Organizational capacity for patient and family engagement in hospital planning and improvement: interviews with patient/family advisors, managers and clinicians

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Abstract

Background: Patient and family engagement (PE) in healthcare planning and improvement achieves beneficial outcomes and is widely advocated, but a lack of resources is a critical barrier. Little prior research studied how organizations support engagement specifically in hospitals.

Objective: We explored what constitutes hospital capacity for engagement.

Methods: We conducted descriptive qualitative interviews and complied with criteria for rigour and reporting in qualitative research. We interviewed patient/family advisors, engagement managers, clinicians and executives at hospitals with high engagement activity, asking them to describe essential resources or processes. We used content analysis and constant comparison to identify themes and corresponding quotes and interpreted findings by mapping themes to two existing frameworks of PE capacity not specific to hospitals.

Results: We interviewed 40 patient/family advisors, patient engagement managers, clinicians and corporate executives from nine hospitals (two < 100 beds, four 100 + beds, three teaching). Four overarching themes about capacity considered essential included resources, training, organizational commitment and staff support. Views were similar across participant and hospital groups. Resources included funding and people dedicated to PE and technology to enable communication and collaboration. Training encompassed initial orientation and project-specific training for patient/family advisors and orientation for new staff and training for existing staff on how to engage with patient/family advisors. Organizational commitment included endorsement from the CEO and Board, commitment from staff and continuous evaluation and improvement. Staff support included words and actions that conveyed value for the role and input of patient/family advisors. The blended, non-hospital-specific framework captured all themes. Hospitals of all types varied in the availability of funding dedicated to PE. In particular, reimbursement of expenses and compensation for time and contributions were not provided to patient/family advisors. In addition to skilled engagement managers, the role of clinician or staff champions was viewed as essential.

Conclusion: The findings build on prior research that largely focused on PE in individual clinical care or research or in primary care planning and improvement. The findings closely aligned with existing frameworks of organizational capacity for PE not specific to hospital settings, which suggests that hospitals could use the blended framework to plan, evaluate and improve their PE programs. Further research is needed to yield greater insight into how to promote and enable compensation for patient/family advisors and the role of clinician or staff champions in supporting PE.

Key words: patient participation, patient engagement, hospitals, hospital planning, quality improvement, qualitative research

Introduction

Healthcare organizations are increasingly involving patients (and family) in planning and improving facilities and services. In this context, patient engagement (PE) is defined as patients, families or their representatives and health professionals working in active partnership in organizational design and governance to improve health and healthcare [1]. Accumulated evidence shows that PE at the organizational level can lead to the development of policies, programs or resources that are tailored to patient needs and preferences, resulting in enhanced service delivery, patient experiences and clinical outcomes [2, 3]. However, a lack of organizational resources has been identified as a critical barrier to PE [4, 5].

Two prior research studies provided key foundational insight into the conditions needed to enable PE. Those conditions included processes or tasks, resources and context dedicated to or supportive of PE, which together constituted organizational capacity for PE [6, 7]. An investigation by Baker et al. involving 10 case studies from three countries revealed that ‘engagement-capable’ organizations...
were characterized by the following three key processes: enlisting and preparing patients, supporting staff to engage with patients and visible leadership support for PE [6]. The Measuring Organizational Readiness for Patient Engagement (MORE) framework was developed by Oostendorp et al. using a two-round Delphi survey completed by healthcare managers, policy makers, clinicians, patients and researchers from 16 countries [7], MORE includes 22 items reflecting organizational capacity for PE described as tasks (e.g. sharing the organizational vision for PE with all employees), resources (e.g. training health professionals in PE) and context (e.g. performance measures include PE). Although both frameworks provided insight into what constitutes organizational capacity for PE (e.g. essential infrastructure), the two frameworks seemingly differ, highlighting the need for additional insight into the components of organizational capacity.

Moreover, prior research on PE was largely conducted in primary care rather than hospitals [2], which account for the largest share of health spending in many countries [8]. By virtue of the type and range of care they provide, spanning ambulatory, acute and emergent, capacity required for PE in hospitals may be unique from other care settings. Hospital-based PE studies have identified barriers of PE [4, 5], described projects involving PE [9] or focused on practices used to engage patients in their own clinical care [10]. Given the importance of PE in improving health care quality [2, 3], the need to better understand organizational capacity for PE [6–8] and a lack of such research in hospital settings [2], the overall aim of this study was to explore what constitutes hospital capacity for PE. The objective was to interview those involved in hospital PE to identify existing and needed infrastructure or processes considered essential to PE capacity.

Methods

Approach

We employed a qualitative design to thoroughly explore the recommendations of individuals involved in hospital PE [11]. Interviews were conducted using a qualitative descriptive approach, which does not test or generate theory but instead explores experiences and perspectives and works to identify barriers and suggested solutions for improvement of health services [12]. We complied with the 32-item Consolidated Criteria for Reporting Qualitative Research standards and other techniques for enhancing rigor; for example, we described researcher characteristics (noted the types of individuals on the research team and the training and positions of the primary researchers who analyzed data), the qualitative approach (noted and rationalized the choice of qualitative description), sampling and recruitment methods (described and rationalized the types of persons we wished to interview, how they were identified and how they were contacted), how data saturation was assessed (who established saturation and how), data collection (who conducted interviews and what questions were asked), data analysis (performed in duplicate then reviewed by research team) and all themes (fully reported in online-only file, key themes and exemplar quotes described in text and tables) [13, 14]. The research team contributed to research design and planning, question development, data analysis and interpretation of the findings. The research team included four health services researchers, three patient research partners, two PE managers, a biostatistician and representatives of the Ontario Ministry of Health, Ontario Hospital Association and Canadian healthcare accreditation agency. All participants provided written informed consent prior to interviews. We had no prior relationship with research participants. The University Health Network Research Ethics Board approved the study (Study ID 18–5037).

