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Lessons learned from developing a patient engagement panel: an OCHIN report

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Abstract

There is renewed interest in patient engagement in clinical and research settings, creating a need for documenting and publishing lessons learned from efforts to meaningfully engage patients. This paper describes early lessons learned from the development of OCHIN's Patient Engagement Panel (PEP). OCHIN supports a national network of more than 300 community health centers (CHCs) and other primary care settings that serve over 1.5 million patients annually across nearly 20 states. The PEP was conceived in 2009 to harness the CHC tradition of patient engagement in this new era of patient-centered outcomes research and ensure that patients were engaged throughout the lifecycle of our research projects, from inception to dissemination. Developed by clinicians and researchers within our practiced-based research network (PBRN), recruitment of patients to serve as PEP members began in early 2012. The PEP currently has a membership of 17 patients from 3 states. Over the past 24 months, the PEP has been involved with 12 projects. We describe developing the PEP and challenges and lessons learned (e.g., recruitment, funding model, creating value for patient partners, compensation). These lessons learned are relevant not only for research, but also for patient engagement in quality improvement efforts and other clinical initiatives.

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Introduction

Patient engagement strategies are increasing across healthcare settings in response to the recognized need to more actively include patients' voices in decisions made within the healthcare system. In clinical settings, patients are being recruited to serve on advisory panels and as evaluators of quality improvement projects – allowing patients to be more active participants in their own healthcare (1). In research settings, patients have traditionally been engaged through advocacy groups with an interest in specific conditions (e.g., the American Heart Association, the American Diabetes Association) (2). The Patient-Centered Outcomes Research Institute (PCORI) has also recently created several Patient-Powered Research Networks, which are using a similar specific disease model(3). Modes of community participation are often used in community driven public health research, however, this often partners academics with community-based advocacy organizations and has not traditionally focused on explicitly engaging patients from within the healthcare settings where research and quality improvement projects are being conducted (2, 4-10). Practice-Based Research Networks (PBRNs) are stakeholder-centered organization with an emphasis on engaging community-based clinicians (11, 12) and have explored using community-based participatory research (CBPR) strategies to engage communities and patients in primary care research settings(10). However, most examples of engagement remain project-focused, which limits involvement to singular, discrete scopes of work and prevents patients from participating in activities that span both research projects and the research timeline(9, 13, 14).

Although engaging stakeholders in research and clinical activities is not a new concept, recent efforts by PCORI and others to necessitate meaningful engagement require better ways of defining and measuring patient engagement (15). This renewed interest has led to an increasing number of excellent reviews and conceptual frameworks that have developed shared terminology and common definitions to identify categories of stakeholders, to delineate the roles stakeholders play, and to capture the unique experiences that inform research (16-19). We describe early lessons learned in developing a Patient Engagement Panel for research.

Brief Background regarding OCHIN and the Patient Engagement Panel (PEP)

Founded in 2001, OCHIN is a nonprofit, community-based health information technology (HIT) collaborative based in Portland, OR. Originally called the Oregon Community Health Information Network, it is now referred to as “OCHIN” because it serves more than 300 community health centers (CHCs) in 19 states with over 3,000 providers caring for more than 1,500,000 patients (20-22). As of March 2015, OCHIN's research portfolio included 22

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active projects, including comparative effectiveness, dissemination and implementation, informatics, public health and health services research. CHCs, the majority of OCHIN's membership, have a long history of empowering and engaging patients on their community-based governing boards (23). While OCHIN researchers had developed mechanisms for engaging patients and communities in specific research projects (24) (e.g., community retreats, focus groups, patient interviews, and project advisory councils), we had not explicitly structured research governance in a way that enabled direct patient engagement in all aspects of the work longitudinally. The OCHIN Patient Engagement Panel (PEP) was conceived in 2009 to harness the CHC tradition of patient engagement in this new era of patient-centered outcomes research. Over the following six years the progression of the PEP from concept to practice was not without barriers or important discoveries.

Challenges and Lessons Learned

1. Recruiting a diverse, representative patient sample

We continue to face the challenge of recruiting PEP members representative of a range of different backgrounds or hard to reach groups (2, 13, 25). FQHC patient and community boards have also reported struggling to represent the homeless, the single parent, the less-educated, the disabled, and patients living in poverty (1). Our major barriers included finding people who were interested in participating in this unfamiliar undertaking and ensuring that those who did express interest were able to join despite logistical or geographical barriers. Lessons Learned: In the beginning, we limited the PEP membership to English-speakers who were competent using technology (email, computer, remote meeting software) and were available during weekday meeting times. We learned that patients who self-select to participate in this kind of endeavor are not ‘average’ patients and come with drive and direction, which provided necessary momentum. The founding PEP members are now leading the PEP and help to recruit members and foster a collaborative, supportive environment. Over the past two years, the PEP has been involved with 12 projects as advisors and patient experts. The most active members serve as patient co-investigators on several projects (26), present at national conferences and help develop research proposals and manuscripts (27).

