

Eliciting stakeholder preferences for patient-centered research

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Background: Rather than identifying exposures and outcomes for research solely based on interests of medical professionals, there is a need for research that answers questions that are important to patients, so that they may make treatment decisions based on evidence that reflect their individual preferences.

Objective: To identify exposures and outcomes of interest that could be studied with electronic health record data from inpatient care.

Design, setting, participants: Mixed-methods analysis of semi-structured interviews administered in 2017 to 76 patients and 26 physicians who receive or provide care at Beth Israel Deaconess Medical Center in Boston, MA.

Measurements: After conducting detailed semi-structured interviews about topics of interest that can be studied using electronic health records of inpatient care, we used an inductive approach to identify themes about the health care experience.

Results: Participants reported concerns about adverse effects of medication changes, drug interactions, and surgery and other invasive procedures. The outcomes of greatest concern to them were in-hospital deaths and hospital-acquired infections. Participants commented on the importance of clear communication and information transfers, the hospital environment, accurate skills and knowledge, and upholding patient dignity and respect.

Conclusion: Engaging patients and physicians in the research development process provided insight to the exposures and outcomes they consider important. Our questions about exposures and outcomes of interest were restricted to topics that could be studied with electronic health record data from inpatient care, but using a similar approach to elicit feedback about the health care experience could be used to glean insight for other areas of future research.

Keywords: patient-oriented methods, clinical, health communication

Background

Rather than identifying exposures and outcomes for research solely based on interests of medical professionals, there is a need for research that answers questions that are important to patients, so that they may make treatment decisions based on evidence that reflect their individual preferences.^{1,2}

For instance, oncologists may place greater value on interventions that promote gains in survival, whereas patients may assign a higher value to treatments that enhance quality of life.³ By involving patients, caregivers, clinicians, and others involved in health care in identifying exposures and outcomes to be studied, the focus of clinical research may be more relevant to the community. Agencies such as the National Institutes of Health and Patient-Centered Outcomes Research Institute (PCORI) aim to close this gap by inviting stakeholders to engage in the research process.¹ PCORI defines stakeholder as any individual or entity involved in the health care process,

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such as patients, caregivers, clinicians, community members, health care purchasers, payers, industry, hospitals and other health systems, policy makers, training institutions, and researchers.⁴

With the rapid expansion, integration, and availability of electronic health information such as inpatient medications, diagnoses, and procedures, there are new opportunities to conduct large studies with detailed health data without the need to recruit and interview patients or the need to rely on self-reported information.⁵ Yet this increased data availability has not been met with increased research to seek guidance on exposures and outcomes from interested parties. We therefore conducted a mixed methods study of 102 patients and physicians in a large tertiary care hospital. We implemented an approach to identify exposures and outcomes of interest to patients and physicians and that could be studied with electronic data generated during routine inpatient care.

Methods

Beth Israel Deaconess Medical Center (BIDMC) is a tertiary care teaching hospital with 673 beds and had 40,656 inpatient discharges in 2017. Embedded within BIDMC is a large, academic primary care practice, Health Care Associates (HCA), with four practice sites across the Boston-based medical center. In 2017, HCA provided care for over 41,500 patients with 271,063 outpatient visits. We identified a convenience sample of patients who receive their primary care at HCA and physicians who provide care for patients admitted to the BIDMC.

A convenience sample of HCA primary care providers provided written permission to contact potentially eligible individuals. To be eligible, patients had to communicate in English and have had at least one outpatient visit to HCA in the prior 24 months. Patients were contacted by a letter sent to their home with a description of the study and the opportunity to opt out. Reasons for opting out were collected. We also recruited a convenience sample of BIDMC-affiliated physicians who provide medical care for inpatients. We targeted physicians across a range of medical and surgical specialties as well as hospitalists. Physicians were contacted by email with a description of the study and option to opt out. We contacted patients by phone and physicians by email up to ten times to see if they were interested in participating in our study. All participants were mailed written information about the study and a copy of the informed consent form, and they were invited to complete the interview over the phone or in-person in a private office. Recruitment and data

collection were conducted simultaneously; invitation letters were mailed in batches, follow-up calls were made in waves, and enrollment and interviews were scheduled as soon as participants agreed and were available.

