

Developing a Patient- and Family-Centered Research Agenda for Hospital Medicine: The Improving Hospital Outcomes through Patient Engagement (i-HOPE) Study

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BACKGROUND: Patient, caregiver, and other stakeholder priorities have not been robustly incorporated into directing hospital-based research and improvement efforts.

OBJECTIVE: To systematically engage stakeholders to identify important questions of adult hospitalized patients and to create a prioritized research agenda for improving the care of adult hospitalized patients.

DESIGN: A collaborative approach to stakeholder engagement and research question prioritization.

SETTING & PARTICIPANTS: Researchers and patients from eight academic and community medical centers partnered with 39 patient, caregiver, professional, research, and medical organizations.

METHODS: We applied established standards for formulating research questions and stakeholder engagement. This included: a multi-pronged, inclusive patient and stakeholder engagement strategy; surveys of patients and stakeholder organizations to identify important questions; content analysis of submitted

questions; and a 2-day in-person meeting with stakeholder organization representatives and patient partners to prioritize and rank submitted questions.

RESULTS: A total of 499 respondents including patients, caregivers, healthcare providers, and researchers from 39 organizations submitted 782 research questions. These questions were categorized into 70 distinct topics—52 that were health system related and 18 disease specific. From these categories, we identified 36 common questions; the final 11 questions were identified, prioritized and ranked during an in-person priority-setting meeting. Questions considered highest priority related to ensuring shared treatment and goals of care decision making and improving hospital discharge handoff to other care facilities and providers.

CONCLUSION: We identified 11 prioritized research questions that should galvanize funders, researchers, and patient advocates to address and improve the care of hospitalized adult patients. *Journal of Hospital Medicine* 2020;15:331-337. © 2020 Society of Hospital Medicine

Thirty-six million people are hospitalized annually in the United States,¹ and a significant proportion of these patients are rehospitalized within 30 days.² Gaps in hospital care are many and well document-

ed, including high rates of adverse events, hospital-acquired conditions, and suboptimal care transitions.³⁻⁵ Despite significant efforts to improve the care of hospitalized patients and some incremental improvement in the safety of hospital care, hospital care remains suboptimal.⁶⁻⁹ Importantly, hospitalization remains a challenging and vulnerable time for patients and caregivers.

Despite research efforts to improve hospital care, there remains very little data regarding what patients, caregivers, and other stakeholders believe are the most important priorities for improving hospital care, experiences, and outcomes. Small studies described in brief reports provide limited insights into what aspects of hospital care are most important to patients

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Published online first May 20, 2020.

Find additional supporting information in the online version of this article.

Received: September 8, 2019; Revised: December 15, 2019;

Accepted: January 15, 2020

© 2020 Society of Hospital Medicine DOI 10.12788/jhm.3386

TABLE 1. Summary of I-HOPE Study Methods to Formulate and Prioritize a Set of Patient-Centered Research Questions to Improve the Care and Experiences of Hospitalized Patients and Their Families

Phase 1
9 clinical researchers, 9 patient/caregivers, and 2 administrators formed a project steering committee.
Phase 2
List of potential stakeholder organizations identified.
Phase 3
39 patient, caregiver, medical, professional, research, and quality improvement stakeholder organizations agreed to participate and were engaged.
Phase 4
Online survey sent to stakeholder organization leadership and members asking for the most important questions about hospitalization and/or suggestions for improvement.
Phase 5
499 respondents (patients, caregivers, healthcare providers, researchers) from 39 organizations submitted 782 questions. These were analyzed using qualitative content analysis and categorized into 70 categories.
Phase 6
Using quantitative content analysis, 36 commonly submitted questions from these 70 categories were identified.
Phase 7
The 36 most commonly submitted questions were sent to stakeholder organizations and patient partner networks for review and evaluation.
Phase 8
43 stakeholders from 37 unique stakeholder organizations attended a 2-day in-person meeting to create a final prioritized list of rank-ordered 11 questions.