We created a brief, lay-language description of the expected role, time commitment, and potential benefits [Appendix A] for potential PEP members. In the second year of PEP recruitment, we focused on diversifying the PEP with guidance from our founding members (e.g., improving the recruitment materials, identifying recruitment outlets). The 17 current PEP members now represent 3 states; meetings are held on a regular weekday evening to increase participation opportunities (acknowledging shifting schedules this meeting time is frequently reviewed to ensure it still works for the majority of the group), and we offer food and travel compensation to members that join in person. We have loaned a laptop computer to one member and a purchased a cell phone compatible headset for another to help ease the difficulties of participating in conference calls. While the PEP members have become more diverse in age and geographic dispersion the group is still aspiring to be even more representative of the OCHIN patient population as it matures.

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2. Creating a sustainable funding structure

Building a sustainable funding structure for the PEP has been a challenge, especially as the scope of the PEP moves beyond research projects. We found that federally-funded research grants did not allow costs that were necessary to PEP members, such as parking, reimbursement for phone calls, and training opportunities. Lessons Learned: We started out using research grants and were also able to leverage infrastructure development grants from HRSA, NIH and PCORI to fund the PEP. OCHIN as an organization has prioritized this work and hired a full time patient engagement coordinator position who oversees a modest budget. This role has primarily been funded by an infrastructure grant and provides oversight for all patient engagement activities, from research-specific (scoping the patient role on a research project, identifying patients interested in the content area who are willing to serve in an official capacity) to organizational policy development (coordinating workgroups to support patient engagement strategies in CHCs, negotiating reimbursement with funders). Further opportunities for funding this work may include private nonprofits with more diverse funding initiatives and budgeting this work in future traditional research proposals that incorporate patient engagement explicitly. We have also discussed holding PEP fundraisers or creating an endowment for the PEP. As a learning organization, we realize that evaluation is critical to the continued success of an initiative such as the PEP; starting in 2015, we will be evaluating both process and outcome measures and are confident that demonstrating the successes will help with continued funding.

3. Creating added value for PEP members

Initially we felt that researchers were gaining more from the PEP than the patients. To overcome this, we had a philosophy that there needed to be added value for PEP members. Lessons Learned: After making the decision to start a PEP, we felt it was very important to engage patients in the establishment of the group. While the PBRN and OCHIN leadership envisioned the role of the PEP, this further progressed once our founding patient members were recruited. The members participated in discussions outlining the role the PEP would play in research question development, study design and dissemination. The role description we currently use is: “The PEP gives patients a way to actively advise and guide decision makers, providers and researchers in work to improve patients' healthcare experiences and treatment options. Patient PEP members are sought out to serve in an advisory capacity on grant proposal development, patient recruitment models, tool development, project communication, changes to clinic workflows, and dissemination for patient populations.”

PEP members are encouraged to pursue continuing education opportunities, including research-specific training by local organizations, conferences relevant to their research interests and IRB trainings (enabling patients to be added to IRB protocols as co-investigator and study staff). In addition, members are also encouraged to participate in dissemination activities by having the opportunity to present findings at research conferences, annual meetings and webinars. A ‘Research 101’ curriculum is being developed at OCHIN, in partnership with PCORI, to serve as an orientation and learning opportunity for current and future PEP members.

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4. Being equitable and transparent with compensation

A major challenge was establishing a compensation mechanism. We originally envisioned compensating members with a generous hourly rate of their time, akin to the compensation model for consultants on grant funded research studies. During discussions with PEP members, several barriers to our planned approach were raised. Many CHC patients are low-income individuals and depend on social services with income qualifications. If PEP members were paid in this way, the extra income might disqualify them for needed services. Lessons Learned: Working in partnership with PEP members, we have moved to a different compensation model, which is based on the idea that compensation must be equitable and transparent but does not need to be the same for everyone. PEP members reported that they were happy to volunteer their time, interested in opportunities to attend and present at research conferences, and said they would welcome receiving a token of appreciation (e.g., gift card, travel reimbursement, donation on their behalf to a charity). We now work with PEP members to determine a customized compensation model.

Conclusions

OCHIN's PEP demonstrates the feasibility of incorporating a patient voice throughout the research life cycle, with opportunities to amplify it in additional non-research initiatives. A multi-step, collaborative process was successfully used to identify and recruit patients, develop a shared vision and agree on equitable compensation models. Many of the lessons learned through this work are transferrable to quality improvement and innovations in health care settings which will benefit from patient involvement.

We started small with a phased approach, and are now recruiting a more diverse panel by offering expanded meeting time options, research training opportunities, and technology assistance. We are exploring alternative funding models and creating a tailored compensation model based on individual members' needs. We recognize that the patients who choose to participate in this work are likely to be more engaged in their healthcare. Therefore, these findings may be limited to similar, activated patient populations. Further research is needed in the area of engagement of patients on a larger, population-wide level.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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