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Patient and family engagement: a survey of US hospital practices

Jeph Herrin,[1,2] Kathleen G Harris,[1] Kevin Kenward,[1] Stephen Hines,[1] Maulik S Joshi,[1] Dominick L Frosch[3,4]

▸ Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/bmjqs-2015-004006)

[1]Health Research & Educational Trust, American Hospital Association, Chicago, Illinois, USA
[2]Division of Cardiology, Yale University School of Medicine, New Haven, Connecticut, USA
[3]Gordon & Betty Moore Foundation, Palo Alto, USA
[4]Department of Medicine, University of California, Los Angeles, California, USA

Correspondence to
Kathleen Harris, Health Research & Educational Trust, American Hospital Association, 155 N Wacker Drive Suite 400, Chicago, IL 60606, USA; kharris@aha.org

Received 26 January 2015
Revised 26 May 2015
Accepted 28 May 2015
Published Online First 16 June 2015

To cite: Herrin J, Harris KG, Kenward K, *et al*. *BMJ Qual Saf* 2016;**25**:182–189.

ABSTRACT

Background Patient and family engagement (PFE) in healthcare is an important element of the transforming healthcare system; however, the prevalence of various PFE practices in the USA is not known.

Objective We report on a survey of hospitals in the USA regarding their PFE practices during 2013–2014.

Results The response rate was 42%, with 1457 acute care hospitals completing the survey. We constructed 25 items to summarise the responses regarding key practices, which fell into three broad categories: (1) organisational practices, (2) bedside practices and (3) access to information and shared decision-making. We found a wide range of scores across hospitals. Selected findings include: 86% of hospitals had a policy for unrestricted visitor access in at least some units; 68% encouraged patients/families to participate in shift-change reports; 67% had formal policies for disclosing and apologising for errors; and 38% had a patient and family advisory council. The most commonly reported barrier to increased PFE was 'competing organisational priorities'.

Summary Our findings indicate that there is a large variation in hospital implementation of PFE practices, with competing organisational priorities being the most commonly identified barrier to adoption.

INTRODUCTION

A growing body of evidence shows that a more engaged patient experiences better health outcomes and lower use of healthcare services. The term 'patient engagement' encompasses a number of related concepts, including 'patient-centred care'[1] and 'shared decision-making',[2] all of which build on the idea of involving patients as partners in their care. Under this broad umbrella term, there is evidence that patient engagement is associated with fewer adverse events,[3] better patient self-management,[4 5] fewer diagnostic tests,[6] decreased use of healthcare services[7] and shorter lengths of stay in hospitals.[8]

There is also evidence that patients benefit when family members play an active part in the patient's care. For example, one study found that family members gave new information 46% of the time when present during rounds.[9] Family members can take on many roles, such as participating in care coordination and assessing care practices for consistency, accuracy and safety.[10] They play an especially important role when patients are not physically or cognitively able to participate in their own care, and family members become the surrogate decision-makers.[11] Further, organisational policies supporting family involvement, such as extended visiting hours, may affect health outcomes; one study reported that longer visiting hours in the intensive care unit were linked to a reduction in cardiovascular complications, possibly through patients' reduced anxiety and better hormonal profiles.[12]

While continuing to grow, the evidence is not entirely positive; for example, one study found that patient-centred communication was associated with longer visit length.[6] In addition, a focus group study found that some people would like their providers to tell them what to do rather than engage in shared decision-making with them.[13]

Multiple mechanisms have been proposed to link patient and family engagement (PFE) to better outcomes. One hypothesis is that when clinicians engage patients and their family members as active partners in their care, the patients and family members can provide information missing from medical charts and can recognise and speak up about errors in care delivery.[9] Another is that when patients help make the decisions about

which treatment options would be the most favourable, they are more likely to follow the selected treatment plans.[14] Additionally, when patients can better communicate their questions and concerns, they may be better able to understand, and more likely to adhere to, their treatment protocols.[4 15] It is also possible that when clinicians give patients the confidence and skills to manage their conditions, patients will play more effective roles in self-care.[16] Furthermore, when patients and family members serve as advisors to hospitals, they can help improve the experiences of patients and families in ways that lead to favourable outcomes.[17] The comparative importance of these proposed mechanisms is unknown, and there is currently limited or conflicting evidence to support them.

However, regardless of the mixed evidence regarding specific mechanisms and outcomes, there is growing agreement that effective PFE is foundational to improving patient experience and clinical outcomes and decreasing use of unnecessary healthcare services. This agreement has led to an increased emphasis on and expansion of PFE practices by healthcare leaders and providers.

This expansion has been reinforced by financial incentives for hospitals. As part of the Patient Protection and Affordable Care Act, Medicare payments to hospitals are affected by Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) scores.[18] HCAHPS includes some items that directly relate to patient engagement, specifically those regarding doctor and nurse communication, and evidence links greater patient engagement to higher patient ratings of hospital quality.[3]

In this study, we build on the framework proposed by Carman *et al*[19] and define PFE as (1) a set of beliefs and behaviours by patients, family members and health professionals; (2) features of organisational design and procedures; and (3) a set of organisational policies, all designed to ensure the inclusion of patients and their family members as active members of the healthcare team as well as encourage collaborative partnerships with providers, patients and their families. Given the evidence that PFE is associated with better health outcomes, higher patient ratings of hospital quality and lower use of healthcare services, it is surprising how little is known about actual practices and policies of hospitals in the USA.

Thus, we undertook a national survey of hospitals about their use of a range of recommended strategies, including patient and family advisory councils, online access to medical records, health education materials in other languages, 24 h visitation policies, nurse shift-change reports at patients' bedsides, decision aids, and physician and nurse training in patient engagement. We also surveyed hospitals about their perceived barriers to adopting PFE practices. The purpose of this project was twofold: (1) to describe the degree to which a core set of recommended PFE practices is currently being used in a sample of US hospitals; and (2) to determine the relative significance of perceived barriers to PFE.