All participants who enrolled in the study provided verbal consent. A single investigator conducted the semi-structured interview (see Supplementary materials) for all participants. The interviews were audio recorded. We asked participants to identify possible harmful exposures and consequent adverse outcomes in the hospital setting, and to rank their suggestions from highest to lowest priority as research targets. If the suggestions were not amenable to examination from routinely collected electronic health data, we asked participants to consider exposures and outcomes that would typically be recorded in electronic health records. We transcribed the recorded interviews to obtain information on exposures and outcomes of interest and to conduct qualitative analyses to gain greater insight about stakeholder interests and concerns. Study data were collected and managed using REDCap electronic data capture tools hosted at Harvard T.H. Chan School of Public Health.⁶

Analysis

We conducted a mixed methods study⁷ to gain insight about exposures and outcomes of interest to physicians and patients that can be studied using inpatient electronic health data, a rapidly expanding resource. In this approach, we combined quantitative and qualitative approaches, by asking participants about exposures and outcomes of interest, and calculating the frequency of each response. In addition to this quantitative presentation of the data, we used an inductive analysis⁸ of the qualitative data from the transcribed interviews about health exposures and outcomes. Using this approach, we identified themes in participants' research interests that would not be readily apparent from their listed suggestions of exposures and outcomes. Three authors (EM, JD, and MAM) independently read transcribed interviews from five patients and five physicians to identify themes, and we developed definitions of these themes. Based on the themes, two authors (EM and JD) independently reviewed a second sample of five patient and five physician transcribed interviews, and coded the texts according to the identified themes. After a third reviewer (MAM) compared the coded interviews to assure that the themes were clearly defined, a fourth reviewer (ACJ) examined these interviews. The themes were further refined through discussion until we reached a final agreement by

consensus. Transcripts were reviewed until themes reached saturation.

Results

The enrollment of study participants is depicted in Figure 1. Among 315 individuals contacted to participate, only 16% (49 patients and three physicians) declined to participate. We were unable to contact eight potential participants and there was one incomplete interview. Recruitment and enrollment happened simultaneously. Therefore, once the recruitment goals were met ($n=76$ patients and 26 physicians), we closed recruitment before we could follow-up and enroll the remaining 152 people. Of those who were invited, 102 completed the study (84 phone interviews, 18 interviews in-person) including 76 of the 236 (32%) patients and 26 of the 79 (33%) physicians.

Approximately two-thirds of the participants in the study were women, the majority were White and had a high level

of education (Table 1). The median time for completing the interview following the consent process was 28 minutes. Physicians were most likely to report exposures of medication changes and interactions, surgery and other invasive procedures, and exposure to lines, catheters and needles. Patients were also most likely to report exposures of medication changes and interactions and surgery and other invasive procedures, but they also frequently reported hospital-acquired infections. Regarding outcomes of great concern, physicians were most likely to report hospital-acquired infections and bleeding whereas patients were most likely to report death and hospital-acquired infections as the outcomes of greatest importance for future research using inpatient electronic health data. (Table 2).

In addition to the specific exposures and outcomes identified by participants, our qualitative analysis allowed us to identify seven themes that provide context for physicians' and patients' values about the health care experience.