and to their families.¹⁰⁻¹³ These small studies suggest that communication and the comfort of caregivers and of patient family members are important priorities, as are the provision of adequate sleeping arrangements, food choices, and psychosocial support. However, the limited nature of these studies precludes the possibility of larger conclusions regarding patient priorities.¹⁰⁻¹³

The evolution of patient-centered care has led to increasing efforts to engage, and partner, with patients, caregivers, and other stakeholders to obtain their input on healthcare, research, and improvement efforts.¹⁴ The guiding principle of this engagement is that patients and their caregivers are uniquely positioned to share their lived experiences of care and that their involvement ensures their voices are represented.¹⁵⁻¹⁷ Therefore to obtain greater insight into priority areas from the perspectives of patients, caregivers, and other healthcare stakeholders, we undertook a systematic engagement process to create a patient-partnered and stakeholder-partnered research agenda for improving the care of hospitalized adult patients.

METHODS

Guiding Frameworks for Study Methods

We used two established, validated methods to guide our collaborative, inclusive, and consultative approach to patient and stakeholder engagement and research prioritization:

- The Patient-Centered Outcomes Research Institute (PCORI) standards for formulating patient-centered research questions,¹⁸ which includes methods for stakeholder engagement that ensures the representativeness of engaged groups and dissemination of study results.¹⁸
- The James Lind Alliance (JLA) approach to “priority setting partnerships,” through which patients, caregivers, and clinicians partner to identify and prioritize unanswered questions.¹⁹

The Improving Hospital Outcomes through Patient Engagement (i-HOPE) study included eight stepwise phases to formulate and prioritize a set of patient-centered research questions to improve the care and experiences of hospitalized patients and their families.²⁰ Our process is described below and summarized in Table 1.

Phases of Question Development

Phase 1: Steering Committee Formation

Nine clinical researchers, nine patients and/or caregivers, and two administrators from eight academic and community hospitals from across the United States formed a steering committee to participate in teleconferences every other week to manage all stages of the project including design, implementation, and dissemination. At the time of the project conceptualization, the researchers were a subgroup of the Society of Hospital Medicine Research Committee.²¹ Patient partners on the steering committee were identified from local patient and family advisory councils (PFACs) of the researchers' institutions. Patients partners had previously participated in research or improvement initiatives with their hospitalist partners. Patient partners received stipends throughout the project in recognition of their participation and expertise. Included in the committee was a representative from the Society of Hospital Medicine (SHM)—our supporting and dissemination partner.

Phase 2: Stakeholder Identification

We created a list of potential stakeholder organizations to participate in the study based on the following:

- Organizations with which SHM has worked on initiatives related to the care of hospitalized adult patients
- Organizations with which steering committee members had worked
- Internet searches of organizations participating in similar PCORI-funded projects and of other professional societies that represented patients or providers who work in hospital or post-acute care settings
- Suggestions from stakeholders identified through the first two approaches as described above

We intended to have a broad representation of stakeholders to ensure diverse perspectives were included in the study. Stake-

holder organizations included patient advocacy groups, providers, researchers, payers, policy makers and funding agencies.

Phase 3: Stakeholder Engagement and Awareness Training Representatives from 39 stakeholder organizations who agreed to participate in the study were further orientated to the study rationale and methods via a series of interactive online webinars. This included reminding organizations that everyone's input and perspective were valued and that we had a flat organization structure that ensured all stakeholders were equal.

Phase 4: Survey Development and Administration

We chose a survey approach to solicit input on identifying gaps in patient care and to generate research questions. The steering committee developed an online survey collaboratively with stakeholder organization representatives. We used survey pretesting with patient and researcher members from the steering committee. The goal of pretesting was to ensure accessibility and comprehension for all potential respondents, particularly patients and caregivers. The final survey asked respondents to record up to three questions that they thought would improve the care of hospitalized adult patients and their families. The specific wording of the survey is shown in the Figure and the entire survey in Appendix Document 1.