METHODS

Overview

We conducted a cross-sectional survey of a random sample of hospitals in the USA. The survey was developed in conjunction with a panel of experts on PFE and mailed to 3500 randomly selected hospitals. We report on the survey results regarding adoption of PFE practices and the barriers to PFE.

Survey

To develop the questionnaire, we reviewed the literature and identified a number of PFE strategies to be assessed, and searched the literature and the internet for existing surveys of PFE. We then convened a technical expert panel (TEP) of 12 external experts with experience or expertise in providing patient-centred care; implementing patient-centred models of care; patient safety awareness; organisational development and management; healthcare quality research; and PFE in planning, delivery and evaluation of healthcare services (see online supplementary appendix A for list of experts). We presented the TEP with a draft survey; suggestions from the TEP were incorporated into a revision, which was then shared again with the TEP; the process repeated for multiple iterations. The final instrument was comprised of 38 items, which measured PFE on 20 distinct topics (see online supplementary appendix B). Items included 37 questions on the implementation of PFE strategies and one multiple-response item concerning perceived barriers to additional implementation.

Sampling

Surveyed hospitals were chosen at random from the 2012 American Hospital Association (AHA) Annual Survey.[20] We excluded hospitals that were not acute care hospitals, which left 5290 hospitals. We calculated that to detect a difference of 10% between a subset of 25% of the hospitals reporting and the remaining 75%, we would need 1028 responses. Our initial sample was based on an anticipated 50% response rate. The sampling was done in two stages; an initial sample of 2000 hospitals was surveyed in July 2013. Because of a lower-than-expected response rate, this was followed by a second sample of 1500 in October 2013. The two samples were pooled for analysis. Because of closures, mergers and inaccurate mailing information in the AHA survey file, the number of actual hospitals sampled was 3442. The survey was sent to CEOs at each hospital; hospitals could return the paper form or fill out an electronic version online. Sampling stage and mode of administration had no substantive relationship to reported

findings. We used a number of strategies to increase the response rate, including a two-page pre-announcement about the survey at the Health Forum/AHA Annual Summit; second, third and fourth mailings to hospitals; calls to all non-responders after the fourth mailings; announcements about the survey in AHA newsletters; survey promotion by the TEP and the AHA/Health Research & Educational Trust Hospital Engagement Network; and letters to hospital CEOs from state hospital associations.

Data sources and variables

We linked the PFE surveys to the AHA Annual Survey in order to determine hospital teaching status (none, residency programme, Council of Teaching Hospitals (COTH)); ownership (private not-for-profit, private for-profit, US Department of Veterans Affairs (VA) or other government); number of beds (≤25, 26–100, 101–200, 201–300, >300); critical access hospital (CAH) status; urban-continuum status (division, metro, micro, rural); and geographic region. We separated VA hospitals from other government hospitals because an initial inspection of survey results showed a strong pattern of differences between the two.

PFE scoring

To facilitate evaluation and comparison of hospitals with respect to PFE, we used the original survey to construct a set of summary items. This approach allowed us to combine items that had dependencies and categorise items that had multiple response options. The PFE summary items were constructed in consultation with the TEP in regards to which survey items, if any, could be excluded. The summary items were structured according to the topics of the questionnaire, with items selected from each topic. We grouped these items into three broad categories: (1) organisational practices, (2) bedside practices and (3) patient and family access to information and support for shared decision-making.

Analysis

We summarised the characteristics of hospitals that responded to the survey and compared them to those of the hospitals that did not respond or were not sampled, using χ^2-tests to test for differences between the two groups.

The survey contained questions about 17 specific barriers to hospital adoption of PFE practices, each with a response scale of 1–5, in which 1 was 'no barrier' and 5 was 'significant barrier'. To facilitate analysis and interpretation, we dichotomised the responses for each of the 17 items into 1–3 ('not a significant barrier') or 4–5 ('significant barrier'), and reported the frequency of hospitals citing each as a significant barrier.

All analyses were done using Stata version 13.1 (Stata Corp, 2014, College Station, Texas, USA).

RESULTS

Of the 3442 hospitals surveyed, 1457 (42.4%) responded. The 1457 hospitals differed significantly from non-surveyed acute care hospitals on all characteristics except CAH status, with moderately higher likelihood of being COTH, public or not-for-profit, larger bed size, urban and in New England or the South Atlantic (see table 1). Eighteen per cent of respondents were hospital CEOs, with the remaining surveys being completed by other hospital staff.

The 25 items and their frequencies are given in table 2. Of the 25 items, 49% of hospitals had 9 or more fully implemented.

Barriers

The barriers included in the PFE survey are listed in table 3 in order of the frequency with which respondents rated them as significant barriers. Fifty-one per cent of respondents identified competing organisational priorities as a significant barrier, followed by time to set up and implement advisory programmes, time required for rounds and shift changes that engage patients, and financial support for PFE activities.

DISCUSSION

Findings

In this first ever survey of the PFE strategies and policies implemented at hospitals across the USA, we found a wide variation in practices. Among the most widely adopted organisational practices, 88% had written policies on patients' rights to identify which of their personal contacts they would like to have actively involved in their care, 86% had a policy for unrestricted visitor access in at least some units and 67% had formal policies for disclosing and apologising for medical errors. Within this same domain, the least frequently adopted included the involvement of patients and family members as either educators or content developers when training clinical staff (7%), patient and family advisory councils meeting within the last 12 months (21%), and patient and family members sitting on the patient and family advisory councils (23%).

