


What works for engaging lay stakeholders: Advice from a patient and caregiver group

Betty L. Kaiser PhD, RN¹ , Gay R. Thomas MA¹, Julie A. Keating PhD², Nicole Brys MPH^{2,3}, Mary Jo Knobloch PhD, MPH^{2,3} and Nasia Safdar MD, PhD^{2,3}

¹School of Nursing, University of Wisconsin–Madison, Madison, Wisconsin, ²William S. Middleton VA Hospital, Madison, Wisconsin and ³Division of Infectious Diseases, Department of Medicine, University of Wisconsin–Madison, Madison, Wisconsin

To the Editor—Patients and family members are playing an increasingly active role as stakeholders in healthcare-associated infection (HAI) research. HAI researchers have engaged lay stakeholders to provide input on research agendas,^{1,2} educational interventions,³ and interpretation of data on patients' experiences of hospital practices.⁴ Recommendations for effective patient engagement include gathering input on stakeholders' experiences of engaging with researchers to help researchers evaluate and improve their engagement practices.⁵

For a recent 2-year project, our research team (Keating, Brys, Knobloch, Safdar) developed a patient and caregiver stakeholder (PCS) group of people who had personal experience with HAI. We met with the group 9 times to generate a stakeholder-driven HAI research agenda (details are described elsewhere).^{2,6} At the end of the project, the 7 members of the PCS group participated in individual telephone interviews to talk about their experiences. Consultants with the Wisconsin Network for Research Support (Kaiser and Thomas), a patient and community engagement center based at the University of Wisconsin–Madison School of Nursing, conducted the interviews using a set of 13 questions (Table 1). Interview notes were imported into NVivo Pro version 11 software. WINRS consultants coded the interview data independently and met to compare and revise codes to achieve 100% agreement. Two primary themes emerged from content analysis: the value of participating in the PCS group and the meeting experience for members.

The value of participating in the PCS group was expressed through 2 subthemes: making a meaningful contribution and influencing researcher and clinician attitudes through personal HAI stories. Members said that their work on the project could have a direct impact on patients in the future. One person said, "Saving one person from getting HAI means saving people's lives." Another said, "I want to proactively make sure that what I've been through doesn't happen to anyone else."

Group members described how sharing their stories helped researchers understand the patient experience. "[Researchers and providers] get a face to go with the clinical data. When people describe what is really involved, providers are amazed. It's eye-opening!" Members described the atmosphere at meetings as friendly and conducive to frank conversation, and members felt comfortable sharing their stories, even when they met with an institutional stakeholder (IS) group of clinicians and infection control professionals involved in the project. Members talked enthusiastically about meetings with the IS group. As one PCS member said, "They were hungry for what we wanted to share with them."

The second major theme in the interviews, the meeting experience for members, was expressed in 2 subthemes: limited orientation of group members and meeting content and processes. Few members remembered learning anything about the group's purpose, the role of members, or details about structure and content of meetings. One member said, "I think it took me 2–3 meetings to understand what I was supposed to be doing." Members offered suggestions for systematically preparing people to participate on an advisory board.

Table 1. Interview Questions for Patient and Caregiver Stakeholder (PCS) Group Members