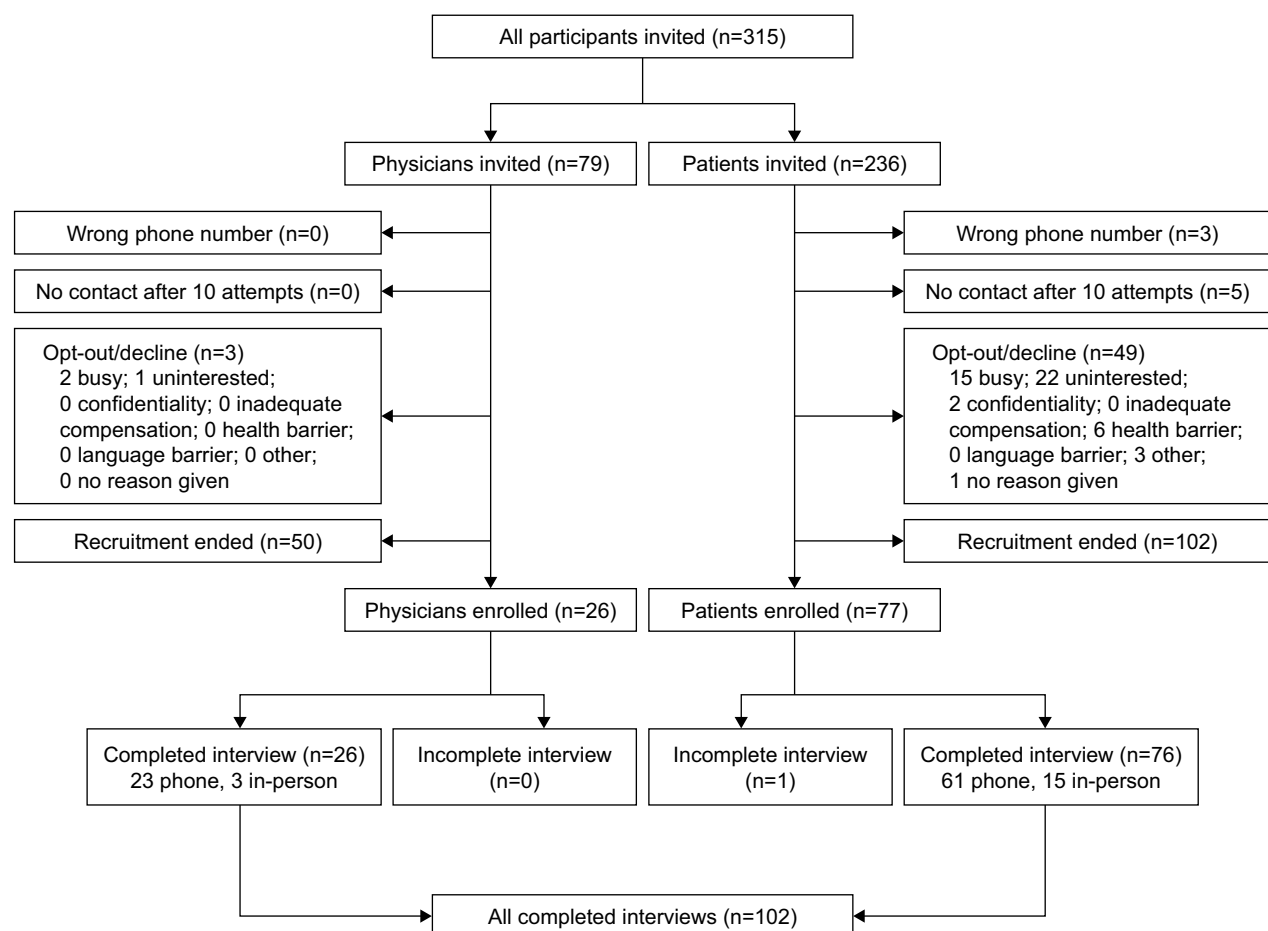


Figure 1 Participant recruitment and enrollment process of 26 Beth Israel Deaconess Medical Center physicians and 76 Health care Associate patients from January to July 2017.

Table 1 Characteristics of 102 patient and physician study participants from January–July 2017, mean \pm standard deviation or n (%)