Among the most widely adopted PFE bedside practices, 80% at least sometimes employed the use of white boards in patients' rooms, and 68% practised teach-back with patients in at least some units. The least frequently adopted practice was conducting multidisciplinary rounds with patients and families (61%).

Among practices related to patient and family access to information and support for shared decision-making, the most widely adopted practice was allowing patients to examine their health records either anytime (42%) or by appointment or consult (44%). The second most common was taking steps to address health literacy and language issues (73%). The least

Table 1 Characteristics of hospitals included compared with those not surveyed

Characteristic	Not included	Responded	All eligible	p Value
N	3833 (100.0)	1457 (100.0)	5290 (100.0)	
Teaching				0.000
None	3215 (83.9)	1116 (76.6)	4331 (81.9)	
Residency	449 (11.7)	185 (12.7)	634 (12.0)	
COTH	169 (4.4)	156 (10.7)	325 (6.1)	
Ownership				0.000
Government	832 (21.7)	351 (24.1)	1183 (22.4)	
Non-profit	2008 (52.4)	866 (59.4)	2874 (54.3)	
Profit	900 (23.5)	208 (14.3)	1108 (20.9)	
VA	93 (2.4)	32 (2.2)	125 (2.4)	
Beds (category)				0.000
≤25	927 (24.2)	267 (18.3)	1194 (22.6)	
26–100	1192 (31.1)	384 (26.4)	1576 (29.8)	
101–200	742 (19.4)	294 (20.2)	1036 (19.6)	
201–300	439 (11.5)	154 (10.6)	593 (11.2)	
301+	460 (12.0)	358 (24.6)	818 (15.5)	
Missing	73 (1.9)	0 (0.0)	73 (1.4)	
Critical access hospital				0.241
No	2863 (74.7)	1111 (76.3)	3974 (75.1)	
Yes	970 (25.3)	346 (23.7)	1316 (24.9)	
Urban status				0.036
Division	535 (14.0)	228 (15.6)	763 (14.4)	
Metro	1766 (46.1)	662 (45.4)	2428 (45.9)	
Micro	629 (16.4)	267 (18.3)	896 (16.9)	
Rural	903 (23.6)	300 (20.6)	1203 (22.7)	
Region				0.000
New England	125 (3.3)	86 (5.9)	211 (4.0)	
Mid Atlantic	329 (8.6)	125 (8.6)	454 (8.6)	
South Atlantic	509 (13.3)	255 (17.5)	764 (14.4)	
East North Central	536 (14.0)	183 (12.6)	719 (13.6)	
East South Central	543 (14.2)	243 (16.7)	786 (14.9)	
West North Central	350 (9.1)	95 (6.5)	445 (8.4)	
West South Central	654 (17.1)	186 (12.8)	840 (15.9)	
Mountain	304 (7.9)	140 (9.6)	444 (8.4)	
Pacific	428 (11.2)	140 (9.6)	568 (10.7)	
Other	54 (1.4)	4 (0.3)	58 (1.1)	
Missing	1 (0.0)	0 (0.0)	1 (0.0)	

COTH, Council of Teaching Hospitals; VA, US Department of Veterans Affairs.

commonly reported practice was giving patients 24 h online access to their personal health information (28%). These findings are difficult to interpret, in part because of the inherent limitations of a survey. Responses may not correspond to actual practices at the hospital, and there may be differences across hospitals in what a particular practice actually means. To study this further, we contacted some of the 71% of hospitals that said they provided decision aids to patients and asked them for copies of decision aids they used. A large majority of the materials they provided were simply educational materials, such as pamphlets that did not fit the technical definition provided in the survey ('informational health materials and literature that help people become involved in decision-making by making explicit the decision that needs to be made, providing information about treatment options and outcomes, and helping the patient clarify personal values'). There are likely other item responses that similarly overstate or understate actual PFE; however, as suggested by the decision aid example, we think it is more likely that our results overstate rather than understate the use of PFE practices.

It is also important to recognise that the survey's checklist format does not capture the depth of

Table 2 Constructed composite items

	Count	(%)
1. Organisational practices to support PFE		
Formal self-assessment of PFE practices		
No	902	(61.9)
>12 months ago	168	(11.5)
Within 12 months	344	(23.6)
Missing	43	(3.0)
Patient and family advisory council		
No	883	(60.6)
Some units	195	(13.4)
Hospital-wide	364	(25.0)
Missing	15	(1.0)
Patient and family advisory council meetings within the last 12 months		
None	256	(17.6)
1–3	27	(1.9)
≥4	278	(19.1)
Missing	896	(61.5)
Percent of patient and family advisory council who are patients/family members		
None/no council	1114	(76.5)
1–50%	96	(6.6)
51–100%	234	(16.1)
Missing	13	(0.9)
Patients/family members in hospital committees		
Low	633	(43.4)
Medium	222	(15.2)
High	31	(2.1)
Missing	571	(39.2)
Written policy on patients' rights to specify which family members or other partners in care will be actively involved in their care		
No	74	(5.1)
Yes	1281	(87.9)
Missing	102	(7.0)
Policy facilitating unrestricted access		
No	153	(10.5)
Some units	411	(28.2)
All units	841	(57.7)
Missing	52	(3.6)
Formal policy for disclosing/apologising for errors		
No	355	(24.4)
Yes	971	(66.6)
Missing	131	(9.0)
Patients/families routinely interviewed for root-cause analysis		
No	636	(43.7)
Yes	684	(46.9)
Missing	137	(9.4)
Hospital provides training to physicians on partnering		
No/Unknown	918	(63.0)
Yes	392	(26.9)
Missing	147	(10.1)
Hospital provides training to nurses on partnering		
No/Unknown	490	(33.6)
Yes	823	(56.5)
Missing	144	(9.9)
Proportion of staff receiving training on partnering		
None	480	(32.9)
1–50%	565	(38.8)
51–100%	168	(11.5)
Missing	244	(16.7)
Patients/family members involved in training clinical staff (either as educators or content developers)		
Low	210	(14.4)
Medium	72	(4.9)
High	35	(2.4)
Missing	1140	(78.2)
Clinical staff trained in how to communicate with patients		
Low	185	(12.7)
Medium	412	(28.3)
High	221	(15.2)
Missing	639	(43.9)
Metrics used to track implementation of PFE strategies		
None	537	(36.9)
1–4 metrics	499	(34.2)
5+ metrics	211	(14.5)
Missing	210	(14.4)
2. PFE practices at the bedside		
Patients/family encouraged to participate in nurse shift-change report		
No	359	(24.6)
Some units	409	(28.1)
All units	583	(40.0)
Missing	106	(7.3)
Multidisciplinary rounds conducted with patients/family members		
No	454	(31.2)
Some units	583	(40.0)
All units	312	(21.4)
Missing	108	(7.4)
Teach-back used with patients		
None	227	(15.6)
Some	586	(40.2)
All units	406	(27.9)
Missing	238	(16.3)
White board for patients' daily care		
Seldom/never	148	(10.2)
Sometimes	1140	(78.2)
Often/always	30	(2.1)
Missing	139	(9.5)