We chose three questions because that is the number of entries per participant that is recommended by JLA; it also minimizes responder burden.¹⁹ We asked respondents to identify the stakeholder group they represented (eg, patient, caregiver, healthcare provider, researcher) and for providers to identify where they primarily worked (eg, acute care hospital, post-acute care, advocacy group).

Survey Administration. We administered the survey electronically using Research Electronic Data Capture (REDCap), a secure web-based application used for collecting research data.²² Stakeholders were asked to disseminate the survey broadly using whatever methods that they felt was appropriate to their leadership or members.

Phase 5: Initial Question Categorization Using Qualitative Content Analysis

Six members of the steering committee independently performed qualitative content analysis to categorize all submitted questions.^{23,24} This analytic approach identifies, analyzes, and reports patterns within the data.^{23,24} We hypothesized that some of the submitted questions would relate to already-known problems with hospitalization. Therefore the steering committee developed an a priori codebook of 48 categories using common systems-based issues and diseases related to the care of hospitalized patients based on the hospitalist core competency topics developed by hospitalists and the SHM Education Committee,²⁵ personal and clinical knowledge and experience related to the care of hospitalized adult patients, and published literature on the topic. These a priori categories and their definitions are shown in Appendix Document 2 and were the basis for our initial theory-driven (deductive) approach to data analysis.²³

How to complete this survey

Are you a patient or caregiver? Think about your experience during and after any hospital stay. Think about the questions that you had *during* the hospital stay or *after* you left the hospital that were left unanswered or that were confusing.

Are you a healthcare provider or a member of a healthcare-related organization? Are there any uncertainties about patient care during and after the hospital stay, or areas where you feel there should be more evidence to guide care? This could include any aspect of care—treatments, processes, decision making, discharge planning, etc.

Please share these questions with us!

The question(s) that you share about the hospital stay experience or about the after-hospital experience could lead to the development of helpful solutions that would improve care for patients and patient families in the future. Please participate in this survey by sharing your unanswered question(s) with us.

Your questions will be confidential and your name will not be used.

Please enter your first question here. After submitting your first question, you will be asked if you would like to submit additional questions, up to 3 questions.

FIG. Study survey text and question

Once coding began, we identified 32 new and additional categories based on our review of the submitted questions, and these were the basis of our data-driven (inductive) approach to analysis.²³ All proposed new codes and definitions were discussed with and approved by the entire steering committee prior to being added to the codebook (Appendix Document 2).

While coding categories were mutually exclusive, multiple codes could be attributed to a question depending on the content and meaning of a question. To ensure methodological rigor, reviewers met regularly via teleconference or communicated via email throughout the analysis to iteratively refine and define coding categories. All questions were reviewed independently, and then discussed, by at least two members of the analysis team. Any coding disparities were discussed and resolved by negotiated consensus.²⁶ Analysis was conducted using Dedoose V8.0.35 (Sociocultural Research Consultants, Los Angeles, California).

Phase 6: Initial Question Identification Using Quantitative Content Analysis

Following thematic categorization, all steering committee members then reviewed each category to identify and quantify the most commonly submitted questions.²⁷ A question was determined to be a commonly submitted question when it appeared at least 10 times.

Phase 7: Interim Priority Setting

We sent the list of the most commonly submitted questions (Appendix Document 3) to stakeholder organizations and patient partner networks for review and evaluation. Each organization was asked to engage with their constituents and leaders to collectively decide on which of these questions resonated and was most important. These preferences would then be used during the in-person meeting (Phase 8). We did not provide stakeholder organizations with information about how many times each question was submitted by respondents because we felt this could potentially bias their decision-making processes such that true importance and relevance would not be obtained.

