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Consensus on how to optimize patient/family engagement in hospital planning and improvement: Delphi survey

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Consensus on how to optimize patient/family engagement in hospital planning and improvement: Delphi survey

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ABSTRACT

Objective

Patient and family engagement (PE) in health service planning and improvement is widely advocated, yet little prior research offered guidance on how to optimize PE, particularly in hospitals. This study aimed to engage stakeholders in generating evidence-informed consensus on recommendations to optimize PE.

Design

We transformed PE processes and resources from prior research into recommendations that populated an online Delphi survey.

Setting and participants

Panelists included 58 persons with PE experience including: 22 patient/family advisors and 36 others (PE managers, clinicians, executives, researchers) in Round #1 (100%) and 55 in Round #2 (95%).

Outcome measures

Ratings of importance on a seven-point Likert scale.

Results

Of 50 recommendations, 80% or more of panelists prioritized 32 recommendations (27 in Round #1, 5 in Round #2) across 5 domains: 5 engagement approaches, 4 strategies to identify and integrate diverse patient/family advisor perspectives, 9 strategies to enable meaningful engagement, 9 strategies by which hospitals can champion PE, and 5 elements of hospital capacity considered essential for supporting PE. There was high congruence in rating between patient/family advisors and healthcare professionals for all but 6 recommendations that were highly-rated by patient/family advisors but not by others: capturing diverse perspectives, including a critical volume of advisors on committees/teams, prospectively monitoring PE, advocating for government funding of PE, including PE in healthcare worker job descriptions, and sharing PE strategies across hospitals.

Conclusions

Decision-makers (e.g. health system policy-makers, hospitals executives and managers) can use these recommendations as a framework by which to plan and operationalize PE, or evaluate and improve PE in their own settings. Ongoing research is needed to monitor the uptake and impact of these recommendations on PE policy and practice.

KEYWORDS

Patient and family engagement, hospitals, quality improvement, Delphi technique

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Strengths and limitations of this study

- Recommendations were evidence-based, having been derived from prior research
- Recommendations were rated by 58 persons with lived experience of PE: 22 patient/family advisors and 36 PE managers, clinicians, executives, researchers
- We employed rigorous methods: large panel size enhanced reliability; two rounds of rating minimized respondent fatigue, which achieved a high response rate (100% Round 1, 95% Round 2); strong definition of consensus to yield high-priority recommendations (≥80% of panelists rated 6 or 7 or Likert scale to retain); and compliance with research and reporting criteria for Delphi studies to enhance rigour.
- Panelists were volunteers so their views may differ from those of other patients, patient/family advisors or healthcare professionals.
- The findings may not be relevant in countries outside of Canada with differing cultural and health system contexts.

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INTRODUCTION

Hospitals provide inpatient, outpatient and emergency services, and account for the largest share of health spending in many countries.[1] Research in many jurisdictions shows that the quality and safety of hospital care is inconsistent.[2-5] Hence, hospitals continuously strive to improve the organization and delivery of services. One approach gaining prominence worldwide is to engage patients or family/care partners (henceforth, patients) in planning, evaluating and improving health services for the benefit of all patients. In this context, patient engagement (PE) is defined as patients, families or their representatives, and health professionals working in active partnership to improve health services.[6] While evidence is accumulating on engaging patients in research,[7] and in their own health and healthcare,[8] our prior scoping review identified only 10 studies of PE for healthcare planning and improvement specifically in hospitals, which are unique from other healthcare settings in size, staffing and service delivery.[9] PE has been associated with a range of benefits such as enhanced governance and clinical processes, new or improved patient resources, and efficient service delivery.[10] Healthcare decision-makers, including policy-makers who fund hospitals, hospital managers who organize services and clinicians who directly engage patients, require knowledge of the conditions (e.g. resources, processes) that optimize PE to inform resource allocation.

We surveyed managers at hospitals in Ontario, Canada to describe PE. While infrastructure and processes varied across 91 participating hospitals, we identified hospitals of all types (<100 beds, 100+ beds, teaching) with high capacity for PE, distinguished by PE activity organization wide across multiple departments, and use of largely collaborative rather than consultative PE approaches.[11] We interviewed patient/family advisors, PE managers, clinicians and executives at hospitals with high PE capacity who identified infrastructure and processes needed to support PE. Participants also reported a range of beneficial impacts including improved PE capacity (new PE processes were developed and spread across departments, those involved became more adept and engaged) and clinical care at multiple levels: hospital (new/improved policies, strategic plans, facilities, programs), clinician (greater efficiency in service delivery, enhanced job satisfaction, improved patient-staff communication) and patient (educational material, discharge processes and information, improved hospital experience, decreased wait times, reduced falls, lower readmission rates).[12-13]

Given the widespread interest in PE and demonstrated benefits, and lack of insight on how to optimize PE in hospitals,[9,10] the overall aim of this study was to build on our prior research,[11-13] and issue guidance for optimizing PE in hospital planning and improvement. The specific objective was to engage stakeholders in establishing consensus on priority recommendations derived from evidence generated by our prior research. The output, resources and processes that enable hospital PE, could be used by decision-makers to plan, support or improve hospital PE.

METHODS

Approach

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We employed the Delphi technique, a widely-used method for generating consensus on strategies, recommendations, or quality measures.[14-16] This technique is based on one or more rounds of survey in which expert panelists independently rate recommendations until a degree of consensus is achieved. We complied with the Conducting and Reporting of Delphi Studies criteria to enhance rigor.[17] The University Health Network Research Ethics Board approved this study (REB #18-5307).

Sampling and recruitment

A review of Delphi studies showed that the median number of panelists was 17 (range 3 to 418).[18] Other research found that reliability of Delphi rating increased with panel size.[19] To ensure that multiple perspectives were considered, we aimed to include a minimum of 20 persons with experience as patient/family advisors and 20 professionals of diverse specialties with knowledge or experience of PE. We recruited Canadian patient/family advisors aged 18+ and health professionals (PE managers, clinicians, executives) affiliated with 91 Ontario hospitals that responded to our prior survey and agreed to be contacted for future studies,[11] and identified other Canadian patient/family advisors, clinicians and researchers with experience in PE on publicly-available websites.

Survey development

We derived recommendations to be rated by panelists from aforementioned interviews with patient/family advisors, PE managers, and clinicians or executives affiliated with hospitals with high PE capacity.[12-13] NN and ARG extracted data on all unique enablers and barriers of PE, or suggested strategies for promoting or supporting PE, and worded those as recommendations. We organized the 48 recommendations by domains that inductively emerged from our prior research: engagement approaches, strategies to identify and integrate diverse perspectives, strategies to enable patient/family engagement, strategies to champion patient/family engagement and hospital capacity for patient/family engagement.[12-13] The research team reviewed recommendations for clarity and relevance (Supplementary File 1).

Data collection and analysis

We transformed recommendations into a Round One online survey using REDCap. We asked panelists to rate each recommendation on a 7-point Likert scale (1 strongly disagree, 7 strongly agree), comment on the relevance or wording of each recommendation if desired, and suggest additional recommendations not included in the survey. We emailed Instructions and survey link to panelists on May 19 2021, with reminders at one and two weeks. Based on results, we developed a Round One summary report that included Likert scale response frequencies and comments for each recommendation, which we organized by those retained (rated by at least 80% of panelists as 6 or 7), discarded (rated by at least 80% of panelists as 1 or 2) or no consensus (all others), along with newly suggested recommendations. Standard Delphi protocol suggests that two rounds of rating with agreement by at least two-thirds of panelists to either retain or discard items will prevent respondent fatigue and drop-out.[17,18] We conducted two rounds of rating; however, to yield unequivocal recommendations, we considered 80% to indicate consensus. On June 18 2021, we emailed panelists the Round One summary report with a link to the Round Two survey, formatted similarly to the Round One survey, to prompt

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rating of recommendations that did not achieve consensus for inclusion or exclusion in Round One. We emailed a reminder at one, two and three weeks. We analyzed and summarized Round Two responses as described for Round One.

Patient and public involvement

Three patient and family advisors were involved in planning the multi-part study that informed this final component of that study. Patient and family advisors were included as expert panelists in this study to rate the importance of recommendations for resources and processes that optimize hospital PE.

RESULTS

Panelists

Of 109 persons invited to participate, 58 agreed (Table 1). The response rate for Round One was 100.0%, and for Round Two, 94.8% (55/58). Round Two non-responders included 1 PE researcher, 1 executive, and 1 clinician from a teaching hospital.

Table 1. Participants

Participant type	Hospital type			Others	Sub-Total
	<100 beds	100+ beds	Teaching		
Patient/family advisors	3	10	5	4	22
PE managers	4	9	5	---	18
Clinicians	3	4	2	---	9
Executives	---	---	1	3	4
Researchers	---	---	---	5	5
Sub-total	10	23	13	12	58

Delphi results

Supplementary File 2 details the recommendations retained, discarded or that achieved no consensus in Rounds One and Two. Figure 1 summarizes the number of recommendations retained, discarded or with no consensus in each Round. Of the 50 recommendations considered, 32 achieved consensus to retain: 27 in Round One and 5 in Round Two.

Prioritized recommendations

Table 2 lists 32 retained recommendations including: 5 engagement approaches, 4 strategies to identify and integrate diverse patient/family advisor perspectives, 9 strategies to enable meaningful engagement, 9 strategies by which hospitals can champion PE, and 5 elements of hospital capacity considered essential for supporting PE. Three recommendations were retained by 100.0% of panelists: In advance of meetings or activities, hospitals should provide patient/family advisors with agendas, background information or briefing material to help them prepare and then actively participate (#15); Hospitals should foster an organization-wide culture of respect and support for patient/family engagement (#27); and Hospitals should share results or outcomes with involved patient/family advisors so that they are aware of how their input and decisions contributed to planning and improvement (#30). Table 2 identifies the 16

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(50.0%) recommendations scored by 90.0% or more of panelists to retain, and the 16 (50.0%) scored by 80.0% to 89.9% of panelists to retain.

Table 2. Recommendations that achieved consensus to retain

Domain	Recommendation (% panelist who rated Likert scale 6 or 7 to retain)
Engagement approaches 5/6 retained	Patient/family advisors with appropriate skills should be engaged in decisions for hospital activities whenever possible, including governance, strategy planning, and designing, developing, evaluating or improving facilities, programs, healthcare services, care practices, quality and safety, or resources/materials (86.2)
	Hospitals should establish and maintain at least one Patient and Family Advisory Committee (87.9)
	In addition to one or more Patient and Family Advisory Committee's, hospitals should engage patient/family advisors using multiple forms of engagement (e.g. standing committees, project teams) (96.5)
	Patient and family engagement should take place in-person whenever possible to build rapport, but virtual options and technology should be offered to enhance convenience and connectivity and suit diverse preferences (**please rate this for a non-pandemic context) (83.3)
	Hospitals should employ a range of approaches to engage patient/family advisors including collaboration (e.g. member of project teams or committees), consultation (e.g. surveys, interviews, focus groups) or blended approaches (e.g. collaboration and consultation approaches for the same initiative) (93.1)
Strategies to identify and integrate diverse perspectives 4/5 retained	Hospitals should build patient/family engagement programs that welcome persons with diverse experiences, characteristics, abilities and resources representative of the communities they serve, and do so in a culturally safe manner or setting (98.3)
	Hospitals should recruit patient/family advisors using a range of strategies (e.g. social media, email, newspaper ads, word of mouth, through community organizations) and in languages or settings tailored to the community they serve to achieve diversity (91.2)
	In prioritizing what benefits many, hospitals should also use a health equity lens to ensure that they are improving quality of care for at risk populations in their community (98.2)
	Hospitals should ensure that there is ongoing recruitment and onboarding of new patient and family advisors to enhance diversity and supplement the contributions of long-standing experienced patient/family advisors (96.6)
Strategies to enable patient/family engagement 9/14 retained	Once recruited, hospitals should provide patient/family advisors with ongoing support and education about roles and responsibilities, organizational culture and strategic priorities to prepare them for engagement, possibly through mentorship by existing experienced patient/family advisors (96.5)
	In advance of deployment, hospitals should orient patient/family advisors to the background, purpose, and goals of a specific committee or project (e.g. share documents, meet with project or committee leader) (96.6)
	In advance of meetings or activities, hospitals should provide patient/family advisors with agendas, background information, briefing material and the name of a liaison who can answer questions to help them prepare and then actively participate (100.0)
	Hospitals should train project leaders, committee chairs, healthcare workers and staff on how to foster a team environment, and effectively engage with and support patient/family advisors (89.7)
	Hospitals should involve patient/family advisors in reviewing and delivering training to existing healthcare workers and staff, and orienting new healthcare workers/staff to patient engagement (84.5)
	Hospitals should engage patient/family advisors early and throughout planning or improvement activities (94.8)

