, the same researcher said, ‘We need to make the change that Charles suggested.’ Those positive comments really increased my comfort level. I felt a part of the team from the beginning, but those comments made me feel as if my contributions were especially valuable.”

For Marian, it was her researcher counterpart who set the example for the whole team. She remembered, “The principal investigator, with his tone and body language, always engaged us. We were usually the first agenda item: They asked what we, the patients, wanted to do first. They also always helped us to understand the terms. They were very intentional about checking in and giving us access to the same resources, and that makes a difference.” For Samantha, knowing that other research team members were counting on her helped her feel invested, “They would send out emails to see if I could take a look at something. Then they would follow-up and say, ‘We’re waiting on a response from you before we move forward.’ That’s how I knew my contributions mattered. I really felt like I was part of the team.”

Being a team player also means commitment to helping researcher colleagues gain insights into patient perspectives and experiences. Nina was one of a four-member stakeholder advisory committee on her Pilot Project. She advised, “This is important if patients are doing the first work with PIs. It’s important that we do it right the first time. Co-learning is really important. I learned the more technical elements of research. Math was a language I didn’t speak. And [the principal investigator] learned how to speak more with patients and the importance of including patients.”

Patient Expertise

Stakeholder partners can bring unique and important perspectives to the table. While a researcher can study a disease or condition to understand its underlying biology and psychological impacts, appreciating what it’s like to live daily with a chronic condition lends a whole new layer of understanding to the research endeavor. Samantha observed, “Because this is something I work with every day, and I live with every day, I had insights [the research team] wasn’t aware of.”

Translation was a large part of these stakeholder partners’ roles. Their ability to decipher and interpret the interview transcripts from patients recruited as human subjects for their studies generated new insights for the research team. Patrick was actually recruited to serve as a patient co-investigator in his patient exam room. His doctor was a co-investigator on the newly proposed study, and after several months of patient-provider interactions, he felt Patrick would be a good fit for the team. Patrick’s team members wanted to gather information about the [research subjects’] experiences both in the hospital, and activities/outcomes post-discharge. He was the first person to provide input on: 1) Will patients understand the questions? 2) How long will the interview take?, and 3) Which questions are redundant, etc.? The research team then made changes based on the considerations he offered. Not only did Patrick help shape the interview questions and format, but he also provided insights no other team member could contribute. “[The research team] asked my opinion and they listened to my suggestions. When a congestive heart failure (CHF) patient [respondent] said, ‘I miss my old life;’ what did they mean by that? Those were the types of things that I could translate and bring more meaning to than fellow research team members.” Patrick, reflecting on his own experience with CHF, described for the research team how changes to his lifestyle, with a focus on diet, stress management, new medications, and the fear of possible surgery, impacted him daily.

Marian relayed that her confidence grew over the course of the project. With every insight she offered to the team, she demonstrated her value, both to her research colleagues and herself. “Giving advice [to the research team] strengthened our relationship. Our patient perspective gave us expertise that the team didn’t have, but it took us some time for us to gain that confidence. Eventually we saw that our comments made a difference. Things that were easy for me were hard for [the researchers].”

She also captured both the challenge and promise of offering patient feedback in the service of healthcare system improvement: “I was just the mom of one child, trying to speak for a lot of people. But I found that there are so many things that connect us all as humans that really matter. The health system is so busy trying to do the right thing that they miss details, like closing the door when they leave the room. Once you start giving [the research team] information, giving your opinion, you see the value.”

Understanding the Stakeholder’s Role and Limitations to Involvement

All seven stakeholder partners contributed value through their respective project roles. While their personal experience is what informs their knowledge of the research subject, it is possible that they felt emboldened by seeing and being part of the “bigger picture”. Other research suggests that empowerment is one of the outcomes of research engagement.⁷ By empowering participants early on in the process, these authors suggest that stakeholder partners are in a stronger position to contribute meaningfully to the dialogue and make more impact. Called to extrapolate beyond their individual experiences to inform an evidence base for “people like them,” the stakeholder partners in these projects played an important role in humanizing the experience of what it means to live with a disease/condition or experience a test/treatment.