Continued

Table 2 Continued

	Count	(%)
3. Access to information and support for shared decision-making		
Online access to personal health information		
No	946	(64.9)
Yes	404	(27.7)
Missing	107	(7.3)
Patients are given information on accessing health records		
No	274	(18.8)
Yes	1070	(73.4)
Missing	113	(7.8)
Patients can examine their health records		
No	94	(6.5)
Appointment/consult only	639	(43.9)
Anytime while in the hospital	610	(41.9)
Missing	114	(7.8)
Health literacy and language issues addressed		
None	238	(16.3)
Some	701	(48.1)
All	361	(24.8)
Missing	157	(10.8)
Patients are provided with decision aids		
No	425	(29.2)
Yes	1032	(70.8)
Patients and families can activate a rapid response team		
No rapid response team	280	(19.2)
No	234	(16.1)
Through hospital staff	225	(15.4)
Directly	604	(41.5)
Missing	114	(7.8)

PFE, patient and family engagement.

hospitals' commitment to PFE. It is conceivable that a hospital has 'fully implemented' many of our 25 summary items but only in a cursory manner; on the other hand, a hospital may be more effective at PFE because of an active and integrated patient and family advisory council that has focused strongly on only a few key strategies.

Yet even with these inherent restrictions on interpretation, we think the survey provides clear evidence that there is large variation in adoption of practices across hospitals in the USA. While few hospitals have adopted a wide range of practices, a number of practices are in widespread use, and some hospitals have adopted a large number of them. The availability of clinical information systems, support from clinicians or administrators, and concerns related to privacy or risk management were not identified by many respondents as significant barriers. However, over half of responding hospitals viewed competing organisational priorities as a significant barrier. A lack of financial support for PFE activities and a lack of time to implement advisory programmes and specific PFE practices were identified as significant barriers in >30% of responding hospitals.

Table 3 Barriers to patient and family engagement (PFE)

Barriers	Significant barrier n	(%)
Competing organisational priorities	652/1276	(51.1)
Time it takes to set up and implement advisory programmes	545/1284	(42.4)
Time available for rounds, shift changes, etc.	409/1282	(31.9)
Amount of financial support for PFE activities	411/1289	(31.9)
Training of clinical providers in how to engage with patients	327/1282	(25.5)
Degree of transparency of medical cost information enabling patients to compare	319/1277	(25.0)
Availability of clinical information systems	284/1283	(22.1)
Support for PFE from clinicians	224/1282	(17.5)
Patient's willingness to participate in care activities	210/1280	(16.4)
Risk management concerns	200/1282	(15.6)
Degree of transparency of quality information enabling patients to compare	184/1278	(14.4)
Privacy/Health Insurance Portability and Accountability Act concerns	180/1284	(14.0)
Differences in language between patient and healthcare provider	156/1289	(12.1)
Cultural differences between patient and healthcare provider	119/1289	(9.2)
Leadership commitment to PFE activities	119/1288	(9.2)
Support for PFE from hospital administrators	109/1285	(8.5)
The literature/evidence supporting the usefulness of PFE	98/1275	(7.7)

Implications

There are no prior comprehensive surveys of PFE, so we have few benchmarks against which to compare our results. The Centers for Medicare & Medicaid Services (CMS) records some aspects of PFE at hospitals across the country. It tracks whether lab results, tests and referrals are available electronically to patients; it also compiles patient ratings of how well nurses and doctors communicate with patients (including about medications and what to do during recovery at home).[21] However, CMS does not collect information on the full range of hospital practices and policies reported here. Thus, our survey represents the best current evidence about what US hospitals are doing to engage patients and families and which barriers pose the most significant challenges. Moreover, it provides an important baseline to assess progress over time. While we believe that the use of PFE practices in hospitals is more extensive now than it was several years ago, significant opportunities to expand the use of PFE practices in American hospitals exist; such an expansion is likely to benefit both patients and the hospitals that care for them. Our findings suggest that this expansion will require changes in the priorities and resource-allocation decisions of hospital leaders. These changes are more likely if research continues to demonstrate the positive impacts of PFE practices on patients and hospital operations.