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	At the outset of new committees or projects, the Chair should explicitly establish roles and responsibilities collaboratively with and for all involved including patient/family advisors and healthcare workers, and prospectively revisit roles as projects evolve (89.3)
	Hospital healthcare workers and staff should demonstrate that they value patient/family advisor input and decisions by meaningfully engaging with patient/family advisors, basing decisions on their perspectives and telling patient/family advisors that they are valued (89.1)
	Hospitals should routinely check with patient/family advisors to confirm that interim or near-to-final decisions or outputs accurately captured their perspectives and explain why, if any, were not captured (87.7)
Strategies to champion patient/family engagement 9/11 retained	Hospitals should convey an organizational commitment to patient/family engagement by acknowledging it in their hospital values statement and strategic plan, and continuously update values/strategic plan as patient/family engagement evolves (94.6)
	Hospitals should foster an organization-wide culture of respect and support for patient/family engagement (100.0)
	To establish a philosophical commitment, hospitals should promote the view that patient/family advisors bring diverse expertise, skills and perspectives, which should be valued equally to those of healthcare workers (82.8)
	Senior administrative and clinical leaders should model patient/family engagement (98.1)
	Hospitals should share results or outcomes with involved patient/family advisors so that they are aware of how their input and decisions contributed to planning and improvement (100.0)
	The hospital CEO and Board members should visibly endorse patient/family engagement by promoting it throughout the hospital to all staff and patients (e.g. in waiting rooms) to create awareness of how patient/family advisors worked with healthcare workers/staff on planning and improvement (87.5)
	Hospitals should share patient/family engagement opportunities, activities, outputs and impacts with the broader community through various platforms as a means of patient/family advisor recruitment and to create awareness about how the hospital is addressing their needs (93.1)
	Chairs of standing committees or project teams should assess acceptability in advance, and then routinely consult with patient/family advisors throughout meetings to ensure they understand acronyms, medical terms or issues under discussion, ask if they have any questions, or wanted to articulate ideas or feedback, and adjust pace as necessary (80.8)
	Hospitals should include at least one patient/family advisor on the Board or Committees of the Board as voting members (80.0)
Hospital capacity for patient/family engagement 5/12 retained	Hospitals should allocate dedicated operational funding to nurture and maintain patient/family engagement including one or more Patient and Family Advisory Committee's and other engagement activities (84.2)
	Hospitals should encourage healthcare workers to participate in patient/family engagement, and recognize their efforts (e.g. in annual performance reviews) (80.0)
	Hospitals should ideally employ a dedicated patient engagement manager to promote and support patient/family engagement, or include this responsibility in an existing closely-related portfolio (e.g. patient relations manager, human resources personnel) (88.7)
	Hospitals should employ dedicated patient engagement staff who are driven by person-centred values and possess skills in reflective listening, compassionate communication, and project coordination and facilitation (84.5)
	Hospitals should regularly evaluate patient/family engagement practices and make improvements based on patient/family advisor, healthcare worker and staff feedback, and reflection on what worked and what did not work (93.0)

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Agreement and Differences

Ratings for the 32 retained recommendations were similar between patient/family advisor panelists and others (PE managers, clinicians, executives, researchers). Of the remaining 18

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recommendations that failed to achieve consensus, patient/family advisors and others similarly rated 12 recommendations. Table 3 shows the 6 recommendations where at least 80% of patient/family advisors scored to retain and others did not along with select comments to illustrate diverging views. For example, the two groups differed in rating of recommendation #9: Hospitals should seek to identify and address issues that are priorities for, and of benefit to all patients and families they serve rather than focusing only on issues common to the majority. Patient/family advisor panelists raised concerns about equity and diversity, and thought that ignoring issues not faced by the majority of patients may lead to a worsening situation that does impact the majority. In contrast, other panelists said that it was not always possible to address all issues due to lack of resources, focus on hospital priorities, and government mandates. The 5 additional recommendations prioritized by patient/family advisors but not by other panelists included: Hospitals should include at least one and preferably more patient/family advisors on any committee or project team (#22); Patient and Family Advisory Committees should routinely review interim progress, decisions or outputs of standing committees or project teams to ensure that decisions reflect patient/family advisor perspectives (#24); Hospitals should appeal to government, which advocates for patient/family engagement, for dedicated funding to support patient/family engagement (#38); Hospitals should include patient/family engagement activities into appropriate healthcare worker and staff job descriptions as part of the Human Resource commitment to person-centred care (#42); and Hospitals should encourage, support and facilitate collaboration with Patient and Family Advisory Committees from other hospitals and Patient Family Advisory Bodies to foster a community of learning (#50).

Table 3. Recommendations with no consensus where rating differed between panelists

Recommendation (as worded in Round 2)	Rating (% who rated to retain)		Exemplar comments
	Round 1	Round 2	
(9) Hospitals should seek to identify and address issues that are priorities for, and of benefit to all patients and families they serve rather than focusing only on issues common to the majority	Patients 54.5 Others 60.0	Patients 86.4 Others 64.5	Patients • Issues that affect smaller populations are often under-studied, poorly resourced and given less visibility. • Failure to look beyond the issues that are overtly common to the majority leaves a risk of bypassing details of a critical nature that may well be or may well become an issue to the majority. Others • The PFAC cannot be all things to all people and to some degree the work of the PFAC needs to support hospital priorities and vice versa. • With limited resources you do need some principles or criteria in place for how to go about selecting the issues that need change/improvement.
(22) Hospitals should include at least one and preferably more patient/family	Patients 72.7 Others 38.9	Patients 90.9 Others 59.4	Patients • Avoids tokenism. • Important to get more than one viewpoint but must be balanced with the size of the project and committee.

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advisors on any committee or project team			• Basic is to have 2 per project as a minimum. I have also seen that some committees go with percentages. Others • I think this has to be balanced with number of advisors and requests you have or you quickly burn out people. • Surely we can find other mechanisms for involvement that are not so focused on this one strategy of "patient/family advisors on every committee/project team"?
(24) Patient and Family Advisory Committees should routinely review interim progress, decisions or outputs of standing committees or project teams to ensure that decisions reflect patient/family advisor perspectives	Patients 76.2 Others 72.2	Patients 86.4 Others 66.7	Patients • We are already doing this at six monthly intervals in our hospital as it provides an excellent insight into the progress of decisions or outputs of the PFA committee. • This would prove that patient /family input is valued. It may also improve retention of patient/family advisors on these committees. Others • Sometimes decisions don't always go the way that everyone wants. the important piece here is that various perspectives were brought to the fore, listened to, respected, weighed....and then decisions get made. • This statement removes the meaning of "partnership". Decisions and outputs need to reflect all perspectives and opinions and PFAC needs to support the give and take of this relationship.
(38) Hospitals should appeal to government, which advocates for patient/family engagement, for dedicated funding to support patient/family engagement	Patients 81.8 Others 72.2	Patients 90.9 Others 69.7	Patients • The hospital AND the Patient and Family Advisory Group should be consistently lobbying the government to financially support the hospitals efforts ensure the interests of it's "customers" and community are represented. • Government funding would be of great benefit to PFA Committees as most hospital budgets are so limited that they are not in a position to provide funding Others • I would love to see paid PFP positions and more project funding, but the dollars would be taken from patient care delivery somewhere else. • I worry saying this gives hospitals an excuse to not do it. Many hospitals are doing quite well in engagement as they make it a strategic priority within current funding models.
(42) Hospitals should include patient/family engagement activities into appropriate healthcare worker and staff job descriptions as part of the Human Resource commitment to	Patients 80.0 Others 75.0	Patients 81.9 Others 71.9	Patients • Extremely important for staff to know that organization invites and values the input of patient and family advisors • A good way to provide information about the patient/family advisors role. • Need buy in and involvement of health care workers for success. Others (comments supportive) • It needs to be built into policy/structures so that it becomes embedded and normalized and expected • Especially leadership roles

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person-centred care			• Although a great idea, hospitals need to start with a philosophy and orientation for staff on the role of engaging advisors
(50) Hospitals should encourage, support and facilitate collaboration with Patient and Family Advisory Committees from other hospitals and Patient Family Advisory Bodies to foster a community of learning	---	Patients 86.4 Others 60.6	Patients • Collaboration with groups from other organizations is a valuable way to gain insight into different processes and protocols that have been tried and proven to be effective or conversely have been utilized and were found to be an ineffective mechanism to reach patient and family advisory objectives. • This could be extremely beneficial within clusters of smaller hospitals. • Learning from each other and not re-inventing the wheel, so to speak, might save everyone time, energy and frustration. Others • From my experience, hospital committees are typically focused on site-specific issues, and while root causes may be similar across the sector, the specific actions are often very local. • Patient Family Advisors/Partners are already finding that they have multiple requests for involvement…we need to consider that they are volunteers and often are dealing with health issues either themselves or their family.

DISCUSSION

Rating of 50 recommendations for resources or processes to support hospital-based PE by 58 panelists (22 patient/family advisors; 36 PE managers, clinicians, executives, researchers) in a two-round Delphi survey resulted in consensus by 80% or more on the importance of 32 recommendations across 5 domains: 5 engagement approaches, 4 strategies to identify and integrate diverse patient/family advisor perspectives, 9 strategies to enable meaningful engagement, 9 strategies by which hospitals can champion PE, and 5 elements of hospital capacity considered essential for supporting PE. Of the 32 recommendations, 16 (50.0%) were rated important by 90%+ of panelists (3 recommendations by 100.0%), and 16 (50.0%) by 80% to 89.9% of panelists. There was high congruence in rating between patient/family advisors for all but 6 recommendations that did not achieve consensus.

Strengths of this study included: rating of recommendations by a panel comprised of patient/family advisors (who are themselves patients or family of patients) and interdisciplinary healthcare professionals; recommendations rated by panelists were derived from prior research involving patients, family and healthcare professionals, and thus evidence-based;[12-13] the large panel size enhanced reliability; two rounds of rating minimized respondent fatigue, which achieved a high response rate in both rounds; and we used a strong definition of consensus to yield high-priority recommendations. We optimized rigor by complying with research and reporting criteria for Delphi studies.[14-19] We must acknowledge limitations. Panelists were volunteers so their views may be biased; however, we specifically recruited individuals for their expertise, and potential bias was off-set by review of evidence-based recommendations. Panelist views may differ from those of other patients, patient/family advisors or healthcare professionals. The findings may not be generalizable in countries outside of Canada with differing cultural and health system contexts.

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As noted, research on PE has largely focused on engaging patients in research or in their own health care,[7,8] with very little prior research on how to enable PE in hospital-based planning and improvement.[9,10] A survey of clinicians from a university hospital in France reported only the types of activities in which patients were involved (e.g. developing care pathways, and educational programs for patients and healthcare professionals).[20] A systematic review of 11 qualitative studies of patient involvement in quality improvement (unclear if any studies based in hospitals) revealed that a key barrier was limited power of patients to influence decision-making given little power over healthcare professionals.[21] A survey of managers from 74 hospitals across 7 European countries found that few hospitals involved patients in quality improvement (e.g. developing quality criteria, designing processes, or being a member of quality committees or project teams).[22] Our research goes beyond reporting the activities in which patients are engaged or barriers of engagement to describe processes and infrastructure essential to PE based on the views of patient/family advisors and healthcare professionals with lived experience of hospital PE.

A notable finding was the high degree of agreement between patient/family advisors and other panelists on priority recommendations. This likely reflects the fact that all panelists had considerable experience in PE, and largely represented hospitals with high PE capacity and activity. Both factors underscore the relevance and validity of the recommendations, which form a concrete framework that can be broadly applied: hospitals newly embarking on PE can use the framework to develop strategic and operational plans specific to PE, and hospitals that already implemented PE can use the framework to evaluate their own activities, identify areas needing improvement, and strengthen PE. One challenge may be the large number of recommendations that achieved consensus. Organizations with limited resources could employ a staggered approach, whereby the recommendations that achieved the highest consensus could be implemented first. These recommendations were generated by persons largely affiliated with hospitals having high PE activity and capacity who self-reported numerous beneficial impacts on PE capacity, clinical care, and patient outcomes,[12-13] therefore ongoing research is needed to confirm the uptake of these recommendations, including their influence on policy at the health system or hospital level, and on various impacts in hospitals both new and established PE.

In conclusion, while PE in health service planning and improvement is widely advocated, little prior research offered guidance on how to optimize PE, particularly in hospital settings. Through a series of studies, we identified resources and processes required for hospital-based PE,[12-13] culminating in the current Delphi survey, in which 58 patient/family advisors, PE managers, clinicians, executives and researchers with experience and expertise in PE prioritized recommendations reflecting resources and processes to optimize PE. Decision-makers (e.g. health system policy-makers, hospitals executives and managers) can use the resulting 32 recommendations as a framework by which to plan and operationalize PE, or evaluate and improve PE in their own settings.

Author contributions

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ARG, GRB, LM, KS, RU and WPW conceived and planned the study. ARG acquired funding and supervised NNA. NNA and ARG coordinated the study, and collected and analyzed data. All authors reviewed and interpreted data; and contributed to, reviewed and approved this final version.