Sampling and recruitment

We used purposive sampling to recruit individuals whose PE experiences and perspectives might vary by role (managers responsible for PE, patients/family, clinicians, corporate executives), type of hospital (<100 beds, 100+ beds, teaching) and healthcare region in Ontario, Canada. We also used snowball sampling, a standard approach in qualitative research, by first interviewing PE managers, who then referred us to patients/family, clinicians and corporate executives. We recruited participants from hospitals with high PE capacity identified by our prior survey of hospital PE managers in which they were asked about infrastructure and processes for PE [3]. Using Multiple Correspondence Analysis, a form of multivariate analysis, hospitals with high capacity for PE were distinguished from others by the following two characteristics: they featured PE in planning and improvement activities across multiple clinical and corporate departments and they employed a variety of engagement approaches (e.g. inform and consult through surveys or interviews and involve and partner in standing committees or project teams). While that prior research did not assess outcomes associated with high PE capacity, individuals recruited from these hospitals could speak about the capacity needed to undertake PE. We aimed to recruit one PE manager, two patients/family and two clinicians from two hospitals of each type for a minimum total of 30 interviews. We first contacted PE managers by email on 13 January 2020 and closed recruitment on 16 July 2020. We sampled concurrently to data collection and analysis and proceeded until thematic saturation was achieved, meaning no further unique themes emerged with successive interviews. We determined this by discussion among the investigators.

Data collection

We conducted interviews by telephone between 21 January 2020 and 16 July 2020. NA (MPH, Research Associate) and ARG (PhD, Senior Scientist/Professor) jointly conducted the first two interviews, independently reviewed transcripts, then discussed and refined wording of interview questions. NA subsequently conducted all interviews. As noted, qualitative description is neither based on nor generates theory [12], and there is no validated instrument that measures organizational capacity for PE to inform interview questions. In keeping with the goal of qualitative description to identify barriers and corresponding solutions, we derived interview guide questions (Supplementary File 1) based on the study objective (‘to identify existing and needed infrastructure or processes considered essential to PE capacity’) and employed broad open questions to avoid leading interview participants: what characteristics or conditions led to successful PE, what key challenges did you experience and how did you overcome them or what would you do differently and what could better equip hospitals to support PE. Interviews ranging from 21:38 to 73:29 min were audio-recorded and transcribed.
Table 1 Participant characteristics

| Role                        | Affiliation by hospital type | Sub-total |
|-----------------------------|-----------------------------|-----------|
|                             | <100 beds | 100+ beds | Teaching |          |
| PE managers                 | 2         | 4         | 2        | 8        |
| Patient/family advisors     | 4         | 10        | 6        | 20       |
| Clinicians                  | 2         | 6         | 2        | 10       |
| Corporate executives        | 0         | 1         | 1        | 2        |
| Sub-total                   | 8         | 21        | 11       | 40       |

Data analysis
We employed content analysis to identify themes inductively through constant comparison and used Microsoft Office (Word, Excel) to manage data [11, 12]. NA and ARG independently coded the first two interviews, then discussed coding to develop a preliminary codebook of themes and exemplar quotes (first-level coding). NA coded subsequent interviews to expand or merge themes (second-level coding). NA and ARG met on two subsequent occasions to review, discuss, and refine coding. We tabulated data (themes, quotes) by participant role and hospital type to compare themes. The research team then reviewed themes and quotes.

We blended existing non-hospital-specific frameworks describing PE capacity to further interpret findings and identify if or how capacity for PE was unique to hospitals [6, 7]. All 22 components of Oostendorp’s MORE framework aligned with the three key processes of Baker et al.’s Engagement-Capable Environment framework (enlist and prepare patients, support staff to engage patients, leaders visibly support PE), although not as organized by MORE’s three categories (resources, tasks, context) [6, 7]. NA and ARG independently mapped themes and exemplar quotes to the blended framework. NA and ARG then compared mapping, which the research team then reviewed and interpreted.

Results
Participants
We interviewed 40 participants, including 20 patient/family advisors, 10 clinicians, 8 PE managers and 2 corporate executives who were affiliated with nine hospitals: two <100 beds (8 participants), four 100+ beds (21 participants) and three teaching (11 participants) hospitals (Table 1). Patient/family advisors had a mean age of 66.2 years, 75.0% were women, and 90.0% identified as Caucasian. Clinicians were 90.0% women and all were mid- or late-career. Clinicians included one physician, six nurses, one social worker and two occupational therapists. PE managers had a mean 10.9 years of experience in PE roles and 75.0% were women. One corporate executive was a woman. One corporate executive was early-career, the other mid-career.