Phase 8: In-person Meeting for Final Question Prioritization and Refinement

Representatives from all 39 participating stakeholder organizations were invited to participate in a 2-day, in-person meeting to create a final prioritized list of questions to be used to guide patient-centered research seeking to improve the care of hospitalized adult patients and their caregivers. This meeting was attended by 43 stakeholders (26 stakeholder organization representatives and 17 steering committee members) from 37 unique stakeholder organizations. To facilitate the inclusiveness and to ensure a consensus-driven process, we used nominal group technique (NGT) to allow all of the meeting participants to discuss the list of prioritized questions in small groups.²⁸ NGT allows participants to comprehend each other's point of view to ensure no perspectives are excluded.²⁸ The NGT was followed by two rounds of individual voting. Stakeholders were then asked to frame their discussions and their votes based on the perspectives of their organizations or PFACs that they represent. The voting process required participants to make choices regarding the relative importance of all of the questions, which therefore makes the resulting list a true prioritized list. In the first round of voting, participants voted for up to five questions for inclusion on the prioritized list. Based on the distribution of votes, where one vote equals one point, each of the 36 questions was then ranked in order of the assigned points. The rank-ordering process resulted in a natural cut point or delineated point, resulting in the 11 questions considered to be the highest prioritized questions. Following this, a second round of voting took place with the same parameters as the first round and allowed us to rank order questions by order of importance and priority. Finally, during small and large group discussions, the original text of each question was edited, refined, and reformatted into questions that could drive a research agenda.

Ethical Oversight

This study was reviewed by the Institutional Review Board of the University of Texas Health Science Center at San Antonio and deemed not to be human subject research (UT Health San Antonio IRB Protocol Number: HSC20170058N).

RESULTS

In total, 499 respondents from 39 unique stakeholder organizations responded to our survey. Respondents self-identified into multiple categories resulting in 267 healthcare providers, 244 patients and caregivers, and 63 researchers. Characteristics of respondents to the survey are shown in Table 2.

An overview of study results is shown in Table 1. Respondents submitted a total of 782 questions related to improving the care of hospitalized patients. These questions were categorized during thematic analysis into 70 distinct categories—52 that were health system related and 18 that were disease specific (Appendix 2). The most frequently used health system-related categories were related to discharge care transitions, medications, patient understanding, and patient-family-care team communication (Appendix 2).

TABLE 2. **Characteristics of Survey Respondents^a**

Responder Type	
Patient	117
Caregiver	127
Healthcare Provider	267
Researcher	63
Policy Maker	10
Payer	4
Industry	4
Responder Location/Setting ^b	
Acute Care Hospital	189
Higher Education Institution	33
Health System	26
Post-Acute Care (eg, Skilled Nursing Facility)	15
Primary Care Clinic	35

^aCategories are not mutually inclusive; responders can belong to multiple categories.

^bRefers to participants other than patients/caregivers.

From these categories, 36 questions met our criteria for “commonly identified,” ie, submitted at least 10 times (Appendix Document 3). Notably, these 36 questions were derived from 67 different coding categories, of which 24 (36%) were a priori (theory-driven) categories²³ created by the Steering Committee before analysis began and 43 (64%) categories were created as a result of this study's stakeholder-engaged process and a data-driven approach²³ to analysis (Appendix Document 3). These groups of questions were then presented during the 2-day, in-person meeting and reduced to a final 11 questions that were identified in rank order as top priorities (Table 3). The questions considered highest priority related to ensuring shared treatment and goals of care decision making, improving hospital discharge handoff to other care facilities and providers, and reducing the confusion related to education on medications, conditions, hospital care, and discharge.

DISCUSSION

Using a dynamic and collaborative stakeholder engagement process, we identified 11 questions prioritized in order of importance by patients, caregivers, and other healthcare stakeholders to improve the care of hospitalized adult patients. While some of the topics identified are already well-known topics in need of research and improvement, our findings frame these topics according to the perspectives of patients, caregivers, and stakeholders. This unique perspective adds a level of richness and nuance that provides insight into how to better address these topics and ultimately inform research and quality improvement efforts.