	Physicians (n=26)	Patients (n=76)	All (n=102)
Age (years)	48.0 \pm 9.3	54.4 \pm 15.1	52.8 \pm 14.1
Women	11 (42.3%)	57 (75.0%)	68 (66.7%)
Ethnicity			
Not Hispanic or Latino	22 (84.6%)	69 (90.8%)	91 (89.2%)
Hispanic or Latino	4 (15.4%)	7 (9.2%)	11 (10.8%)
Race			
American Indian/Alaska Native	0	1 (1.3%)	1 (1.0%)
Asian	4 (15.4%)	4 (5.3%)	8 (7.8%)
Black or African American	1 (3.8%)	10 (13.2%)	11 (10.8%)
White	21 (80.8%)	57 (75.0%)	78 (76.5%)
More than one race	0	1 (1.3%)	1 (1.0%)
Unknown/not reported	0	3 (3.9%)	3 (2.9%)
Highest level of education			
Less than high school	0	1 (1.3%)	1 (1.0%)
High school graduate, diploma or equivalent (GED)	0	3 (3.9%)	3 (2.9%)
Some college credit, no degree	0	9 (11.8%)	9 (8.8%)
Trade/technical/vocational training	0	2 (2.6%)	2 (2.0%)
College graduate	0	28 (36.8%)	28 (27.5%)
Advanced degree	26 (100.0%)	33 (43.4%)	59 (57.8%)
Occupation			
Medical doctor, hospitalist	12 (46.2%)	0 (0.0%)	12 (11.8%)
Medical doctor, medical	9 (34.6%)	0 (0.0%)	9 (8.8%)
Medical doctor, surgical	5 (19.2%)	0 (0.0%)	5 (4.9%)
Professional/executive/supervisory/technical		37 (48.7%)	37 (36.3%)
Retired		20 (26.3%)	20 (19.6%)
Sales, homemaker, self-employed, clerical		9 (11.8%)	9 (8.8%)
Unemployed		5 (6.6%)	5 (4.9%)
Laborer		3 (3.9%)	3 (2.9%)
Student		1 (1.3%)	1 (1.0%)
Unspecified		1 (1.3%)	1 (1.0%)

Abbreviation: GED, general educational development.

Table 3 includes example statements from physicians and from patients related to each of the themes described below:

Theme 1 – Information transfers

Patients and physicians frequently commented on the importance of clear communication and accurate information transfer between providers and information transfer between providers and patients. Participants noted that being hospitalized was a good opportunity to clarify treatment confusion and communicate care instructions: “Being informed, well informed. Your doctor informing you of the pros and cons of whatever the illness is and how it is going to be treated.” Participants also noted the dangers of poor information transfer in the hospital. A physician stated that, “There are a lot of potential harms that are caused by human factors like poor communication.” Included here are provider teams working together to provide care. Participants commonly reported communication as an exposure of interest, suggesting that there is a prevalent concern that communication affects health outcomes.

Theme 2 – Processes of care

Participants shared several examples of the processes of care formalized through protocols and procedures to address quality measures, health monitoring, and obtaining extensive medical histories. The organizational environment that accounts for each step within a patient’s care was highlighted: “The use of IVs and catheters and all of the, all of the other instruments that hospitals seem to take a great care to ensure that those are properly disposed of and carefully wrapped and protected, you know, prior to use so that’s probably a good thing that’s happening right now.”

Theme 3 – Provider skills and knowledge

Both patients and physicians noted the importance of a provider’s ability to perform necessary and appropriate procedures, to have adequate knowledge of treatment, and to properly diagnose patients; they also voiced concerns that a lack of knowledge and skill can result in errors with adverse consequences. For instance, participants frequently suggested infection as an important adverse event in the

