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INITIATIVE TO SUPPORT PATIENT INVOLVEMENT IN RESEARCH (INSPIRE)

Findings from Phase I Interviews

Authors:

Danielle Lavallee, PharmD, PhD

John L. Gore, MD, MS

Sarah O. Lawrence, MA

Johanna Lindsay

Shannon Marsh, JD

Mary R. Scott

Karen Wernli, PhD

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For an immediate response, contact Sarah Lawrence at lawreso@uw.edu.

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Overview

Why we started this project…

As patients, clinicians, and researchers, our team represents diverse experiences with and knowledge about patient-researcher collaborations in healthcare research. We recognized an opportunity to learn from each other and the broader patient-centered outcomes research community to develop tools, resources, and best practices to support future successful collaborative efforts. The resulting Initiative to Support Patient Involvement in Research (INSPIRE) reflects what our group of patients, clinicians, and researchers see as important and needed work to continue efforts making the patient's voice central to research with the end goal of creating high quality research that is accessible to people making healthcare decisions.

Who we talked to…

We reached out to principal investigators of Patient-Centered Outcomes Research Institute (PCORI)-funded projects awarded between January 2012 and March 2015 in the Pacific Northwest region (Alaska, Idaho, Montana, Oregon, Washington, and Wyoming). We selected this group based on the expectation that each project would have direct experience and knowledge of patient-researcher partnerships, as this is a key tenant for PCORI funding. Further, the Pacific Northwest region includes a diverse portfolio of 35 projects from which to learn. Upon contacting principal investigators, we requested permission to speak with patient partners for the respective project. This allowed us to hear from both the researcher and patient about how partnerships function and what tools, resources, and trainings were necessary to support and sustain engagement.

What we asked…

We conducted telephone interviews using semi-structured interview guides, developed for both researchers and patient partners. This allowed us to ask a common set of questions of each person interviewed while allowing room to probe on specific topics unique to or relevant for each project and perspective. Topics covered in each interview included the structure of the partnership; important skills for researchers and patient/caregivers engaged in research partnerships; and tools, resources, and training both utilized and needed to support and sustain current and future work.

What we heard…

We conducted a total of 37 interviews – 23 individuals represented the researcher perspective, and 14 individuals represented the patient/caregiver perspective. Interviews represented two-thirds (i.e., 23 of 35) of the eligible projects in the Pacific Northwest region. Diverse approaches to patient-researcher partnerships were described inclusive of both consultative and collaborative approaches. Developing relationships with patients, or others new to research and engaging them as partners requires adequate support, both for the research team as well as patients. Researchers need to allot appropriate timelines, staffing and funds for engagement. Patients need access to the research community in a manner that supports involvement during research development. Further, given that research involvement often comes on top of personal life, work commitments and health, it is important that researchers identify novel approaches to engagement to facilitate involvement. While enthusiasm exists for patient-researcher partnerships, continued work to support community learning in this space is warranted.

Introduction

Until recently, patient participation in research was limited to involvement as subjects enrolled in research studies. The establishment of the Patient-Centered Outcomes Research Institute (PCORI) caused a significant paradigm shift in healthcare research in the United States by making the direct involvement of patients and caregivers throughout the research process a cornerstone of patient-centered outcomes research (PCOR).[1] PCOR includes patients as partners in research emphasizing the unique perspective and experience they represent. Further, patients use research findings to make healthcare decisions and thus deserve to have significant input into research conducted. When done well, patient involvement in research brings awareness to issues of greatest importance to patients, ensures accountability and transparency in research, and guarantees that patients obtain access to research findings in a manner that could inform their care as new evidence is developed.[2-7]

While patient involvement is an important step forward in improving how healthcare research is conducted, it requires that both researchers and patients have access to appropriate training, support, and resources to ensure success.[8] Indeed, two recent systematic reviews of stakeholder engagement in comparative effectiveness and PCOR highlighted the need for training and tool development for both researchers and patients to support future stakeholder-engaged research activities.[9,10]

Before extensive efforts are undertaken to create new resources, it is important to understand what currently exists. Patient involvement in research is not a new concept. For many years, patients have partnered with researchers in specific and distinct areas of healthcare research, participating in the peer-review process for research funding, assisting with systematic reviews of the evidence and as members of the research team.[11-15] As a result, training, tools, and resources generated to support these efforts exist, but to date, no clear forum for sharing and disseminating available resources has been established. The goal of INSPIRE is to build infrastructure to share existing and newly developed resources that will facilitate PCOR training, support, and networking for both patients and researchers across diverse areas of healthcare. Through cataloging current materials and creating a central portal for access, we seek to reduce duplicative efforts in the future.

The INSPIRE project involves four phases: 1) interviews with patients and researchers involved in PCOR to identify existing resources and gaps in resources; 2) compilation and review of existing resources and tools with a review of content, readability, and target audience; 3) development and conduct of a multi-stakeholder workshop to advance the sustainability of patient-researcher collaborations; and 4) development and dissemination of training and resources to the PCOR community. Dissemination of materials will occur through a web-based portal available to the PCOR community on the currently existing CERTAIN Patient Advisory Network website (www.certainpatientadvisors.org). The following report presents a synthesis of the themes we heard in interviews with patients and researchers and existing resources and training identified as part of the first phase of research. To respect the diversity of views presented, we refer to the perspective the individual represented (parent, patient, caregiver) when referenced specifically in the report. However, when referencing in aggregate, we utilize the terms patient partner or patient engagement. We conclude with recommendations for developing future tools, trainings, and resources to support and sustain patient-researcher partnerships.

Approach

INSPIRE investigators reached out to principal investigators of PCORI-funded projects (Appendix A) awarded between January 2012 and March 2015 in the Pacific Northwest region (Alaska, Idaho, Montana, Oregon, Washington, Wyoming) as this information is available to the public. We selected this group based on the expectation that each project would have direct experience and knowledge of patient-researcher partnerships, as this is a key tenant of PCORI funding. The Pacific Northwest region includes a diverse portfolio of 35 projects that spans the breadth of PCORI's funding priorities (with the exception of Communication and Dissemination Research) from which to learn. Upon contacting principal investigators, we asked to be connected with research partners for the respective project, in order to learn from a broad range of perspectives. We asked both researchers and patient partners about how partnerships function and what tools, resources, and trainings were necessary and important to support and sustain engagement.

We conducted telephone interviews using semi-structured interview guides developed for both researchers and patient partners (Appendix B). This allowed us to ask a common set of questions of each person while allowing room to probe on specific topics unique to or relevant for each project. Topics covered in the interviews included a description of the structure of the partnership; identification of important skills for researchers and patients engaged in research partnerships; and tools, resources, and trainings used by each research team and judged important to supporting and sustaining current and future work.

Interviews were recorded and transcribed with consent from participants. Transcripts were uploaded into Dedoose (www.dedoose.com) for review and coding. Our Phase I procedures were submitted to and approved by the Institutional Review Board at the University of Washington.

Findings

We conducted a total of 37 interviews, involving 23 of the 35 eligible PCORI-funded projects in the Pacific Northwest region (66% participation rate). Among those interviewed, 23 interviewees represented the researcher perspective and 14 individuals were patient, parent, or research advocate partners. Of the 12 projects not included in these findings, 3 project principal investigators declined participation due to time constraints, 6 were not responsive to requests, and 3 agreed to participate initially but did not respond to subsequent scheduling requests.

In this report, we present the findings of the interviews. We describe the different structures for engagement and approaches for identifying collaborators. We focus specifically on patient and researcher views on knowledge, skills, and training necessary for successful research collaboration; challenges for patient-researcher collaborations; and overarching themes heard relating to patient engagement in research.