Limitations

This study has the limitations of any observational study in that it cannot establish any causality between reported barriers and PFE practices. In addition, the sample of respondents is not random; while hospitals that were not sampled or did not respond to the survey were similar to the respondents with respect to important hospital characteristics, respondents may have differed systematically from non-respondents with respect to PFE. Respondent bias is a particular concern because of the low response rate, with fewer than half of surveyed hospitals replying. The response rate and the number of missing responses may also be related to the length and complexity of the survey and might have been improved with additional development and testing. Non-response is also likely correlated with reduced use of PFE, biasing our results towards higher reporting of PFE practices.[22] More importantly, because all measures are self-reported by a single individual in the hospital, hospital responses may not correspond to actual implementation, particularly on items in which the PFE practice's definition may be unclear (such as in the example of decision aids discussed above). Related to this, the individual responding differed from hospital to hospital, and his or her position may be related to reporting bias; CEOs may under-report strategies of which they are unaware (eg, teach-back to patients). Thus, an important limitation is that our survey results may misstate the actual use of PFE strategies and policies in the surveyed hospitals; however, we think it is more likely that our results overstate rather than understate the use of PFE practices. A final limitation is that while we strove to identify all areas of PFE for inclusion in the survey by researching the literature and receiving input from external experts, in retrospect, there are PFE practices that were omitted (eg, live translation services).

Future research

Further research examining PFE strategy use is warranted, given the variable rates of PFE reported. It is possible that some of these hospitals may engage patients and family members through informal processes not captured in the questions we asked. For example, a hospital could have a policy of limited visiting hours, but staff might allow family members to see patients at any time. Related to this, and as mentioned above, there may be additional practices at hospitals that were not included in our survey questions, and efforts should be made to identify and measure these. Parallel work by others, for instance, has identified additional practices.[23]

Research to better determine which PFE activities are genuinely helpful is also warranted. Measures of how well PFE strategies are being implemented will provide useful data to hospitals and allow researchers to better understand how well-executed PFE strategies are influencing outcomes and patient experiences.

Despite the limitations of this study, it provides the clearest picture thus far of how extensively US hospitals are employing common PFE strategies and which barriers are the largest impediments to progress.

CONCLUSION

This is the first study to assess what tactics US hospitals currently employ in order to engage with patients and their family members in patient care. We found that about half of US hospitals were fully engaged in 9 or more of 25 PFE strategies for which there is expert consensus. Some key practices have been widely adopted. Efforts to promote these practices need to continue and be coupled with assistance to ensure that PFE activities are genuinely beneficial instead of simply perfunctory. Variance in adoption can be explained by factors associated with leadership choices and resource-allocation decisions. Because increased PFE use is associated with improved patient outcomes, higher patient ratings of hospital quality and decreased use of healthcare services, it is recommended that hospitals make PFE practices a priority. Moreover, creating measures that will allow hospital leaders to determine whether the PFE practices they are using have genuine value is essential. Aligning incentives for PFE to measures of the efficacy of PFE practices, rather than to the mere existence of PFE practices, will yield better outcomes for patients and better health policy.

Contributors JH performed data analysis and interpretation and helped draft the manuscript. KH helped with data acquisition efforts and drafting the manuscript. KK helped create the survey and assisted in sending out the survey and data acquisition. He also helped with data analysis, data interpretation and the drafting of the manuscript. SH helped create the survey and assisted in data analysis, data interpretation and drafting the manuscript. MJ helped create the survey and assisted in data analysis and drafting the manuscript. DF helped create the survey and assisted in drafting the manuscript.

Funding The Gordon and Betty Moore Foundation (grant number 3903).

Competing interests None declared.

Ethics approval Health Research & Educational Trust IRB.

Provenance and peer review Not commissioned; externally peer reviewed.

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APPENDIX A
Names of experts consulted:

Susan Baade, M.P.H.
Carrie Brady, J.D.
Kristin Carman, Ph.D., M.A.
Jana Beth Deen, R.N., B.S.N., J.D.
Sue Collier, M.S.N., R.N., F.A.B.C.
Susan Edgman-Levitan, P.A.
Susan Frampton, Ph.D.
Seth Glickman, M.D., M.B.A.
Helen Haskell, M.A.B.
Beverly Johnson
Kathryn Leonhardt, M.P.H., M.D.
Gregory Makoul, M.S., Ph.D.
Gail Nielsen, B.S.H.C.A., F.A.H.R.A., R.T.R.
Shoshanna Sofaer, M.P.H., Dr.P.H.

APPENDIX B.

PATIENT AND FAMILY ENGAGEMENT SURVEY

1. Has the hospital conducted a formal self-assessment to determine the extent to which various patient and family engagement practices are used in the hospital?

   ❑ Yes, within the last 12 months ❑ Yes, more than 12 months ago ❑ No

This group of questions relates to how the hospital partners with patient and family advisors.

2. Does your hospital have a patient and family advisory council that is hospital-wide, only in a unit or units of the hospital, or no hospital-wide patient and family advisory council?
   - ❑ Hospital-wide
   - ❑ Only in one or more units, but not hospital-wide (Skip to question 7)
   - ❑ There are no patient and family advisory councils (Skip to question 7)

3. Does the patient and family advisory council have bylaws or a written charter?
   - ❑ Yes
   - ❑ No

4. How many times has the patient and family advisory council met in the last 12 months?

   _____ time(s)

5. What percent of the patient and family advisory council members are patients and family members?

   _____ %

6. How long has the hospital had a patient and family advisory council?
   - ❑ Less than 12 months
   - ❑ 12 months to 24 months
   - ❑ More than 24 months

7. This question lists committees and work groups that may exist in the hospital. If your hospital uses a different name for its committee/workgroup, please choose the closest match. For example, your hospital may have a Quality Council. The closest match would be Quality/Performance Improvement/Patient Safety Team.

For each committee/work group, please indicate (1) whether or not it exists, (2) whether or not the committee/work group is led or co-led by a patient or family member, and (3) whether or not there are at least TWO patients or family members that serve on the committee/work group.