Supplementary File 2 includes data. Themes with select quotes are discussed here. There was no discrepancy in themes by role (patient/family advisor, PE managers, clinicians, corporate executives) or hospital type (<100 beds, 100+ beds, teaching). Patient/family advisors expressed several unique themes noted throughout the following results, possibly because they comprised half of the interview participants or because of their unique perspective.

Essential components of hospital capacity for PE
When asked about capacity required for PE, participants described multiple conditions and processes, either present or absent, categorized as resources, training, organizational commitment and staff support (Table 2). When present, capacity resulted in PE being ‘inter-woven into the culture of the organization’.

Resources
Resources included operational funding, people and technology. Funding was used to establish, engage, maintain and compensate a group of patient/family advisors and to cover the cost of release time for staff so they could participate in PE activities. Resources also included PE managers and staff dedicated to PE and other hospital staff, referred to as ‘champions’, who were essential to facilitating PE activities.

We chose representatives from each of our programs so that when our patient and family advisors were rotating sites that they had at least one contact person and point where they felt comfortable and that they could go to

It’s a gaping hole in engagement that the only person in the room not being paid to be there is the patient, whose voice is apparently critical to the work. The advisors at my hospital essentially pay to volunteer. They pay their mileage or their time, they take time off work, they may pay for babysitters

Training
Training for patient/family advisors included general orientation sessions or readings, meetings or workshops specific to assigned PE activities. Training for staff included orientation sessions for both current and newly hired staff on how to engage with patient/family advisors. One corporate executive noted that establishing roles and responsibilities for all involved at the outset of PE projects should be part of orientation sessions and was essential to project success.

Every month at orientation, we as patient advisors have an hour and a half to spend with new staff. I got a chance to talk about what a patient advisor is, what we do, etc. (005 patient/family teaching)
| Category | Theme | Enablers | Barriers |
|----------|-------|----------|----------|
| Resources | Operational funding dedicated to PE activities | It definitely takes resources to recruit and orient and nurture the patient and family advisory group (004 PE manager teaching) | There's no funding. So that's an important piece I think that's missing (027 PE manager <100) |
| | Compensation for patients and release time for staff | They [patient/family advisors] get paid to work here because they are just so enmeshed in all of the things that we do (008 clinician teaching) | Some type of financial resources for them [PFAs] because they spend a lot of time at the hospital... it would be nice if we could give them some type of stipend for the time and commitment that they have within the organization (040 clinician 100+) |
| | Staff who are responsible for and enable PE (dedicated manager and staff/staff champions) | I have many staff that join me in running our Patient and Family Advisory Council (010 PE manager 100+) | Well I think in an ideal world we would have more people involved. |
| | | When we were rolling it out and doing all the initiatives, we were lucky to have the 70 staff champions to help us do all those different things because otherwise it would just be exhausting (006 clinician <100) | If more people are facilitating patient engagement in an organization beyond my role then we can facilitate more patient engagement because people need support (011 PE manager 100+) |
| | Technology to support PE | We use a lot of different types of technologies to help to promote people participating and having an opportunity to share (010 PE manager 100+) | Well the biggest challenge is trying to create buy-in with staff with regards to time constraints because we're too busy for this stuff (006 clinician <100) |
| | | You know there's a lot we can do virtually and we figured this out early on (031 clinician 100+) | I'm trying to engage our PFAC and I'm having to do it on my own. |
| | | | The hospital hasn't found a virtual system across the board that can work, and even the ones that we have, have limitations in terms of how many people can join... So just really supporting more technological kind of advances to grow our connections and communication with our PFAC members (034 clinician 100+) |
| | | | We do it [Patient Family Advisory Committee work] mostly by paper unless we bring in our own tablets. The Board has secure emails, we are using our personal ones. The hospital does not have a Zoom account and we were using one of the member's Zoom accounts (036 patient/family <100) |
| | | | | Small/rural |
| Organization size | | | Small/rural |
| | | | Because we are a small hospital and it's in a rural setting, it's a totally different environment from, say, a big city. I regard myself as a liaison between my community and my hospital. So if someone has been in the hospital setting and said to me, I had a bad experience, I'll go back to my committee, I keep it confidential, we look into it (035 patient/family <100) |
| | | | In more rural areas, you have to deal with the internet bouncing in and out, and not always being the most secure (036 patient/family <100) |
| | | | Being a rural hospital, all we have is a local radio station and newspaper, which is filled with adverts for patient representatives now (035 patient/family <100) |
| | | | Part of the challenge with <hospital name> is simply its size. It's just a huge organization. I think a big challenge is coordination of different activities involving patients (014 patient/family teaching) |
| | | | Large |
| Training for patients and staff | | | -
| Background information for patients | They sent us lots of things to read for background or samples of things and then we would be able to go ahead and do what was required (014 patient/family teaching) | - |
| | | We usually have an education session for about a half an hour before we get into the meeting (036 patient/family <100) | - |