The question considered to be the highest priority area for

TABLE 3. Rank-Ordered, Prioritized List of Research Questions Related to the Care of Hospitalized Adult Patients^a

Question in the Words of Patients ^a and Stakeholders	Reformatted as a Research Question
1 How can we ensure shared decision making and that patients and families are included in treatment decision making and goals of care discussion?	What interventions ensure that patients share in decision making regarding their goals and plans of care?
2 How can the hospital discharge handoff to other care facilities (eg, SNFs), primary care providers, and specialists be made smoother?	What are the most effective discharge handoff practices between hospitals and other providers?
3 How can education on medications, medical conditions, hospital care, and discharge be better coordinated by the care team and not so confusing and overwhelming to patients?	How can the care team best coordinate education on medications, medical conditions, hospital care, and discharge for hospitalized patients to minimize confusion?
4 How can patients, family members, other caregivers, and healthcare teams work together to create effective discharge experiences that allow patients to feel empowered to manage their health once they get home?	For inpatients, what comprises a collaborative discharge process that fosters understanding, empowerment, and effective management of their health at home?
5 How do we ensure that information provided by the care team during hospitalization and at discharge was clearly understood and clearly communicated by patients and caregivers?	What are effective strategies for identifying and overcoming barriers to comprehension of information delivered to patients during hospitalization and at discharge?
6 How can we use telemedicine technology to improve transitions of care and reduce rehospitalization?	Can telemedicine technology be used to reduce readmissions or improve transitions of care in hospitalized patients?
7 Who do I call if I have any questions after I have been discharged?	Who should the patient call after discharge if they have questions, concerns, or need to be connected to appropriate resources?
8 Did your healthcare providers explain to you what your problem or diagnosis is, what steps were done to explore that condition, what treatment was undertaken, and what will still need to be done after discharge?	What are the most effective ways for patients and providers to partner in understanding information about diagnosis, steps taken to explore it, treatments undertaken, and what needs to happen after discharge?
9 What are patient expectations related to the treatment of pain/chronic pain?	What are patients' expectations related to the treatment of pain?
10 Which interventions improve medication reconciliation at key time points of the care trajectory (hospital/home, admission/discharge), and what are each intervention's outcomes?	What are the best interventions to achieve medication optimization throughout the patient's care trajectory?
11 Can hospital staff be more transparent about hospital practices (eg, parking, cafeteria, rules about protocol for entering patient rooms, rounds, and sleep interruptions)?	Would providing more clear and accessible information regarding hospital practices (eg, parking, cafeteria, protocols for entering patient rooms, etc) result in improved patient experiences compared with current practices?

^aPatient(s) includes patients, families, caregivers, and surrogates
Abbreviation: SNF, skilled nursing facility.

future research and improvement surmised how it may be possible to implement interventions that engage patients in shared decision making. Shared decision making involves patients and their care team working together to make decisions about treatment, and other aspects of care based on sound clinical evidence that balances the risks and outcomes with patient preferences and values. Although considered critically important,²⁹ a recent evaluation of shared decision making practices in over 250 inpatient encounters identified significant gaps in physicians' abilities to perform key elements of a shared decision making approach and reinforced the need to identify what strategies can best promote widespread shared decision making.³⁰ While there has been considerable effort to facilitate shared decision making in practice, there remains mixed evidence regarding the sustainability and impact of tools seeking to support shared decision making, such as decision aids, question prompt lists, and coaches.³¹ This suggests that new approaches to shared decision making may be required and likely explains why this question was rated as a top priority by stakeholders in the current study.

Respondents frequently framed their questions in terms of their lived experiences, providing stories and scenarios to il-

lustrate the importance of the questions they submitted. This personal framing highlighted to us the need to think about improving care delivery from the end-user perspective. For example, respondents framed questions about care transitions not with regard to early appointments, instructions, or medication lists, but rather in terms of whom to call with questions or how best to reach their physician, nurse, or other identified provider. These perspectives suggest that strategies and approaches to improvement that start with patient and caregiver experiences, such as design thinking,³² may be important to continued efforts to improve hospital care. Additionally, the focus on the interpersonal aspects of care delivery highlights the need to focus on the patient-provider relationship and communication.

