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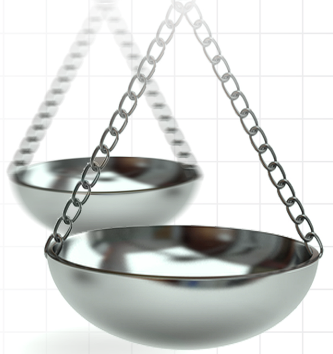

Patient engagement in patient-centered outcomes research: challenges, facilitators and actions to strengthen the field

Journal of **Comparative Effectiveness Research**

Aim: To describe challenges to and facilitators of patient engagement to inform future strategies and suggested actions to strengthen engagement. **Methods:** Interviews with 19 principal investigators of projects funded by the Patient-Centered Outcomes Research Institute and with 33 patients from 18 of the 19 projects. **Results:** Facilitators included using existing resources, having clear goals, educating patients and treating patients respectfully. Logistical challenges included extra time and work, institutional barriers and difficulty having meetings. Substantive challenges to selecting, educating and engaging patients, and incorporating feedback were also reported. **Conclusion:** To bolster the infrastructure for engagement, we suggest funders, institutions and researchers focus on resources and training for researchers and patients, networks and programs to connect stakeholders and model policies.

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Patient engagement, the practice of involving patients in research in ways other than as subjects [1,2], reportedly enhances the relevance of research to patients and improves dissemination and uptake of findings [1,3–5]. Patient engagement has been described as a fundamental aspect of comparative effectiveness research (CER) and patient-centered outcomes research (PCOR) [6,7], which is designed to answer research questions that help patients and caregivers make informed healthcare decisions [8]. In fact, the Patient-Centered Outcomes Research Institute (PCORI), a nonprofit PCOR funding organization, requires patient engagement [9], contributing to its proliferation.

Despite growing recognition that patient engagement is essential to PCOR and CER, there is limited information for researchers. The literature, which ranges from reviews [1,3–5,10] and conceptual articles [11,12] to individual case studies [7,13–15] and blogs [16], contributes to an emerging body of evidence on exemplary practices and persistent challenges. Specifically, the literature describes helpful techniques, such as establishing clear roles [7,13], building equitable and enduring partnerships [11] and using particular engagement strategies [14–17], while reported challenges include lack of time, resources and training [1,3–4,10,18–19], and difficulty finding representative patients [1,12,17]. This information is mostly from reviews of individual studies or reports from individual researchers rather than empirical studies of the collective experiences of researchers and patients.

Prevailing calls for researchers to disseminate lessons learned on engaging patients in PCOR and CER [20–22] highlight the present need for evidence-informed practical guidance about patient engagement to educate the increasing number of interested researchers. Further, a better understanding of current challenges and potential ways to address them could help researchers avoid common pitfalls while identifying areas where additional actions to mitigate such challenges are warranted.

Researchers funded under PCORI's earliest initiatives navigated patient engagement with limited guidance. The experiences of these pioneering researchers and the patients they engaged offer insights that can inform engagement strategies and actions funders, institutions and researchers may consider to advance the field of patient engagement.

Methods

The aim of this study was to understand facilitators of patient engagement, challenges and strategies to address challenges using qualitative interviews with PCORI-funded principal investigators and patients engaged in their projects. Approval by an institutional review board (IRB) at Johns Hopkins Bloomberg School of Public Health was obtained.

Sampling

Purposeful sampling was used to select projects from PCORI's earliest funding awards, the 50 Pilot Projects (2-year projects awarded in June 2012) [23] and the 25 Cycle I Awards (3-year projects awarded in December 2012) [24], because they were furthest underway when interviews were conducted (December 2013 through May 2014).

The goal of sampling was to include projects using different engagement approaches (advisory groups, patient coinvestigators, patient research team members, focus groups, interviews and surveys) while also capturing diversity with respect to the patients engaged, the research topic and whether patients and researchers had prior relationships with each other. Funding applications were reviewed to identify projects with patient engagement, and projects were then selected following the criteria.