(continued)
| Category | Theme | Enablers | Barriers |
|----------|-------|----------|----------|
| Establish roles and responsibilities for all involved | Something that we do upfront is define everybody's, including the PFA, roles, responsibilities and comfort level in executing the activity as outlined because otherwise we’re not going to be successful (032 corporate executive 100+). | – |
| Orientation for existing and new staff | We just held a big orientation event in October... we invited leaders to come and learn about being effective leaders in patient engagement (011 PE manager 100+). The staff and leaders received training on how to effectively engage with patient partners (029 patient/family 100+). | – |
| Organizational commitment to PE | I do think having the PFA program owned by the CEO and VP Clinical really helped it. So it wasn’t something off to the side it was literally at the core of operational activity (020 PE manager 100+). Having a Board member sit on the PFAC, and bring those minutes to the Board [Quality] Committee and to the full Board ensures that if they need different equipment or whatever that it’s not just being minuted in a meeting and then never done (001 PE manager <100). | – |
| Staff commitment | I was struck by the level of commitment; that staff showed to this [PE activity]. They truly were committed to having the patient voice embedded in it... They’re really genuine; this is embedded in their thinking that the patient is the most important person (015 patient/family teaching). The most important thing is the support that the PFA program gets from the staff at the hospital... It is a very strongly supported program from the doctors and all the administration. They really see the value of bringing the patient to the centre of the activity (016 patient/family 100+). | I would try to build the culture that says that patient partners really can bring a lot of added value to any decision and any new program (014 patient/family teaching). Acceptance of the patient having a much more enhanced role is a barrier for sure. So physicians had to sit at the same table as their patient and talk about things that they weren’t doing well and that’s not easy... our physicians were uncomfortable (001 PE manager <100). The staff were very nervous about having a patient involved and there was a lot of tension in the room when I sat down at the table, I could feel it... We recognize that the staff are very intimidated by the fact that what they hear from patients are mostly complaints. That’s not who we want to be (007 patient/family teaching). |
| PE is evaluated and improved | We always survey and get feedback from the patient and family advisors on how we can improve engagement, how we can improve their affiliation within a project based on interest, expertise and also looking at other improvements and engagement in a more efficient and effective way (032 corporate executive 100+). | – |
| Staff support | <Hospital name> has a way of treating all voices equally. There’s no feeling of hierarchy when you’re there. As a patient representative, the chief-of-staff does not make you feel like there’s a hierarchy (007 patient/family teaching). We’re not treated as add-on's, we’re not treated as must do’s, or an irritant to the system, we’re treated as a resource that adds quality to the hospital experience (014 patient/family teaching). | One of the barriers is that as a patient-family advisor I certainly understand things from a patient perspective; but I’m not clinical. I don’t understand the acronyms; I certainly am not up to speed on a routine basis. So as an advisor you sit on a committee with highly skilled clinicians and doctors and surgeons and so on and it is sometimes somewhat embarrassing to ask questions that should be obvious but they’re not to patients (039 patient/family teaching). I think scheduling my attendance was a challenge. I wasn’t really part of those doodle polls to see when people were available. I think the structure of the meetings and when and how they took place was built around the availability of the leadership, I was sort of told when and where the meeting would take place and it was hoped that I could attend. So I don’t think I was on equal footing in that respect (029 patient/family 100+). |

**Table 2 (Continued)**

| Table 2 (Continued) | Exemplar quotes |
|----------------------|-----------------|
| **Category** | **Theme** | **Enablers** | **Barriers** |
| Establish roles and responsibilities for all involved | Something that we do upfront is define everybody’s, including the PFA, roles, responsibilities and comfort level in executing the activity as outlined because otherwise we’re not going to be successful (032 corporate executive 100+). | – |
| Orientation for existing and new staff | We just held a big orientation event in October... we invited leaders to come and learn about being effective leaders in patient engagement (011 PE manager 100+). The staff and leaders received training on how to effectively engage with patient partners (029 patient/family 100+). | – |
| Organizational commitment to PE | I do think having the PFA program owned by the CEO and VP Clinical really helped it. So it wasn’t something off to the side it was literally at the core of operational activity (020 PE manager 100+). Having a Board member sit on the PFAC, and bring those minutes to the Board [Quality] Committee and to the full Board ensures that if they need different equipment or whatever that it’s not just being minuted in a meeting and then never done (001 PE manager <100). | – |
| Staff commitment | I was struck by the level of commitment; that staff showed to this [PE activity]. They truly were committed to having the patient voice embedded in it... They’re really genuine; this is embedded in their thinking that the patient is the most important person (015 patient/family teaching). The most important thing is the support that the PFA program gets from the staff at the hospital... It is a very strongly supported program from the doctors and all the administration. They really see the value of bringing the patient to the centre of the activity (016 patient/family 100+). | I would try to build the culture that says that patient partners really can bring a lot of added value to any decision and any new program (014 patient/family teaching). Acceptance of the patient having a much more enhanced role is a barrier for sure. So physicians had to sit at the same table as their patient and talk about things that they weren’t doing well and that’s not easy... our physicians were uncomfortable (001 PE manager <100). The staff were very nervous about having a patient involved and there was a lot of tension in the room when I sat down at the table, I could feel it... We recognize that the staff are very intimidated by the fact that what they hear from patients are mostly complaints. That’s not who we want to be (007 patient/family teaching). |
| PE is evaluated and improved | We always survey and get feedback from the patient and family advisors on how we can improve engagement, how we can improve their affiliation within a project based on interest, expertise and also looking at other improvements and engagement in a more efficient and effective way (032 corporate executive 100+). | – |
| Staff support | <Hospital name> has a way of treating all voices equally. There’s no feeling of hierarchy when you’re there. As a patient representative, the chief-of-staff does not make you feel like there’s a hierarchy (007 patient/family teaching). We’re not treated as add-on’s, we’re not treated as must do’s, or an irritant to the system, we’re treated as a resource that adds quality to the hospital experience (014 patient/family teaching). | One of the barriers is that as a patient-family advisor I certainly understand things from a patient perspective; but I’m not clinical. I don’t understand the acronyms; I certainly am not up to speed on a routine basis. So as an advisor you sit on a committee with highly skilled clinicians and doctors and surgeons and so on and it is sometimes somewhat embarrassing to ask questions that should be obvious but they’re not to patients (039 patient/family teaching). I think scheduling my attendance was a challenge. I wasn’t really part of those doodle polls to see when people were available. I think the structure of the meetings and when and how they took place was built around the availability of the leadership, I was sort of told when and where the meeting would take place and it was hoped that I could attend. So I don’t think I was on equal footing in that respect (029 patient/family 100+). |
Organizational commitment
Organizational commitment to PE included endorsement at the level of the CEO and Board, which was enacted by involving patient/family advisors as Board members, or instating Board members on patient/family advisory committees. One corporate executive said that the hospital constantly strived to evaluate and improve PE based on feedback from patient/family advisors.