1. You have attended meetings of the PCS group for more than a year. What is it that keeps you coming?
2. Imagine that you are talking with someone who is thinking about joining a group like the PCS. They ask you "Why should I join a group like this?" What would you tell them?
3. In your opinion, what do <the PI> and her team get from meeting with the PCS group?
4. Please think back on the past year of PCS group meetings. How did the research team prepare you for the work you have done at meetings? Would you recommend any additional training to prepare people to participate effectively in a group like the PCS?
5. Please tell me about the agendas and other materials you received before meetings. How useful were these materials in preparing for the meeting? Do you have any advice about how to improve these materials?
6. Now I have some questions about the actual meetings. Did meetings run smoothly? Did people consistently use language that made sense to you? (If not, do you have an example of when the conversation was confusing or people used words that didn't make sense to you?)
7. One of the regular activities at the PCS group meetings was the "Little Black Book." Tell me what you thought of this activity.
8. Please tell me what it was like to be in a meeting with the institutional stakeholders. (Prompts: How were these meetings different from the PCS group meetings? What was it like to share your story and ideas in this group? Did you and other members of the PCS group have a chance to share as much as you wanted?)
9. After meetings, how did the research team update you on how they used feedback from the PCS group?
10. Now that you've been a member of the PCS group, has your attitude toward researchers changed? Toward healthcare providers? Toward <the university>? (If yes, ask how attitude has changed.)
11. Is there anything that would have made your experience in the PCS group better for you personally?
12. Based on your experience with the PCS, do you have any advice for researchers who want to put together a similar group of patient and family advisors?
13. Is there anything else you want to say about being a PCS member?

Author for correspondence: Betty L. Kaiser, University of Wisconsin–Madison, 701 Highland Ave, Madison, Wisconsin. Email: blkaiser@wisc.edu


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Members commented on several issues related to meeting content and processes. They thought that their joint meetings with the PI and IS group were valuable for developing the stakeholder-driven research agenda. Several suggested that joint meetings should have occurred earlier and more often. Most members said that the language used by the research team in meetings was appropriate for people who did not have a background in healthcare. However, one member noted that he sometimes looked for definitions of terms after meetings, and another said that the research team used too many acronyms. Members were concerned that people who participated in meetings remotely, or who did not use a computer and email, may not have had comparable opportunities to contribute. Finally, members wished that they had heard more about how the researchers would build on the project and whether they would involve the PCS group in future projects. “We did all this work—what’s going to happen now? It was not as clear as you would hope it would be.”

In summary, PCS members identified several elements of engagement that worked well in this project and several areas for improvement. The collegial atmosphere established by the research team helped members feel comfortable sharing their stories and perspectives. Members highly valued meetings that involved the PI and IS group, as these interactions offered an opportunity to see the direct impact of PCS contributions on the project. Based on member’s comments, we identified additional strategies that can help us enhance the experience of stakeholders on future projects.

1. Conduct a structured orientation to prepare stakeholders.⁷ Content should address the project goal and intended outcomes; role of PCS group members and other stakeholders; and mutual expectations for stakeholders and the project team.
2. Provide a comparable meeting experience for all stakeholders, regardless of differences in access to computers/smartphones or ability to participate in person. If members participate remotely, facilitators can use round-robin activities to ensure that all members have opportunities to contribute.
3. Use plain language that everyone can understand during meetings, in materials, and in communications.
4. Provide meaningful closure by explicitly discussing the research team’s plans for the future, including future involvement of the PCS group.

The results of this evaluation represent findings from one group of patient and caregiver stakeholders and are not generalizable to all HAI research that involves patient stakeholders. However, the strategies for effective engagement that emerged may provide a useful starting point for HAI researchers planning to involve patients and caregivers as advisors.

Author ORCIDs. Betty L. Kaiser,  0000-0001-6119-0205

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Current status of infection control professionals in a Chinese city

Peijin Zhang MM and Liling Tang MB 

Department of Hospital Infection Management, Yijishan Hospital of Wannan Medical College, Wuhu City, Anhui, China

To the Editor—Healthcare-associated infection (HAI) management is an important component of medical quality management; it directly affects the quality of healthcare and patient safety.¹ With

Author for correspondence: Liling Tang MB, Yijishan Hospital of Wannan Medical College, 2 West Zheshan Rd, 241001, Anhui Province, China. Email: yjsykg2017@sina.com

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advances in medical technology, the HAI problem has become more and more prominent, which has put forward higher work requirements for infection control professionals (ICPs). More than 40 years ago, the Centers for Disease Control and Prevention (CDC) conducted the national Study on the Efficacy of Nosocomial Infection Control (SENIC).² Its findings suggested that an adequate staffing ratio of ICPs had lower rates of HAI. Similarly, a number of other studies reported that high levels of