Table 2 Commonly reported exposures and outcomes of interest

	Physician (n=82 suggestions)	Patient (n=239 suggestions)	All (n=321 suggestions)
Exposures of interest			
Medication changes and interactions	25 (30.5%)	48 (20.1%)	73 (22.7%)
Surgery and other invasive procedures	16 (19.5%)	50 (20.9%)	66 (20.6%)
Hospital acquired infection	2 (2.4%)	52 (21.8%)	54 (16.8%)
Medication error	4 (4.9%)	30 (12.6%)	34 (10.6%)
Lines, catheters, and needles	10 (12.2%)	10 (4.2%)	20 (6.2%)
Hand hygiene	1 (1.2%)	14 (5.9%)	15 (4.7%)
Falls	4 (4.9%)	7 (2.9%)	11 (3.4%)
Communication	2 (2.4%)	5 (2.1%)	7 (2.2%)
Wrong site/side surgery	0	5 (2.1%)	5 (1.6%)
Clotting/bleeding	2 (2.4%)	2 (0.8%)	4 (1.2%)
Lung complication/respiratory arrest	0	4 (1.7%)	4 (1.2%)
Neurological issues	0	4 (1.7%)	4 (1.2%)
Allergic reaction ^a	0	3 (1.3%)	3 (0.9%)
Ventilator	2 (2.4%)	0	2 (0.6%)
Other	14 (17.1%)	5 (2.1%)	19 (5.9%)
Outcomes of interest			
Death	5 (6.1%)	56 (23.4%)	61 (19.0%)
Hospital acquired infection	15 (18.3%)	40 (16.7%)	55 (17.1%)
Allergic reaction	7 (8.5%)	14 (5.9%)	21 (6.5%)
Neurological issues	4 (4.9%)	14 (5.9%)	18 (5.6%)
Bleeding	11 (13.4%)	4 (1.7%)	15 (4.7%)
Prolonged hospital stay	2 (2.4%)	13 (5.4%)	15 (4.7%)
Surgery and other invasive procedures	1 (1.2%)	13 (5.4%)	14 (4.4%)
Lung complication/respiratory arrest	8 (9.8%)	5 (2.1%)	13 (4.0%)
Cardiovascular disease	4 (4.9%)	6 (2.5%)	10 (3.1%)
Acute kidney injury	5 (6.1%)	4 (1.7%)	9 (2.8%)
Amputation and limb ischemia	0	9 (3.8%)	9 (2.8%)
Falls	0	9 (3.8%)	9 (2.8%)
Clotting	4 (4.9%)	2 (0.8%)	6 (1.9%)
Hospital acquired pneumonia	3 (3.7%)	3 (1.3%)	6 (1.9%)
Multiple organ failure	3 (3.7%)	3 (1.3%)	6 (1.9%)
Sepsis	1 (1.2%)	5 (2.1%)	6 (1.9%)
Blood pressure regulation	2 (2.4%)	2 (0.8%)	4 (1.2%)
Blood sugar regulation	1 (1.2%)	3 (1.3%)	4 (1.2%)
Liver issues	1 (1.2%)	3 (1.3%)	4 (1.2%)
Pain	0	4 (1.7%)	4 (1.2%)
Medication changes and interactions	1 (1.2%)	2 (0.8%)	3 (0.9%)
Psychological distress	1 (1.2%)	2 (0.8%)	3 (0.9%)
Wrong site/side surgery	0	3 (1.3%)	3 (0.9%)
Gastrointestinal complications	0	2 (0.8%)	2 (0.6%)
Readmission	0	2 (0.8%)	2 (0.6%)
Surgical complication	0	2 (0.8%)	2 (0.6%)
Other	3 (3.7%)	14 (5.9%)	17 (5.3%)

Note: ^aSome participants suggested allergic reaction as an exposure that may result in higher risk of in-hospital mortality.

hospital setting, and they posited that it may be attributable to provider skills. A patient said, “You’re relying on somebody to do their job well and make sure the tools are sterile.” The avoidance of this harm depends on provider’s skill and knowledge. Provider skills and knowledge were also noted as impacting a patient’s trust and confidence on their providers’ skills.

Theme 4 – Proposing solutions

When prompted about possible hospital harms and outcomes, participants provided a means of solving or dealing with an issue or difficult situation. For instance, medication changes and interactions was a commonly reported exposure of interest and allergic reactions ranked high on reported outcomes of interest. One patient suggested the harm of taking a

Table 3 Themes and representative quotes that emerged from stakeholder interviews