During recruitment, researchers were asked to participate in an interview and refer up to two patients who were actively engaged in their projects and had different backgrounds or experiences so that a diversity of patient perspectives could be included. Researchers obtained permission before sharing patients' contact information, and patients were then contacted. When two patients from a project were interviewed, the way in which they were different depended upon the make-up of the group but could include differences with respect to affiliation with advocacy organizations, health status and experience with the study condition, previous experience engaging in research, pre-existing relationships with the researcher, professional experience in the medical field, age or gender.

Interviews & questionnaires

Interviews were audio-recorded and oral consent was obtained. During recruitment and consent, participants were told that the interviewer (LE) worked at PCORI, which was aware of but had no involvement in the project. Participants were informed that the project comprised the research for the student's doctoral dissertation, and that PCORI would have no access to information about which studies or individuals participated, nor would PCORI have access to any data.

Participants completed a brief, demographic questionnaire with questions on gender, race, education, employment and prior experience engaging in research. The interview guide focused on participants' experiences with patient engagement for the project including how they thought it was going, what had and had not worked well and what strategies had been used to address challenges and support engagement (interview guides are included in the Supplementary Appendix).

Prior to data collection, a researcher from this study solicited feedback from a community research advisory council by leading an in-person discussion on the study, sharing materials and fielding questions from council members who provided written feedback after the meeting. In response, several changes, particularly to the interview guide, were made to make the study more acceptable to patients. The researcher then presented to the council to explain how feedback was used.

Analysis

Data collection and analysis occurred iteratively with interviews conducted until informational redundancy was reached. Audio-recordings were transcribed and reviewed. A coding scheme was developed deductively from interview questions and inductively from open coding to capture emergent topics. Codes were applied to transcripts using ATLAS.ti [25] and organized around salient themes. A second coder coded six transcripts to assess reliability; a high concordance between coders was obtained.

Results

Participants

A total of 67 out of the 75 projects engaged patients and were thus eligible. A total of 33 researchers were recruited; 19 participated and 14 declined, yielding a response rate of 58%. Of those that declined, two did not respond after four attempts and the others cited lack of time (n = 4), IRB concerns (n = 1), not yet engaging patients (n = 1), not comfortable having patients interviewed (n = 4) and no longer able to contact patients whom they engaged (n = 2). Interviews, which lasted an average of 45 min, were conducted in person or by phone with 19 researchers from 19 projects. Most researchers were white (n = 17), and about half were female (n = 10), had served as researcher on seven or more grants including their PCORI project (n = 9), and had experience engaging patients (n = 10).

37 patients were approached for interviews; 33 participated and 4 declined, yielding a response rate of 89%. One declining patient did not respond, one cited lack of time and two cited lack of interest. A total of 33 patients (from 18 of the same 19 projects) were interviewed in person or by phone, with interviews lasting an average of 42 min. Most patients were white (n = 26), and over two-thirds were female (n = 23), employed (n = 24) and at least college educated (n = 25). About half had a chronic condition (n = 17), and more than a third had previously engaged in research (n = 13). Recruitment numbers are summarized in Table 1.

Engagement approaches

Most projects used multiple engagement approaches (n = 14), including involving patients in advisory groups (n = 16), as coinvestigators or research team members (n = 9), in focus groups or interviews (n = 7) and in surveys (n = 3). Advisory groups usually met at least quarterly. Coinvestigators and research team members met regularly with researchers. Focus groups, interviews and surveys usually involved single meetings to get feedback. Nearly half of projects (n = 9) engaged patients in pilot testing study materials, and over half (n = 11) reported pre-existing researcher–patient relationships. Additional information on the effects of engagement in these projects is reported elsewhere [26].

Facilitators

Note: Quotations from interviews are labeled by random project number and respondent type (researcher or patient).

Researchers and patients described several key facilitators to patient engagement, which are described below and summarized in Table 2.

Existing resources

About a third of researchers (n = 6) reported engaging patients from established advisory councils. This strategy enabled researchers to connect with patients who were familiar with clinical practice and research, which, as one patient described, was *"wonderful for us because it has been a way to have people who are trained"* (Project #101).

