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## Patients as stakeholders: Developing a patient-centered healthcare epidemiology research agenda

Julie A. Keating PhD<sup>1</sup>, Nicole Brys MPH<sup>1,2</sup>, Mary Jo Knobloch PhD, MPH<sup>1,2</sup> and Nasia Safdar MD, PhD<sup>1,2</sup>

<sup>1</sup>William S. Middleton VA Hospital, Madison, Wisconsin and <sup>2</sup>Division of Infectious Diseases, Department of Medicine, University of Wisconsin-Madison, Madison, Wisconsin

*To the Editor*—Due to its many benefits, stakeholder engagement in health research has been increasingly prioritized in recent years.<sup>1–9</sup> Engagement throughout the research cycle, from idea development through dissemination of results, helps to ensure

**Table 1.** Patient-Perceived Implementation Barriers to HAI Prevention Strategies

| Prevention Strategies   | Individual-Level Barriers   | Provider- and Institutional-Level Barriers  |
|---|---|---|
| Environment, equipment as infection source; compliance with and/or impact of gowning and/or gloving (contact precautions) protocols | <ul style="list-style-type: none"> <li>• Fear that care will be negatively impacted by addressing variation in compliance with contact precautions</li> <li>• Difficulty maintaining hand hygiene while hospitalized</li> <li>• Patient gowns not changed while hospitalized</li> <li>• Stigma of isolation and contact precautions</li> </ul>  | <ul style="list-style-type: none"> <li>• Inconsistent messaging between providers</li> <li>• Inconsistent protocol compliance</li> <li>• Lack of ownership in implementing practices</li> <li>• Not involving patients and/or caregivers in conversations</li> <li>• Inconsistent and/or unclear policies and procedures</li> <li>• Unclear division of responsibilities</li> <li>• Lack of training and resources for environmental services</li> <li>• Lack of leadership support</li> <li>• Lack of wearer-friendly gowns, gloves, and/or masks</li> <li>• Challenges in reprocessing and/or cleaning surgical equipment</li> </ul>  |
| Presurgical preparation (CHG bathing, <i>Staphylococcus aureus</i> testing, lifestyle changes)                                      | <ul style="list-style-type: none"> <li>• Lack of education about preparation for surgery and the risks of not preparing</li> <li>• Variation in procedural information</li> <li>• Variation in products and use</li> <li>• Not preparing for surgery</li> </ul>   | <ul style="list-style-type: none"> <li>• Inconsistent messaging between providers</li> <li>• Inconsistent provider involvement</li> <li>• Lack of access and/or encouragement to learn best practices</li> <li>• Variation in evidence for and priority of practices</li> <li>• Variation in practices and policies</li> <li>• No standardized CHG dilution methods</li> <li>• Lack of support to implement new practices</li> </ul>  |
| Laboratory testing and antimicrobial stewardship  | <ul style="list-style-type: none"> <li>• Belief that antibiotics are always helpful</li> <li>• Variation in insurance coverage for therapies</li> <li>• Not discussing therapeutic choices with providers</li> <li>• Lack of education and/or understanding about antibiotic reason, use (ie, frequency and duration), and side effects</li> <li>• Distrust of new therapies</li> </ul> | <ul style="list-style-type: none"> <li>• Overtesting</li> <li>• Lack of procedures to stop antibiotic course based on test results</li> <li>• Impacts of patient-reported allergy to prescription (without documented allergy testing)</li> <li>• Fear of negative rating from patient for not prescribing an antibiotic</li> <li>• Inconsistent messaging between providers</li> <li>• Formulary restrictions</li> <li>• Limited research and/or education on new evidence-based practices and alternatives (eg, probiotics)</li> <li>• Lack of educational outreach in community</li> <li>• Impact of telemedicine</li> <li>• Reimbursement policies</li> <li>• Underusing and/or excluding pharmacists on patient care team</li> <li>• Antifungals and/or antivirals not included in stewardship</li> <li>• Lack of standardized scripts for supplies</li> </ul> |

Note. HAI, healthcare-associated infections; CHG, chlorhexidine gluconate.

**Author for correspondence:** Julie Keating, William S. Middleton Veterans Hospital, 2500 Overlook Terrace, Madison, WI, USA 53705. E-mail: [julie.keating@va.gov](mailto:julie.keating@va.gov)

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that research questions and outcomes are meaningful and relevant to stakeholders,<sup>3,4</sup> and it may also improve research quality and appropriateness.<sup>4–6,9</sup>

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Given the threat of healthcare-associated infections (HAIs) to patient safety,<sup>10</sup> stakeholder engagement is critical in healthcare epidemiology. Effective HAI prevention and control require collaboration between multiple stakeholders: clinicians, other providers directly or indirectly involved in patient care, healthcare administrators, caregivers, and patients. Despite progress in understanding pathogens, epidemiology, and prevention and control mechanisms, many research gaps remain.<sup>10</sup> Because patients and caregivers have not previously been involved as stakeholders in HAI research, their perspectives on these gaps are poorly understood. We believe that increasing the engagement of patients and caregivers in HAI research is necessary to address existing gaps in knowledge related to HAI prevention.

To develop a patient-centered HAI research agenda, we convened a patient and caregiver stakeholder (PCS) group of 7 older adults (4 men, 3 women, most >50 years old) from Wisconsin. All members had experience as a patient or as a caregiver to a patient with an HAI, and 2 members had additional professional medical experience. Before discussing the research agenda, the PCS group members received initial training in HAI research, terminology, and concepts, and they participated in preparatory activities such as describing their perceptions of environmental contamination in a hospital room and meeting with institutional stakeholders to discuss HAI work.

Research agenda discussions centered on a subset of strategies identified by the Society for Healthcare Epidemiology of America (SHEA)<sup>10</sup>: (1) evaluation of environment and equipment sources for infection; (2) compliance with and impact of contact precautions; (3) patient presurgical preparation; and (4) antibiotic stewardship, particularly the role of pharmacists. In consultation with the Wisconsin Network for Research Support ([www.winrs.nursing.wisc.edu/](http://www.winrs.nursing.wisc.edu/)), we designed an activity for stakeholders to identify their perceived individual (patient and/or caregiver) and provider- or institutional-level barriers to implementing a strategy. Their ideas were elaborated through discussions with the research team, and the resulting barriers represent potential targets for intervention in future patient-centered HAI research (Table 1).

Patient feedback provides important context to previously described HAI prevention research topics.<sup>10</sup> For example, patients highlighted concern that care may be negatively impacted by asking providers about noncompliance with contact precaution protocols. While HAI research is often focused within healthcare settings, patients wanted to know the steps they could take outside the healthcare setting to reduce their risk of acquiring HAIs. However, the demographics of the PCS group may limit the generalizability of these results to other patient populations.

These perspectives have been critical as we identify priority areas for investigation and as we engage patients in developing research projects to address these areas. We encourage other

researchers to consult with patients and caregivers in setting their research agendas and to develop a patient-centered plan aligned with the needs of those who know the most about living with an HAI.

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