

Setting an Agenda for Hospital Medicine Research: Making Sure the Right People Are at the Table

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Unlike other service industries, US healthcare has been slower to adopt an approach of asking users (patients) how to make things better. However, patient engagement in systems of healthcare (eg, Patient and Family Advisory Councils [PFAC]) and health system-based research (eg, Patient Centered Outcomes Research Institute [PCORI]) are gaining currency in the United States.^{1,2}

Increasing patient/family involvement in health systems research design, especially in terms of setting research priorities, may lead to improved patient outcomes and experience. Patients and investigators have coproduced research agendas,¹ typically for specific diagnoses or with a focus on ambulatory care.³ To date, few efforts have actively engaged patients/families as true partners in identifying research gaps in the inpatient setting.^{3,4}

In their prospective study, Harrison et al⁵ used a systematic approach and methods established by PCORI and the James Lind Alliance to establish a patient-centered research agenda for improving care of hospitalized adult patients. They formed a national steering committee of clinical researchers, patients and caregivers, administrators, and stakeholder organizations. A survey was distributed to about 500 similar stakeholders to generate a list of potential research questions, which were sorted, analyzed, ranked, and prioritized based on frequency. The steering committee ultimately identified an agenda of 11 system of care–related research questions. The highest priority questions focused on ensuring shared decision making (SDM) and transitions of care.

This study has several strengths. Patients served as coleads on the steering committee and were engaged early and often throughout the process, considered a Tier 1, or deliberative, engagement approach.¹ This is in contrast to a consultative, or Tier 2, approach in which patients serve as consultants and comment later in the process.¹ As Harrison et al. demonstrate, including patients impacted the breadth and depth of results. An emphasis on patient perspectives seems to have led to recognition of topics that clinical researchers did not develop a priori. Some patient-proposed research topics, such as best

modes to navigate the hospital and visiting hours, suggest a bigger question beyond patient experience: How might attention to details minimize disorientation, which likely detracts from ability to engage in care?

The most highly ranked research question regarded study of interventions that would ensure SDM among patients and physicians. SDM-based interventions in pediatrics have led to significantly improved knowledge and lower decisional conflict.⁶ Many SDM-based interventions use decisional aids, which are tools that facilitate patient/family involvement in decision making for specific clinical situations (eg, end of life care, oral vs. intravenous antibiotics). Future work can focus on designing interventions that further enable SDM regardless of the scenario, such as enhancing provider training.⁶

More than half of the research questions ranked by the investigators related to transitions of care, including ensuring proper comprehension of and adherence to postdischarge care plans, medical provider handoffs, and mechanisms for communication after discharge. Interventions that promote inpatient physician and nurse use of health literacy–informed communication strategies, such as teach back, providing instructions using plain language or enhanced with graphics, or providing opportunities to practice follow-up care prior to discharge, may be beneficial.⁷

Moving from understanding to execution is another gap recognized in this study. Improving resources and care in the home after discharge also would likely improve outcomes. Industry, with use of rapid-cycle improvement methods, has already implemented comprehensive, home-based approaches focusing on enhanced presence of care team members (including physicians, nurses, and social workers) in the home. Team tasks include verifying that prescriptions are filled and medications are taken properly and ensuring that social needs are met, which could possibly lead to decreased healthcare utilization.⁸ Additional innovative strategies that leverage technology to optimize information exchange and facilitate post-discharge communication when questions arise (eg, telemedicine as suggested by stakeholders in this study) may also be beneficial. Such strategies, as well as models established by industry, should be further studied as part of interventions that also incorporate the perspective of patients, caregivers, and other stakeholders.

The study had a few limitations. This study, while national in scope, did not provide patient/caregiver demographics or preferred language, so it is unclear if participation was inclu-

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sive of all populations. Use of qualitative methods, including this study's apparently modified Delphi approach, is important to ensuring equal consideration is given to all suggestions—but this only works if the stakeholders are representative. Patients and caregivers were primarily recruited from PFAC, which represent a more activated constituency and often lacks demographic diversity.⁹ Given that “care of vulnerable populations” was an infrequently proposed question category, future work would benefit from oversampling from marginalized, underrepresented groups.

While the study's aim was development of a research agenda for adult patients, children, especially those who are medically complex, and their caregivers may experience similar issues. There may be barriers related to hospitalizations and transitions unique to children given their inherent dependent status. Future work could incorporate similar methods and engage children and their caregivers in setting a pediatric hospital medicine research agenda.

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