I think the CEO and the executive leadership believe engagement is essential; it’s not nice to have, it’s a need to have. That filters down in all the work I see (029 patient/family 100+)

We always survey and get feedback from the patient and family advisors on how we can improve engagement… (032 corporate executive 100+)

Patient/family advisors emphasized that hospital commitment to PE was also evident in the actions of hospital staff, including physicians and administrators. This was not always the case; in some hospitals, staff were uncomfortable with feedback from patient/family advisors.

The staff were very nervous about having a patient involved and there was a lot of tension in the room when I sat down at the table (007 patient/family teaching)

One patient/family advisor said that it would be important to widely communicate the impact of their involvement in planning and improvement to the general public.

We really need to find some way to get the information out to the public about what the work these hospitals are doing with their community members involved (035 patient/family <100)

Staff support
Patient/family advisors emphasized that staff behaviour encouraged and supported patient/family participation and conveyed value for their role. In such cases, staff were receptive to their input, treated them as equals, expressed genuine interest in their ideas and opinions and used their feedback to make decisions. Staff also explicitly expressed appreciation to patient/family advisors for their input.

There hasn’t been anything that I’ve been involved in at the hospital where I haven’t felt like I’d been valued. I didn’t feel like I was just a warm body sitting on a chair around a committee table (019 patient/family 100+)

We’re not treated as add-on’s, we’re not treated as must do’s, or an irritant to the system, we’re treated as a resource that adds quality to the hospital experience… Somebody comes back to you and says, here’s how your comments changed what we did (014 patient/family teaching)

In contrast, some patient/family advisors said they were not consulted in scheduling meetings at a mutually convenient time and details or acronyms were not explained to them during meetings such that they could actively contribute.

Comparison with a blended framework of capacity for PE
Our findings corresponded to all components of the blended framework of PE capacity (Table 3). For example, Baker et al. include ‘enlists and prepare patients’, Oostendorp et al. include ‘access to patient representatives’ and participants in our study recommended “operational funding dedicated to PE (establish, maintain, engage patient-family advisors). No additional unique themes emerged. Mapping concordance suggests that capacity for PE in hospitals is similar to that in other health care settings and further bolsters our findings.

Discussion
Statement of principal findings
Interviews with 40 patient/family advisors, PE managers, clinicians and executives involved in PE at diverse hospitals generated insight into capacity considered essential to PE including resources, training, organizational commitment and staff support. Resources included funding and people dedicated to PE and technology to enable communication and collaboration. Training encompassed initial orientation and project-specific training for patient/family advisors, orientation for new staff and training for existing staff on how to engage with patient/family advisors. Organizational commitment included endorsement from the CEO and Board, commitment from staff and continuous evaluation and improvement. Staff support included words and actions that conveyed value for the role and input of patient/family advisors. The blending of two prior frameworks, not developed specifically for hospitals, captured all themes that emerged from this research.

Strengths and limitations
Strengths of this research included use of robust qualitative methods that complied with reporting criteria and standard techniques for ensuring rigour [11–14]. The research was guided by multiple points of input and review by an interdisciplinary research team that included three patient research partners with hospital PE experience. Given that participants were affiliated with hospitals with a high level of PE activity, they provided insight based on considerable experience and related expertise developed through active involvement in PE. Participants represented different roles and hospital types, and there was a high level of agreement across types of participants and hospitals. Beyond analyzing and reporting themes reflecting participant recommendations, we mapped our hospital-specific themes to two general framework of PE capacity, demonstrating good concordance between prior frameworks and with our findings [7]. With respect to limitations, all participants were affiliated with hospitals in one Canadian province, therefore findings may not be relevant to hospitals in other countries with differing PE practices or health systems. The study was conducted during the COVID-19 pandemic so few corporate executives were available for interviews. We used snowball sampling, relying on PE managers to refer us to patients/family and staff involved in PE projects, which may have led to recruiting individuals with biased views on PE capacity. This did not appear to be the case because participants described instances where capacity was sufficient and where it was lacking. Given that leaders are essential to
### Table 3: Mapping of our findings to existing frameworks of organizational capacity for PE