Building Patient-Researcher Collaborations

Structures for Engagement

Researchers and patient partners described both consultative and collaborative approaches to engagement.[2] Consultative approaches, described in the literature as one-way engagement where individuals advise or provide solicited feedback[2], include engagement structures where the patient representatives serve as advisors through councils or stakeholder advisory boards. In this capacity, the research team consults with advisors on specific aspects of research. Collaborative approaches are defined as partnerships or efforts that create opportunities for shared learning and direction of research.[2] In this capacity, patient partners participate directly on the research team with similar roles and responsibilities as other investigators, including regular attendance and participation in team meetings and active involvement in discussions and decisions made as part of the research process. Table 1 presents examples of both consultative and collaborative activities described. A few examples emerged where patient partners took the lead on specific activities within the research project. In one study, patient partners attended focus groups and assisted with facilitation. In another, patient partners led the development of clinician training to facilitate patient-clinician communication. Patient partners themselves described active participation on panel presentations and work to author or co-author publications and blogs disseminating information about research and research findings.

Table 1: Patient Engagement Activities Described by Interviewees	
Consultative Engagement Activities	• Provide input on study design or protocol decisions • Participate as advisors on multi-stakeholder advisory councils • Attend meetings to learn about study updates and progress • Review questionnaires • Provide feedback on patient/family facing materials • Share perspective and experience of specific health conditions or experiences with care • Discuss aspects of patient-clinician interactions • Provide input on issues related to data governance and confidentiality • Provide input on recruitment and retention plans • Provide input or feedback on findings as interpreted by the research team • Provide input and guidance on plans for disseminating research findings to a broader community
Collaborative Engagement Activities	• Identify research topics • Expand patient advisory group • Lead and conduct outreach to broader patient community for input on study activities • Ensure study addresses topics important to patients • Create and refine patient-facing study materials (e.g., recruitment flyers and scripts, questionnaires, cover letters, etc.) • Assist with focus group facilitation • Discuss and trouble-shoot challenges arising throughout the study (i.e., slow patient recruitment, challenges experienced such as patient reactions to questionnaires administered on sensitive topics) • Lead development of research products (e.g., trainings, webinars, reports) • Participate in evaluation of engagement processes • Create materials to support patient engagement (e.g., glossaries, manuscripts describing engagement, tips for engagement, etc.) • Present as part of panel discussions a local, regional and national meetings • Author/co-author publications • Assist with data analysis interpretation • Vote on or participate in research study-related decisions

In a number of cases, the structure of engagement included a blend of both consultative and collaborative approaches. This involves patient partners serving as research team members with the addition of an advisory council or stakeholder advisory group convening on a more infrequent basis (e.g., annual/bi-annual/quarterly) to receive project updates and provide consult as warranted. In this manner, researchers described having the ability to not only work directly with patients as part of the research team but also harness input of a larger and potentially more diverse group of individuals on specific issues or tasks throughout the research process.

> *On our core team we have some patients who are engaged in terms of our regular meetings and planning. We've also, through the work we did in Tier one, we engaged with a number of existing community coalitions. We tried to go to some of the community groups that were already in place to just talk about the network we were developing and to invite both the organization that was represented to be a community partner or an organizational partner on our developing research coalition, and then we let people who were interested sign up to be research ambassadors, or individuals that if there was a research question that was raised, or a project that emerged in their area of interest they could be notified. We've built engagement into all phases of our partnership, from the core team to having more diffused partners.* ***-Researcher***

In addition to formal structures for patient engagement, a few researchers described qualitative research-based activities, such as interviews, surveys, and focus groups as mechanisms to engage patients and inform research activities. Only individuals representing the research perspective described this as a method for engaging patients. While such research methods are ideal for soliciting specific input from a selected group of individuals about knowledge, beliefs, and experience on a given topic or issue, it is not clear to researchers how or if this fits into the paradigm for engagement. Some see qualitative research methods as a successful strategy for engaging patients in that it is a systematic approach to obtaining input to inform and guide research. Others challenged that it does not fit the spirit of patient-engaged research in that the individuals are consented as participants in a research activity rather than working with the research team as partners and advisors.

Challenges to Structuring Engagement

Developing and implementing an engagement strategy as part of research takes time and dedicated financial and staffing resources. These realities presented a challenge for those new to engaging patients as partners. In most cases, active engagement often started after research funding was in place. When patient partners were involved in the development of the proposal, it was limited to a more consultative capacity. Limitations described by researchers for involving patients early in topic and proposal development included short timelines for developing proposals, topics and topic areas for research driven by the funding agency, lack of established networks for co-creating research proposals, and lack of funding available to support efforts of engagement for the support of proposal writing.

> *This is not an activity to be taken lightly, in terms of the fact that it does take a huge investment of time in orienting and working to engage your patient partners. And time for them to get incorporated to their teams. I think in general researchers and PCORI at the beginning said, "Let's put patients on research teams." And I will admit I thought, "How hard can that be?" And it really is not an easy task.* ***-Researcher***

> *I don't know if you're on any boards, but it's kind of the same thing where when you only go there for two hours a month or whatever and you have a couple of hours prep, it's not a lot for something that's an ongoing mission that carries forward. So I think in an ideal scenario, there would be more time that people are spending getting and staying up to speed so that they haven't forgotten everything by the time the next meeting is. The challenge with that is that if the time commitment were more, I probably wouldn't have participated from the beginning, because I don't have a lot of time to give.* ***-Patient Partner***

Many individuals noted that patient engagement required additional time and dedicated financial and staffing resources. Researchers focused on additional time and staffing support necessary for planning and supporting patient involvement. Patient partners also noted time required to stay meaningfully engaged and up-to-date on activities. Managing the ebb and flow of research activities – in particular sustaining involvement over time – was also a noted challenge both in managing workload as well as keeping people well-informed throughout the study. A number of patient partners expressed the challenge of balancing staying engaged and meaningfully contributing with time required to do so. A few spoke of the challenge encountered managing scope creep, when a number of new opportunities are presented for involvement (e.g., writing blogs, participating in panel presentations, attending conferences, etc.) that are interesting to patient partners but require significantly more time commitment than originally planned.

Patients cited additional challenges for engagement. Most patients are participating as research partners or advisors in addition to other work or family commitments. As such, the ability to travel, take time off of work, or meet during regular business hours may be impeded. Further, access to the internet or relevant software programs, printers for printing materials, and lack of familiarity with web-based communication and web-conference software may impede participation. It was advised by many interviewed that researchers should be cognizant of such barriers when planning for engagement and have a plan for how to overcome them.

PCORI instigated a significant shift in the research community when it established expectations for patient engagement as a core aspect of funding of healthcare research projects. While this shift is viewed as exciting and important among those interviewed, the "newness" of the experience has proved to be a challenge for many. Many researchers noted struggling with providing enough context about the research process and allowing enough time for meaningful participation of patient partners and advisors. Further, the evidence about what constitutes successful or meaningful engagement is still emerging. As a result, researchers feel that engagement is an experiment in and of itself.

Key Findings for Structuring Engagement

- PCORI-funded projects include consultative and collaborative approaches to engagement.
- No one clear strategy for structuring partnership exists. Structures appear to be driven by needs of the project and experience of the principal investigator.
- Limited experience with engagement combined with limited evidence on how to build successful partnerships presents a challenge for both researchers and patients.
- Collaboration evolves over time and may create new opportunities for patients to get involved above and beyond initial plans. Regular review of work and expectations should occur to discuss interests and ensure adequate support is allotted.
- Appropriate allocation of time, staffing, and budget are necessary for engagement activities.