Clear goals

About a third of researchers (n = 7) and nearly a fifth of patients (n = 6) described the importance of communicating goals for engagement. As one researcher said: *"You just have to be so clear why you're doing this, to yourself and to the people that are participating"* (Project #113). About a fourth of patients (n = 8) described receiving agendas for upcoming meetings or meeting summaries, which were helpful.

Patient education

Educating patients was regarded as crucial. About a quarter of researchers (n = 5) described helpful techniques including developing plain language handouts, sharing articles and presenting on study topics. One researcher created a glossary, which the patient described as essential: *"I need to understand those medical terms because I don't have a medical degree"* (Project #102). Another researcher designed a training in which a lecture for clinicians was adapted for patients. This method's success reinforced the researcher's belief that anyone can become proficient in advanced topics when information in provided appropriately. A patient described the training as putting *"everybody on a more equal plane… so that we all shared the same language and can speak about it in a way that was medically relevant"* (Project #104).

Respectful treatment

Over half of researchers (n = 10) and nearly two-thirds of patients (n = 21) described at least one of three ways in which it was helpful for researchers to treat patients

Table 1. Overview of recruitment and enrollment numbers.

	Pilot projects		Cycle I awards		Total	
	Researchers	Patients	Researchers	Patients	Researchers	Patients
Eligible	42	n/a	25	n/a	67	n/a
Recruited	19	18	14	19	33	37
Declined	10	2	4	2	14	4
Interviewed	9	16	10	17	19	33
Response rate	9/19 (47%)	16/18 (89%)	10/14 (71%)	17/19 (89%)	19/33 (58%)	33/37 (89%)

This table reports the numbers that were eligible, recruited, declined participation and participated as well as the response rate (the number participated divided by the number recruited) for researchers and patients by funding cycle and in total. The total number of patients engaged in eligible projects was not available, indicated by 'n/a' in the patient columns.

Table 2. Facilitators of patient engagement.

Facilitator	Illustrative quotation†
Use of existing resources: – Established advisory councils to find patients to engage	*"We got help from the head of the patient resource center at (the researcher's institution) to identify some patients and family representatives who already were serving on these kinds of committees and were interested."* (Project #112, Researcher)
Clear goals: – Knowing goals for patient engagement – Informing patients about goals	*"Just making clear what the expectations are, of their role, and giving them feedback periodically and updates... so that they don't feel like their review or feedback was for naught."* (Project #111, Researcher)
Patient education: – Research methods – Study topic – Technical terms	*"When you bring in stakeholders that are not physician slash researchers, whether they are a patient or not a patient, you have to get people to a certain level in order to be able to interact. There has to be common understanding to get people to a certain level, so things like developing a glossary, right? It's time consuming, but it's really essential to do in educating and making sure that people can actively contribute to conversations about research."* (Project #102, Researcher)
Respectful treatment of patients: – Acting politely – Valuing patient input – Promoting equality	*"Just the basic respect for each other's expertise and understanding that our community members are experts in their community; and they bring that to the table, to us. And we are experts in research design and research, and those types of things, and we bring that to the table. We each bring something different, but it's equally as important."* (Project #105, Researcher)

†Quotations from interviews are labeled by random project number and respondent type (researcher or patient).

with respect. First, about a fifth of researchers (n = 4) and a fourth of patients (n = 9) described how researchers acted politely by, for example, completing paperwork for compensation, accommodating schedules, holding meetings at convenient locations and building rapport. As one patient said: *"They feed us and they make sure we're all comfortable and they engage us on a personal level"* (Project #103).

Second, over half of researchers (n = 10) and patients (n = 17) described the importance of respecting patient input by soliciting and valuing patient opinions. As one researcher stated: *"Being respectful of (patients') expertise is enormous"* (Project #104). Nearly a third of researchers (n = 6) described respecting patient input by reporting back how it was or was not used: *"If you consider something and decide not to respond to it: 'We didn't do that earlier and here's the reason why'... Really just do things that make them feel like you are treating them respectfully"* (Project #112, Researcher). Respectful actions fostered strong relationships and spurred patient participation.