Committee or Work Group	(1) This Committee/Work Group exists in this hospital		(2) Led or Co-led by Patient or Family Member		(3) There are at least TWO patients or family members that serve on the Committee/Workgroup	
	Yes	No	Yes	No	Yes	No

Facility Design	❑	❑	❑	❑	❑	❑
Patient Experience	❑	❑	❑	❑	❑	❑
Patient/Family Education	❑	❑	❑	❑	❑	❑
Hospital's Board of Trustees	❑	❑	❑	❑	❑	❑
Board Quality and Patient Safety Committee	❑	❑	❑	❑	❑	❑
Committee or Work Group	(1) This Committee/Work Group exists in this hospital		(2) Led or Co-led by Patient or Family Member		(3) There are at least TWO patients or family members that serve on the Committee/Workgroup	
	Yes	No	Yes	No	Yes	No
Quality/Performance Improvement/Patient Safety Teams Please specify projects or teams _____	❑	❑	❑	❑	❑	❑
Other, please specify: _____	❑	❑	❑	❑	❑	❑

<u>This group of questions relates to family presence (visitor) policies and practices.</u>

8. Is there a written policy that supports patients' rights to identify their preferences with respect to which family members or other partners in care they would (and would not) like to have actively involved in their care?

❑ Yes ❑ No

9. Please indicate whether or not the hospital has a policy or guidelines that facilitate unrestricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference.

❑ Exists across all units ❑ Exists across some units ❑ Does not exist in any hospital unit

(Skip to question 10) (Skip to question 10)

For each of the following hospital units, please indicate whether or not the hospital has a policy or guidelines which facilitate unrestricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference.

Unit	This Unit Does Not Exist in This Hospital	Has a Policy/Guidelines Which Facilitate Unrestricted Access	
		Yes	No
Behavioral Health (Substance Abuse, Mental Health, Psychiatric)	❑	❑	❑
Emergency Department	❑	❑	❑
Maternity Unit	❑	❑	❑
Medical Unit	❑	❑	❑

Surgical Unit	❑	❑	❑
Pediatric Unit	❑	❑	❑
Other (Non-ICU) Specialty Units	❑	❑	❑
Coronary Care Units (CCU)	❑	❑	❑
Medical Intensive Care Units (MICU)	❑	❑	❑
Neonatal Intensive Care Units (NICU)	❑	❑	❑
Pediatric Intensive Care Units (PICU)	❑	❑	❑
Post Anesthesia Care Unit (PACU)	❑	❑	❑
Surgical Intensive Care Units (SICU)	❑	❑	❑
Other ICU Unit	❑	❑	❑
Other Unit	❑	❑	❑

This group of questions relates to practices that help patients make decisions

10. Are patients provided with decision aids for various health conditions? Patient decision aids are informational health materials and literature that help people become involved in decision making by making explicit the decision that needs to be made, providing information about treatment options and outcomes, and helping the patient clarify personal values.

❑ Yes
❑ No (Skip to question 12)

11. Please indicate whether or not patients receive decision aids through each of the following methods:

	Yes	No
A formal or central hospital service that provides all patients with decision aids for various health conditions	❑	❑
Decision aids are provided to patients by specialty units	❑	❑

12. Does the hospital calculate readability levels or scores of any informational health materials distributed by the hospital (using tools such as Kincaid, Flesch Index, SAM: Suitability Assessment of Materials)?

❑ Yes ❑ No

13. Does the hospital consistently provide non-written materials such as picture books, videotapes, or audiotapes to convey important information to patients with limited ability to obtain, process or understand basic health information and services needed to make appropriate health decisions?

Picture Books	❑ Yes	❑ No
Video Tapes	❑ Yes	❑ No
Audiotapes or multi-media presentations	❑ Yes	❑ No

14. Please indicate whether or not the hospital provides patients and families with the following materials in different languages.

	Yes	No
Both written and non-written materials	❑	❑
Just written materials	❑	❑
Just non-written materials	❑	❑

15. In general (exceptions being the right to access psychotherapy, notes or information compiled for use in litigation and records the provider determines could result in harm to you or another person), can patients examine their health record while they are in the hospital?

❑ Patients can examine their health records anytime while in the hospital.

❑ Patients can examine their health record by appointment only or in consultation with their physician.

❑ Patients are not allowed to examine their health record while in the hospital.

16. Is information given to patients on how to access their health record? ❑ Yes ❑ No

17. Please indicate whether or not patients can update the following information in their health record.

	Yes	No	Not Applicable
Who the patient's preferred family or partners in care are	❑	❑	❑
How family or care partners may participate in care and decision making	❑	❑	❑
Demographic information	❑	❑	❑
Progress notes	❑	❑	❑
Family medical history	❑	❑	❑
Allergic episodes	❑	❑	❑
Lab test results	❑	❑	❑
Do not resuscitate (DNR) orders	❑	❑	❑
Proxies	❑	❑	❑
Advanced directives	❑	❑	❑
Any information	❑	❑	❑

18. Does the hospital provide patients access to a patient portal (a secure online website that gives patients convenient 24-hour access to personal health information from anywhere with an Internet connection)?

❑Yes ❑No

<u>This group of questions relates to practices used at the bedside.</u>

19. Are patients and/or family members encouraged to participate in the nurse bedside change of shift report?

❑ Yes, across all units (Skip to question 20)

❑ Yes, across some units

❑ No, not in any hospital unit (Skip to question 20)

For each unit listed below, please indicate whether or not patients and/or family members are encouraged to participate in the nurse bedside change of shift report.