- Researchers report challenges in patient collaboration during research development, a period in time where funding is not yet established.
- Patients report additional challenges including managing health and engagement, balancing involvement with work and family commitments.
- Case studies highlighting different approaches to structuring engagement from current research efforts, including opportunities and challenges, would help support current and new PCOR investigators.

Identifying Patient Partners for Research

Approaches to identifying patient partners and advisors for research projects varied based on the experience of the principal investigator, goals of the project, and presence of existing relationships. Researchers sought to identify partners and advisors that could represent and articulate a specific experience with a health condition or topic, health system, or care experience. When possible, researchers worked within established networks to identify patient partners. Examples included relationships with the healthcare organization through advisory board participation, involvement on research-specific advisory boards or governance committees, or experience as a patient or caregiver within a clinical practice setting. For example, one patient partner described her experience working on the governance council of a healthcare organization. For a number of years, she participated on advisory councils for the organization, and the opportunity to participate as a patient partner provided a new opportunity for her to get involved in her current organization through research, which she welcomed. The existing infrastructure allowed for quickly identifying individuals who possess knowledge of and experience with the research/healthcare organization – an important perspective notably valued by the research team interested in ensuring research activities would reflect, in part, the experience of care within the organization.

Identifying patient partners from individual clinical practice sites brought conflicting perspectives from researchers. On one side, established relationships were recognized as important and valuable to the process. Clinicians are often able to identify patients they have treated in the past who have relevant or unique experiences and the ability to share it with a diverse audience. On the other hand, some interviewees expressed that clinical researchers should avoid engagement of current or past patients, due to the fact that the doctor-patient relationship is built on a patient entrusting his or her wellbeing to the physician, and any interactions outside that relationship could influence the ability of both parties to freely express and listen to the views and perspectives without bias.

Interviewees also reported connecting through prior research activities. Most commonly, this prior experience stemmed from individuals being consented participants in prior research activities. In some cases, the PCORI-funded project stemmed from prior research where patient partners previously served as consented participants. As a result, these former research participants provided a network of individuals to start outreach among for forming new partnerships. One caution noted for this approach is the need to obtain approval from the Institutional Review Board or ethics committee to conduct outreach to past consented research participants, so as to comply with laws protecting personal health information. For this reason, researchers utilized this approach only after projects received funding. One researcher described a new approach created for future studies to address this issue. As new studies emerge that involve patient recruitment, study teams are including an invitation to learn about participation in a patient advisory network that functions to involve the patient voice and perspective in future research initiatives. The goal of this work is to develop a community of people interested in advising and partnering on future research.

> *We sent letters to about 100 people that had participated in my research and said if you're interested in this, then fill out this little questionnaire. And so out of 100 we sent out, I think we got like 10 back. People said they were interested. And you know, there were some pretty general, you know, if you have any experience in working in a group, do you have time to do this, some pretty basic questions. And then I had my project manager interview each of the people and then we got it down to five that we interviewed and then we got it down to three or four.* ***-Researcher***

A number of those interviewed worked directly with advocacy and community organizations. This included principal investigators leading PCORI-funded projects from the patient community. Collaboration and consultation with such groups included soliciting input on research proposals, working in collaboration to obtain input from a broader group of patients/advocates through the established network, and identifying individuals with specific skills and experience to serve formally as advisors and/or partners on a research project. Both researchers and patient partners recognized the importance of engaging with existing organizations. In particular, a number of researchers commented on their existing relationships with patient advocacy organizations through regular encounters at national meetings. Representatives from advocacy organizations help articulate a perspective representing a broader patient base versus a singular experience. Such groups are engaged as part of building networks and identifying opportunities to work together, particularly in the Tier I/Tier II projects. In particular, it was noted that advocacy groups often have an established presence in the community and share similar interests and goals.

Challenges to Identifying Research Partners

Identifying patient partners who are interested, willing, and available to engage in research was a challenge expressed by a number of interviewees. Outreach and processes for identifying potential partners described included formal (e.g., posting of announcements/flyers, outreach to new organizations) and informal (e.g., outreach through personal networks and word-of-mouth connections) approaches, both of which met with mixed success. When informal approaches were used, roles and expectations about involvement were often broadly described. Researchers provided study abstracts to provide context about the work, but more formal descriptions about the patient partner role were seldom provided. As a result, clarity of roles and expectations were often lacking. While formal approaches for identifying patient partners provided clear information about roles and expectations for involvement, one researcher found presenting roles and expectations in a formalized manner (e.g., goals of engagement, expected activities involved, expected time commitment, etc.) could be overwhelming to potential partners and deter participation.

While researchers were able to clearly articulate approaches for identifying patient partners, the process for becoming involved as a partner was not always clear. While the majority of individuals interviewed were able to articulate how they either identified partners or were identified themselves to participate, a few people spoke to the lack of clarity in the process. For example, one person expressed uncertainty about how they were identified but assumed it was through involvement in prior volunteer and advocacy work. In another instance, a researcher noted that a stakeholder advisory board broadly informs their research center's work. This included the PCORI-funded projects as well as others research initiatives. As a result, the individuals serving as stakeholders for the PCORI-funded project would likely not recognize a formal role on the project, as research projects were not clearly delineated.

> *And we were surprised that how few people, even though they were well attended we often have 30 people at the meetings, it was hard to get people, you know, people who could give us the time. You know, they say "Oh, this is very interesting," you know, very interested but then it was hard to get people that really have the time to commit.* ***-Patient***

An additional challenge that interviewees noted focused on ensuring representation of diverse experiences and perspectives across a range of characteristics among patient partners (e.g., health conditions, healthcare settings and treatments, age, gender, cultural traditions, geography, etc.). Approaches described to help broaden the perspectives represented included involvement of more than one patient partner on the research team, the development of patient advisory boards, involvement of patient partners actively engaged in patient advocacy or support groups, and outreach to patient communities through social media. The number of patient partners or advisors ranged across projects. When described as patient partners, a range of 1-4 individuals served on any given project. Advisory boards included greater representation ranging from 4 participants and up. One researcher described the approach for selecting advisors to serve on an advisory board for a research project that required diverse perspectives on a potentially contentious topic. Selection of patient partners included deliberative outreach to key advocacy organizations with diverse patient constituencies and diverse views on the topic at hand.

Involvement of representatives with patient advocacy organizations did raise some concerns among researchers. One person stated a concern about bias towards an agenda while another noted concern that experience with advocacy organizations (or other formal training in research advocacy) acclimates an individual to the research culture in a manner that may cloud or obscure a person's view about the research topic at hand. For this reason naivety to the research process was preferred. From the patient perspective, speaking for all patients can be intimidating, especially if your experience is limited to your own. For example, one parent partner described the challenge and burden she experienced representing the parent view for an entire region. Patients recognize that people's health experiences and challenges are diverse and felt that experience should be recognized and integrated into engagement efforts.

> *I think, you know, describing some of the protocols and, you know, the intervention elements across language becomes more complicated. You know, and then this also makes the presumption that whoever you're dealing with in the other language is literate in that language, which is not always the case. So I don't have great solutions for that.* ***-Researcher***

The diverse experiences of patients are not limited to the research topic under consideration. Different communities have different needs. Challenges with geographic, ethnic, cultural, and socioeconomic diversity arose. Tools and resources to identify and support collaboration with underrepresented populations are needed.

Researchers also noted concern about identifying patient partners facing challenging issues regarding personal health or health of their children. This view reflected an understanding that the condition under study significantly impacts patients and their families. Researchers expressed wanting to respect this and not burden people with additional work or requests. As a result, researchers expressed concern that the perspective represented would reflect that of perhaps younger and healthier patients, missing an important view from those patients who are experiencing a more advanced stages of a condition.