Third, nearly half of researchers (n = 9) demonstrated respect to patients by promoting equality. One researcher, for example, had stakeholders develop guiding principles to *"enforce the fact that everybody's voice was equal"* (Project #102), and another four researchers used first names instead of professional titles. A few patients (n = 5) reported how being involved in decision-making enhanced respect. Researchers found it helpful to elevate patients to leadership roles. As one researcher stated, *"Doing things behaviorally that demonstrate that you are behind some level of equality in power here, in this situation, is very, very important"* (Project #101).

Logistical challenges

Challenges pertaining to planning for patient engagement were more commonly reported by researchers than patients and are described below and in Table 3.

Extra time & work

Over half of researchers (n = 11) failed to anticipate the extent of work and time needed for engagement. As one researcher reported, *"It really takes time to set up this process and to do it well"* (Project #108). Researchers also faced challenges with the work necessary to incorporate feedback. As one researcher stated, *"You're on a fixed timeline and a fixed budget; that's been challenging"* (Project #107). A few researchers (n = 3) noted that *"lessons learned would be to anticipate that and work it into the timeline"* (Project #109, Researcher).

Institutional barriers

About half of researchers (n = 9) faced institutional barriers. Arranging compensation, for example, was administratively onerous: *"Invoicing everybody for their time and doing all the paperwork to pay them for each of the calls takes time, and I would say we underestimated that"* (Project #113, Researcher). One researcher expressed frustration that her institution capped compensation to patients, who sometimes missed work or needed childcare to participate.

About a third of researchers (n = 6) reported difficulty with IRBs. A few IRBs misunderstood that engaged patients were different from research subjects and did not need to sign consent forms; researchers resolved this by communicating with IRBs. There were also challenges with the IRB – it required human subjects protections training, with one researcher reporting that it required *"a huge amount of resource,"* and a patient from that project calling it *"one of the toughest hurdles"* (Project #115).

Scheduling & having meetings

About a quarter of researchers (n = 5) faced difficulty having meetings, which some addressed by scheduling meetings when patients were already at the institution or holding multiple meetings to accommodate schedules. A few patients (n = 5) reported difficulty meeting in-person because of physical impediments or transportation issues; two researchers responded by meeting virtually. Projects using high technology strategies generally had success, but such strategies could have drawbacks such as patients having difficulty accessing or using the Internet. One researcher addressed this challenge by mailing materials to a patient with no Internet access, and two researchers switched from virtual to in-person meetings in response to patients' preferences.

Substantive challenges

Researchers and patients both reported substantive challenges to conducting patient engagement, which are described below and summarized in Table 4.

Selecting patients

Researchers and patients described challenges to selecting patients for engagement. About half of researchers (n = 9) expressed concern that patients were not representative of the patient population. Most were unable to address this; however, one researcher recruited from several groups to include healthy, ill, at-risk, low-income and higher income patients. Alternatively, two researchers prioritized patients with experience over achieving representativeness.

Although researchers generally spoke highly of the patients they selected, about a fifth (n = 4) suggested more screening was needed: *"I would probably figure out a way to recruit patients more like a job interview… I would invest a lot more time in recruiting and selecting patients that would fit with the team"* (Project #115). A third of

Table 3. Logistical challenges to patient engagement.

Logistical challenge	Illustrative quotation[†]
Extra time and work: – Work building capacity and organizing engagement – Time and effort for patient engagement	*"It's much easier… just to drive it forward. When you have to back up a little bit and get input and be participatory, it's time consuming, and I would suspect that many researchers would be challenged by this model."* (Project #118, Patient 1)
Institutional barriers: – Administrative hurdles – IRB challenges	*"Just the logistics…it is a challenge, like institutionally, how do you pay these folks, those kinds of things. And you know, the IRB issues, they're just red tape, extra red tape."* (Project #107, Researcher)
Difficulty holding meetings: – Scheduling challenges – Issues with meeting modality (in-person or virtual)	*"There are things I think everyone faces – logistical challenges… Physically meeting is hard. Some folks are disabled now. Some people work and have lives. And it's just hard… any meeting with more than two people, it's really hard to orchestrate."* (Project #117, Researcher)

[†] Quotations from interviews are labeled by random project number and respondent type (researcher or patient).
IRB: Institutional review board.

Table 4. Substantive challenges to patient engagement.