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Competing interests
The authors declare no competing interests

Patient consent
Not applicable

Ethics approval
This study was approved by the <anonymized name of research ethics board> (REB #18-5307).

Data availability statement
All data are included in the manuscript and supplementary files.

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FIGURE LEGEND

Figure 1. Delphi summary
PDF file
Flow diagram depicting each stage of the Delphi process

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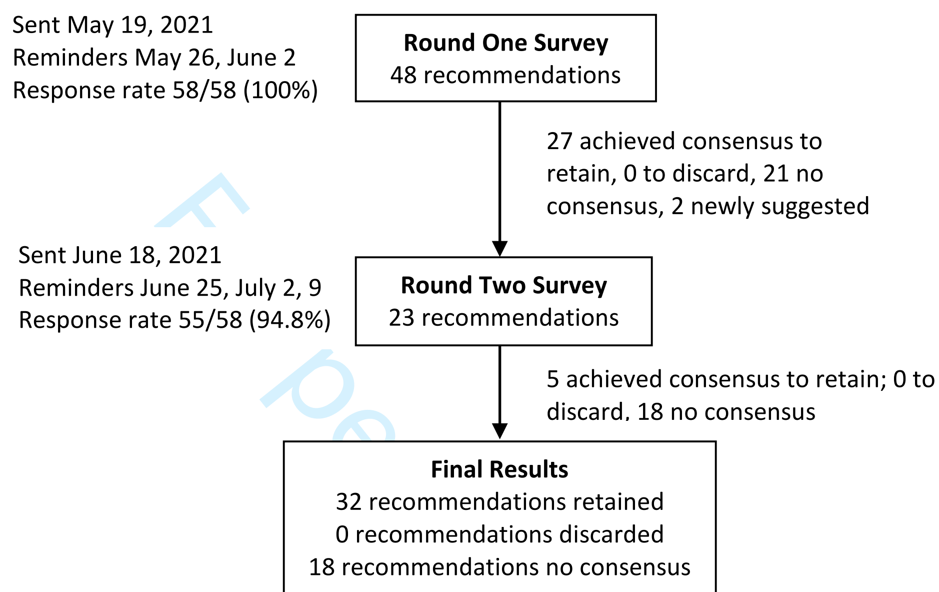

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Supplementary File 1. Hospital PE recommendations by domain derived from prior research

Engagement approaches

1	Patient/family advisors should be involved in decision-making for all hospital activities including governance, strategy planning, and designing, developing, evaluating or improving facilities, programs, healthcare services, care practices, quality and safety, or resources/materials
2	Hospitals should establish and maintain at least one patient/family advisory committee (PFAC)
3	In addition to a general PFAC, hospitals should consider establishing PFACs for departments or units that represent the hospital's clinical priorities
4	In addition to one or more PFACs, hospitals should engage patient/family advisors in a variety of ways (e.g. standing committees, project teams)
5	Patient and family engagement should take place in-person whenever possible to build rapport (please rate this for a non-pandemic context)
6	Hospitals should employ a range of engagement approaches including collaboration (e.g. member of project teams or committees), consultation (e.g. surveys, interviews, focus groups) or blended approaches (e.g. collaboration and consultation approaches for the same initiative)

Strategies to identify and integrate diverse perspectives

7	Hospitals should build patient/family engagement programs that welcome persons with diverse characteristics and provide a culturally safe environment
8	Hospitals should recruit patient/family advisors using a range of strategies (e.g. social media, email, newspaper ads, word of mouth, posting formal job descriptions) to achieve diversity
9	Hospitals should seek to address issues that are likely to benefit the majority of people they serve
10	Hospitals should also ensure that in prioritizing what benefits many, they also use a health equity lens to ensure that they are improving quality of care for disadvantaged populations in their community
11	Hospitals should ensure that there is ongoing recruitment and onboarding of new patient and family advisors to avoid deploying the same persons to multiple projects (to reduce burden on the few, and enhance diversity)

Strategies to enable patient/family engagement

12	Once recruited, hospitals should provide patient/family advisors with support and education about roles and responsibilities, organizational culture and strategic priorities to prepare them for engagement
13	In advance of deployment, hospitals should orient patient/family advisors to the background, purpose, goals and participants of a specific committee or project

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14	Once deployed, committees or project teams should involve patient/family advisors and committee/project team members in team-building exercises to build relationships
15	In advance of meetings or activities, hospitals should provide patient/family advisors with agendas, background information or briefing material to help them prepare and then actively participate
16	Hospitals should train healthcare workers and staff on how to effectively engage with patient/family advisors
17	Hospitals should involve patient/family advisors in training existing healthcare workers and staff and orienting new healthcare workers/staff to patient engagement
18	Hospitals should engage patient/family advisors early and throughout planning or improvement activities
19	Hospitals should include patient/family advisors in polls to establish meeting times, and schedule meetings at times that are suitable for patient/family advisors (e.g. evenings after work or child care)
20	At the outset of new committees or projects, the Chair should explicitly establish roles and responsibilities for all involved including patient/family advisors and healthcare workers
21	Hospital healthcare workers and staff should understand the value of patient/family input and decisions and explicitly convey value by meaningfully engaging with patient/family advisors and acknowledging the value of their role
22	Hospitals should include a critical volume of patient/family advisors on any committee or project team
23	Hospitals should require that decision-making quorum include at least one patient/family advisor
24	PFACs should routinely review interim progress, decisions or outputs of standing committees or project teams to ensure that patient/family advisor perspectives informed decisions
25	Hospitals should check with patient/family advisors to confirm that interim or near-to-final decisions or outputs accurately captured their perspectives

Strategies to champion patient/family engagement

26	Hospitals should convey an organizational commitment to patient/family engagement by acknowledging it in their hospital values statement and strategic plan
27	Hospitals should foster an organization-wide culture of respect and support for patient/family engagement
28	To establish a philosophical commitment, hospitals should promote that patient/family advisors be viewed as experts on the patient perspective, which should be valued equally to the perspective of healthcare workers

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29	The hospital CEO and Board members should visibly endorse and inform about patient/family engagement by promoting it across the hospital to all staff and patients (e.g. in waiting rooms)
30	Senior administrative and clinical leaders should model patient/family engagement
31	Hospitals should share patient/family engagement opportunities, activities, outputs and impacts with the broader community as a means of patient/family advisor recruitment and to create awareness about how the hospital is addressing their needs
32	Hospitals should share results or outcomes with involved patient/family advisors, and more broadly throughout the hospital to create awareness of how patient/family perspectives contributed to planning and improvement
33	Chairs of standing committees or project teams should routinely consult with patient/family advisors throughout meetings to ensure they understand issues under discussion, ask if they have any questions, or wanted to articulate ideas or feedback, and adjust pace as necessary
34	Hospitals should include a Board member on the PFAC who could convey concerns or ideas directly to the Board
35	Hospitals should include patient/family advisors on the Board or Committees of the Board as voting members
36	Hospitals should make the PFAC accountable to the Board for planning and improvement activities

Hospital capacity for patient/family engagement

37	Hospitals should allocate dedicated operational funding to nurture and maintain patient/family engagement including one or more PFACs and other engagement activities
38	Hospitals should appeal to government, which advocates for patient/family engagement, for dedicated funding to support patient/family engagement
39	Hospitals should reimburse patient/family advisors for expenses incurred (e.g. use of their own computers, printing costs, gas, mileage, parking, child care)
40	Hospitals should building patient/family engagement compensation and reimbursement into their yearly operational budgets
41	Hospitals should compensate patient/family advisors for their time spent contributing to patient engagement activities and for taking time off work to participate in those activities
42	Hospitals should include patient/family engagement activities into appropriate healthcare worker and staff job descriptions as part of the Human Resource commitment to person-centred care
43	Hospitals should cover the cost of release time for staff so they can participate in engagement activities

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44	Hospitals should encourage and reward healthcare workers for participating in patient/family engagement
45	Hospitals should provide access to technology for patient/family advisors so they can fully engage in activities (e.g. email accounts, lap tops, digital applications)
46	Hospitals should employ a dedicated PE manager to promote and support patient/family engagement
47	Hospitals should employ dedicated PE staff who are driven by person-centred values and possess skills in reflective listening, compassionate communication, and project coordination and facilitation
48	Hospitals should regularly evaluate patient/family engagement practices and make improvements based on patient/family advisor feedback, and reflection on what worked and what did not work

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Supplementary File 2. Hospital PE recommendations retained, discarded and with no consensus by two-round Delphi survey

Domain	Recommendation	Suggested revision	Round One (rating)	Round Two (rating)	Result
Engagement approaches	Patient/family advisors should be involved in decision-making for all hospital activities including governance, strategy planning, and designing, developing, evaluating or improving facilities, programs, healthcare services, care practices, quality and safety, or resources/materials	Patient/family advisors with appropriate skills should be engaged in decisions for hospital activities whenever possible, including governance, strategy planning, and designing, developing, evaluating or improving facilities, programs, healthcare services, care practices, quality and safety, or resources/materials	Retain (86.2)	---	Retain
	Hospitals should establish and maintain at least one Patient and Family Advisory Committee	---	Retain (87.9)	---	Retain
	In addition to a general Patient and Family Advisory Committee, hospitals should consider establishing Patient and Family Advisory Committee's for departments or units that represent the hospital's clinical priorities	In addition to a general Patient and Family Advisory Committee, hospitals should consider establishing Patient and Family Advisory Committees for units or programs that represent the hospital's clinical priorities, or embed patient/family advisors in priority unit-/program-specific advisory committees	No consensus (64.3)	No consensus (77.4)	No consensus
	In addition to one or more Patient and Family Advisory Committee's, hospitals should engage patient/family advisors in a variety of ways (e.g. standing committees, project teams)	In addition to one or more Patient and Family Advisory Committee's, hospitals should engage patient/family advisors using multiple forms of engagement (e.g. standing committees, project teams)	Retain (96.5)	---	Retain
	Patient and family engagement should take place in-person whenever possible to build rapport (please rate this for a non-pandemic context)	Patient and family engagement should take place in-person whenever possible to build rapport, but virtual options and technology should be offered to enhance convenience and connectivity and suit diverse preferences (**please rate this for a non-pandemic context)	No consensus (72.4)	Retain (83.3)	Retain
	Hospitals should employ a range of engagement approaches including collaboration (e.g. member of project teams or committees), consultation (e.g. surveys, interviews, focus groups) or blended approaches (e.g. collaboration and consultation approaches for the same initiative)	Hospitals should employ a range of approaches to engage patient/family advisors including collaboration (e.g. member of project teams or committees), consultation (e.g. surveys, interviews, focus groups) or blended approaches (e.g. collaboration and consultation approaches for the same initiative)	Retain (93.1)	---	Retain
Sub-total			4	1	5
Strategies to identify and integrate	Hospitals should build patient/family engagement programs that welcome persons with diverse characteristics and provide a culturally safe environment	Hospitals should build patient/family engagement programs that welcome persons with diverse experiences, characteristics, abilities and resources	Retain (98.3)	---	Retain

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diverse perspectives		representative of the communities they serve, and do so in a culturally safe manner or setting			
	Hospitals should recruit patient/family advisors using a range of strategies (e.g. social media, email, newspaper ads, word of mouth, posting formal job descriptions) to achieve diversity	Hospitals should recruit patient/family advisors using a range of strategies (e.g. social media, email, newspaper ads, word of mouth, through community organizations) and in languages or settings tailored to the community they serve to achieve diversity	Retain (91.2)	---	Retain
	Hospitals should seek to address issues that are likely to benefit the majority of people they serve	Hospitals should seek to identify and address issues that are priorities for, and of benefit to all patients/families they serve rather than focusing only on issues common to the majority	No consensus (57.9)	No consensus (73.6)	No consensus
	Hospitals should also ensure that in prioritizing what benefits many, they also use a health equity lens to ensure that they are improving quality of care for disadvantaged populations in their community	In prioritizing what benefits many, hospitals should also use a health equity lens to ensure that they are improving quality of care for at risk populations in their community	Retain (98.2)	---	Retain
	Hospitals should ensure that there is ongoing recruitment and onboarding of new patient and family advisors to avoid deploying the same persons to multiple projects (to reduce burden on the few, and enhance diversity)	Hospitals should ensure that there is ongoing recruitment and onboarding of new patient and family advisors to enhance diversity and supplement the contributions of long-standing experienced patient/family advisors	Retain (96.6)	---	Retain
Sub-total			4	0	4
Strategies to enable patient/famil y engagement	Once recruited, hospitals should provide patient/family advisors with support and education about roles and responsibilities, organizational culture and strategic priorities to prepare them for engagement	Once recruited, hospitals should provide patient/family advisors with ongoing support and education about roles and responsibilities, organizational culture and strategic priorities to prepare them for engagement, possibly through mentorship by existing experienced patient/family advisors	Retain (96.5)	---	Retain
	In advance of deployment, hospitals should orient patient/family advisors to the background, purpose, goals and participants of a specific committee or project	In advance of deployment, hospitals should orient patient/family advisors to the background, purpose, and goals of a specific committee or project (e.g. share documents, meet with project or committee leader)	Retain (96.6)	---	Retain
	Once deployed, committees or project teams should involve patient/family advisors and	Once deployed, committees or project teams should involve patient/family advisors and committee/project team members in team-building exercises to build	No consensus (68.4)	No consensus (65.5)	No consensus