Key Findings for Identifying Research Partners

- Existing organizational infrastructure or established relationships are critical to identifying research partners.
- Patient advocacy and community organizations help articulate a perspective representing a broader patient base versus a singular experience.
- Lack of clarity exists on how clinician-patient relationships translate into research.
- Ensuring diverse patient experiences, values, and perspectives remains a challenge for patient engagement.
- Tools and resources to identify and support collaboration with underrepresented populations are needed.
- Clear roles and expectations for involvement are necessary.

Important Knowledge, Experience, Skills, & Attitudes for Engagement

Researchers and patients described important knowledge, experience, skills, and attitudes that aided and strengthened collaborative relationships. Some items were explicit, such as a patient's knowledge of and experience with a particular health condition or a researcher's training in qualitative research. Others included personal attributes such as interpersonal skills and acceptance of diverse views. Table 2 summarizes knowledge and skillsets identified by interviewees as important to forming a strong collaborative researchers-patient working relationship. Superscript letters represent cases where patients (^{P}) or researchers (^{R}) noted the importance of a particular item for the other perspective, or when both perspectives (^{B}) noted an item's importance.

Table 2: Important Knowledge, Experience, Skills & Attitudes

	Researchers	Patients
Knowledge	• Formal training in qualitative research • Training in community based participatory research • Knowledge of group processes • Recognition that patient experience is personal and that time and respectful atmosphere is required to foster a working relationship^{P}	• Knowledge of research advocacy • Knowledge of the specific health system or care experience if relevant • Recognition of the broader patient experience • Knowledge of issues for specific communities
Experience	• Experience facilitating groups^{B} • Clinical experience (direct patient engagement through clinical work improves one's communication skills) • Experience with community-based participatory research or projects with community engagement element	• Personal experience with the topic of research • Experience with specific healthcare systems • Experience with patient advocacy groups • Experience with community work or volunteer groups (or other group work experience) • Experience in leadership positions • Professional experience useful, including marketing and communication, web design, facilitation skills, clinical experience (in an unrelated field), project management
Skills	• Patience for engaging people new to research collaborations^{P} • Effective time management skills^{B} • Organization skills^{B} • Communication skills (writing and speaking)^{B} • Team oriented • Good interpersonal skills • Accountable	• Active listener • Willing to ask questions/learn • Familiarity with technology • Organization skills^{B} • Provides perspective that is broader than individual experience • Interpersonal skills • Communication skills (writing and speaking) • Accountable • Ability to present perspective in a balanced way, free from agenda
Attitudes & Beliefs	• Demonstrates perceived value of patient involvement in research • Enjoys working collaboratively with others • Respectful of all team members • Commitment to patient engagement as an integral part of research • Openness to change based on input • Willing to change course or try new approaches to engagement (e.g., past the traditional research meeting)	• Supportive of research and the research process • Open to diverse opinions and perspectives^{B} • Passionate about topics • Respectful of all team members • Enjoys working collaboratively with others • Willing to take on new challenges and experiences for involvement

Indicates the perspective noting the importance of a stated quality or skill for the opposite perspective: ^{P}Patient; ^{R}Researcher; ^{B}Both

Researchers

Researchers interviewed reported that prior experience with patient engagement provided them with the most guidance for establishing new collaborative relationships as part of research. This included experience grounded in community-based participatory research (CBPR), which is a particular area of research focused on conducting research activities in partnership with the community. Facilitation skills and knowledge of group processes gained either through formal training or work experience were frequently noted as helpful by both patients and researchers. Patients specifically noted that the environment for collaboration was critical. Researchers who possessed interpersonal skills and an ability to make people, especially those new to research, feel welcomed and valued was very important to ensuring a successful partnership.

> *I think you run, I think an inherent challenge of this work is being willing to let a protocol morph based on feedback. Which is, to me, a new idea, a new paradigm.* ***-Researcher***

Researchers who described their work as CBPR explained that experience engaging communities in research aided their work in patient engagement. The skills necessary for engaging patients are similar to those used for engaging community partners and involve activities such as town hall meetings, bringing in non-researchers to discuss community needs and opportunities for research, and working with the community to identify how to support dissemination of research findings to the broader community. Most importantly, the culture of CBPR is based in working alongside communities. This acceptance of and commitment to engagement as a core value of research is significant, as those new to engaging patients and other stakeholders cite limited evidence on the impact of engagement on research processes. Work from this field needs to be shared more widely so that impacts of engagement can be appreciated.

A few researchers noted that clinical experience working with patients aided their ability to engage patients as part of research. In particular, it aided their ability to break down complex topics. Clinician researchers working in pediatrics and mental health specifically noted that patient engagement in research is a natural extension of their work, since working closely with patients and patient families is a core part of successful clinical care.

> *You know, we have another grant that is pending in which we were more deliberate in patient engagement in terms of identifying individuals, and at least the other project that we have submitted a grant for, has a more defined and particular role for the patient council in accomplishing the research aims.*
> ***-Researcher***

Finally, researchers noted that their own experience with patient engagement increased their confidence and skills. One researcher noted facing challenges with initial attempts for engaging patients but felt that the research team was learning through experience and becoming more deliberate in their approaches.

Patient partners noted researcher skills and traits they found important. Researchers and research teams creating welcoming environments, allowing time for questions and learning, and creating space to get to know patient partners personally and beyond meetings and research project milestones were highlighted as important. Communication skills, and in particular facilitation skills, were valued, as it ensured that information about the project or other related activities was clearly communicated and that efforts to ensure equal participation were made. A number of patient partners also noted that patience and empathy were important to ensure patients are provided the time and safe environment to allow them to share their experiences – which at times may require them to revisit emotional points in their healthcare journey.

Patient Partners

Interviewees from both research and patient partner perspectives overwhelmingly agreed that patient partners should have knowledge of and experience with the topic of research. In addition to this knowledge and experience, many individuals spoke about searching for partners that could also speak more broadly to issues of importance to specific populations and communities. This could be through involvement in support groups, work with advocacy organizations, or through informal networking with other patients. For example, one project centered on topics for research among older adults. The patient partner provided experience on the clinical topic but also helped the research team think about issues older patients face outside of health. This insight was noted as instrumental in developing the materials utilized in the study. Another investigator expressed the importance of having community workers on the team who could speak to issues people in a low-income, under-represented population experienced to inform decisions about the study development.

> *As we encounter each different thing with my child, you could say I get a little micro degree in it. So while she was in the NICU I got a micro degree in Neonatology. When she was going to see a developmental pediatrician I, you know, got a mini micro degree in developmental, in developmental elements of pediatrics and what I needed to watch out for and understand so that I'm able, so that I am better able to ask the right questions and understand anything, understand the recommendations. So my research and experience tends to center around the needs of my child more than it does the research. As a result of that, what I share and what I know is based upon what I see within the medical industry and how I've been able to advocate around that for my child.*
>
> ***-Parent Partner***

In addition to knowledge related to the research topic, patients also noted the value their professional experience added to the research team. For example, one person noted her experience with conducting focus groups and thus her ability to contribute to the research activities in this area. Others noted professional work in communication, media, community organizations, volunteer services, experience in different areas of research, and information technology as all contributing to their work in research projects. While some researchers echoed the sentiment that professional experience added to patient partners value to the team, it was not something that was specifically sought out during the recruitment process. In some cases, professional experience had not been formally addressed as part of the collaboration, and as a result, researchers were unaware of the added knowledge and experience patients could bring to the project.

As with researchers, interpersonal skills, communication skills, organization, and respect for diverse views and experience were expressed as important for patients collaborating in research. Additionally, passion for the topic, commitment to advancing healthcare through research, and willingness to learn were also noted as important.