Questions submitted by respondents demonstrated a stark difference between "patient education" and "patient understanding," which suggests that being provided with education or education materials regarding care did not necessarily lead to a clear patient understanding. The potential for lack of understanding was particularly prominent in the context of care plan development and during times of care transition—topics that were encompassed in 9 out of 11 of our prioritized research questions. This may suggest that approaches that

improve the ability for healthcare providers to deliver information may not be sufficient to meet the needs of patients and caregivers. Rather, partnering to develop a shared understanding—whether about prognosis, medications, hospital, or discharge care plans—is critical. Improved communication practices are not an endpoint for information delivery, but rather a starting point leading to a shared understanding.

Several of the priority areas identified in our study reflect the immensely complex intersections among patients, caregivers, clinicians, and the healthcare delivery system. Addressing these gaps in order to reach the goal of ideal hospital care and an improved patient experience will likely require coordinated approaches and strong involvement and buy-in from multiple stakeholders including the voices of patients and caregivers. Creating patient-centered and stakeholder-driven research has been an increasing priority nationally.³³ Yet to realize this, we must continue to understand the foundations and best practices of authentic stakeholder engagement so that it can be achieved in practice.³⁴ We intend for this prioritized list of questions to galvanize funders, researchers, clinicians, professional societies, and patient and caregiver advocacy groups to work together to address these topics through the creation of new research evidence or the sustainable implementation of existing evidence.

Our findings provide a foundation for stakeholder groups to work in partnership to find research and improvement solutions to the problems identified. Our efforts demonstrate the value and importance of a systematic and broad engagement process to ensure that the voices of patients, caregivers, and other healthcare stakeholders are included in guiding hospital research and quality improvement efforts. This is highlighted by the fact our results of prioritized category areas for research were largely only uncovered following the creation of coding categories during the analysis process and were not captured using a priori categories that were expected by the steering committee.

The strengths of this study include our attempts to systematically identify and engage a wide range of perspectives in hospital medicine, including perspectives from patients and their caregivers. There are also acknowledged limitations in our study. While we included patients and PFACs from across the country, the opinions of the people we included may not be representative of all patients. Similarly, the perspectives of the other participants may not have completely represented their stakeholder organizations. While we attempted to include a broad range of organizations, there may be other relevant groups who were not represented in our sample.

In summary, our findings provide direction for the multiple stakeholders involved in improving hospital care. The results will allow the research community to focus on questions that are most important to patients, caregivers, and other stakeholders, reframing them in ways that are more relevant to patients' lived experiences and that reflect the complexity of the issues. Our findings can also be used by healthcare providers and delivery organizations to target local improvement efforts. We hope that patients and caregivers will use our results to

advocate for research and improvement in areas that matter the most to them. We hope that policy makers and funding agencies use our results to promote work in these areas and drive a national conversation about how to most effectively improve hospital care.

Acknowledgments

The Society of Hospital Medicine (SHM) provided additional administrative, logistical, and technical support.

The authors would like to thank all patients, caregivers, and stakeholders who completed the survey. The authors also would like to acknowledge the organizations and individuals who participated in this study (see Appendix Document 4 for full list). At SHM, the authors would like to specifically thank Claudia Stahl, Jenna Goldstein, Kevin Vuernick, Dr Brad Sharpe, and Dr Larry Wellikson for their support.

Disclosures: Drs Leykum and Fletcher receive salary support from the Department of Veterans Affairs. Dr Chopra, Ms Wurst, Ms Hagan, Ms Archuleta, Ms Avita, Dr Fang, Dr Harrison, Mr Banta, Ms Coker, Dr Fletcher, Dr Jawali, Dr Mullick, Ms Ziegler, and Dr Eid received funding from the Patient Centered Outcomes Research Institute during the conduct of this study. Dr Burden, Mr Nyenpan, Ms Silva, and Ms Benn have nothing to disclose.

Funding: This study was funded by a Patient Centered Outcomes Research Institute (PCORI) Eugene Washington Engagement Award (#3939).

Disclaimer: The statements presented in this publication are solely the responsibility of the authors and do not necessarily represent the views of the Department of Veterans Affairs, Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors, or Methodology Committee.

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