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	committee/project team members in team-building exercises to build relationships	relationships (e.g. spend time getting to know each member)			
	In advance of meetings or activities, hospitals should provide patient/family advisors with agendas, background information or briefing material to help them prepare and then actively participate	In advance of meetings or activities, hospitals should provide patient/family advisors with agendas, background information, briefing material and the name of a liaison who can answer questions to help them prepare and then actively participate	Retain (100.0)	---	Retain
	Hospitals should train healthcare workers and staff on how to effectively engage with patient/family advisors	Hospitals should train project leaders, committee chairs, healthcare workers and staff on how to foster a team environment, and effectively engage with and support patient/family advisors	Retain (89.7)	---	Retain
	Hospitals should involve patient/family advisors in training existing healthcare workers and staff and orienting new healthcare workers/staff to patient engagement	Hospitals should involve patient/family advisors in reviewing and delivering training to existing healthcare workers and staff, and orienting new healthcare workers/staff to patient engagement	Retain (84.5)	---	Retain
	Hospitals should engage patient/family advisors early and throughout planning or improvement activities	---	Retain (94.8)	---	Retain
	Hospitals should include patient/family advisors in polls to establish meeting times, and schedule meetings at times that are suitable for patient/family advisors (e.g. evenings after work or child care)	Hospitals should gauge the availability of patient/family advisors to establish meeting times, and schedule meetings at times that are suitable for patient/family advisors (e.g. evenings after work or child care)	No consensus (79.3)	No consensus (72.7)	No consensus
	At the outset of new committees or projects, the Chair should explicitly establish roles and responsibilities for all involved including patient/family advisors and healthcare workers	At the outset of new committees or projects, the Chair should explicitly establish roles and responsibilities collaboratively with and for all involved including patient/family advisors and healthcare workers, and prospectively revisit roles as projects evolve	Retain (89.3)	---	Retain
	Hospital healthcare workers and staff should demonstrate that they value patient/family advisor input and decisions by meaningfully engaging with patient/family advisors and telling patient/family advisors that they are valued	Hospital healthcare workers and staff should demonstrate that they value patient/family advisor input and decisions by meaningfully engaging with patient/family advisors, basing decisions on their perspectives and telling patient/family advisors that they are valued	Retain (89.1)	---	Retain
	Hospitals should include a critical volume of patient/family advisors on any committee or project team	Hospitals should include at least one and preferably more patient/family advisors on any committee or project team	No consensus (51.7)	No consensus (72.2)	No consensus
	Hospitals should require that decision-making quorum include at least one patient/family advisor	Hospitals should require that decision-making quorum for committees or project teams include at least one patient/family advisor	No consensus (62.5)	No consensus (63.0)	No consensus
	Patient and Family Advisory Committee's should routinely review interim progress, decisions or outputs of standing committees or project teams	Patient and Family Advisory Committees should routinely review interim progress, decisions or outputs of standing	No consensus (73.7)	No consensus (74.5)	No consensus

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	to ensure that patient/family advisor perspectives informed decisions	committees or project teams to ensure that decisions reflect patient/family advisor perspectives			
	Hospitals should check with patient/family advisors to confirm that interim or near-to-final decisions or outputs accurately captured their perspectives	Hospitals should routinely check with patient/family advisors to confirm that interim or near-to-final decisions or outputs accurately captured their perspectives and explain why, if any, were not captured	Retain (87.7)	---	Retain
Sub-total			9	0	9
Strategies to champion patient/family engagement	Hospitals should convey an organizational commitment to patient/family engagement by acknowledging it in their hospital values statement and strategic plan	Hospitals should convey an organizational commitment to patient/family engagement by acknowledging it in their hospital values statement and strategic plan, and continuously update values/strategic plan as patient/family engagement evolves	Retain (94.6)	---	Retain
	Hospitals should foster an organization-wide culture of respect and support for patient/family engagement	---	Retain (100.0)	---	Retain
	To establish a philosophical commitment, hospitals should promote that patient/family advisors be viewed as experts on the patient perspective, which should be valued equally to the perspective of healthcare workers	To establish a philosophical commitment, hospitals should promote the view that patient/family advisors bring diverse expertise, skills and perspectives, which should be valued equally to those of healthcare workers	Retain (82.8)	---	Retain
	Senior administrative and clinical leaders should model patient/family engagement	---	Retain (98.1)	---	Retain
	Hospitals should share results or outcomes with involved patient/family advisors so that they are aware of how their input and decisions contributed to planning and improvement	---	Retain (100.0)	---	Retain
	The hospital CEO and Board members should visibly endorse patient/family engagement by promoting it throughout the hospital to all staff and patients (e.g. in waiting rooms) to create awareness of how patient/family perspectives contributed to planning and improvement	The hospital CEO and Board members should visibly endorse patient/family engagement by promoting it throughout the hospital to all staff and patients (e.g. in waiting rooms) to create awareness of how patient/family advisors worked with healthcare workers/staff on planning and improvement	Retain (87.5)	---	Retain
	Hospitals should share patient/family engagement opportunities, activities, outputs and impacts with the broader community as a means of patient/family advisor recruitment and to create awareness about how the hospital is addressing their needs	Hospitals should share patient/family engagement opportunities, activities, outputs and impacts with the broader community through various platforms as a means of patient/family advisor recruitment and to create awareness about how the hospital is addressing their needs	Retain (93.1)	---	Retain

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	Chairs of standing committees or project teams should routinely consult with patient/family advisors throughout meetings to ensure they understand issues under discussion, ask if they have any questions, or wanted to articulate ideas or feedback, and adjust pace as necessary	Chairs of standing committees or project teams should assess acceptability in advance, and then routinely consult with patient/family advisors throughout meetings to ensure they understand acronyms, medical terms or issues under discussion, ask if they have any questions, or wanted to articulate ideas or feedback, and adjust pace as necessary	No consensus (77.2)	Retain (80.8)	Retain
	Hospitals should include a Board member on the Patient and Family Advisory Committee who could convey concerns or ideas directly to the Board	As a way to hold the Board accountable to the Patient and Family Advisory Committee, hospitals should include a Board member on the Patient and Family Advisory Committee who could convey concerns or ideas directly to the Board	No consensus (68.4)	No consensus (58.5)	No consensus
	Hospitals should include patient/family advisors on the Board or Committees of the Board as voting members	Hospitals should include at least one patient/family advisor on the Board or Committees of the Board as voting members	No consensus (70.2)	Retain (80.0)	Retain
	Hospitals should make the Patient and Family Advisory Committee accountable to the Board for planning and improvement activities	Hospitals should make the Patient and Family Advisory Committee accountable to the Board or a Committee of the Board for planning and improvement activities	No consensus (52.6)	No consensus (64.2)	No consensus
Sub-total			7	2	9
Hospital capacity for patient/famil y engagement	Hospitals should allocate dedicated operational funding to nurture and maintain patient/family engagement including one or more Patient and Family Advisory Committee's and other engagement activities	---	Retain (84.2)	---	Retain
	Hospitals should appeal to government, which advocates for patient/family engagement, for dedicated funding to support patient/family engagement	---	No consensus (75.9)	No consensus (78.2)	No consensus
	Hospitals should reimburse patient/family advisors for expenses incurred (e.g. use of their own computers, printing costs, gas, mileage, parking, child care)	Hospitals should reimburse patient/family advisors for pre-determined, clearly defined expenses incurred (e.g. use of their own computers, printing costs, gas, mileage, parking, child care)	No consensus (69.0)	No consensus (74.5)	No consensus
	Hospitals should compensate patient/family advisors for their time spent contributing to patient engagement activities and for taking time off work to participate in those activities	---	No consensus (44.8)	No consensus (63.6)	No consensus
	Hospitals should build patient/family engagement compensation and reimbursement into their yearly operational budgets	---	No consensus (63.2)	No consensus (36.4)	No consensus
	Hospitals should include patient/family engagement activities into appropriate	---	No consensus (76.8)	No consensus (75.9)	No consensus

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	healthcare worker and staff job descriptions as part of the Human Resource commitment to person-centred care				
	Hospitals should cover the cost of release time for staff so they can participate in patient/family engagement activities	---	No consensus (66.7)	No consensus (61.8)	No consensus
	Hospitals should encourage and reward healthcare workers for participating in patient/family engagement	Hospitals should encourage healthcare workers to participate in patient/family engagement, and recognize their efforts (e.g. in annual performance reviews)	No consensus (62.5)	Retain (80.0)	Retain
	Hospitals should provide access to technology for patient/family advisors so they can fully engage in activities (e.g. email accounts, laptops, digital applications)	Hospitals should assess access to technology for patient/family advisors and provide supports to those in need so they can fully engage in activities (e.g. email accounts, laptops, digital applications)	No consensus (77.2)	No consensus (74.1)	No consensus
	Hospitals should employ a dedicated patient engagement manager to promote and support patient/family engagement	Hospitals should ideally employ a dedicated patient engagement manager to promote and support patient/family engagement, or include this responsibility in an existing closely-related portfolio (e.g. patient relations manager, human resources personnel)	No consensus (75.9)	Retain (88.7)	Retain
	Hospitals should employ dedicated patient engagement staff who are driven by person-centred values and possess skills in reflective listening, compassionate communication, and project coordination and facilitation	---	Retain (84.5)	---	Retain
	Hospitals should regularly evaluate patient/family engagement practices and make improvements based on patient/family advisor feedback, and reflection on what worked and what did not work	Hospitals should regularly evaluate patient/family engagement practices and make improvements based on patient/family advisor, healthcare worker and staff feedback, and reflection on what worked and what did not work	Retain (93.0)	---	Retain
Sub-total			3	2	5
Indicators suggested in Round One and rated in Round Two	All recommendations should refer to “patient/family partners” rather than “patient/family advisors” to reflect the aim of true engagement	---	---	No consensus (65.5)	No consensus
	Hospitals should encourage, support and facilitate collaboration with Patient and Family Advisory Committees from other hospitals and Patient Family Advisory Bodies to foster a community of learning	---	---	No consensus (70.9)	No consensus
Sub-total			---	0	0

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CREDES Checklist
Recommendations for the Conducting and REporting of DElphi Studies

Items	Location in manuscript
Purpose and rationale. The purpose of the study should be clearly defined and demonstrate the appropriateness of the use of the Delphi technique as a method to achieve the research aim. A rationale for the choice of the Delphi technique as the most suitable method needs to be provided.	Introduction page 3; Approach page 3-4
Expert panel. Criteria for the selection of experts and transparent information on recruitment of the expert panel, sociodemographic details including information on expertise regarding the topic in question, (non)response and response rates over the ongoing iterations should be reported.	Sampling and recruitment, page 4
Description of the methods. The methods employed need to be comprehensible; this includes information on preparatory steps (How was available evidence on the topic in question synthesised?), piloting of material and survey instruments, design of the survey instrument(s), the number and design of survey rounds, methods of data analysis, processing and synthesis of experts' responses to inform the subsequent survey round and methodological decisions taken by the research team throughout the process.	Page 3 to 4
Procedure. Flow chart to illustrate the stages of the Delphi process, including a preparatory phase, the actual 'Delphi rounds', interim steps of data processing and analysis, and concluding steps.	Figure 1
Definition and attainment of consensus. It needs to be comprehensible to the reader how consensus was achieved throughout the process, including strategies to deal with non-consensus.	Data collection and analysis, page 4
Results. Reporting of results for each round separately is highly advisable in order to make the evolving of consensus over the rounds transparent. This includes figures showing the average group response, changes between rounds, as well as any modifications of the survey instrument such as deletion, addition or modification of survey items based on previous rounds.	Page 4 to 6, Supplementary Files 1 and 2
Discussion of limitations. Reporting should include a critical reflection of potential limitations and their impact of the resulting guidance.	Page 7 to 8
Adequacy of conclusions. The conclusions should adequately reflect the outcomes of the Delphi study with a view to the scope and applicability of the resulting practice guidance.	Page 8

Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. Palliat Med. 2017;31: 684–706.

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Consensus on how to optimize patient/family engagement in hospital planning and improvement: a Delphi survey

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Consensus on how to optimize patient/family engagement in hospital planning and improvement: a Delphi survey

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ABSTRACT

Objective

Patient and family engagement (PE) in health service planning and improvement is widely advocated, yet little prior research offered guidance on how to optimize PE, particularly in hospitals. This study aimed to engage stakeholders in generating evidence-informed consensus on recommendations to optimize PE.

Design

We transformed PE processes and resources from prior research into recommendations that populated an online Delphi survey.