Challenges Faced by Researchers and Patients

Researchers and patients recognized the importance of understanding where an individual is with regards to their health. It is important that patient partners be at a point in their healthcare journey where they are not overwhelmed by or emotionally enmeshed in their experience and have the ability, time, and energy to share their particular knowledge. Researchers voiced challenges in wishing to engage patients but fearing that the request would add an unnecessary burden to patients – especially those individuals facing health conditions with high symptom burden. Similarly, patients recognized the importance of placing their health or health of loved ones as priority and felt pulled at times for balance.

Belief about the appropriate level of knowledge of research methods patients possess varied among individuals interviewed. While researchers and patients agree that knowledge of and experience with the research topic was important, there was disagreement on the right level of research knowledge and experience among patient partners. Some researchers expressed that formal research training for patient partners is not necessary, and in fact a drawback, as it potentially skews the individual's perspective. This perspective was largely held by individuals engaging patients primarily in the advisory capacity, rather than as patient partners. Alternatively, other researchers felt that a basic understanding of research provided an advantage. In particular, it helped alleviate the need to provide training about research, especially when it is not clear how best to support or train individuals about research. From the patient perspective, knowledge about research included context of the specific research project as well as research methodology, terminology, processes, and less frequently, statistics. The majority of patients engaged as partners in research felt this information supported involvement. Specifically, knowledge improved confidence as a team member and ability to contribute. In only a few cases did patients express that they did not have a particular interest in learning research skills but rather preferred to support efforts by providing input from the patient perspective as relevant to the research.

> *You know, it's pretty easy to find a patient, you know, maybe it's somebody who was a patient but they had some, you know, research training in the back, and so they're really kind of excited about being part of a research team. I don't think patients are junior researchers. I think their role is distinctly different.* ***-Researcher***

Key Findings for Knowledge, Experience, Skills, & Attitudes for Engagement
• Experience with patient and/or community engagement builds knowledge and confidence for future work.
• The patient's knowledge, experience, and perspective about the research topic are critical.
• Patient partners and researchers both express difficulties ensuring the breadth of patient experiences and needs are represented.
• Researchers need to demonstrate a commitment to patient engagement and create an environment supportive of engagement.
• Patient partners and researchers both expressed the importance of interpersonal skills for effective collaborations.
• Conflicting views on the appropriate level of research training exists among researchers and patient partners.

Resources & Training to Support Engagement

Resources

Resources described to support engagement centered on reducing barriers for patient engagement, including providing financial support to patient partners to offset costs associated with time off work or travel and parking. When travel occurred as part of the research project, including trips to meetings, travel stipends were provided to cover expenses. A few examples existed where patient partners were provided space to work at the research organization as well as access to library and computer resources. This facilitated the patient partner's ability to access information. In addition, patient partners remarked that it demonstrated both the research team and organizations commitment to patient engagement. Other resources noted as helpful included information about the organization, information about the research team, and access to file sharing platforms used by the research team.

Training

Overall, few interviewees cited existing training accessed for engagement. In part, this reflected the fact that many are new to this process and unaware of where to go to access training and support for patient engagement. When discussing training for engagement, most interviewees focused on information provided about the specific research project rather than training about patient engagement. Information about the project in the form of research abstracts or the full proposal served as one form of training for patients about the specific study. Researchers also described setting aside time before meetings to provide additional context or to answer questions about research in general or more specifically about the project. Some research teams developed training about the research process to orient patients to research, but this did not consistently occur. Among Tier I/II projects, which are focused on building out communities to support research, creation of presentations to orient people to the importance of research and engagement was described. Additional training materials developed included glossaries of acronyms and research terminology, information about the research organization, and information about roles and responsibilities for the project.

> *It's also interesting and helpful the team has been to a couple national conferences and has brought back pictures and posters and just information from other projects which kind of gives you a bigger scope of kind of this whole nationwide team looking at this issue.*
> ***-Researcher***

Existing training resources accessed to support engagement of patients and resources developed to support engagement are listed in Table 3. Common training provided to patients included Institutional Review Board required training such as HIPAA training and training on human subjects and ethical research practices. One researcher described undergoing media training provided by the research institution along with the patient partners following media requests to report about their work. Some CBPR researchers described accessing information from other organizations training or guidance on engagement. For example, the Detroit Community-Academic Urban Research Center Resources includes a number of tools and resources to guide researchers on community engagement.

Table 3. Existing Training Reported by Interviewees

	Existing Training
Researchers	• Agency for Healthcare Research and Quality Resources for Involving Stakeholders (http://effectivehealthcare.ahrq.gov/) • Aligning Forces for Quality (http://forces4quality.org/) • Community Café Training • Community Campus Partnership for Health Toolkit (https://ccph.memberclicks.net/toolkits-databases) • Community Health Improvement and Research Partnership (CHIRP) Training Materials (https://www.ohsu.edu/xd/outreach/oregon-rural-health/hospitals/chip/chirp-training-materials.cfm) • The Detroit Community-Academic Urban Research Center Resources: (http://www.detroiturc.org/about-the-urc.html) • North American Primary Care Research Group Engagement Resources (http://www.napcrg.org/Resources) • PCORI Patient and Family Rubric • PCORI Webinars & Case Studies on patient engagement • Project Tres Training in Research Ethics and Standards: (www.nationalethicscenter.org/tres) • Training materials from the National Library of Medicine on Comparative Effectiveness Research (https://www.nlm.nih.gov/) • Reference textbooks: ○ *What is a P-Value Anyway? 34 stories to help you actually understand statistics* (Andrew Vickers) ○ *Epidemiology* (Leon Gordis)
Patients	• Children's Hospital of Philadelphia (CHOP) Family Advisor Training • Cochrane Collaboration Training (http://us.cochrane.org/CUE) • Institute for Patient and Family Centered Care Resources (http://www.ipfcc.org) • Patient Advocates in Research training (Parkinson's Disease Foundation) (http://www.pdf.org/pair) • PCORI Webinars & Case Studies on patient engagement • Stanford Online Statistics Training (http://online.stanford.edu/)

Patients rarely described formal training provided by the institution outside of context for the proposed work, HIPAA training or ethical research training. Any additional training obtained occurred through involvement with specific organizations. For example, one person described training with the Parkinson's Disease Foundation's Patient Advocates in Research training program, while another described training through a patient and family advisory council. Some patient partners undertook efforts on their own to learn more about research through web-based searches, through online course work, and through viewing online webinars provided by PCORI.

Training needs varied across interviewees. Researchers described needs for better tools to support engagement, including checklists to plan for engagement and processes to evaluate work. In addition, interest in learning from others about training and tools provided to support engagement was noted. Patients requested access to glossaries of research terminology and information about the research process. Access to information on training on research methods was requested only by a few patient partners and appeared to be reflective of their level of involvement with a given project. All patients undergoing research ethics training requested that training be audience-appropriate.

Table 4: Training and Resource Needs Reported to Support Collaboration

Researchers	• Tools to develop an engagement strategy (checklists for engagement) • Examples of job or role descriptions drafted for patients • Case studies on engagement or opportunities to learn about how others are successfully engaging patients • Resources for researchers to explain or share with patients new to the experience about what partnering in research means • Research 101 (or overview of the research process) to provide patients • Better research ethics training for patients
Patients	• Research 101 (or overview of the research process) • Training on how research is funded • Jargon busters or glossaries of terminology for reference • Audience specific research ethics training • Training on the context of the research project • Training on roles and responsibilities of patient partners • Access to research methods training (if requested)

Key Findings for Resources & Training

- Limited knowledge of existing training and resources exists.
- Lack of knowledge of existing resources spurs teams to create new materials to support collaboration
- Resources for patient engagement financial support to offset costs associated with time off work, costs for meeting attendance (e.g., parking), and travel for conferences or other purposes are important.
- Providing space to work at the research organization, as well as access to library and computer resources, is valued by patient partners.
- Periodically restating the goals and mission of the research conducted is important to refocus the group.
- Training should be developed for the needs of the audience.