Themes	Representative quotes	
	Patients	Physicians
Information transfer	<p>“Not knowing all the information before you come in and you wake up from surgery and it’s a totally different outcome than what you expected, that could be traumatizing if you’re not given all that information. Or not given all the information of how you’re going to recover.”</p> <p>“It’s a good setting for your primary care giver to explain to you things and you could have the results right away to give to your patients and any other kind of advice that your doctor could give you is right there and then.”</p>	<p>“I think for patients its extremely jarring for patients when they feel like teams aren’t working together, even seem like they communicate with each other, and there’s a disconnected plan or even a contradictory plan which happens all the time.”</p> <p>“Language barriers, whether that requires intermediaries and different resources in a resource-constrained environment when you do not have time.”</p>
Processes of care	<p>“The anesthesiologist has to be very good and pay attention to what they’re doing. It could be the tools they’re using that aren’t sterile in the surgery or it could just be a plain old mistake that they make, you know?”</p> <p>“I think the monitoring, I mentioned this before, but I’m really impressed with the nursing centers and the ongoing monitoring of vital signs.”</p> <p>“Sometimes you know because of a fault by the prescribing practitioner or nurses maybe they gave wrong medications.”</p>	<p>“Well, things can definitely go wrong, you know. You have a complication during the surgery, during the surgery or post-operative. You know, maybe there was an accidental laceration of something or uncontrolled bleeding or interoperative hypertension. And then post-op, people get infections.”</p> <p>“... not getting an antibiotic if one provider forgets to relay that to someone else who, you know is providing it to the patient.”</p> <p>“Yeah, so ... my particular pet peeve is transfers of care, lack of continuity in overall care of the patient.”</p> <p>“Sometimes you know when the system is not set up right ...”</p>
Provider skills and knowledge	<p>“Well maybe wrong medication given to a patient. Sometimes you know because of a fault by the prescribing practitioner or nurses maybe they gave wrong medications.”</p>	<p>“I think you know, supervising a resident doing a central line could cause a pneumothorax or you know a carotid artery puncture for example.”</p> <p>“I would not be surprised if that still occurs because part of that depends on you knowing the name of the agent and some house staff do not. They think they do but they actually do not.”</p> <p>“There’s no expert that can do this and it falls on who’s on call that day and it could happen that they haven’t done that procedure since 20 years ago.”</p>
Proposing solutions	<p>“I do not know what the protocol could be to help improve that because being on the cost side is to try to be the least invasive as possible to see how that could be ... lead to the other ... multiple surgeries.”</p>	<p>“I mean there’s actually really interesting studies in the past couple of years about the influence of rudeness on a team’s performance.”</p>
Respect	<p>“And I always come to them with intellect and be honest about my condition and they respect that and are great doctors so as a patient I can expect this at any point they can explain but there aren’t any ... I go there expecting to be treated well and then I do, I do and I am ... Also if the patient’s privacy is not honored because you could hear some nurses or some other practitioner talking about your condition to other people about your consent maybe.”</p>	<p>“The best experience for a patient will occur when individuals are really caring ... So I think for patients feeling really heard and working with doctors and nurses who really make an effort to develop a sense of trust and communicating clearly between team members is going to give the patient the better experience.”</p> <p>“But you know, good exposures are kind of the absence of bad exposures plus respect, dignity, comfort, clarity, precision.”</p>
Support and relationships	<p>“... the care and the attention of the caregivers ...”</p> <p>“... or the family members are not being involved in the care and some of the elderly patients sometimes get agitated...on top of the new environment and the cultural differences and the language barriers so it has some bad effect on the patient.”</p>	<p>“I think it’s very hard to understand how to care for someone if you never knew them well.”</p>
Normalizing risk	<p>“Mistakes are made but not intentionally.”</p>	<p>“I think there are some known rate of complications from surgeries that are going to occur no matter how careful we try to be.”</p> <p>“Nobody obviously meant for that to happen.”</p>

medication that causes discomfort, and began to propose a solution: “The doctor could maybe at that point throttle the dosage or change to a secondary type of medication vs the patient sitting in discomfort and maybe isn’t tolerating the medication properly.”

Theme 5 – Respect

Participants expressed the importance of upholding patient dignity and respect for their privacy and cited the lack of respect as negative outcome in the hospital setting. When prompted about good hospital exposures and outcomes, a patient offered, “You know, being treated with respect.”

