

Special Report

Learning to “Swim” with the Experts: Experiences of Two Patient Co-Investigators for a Project Funded by the Patient-Centered Outcomes Research Institute

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ABSTRACT

The Patient-Centered Outcomes Research Institute (PCORI), established in 2010, launched a new model of incorporating stakeholder perspectives into health care research. To ensure that PCORI-funded studies address issues important to health care consumers, all projects must fully involve patients and other stakeholders in every step of the research process: from planning and design to implementation and dissemination of results.

As members of the first cohort of PCORI-funded researchers, our team was on the forefront of developing new approaches to engaging patients in research. One innovation we pioneered was the creation of a “patient co-investigator” role for two nonscientists who were recruited to be active members of the research team throughout the project. This commentary, based on our experiences, aims to help other research teams to 1) understand how to effectively collaborate with stakeholder team members such as patients; 2) anticipate possible challenges; and 3) offer tools for the orientation, training, and integration of patients into a scientific team. Written from the perspective of two PCORI patient co-investigators, our commentary provides lessons learned and recommendations about incorporating nonscientists into research teams.

Specifically, we suggest recruiting people with a record of relevant volunteer experience and commitment; establishing a formal application process that provides candidates with details about expectations and responsibilities; and providing comprehensive orientation with ongoing training, encouragement, and support. We hope the points in this commentary help research teams that are incorporating patient co-investigators move toward a positive and productive experience.

INTRODUCTION: CONTEXT FROM THE PRINCIPAL INVESTIGATOR

“Because engagement of this depth is new to many researchers and patients alike, we’re developing methods to improve our ability to incorporate patients’ perspectives in research. Patient-centered research methods that are transparent and scientifically sound will enhance the credibility and usefulness of the studies we fund.”—Joe V Selby MD, MPH, Executive Director of the Patient-Centered Outcomes Research Institute (PCORI).¹

During the last 10 to 15 years, health care systems have increasingly included patients in the design, implementation, and evaluation of projects to improve health care.²⁻⁶ Now, with the creation of PCORI in Washington, DC, patients are even more involved in health services research. Created as part of the Affordable Care Act, PCORI is charged with providing patients, their families, and clinicians with trustworthy information to help them make better-informed health care choices.⁷

The goal of PCORI is to “close the gaps in evidence needed to improve key health outcomes.” To do this, PCORI states, “we identify critical research questions, fund patient-centered comparative clinical effectiveness research, or CER, and disseminate the results in ways that the end-users of our work will find useful and valuable.”⁸ A key feature of all PCORI-funded projects is that patients and other stakeholders provide input throughout the project. One reason this model is novel is that PCORI requires patients on research teams to make important and ongoing contributions into the research design and implementation, and it allows for financial compensation of these patient partners. This goes well beyond previous methods for encouraging inclusion of patients in research.⁹

As the leader of one of the first PCORI-funded projects, I (CH) had the honor of collaborating with two stakeholder co-investigators, recruited for their knowledge, experience, and dedication to the community health issues addressed in our study. In the rest of this commentary, they describe their experience and give recommendations for successfully integrating patient partners into a scientific team.

REPORT FROM PATIENT CO-INVESTIGATORS

We (MR, JT) are patient co-investigators on a Group Health Research Institute (GHRI) team that received 1 of the first 25 PCORI awards in May

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2012. Our project, Learning to Integrate Neighborhoods and Clinical Care (LINCC), has 2 major components. The first is piloting and evaluating an innovative approach to involving patients in care redesign. The second is designing, implementing, and evaluating, in collaboration with clinical staff and other stakeholders, a new role in primary care teams: the community resources specialist. We were recruited to be active members of the LINCC research team, and here we share our experience, starting with being invited to join.

Becoming Patient Co-investigators

When developing the LINCC proposal for PCORI, the team asked Group Health Cooperative (Group Health), the parent organization of GHRI, to recommend patients with experience and a high level of engagement in collaborative projects with the health care system. Group Health patients are involved in ongoing work such as standing advisory committees and shorter-term projects such as redesigning clinics. The research team wanted people with skills in collaboration and leadership as well as knowledge and experience in the following areas: community engagement/organizing, community resources, health care system design, and group facilitation.

One of us (JT) has knowledge of and is active within the Muslim and interfaith communities in the Puget Sound region of Washington State, and serves on non-profit and governmental committees. She founded six community-building projects that address socioeconomic disparities through poverty awareness and resource-based solutions. The other of us (MR) brings professional experience in community engagement and facilitation. She also has extensive experience volunteering at Group Health and being the primary caretaker for her husband during a serious illness while at the same time being the caregiver for her aging mother-in-law.