Themes of Engagement

In reviewing the transcripts, our team identified attributes of engagement both patients and researchers frequently mentioned in their reflections and thoughts about their experiences. They included aspects of partnerships that are often times difficult to quantify – relationships, value, respect, and trust.

Relationships

Researchers and patient partners frequently noted the importance of building relationships as integral to collaboration. The role relationships play in facilitating and fostering the research experience is important. By nature of their working environment and professional communities, the research team has an established common thread from which to build relationships. The phrase "water cooler talk" was noted to describe the ability of research teams to get to know each other outside of the context of work together. This is not the case for patient partners. The importance and value of efforts to build relationships beyond the research project with were noted by both researchers and patients. One patient partner described her experience going on hikes with the principal investigator of the research project and the importance of building community among their group. One researcher described efforts to develop relationships with the parent advisory council through the first year of the project, recognizing the importance of establishing relationships both among the parent advisors as well as with the research team. During monthly teleconferences held throughout the first year, the designated engagement lead spent much of the time asking the group about their concerns. Through open discussion, they not only learned more about the parents but the parents got to know each other as well – an important need for the group. In addition to the relationships built, the research team gained new insight and ideas to advance research by listening to experiences, ideas and concerns voiced during discussions.

> *I mean, something that has come through for us really strongly is the fact that you are building long term relationships. Not just a transaction related to a specific project.* ***-Researcher***

Researchers and patient partners noted the challenge of scheduling in-person meetings – especially when not all individuals live in the same geographic location. Despite this challenge, both researchers and patient partners noted the importance of in-person interactions to build relationships.

> *So, since the time I've met the research team in person, it's absolutely has meant a lot to me. I now have an image and a sense a little bit of these other people in a more three-dimensional way that I can sort of conjure them up, right, when I'm--when we're still participating by phone with the group. And I think that's really human nature.* ***-Patient***

Value

Value of engagement emerged in a number of ways. Researchers noted the value of engagement on their professional experience with research, value to research through improved quality in research processes and products, and value of the people willing to share important and personal experience. Researchers value the commitment patient partners place on engagement. A number of researchers expressed the dedication and time patient partners put into their work on the team noting the thoughtful and robust feedback and input received.

> *Right from the get go, the conference calls, the quality of the conference call is relative to most conference calls. People are fully engaged, they're not doing their e-mail, you know, they're not on mute. All this kind of nonsense that, you know, all this time wasting that you have in professional calls when people are multitasking, you don't have any of that. So the calls are an hour an half, they're long calls, and people are energized by them. I'm energized by them. I kind of, I've been surprised at how much I've enjoyed it.* ***-Researcher***

Patients commented on the importance of feeling valued as part of the research team, of valuing the opportunity to help shape research, of learning more about research, and of learning from other patients and families with similar experiences. A number of patient partners participating on research teams expressed feeling intimidated in initial meetings. Such feelings were quickly overcome through actions of the research team to make them feel welcome by being inclusive, eager to hear their opinions, and support of their participation. The sense of inclusion and partnership was both valued by patients and made them feel very much part of the research team.

Patients also remarked on the value of learning from other patients and families. Getting to know people experiencing similar issues in their health, or the health of loved ones provides a sense of community as well as an opportunity to learn from others experience.

> *I think that this program also helped me, because even though I am not as far along in my journey as some of the other parents, I can see how some of the things that I've learned and processed can help them as well as the process of me learning from them and how -- what they've already accomplished.* ***-Parent Partner***

Respect & Trust

Respect and trust were two constructs tied closely together. Respect, as described by patients and researchers, was demonstrated by timely communication, being open to diverse views and perspectives, active listening, providing adequate time and opportunity for discussion, and transparency on how patient involvement informs decisions made. Providing adequate tools and resources for involvement were also noted as important to ensure patients could fully participate in the process.

Respectful processes led to expressions of trust in the research team and the research as a whole. Individuals representing the patient perspective need to be able to trust that they are being genuinely heard, listened to, and taken seriously. It was also noted that trust builds over time with the development of relationships, and this should be recognized by those researchers and patients forging new collaborations.

Key Findings for Themes of Engagement

- Relationships, value, respect, and trust are critical elements of successful partnerships and all develop over time.
- Efforts to develop relationships outside of the research project are important to successful partnerships.
- Researchers believe patient involvement brings value to research through improved quality in research processes and products.
- Researchers value people willing to share important and personal experience.
- Patients value the opportunity to advance research, to learn about the research process, and to connect with and learn from other patients and families experiences.
- Providing adequate time and opportunity for discussion and transparency on how patient involvement informs decisions made helps build trust.

Summary

The INSPIRE initiative sought to learn from the experiences of researchers and patients engaged in PCORI-funded research to learn about approaches to engagement and strategies for building collaborative partnerships. Engaging patients in research activities is a core requirement for PCORI funding and thus a motivator for researchers to develop processes to support patient involvement throughout the course of proposed work. Yet this was not the sole motivator expressed by researchers. Researchers noted how patient engagement offered the opportunity to ground research in relevant issues, to understand the implications of research from the patient perspective, to help bridge the gap between research and practice, to assist with translation of research to the community, and to obtain assistance in developing patient-facing materials and messaging.

> *For me this was an opportunity to help answer research questions that are really concerning to real communities. So to create more relevant research space.* ***-Researcher***

Patients partnering in research expressed a number of motivations for getting involved. The majority of patient partners expressed the importance of having the opportunity to improve, advance, and change healthcare as a result of partnering on projects. For patients, involvement is more than just the research. It is a commitment to advancing patient care and outcomes for other patients and families experiencing similar issues – both present and future. Patient partners also noted motivations such as helping improve representation in research for underrepresented communities and patients, learning more about research, and learning more about the research organization. Individuals affiliated with advocacy organizations or involved in other volunteer activities additionally expressed a motivation for taking part in a new opportunity to provide the patient voice through partner or advisory roles in research.

> *I read this book somewhere about how people don't want quarter inch drills they want quarter inch holes and that's kind of the concept that I think is really important for research projects is and it kind of goes back to my concept, you know, what I said earlier about people don't care about the burden of asthma on society, they care about the fact that their kid can't breathe.* ***-Patient***

At the core, however, many patients expressed the belief that through involvement in research, they could drive change at the patient level. In particular, patients noted the opportunity to bridge the gap between research and policy and the needs of patients, parents, and caregivers. The ability to inform research and ensure that research remains focused on patient care and creating actionable findings was frequently expressed as a primary purpose for involvement.

Challenges noted by both researchers and patients reflect those consistent with literature on engagement. Developing relationships with patients, or others new to research and engaging them as partners requires adequate support, both for the research team as well as patients. Researchers need to allot appropriate timelines, staffing, and funds for engagement. Patients need access to the research community in a manner that supports involvement during research development. Further, given that research involvement comes on top of personal life, work commitments, and health, it is important that researchers identify novel approaches to engagement to facilitate involvement.

