



Contents lists available at ScienceDirect

## American Journal of Infection Control

journal homepage: [www.ajicjournal.org](http://www.ajicjournal.org)

## Major Article

## Engaging patients in health care epidemiology research: A case example

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## Key words:

Patient engagement  
Patient-centered outcomes research  
Stakeholder engagement

**Background:** We describe stakeholder engagement from a Patient-Centered Outcomes Research Institute–funded project to identify patients' research priorities for health care–associated infections (HAI). We summarize insights from these activities to highlight feasibility and benefits of stakeholder engagement in health care epidemiology research.

Patients and caregivers who had an HAI experience were involved in a patient and caregiver stakeholder group. We engaged clinicians, infection prevention experts, state public health professionals, and quality improvement experts in an institutional stakeholder (IS) group in an academic tertiary care medical center.

**Methods:** Through individual and combined group activities, we identified stakeholders' HAI research priorities. Existing engagement resources from the Wisconsin Network for Research Support (WINRS) guided the process.

**Results:** Given the patients' and caregivers' experiences with HAIs, their perspectives broadened IS understanding of the impact of HAIs and the relevance of proposed research topics. After introductory activities described here, the patient and caregiver stakeholder group actively engaged with researchers and the IS group in discussing complex systems-level topics to reduce HAIs. We have sustained this engagement through continued collaboration.

**Conclusions:** Our engagement experience provides one example of how patients can be engaged in health care epidemiology research. Our experiences and lessons learned may be helpful to others interested in stakeholder engagement.

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A major reason for the gap between what we know (evidence) and what we do (practice) is that, in most cases, research has been poorly aligned with the needs and priorities of the end-users—those stakeholders who are most affected by the research.<sup>1,2</sup> This poor alignment hinders the translation of research findings and slows progress in improving health outcomes.<sup>1,2</sup> Recognizing this problem, several US federal agencies have called for and funded stakeholder engagement activities in recent years.<sup>1</sup>

Stakeholder engagement in health care research is defined as the “meaningful involvement of patients, caregivers, clinicians and other health care stakeholders throughout the research process—from topic selection through design and conduct of

research to dissemination of results.”<sup>3</sup> Evidence suggests that engagement leads to research questions and outcomes that are more meaningful and relevant to patients and other stakeholders.<sup>4,5</sup> Engagement has also been shown to improve the quality and appropriateness of research.<sup>5–11</sup> Additional hypothesized benefits include more efficient dissemination and implementation of findings,<sup>6–12</sup> improved decision-making,<sup>4</sup> increased health care satisfaction,<sup>4,5</sup> and optimal health outcomes.<sup>4,5</sup>

In health care epidemiology research, stakeholders are most often patients, caregivers, and clinicians. Qualitative studies have sought to obtain input from patients and providers on infection control interventions,<sup>13–15</sup> but, to our knowledge, engagement during *all* phases of the research process has not been reported. To highlight how stakeholder engagement can be applied to health care epidemiology research, we describe our stakeholder engagement experience and lessons learned. Our aim is to bring attention to the feasibility and benefits of stakeholder engagement and provide guidance to researchers who want to explore stakeholder engagement to increase the relevance and impact of their epidemiologic research.

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Financial support: N.S. received a Eugene Washington PCORI Engagement Award from the Patient-Centered Outcomes Research Institute (2680-UWisc).

Conflicts of interest: None to report.

## METHODS

In 2015, our institution was awarded a 2-year Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington Engagement contract to build capacity to engage stakeholders in our health care-associated infections (HAI) research activities.<sup>16</sup> We formed 2 parallel engagement groups that we ultimately brought together to finalize the research agenda. The patient and caregiver stakeholder (PCS) group was composed of patients and caregivers with personal experience with HAIs. The institutional stakeholder (IS) group included clinicians, infection preventionists, and public health and quality improvement professionals. The primary goal of the PCORI project was to engage both groups in effectively prioritizing HAI prevention and treatment topics to guide our future work.

When our PCORI project began, members of our research team had expertise in HAIs, quantitative and qualitative research, and curriculum development, but they lacked experience in stakeholder engagement. To support the project launch, the team used the following resources at our institution that support engagement in research:

- The University of Wisconsin (UW) Institute for Clinical and Translational Research (ICTR)<sup>17</sup> provides stakeholder engagement resources and support to researchers as part of its mission to facilitate the efficient translation of health care research findings into practice. We used their training opportunities and publicly available resources on their website.<sup>18</sup> We also sought advice from UW researchers affiliated with ICTR who had experience engaging stakeholders.
- The Wisconsin Network for Research Support (WINRS; <https://winrs.nursing.wisc.edu/>) offers consultation services to assist researchers with effective patient and stakeholder communication and engagement, particularly when working with under-represented or hard-to-reach communities.<sup>19,20</sup> We collaborated with WINRS throughout the project.