Substantive challenge	Illustrative quotation†
Challenges selecting patients: – Identifying patients who would be a good fit with the team – Identifying patients who could focus on needs of patient population	*"It can be a detriment in the sense that if people need to talk more than listen, they may not be ready to be an active participant in a way that is helpful… People who have used their experience to understand the larger experience of other people involved in your care can be very helpful."* (Project #114, Patient 2)
Challenges educating patients: – Research methods – Study topic – Technical terms	*"When you involve non-professional science people in a science team, you're going to have a lot of time taken out of a meeting to discuss something that… we don't understand."* (Project #115, Patient 2)
Challenges engaging patients: – Researchers feeling unprepared – Patients feeling unable to participate	*"It feels very fragmented because we don't meet very often. Sometimes it's easy to lose the thread of what's going on… so that makes it a little harder, I think, to stay focused."* (Project #103, Patient 2)
Challenges incorporating patient feedback: – Lack of time or resources – Feasibility concerns – Scientific inappropriateness – Difficulty sharing control	*"There was a suggestion that we have this survey available in other languages and so we examined that and it would've been good… But it's hard, and there's a limit to the money."* (Project #103, Patient 1)

†Quotations from interviews are labeled by random project number and respondent type (researcher or patient).

patients (n = 11) articulated the importance of screening. As one patient commented, if a patient *"has not been… screened or any due diligence done,"* researchers might select a patient *"who is just coming in to complain about their lot in life; it is not going to help a study"* (Project #116). While researchers emphasized identifying patients who worked well with their team, patients emphasized identifying patients who adopted the perspective of the patient population rather than focusing on themselves.

Patients also described the ideal type of patient to engage. A few (n = 7) believed that regular patients with no medical background provided an outside perspective while about as many (n = 6) believed trained advocates provided contextualized input that regular patients could not. A few patients (n = 4) saw equal and complimentary value in both, suggesting advocates could set agendas and regular patients could serve as sounding boards.

Educating patients

It was difficult for researchers to educate patients about study topics and research concepts. About half of researchers (n = 9) and a third of patients (n = 12) noted that if time were not dedicated to education, patients' lack of familiarity could delay meetings, impede contributions and foster dissatisfaction. Further, patients reported needing courage to request clarifications: *"I have got to have the guts to ask: 'Can I just ask a question? Can you just explain to me what you just said in terms that I can understand?'"* (Project #102).

Few resolutions to improve patient education were reported. One researcher established a 'pre-meeting' with patients before larger stakeholder group meetings so patients could get answers to questions and clarification on acronyms.

Engaging patients

Researchers and patients described challenges they faced during engagement activities. About a third of researchers (n = 6), mostly without prior engagement experience, reported feeling unprepared. These researchers did not fully grasp what engagement entailed or how to do it well and subsequently struggled to find appropriate activities, formats or questions to ask patients. Researchers mostly resolved this challenge through trial and error. For example, one researcher discovered that asking targeted questions yielded better feedback than did asking for general comments.

About a quarter of researchers (n = 5), both with and without prior experience, expressed a need for training, with two noting disparities between researcher and patient training: *"(The institution) spends a half day conditioning the patient or teaching patients how to interact with the researchers, but there's no effort to condition the researchers"* (Project #102, Researcher).

About a fourth of patients (n = 8) reported feeling frustrated when researchers used jargon because it impeded their participation. One patient described meetings as *"all research stuff; it was all these acronyms…*

that really didn't have a lot of meaning" (Project #117). A quarter of researchers (n = 5) addressed this challenge by pausing to explain any technical language used.

Incorporating patient feedback

Researchers described three kinds of challenges to incorporating patient feedback. First, a third of researchers (n = 7) reported difficulty sharing control of the research with patients because they were not accustomed to it. The second challenge, reported by about a quarter of researchers (n = 5), occurred when feedback could not be implemented because of lack of time and resources or feasibility concerns. For example, patients from one project wanted to include non-English speakers in the study, but researchers lacked resources to translate materials. The third challenge, reported by about a quarter of researchers (n = 5), occurred when researchers viewed feedback as scientifically inappropriate: *"Patients don't have a scientific understanding of research design, so they may want you to do stuff that… might actually compromise, especially, the internal validity"* (Project #119). Researchers did not identify solutions to these challenges; however, about a third (n = 6) found it helpful to explain why feedback was not used.