Limitations of this report should be noted. Our steering committee was surprised by the limited knowledge of existing resources and efforts to support patient involvement in research. We intentionally restricted our outreach to PCORI-funded projects in the greater Northwest Region. As a result, this restricts our knowledge to those projects funded in this region and may miss important perspectives from researchers and patients with different or more expansive experience. For example, patients involved in research advocacy supported through patient and consumer advocacy groups (e.g., Project LEAD through the National Breast Cancer Coalition, Consumer's United for Evidence Based Healthcare (CUE), US funding agencies (e.g., PCORI, National Institutes of Health, and Agency for Healthcare Research and Quality) and international organizations (e.g., INVOLVE, James Lind Alliance). Another limitation includes greater representation from the researcher perspective. Information about the principal investigators, available publically on PCORI's website, served as the initial contact for interviews. In order to reach patient partners, we needed approval and contact information from the principal investigator. If a principal investigator did not respond to requests for interviews or did not forward on patient partner contact information, we could not conduct outreach, and that voice was missing.

Recommendations

PCORI-funded investigators and research partners provide valuable perspectives on the experience of engagement. One-on-one interviews allowed us to explore in-depth the diverse approaches to engagement and collaboration and tips for successful engagement (Appendix C). In particular, we identified recommendations for supporting the PCOR community outlined below.

- Create listservs or communities specific to patient engagement, where experiences, challenges, and successes can be shared and feedback can be solicited
- Provide access to information about tools and trainings developed (or in development) as part of other PCORI-funded projects to reduce rework or duplicative efforts of other research teams (perhaps a central repository of tools)
- Recognize the time and effort involved in patient engagement through expanded budget or timeline from funding announcement to proposal due date
- Allow time in the proposal-writing or immediate post-funding phase for co-planning or developing of engagement plans
- Help investigators plan for needed input from stakeholders by building in reviews to milestones (e.g., additional milestone of sending draft product to stakeholders or a milestone around a brief summary of how stakeholder input changed product that is well in advance of final research product milestone date)
- Create a national database of interested partners, like clinicaltrials.gov – from both researcher and patient point of view
- Develop IRB guidance normalizing outreach to study participants for future advisory opportunities or to build in dissemination of results piece
- Develop models for patient engagement in research based on INSPIRE work
- Create guidance on minimum expectations for evaluating patient engagement in research

- Develop bibliographies for various aspects of patient engagement – planning for, models for, evaluation, patients new to research, etc.
- Employ user-centered design principles to create a searchable website for making existing resources available in an organized and searchable way for patients and researchers
- Make available training materials, including glossaries, to bridge language gap between patients and researchers
- Create archived webinars or case studies focused on challenges faced in PCOR collaborations (e.g., institutional barriers for engagement, power balance and patient-research partnerships, managing diversity in engagement, evaluating effective engagement, etc.)
- Incorporate training on patient engagement into educational curriculum for healthcare research
- Establish guidelines for systematic reporting on patient engagement as part of research findings and manuscripts

Appendix A: INSPIRE Phase I Interview Guides

Patient Partner Interview Guide

INTRODUCTION

The goal is to introduce the topic/goal of the interview.

The goal for today's discussion is to learn about your approach to building partnerships with your Principal Investigator and research team to support patient-centered outcomes research. In particular, we are interested in hearing your thoughts about what constitutes a successful patient-researcher collaboration, learning about tools and resources you have found helpful in your work to support meaningful collaborations, and learning about the gaps (or perceived needs) for tools and resources to further support patient-researcher collaborations.

SECTION 1: EXPERIENCE

Our first questions are related to your overall experience as a Patient Partner on a research project.

- Please describe your experience as a Patient Partner on the project.
- How were you identified as a Patient Partner for your project? (e.g., approached by the research team, reached out to research team as a potential advisor, connected through another organization or person)
    - At what point did you become involved in the project (proposal development, upon funding, etc)?
- When you were approached to participate in your project, what did you understand your role to be as part of the project?
    - Was your role clearly defined and communicated to you?
    - Was your anticipated time commitment clearly laid out for you?
    - What was your understanding of your role at the start, and how has that changed?
    - What information (resources or training) if any did you receive prior to agreeing to participate?

SECTION 2: IMPORTANT SKILLS

The next questions focus on what skills you feel are important to productive patient-researcher collaborations.

- What skills, knowledge, experience, and support has helped you in your work with researchers? (For example, information about the clinical condition, statistics, project milestones and deliverables, etc.)
- What level of knowledge or experience is necessary for patients involved as partners on research teams?
    - Do you feel this varies for activities in research (e.g., topic prioritization, study development)?

- What level of knowledge, experience, or other qualities are necessary for researchers collaborating with patient partners?

SECTION 3: TRAINING & RESOURCE NEEDS

The next questions are related to both educational trainings that helped you understand and fulfill your role as Patient Partner and written or online resources you have accessed in your work. We will also talk about gaps in training or resources you feel currently exist. (If clarification is needed between training and resources: training – in-person or online courses or tutorials; resources - job or role descriptions, glossaries, websites.)

- What, if any, experience did you have prior to working on this project? Did you previously serve as a patient partner on a research project? Have you participated in any training or accessed any resources since becoming involved in the project? (For example, personal experience with clinical condition of project focus, technical or professional experience in the project area, formal patient advocate training, etc.)
- What, if any, training or resources were you offered to support your involvement?
    - Have you helped develop any resources or tools as part of your work on the project?
- What training or resources would you find helpful for improving your confidence, skills, or knowledge to support your involvement in research?
- What training or resources do you think would be most impactful for patients? Researchers?
    - What format do you think would be helpful (video/brochure/planning tool/etc.)?
    - Would you rate this as a high priority need?
    - Would this resource be helpful for researchers? Patients? Both?
- In looking towards your future involvement as a research partner, what training, tools or resources do you feel would be helpful for you and perhaps others?

SECTION 4: EXISTING RESOURCES

Finally, we are interested in any recommendations you might have for organizations or materials that exist to support patients engaging as research partners.

- What current organizations [if any] do you reference to support engaging in research?
    - Have you attended specific trainings or found existing materials helpful?

WRAP-UP

Researcher Interview Guide

INTRODUCTION

The goal is to introduce the topic/goal of the interview.

The goal for today's discussion is to learn about your approach to building partnerships between patients and researchers to support Patient-Centered Outcomes Research. In particular, we are interested in hearing your thoughts about what constitutes a successful patient-researcher collaboration, learning about tools and resources you have found helpful in your work to support meaningful collaborations, and learning about the gaps (or perceived needs) for tools and resources to further support patient-researcher collaborations.

SECTION 1: EXPERIENCE

Our first questions are related to your overall experience with patient engagement from your perspective as a researcher.

- Please describe your experience with patient involvement from your perspective.
    - Were patients actively involved as the proposal was being developed?
    - How were patients identified and involved in the work conducted? (e.g., approached by the research team, reached out to research team as a potential advisor, connected through another organization or person, etc.)
        - Were there existing collaborations that allowed for natural partnerships? If so, please explain.
    - Did you look for particular skills, organizational relationships (i.e., with advocacy organizations), or experiences when looking for partnerships? Why?

SECTION 2: IMPORTANT SKILLS

The next questions focus on what skills you feel are important to productive patient-researcher collaborations.

- What level of knowledge or experience is necessary for patients involved as partners on research teams?
    - Do you feel this varies for activities in research (e.g., topic prioritization, study development)?
- What level of knowledge or experience is necessary for researchers collaborating with patient partners?
- What skills, knowledge, experience, or support has helped you in your work with patients?

SECTION 3: TRAINING & RESOURCE NEEDS

The next questions are related to both educational trainings and written or online resources that either helped you engage patients in your research or that your Patient Partners(s) have accessed to help them perform their roles. We will also talk about gaps in training and resources you feel currently exist. (If clarification is needed between training and resources: training – in-person or online courses or tutorials; resources – job or role descriptions, glossaries, websites.)