### *Patient and caregiver stakeholder group*

Patients and caregivers were involved in the project from its inception. Researchers met with 4 of our existing patient and caregiver contacts to describe the project and obtain feedback during the grant-writing stage. One of the authors (N.S.) had established relationships with these contacts through her clinical practice and work on Wisconsin's statewide HAI advisory committee. These contacts were active in advocacy efforts to improve patient care for HAIs but were not previously engaged in our research before the PCORI project. With permission, we included a patient's story about her HAI experience in the proposal. The stakeholders we spoke to were supportive of the project and provided letters of support for the application.

After being notified of funding, we recruited additional patients and caregivers for the PCS group through word-of-mouth with our existing patient and caregiver contacts. We focused recruitment on adults living in rural areas in Wisconsin because this population tends to experience barriers in accessing health care. In addition, our team wanted to offer this opportunity to Wisconsin residents who do not typically engage with researchers—those living a distance from a major university. Each stakeholder received a \$75 stipend for each in-person meeting they attended. This stipend was intended to reimburse stakeholders for travel costs and time spent preparing for and attending the meetings. We believed that providing this stipend was important to demonstrate that we valued the time, effort, and expertise they were contributing to our research.

We convened 7 meetings of the PCS group over 12 months. Although the focus of each meeting varied, meetings were structured similarly. We sent reminder letters with a summary of the previous meeting in advance. All PCS meetings began with introductions and a

brief review of the project goals and deliverables. Meetings were cofacilitated by the project manager and the principal investigator—an infectious disease physician researcher. To keep members engaged between in-person meetings, PCS group members were invited to collect HAI-related news articles of interest to them and discuss the articles during the meetings. This activity served as a “cue to action” for group members—keeping the topic of HAIs fresh in their minds between meetings.

In consultation with WINRS, we prepared patients and caregivers to effectively participate in developing a research agenda. Rather than presenting a didactic curriculum of research terms and processes, we constructed meaningful meeting activities that helped members share their patient perspectives with the research team. To set expectations, we reviewed the goals of the project, the significance of their feedback, and how their feedback would inform our future research. The PCS group agreed on 3 simple ground rules to promote a safe engagement environment: respect for each other, confidentiality, and a commitment to avoid jargon, acronyms, or overly technical terminology (with explicit encouragement to request clarification of any unclear terms). Patients and caregivers agreed to assist us with understanding issues related to HAIs from the patient perspective, and they agreed to arrive at the meetings prepared to participate and share ideas. We, as a research team, agreed to create and sustain a safe environment for co-learning and sharing, provide specific background information when it was directly relevant to the work of the PCS group, and be transparent about how the PCS group's feedback was being used by regularly reporting on how it was influencing our research. We also provided a brief overview of HAI research and relevant HAI terminology and concepts. Much of the orientation content was drawn from the Toolkit on Patient Partner Engagement in Research, which is publicly available online.<sup>21</sup>

### *Institutional stakeholder group*

This stakeholder group was recruited through our existing network of infection control professionals. Members included the Director of the State of Wisconsin's Antimicrobial Stewardship Program, infection preventionists from the UW Hospital and William S. Middleton Memorial Veterans Hospital in Madison, Wisconsin, and a local health care quality improvement representative. The IS group met twice separately from the PCS group. As in the PCS group, we oriented them to the PCORI project goals and deliverables.

### *HAI prevention and treatment strategies*

We focused engagement on 2 broad topics: HAI prevention and treatment strategies. We suggested 4 to 5 strategies that we identified as promising areas for further research on the basis of current evidence. In collaboration with WINRS, we developed an activity for the PCS and IS groups to separately create lists of the barriers and facilitators that patients, providers, and institutions face when implementing each of the three strategies. This activity helped stakeholders identify aspects of the strategies that might benefit from further research to improve their implementation. The groups then refined the suggested strategies into the 3 strategies they believed were most important for future research.

When the PCS and IS groups were combined, we presented and discussed the top strategies identified by each group and used an anonymous voting system to identify the strategy of highest priority. The discussions in the combined PCS and IS meetings resulted in a research agenda reflecting top stakeholder priorities for HAI prevention and treatment. Although we were prepared to moderate any disagreement over the highest priority strategy, there was generally clear consensus among all stakeholders regarding the top prevention and treatment research priorities.