Setting and participants

Panelists included 58 persons with PE experience including: 22 patient/family advisors and 36 others (PE managers, clinicians, executives, researchers) in Round #1 (100%) and 55 in Round #2 (95%).

Outcome measures

Ratings of importance on a seven-point Likert scale of 48 strategies organized in domains: engagement approaches, strategies to integrate diverse perspectives, facilitators, strategies to champion engagement and hospital capacity for engagement.

Results

Of 50 recommendations, 80% or more of panelists prioritized 32 recommendations (27 in Round #1, 5 in Round #2) across 5 domains: 5 engagement approaches, 4 strategies to identify and integrate diverse patient/family advisor perspectives, 9 strategies to enable meaningful engagement, 9 strategies by which hospitals can champion PE, and 5 elements of hospital capacity considered essential for supporting PE. There was high congruence in rating between patient/family advisors and healthcare professionals for all but 6 recommendations that were highly-rated by patient/family advisors but not by others: capturing diverse perspectives, including a critical volume of advisors on committees/teams, prospectively monitoring PE, advocating for government funding of PE, including PE in healthcare worker job descriptions, and sharing PE strategies across hospitals.

Conclusions

Decision-makers (e.g. health system policy-makers, hospitals executives and managers) can use these recommendations as a framework by which to plan and operationalize PE, or evaluate and improve PE in their own settings. Ongoing research is needed to monitor the uptake and impact of these recommendations on PE policy and practice.

KEYWORDS

Patient and family engagement, hospitals, quality improvement, Delphi technique

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Strengths and limitations of this study

- Recommendations were evidence-based, having been derived from prior research
- Recommendations were rated by 58 persons with lived experience of PE: 22 patient/family advisors and 36 PE managers, clinicians, executives, researchers
- We employed rigorous methods: large panel size enhanced reliability; two rounds of rating minimized respondent fatigue, which achieved a high response rate (100% Round 1, 95% Round 2); strong definition of consensus to yield high-priority recommendations (≥80% of panelists rated 6 or 7 or Likert scale to retain); and compliance with research and reporting criteria for Delphi studies to enhance rigour.
- Panelists were volunteers so their views may differ from those of other patients, patient/family advisors or healthcare professionals.
- The findings may not be relevant in countries outside of Canada with differing cultural and health system contexts.

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INTRODUCTION

Hospitals provide inpatient, outpatient and emergency services, and account for the largest share of health spending in many countries.[1] Research in many jurisdictions shows that the quality and safety of hospital care is inconsistent.[2-5] Hence, hospitals continuously strive to improve the organization and delivery of services. One approach gaining prominence worldwide is to engage patients or family/care partners (henceforth, patients) in planning, evaluating and improving health services for the benefit of all patients. In this context, patient engagement (PE) is defined as patients, families or their representatives, and health professionals working in active partnership to improve health services.[6] While evidence is accumulating on engaging patients in research,[7] and in their own health and healthcare,[8] our prior scoping review identified only 10 studies of PE for healthcare planning and improvement specifically in hospitals, which are unique from other healthcare settings in size, staffing and service delivery.[9] PE has been associated with a range of benefits such as enhanced governance and clinical processes, new or improved patient resources, and efficient service delivery.[10] Healthcare decision-makers, including policy-makers who fund hospitals, hospital managers who organize services and clinicians who directly engage patients, require knowledge of the conditions (e.g. resources, processes) that optimize PE to inform resource allocation.

We surveyed managers at hospitals in Ontario, Canada to describe PE. While infrastructure and processes varied across 91 participating hospitals, we identified hospitals of all types (<100 beds, 100+ beds, teaching) with high capacity for PE, distinguished by PE activity organization wide across multiple departments, and use of largely collaborative rather than consultative PE approaches.[11] We interviewed patient/family advisors, PE managers, clinicians and executives at hospitals with high PE capacity who identified infrastructure and processes needed to support PE. Participants also reported a range of beneficial impacts including improved PE capacity (new PE processes were developed and spread across departments, those involved became more adept and engaged) and clinical care at multiple levels: hospital (new/improved policies, strategic plans, facilities, programs), clinician (greater efficiency in service delivery, enhanced job satisfaction, improved patient-staff communication) and patient (educational material, discharge processes and information, improved hospital experience, decreased wait times, reduced falls, lower readmission rates).[12-13]

Given the widespread interest in PE and demonstrated benefits, and lack of insight on how to optimize PE in hospitals,[9,10] the overall aim of this study was to build on our prior research,[11-13] and issue guidance for optimizing PE in hospital planning and improvement. The specific objective was to engage stakeholders in establishing consensus on priority recommendations derived from evidence generated by our prior research. The output, resources and processes that enable hospital PE, could be used by decision-makers to plan, support or improve hospital PE.

METHODS

Approach

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We employed the Delphi technique, a widely-used method for generating consensus on strategies, recommendations, or quality measures.[14-16] This technique is based on one or more rounds of survey in which expert panelists independently rate recommendations until a degree of consensus is achieved. We complied with the Conducting and Reporting of Delphi Studies criteria to enhance rigor.[17] The University Health Network Research Ethics Board approved this study (REB #18-5307).

Sampling and recruitment

A review of Delphi studies showed that the median number of panelists was 17 (range 3 to 418).[18] Other research found that reliability of Delphi rating increased with panel size.[19] To ensure that multiple perspectives were considered, we aimed to include a minimum of 20 persons with experience as patient/family advisors and 20 professionals of diverse specialties with knowledge or experience of PE. We recruited Canadian patient/family advisors aged 18+ and health professionals (PE managers, clinicians, executives) affiliated with 91 Ontario hospitals that responded to our prior survey and agreed to be contacted for future studies,[11] and identified other Canadian patient/family advisors, clinicians and researchers with experience in PE on publicly-available websites.

Survey development

We derived recommendations to be rated by panelists from aforementioned interviews with patient/family advisors, PE managers, and clinicians or executives affiliated with hospitals with high PE capacity.[12-13] NN and ARG extracted data on all unique enablers and barriers of PE, or suggested strategies for promoting or supporting PE, and worded those as recommendations. We organized the 48 recommendations by domains that inductively emerged from our prior research: engagement approaches, strategies to identify and integrate diverse perspectives, strategies to enable patient/family engagement, strategies to champion patient/family engagement and hospital capacity for patient/family engagement.[12-13] The research team reviewed recommendations for clarity and relevance (Supplementary File 1).

Data collection and analysis

We transformed recommendations into a Round One online survey using REDCap. We asked panelists to rate each recommendation on a 7-point Likert scale (1 strongly disagree, 7 strongly agree), comment on the relevance or wording of each recommendation if desired, and suggest additional recommendations not included in the survey. We emailed Instructions and survey link to panelists on May 19 2021, with reminders at one and two weeks. Based on results, we developed a Round One summary report that included Likert scale response frequencies and comments for each recommendation, which we organized by those retained (rated by at least 80% of panelists as 6 or 7), discarded (rated by at least 80% of panelists as 1 or 2) or no consensus (all others), along with newly suggested recommendations. Standard Delphi protocol suggests that two rounds of rating with agreement by at least two-thirds of panelists to either retain or discard items will prevent respondent fatigue and drop-out.[17,18] We conducted two rounds of rating; however, to yield unequivocal recommendations, we considered 80% to indicate consensus. On June 18 2021, we emailed panelists the Round One summary report with a link to the Round Two survey, formatted similarly to the Round One survey, to prompt

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3 rating of recommendations that did not achieve consensus for inclusion or exclusion in Round
4 One. We emailed a reminder at one, two and three weeks. We analyzed and summarized
5 Round Two responses as described for Round One.
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8 **Patient and public involvement**
9 Three patient and family advisors were involved in planning the multi-part study that informed
10 this final component of that study. Patient and family advisors were included as expert
11 panelists in this study to rate the importance of recommendations for resources and processes
12 that optimize hospital PE.
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15 **RESULTS**
16 **Panelists**
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18 Of 109 persons invited to participate, 58 agreed (Table 1). The response rate for Round One
19 was 100.0%, and for Round Two, 94.8% (55/58). Round Two non-responders included 1 PE
20 researcher, 1 executive, and 1 clinician from a teaching hospital.
21
22
23 Table 1. Participants

Participant type	Hospital type			Others	Sub-Total
	<100 beds	100+ beds	Teaching		
Patient/family advisors	3	10	5	4	22
PE managers	4	9	5	---	18
Clinicians	3	4	2	---	9
Executives	---	---	1	3	4
Researchers	---	---	---	5	5
Sub-total	10	23	13	12	58

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35 **Delphi results**
36 Supplementary File 2 details the recommendations retained, discarded or that achieved no
37 consensus in Rounds One and Two. Figure 1 summarizes the number of recommendations
38 retained, discarded or with no consensus in each Round. Of the 50 recommendations
39 considered, 32 achieved consensus to retain: 27 in Round One and 5 in Round Two.
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43 **Prioritized recommendations**
44 Table 2 lists 32 retained recommendations including: 5 engagement approaches, 4 strategies to
45 identify and integrate diverse patient/family advisor perspectives, 9 strategies to enable
46 meaningful engagement, 9 strategies by which hospitals can champion PE, and 5 elements of
47 hospital capacity considered essential for supporting PE. Three recommendations were
48 retained by 100.0% of panelists: In advance of meetings or activities, hospitals should provide
49 patient/family advisors with agendas, background information or briefing material to help them
50 prepare and then actively participate (#15); Hospitals should foster an organization-wide
51 culture of respect and support for patient/family engagement (#27); and Hospitals should share
52 results or outcomes with involved patient/family advisors so that they are aware of how their
53 input and decisions contributed to planning and improvement (#30). Table 2 identifies the 16
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(50.0%) recommendations scored by 90.0% or more of panelists to retain, and the 16 (50.0%) scored by 80.0% to 89.9% of panelists to retain.

Table 2. Recommendations that achieved consensus to retain

Domain	Recommendation (% panelist who rated Likert scale 6 or 7 to retain)
Engagement approaches 5/6 retained	Patient/family advisors with appropriate skills should be engaged in decisions for hospital activities whenever possible, including governance, strategy planning, and designing, developing, evaluating or improving facilities, programs, healthcare services, care practices, quality and safety, or resources/materials (86.2)
	Hospitals should establish and maintain at least one Patient and Family Advisory Committee (87.9)
	In addition to one or more Patient and Family Advisory Committee's, hospitals should engage patient/family advisors using multiple forms of engagement (e.g. standing committees, project teams) (96.5)
	Patient and family engagement should take place in-person whenever possible to build rapport, but virtual options and technology should be offered to enhance convenience and connectivity and suit diverse preferences (**please rate this for a non-pandemic context) (83.3)
	Hospitals should employ a range of approaches to engage patient/family advisors including collaboration (e.g. member of project teams or committees), consultation (e.g. surveys, interviews, focus groups) or blended approaches (e.g. collaboration and consultation approaches for the same initiative) (93.1)
Strategies to identify and integrate diverse perspectives 4/5 retained	Hospitals should build patient/family engagement programs that welcome persons with diverse experiences, characteristics, abilities and resources representative of the communities they serve, and do so in a culturally safe manner or setting (98.3)
	Hospitals should recruit patient/family advisors using a range of strategies (e.g. social media, email, newspaper ads, word of mouth, through community organizations) and in languages or settings tailored to the community they serve to achieve diversity (91.2)
	In prioritizing what benefits many, hospitals should also use a health equity lens to ensure that they are improving quality of care for at risk populations in their community (98.2)
	Hospitals should ensure that there is ongoing recruitment and onboarding of new patient and family advisors to enhance diversity and supplement the contributions of long-standing experienced patient/family advisors (96.6)
Strategies to enable patient/family engagement 9/14 retained	Once recruited, hospitals should provide patient/family advisors with ongoing support and education about roles and responsibilities, organizational culture and strategic priorities to prepare them for engagement, possibly through mentorship by existing experienced patient/family advisors (96.5)
	In advance of deployment, hospitals should orient patient/family advisors to the background, purpose, and goals of a specific committee or project (e.g. share documents, meet with project or committee leader) (96.6)
	In advance of meetings or activities, hospitals should provide patient/family advisors with agendas, background information, briefing material and the name of a liaison who can answer questions to help them prepare and then actively participate (100.0)
	Hospitals should train project leaders, committee chairs, healthcare workers and staff on how to foster a team environment, and effectively engage with and support patient/family advisors (89.7)
	Hospitals should involve patient/family advisors in reviewing and delivering training to existing healthcare workers and staff, and orienting new healthcare workers/staff to patient engagement (84.5)
	Hospitals should engage patient/family advisors early and throughout planning or improvement activities (94.8)