| Baker et al. Engagement-Capable Environment framework [REF] | Oostendorp et al. Measuring Organizational Readiness for Patient Engagement framework [REF] | Current study |
|-------------------------------------------------------------|-----------------------------------------------------------------------------------|--------------|
| **Theme**                                                   | **Exemplar quote**                                                                |              |
| Enlist and prepare patients                                 | Resources—Operational funding dedicated to PE (establish, maintain, engage patient-family advisors) | Any kind of initiative at the hospital, they ask for patient representatives to be on it (018 patient/family 100+) |
| • Ongoing recruitment and preparation of, as well as support for, patients and family members in their roles as patient and family advisors, and as members of various committees. | Resources—Operational funding dedicated to PE (compensation for patient-family advisors) | Everything that touches a patient pretty much has a patient, a patient council or a patient family member at the table (007 patient/family teaching) |
| • Support for patient and family engagement structures and initiatives | Resources to support patients in becoming partners (e.g. recruitment of representatives, training, coaching, money to pay patients for participation) | I had to take time off work; these meetings are scheduled during the work day when staff and leaders are there getting paid already. There was no effort to mitigating the cost for me to take part. My parking was paid for but there was no mileage to get there. There was no consideration of compensating me for being there which I think indicates there’s still work to do. It’s still significant and a gaping hole in engagement that the only person in the room not being paid to be there is the patient whose voice is apparently critical to the work. The advisors I know at my hospital essentially pay to volunteer at the hospital. They pay their mileage or their time; they take time off work, they may pay for babysitters. I think the next step is put your money where your talk is and compensate people so they’re not sacrificing overly much to take part (029 patient/family 100+) |
| • Clearly defined roles, policies and procedures to ensure development of a broad base of representative and effective patients who take part in a wide range of organizational activities | Resources to provide health-related information and support to patients (e.g. access to interpreters, answering questions, helping patients to make decisions) | Some type of financial resources for them [PFAs] because they spend a lot of time at the hospital... it would be nice if we could give them some type of stipend for the time and commitment that they have within the organization (040 clinician 100+) |
| Resources                                                   | Training for patients and staff—Background information for patients                | They sent us lots of things to read for background or samples of things and then we would be able to go ahead and do what was required (014 patient/family teaching) |
| Resources to support patients in becoming partners (e.g. recruitment of representatives, training, coaching, money to pay patients for participation) | Resources—Technology to support PE | We usually have an education session for about a half an hour before we get into the meeting (036 patient/family <100) |

(continued)
| **Baker et al. Engagement-Capable Environment framework [REF]** | **Oostendorp et al. Measuring Organizational Readiness for Patient Engagement framework [REF]** | **Current study** |
|---|---|---|
| **Theme** | **Exemplar quote** | |
| **Context** | **I'm trying to engage our PFAC and I'm having to do it on my own. The hospital hasn't found a virtual system across the board that can work, and even the ones that we have, have limitations in terms of how many people can join. So technological kind of advances to grow our connections and communication with our PFAC members (034 clinician 100+)** | |
| **Patient involvement in planning, implementation, and monitoring of patient engagement** | **Anytime we have any projects, my first question is always: how can we involve our advisors to make sure that they're part of this work (008 clinician teaching)** | |
| **Resources** | **We just held a big orientation event in October...we invited leaders to come and learn about being effective leaders in patient engagement (011 PE manager 100+)** | |
| **Access to expertise in patient engagement** | **We have a fabulous leader for the patient experience partners and so she engages them a lot and empowers them a lot (040 clinician 100+)** | |
| **Time for initial implementation of patient engagement (e.g. time to inform employees about patient engagement processes)** | **There was funding to provide the release time for the staff so we could actually have a good 2-hour meeting with patients (033 patient/family 100+)** | |
| **Time for monitoring implementation of patient engagement (e.g. time for employees to provide feedback)** | **I feel that they [hospital staff] deserve a lot of credit for taking the time in their busyness to make the patients opinions and feelings important (023 patient/family 100+)** | |
| **Time to make patient engagement happen (e.g. revising targets and objectives, longer consultations)** | **There is this continual turn of check points...It provides us with an opportunity to get really meaningful feedback and insight into opportunities for us to improve what we were doing (022 clinician 100+)** | |
| **Train health professionals in patient engagement (e.g. communication and shared decision-making skills)** | **Having enough staff to be able to implement a patient program that is vital and useful and valid is probably most important (015 patient/family teaching)** | |
| **Task** | **The barrier is for leaders to dedicate the time to ensure more patient voices are heard (011 PE manager 100+)** | |
| **Support employees in their efforts to promote patient engagement (e.g. asking what they need and addressing these needs)** | **The biggest challenge is trying to create buy-in with staff with regards to time constraints because we're too busy for this stuff (006 clinician <100** | |
| **Well I think in an ideal world we would have more people involved... If more people are facilitating patient engagement in an organization beyond my role then we can facilitate more patient engagement because people need support (011 PE manager 100+)** | | (continued)
Table 3 (Continued)