Theme 6 – Support and relationships

Participants highlighted the value of providers’ or caregivers’ willingness to provide support, give assistance beyond necessary protocol measures, and formulate rapport and relationships. From the care and attention of caregivers who “go the extra mile” to social and psychological support, participants shared their appreciation for “Developing a better relationship whether it’s with a doctor or an ongoing provider. I think that’s important, especially with older people ... and if you have a new provider every time that could be a challenge, so establishing a relationship would be a positive.”

Theme 7 – Normalizing risk

Although participants commonly reported invasive procedures and hospital-acquired infections as exposures of interest, they also recognized that there is some inevitable level of heightened risk in an in-patient setting: “It’s easy to get an infection in the hospital because it’s the hospital and people are ill,” says one patient; while a physician stated, “... even with all possible precautions taken, I think there’s going to be some degree of infection.”

Discussion

In this study, we aimed to include patients and physicians in identifying exposures and outcomes for clinically relevant research by asking what topics were important to them that could be studied with electronic data from inpatient care. We implemented an approach for gaining insight about exposures and outcomes of interest to patients and physicians so that they may make treatment decisions based on evidence that reflect their preferences.⁹ The high recruitment success depicted in Figure 1 shows that patients and physicians are interested, willing, and able to offer their perspectives.

The opportunity to use mixed methods techniques to identify themes and gain additional insight about values and

concerns of the patients and physicians proved to be both achievable and informative. By obtaining information about exposures and outcomes of interest and combining these findings with an in-depth thematic analysis of the participants’ process in responding to those questions, we were able to glean greater insight into how the respondents’ interests and concerns might have shaped their preferences and their ranking of the priority of these preferences. Furthermore, we identified themes that offered a different framework for understanding patient and physician preferences that would not have emerged without the inductive approach, including comments about an inevitable level of risk in the inpatient setting and the theme of proposing solutions to the concerns that had been raised.

There is increasing interest in addressing the importance of including stakeholders in the research development process.^{1,4} Basic research that is publicly funded needs to consider and protect the public’s interests.¹⁰ Clinical research has room to involve patients and clinicians; patients are prepared to participate in and help formulate meaningful research questions.¹ Different methods have been suggested for eliciting feedback from patients and other stakeholders, including satisfaction surveys and focus groups, presenting hypothetical treatment scenarios, and encouraging participants to elaborate on their understanding of presented choices.^{9,11–13} For example, the Prospective Measure of Preference method measures patient preferences and surgeon choice in complex decision-making that provides choices between standard treatment and alternate options. Identifying treatment preferences is a useful tool to assess willingness of taking part in a specific surgery and allows research to focus on trials that may be most effective.¹¹ The benefits and feasibility of involving the community in the research process has been reported extensively in the literature about methods for community-based participatory research (CBPR) that are used in behavioral research.^{14–16} This approach involves communities in all aspects of the research process,¹⁶ adding to the cost and time to conduct these projects, but also potentially improving the relevance and timeliness of the project.¹⁵ Despite the known value of CBPR and mixed-methods techniques¹⁷ their relevance for epidemiology,¹⁸ and the recognized importance of patient-centered care, studies involving qualitative data remain rare in clinical settings.

We identified patients who receive outpatient medical care at a large urban teaching hospital, since these are individuals who are likely to represent the population who are admitted to this hospital, and we identified physicians

involved in the care of inpatients. The patient and physician experience may vary by the area of medicine and prognosis of the health outcomes. For instance, the perspective and interests of patients and physicians facing issues related to acute care may be different from those who are involved in the decision-making process for preventive services, cancer screening, elective surgeries, and palliative care. By using methods for qualitative analysis, we were able to gain a deeper understanding about gaps in knowledge and issues involved in transitions in care and health communication. The incorporation of mixed methods research in clinical settings presents greater insight on research questions and understanding of complex health problems.¹⁹

Our sample includes people at risk of being hospitalized at BIDMC, but not necessarily people who have been hospitalized. Our participants may have different perspectives and exposures and outcomes of interest than those who are currently facing choices required of inpatient care. They may differ from patients who receive care in suburban practices, concierge practices, safety net hospitals, or community health centers. Rather than recruiting a sample from a large urban hospital, other interview studies have been conducted in a range of settings. For example, a qualitative study with palliative care patients about meaning-making was conducted at a large research institution, a community hospital, and a community mobile clinic.²⁰ Across these settings, they collected information about patients' perspectives and found through chronic and life-limiting illnesses, emphasizing relationships was central to meaning-making. Future research could further explore the diversity of patient research interests within varying clinical settings.