- What, if any, experience in engaging patients did you have prior to working on this project? Have you participated in any training or accessed any resources in your previous experience or to help you with this project?
- What, if any, resources, or tools did you develop for your team to support patient involvement? (e.g., payment policies, communication strategies, job/role descriptions, etc.)
- What strategies do you use to communicate with patient partners?
    - How frequently do you communicate?
- What training or resources would you find helpful for improving your confidence, skills, or knowledge to support your efforts involving patients in research?
- What training or resources do you think would be most impactful for researchers? For patients?
    - What format do you think would be helpful (video/brochure/planning tool/etc.)?
    - Would you rate this as a high priority need?
    - Would this resource be helpful for researchers? Patients? Both?
- What approach, if any, did you take to developing training, resources, or tools for your team to support patient involvement?

SECTION 4: EXISTING RESOURCES

Finally, we are interested in any recommendations you might have for organizations or materials that exist to support researchers engaging patients as research partners.

- Are there current organizations that you reference for support with engaging patients in research?
    - Have you attended specific trainings or found existing materials helpful?

WRAP-UP

Appendix B. PCORI-funded projects in the Pacific Northwest region

All information publicly available on PCORI website (http://www.pcori.org/research-results).

Project Title	State	Award Type	Year Awarded
Connecting Research and Real Life: Building a Network in the Columbia River Gorge	Oregon	Tier I (Tier 2)	2013/2015
Citizen Pscientist	Oregon	Tier I (Tier 2)	2013
Increasing Patient Engagement and Capacity Building between Community Stakeholders and Patients to Improve Diabetes Education and Management among School-Aged Children *new title for Tier II Improving Diabetes Education and Management in Schools: A Community Project - Tier II	Washington	Tier I (Tier 2)	2013/2015
Puget Sound Asthma Coalition: A Community, Clinical, and Academic Partnership *new title for Tier II: Promoting Patient-Centered Research in the Puget Sound Asthma Coalition - Tier II	Washington	Tier I (Tier 2)	2013
Improving the Lives of Alzheimer's Patients and Their Caregivers: A Patient-Centered Statewide Approach	Montana	Tier I (Tier 2)	2013
Patient-Centered Outcomes for the Parkinson's Disease Community in Wyoming *new title for Tier II: Improving the Quality of Care for the Wyoming Parkinson's Disease Community - Tier II	Wyoming	Tier I (Tier 2)	2013
Making Stomach Cancer a Health Priority among Asian Americans *new title for Tier II: Improving Early Detection of Stomach Cancer Among Asian Pacific Americans - Tier II	Washington	Tier I (Tier 2)*Organizaition and Project Title changed	2013
Medication-Taking Preferences & Practices of Patients with Chronic Conditions	Washington	Pilot Projects	2012
Patient Voices: Supporting Patient Involvement in the Learning Healthcare System	Washington	Engagement Award	2014
Engaging Stakeholders to Improve Depression Management in a Tribal Health System	Alaska	Pilot Projects	2012
Extending PROMIS Pain Item Banks: Pain Self-Efficacy and Pain Catastrophizing	Washington	Accelerating PCOR and Methodological Research	2014

Expanding PRO Assessment Integrated into Routine Clinical Care of Patients with HIV to New PROMIS Domains: Identifying Patient Priorities, Developing Cross-Walks with Legacy Instruments, and Evaluating Predictive Validity	Washington	Accelerating PCOR and Methodological Research	2014
A Structured Approach to Prioritizing Cancer Research Using Stakeholders and Value of Information	Washington	Accelerating PCOR and Methodological Research	2013
Comparing Engagement Techniques for Incorporating Patient Input in Research Prioritization	Washington	Accelerating PCOR and Methodological Research	2014
Creating a Clinic-Community Liaison Role in Primary Care: Engaging Patients and Community in Health Care Innovation	Washington	Improving Healthcare Systems	2012
A Comparative Effectiveness Trial of Optimal Patient-Centered Care for US Trauma Care Systems	Washington	Improving Healthcare Systems	2013
Innovative Methods for Parents and Clinics to Create Tools (IMPACCT) for Kids Care	Oregon	Improving Healthcare Systems	2012
Evaluation of a Health Plan Initiative to Mitigate Chronic Opioid Therapy Risks	Washington	Improving Healthcare Systems	2013
Rural Options At Discharge Model of Active Planning (ROADMAP)	Montana	Addressing Disparities	2013
Delivering Patient-Centered Adolescent Preventive Care with Training and Technology	Washington	Improving Healthcare Systems	2014
Comparative Effectiveness of Surveillance Imaging Modalities in Breast Cancer Survivors	Washington	Assessment of Prevention, Diagnosis, and Treatment Options	2013
Evaluation of a Patient-Centered Risk Stratification Method for Improving Primary Care for Back Pain	Washington	Assessment of Prevention, Diagnosis, and Treatment Options	2012
Developmental Trajectories of Impairments, Health, and Participation of Children with Cerebral Palsy	Washington	Assessment of Prevention, Diagnosis, and Treatment Options	2013
Health System Intervention to Improve Communication About End-of-Life Care for Vulnerable Patients	Washington	Improving Healthcare Systems	2013
Improving the Quality of Care for Pain and Depression in Persons with Multiple Sclerosis	Washington	Improving Healthcare Systems	2013
Long Term Outcomes of Lumbar Epidural Steroid Injections for Spinal Stenosis	Washington	Assessment of Prevention, Diagnosis, and Treatment Options	2013
Treatment Options for Depression in Patients Undergoing Hemodialysis	Washington	Assessment of Prevention, Diagnosis, and Treatment Options	2014

Caring for the Whole Person: A Patient-Centered Assessment of Integrated Care Models in Vulnerable Populations	Oregon	Improving Healthcare Systems	2014
Tools and Information to Guide Choice of Therapies in Older & Medically Infirm Patients with AML	Washington	Assessment of Prevention, Diagnosis, and Treatment Options	2013
Guidelines to Practice (G2P): Reducing Asthma Health Disparities through Guideline Implementation	Washington	Asthma Treatment Options for African Americans and Hispanics/Latinos	2013
Accelerating Data Value Across a National Community Health Center Network (ADVANCE)	Oregon	Clinical Data Research Networks	2013
A Pragmatic Trial to Improve Colony Stimulating Factor Use in Cancer	Washington	Pragmatic Clinical Studies and Large Simple Trials to Evaluate Patient-Centered Outcomes	2015

Appendix C. Tips for Effective Engagement

- Plan for Engagement
  - Explore different models for collaboration
  - Allow for flexibility in plans
  - Plan appropriate time for people to share their views and participate
  - Plan appropriate resources for involvement
  - Think outside of traditional research meetings
  - Plan for activities outside of research meetings
- Recognize “non-patient” experience
  - Learn about professional experiences
  - Learn about volunteer experiences
  - Learn about other interests
- Communication is critical
  - Ask about preferences for communications
  - Take time to regularly connect with mission and goals of the project
  - Provide context setting for the project or meeting
  - Use multi-modal approaches to communicating – email, phone, in-person
  - Ensure good facilitation of meetings
- Breakdown the hierarchical structure
  - Learning to take a back seat when appropriate
  - Allow patient partners to lead activities
  - Invite patients to co-present or co-author publications
  - Give back – participate in
  - Create equality among the team
  - Lead by example
- Build relationships
  - Provide an opportunity for the research team, inclusive of patient partners, to get to know each other
  - Dedicate time to get to know patient partners
  - Create and foster relationships with patient and community organizations for future collaborations
- Create a welcoming environment
  - Ensure all members of the team understand the roles and perspectives represented
  - Create ground rules to support respectful discussion
  - Identify a good facilitator for group meetings
- Evaluate engagement
  - Regularly check-in with researchers and patient partners to assess engagement
  - Be able to respond and change course to improve experiences

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