**RESULTS**

*A sustained, engaged stakeholder group*

Throughout the project, stakeholders were enthusiastic and frequently spoke of a desire to stay involved as long-term partners with our research group. Follow-up interviews with PCS group members at the close of the PCORI project underscored this desire to have continued input into current and future research. Knowing our stakeholders were willing to stay engaged, we developed a formal sustainability plan for continued stakeholder engagement beyond the project period. Even after the end of the 2-year PCORI project, we continue to gather our stakeholders’ feedback on our research ideas and grant proposals. We actively pursue funding to include engagement activities as part of our research, seeking out grants that specifically fund engagement (such as PCORI awards) and including engagement activities in the research plan and budget of other grants. We maintain regular contact with stakeholders through a quarterly newsletter with HAI news of interest and additional updates from our group related to proposed and ongoing research projects resulting from the research agenda.

*Research agenda developed by stakeholders*

The primary goal of our stakeholder engagement was to develop a research agenda with priorities for HAI prevention and treatment.

**Table 1**  
Key lessons learned

Lesson	Actions
Seek help and use available resources	<ul style="list-style-type: none"> <li>• Experts in engagement can help create strategic agendas and provide focus for each meeting</li> <li>• Look for widely available toolkits and resources as well as local consultants at your own institution.</li> </ul>
Engagement is a dynamic process	<ul style="list-style-type: none"> <li>• Use your networks to identify stakeholders to participate—whom do your contacts know who might be interested in this kind of opportunity?</li> <li>• Determine an overarching goal for engagement, but consider options for flexibility when developing overall engagement plan and individual meeting agendas.</li> <li>• Be open to opportunities as they come up during engagement—for example, incoming study results, a new funding opportunity, or a story in the news could provide a chance to engage stakeholders in an unanticipated way.</li> <li>• Set clear roles and responsibilities for all groups, including moderators—this fundamental action serves as a foundation for all planned and spontaneous engagement!</li> </ul>
Patients and other stakeholders can collaborate effectively	<ul style="list-style-type: none"> <li>• Build engagement into your proposals, including asking for stakeholder feedback on grant ideas. This action will allow for a holistic consideration of how to integrate stakeholders into all aspects of the research lifecycle and may help to identify areas that need to be adjusted early on.</li> <li>• Seek feedback from stakeholders regularly—what is and is not working? What do they want out of the engagement and what would they like to be doing? Be open to adjusting your plans to ensure that stakeholders continue to be engaged and enthusiastic.</li> <li>• Aim for balanced representation of disparate stakeholder groups (eg, patients, clinicians, researchers) to promote balanced conversation in combined meetings.</li> <li>• Prepare groups of stakeholders in advance of joint meetings to foster relationships and communication.</li> <li>• Consciously promote a culture of respect—both professional <i>and</i> personal—among all groups.</li> </ul>
Engage patients on tough topics: Patients have the experience that counts, even with policy and systems problems	<ul style="list-style-type: none"> <li>• Consider patients’ backgrounds—including their individual experiences with health care—when determining goals for engagement. What are patients passionate about, and what lived experiences do they have that will contribute to our understanding of systemic issues?</li> <li>• Seek under-represented groups in engagement (eg, rural, minority, and military veteran patients and their caregivers) for a more comprehensive understanding of stakeholder perspectives.</li> <li>• Be thoughtful about how best to present information, using plain language, and narrowing topics discussed on the basis of evidence and how feasible they are to research (while being open to new suggestions from the group).</li> </ul>

Using the research agenda outlined in 2014 by the Research Committee of the Society for Healthcare Epidemiology of America as the framework,<sup>22</sup> our stakeholders focused on 4 overarching themes as priorities for future research: (1) optimizing patient preparation for surgery, (2) hospital environments and equipment as critical sources of infection, (3) compliance with and impact of gowning and gloving protocols, and (4) the significance of lab testing and antimicrobial stewardship. We are currently using this agenda and our stakeholders’ feedback to develop project ideas and collaborations.

**DISCUSSION**

Even with limited experience in stakeholder engagement in the research process, we were able to successfully engage patients, caregivers, and institutional stakeholders to develop an HAI research agenda. Through this process, we learned several valuable lessons that inform our continued engagement activities and may also be useful to other researchers considering stakeholder engagement to improve the efficiency, quality, and impact of their research. These lessons are summarized in [Table 1](#) and described in further detail below.