There are some limitations to our study that warrant discussion. This moderately sized study is based on a convenience sample comprised of interested patients and physicians at BIDMC who were available to complete the interview. Therefore, the responses of our participants may not reflect those of other more diverse populations. For instance, we were not able to include other stakeholders, such as health care purchasers, payers, industry, hospitals and other health systems, policy makers, training institutions, and researchers.⁴ Furthermore, the exposures and outcomes suggested by the study participants are contingent on the health care experiences of the respondents and their friends and relatives. In addition, our questions about exposures and outcomes of interest for research were restricted to topics that could be studied with electronic health record data recorded in the routine course of inpatient care, whereas research on the questions that are most important to patients and

physicians may not be possible using electronic health record data. The themes identified with the inductive approach are inevitably shaped by the individuals conducting the analysis, but the study authors include people with different clinical and research backgrounds. Our team includes a clinical physician, epidemiologist, social psychologist, and early career social science researcher.

Patient engagement is needed to identify high-priority research questions. Integrating mixed methods into clinical research can expand our understanding of exposures and outcomes that are of interest to stakeholders such as patients and physicians in order to help develop relevant, responsive research. By gathering this information, patient-centered research can provide greater insight to new outlooks on the health care experience. Our results provide further evidence of the feasibility of incorporating these important perspectives.

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Disclosure

The authors report no conflicts of interest in this work.

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Supplementary material

Semi-structured interview data collection form

Research topics

Based on today's discussion, you will help us identify important research topics that can be studied in people who are hospitalized. We will ask you for guidance on the most meaningful way to report the results of these studies. This will allow us to help physicians and patients make informed decisions. Thank you for taking the time to participate in this study.

What questions do you have at this point?

We are aiming to think of exposures and how they may affect your risk of "adverse events." An adverse event means "harm to a patient as a result of medical care."¹ A report from the Inspector General stated more than 1 in 5 hospitalized patients experience an adverse event, of either permanent or temporary harm.

We have used this report to identify the leading causes of harmful hospital exposures and their complications. We are interested in hospital exposures that vary over time such as drugs or therapies that are taken every so often, surgeries, and other procedures. Further, we are interested in hospital complications that occur suddenly without warning such as a change in mental status, abnormally low blood sugar, inhaling materials into the lungs, and infections.

We will be asking you about the relationships between exposures and their potentially harmful results. An example of a relationship between exposures and their outcomes is the use of a catheter and developing an infection.

What questions do you have at this point?

The relationships that you identify will guide research priorities in future studies using information from patients hospitalized at Beth Israel Deaconess Medical Center. We will not be looking at your medical records and we will not ask you about your personal medical history. We are more interested in hearing your thoughts and suggestions and because of this, there are no right or wrong answers.

Do you have any questions before we begin?

1. We are hoping to identify different adverse events that patients may experience during a hospital stay. The underlying causes that lead to adverse events can result in

permanent or temporary harm. What are possible causes of hospital harms and the effects they may have on one's health in the hospital?

- Probe: Let's think about some adverse events that might happen in the hospital
 - Follow up: What might a patient be exposed to for that complication to occur?
- Probe: These may be issues that have affected you, someone you care about, or issues that you wonder about. What relationships between hospital exposures and outcomes are important to you, your family, or your colleagues/friends?
- Redirect: If conversation is about slowly developing outcomes – Can you think of an example of events that happen suddenly without warning; something you might be able to observe within a hospital stay?
- Close out: Based on our discussion, you recommended that researchers focus on the following harms and adverse events. Can you please rank this list from most to least importance to you?

Table S1 Exposures and outcomes during a hospital stay and ranking of perceived importance

Exposure	Outcome	Rank

2. On the other hand, can you help identify good things that might happen in a hospital setting?

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