We were both excited to participate in this unique opportunity. We thought the aims of the proposal—adding patient input to all levels of research and developing a new primary care role to help patients access community resources—were

much needed in health services and would improve patient experiences. Our participation as active research team members began with reviewing proposal drafts and providing input on topics in which we had expertise. We heard that funding was very competitive and our chances were slim, so we were pleased when we learned that the project was funded. We went from being short-term volunteers to members of a research team conducting a three-year study.

Swimming Lessons: Becoming Part of the Team

Then the real work began. The first few meetings were challenging. This is apparent from the following comment from one of our quarterly surveys, in which the researchers asked our impressions: *“I must remind myself that we are all learning as we build and create a patient integration model into all levels of medical research, most particularly [because] the implementation of patient co-investigators into the science team is a new concept. It reminds me of throwing a person into a not-too-deep pool to learn to swim; then throwing the whole team into a pool to learn at the same time. Some team members know the basic swimming methods and some do not.”*—Patient Co-investigator, quarterly survey response

Receiving adequate compensation for our time, travel, and related expenses has been important in facilitating our participation. We appreciate that our schedules, along with those of all the other team members, were considered when establishing meeting days and times. As the team worked out these logistical details, we began to realize that we were equal players in this project and not just two patients sitting on the sidelines observing. We were introduced to the day-to-day workings of GHRI and given office space, computers, and identification cards. We did paperwork for our monthly stipends and, in general, were treated like employees. Our first-year education and training was extensive, including:

- a self-study program on the Lean quality-improvement process used at Group Health

- human subjects training through the Collaborative Institutional Training Initiative of the University of Miami (CITI; Miami, FL), a national, Web-based, research education program
- education about patient privacy and data protection through Group Health’s employee training system.

Everything was new. We were not prepared for this “job”—which did not have an application process or formal description. In the traditional employment field, all jobs have an explicit description, so not having one made us uncomfortable in the beginning. Without a clear definition of our function and duties, we questioned whether we were qualified and did not know what to expect or what was expected of us. It was hard to get our heads around the fact that our task was to bring our individual patient perspectives to this project. We also wanted an organizational chart that would show our patient co-investigator role in relationship to the team and the entire GHRI staff.

The team members understood our frustrations but, at first, they could answer our questions only with “we don’t know.” They explained that we were all learning about this role together because there were few models of full patient engagement in research on which to draw. With time, we saw that we were part of a national experiment to learn how best to incorporate patients into research teams. This realization opened the door to a deeper understanding of how we could contribute. A tool that helped us better understand our roles and the overall project was a logic model—a visual representation of the project steps, similar to a flowchart—that the research team developed. The LINCC logic model gave us and the team a sense of the big-picture goals of the project and helped clarify timelines and team member responsibilities.

Once regular team meetings began, we were overwhelmed by the language of research and health care, which is filled with acronyms and unfamiliar terms and concepts. Trying to understand the role of each new colleague at the table was frustrating and confusing

because we were still just trying to remember their names. To address this challenge, we began holding half-hour “premeetings” with the project manager before regular research meetings. During premeetings, which are ongoing, we review the upcoming research team meeting agenda; ask and answer questions; and talk about our observations, frustrations, and any assumptions we have drawn about the project. With only the three of us in the room, we feel more comfortable voicing our questions and ideas. Our premeetings allow us to be more prepared to engage productively with the full research team and are invaluable for putting information into context. They have been the most important tool for effectively integrating us with the research team.

Making up a New Stroke as We Go

From project onset, we were told the research team was piloting the patient co-investigator as an innovation in the research world. Our research team had the advantage of being a part of Group Health, which was founded as a consumer-governed health care cooperative and encourages patients to be active in their own care by partnering with their care team. Group Health offers its members opportunities to contribute through patient caucuses, advisory panels, and focus groups. Additionally,

GHRI has a strong record of working with patient participants on clinical studies, but like most research institutions, has limited experience in integrating patients into research teams. Our research team knew they were breaking new ground with our PCORI project.

To capture our experiences and recommendations, the research team implemented two data collection methods. First, a GHRI staff member who was not a part of the LINCC team conducted qualitative interviews with all project team members (including stakeholders in the delivery system). That same staff member plans to do interviews at the end of the project to see how experiences and perspectives changed. Second, we fill out quarterly, online, open-ended patient co-investigator surveys (see Sidebar: Quarterly Survey Questions). The responses are reviewed by the project manager, who writes a summary that we approve before sharing it with the rest of the team. This process gives us a safe way to share our experiences, concerns, and suggestions and to ensure team leaders receive feedback that helps improve our experience on the team. The answers to the seven questions asked in each quarterly survey inform the remainder of this article.