Unit	This Unit Does Not Exist in This Hospital	Patients and/or family members are encouraged to participate in the nurse bedside change of shift report	
		Yes	No
Behavioral Health (Substance Abuse, Mental Health, Psychiatric)	❑	❑	❑
Emergency Department	❑	❑	❑
Maternity Unit	❑	❑	❑
Medical Unit	❑	❑	❑
Pediatric Unit	❑	❑	❑
Surgical Unit	❑	❑	❑
Other (Non-ICU) Specialty Units	❑	❑	❑
Coronary Care Units (CCU)	❑	❑	❑
Medical Intensive Care Units (MICU)	❑	❑	❑
Neonatal Intensive Care Units (NICU)	❑	❑	❑
Pediatric Intensive Care Units (PICU)	❑	❑	❑

Unit	This Unit Does Not Exist in This Hospital	Patients and/or family members are encouraged to participate in the nurse bedside change of shift report	
		Yes	No
Post Anesthesia Care Unit (PACU)	❑	❑	❑
Surgical Intensive Care Units (SICU)	❑	❑	❑
Other ICU Unit	❑	❑	❑
Other Units	❑	❑	❑

20. Are multidisciplinary rounds (planning and evaluating patient care with health professionals from a variety of health disciplines) consistently conducted at the bedside with patients and/or family members?

❑ Yes, across all units (Skip to question 21)

❑ Yes, across some units

❑ No, not in any hospital unit (Skip to question 21)

For each of the following units, please indicate whether or not multidisciplinary rounds (planning and evaluating patient care with health professionals from a variety of health disciplines) are consistently conducted at the bedside with patients and/or family members.

Unit	This Unit Does Not Exist in This Hospital	Multidisciplinary rounds are consistently conducted at the bedside with patients and/or family members	
		Yes	No
Behavioral Health (Substance Abuse, Mental Health, Psychiatric)	❑	❑	❑
Emergency Department	❑	❑	❑
Maternity Unit	❑	❑	❑
Medical Unit	❑	❑	❑
Pediatric Unit	❑	❑	❑
Surgical Unit	❑	❑	❑
Other Non-ICU Specialty Units	❑	❑	❑
Coronary Care Units (CCU)	❑	❑	❑
Medical Intensive Care Units (MICU)	❑	❑	❑
Neonatal Intensive Care Units (NICU)	❑	❑	❑
Pediatric Intensive Care Units (PICU)	❑	❑	❑
Post Anesthesia Care Unit (PACU)	❑	❑	❑
Surgical Intensive Care Units (SICU)	❑	❑	❑
Other ICU Unit	❑	❑	❑
Other Units	❑	❑	❑

	Never	Seldom	Sometimes	Often	Always
21. How often are patients' daily care objectives listed on a white board (also known by the terms marker board, dry-erase board, dry-wipe board, pen-board) in their room?	❑	❑	❑	❑	❑
22. How often do patients or family members add their own notes to the white boards?	❑	❑	❑	❑	❑
23. How often is the white board reviewed with the patient and family?	❑	❑	❑	❑	❑

24. Does the hospital provide a way for patients and their families to call for assistance from a Rapid Response Team (RRT)?

- ❑ The hospital does not have a Rapid Response Team (RRT) (Skip to question 28)
- ❑ Patients or family members can directly call for assistance from the Rapid Response Team (RRT)
- ❑ Patients or family members have to request assistance from a Rapid Response Team (RRT) through hospital staff members
- ❑ The hospital has a Rapid Response Team (RRT) but patients can't activate it (Skip to question 27)

25. How long have you had a policy for families to be able to activate Rapid Response Teams?

- ❑ 12 months or less
- ❑ More than 12 months

26. Is information shared with families and other partners in care on how to activate or request assistance from Rapid Response Teams?

- ❑ Yes
- ❑ No

27. On average, over the past 12 months, how many rapid response calls were either activated or requested by patients or family members each month?

- ❑ 0
- ❑ 1 every other month
- ❑ 1 a month
- ❑ 2 to 3 a month
- ❑ More than 3 a month

28. How frequently is teach-back used during the discharge planning process in each of the units listed below? Teach-back is a way to confirm that the health care provider has explained what the patient needs to know in a manner that the patient understands. Patients understanding is confirmed when they accurately explain it back to the health care provider in their own words. If needed, the health care provider can re-explain and check again.

Unit	Never	Seldom	Sometimes	Often	Always	This Unit Does Not Exist in the Hospital
Behavioral Health (Substance Abuse, Mental Health, Psychiatric)	❑	❑	❑	❑	❑	❑
Emergency Department	❑	❑	❑	❑	❑	❑
Maternity Unit	❑	❑	❑	❑	❑	❑
Medical Unit	❑	❑	❑	❑	❑	❑
Pediatric Unit	❑	❑	❑	❑	❑	❑
Surgical Unit	❑	❑	❑	❑	❑	❑
Coronary Care Units (CCU)	❑	❑	❑	❑	❑	❑
Medical Intensive Care Units (MICU)	❑	❑	❑	❑	❑	❑
Neonatal Intensive Care Units (NICU)	❑	❑	❑	❑	❑	❑
Pediatric Intensive Care Units (PICU)	❑	❑	❑	❑	❑	❑
Post Anesthesia Care Unit (PACU)	❑	❑	❑	❑	❑	❑
Surgical Intensive Care Units (SICU)	❑	❑	❑	❑	❑	❑

29. Does the hospital have a formal policy for disclosing and apologizing for medical errors to patients and families? ❑Yes ❑ No (Skip to question 31)

30. How long has the hospital had a policy for disclosure and apology in place?
❑Less than 12 months ❑12 months to 24 months ❑More than 24 months

31. When a root cause analysis (RCA) investigation is conducted, are patients and/or family members routinely interviewed? ❑Yes ❑ No

32. When a root cause analysis is conducted, are patients and/or family members routinely included as members of the root cause analysis team? ❑ Yes ❑ No

This group of questions relates to equipping staff to engage patients and their families through training and education.