Although the contributions of stakeholder partners cannot be minimized, it is important to recognize what they should and should not be asked to do, which likely varies significantly by research project and stakeholder partner. In these seven projects, it was the non-stakeholder research team members who designed the initial research methodologies, created the IT applications, programed the mathematical equations, and ran statistical analyses. Stakeholder partners then weighed in on specific elements—particularly those with an impact on patient understanding. These projects tended to view their respective roles as symbiotic—each reliant on the other, the whole greater than the sums of its parts.

These stakeholder partners also did not contribute to the selection process for assigning funding to these projects. While all documented stakeholder partners were paid for their time and financially compensated for travel to and from long-distance meetings, none of those interviewed offered to be involved in budget creation for the Pilot Projects, nor were asked to weigh in on budget priorities over the two-year studies.

These seven stakeholder partners also came to understand the limits to their participation, and the challenge of trying to comprehend and inform all aspects of their research projects. They also understood the importance of active participation, and of “stretching themselves” to learn more. As Nina articulated, “I needed updates on the modeling that the research team was using. A research team member informed [the stakeholder advisory group]: ‘Here are our methods. Does anyone have any questions?’ It wasn’t in-depth, but I’m not going to become a statistician. This is very technical work. They introduced me to the mathematical concepts and provided me with enough knowledge to understand what they were doing and why it was important.”

She suggested, “Be willing to do your homework. And be willing to speak up on behalf of patients to make sure that the research is relevant and that it can be communicated to the patients and the public as to why it’s important. Remember you are serving as the patient stakeholder. You don’t have to become a scientist to participate.”

Charles expressed a similar sentiment regarding preparation and participation; “I firmly believe that stakeholder partners have several obligations to the researchers, to the research project itself, and to future stakeholder partners. Stakeholder partners must do their homework! They have to prepare diligently for meetings. They have to learn as much as they can about the research itself and about other research in that area. They should ask for background reading and then be sure to read it.”

Making an Impact

Research suggests that stakeholder engagement can enhance the quality of research⁸ (e.g., improving enrollment rates in studies and making studies more consistent with patients’ values, goals, and preferences) and also improve translation and dissemination efforts⁹,¹⁰ (e.g., increasing the readability and usefulness of plain language summaries). As practical examples, many of the suggestions that the stakeholder partners contributed were adopted, often to the betterment of the project processes or study outcomes.

Patrick improved the patient recruitment success on his Pilot Project, by offering his own insights from being a former patient recruit. In a previous research project where he served as a research subject, Patrick was recruited for participation during a patient encounter. When his clinical visit was complete, the physician informed him that a third party would be presenting him with a new opportunity. After the presentation, he agreed to participate. “I thought the doctor’s office was a very convenient place to recruit possible patients, versus through cold calls. When you’re in the doctor’s office you have a captive audience, and people are already in that mindset. [The research team] incorporated that feedback.”

Eve described how stakeholder input shaped the entire project—in fact—re-directing the study’s focus from inception. “The parent stakeholders in our project shaped the research tremendously. Initially our PI planned to ask families in our Pilot Project, ‘If there was a cure for your child’s chronic condition, what would it look like?’ But participating families felt that had a negative tone. We actually had the experience of living with a child with a chronic condition. They did not. They didn’t realize that when they asked the question that way it seemed like our child’s chronic condition was all negative and we look at it in a positive light. We proposed, ‘How does this disorder impact your child’s life, and how would you like it to change?’ Just the simple change of re-phrasing the question in a positive, pro-active light made all the difference.” Engaging the parent stakeholders as fully vested partners in the research essentially changed the research team’s approach. The stakeholder partners helped correct some of the researchers’ false assumptions about how kids and parents see this disorder and other conditions.

Eve’s principal investigator on her Pilot Project, Elizabeth, echoed her sentiments, “Working with our family partners fundamentally changed the way we talked to parents about their children’s health and healthcare experiences. The partners helped us to understand the importance of asking questions in a particular way – so that our intent was well understood. We made subtle, but really important changes to our research methods. The payoff was huge. The findings mean something—I think research done this way is much more likely to impact healthcare in ways that really matter to children and families. And that’s what we’re really after.”

Lisa’s commitment to ensuring that patients and other non-traditional research stakeholders would have a better chance at understanding the main findings from her Pilot Project led her to create plain language summaries that would have otherwise been absent. She

reported, “I wanted to prepare a summary that was lay-friendly. I started with the abstract and revised it. Then I sent the PI questions about the work, including, ‘Why is this important for patients?’ and ‘Why should we care?’ I don’t think this would have happened unless I explicitly asked the research team why this work was important to patients.”