| Baker et al. Engagement-Capable Environment framework [REF] | Oostendorp et al. Measuring Organizational Readiness for Patient Engagement framework [REF] | Theme | Exemplar quote |
|-----------------------------------------------------------|---------------------------------------------------------------------------------|-------|----------------|
| Context Employee attitudes, beliefs, and experiences regarding patient engagement | Context Frequent and consistent communication about patient engagement | Staff support—Staff encourage and are receptive to patient input | I was struck by the level of commitment; that staff showed to this PE activity. They truly were committed to having the patient voice embedded in it... They're really genuine; this is embedded in their thinking that the patient is the most important person (015 patient/family teaching) |
| Leaders visibly support PE, which is a strategic focus | Context Employee involvement in planning, implementation, and monitoring of patient engagement | Staff support—Staff encourage and are receptive to patient input | If the group doesn’t have a lot of experience with PFA’s it would be a very difficult task to teach the administrators or the folks that are inside the hospital tasked with either the planning or the execution to understand what the role of a PFA is. So there needs to be education from the hospital staff standpoint (016 patient/family 100+)|
| • Leaders enable the transformation of an organization’s culture; articulate and help to embed patient-centred values and strategic focus; provide resources and support; and offer ongoing role-modelling of the behaviours that demonstrate and reinforce the necessary changes. | | | Part of my role as the director, is to really be, I’m absolutely committed. So anytime we have any projects, my first question is always; how can we involve our advisors to make sure that they’re part of this work (008 clinician teaching) |
| • Leaders create an expectation and accountability of staff to partner with patients, involving them not only on decisions on their care, but on issues across the organization that influence policy and practice more broadly. | | | Our culture among staff, they are really committed to improving the patient experience and working with patients as partners (004 PE manager teaching) |
| • Governance also plays an important role. Organizational and system level boards set policies and create expectations that help to shape leadership actions and broader organizational strategies. | Task Develop a shared organisational vision for patient engagement among employees and patients Resources Tools to evaluate the implementation of patient engagement | Organizational commitment—Endorsed by CEO and Board Organizational commitment—PE evaluated and improved | Over the last 5 years we built a culture to really embrace the engagement all the way up to the Board and CEO level. And so that has been a huge enabler of ensuring that patient engagement is successful... I think we just have a real culture of collaboration and integration that exists in the hospital (028 PE manager teaching) We always survey and get feedback from the patient and family advisors on how we can improve engagement (032 corporate executive 100+) Every month at orientation we as patient advisors have an hour and a half to spend with new staff. I got a chance to talk about what a patient advisor is, what we do, etc. (005 patient/family teaching) For orientation, patient engagement has an hour and a half of time blocked in general, the orientation of all new staff and that's everybody from custodial to nursing. So we do an hour and a half presentation and there's three patient family members there and one of us does a talk and then three of us do break-out groups (007 patient/family teaching) |

(continued)
| Baker et al. Engagement-Capable Environment framework [REF] | Oostendorp et al. Measuring Organizational Readiness for Patient Engagement framework [REF] | Theme | Exemplar quote |
|---|---|---|---|
| **Task** | Share the organisational vision for patient engagement with all patients and the public (e.g., information in waiting areas) | Organizational commitment—Communicate about PE to general public | We really need to find some way to get the information out to the public about what the work these hospitals are doing with their community members involves (035 patient/family <100) |
| **Task** | Include patient engagement in all areas of health care services (e.g. policies, processes, position descriptions and training programs) | Organizational commitment—PE interwoven into the culture of the organization | |
| **Task** | Monitor patient engagement in the organisation and giving feedback to employees | Organizational commitment—PE evaluated and improved | We always have a patient or two involved in everything that we do (038 exec teaching) Any new policy, any new plans, you can’t have a committee actually move forward without having patients and families at the table and involved. So that’s a pretty strong statement and what happens is you start to transform culture quite quickly but that’s at the support of our CEO and our senior leadership team. So they’re on board with it and they’ve helped put it into practice (010 PE manager 100+) |
| **Context** | Align patient engagement with organisational priorities | Organizational commitment—Endorsed by CEO and Board | I do think having the PFA program owned by the CEO and VP Clinical really helped it. So it wasn’t something off to the side it was literally at the core of operational activity (020 PE manager 100+) And the patients who participate on the committees feel that they are very valued and that their opinions are a priority and will be heard by the hospital (012 clinician teaching) |
| **Context** | Performance measures include patient engagement | Organizational commitment—Endorsed by CEO and Board | I take a leadership role in ensuring that we’re meeting the accreditation standards related to patient experience (004 PE manager teaching) |
organizational capacity for PE, future research should explore challenges and solutions to hospital PE from this perspective.