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	At the outset of new committees or projects, the Chair should explicitly establish roles and responsibilities collaboratively with and for all involved including patient/family advisors and healthcare workers, and prospectively revisit roles as projects evolve (89.3)
	Hospital healthcare workers and staff should demonstrate that they value patient/family advisor input and decisions by meaningfully engaging with patient/family advisors, basing decisions on their perspectives and telling patient/family advisors that they are valued (89.1)
	Hospitals should routinely check with patient/family advisors to confirm that interim or near-to-final decisions or outputs accurately captured their perspectives and explain why, if any, were not captured (87.7)
Strategies to champion patient/family engagement 9/11 retained	Hospitals should convey an organizational commitment to patient/family engagement by acknowledging it in their hospital values statement and strategic plan, and continuously update values/strategic plan as patient/family engagement evolves (94.6)
	Hospitals should foster an organization-wide culture of respect and support for patient/family engagement (100.0)
	To establish a philosophical commitment, hospitals should promote the view that patient/family advisors bring diverse expertise, skills and perspectives, which should be valued equally to those of healthcare workers (82.8)
	Senior administrative and clinical leaders should model patient/family engagement (98.1)
	Hospitals should share results or outcomes with involved patient/family advisors so that they are aware of how their input and decisions contributed to planning and improvement (100.0)
	The hospital CEO and Board members should visibly endorse patient/family engagement by promoting it throughout the hospital to all staff and patients (e.g. in waiting rooms) to create awareness of how patient/family advisors worked with healthcare workers/staff on planning and improvement (87.5)
	Hospitals should share patient/family engagement opportunities, activities, outputs and impacts with the broader community through various platforms as a means of patient/family advisor recruitment and to create awareness about how the hospital is addressing their needs (93.1)
	Chairs of standing committees or project teams should assess acceptability in advance, and then routinely consult with patient/family advisors throughout meetings to ensure they understand acronyms, medical terms or issues under discussion, ask if they have any questions, or wanted to articulate ideas or feedback, and adjust pace as necessary (80.8)
	Hospitals should include at least one patient/family advisor on the Board or Committees of the Board as voting members (80.0)
Hospital capacity for patient/family engagement 5/12 retained	Hospitals should allocate dedicated operational funding to nurture and maintain patient/family engagement including one or more Patient and Family Advisory Committee's and other engagement activities (84.2)
	Hospitals should encourage healthcare workers to participate in patient/family engagement, and recognize their efforts (e.g. in annual performance reviews) (80.0)
	Hospitals should ideally employ a dedicated patient engagement manager to promote and support patient/family engagement, or include this responsibility in an existing closely-related portfolio (e.g. patient relations manager, human resources personnel) (88.7)
	Hospitals should employ dedicated patient engagement staff who are driven by person-centred values and possess skills in reflective listening, compassionate communication, and project coordination and facilitation (84.5)
	Hospitals should regularly evaluate patient/family engagement practices and make improvements based on patient/family advisor, healthcare worker and staff feedback, and reflection on what worked and what did not work (93.0)

Agreement and Differences

Ratings for the 32 retained recommendations were similar between patient/family advisor panelists and others (PE managers, clinicians, executives, researchers). Of the remaining 18

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recommendations that failed to achieve consensus, patient/family advisors and others similarly rated 12 recommendations. Table 3 shows the 6 recommendations where at least 80% of patient/family advisors scored to retain and others did not along with select comments to illustrate diverging views. For example, the two groups differed in rating of recommendation #9: Hospitals should seek to identify and address issues that are priorities for, and of benefit to all patients and families they serve rather than focusing only on issues common to the majority. Patient/family advisor panelists raised concerns about equity and diversity, and thought that ignoring issues not faced by the majority of patients may lead to a worsening situation that does impact the majority. In contrast, other panelists said that it was not always possible to address all issues due to lack of resources, focus on hospital priorities, and government mandates. The 5 additional recommendations prioritized by patient/family advisors but not by other panelists included: Hospitals should include at least one and preferably more patient/family advisors on any committee or project team (#22); Patient and Family Advisory Committees should routinely review interim progress, decisions or outputs of standing committees or project teams to ensure that decisions reflect patient/family advisor perspectives (#24); Hospitals should appeal to government, which advocates for patient/family engagement, for dedicated funding to support patient/family engagement (#38); Hospitals should include patient/family engagement activities into appropriate healthcare worker and staff job descriptions as part of the Human Resource commitment to person-centred care (#42); and Hospitals should encourage, support and facilitate collaboration with Patient and Family Advisory Committees from other hospitals and Patient Family Advisory Bodies to foster a community of learning (#50).

Table 3. Recommendations with no consensus where rating differed between panelists

Recommendation (as worded in Round 2)	Rating (% who rated to retain)		Exemplar comments
	Round 1	Round 2	
(9) Hospitals should seek to identify and address issues that are priorities for, and of benefit to all patients and families they serve rather than focusing only on issues common to the majority	Patients 54.5 Others 60.0	Patients 86.4 Others 64.5	Patients • Issues that affect smaller populations are often under-studied, poorly resourced and given less visibility. • Failure to look beyond the issues that are overtly common to the majority leaves a risk of bypassing details of a critical nature that may well be or may well become an issue to the majority. Others • The PFAC cannot be all things to all people and to some degree the work of the PFAC needs to support hospital priorities and vice versa. • With limited resources you do need some principles or criteria in place for how to go about selecting the issues that need change/improvement.
(22) Hospitals should include at least one and preferably more patient/family	Patients 72.7 Others 38.9	Patients 90.9 Others 59.4	Patients • Avoids tokenism. • Important to get more than one viewpoint but must be balanced with the size of the project and committee.

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advisors on any committee or project team			• Basic is to have 2 per project as a minimum. I have also seen that some committees go with percentages. Others • I think this has to be balanced with number of advisors and requests you have or you quickly burn out people. • Surely we can find other mechanisms for involvement that are not so focused on this one strategy of "patient/family advisors on every committee/project team"?
(24) Patient and Family Advisory Committees should routinely review interim progress, decisions or outputs of standing committees or project teams to ensure that decisions reflect patient/family advisor perspectives	Patients 76.2 Others 72.2	Patients 86.4 Others 66.7	Patients • We are already doing this at six monthly intervals in our hospital as it provides an excellent insight into the progress of decisions or outputs of the PFA committee. • This would prove that patient /family input is valued. It may also improve retention of patient/family advisors on these committees. Others • Sometimes decisions don't always go the way that everyone wants. the important piece here is that various perspectives were brought to the fore, listened to, respected, weighed....and then decisions get made. • This statement removes the meaning of "partnership". Decisions and outputs need to reflect all perspectives and opinions and PFAC needs to support the give and take of this relationship.
(38) Hospitals should appeal to government, which advocates for patient/family engagement, for dedicated funding to support patient/family engagement	Patients 81.8 Others 72.2	Patients 90.9 Others 69.7	Patients • The hospital AND the Patient and Family Advisory Group should be consistently lobbying the government to financially support the hospitals efforts ensure the interests of it's "customers" and community are represented. • Government funding would be of great benefit to PFA Committees as most hospital budgets are so limited that they are not in a position to provide funding Others • I would love to see paid PFP positions and more project funding, but the dollars would be taken from patient care delivery somewhere else. • I worry saying this gives hospitals an excuse to not do it. Many hospitals are doing quite well in engagement as they make it a strategic priority within current funding models.
(42) Hospitals should include patient/family engagement activities into appropriate healthcare worker and staff job descriptions as part of the Human Resource commitment to	Patients 80.0 Others 75.0	Patients 81.9 Others 71.9	Patients • Extremely important for staff to know that organization invites and values the input of patient and family advisors • A good way to provide information about the patient/family advisors role. • Need buy in and involvement of health care workers for success. Others (comments supportive) • It needs to be built into policy/structures so that it becomes embedded and normalized and expected • Especially leadership roles

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person-centred care			• Although a great idea, hospitals need to start with a philosophy and orientation for staff on the role of engaging advisors
(50) Hospitals should encourage, support and facilitate collaboration with Patient and Family Advisory Committees from other hospitals and Patient Family Advisory Bodies to foster a community of learning	---	Patients 86.4 Others 60.6	Patients • Collaboration with groups from other organizations is a valuable way to gain insight into different processes and protocols that have been tried and proven to be effective or conversely have been utilized and were found to be an ineffective mechanism to reach patient and family advisory objectives. • This could be extremely beneficial within clusters of smaller hospitals. • Learning from each other and not re-inventing the wheel, so to speak, might save everyone time, energy and frustration. Others • From my experience, hospital committees are typically focused on site-specific issues, and while root causes may be similar across the sector, the specific actions are often very local. • Patient Family Advisors/Partners are already finding that they have multiple requests for involvement…we need to consider that they are volunteers and often are dealing with health issues either themselves or their family.

DISCUSSION

Rating of 50 recommendations for resources or processes to support hospital-based PE by 58 panelists (22 patient/family advisors; 36 PE managers, clinicians, executives, researchers) in a two-round Delphi survey resulted in consensus by 80% or more on the importance of 32 recommendations across 5 domains: 5 engagement approaches, 4 strategies to identify and integrate diverse patient/family advisor perspectives, 9 strategies to enable meaningful engagement, 9 strategies by which hospitals can champion PE, and 5 elements of hospital capacity considered essential for supporting PE. Of the 32 recommendations, 16 (50.0%) were rated important by 90%+ of panelists (3 recommendations by 100.0%), and 16 (50.0%) by 80% to 89.9% of panelists. There was high congruence in rating between patient/family advisors for all but 6 recommendations that did not achieve consensus.

Strengths of this study included: rating of recommendations by a panel comprised of patient/family advisors (who are themselves patients or family of patients) and interdisciplinary healthcare professionals; recommendations rated by panelists were derived from prior research involving patients, family and healthcare professionals, and thus evidence-based;[12-13] the large panel size enhanced reliability; two rounds of rating minimized respondent fatigue, which achieved a high response rate in both rounds; and we used a strong definition of consensus to yield high-priority recommendations. We optimized rigor by complying with research and reporting criteria for Delphi studies.[14-19] We must acknowledge limitations. Recommendations were derived from our own prior research [11-13], given that our prior review of PE for healthcare planning and improvement specifically in hospital settings had identified only 10 studies [9]. However, that review included studies published before 2017, so an updated review may be warranted to identify recommendations that reflect international perspectives and compare those recommendations with the findings of this research. Panelists

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were volunteers so their views may be biased, particularly because about half of the originally-invited panelists agreed to participate; however, we specifically recruited individuals for their expertise, and potential bias was off-set by review of evidence-based recommendations. Panelist views may differ from those of other patients, patient/family advisors or healthcare professionals. The findings may not be generalizable in countries outside of Canada with differing cultural and health system contexts.

As noted, research on PE has largely focused on engaging patients in research or in their own health care,[7,8] with very little prior research on how to enable PE in hospital-based planning and improvement.[9,10] A survey of clinicians from a university hospital in France reported only the types of activities in which patients were involved (e.g. developing care pathways, and educational programs for patients and healthcare professionals).[20] A systematic review of 11 qualitative studies of patient involvement in quality improvement (unclear if any studies based in hospitals) revealed that a key barrier was limited power of patients to influence decision-making given little power over healthcare professionals.[21] A survey of managers from 74 hospitals across 7 European countries found that few hospitals involved patients in quality improvement (e.g. developing quality criteria, designing processes, or being a member of quality committees or project teams).[22] Our research goes beyond reporting the activities in which patients are engaged or barriers of engagement to describe processes and infrastructure essential to PE based on the views of patient/family advisors and healthcare professionals with lived experience of hospital PE.

A notable finding was the high degree of agreement between patient/family advisors and other panelists on priority recommendations. This likely reflects the fact that all panelists had considerable experience in PE, and largely represented hospitals with high PE capacity and activity. Both factors underscore the relevance and validity of the recommendations, which form a concrete framework that can be broadly applied: hospitals newly embarking on PE can use the framework to develop strategic and operational plans specific to PE, and hospitals that already implemented PE can use the framework to evaluate their own activities, identify areas needing improvement, and strengthen PE. One challenge may be the large number of recommendations that achieved consensus. Organizations with limited resources could employ a staggered approach, whereby the recommendations that achieved the highest consensus could be implemented first. These recommendations were generated by persons largely affiliated with hospitals having high PE capacity who self-reported numerous beneficial impacts on PE capacity, clinical care, and patient outcomes,[12-13]. High PE capacity hospitals were characterized by PE activity organization wide and use of largely collaborative rather than consultative PE approaches, referring to co-production.[11] Co-production refers to users and professionals who are creating, designing, producing, delivering, assessing, and evaluating the relationships and actions that contribute to the health of individuals and populations, which is fundamental to learning health systems.[23] True co-production requires meaningful engagement or sharing of power between patients and health professionals, yet research suggests that engagement is often token due a variety of barriers.[21,24,25] Therefore ongoing research is needed to confirm the uptake of these recommendations, including their influence

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on policy at the health system or hospital level, and on various impacts in hospitals with both new and established PE.