Discussion

This study identified facilitators of and challenges to engaging patients from select PCORI projects. Facilitators included communicating goals, engaging patients from existing councils, educating patients and treating patients respectfully. Some facilitators reported here are described in the literature, lending further credence to these findings. There are numerous reports expounding strategies such as using existing resources [11], providing training [7,13,17], communicating roles [7,12–13] and treating patients respectfully [11,13]. This study found that it was helpful to engage patients from existing councils; perhaps because it enabled meaningful discussions to take place sooner or lessened researcher burden to educate patients. In fact, patient education, though a facilitator, was a significant challenge because it required skills and resources, which perhaps explains why researchers desired more training on engagement.

Researchers and patients also faced administrative and IRB challenges; difficulty with the time and work necessary for engagement; and challenges selecting and meeting patients, and incorporating feedback. Some of these have been described elsewhere. Reports have identified lack of logistical support, time, resources and training as barriers [1,3,10,19,27–28]; concerns about representativeness [1,12,17,20]; challenges incorporating feedback [10,29]; IRB issues [1,27]; and drawbacks to virtual and in-person meetings [30].

It is remarkable that in this study some researchers experienced challenges where others did not or even excelled, such as with educating and engaging patients, which suggests that researchers could mitigate some challenges if provided additional support. Other challenges, however, were intractable, indicating a concerted effort may be necessary to address them. To bolster the infrastructure for patient engagement, we propose several actions for consideration by funders, institutions and researchers (described below and summarized in Table 5).

Training opportunities

Publicly available trainings for patients on various study topics, research methods and ethics, like what exists for community-based participatory research [31,32], could be adapted for patient engagement in PCOR and CER. Equally important is researcher training on how to engage patients, which could be developed by experienced researchers and sponsored by funders.

Shared resources

Researchers expressed interest in resources to guide engagement activities. To assist researchers in sharing materials, funders could lead efforts to disseminate lessons learned from their funded portfolio by encouraging researchers to develop reports similar to existing resources [7,13–16]. Funders could take a lead role in building repositories of the peer-reviewed and grey literature on evidence-informed practices or could develop their own materials. PCORI's Engagement Rubric, published after projects in this sample were funded, is one such example [33].

Researcher networks

Because the collective action of researchers may help to resolve challenges more efficiently, researchers could develop relationships and share knowledge. Researchers should identify how networking might best occur. One possibility is funder-led collaboratives such as PCORnet, a large network connecting patients, clinicians and health systems to facilitate large-scale CER [34]. Stakeholders could establish committees that bring together expertise on engagement similar to INVOLVE, the National Institute for Health Research's advisory committee on patient engagement [35]. In addition, project officers could connect researchers on an *ad hoc* basis and researchers could form online communities or interest groups at institutions or in professional organizations.

Matching programs

Efforts to link researchers with experienced patients could address challenges to patient selection. PCORI's Ambassador Program is one such program that aims to link*"patients and other stakeholders with common interests and help(s) position them as potential partners"* [36]. While programs alone are unlikely to improve representativeness, coupled with patient outreach and training, they could streamline patient selection and facilitate involvement of diverse populations. Engaging experienced and inexperienced patients together could help prepare a new cadre of patient research partners.

Model policies

To address institutional barriers, researchers, funders or institutions could develop model policies on patient compensation practices and IRB treatment of patients. Such templates could catalyze widely accepted standards on the appropriate treatment of patient research partners, building consensus among stakeholders. In addition, model policies would reduce cumbersome processes and inappropriate treatment of engaged patients, making it easier for researchers to engage patients at their institutions.