Another of the Pilot Project principal investigators, David, who worked closely with his patient co-investigator Charles, offered a tangible example of how active stakeholder partner participation affected his team’s dissemination strategy. He shared, “[Due the participation of stakeholder partners] our analyses and articles have taken a stronger position for enlarging the scope of patient-reported outcomes to argue for adding outcomes that we understand patients desire, even at the cost of making publication harder, because reviewers seemed either to not understand that or to be defensive about it.”

Advice for Future Stakeholders

Having completed their roles with the Pilot Projects, all seven stakeholder partners relayed lessons learned, and offered advice and suggestions to prospective research contributors. They encouraged interested patients and other stakeholders to find opportunities to connect and learn more about ongoing research that affects them or those they love.

Charles offered the following advice to potential stakeholder partners, “If patients fear that the research may be above their level of understanding, I urge them to contact their local hospital, university, or even a larger health insurer in their area to find out about research in their vicinity.” Once interested patients have found out if there is research in their area, they can then connect with one of the researchers and ask if there is an opportunity for patient involvement in the research.

Prospective stakeholder partners were encouraged to approach new projects with a level of openness. Marian suggested, “My advice is to go in with an open mind. All of us go into every situation with preconceived notions. Try to get a good sense of your role. And remember you are there as a peer. For some people that might be hard. But once you’ve been in that patient role, or had a child who needs medical attention, eventually you learn that you have a voice and that voice has a value.” Samantha hoped that more stakeholder partners would be empowered to serve in the research capacity, “I really think that we’re overdue for patient involvement. Without the patient there would be no team, no research. It’s time that patients really get a voice in what’s to be looked at. I think that

it takes a special researcher to be open to patient ideas and I was lucky to have fallen into a group that listened to me and included me.”

Looking back, Nina acknowledged how hard the process was, but yet how pivotal patient time and contributions were to the research project. She recognized, “[Patient engagement] is difficult; [research team members] are statisticians and mathematicians. They are highly technical people who spend 90% of their time on the computer doing math. But team members grew to understand the human side to research as well; not losing sight of that was important.”

Looking Forward: A Need for More Training

Greater stakeholder involvement in research is upon us, but the experiences of these and other stakeholder partners suggest a need for greater training and education to improve the process. This presents a unique opportunity for both research investigators and stakeholder partners to work together to develop relevant training materials. All stakeholder partners profiled had varying levels of training in advance of their Pilot Project participation. Some were required to complete Collaborative Institutional Training Initiative (CITI) training, while others had specific training on facilitation, HIPAA compliance, and/or Institutional Review Board (IRB) regulations, or none at all. There were no consistently applied measures or skills required for their specific project roles, nor previous experiences in the healthcare setting.

As a result of her recent experience Eve is helping the research team to create a support manual for future stakeholder participants. Recalling her feelings as a new participant in the study, she is hoping to shorten the learning curve for interested stakeholders, “Due to the experience I had in [my Pilot Project], I am working with the principal investigator to write a research training guide to help patients and families understand the basic terminology used if they are interested in participating in a study.”

Like Eve, many of the stakeholder partners expressed a strong desire to continue serving alongside the research community. As Carol summed it up, “I like this research stuff. I’m hooked.” They noted that, while most research opportunities are not going to “land on your doorstep,” contributing to the research enterprise is a worthy endeavor and merits pursuit. Continuing to “give back” is stakeholder partner’s primary motivation—and one they believe will create a lasting legacy for active patient and other stakeholder engagement. All have gone on to collaborate on additional research projects, some with the same

research teams and others with new research partners. They now describe themselves as “empowered” research contributors.

Continuing to channel these empowered research contributors and foster new interest is an important endeavor. Outside PCORI, several other funders have undertaken efforts to encourage multi-stakeholder research partnerships, including the DoD Breast Cancer Research Program that has required “consumer advocates” as partners in research for many years. Additionally AHRQ, NIH, and the VA have encouraged stakeholder partner collaborations, and additional funders may benefit from similar considerations and requirements on their released research requests. With each new funded study, stakeholder partners continue to demonstrate the value of their participation to the betterment of the research enterprise.

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