In conclusion, while PE in health service planning and improvement is widely advocated, little prior research offered guidance on how to optimize PE, particularly in hospital settings. Through a series of studies, we identified resources and processes required for hospital-based PE,[12-13] culminating in the current Delphi survey, in which 58 patient/family advisors, PE managers, clinicians, executives and researchers with experience and expertise in PE prioritized recommendations reflecting resources and processes to optimize PE. Decision-makers (e.g. health system policy-makers, hospitals executives and managers) can use the resulting 32 recommendations as a framework by which to plan and operationalize PE, or evaluate and improve PE in their own settings.

Author contributions

ARG, GRB, LM, KS, RU and WPW conceived and planned the study. ARG acquired funding and supervised NNA. NNA and ARG coordinated the study, and collected and analyzed data. All authors reviewed and interpreted data; and contributed to, reviewed and approved this final version.

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Competing interests

The authors declare no competing interests

Patient consent

Not applicable

Ethics approval

This study was approved by the University Health Network Research Ethics Board (REB #18-5307).

Data availability statement

All data are included in the manuscript and supplementary files.

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FIGURE LEGEND

Figure 1. Delphi summary
PDF file
Flow diagram depicting each stage of the Delphi process

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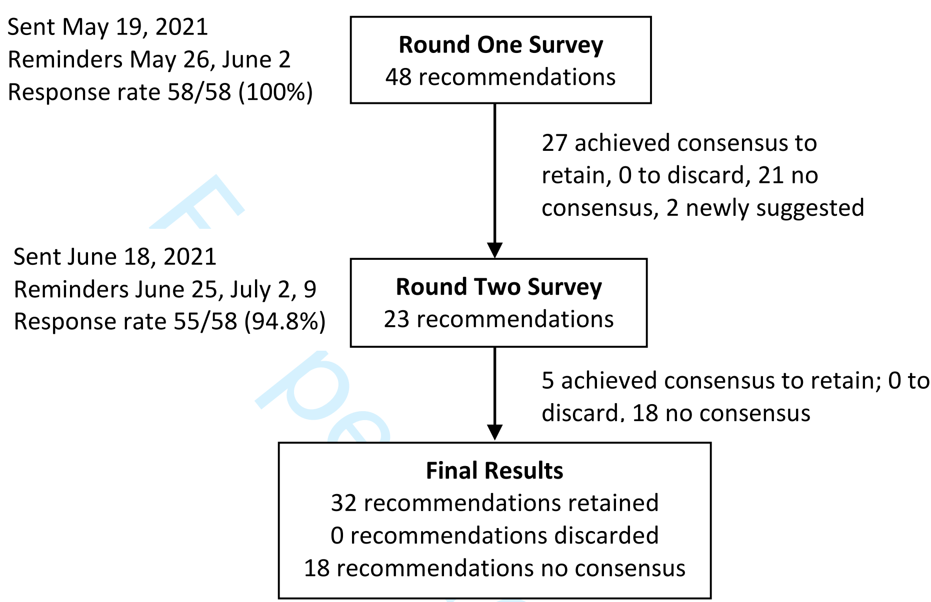

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Supplementary File 1. Hospital PE recommendations by domain derived from prior research

Engagement approaches

1	Patient/family advisors should be involved in decision-making for all hospital activities including governance, strategy planning, and designing, developing, evaluating or improving facilities, programs, healthcare services, care practices, quality and safety, or resources/materials
2	Hospitals should establish and maintain at least one patient/family advisory committee (PFAC)
3	In addition to a general PFAC, hospitals should consider establishing PFACs for departments or units that represent the hospital's clinical priorities
4	In addition to one or more PFACs, hospitals should engage patient/family advisors in a variety of ways (e.g. standing committees, project teams)
5	Patient and family engagement should take place in-person whenever possible to build rapport (please rate this for a non-pandemic context)
6	Hospitals should employ a range of engagement approaches including collaboration (e.g. member of project teams or committees), consultation (e.g. surveys, interviews, focus groups) or blended approaches (e.g. collaboration and consultation approaches for the same initiative)

Strategies to identify and integrate diverse perspectives

7	Hospitals should build patient/family engagement programs that welcome persons with diverse characteristics and provide a culturally safe environment
8	Hospitals should recruit patient/family advisors using a range of strategies (e.g. social media, email, newspaper ads, word of mouth, posting formal job descriptions) to achieve diversity
9	Hospitals should seek to address issues that are likely to benefit the majority of people they serve
10	Hospitals should also ensure that in prioritizing what benefits many, they also use a health equity lens to ensure that they are improving quality of care for disadvantaged populations in their community
11	Hospitals should ensure that there is ongoing recruitment and onboarding of new patient and family advisors to avoid deploying the same persons to multiple projects (to reduce burden on the few, and enhance diversity)

Strategies to enable patient/family engagement

12	Once recruited, hospitals should provide patient/family advisors with support and education about roles and responsibilities, organizational culture and strategic priorities to prepare them for engagement
13	In advance of deployment, hospitals should orient patient/family advisors to the background, purpose, goals and participants of a specific committee or project

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14	Once deployed, committees or project teams should involve patient/family advisors and committee/project team members in team-building exercises to build relationships
15	In advance of meetings or activities, hospitals should provide patient/family advisors with agendas, background information or briefing material to help them prepare and then actively participate
16	Hospitals should train healthcare workers and staff on how to effectively engage with patient/family advisors
17	Hospitals should involve patient/family advisors in training existing healthcare workers and staff and orienting new healthcare workers/staff to patient engagement
18	Hospitals should engage patient/family advisors early and throughout planning or improvement activities
19	Hospitals should include patient/family advisors in polls to establish meeting times, and schedule meetings at times that are suitable for patient/family advisors (e.g. evenings after work or child care)
20	At the outset of new committees or projects, the Chair should explicitly establish roles and responsibilities for all involved including patient/family advisors and healthcare workers
21	Hospital healthcare workers and staff should understand the value of patient/family input and decisions and explicitly convey value by meaningfully engaging with patient/family advisors and acknowledging the value of their role
22	Hospitals should include a critical volume of patient/family advisors on any committee or project team
23	Hospitals should require that decision-making quorum include at least one patient/family advisor
24	PFACs should routinely review interim progress, decisions or outputs of standing committees or project teams to ensure that patient/family advisor perspectives informed decisions
25	Hospitals should check with patient/family advisors to confirm that interim or near-to-final decisions or outputs accurately captured their perspectives

Strategies to champion patient/family engagement

26	Hospitals should convey an organizational commitment to patient/family engagement by acknowledging it in their hospital values statement and strategic plan
27	Hospitals should foster an organization-wide culture of respect and support for patient/family engagement
28	To establish a philosophical commitment, hospitals should promote that patient/family advisors be viewed as experts on the patient perspective, which should be valued equally to the perspective of healthcare workers

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29	The hospital CEO and Board members should visibly endorse and inform about patient/family engagement by promoting it across the hospital to all staff and patients (e.g. in waiting rooms)
30	Senior administrative and clinical leaders should model patient/family engagement
31	Hospitals should share patient/family engagement opportunities, activities, outputs and impacts with the broader community as a means of patient/family advisor recruitment and to create awareness about how the hospital is addressing their needs
32	Hospitals should share results or outcomes with involved patient/family advisors, and more broadly throughout the hospital to create awareness of how patient/family perspectives contributed to planning and improvement
33	Chairs of standing committees or project teams should routinely consult with patient/family advisors throughout meetings to ensure they understand issues under discussion, ask if they have any questions, or wanted to articulate ideas or feedback, and adjust pace as necessary
34	Hospitals should include a Board member on the PFAC who could convey concerns or ideas directly to the Board
35	Hospitals should include patient/family advisors on the Board or Committees of the Board as voting members
36	Hospitals should make the PFAC accountable to the Board for planning and improvement activities

Hospital capacity for patient/family engagement

37	Hospitals should allocate dedicated operational funding to nurture and maintain patient/family engagement including one or more PFACs and other engagement activities
38	Hospitals should appeal to government, which advocates for patient/family engagement, for dedicated funding to support patient/family engagement
39	Hospitals should reimburse patient/family advisors for expenses incurred (e.g. use of their own computers, printing costs, gas, mileage, parking, child care)
40	Hospitals should building patient/family engagement compensation and reimbursement into their yearly operational budgets
41	Hospitals should compensate patient/family advisors for their time spent contributing to patient engagement activities and for taking time off work to participate in those activities
42	Hospitals should include patient/family engagement activities into appropriate healthcare worker and staff job descriptions as part of the Human Resource commitment to person-centred care
43	Hospitals should cover the cost of release time for staff so they can participate in engagement activities

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44	Hospitals should encourage and reward healthcare workers for participating in patient/family engagement
45	Hospitals should provide access to technology for patient/family advisors so they can fully engage in activities (e.g. email accounts, lap tops, digital applications)
46	Hospitals should employ a dedicated PE manager to promote and support patient/family engagement
47	Hospitals should employ dedicated PE staff who are driven by person-centred values and possess skills in reflective listening, compassionate communication, and project coordination and facilitation
48	Hospitals should regularly evaluate patient/family engagement practices and make improvements based on patient/family advisor feedback, and reflection on what worked and what did not work

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Supplementary File 2. Hospital PE recommendations retained, discarded and with no consensus by two-round Delphi survey

Domain	Recommendation	Suggested revision	Round One (rating)	Round Two (rating)	Result
Engagement approaches	Patient/family advisors should be involved in decision-making for all hospital activities including governance, strategy planning, and designing, developing, evaluating or improving facilities, programs, healthcare services, care practices, quality and safety, or resources/materials	Patient/family advisors with appropriate skills should be engaged in decisions for hospital activities whenever possible, including governance, strategy planning, and designing, developing, evaluating or improving facilities, programs, healthcare services, care practices, quality and safety, or resources/materials	Retain (86.2)	---	Retain
	Hospitals should establish and maintain at least one Patient and Family Advisory Committee	---	Retain (87.9)	---	Retain
	In addition to a general Patient and Family Advisory Committee, hospitals should consider establishing Patient and Family Advisory Committee's for departments or units that represent the hospital's clinical priorities	In addition to a general Patient and Family Advisory Committee, hospitals should consider establishing Patient and Family Advisory Committees for units or programs that represent the hospital's clinical priorities, or embed patient/family advisors in priority unit-/program-specific advisory committees	No consensus (64.3)	No consensus (77.4)	No consensus
	In addition to one or more Patient and Family Advisory Committee's, hospitals should engage patient/family advisors in a variety of ways (e.g. standing committees, project teams)	In addition to one or more Patient and Family Advisory Committee's, hospitals should engage patient/family advisors using multiple forms of engagement (e.g. standing committees, project teams)	Retain (96.5)	---	Retain
	Patient and family engagement should take place in-person whenever possible to build rapport (please rate this for a non-pandemic context)	Patient and family engagement should take place in-person whenever possible to build rapport, but virtual options and technology should be offered to enhance convenience and connectivity and suit diverse preferences (**please rate this for a non-pandemic context)	No consensus (72.4)	Retain (83.3)	Retain
	Hospitals should employ a range of engagement approaches including collaboration (e.g. member of project teams or committees), consultation (e.g. surveys, interviews, focus groups) or blended approaches (e.g. collaboration and consultation approaches for the same initiative)	Hospitals should employ a range of approaches to engage patient/family advisors including collaboration (e.g. member of project teams or committees), consultation (e.g. surveys, interviews, focus groups) or blended approaches (e.g. collaboration and consultation approaches for the same initiative)	Retain (93.1)	---	Retain
Sub-total			4	1	5
Strategies to identify and integrate	Hospitals should build patient/family engagement programs that welcome persons with diverse characteristics and provide a culturally safe environment	Hospitals should build patient/family engagement programs that welcome persons with diverse experiences, characteristics, abilities and resources	Retain (98.3)	---	Retain

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diverse perspectives		representative of the communities they serve, and do so in a culturally safe manner or setting			
	Hospitals should recruit patient/family advisors using a range of strategies (e.g. social media, email, newspaper ads, word of mouth, posting formal job descriptions) to achieve diversity	Hospitals should recruit patient/family advisors using a range of strategies (e.g. social media, email, newspaper ads, word of mouth, through community organizations) and in languages or settings tailored to the community they serve to achieve diversity	Retain (91.2)	---	Retain
	Hospitals should seek to address issues that are likely to benefit the majority of people they serve	Hospitals should seek to identify and address issues that are priorities for, and of benefit to all patients/families they serve rather than focusing only on issues common to the majority	No consensus (57.9)	No consensus (73.6)	No consensus
	Hospitals should also ensure that in prioritizing what benefits many, they also use a health equity lens to ensure that they are improving quality of care for disadvantaged populations in their community	In prioritizing what benefits many, hospitals should also use a health equity lens to ensure that they are improving quality of care for at risk populations in their community	Retain (98.2)	---	Retain
	Hospitals should ensure that there is ongoing recruitment and onboarding of new patient and family advisors to avoid deploying the same persons to multiple projects (to reduce burden on the few, and enhance diversity)	Hospitals should ensure that there is ongoing recruitment and onboarding of new patient and family advisors to enhance diversity and supplement the contributions of long-standing experienced patient/family advisors	Retain (96.6)	---	Retain
Sub-total			4	0	4
Strategies to enable patient/famil y engagement	Once recruited, hospitals should provide patient/family advisors with support and education about roles and responsibilities, organizational culture and strategic priorities to prepare them for engagement	Once recruited, hospitals should provide patient/family advisors with ongoing support and education about roles and responsibilities, organizational culture and strategic priorities to prepare them for engagement, possibly through mentorship by existing experienced patient/family advisors	Retain (96.5)	---	Retain
	In advance of deployment, hospitals should orient patient/family advisors to the background, purpose, goals and participants of a specific committee or project	In advance of deployment, hospitals should orient patient/family advisors to the background, purpose, and goals of a specific committee or project (e.g. share documents, meet with project or committee leader)	Retain (96.6)	---	Retain
	Once deployed, committees or project teams should involve patient/family advisors and	Once deployed, committees or project teams should involve patient/family advisors and committee/project team members in team-building exercises to build	No consensus (68.4)	No consensus (65.5)	No consensus