Interpretation within the context of the wider literature

Prior research regarding PE largely focused on engaging individuals in their own clinical care or as members of research teams [10, 15, 16]. For example, a scoping review of 87 articles described how patients participated in their own care while hospitalized [10], and a systematic review of 142 studies described identified the research tasks in which patients were most commonly engaged and barriers of doing so resulted in potentially tokenistic involvement [16]. Other research on PE in healthcare organizations was conducted in the primary care context, revealing numerous barriers [2, 4, 5]. For example, a narrative review of 30 articles of patient/family partnership in ambulatory care quality improvement found that providers were uncertain about how best to involve patients and family or did not consider partnerships due to a lack of resources, and patients/family were not interested or comfortable with participating [4]. A review of qualitative research identified a range of enablers and barriers of PE in quality improvement in the primary care context [17]. Synthesized findings identified two over-arching themes: patient involvement in quality improvement was enabled by clearly establishing roles from the outset and training patients, and with such support, unexpected innovations occurred. Little prior research examined infrastructure for organizational-level PE in hospitals. Malloggi et al. surveyed 213 healthcare workers in a French university hospital, revealing they had engaged patients in developing care pathways, patient education programs and continuing education of healthcare professionals, but not the underlying resources or processes [18]. A scoping review specific to hospital-based PE for planning and improvement included only 10 studies published in 2016 or earlier [3]. Included studies provided little detail about precisely how patients were engaged. For example, a survey of hospital quality managers found that 50% of hospitals engaged patients, and in 65% of those hospitals, patients were members of quality committees, but the survey did not gather information about organizational characteristics that supported PE [10]. Thus, our research is unique from prior research, as it focused on PE for planning and improvement specifically in hospital settings and provided insight into what constitutes hospital capacity for PE based on the perspectives of a range of stakeholders (patient/family advisors, PE managers, clinicians, executives) affiliated with diverse hospitals (<100 beds, 100+ beds, teaching) featuring high level PE activity.

Implications for policy, practice and research

Several key findings warrant discussion. Hospitals of all types varied in the availability of funding dedicated to PE. Across most participant and hospital types, reimbursement of expenses and compensation for time and contributions were not provided to patient/family advisors. Paying patients is increasingly viewed as a fair and essential practice that reduces power imbalances, shows respect and value for patient/family advisors, demonstrates organizational commitment to PE and eliminates barriers to participation, thereby enhancing equity and diversity [6]. Four patients with international engagement experience offered guidance on appropriate levels of payment for different types of contributions [19]. Another study involving a survey and workshop with patients with engagement experience revealed that compensation eliminates barriers to participation among marginalized groups [20]. Further investigation is needed to establish why, when PE is widely considered essential, patient/family advisors continue to function as volunteers. We also identified a range of enablers and barriers of identifying and meaningfully engaging patient-family representatives in hospital PE [20]. Those findings are reported elsewhere in detail, but in brief, included engaging diverse patients, prioritizing what benefits many, matching patients to projects, involving a critical volume of patients, requiring at least one patient for quorum and asking involved patients to review outputs.

This study revealed that skilled and supportive staff are considered an essential component of hospital PE capacity. A literature review and interviews with 15 engagement professionals (setting of care not specified) and 16 consumers identified multiple responsibilities of engagement professionals organized in the following four categories: advocacy, education, facilitation and administration [21, 22]. The same study also revealed the important role of champions. While prior research has examined the roles, attributes and impact of opinion leaders and middle managers in improving quality of care [23, 24], the concept of champions has not been explored in the PE context. Future research is needed to more thoroughly understand how clinician champions promote and enable PE, and the potentially intersecting champion roles of high-level executives, PE managers and clinicians.

Themes that emerged in this study reflecting components of capacity considered essential to hospital PE mapped to two prior frameworks that were not specific to hospital planning and improvement (Table 3) [6, 7]. For example, both frameworks generated by Baker and Oostendorp referred to resources dedicated to enlisting, training and supporting patient/family involvement as did our study. Both frameworks referred to enabling staff to support patient/family involvement, and our study also found that staff training and dedicated staff (PE managers, clinical champions) enabled PE. The two frameworks and our study confirmed that visible leadership commitment to PE such as an explicit vision and communication about PE create an environment conducive to PE. This concordance between two foundational frameworks developed through research in multiple countries and with our results in Canada in the context of hospital PE underscores the reliability of our findings and their transferability or relevance beyond our research setting. Concordance also suggests that the blended framework may be a suitable tool for hospitals to evaluate and strengthen their PE programs. Hospital executives, clinicians engaged in PE or PE managers could use the blended framework to assess their current PE infrastructure and processes, and where gaps were identified, allocate resources. Hospitals newly embarking on PE could use the blended framework as the basis for strategic and operational planning.

Conclusions

This study aimed to explore what constitutes hospital capacity for PE in planning and improvement activities. Interviews with 40 patient/family advisors, PE managers, clinicians and
executives affiliated with hospitals featuring high levels of PE activity revealed multiple components of hospital PE capacity organized in four over-arching themes: resources, training, organizational commitment and support from staff. The findings build on prior research that focused on PE in individual clinical care, research or primary care planning and improvement. The findings closely aligned with prior frameworks of organizational capacity for PE not specific to hospital settings, which suggests that hospitals could use the blended framework to plan, evaluate and improve their PE programs. Further research is needed to yield greater insight into how to promote and enable compensation for patient/family advisors and the role of clinician or staff champions in supporting PE.

**Supplementary material**

Supplementary material is available at *International Journal for Quality in Health Care* online.

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**Contributorship**

G.R.B., L.M., K.S., R.U., W.W. and A.R.G. conceptualized and designed the study. N.A. and A.R.G. collected and analyzed data. All authors reviewed and interpreted the data. All authors drafted or revised the manuscript and gave final approval of the version to be published.

**Ethics and other permissions**

The University Health Network Research Ethics Board approved this research. Participants provided informed consent prior interviews.

**Data availability statement**

The data underlying this article are available in the article and in its online supplementary material.

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