The first year, our survey answers reflected substantial frustration because we did not know how we could best contribute to the project or whether our knowledge base was a help or hindrance. The survey results showed that over time, we came to understand how valued we were by the other members of the research team and the reasons why patient involvement was critical to the project. We saw how simply being present at the table kept the scientists clear about and dedicated to PCORI’s overarching goals and principles. Sometimes, other research team members commented that they can become overly focused on their specific role or tasks in the project. As patient co-investigators, we help keep the patient-centered outcomes approach at the forefront of the research team’s awareness at every meeting. For example, during a conversation about compensating patients for their participation in our co-design event, our

patient co-investigators pointed out that we needed to ensure that the way we paid our patient advisors did not compromise any public benefits they might currently be receiving.

Research team members are friendly, accommodating, and eager to hear our opinions, and as a result, we have felt at ease voicing our perspectives. Often just asking a question spurs a lively discussion that would not have happened otherwise. We feel good knowing that we contribute just by asking about something we don’t understand, and we are pleased to add value to the process.

The LINCC project has been a learning experience in which we have experimented with how best to fulfill the project requirements and honor the PCORI mission. It has been humbling knowing how vital we are to LINCC, and we are proud to be part of this pioneering PCORI effort. Having novice patient co-investigators as part of a research team is innovative. Our participation satisfies our desire to be involved in our community, provide information to our health care providers to help them improve care, and take ownership of our own care.

Although PCORI funding for the LINCC project will finish in 2016, we have found that our views will continue to be valued and sought. We can still shed new light on the research. The LINCC community resource specialists are now in clinics. As members of the research team, we actively participated in selecting the clinics where they would work, determining the scope of the advisory committees and agendas that would guide them, and designing workshops to train patient advisors who participated in co-designing the new community liaison role. In addition, we helped select and/or develop the patient survey questions used to evaluate the program.

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Quarterly Survey Questions

1. What have you learned this last quarter?
2. What did you feel were your most important contributions during last quarter?
3. What support or information do you need?
4. Do you feel you are being used effectively? Why or why not?
5. Do you feel you are a respected and valued member of the team? Why or why not?
6. What recommendations do you have to offer the team for improving collaboration with the patient co-investigators?
7. What lessons learned have come up that you think might inform others who are interested in involving patient co-investigators?

Lessons Learned

We hope that sharing our experiences and insights will make the process of learning to “swim” easier and more efficient for other research teams interested in incorporating patient co-investigators. Success begins with recruitment. Think broadly about whom you want to recruit and find innovative ways to spread the word. Use interviews to find skills that may not be on the candidates’ resumes, such as an eagerness to learn. Make sure all candidates understand that they are making a commitment to a long-term project. Being part of a team means showing up and contributing. If candidates cannot consistently do this for the entire project, the patient-centeredness is diluted. Other lessons learned are included in the Sidebar: Key Lessons Learned.

CONCLUSION

We believe our participation and involvement in one of the first PCORI-funded research projects has been worth our time and worth the time and financial commitment of our research institution. Foundational elements of this success have been that we feel fully

respected and part of the LINCC team. Our contributions as patients, laypeople, and nonscientists have been given value equal to the perspectives of the other members of the research team. We feel that our experience in this early PCORI project has given us an opportunity to be agents of positive change. We hope that the lessons learned that we provide in this article make it easier for other research teams to integrate patients as partners in research and to help them maximize their input as colleagues who have unique and valuable perspectives. ❖

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Key Lessons Learned

1. Have an application with a cover letter explaining the scope of the project, the time expected, reimbursements, and requirements
2. Conduct formal interviews with prospective patient co-investigators
3. Be prepared to orient patient co-investigators with resources such as:
 - a general job description (knowing the role might change over time)
 - names and roles of each team member
 - an organizational chart with each team member and co-investigator
 - a project logic model, flowchart, and/or timeline
 - background material (such as this article) about how a research team works
 - required tax and business forms (W2, 1099, travel forms, etc)
 - initial meetings to welcome patient co-investigators and provide them with office resources such as a desk, computer, and phone
 - remote e-mail access with the ability to download attachments
 - handouts with definitions of relevant research and health care terms
 - human subjects training that is available in a variety of languages and that is at a literacy level accessible to lay people (the Collaborative Institutional Training Initiative of the University of Miami system we used was too specialized)
 - support for completing organizational compliance and training requirements
 - premeetings to help prepare and integrate patient co-investigators into larger research team meetings
 - clear explanations of acronyms and unfamiliar terms and concepts
4. Be patient, encouraging, and supportive with the patient co-investigators as they learn and throughout the project