33. Does the hospital provide training for physicians, nurses and other clinical staff on partnering with patients and families in the care plan decision-making process?

	Yes	No	Don't Know
Physician Training	❑	❑	❑
Nurse Training	❑	❑	❑
Other Clinician Training	❑	❑	❑

34. **For each of the following training areas, please indicate whether or not patients or family members participate as educators or content developers in the training of physicians, nurses and other clinical staff, or do not participate in that training area at all.**

Training Area	Physician Training		Nurse Training		Other Clinical Staff Training		Patients or family members do not participate as educators or content developers in this training area
	Yes	No	Yes	No	Yes	No	
New employee orientation	❑	❑	❑	❑	❑	❑	❑
In-service education for clinical staff	❑	❑	❑	❑	❑	❑	❑
Programs for medical staff	❑	❑	❑	❑	❑	❑	❑
Partnering with patients and families in the care plan decision-making process	❑	❑	❑	❑	❑	❑	❑

35. What proportion of the hospital's physicians, nurses, and other clinical staff has received training on partnering with patients and families in the care plan decision-making process?

	0%	Between 1% and 25%	Between 26% and 50%	Between 51% and 75%	Between 76% and 99%	100%
Physicians	❑	❑	❑	❑	❑	❑
Nurses	❑	❑	❑	❑	❑	❑
Other Clinicians	❑	❑	❑	❑	❑	❑

36. For each of the following practices, please indicate whether or not there is formal training provided to physicians, nurses and other clinical staff in how to communicate with patients.

	Training Provided to:					
Patient Communication Training	Physicians		Nurses		Other Clinical Staff	
	Yes	No	Yes	No	Yes	No
How to encourage patients and families to ask questions	❑	❑	❑	❑	❑	❑
How to encourage patients and families to give their opinions and express concerns	❑	❑	❑	❑	❑	❑
Approaches for eliciting the values of patients and families	❑	❑	❑	❑	❑	❑
Approaches for eliciting the goals of patients and families	❑	❑	❑	❑	❑	❑
Approaches for eliciting the needs of patients and families	❑	❑	❑	❑	❑	❑

How to create opportunities to hear from patients and family members about their perspective of the care experience at the hospital	❑	❑	❑	❑	❑	❑
How to respond when people complain	❑	❑	❑	❑	❑	❑
How to involve patients and families in process improvement, redesign work, and/or committees	❑	❑	❑	❑	❑	❑
Using teach-back methods	❑	❑	❑	❑	❑	❑
Disclosing and apologizing for medical errors	❑	❑	❑	❑	❑	❑

The next group of questions relate to barriers to implementing patient and family engagement practices and monitoring and measuring engagement strategies.

37. Please rate each item below as to your perception of the degree it presents a barrier to your hospital in implementing patient and family engagement strategies on a scale ranging from 1 (no barrier) to 5 (significant barrier).

Barrier	No Barrier				Significant Barrier
	1	2	3	4	5
Differences in language between patient and health care provider	❑	❑	❑	❑	❑
Cultural differences between patient and health care provider	❑	❑	❑	❑	❑
Leadership commitment to patient and family engagement activities	❑	❑	❑	❑	❑
Amount of financial support for patient and family engagement activities	❑	❑	❑	❑	❑
Support for patient and family engagement from clinicians	❑	❑	❑	❑	❑
Support for patient and family engagement from hospital administrators	❑	❑	❑	❑	❑
Training of clinical providers in how to engage with patients	❑	❑	❑	❑	❑
Availability of clinical information systems	❑	❑	❑	❑	❑
Patient's willingness to participate in care activities	❑	❑	❑	❑	❑
The literature/evidence supporting the "usefulness" of patient and family engagement practices	❑	❑	❑	❑	❑
Time available for rounds, change of shift, etc.	❑	❑	❑	❑	❑
Time it takes to set up and implement advisory programs	❑	❑	❑	❑	❑
Privacy/HIPAA concerns	❑	❑	❑	❑	❑
Risk management concerns	❑	❑	❑	❑	❑
Competing organizational priorities	❑	❑	❑	❑	❑
Degree of transparency of medical cost information enabling patients to compare the price of health care services and	❑	❑	❑	❑	❑

products so they can make informed choices among doctors and hospitals					
Degree of transparency of quality information enabling patients to compare the quality of health care services	❑	❑	❑	❑	❑

38. Please indicate whether or not each of the following metrics is regularly or periodically used by the hospital to track the implementation of patient and family engagement strategies.

	Yes	No
The number of advisory councils across the hospital	❑	❑
Ratio of patient and family members to staff on advisory councils	❑	❑
Number of patient and family advisors serving on committees or Quality Improvement (QI) teams	❑	❑
Number of staff trained in partnering with families	❑	❑
Number of staff trained in communicating to support patient and family engagement	❑	❑
Changes in patients' ratings of hospital care as patient and family engagement strategies are implemented	❑	❑
Changes in clinical process and outcomes as patient and family engagement strategies are implemented	❑	❑
Changes in market or financial performance as patient and family engagement strategies are implement	❑	❑
Other (please specify)	❑	❑

39. What is your position in the hospital?

- ❑ Chief Executive Officer (CEO)
- ❑ Chief Operating Officer (COO)
- ❑ Chief Medical Officer (CMO)
- ❑ Chief Nursing Officer (CNO)
- ❑ Other (Please specify) _____

40. Other than the practices identified in this survey, please describe below any additional successful patient and family engagement practices that you have implemented in your hospital or system.

Please provide below your contact information so that we can learn more about your hospital's promising practices.

Name: _____

Title: _____

Phone: _____

Email: _____