Limitations

This study has limitations. First, because it included PCORI projects, which are unique given their support for engagement, generalizability may be limited. However, challenges were identified among these well-resourced projects, and several findings reported here reflect the literature, suggesting broader relevance. Second, projects were funded early in PCORI's lifespan, which may make them different. Compared with later projects, early funding recipients may have had more engagement experience or they may have known less about successful strategies because fewer resources were available. Nonetheless, experiences from early funding recipients are likely to resonate with others. In addition, although data for this project were collected 3 years ago, the authors have not found any evidence in the literature to suggest that these challenges have been resolved. In fact, the literature suggests the contrary, highlighting the need for recommendations such as the ones provided here. A final limitation is that researchers who declined participation, who were more senior and may have had more experience, could have had different experiences that were not captured. However, researchers with and without experience reported challenges in this study.

Conclusion

This study described facilitators of patient engagement, from which researchers can learn, and it identified challenges that could be addressed through combined approaches involving researchers, institutions and funders. Suggested actions to tackle existing challenges include the provision of resources and training, the

Table 5. Suggested actions for researchers, institutions and funders.

Proposed actions for consideration	Challenges addressed	Possible actors
Training opportunities: – Patient-focused trainings on study topics, research methods and ethics – Researcher-focused trainings on patient engagement	Challenges educating and engaging patients	Researchers; funders
Shared resources: – Repositories of peer-reviewed and grey literature on successful strategies – Case studies – Guidance materials	All challenges	Researchers; funders
Researcher networks: – Funder-led collaboratives – *Ad hoc* connections by project officers – Online communities – Interest groups at institutions or professional organizations	All challenges	Researchers; funders; institutions
Matching programs: – Programs to facilitate connections between researchers and patients	Challenges selecting patients	Funders
Model policies: – Patient compensation policies – Policies on IRB treatment of patients engaged in research	Institutional barriers	Researchers; funders; institutions

IRB: Institutional review board.

creation of networks and programs to connect patients and researchers and the development of model policies.

Future perspective

Findings from this study underscore the significant commitment that the practice of patient engagement requires. The challenges experienced by early PCORI funding recipients, who included both those with and without experience engaging patients, highlight several areas where additional resources, supports or structural changes to the research enterprise are needed to strengthen patient engagement. Funders who require or encourage patient engagement, PCOR and CER researchers, and research institutions have been presented with a number of evidence-informed strategies that could mitigate challenges to patient engagement and facilitate successful practice. Seizing upon these opportunities to bolster the infrastructure for patient engagement will enhance the field of PCOR and CER by better enabling such research to truly incorporate and reflect the patient perspective, a defining aspect of such research. Future research should assess the effectiveness of proposed actions in strengthening engagement. As opportunities for patient engagement grow, a collective effort to help researchers overcome challenges and successfully engage patients remains essential.

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Supplementary data

To view the supplementary data that accompany this paper please visit the journal website at: www.future-science.com/doi/full/10.2217/cer-2016-0075

Summary points

Background

- Patient engagement is increasingly recognized as an essential aspect of comparative effectiveness research and patient-centered outcomes research.
- Information on strategies that facilitate patient engagement and a better understanding of challenges to patient engagement could inform future practices and identify areas where additional actions are needed to mitigate challenges.

Facilitators & challenges

- Reported facilitators to engagement included using existing resources, having clear goals, educating patients, and treating patients respectfully.
- Reported logistical challenges to patient engagement – that is challenges planning for engagement – included the extra time and work needed to organize activities, institutional barriers, and difficulty scheduling and having meetings.
- Reported substantive challenges to conducting patient engagement included challenges selecting, educating and engaging patients, as well as challenges incorporating patient feedback.

Suggested actions for consideration

- To bolster the infrastructure for patient engagement, we propose several actions for consideration by funders, institutions and researchers.
- Training opportunities for both researchers and patients.
- Shared resources including repositories of the literature, case studies, and guidance materials.
- Researcher networks to support shared learning.
- Funder-initiated matching programs to facilitate connections between researchers and patients.
- Model policies on patient compensation and institutional review board treatment of patients engaged in research.

Conclusion

- Findings on challenges to patient engagement highlight several areas where additional resources, supports, or structural changes to the research enterprise are needed to strengthen patient engagement.
- Seizing upon opportunities to bolster the infrastructure for patient engagement will enhance the field of patient-centered outcomes research and comparative effectiveness research by better enabling such research to truly incorporate and reflect the patient perspective, a defining aspect of such research.

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