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	committee/project team members in team-building exercises to build relationships	relationships (e.g. spend time getting to know each member)			
	In advance of meetings or activities, hospitals should provide patient/family advisors with agendas, background information or briefing material to help them prepare and then actively participate	In advance of meetings or activities, hospitals should provide patient/family advisors with agendas, background information, briefing material and the name of a liaison who can answer questions to help them prepare and then actively participate	Retain (100.0)	---	Retain
	Hospitals should train healthcare workers and staff on how to effectively engage with patient/family advisors	Hospitals should train project leaders, committee chairs, healthcare workers and staff on how to foster a team environment, and effectively engage with and support patient/family advisors	Retain (89.7)	---	Retain
	Hospitals should involve patient/family advisors in training existing healthcare workers and staff and orienting new healthcare workers/staff to patient engagement	Hospitals should involve patient/family advisors in reviewing and delivering training to existing healthcare workers and staff, and orienting new healthcare workers/staff to patient engagement	Retain (84.5)	---	Retain
	Hospitals should engage patient/family advisors early and throughout planning or improvement activities	---	Retain (94.8)	---	Retain
	Hospitals should include patient/family advisors in polls to establish meeting times, and schedule meetings at times that are suitable for patient/family advisors (e.g. evenings after work or child care)	Hospitals should gauge the availability of patient/family advisors to establish meeting times, and schedule meetings at times that are suitable for patient/family advisors (e.g. evenings after work or child care)	No consensus (79.3)	No consensus (72.7)	No consensus
	At the outset of new committees or projects, the Chair should explicitly establish roles and responsibilities for all involved including patient/family advisors and healthcare workers	At the outset of new committees or projects, the Chair should explicitly establish roles and responsibilities collaboratively with and for all involved including patient/family advisors and healthcare workers, and prospectively revisit roles as projects evolve	Retain (89.3)	---	Retain
	Hospital healthcare workers and staff should demonstrate that they value patient/family advisor input and decisions by meaningfully engaging with patient/family advisors and telling patient/family advisors that they are valued	Hospital healthcare workers and staff should demonstrate that they value patient/family advisor input and decisions by meaningfully engaging with patient/family advisors, basing decisions on their perspectives and telling patient/family advisors that they are valued	Retain (89.1)	---	Retain
	Hospitals should include a critical volume of patient/family advisors on any committee or project team	Hospitals should include at least one and preferably more patient/family advisors on any committee or project team	No consensus (51.7)	No consensus (72.2)	No consensus
	Hospitals should require that decision-making quorum include at least one patient/family advisor	Hospitals should require that decision-making quorum for committees or project teams include at least one patient/family advisor	No consensus (62.5)	No consensus (63.0)	No consensus
	Patient and Family Advisory Committee's should routinely review interim progress, decisions or outputs of standing committees or project teams	Patient and Family Advisory Committees should routinely review interim progress, decisions or outputs of standing	No consensus (73.7)	No consensus (74.5)	No consensus

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	to ensure that patient/family advisor perspectives informed decisions	committees or project teams to ensure that decisions reflect patient/family advisor perspectives			
	Hospitals should check with patient/family advisors to confirm that interim or near-to-final decisions or outputs accurately captured their perspectives	Hospitals should routinely check with patient/family advisors to confirm that interim or near-to-final decisions or outputs accurately captured their perspectives and explain why, if any, were not captured	Retain (87.7)	---	Retain
Sub-total			9	0	9
Strategies to champion patient/famil y engagement	Hospitals should convey an organizational commitment to patient/family engagement by acknowledging it in their hospital values statement and strategic plan	Hospitals should convey an organizational commitment to patient/family engagement by acknowledging it in their hospital values statement and strategic plan, and continuously update values/strategic plan as patient/family engagement evolves	Retain (94.6)	---	Retain
	Hospitals should foster an organization-wide culture of respect and support for patient/family engagement	---	Retain (100.0)	---	Retain
	To establish a philosophical commitment, hospitals should promote that patient/family advisors be viewed as experts on the patient perspective, which should be valued equally to the perspective of healthcare workers	To establish a philosophical commitment, hospitals should promote the view that patient/family advisors bring diverse expertise, skills and perspectives, which should be valued equally to those of healthcare workers	Retain (82.8)	---	Retain
	Senior administrative and clinical leaders should model patient/family engagement	---	Retain (98.1)	---	Retain
	Hospitals should share results or outcomes with involved patient/family advisors so that they are aware of how their input and decisions contributed to planning and improvement	---	Retain (100.0)	---	Retain
	The hospital CEO and Board members should visibly endorse patient/family engagement by promoting it throughout the hospital to all staff and patients (e.g. in waiting rooms) to create awareness of how patient/family perspectives contributed to planning and improvement	The hospital CEO and Board members should visibly endorse patient/family engagement by promoting it throughout the hospital to all staff and patients (e.g. in waiting rooms) to create awareness of how patient/family advisors worked with healthcare workers/staff on planning and improvement	Retain (87.5)	---	Retain
	Hospitals should share patient/family engagement opportunities, activities, outputs and impacts with the broader community as a means of patient/family advisor recruitment and to create awareness about how the hospital is addressing their needs	Hospitals should share patient/family engagement opportunities, activities, outputs and impacts with the broader community through various platforms as a means of patient/family advisor recruitment and to create awareness about how the hospital is addressing their needs	Retain (93.1)	---	Retain

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	Chairs of standing committees or project teams should routinely consult with patient/family advisors throughout meetings to ensure they understand issues under discussion, ask if they have any questions, or wanted to articulate ideas or feedback, and adjust pace as necessary	Chairs of standing committees or project teams should assess acceptability in advance, and then routinely consult with patient/family advisors throughout meetings to ensure they understand acronyms, medical terms or issues under discussion, ask if they have any questions, or wanted to articulate ideas or feedback, and adjust pace as necessary	No consensus (77.2)	Retain (80.8)	Retain
	Hospitals should include a Board member on the Patient and Family Advisory Committee who could convey concerns or ideas directly to the Board	As a way to hold the Board accountable to the Patient and Family Advisory Committee, hospitals should include a Board member on the Patient and Family Advisory Committee who could convey concerns or ideas directly to the Board	No consensus (68.4)	No consensus (58.5)	No consensus
	Hospitals should include patient/family advisors on the Board or Committees of the Board as voting members	Hospitals should include at least one patient/family advisor on the Board or Committees of the Board as voting members	No consensus (70.2)	Retain (80.0)	Retain
	Hospitals should make the Patient and Family Advisory Committee accountable to the Board for planning and improvement activities	Hospitals should make the Patient and Family Advisory Committee accountable to the Board or a Committee of the Board for planning and improvement activities	No consensus (52.6)	No consensus (64.2)	No consensus
Sub-total			7	2	9
Hospital capacity for patient/famil y engagement	Hospitals should allocate dedicated operational funding to nurture and maintain patient/family engagement including one or more Patient and Family Advisory Committee's and other engagement activities	---	Retain (84.2)	---	Retain
	Hospitals should appeal to government, which advocates for patient/family engagement, for dedicated funding to support patient/family engagement	---	No consensus (75.9)	No consensus (78.2)	No consensus
	Hospitals should reimburse patient/family advisors for expenses incurred (e.g. use of their own computers, printing costs, gas, mileage, parking, child care)	Hospitals should reimburse patient/family advisors for pre-determined, clearly defined expenses incurred (e.g. use of their own computers, printing costs, gas, mileage, parking, child care)	No consensus (69.0)	No consensus (74.5)	No consensus
	Hospitals should compensate patient/family advisors for their time spent contributing to patient engagement activities and for taking time off work to participate in those activities	---	No consensus (44.8)	No consensus (63.6)	No consensus
	Hospitals should build patient/family engagement compensation and reimbursement into their yearly operational budgets	---	No consensus (63.2)	No consensus (36.4)	No consensus
	Hospitals should include patient/family engagement activities into appropriate	---	No consensus (76.8)	No consensus (75.9)	No consensus

	healthcare worker and staff job descriptions as part of the Human Resource commitment to person-centred care				
	Hospitals should cover the cost of release time for staff so they can participate in patient/family engagement activities	---	No consensus (66.7)	No consensus (61.8)	No consensus
	Hospitals should encourage and reward healthcare workers for participating in patient/family engagement	Hospitals should encourage healthcare workers to participate in patient/family engagement, and recognize their efforts (e.g. in annual performance reviews)	No consensus (62.5)	Retain (80.0)	Retain
	Hospitals should provide access to technology for patient/family advisors so they can fully engage in activities (e.g. email accounts, laptops, digital applications)	Hospitals should assess access to technology for patient/family advisors and provide supports to those in need so they can fully engage in activities (e.g. email accounts, laptops, digital applications)	No consensus (77.2)	No consensus (74.1)	No consensus
	Hospitals should employ a dedicated patient engagement manager to promote and support patient/family engagement	Hospitals should ideally employ a dedicated patient engagement manager to promote and support patient/family engagement, or include this responsibility in an existing closely-related portfolio (e.g. patient relations manager, human resources personnel)	No consensus (75.9)	Retain (88.7)	Retain
	Hospitals should employ dedicated patient engagement staff who are driven by person-centred values and possess skills in reflective listening, compassionate communication, and project coordination and facilitation	---	Retain (84.5)	---	Retain
	Hospitals should regularly evaluate patient/family engagement practices and make improvements based on patient/family advisor feedback, and reflection on what worked and what did not work	Hospitals should regularly evaluate patient/family engagement practices and make improvements based on patient/family advisor, healthcare worker and staff feedback, and reflection on what worked and what did not work	Retain (93.0)	---	Retain
Sub-total			3	2	5
Indicators suggested in Round One and rated in Round Two	All recommendations should refer to "patient/family partners" rather than "patient/family advisors" to reflect the aim of true engagement	---	---	No consensus (65.5)	No consensus
	Hospitals should encourage, support and facilitate collaboration with Patient and Family Advisory Committees from other hospitals and Patient Family Advisory Bodies to foster a community of learning	---	---	No consensus (70.9)	No consensus
Sub-total			---	0	0

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CREDES Checklist
Recommendations for the Conducting and REporting of DElphi Studies

Items	Location in manuscript
Purpose and rationale. The purpose of the study should be clearly defined and demonstrate the appropriateness of the use of the Delphi technique as a method to achieve the research aim. A rationale for the choice of the Delphi technique as the most suitable method needs to be provided.	Introduction page 3; Approach page 3-4
Expert panel. Criteria for the selection of experts and transparent information on recruitment of the expert panel, sociodemographic details including information on expertise regarding the topic in question, (non)response and response rates over the ongoing iterations should be reported.	Sampling and recruitment, page 4
Description of the methods. The methods employed need to be comprehensible; this includes information on preparatory steps (How was available evidence on the topic in question synthesised?), piloting of material and survey instruments, design of the survey instrument(s), the number and design of survey rounds, methods of data analysis, processing and synthesis of experts' responses to inform the subsequent survey round and methodological decisions taken by the research team throughout the process.	Page 3 to 4
Procedure. Flow chart to illustrate the stages of the Delphi process, including a preparatory phase, the actual 'Delphi rounds', interim steps of data processing and analysis, and concluding steps.	Figure 1
Definition and attainment of consensus. It needs to be comprehensible to the reader how consensus was achieved throughout the process, including strategies to deal with non-consensus.	Data collection and analysis, page 4
Results. Reporting of results for each round separately is highly advisable in order to make the evolving of consensus over the rounds transparent. This includes figures showing the average group response, changes between rounds, as well as any modifications of the survey instrument such as deletion, addition or modification of survey items based on previous rounds.	Page 4 to 6, Supplementary Files 1 and 2
Discussion of limitations. Reporting should include a critical reflection of potential limitations and their impact of the resulting guidance.	Page 7 to 8
Adequacy of conclusions. The conclusions should adequately reflect the outcomes of the Delphi study with a view to the scope and applicability of the resulting practice guidance.	Page 8

Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. Palliat Med. 2017;31: 684–706.

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