*Lesson 1: Seek help and use available resources*

We found that time and willingness to thoughtfully plan for the engagement process was paramount to successful engagement. Our

team had limited experience with stakeholder engagement when we developed our engagement plan. Fortunately, many helpful resources are available to help guide engagement activities. Taking the time seek out and learn from existing engagement professionals was essential to the success of our project. WINRS' advice and support were invaluable. Although based at UW, WINRS provides consultation nationally on a fee-for-service basis. The engagement resources available through UW ICTR, including online trainings and toolkits (on the UW ICTR website), were also helpful.<sup>18</sup> As the value of engagement in research continues to be recognized, many research institutions are developing their own resources. In addition to local resources, a wealth of literature<sup>1,4,8,9,11,19,20,23–28</sup> and toolkits<sup>21,29–32</sup> are available to support engagement planning.

### *Lesson 2: Engagement is a dynamic process that requires flexibility*

Thoughtful planning for the engagement process is essential, but it is impossible to plan for the unforeseen changes in circumstance that will inevitably occur. Therefore flexibility and being able to “seize” an opportunity are critical throughout the engagement process. For example, we initially budgeted to use radio ads for PCS recruitment; however, we were able to create the PCS group through internal recruitment. We instead used this funding to produce radio ads to increase the public's awareness of HAIs and the importance of antibiotic stewardship. PCS group members were deeply involved in developing the content of these ads, and 3 of the ads featured the voices of group members. This activity turned out to be a concrete way to build both the stakeholders' and our own engagement skills before developing the research agenda.

### *Lesson 3: Patients and researchers can be effectively engaged together*

The literature on engagement suggests that combining patients and caregivers in a group with institutional stakeholders (including researchers) is likely to create a hierarchy that will inhibit patient and caregiver engagement.<sup>2</sup> There are several strategies that can be used to minimize perceived hierarchies between stakeholders and promote effective engagement within blended groups. First, blended stakeholder groups should have balanced representation between patients/caregivers and institutional stakeholders. Our PCS and IS groups each had about the same number of people in them for balance in the combined meetings.

Preparing both patient/caregiver and institutional stakeholders to work together is another important strategy. We initially separated our patient/caregiver and institutional panels, which served 2 purposes. First, both groups had ample time to become oriented to their work and gain confidence sharing their perspectives. Second, it allowed us to get to know the stakeholders and get a sense of their personalities, backgrounds, and experiences with HAIs. After observing the confidence and communication skills of the PCS group members in the first few meetings, we determined that it would be beneficial and productive to engage the 2 groups together earlier rather than later and thus adjusted our engagement plan—again demonstrating flexibility. In fact, the PCS members were anxious to meet with our other stakeholders.

A final strategy to promote the success of blended stakeholder groups is to explicitly acknowledge the expertise each stakeholder brings to the table. At the first combined meeting, PCS group members shared their HAI stories to demonstrate their expertise based on firsthand experiences and to help the IS group members better understand what is important to patients and caregivers. We believe these strategies helped promote effective engagement in the combined meeting. Multiple PCS members stated that they enjoyed hearing about the institutional stakeholders' work and expressed the need for additional combined meetings.

### *Lesson 4: Avoid the assumption that patient stakeholders cannot be engaged in complex, systems-level medical topics*

Initially, we thought it would be challenging to engage patients and caregivers in HAI research because many strategies to reduce HAIs intervene on the system or provider level rather than the patient level. However, we quickly realized that patients' lived experiences receiving medical care for HAIs had fully prepared them to provide valuable feedback on a wide array of HAI topics—whether systems level or individual patient level. This experience provides valuable perspectives on possible downstream effects of organizational policy and systems interventions.

## LIMITATIONS

This report describes only 1 example of patient engagement in developing a research agenda for the prevention and treatment of HAIs and therefore may not be relevant to engagement in all health care epidemiology research. However, we tried to share broad insights we believed would be relevant and useful to researchers regardless of research topic and engagement setting. Although this is just one example, we are encouraged by results of our project and how our patients and caregivers continue to be enthusiastic about working with us on future projects.

## CONCLUSIONS

Our PCORI engagement project is just one example of how stakeholder engagement can be applied to health care epidemiology research. On the basis of recent literature and our experience, we believe that engaging a diverse combination of key stakeholders in the development of an HAI research agenda will increase the value of evidence generated, the efficiency of efforts, and the efficiency of the uptake of findings. Through this process, our team identified key lessons learned that may be helpful to others interested in stakeholder engagement. Ultimately, the goal of engagement in research is to improve health care outcomes—engaging stakeholders early and often during the research process will help to ensure that we are focusing on the outcomes of highest importance to those individuals who are most impacted by our decisions.

## Acknowledgment

The Wisconsin Network for Research Support aided in editing the manuscript.

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