

Patient and Family Engagement in the ICU Untapped Opportunities and Underrecognized Challenges

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Abstract

The call for meaningful patient and family engagement in health care and research is gaining impetus. Healthcare institutions and research funding agencies increasingly encourage clinicians and researchers to work actively with patients and their families to advance clinical care and research. Engagement is increasingly mandated by healthcare organizations and is becoming a prerequisite for research funding. In this article, we review the rationale and the current state of patient and family engagement in patient care and research in the ICU. We identify opportunities to strengthen engagement in patient care by promoting greater patient and family involvement in care delivery and supporting their

participation in shared decision-making. We also identify challenges related to patient willingness to engage, barriers to participation, participant risks, and participant expectations. To advance engagement, clinicians and researchers can develop the science behind engagement in the ICU context and demonstrate its impact on patient- and process-related outcomes. In addition, we provide practical guidance on how to engage, highlight features of successful engagement strategies, and identify areas for future research. At present, enormous opportunities remain to enhance engagement across the continuum of ICU care and research.

Keywords: patient participation; health care; research; critical care; delivery of health care

Meaningful patient and family engagement requires that health practitioners and researchers actively partner with patients, families, and organizations to advance care and research (1). These partnerships herald a departure from paternalism and the traditional disease-centered approach to health care and acknowledge that patients and families hold unique expertise and experiences that can improve clinical care and research (2). In this paradigm, both healthcare reform and research design and implementation require public consultation and pluralistic decision-making models (3).

Patient and family engagement is a laudable goal, but it is not a simple matter (4). Regardless of the activity, patient and family engagement takes place within a context reflecting the environment and culture, healthcare system, and society. Participants bring diverse beliefs, desires, experiences, and needs to engagement activities that may influence participation and decision-making. Strategies that render patient and family engagement effective in one setting may not be generalizable to the ICU, and barriers encountered in other contexts may be expressed differently in the ICU. The ICU context is shaped by critical

illness and the heterogeneity of patients' prior health states and subsequent recovery trajectories. Patient and family engagement may occur in the three distinct, but often overlapping, phases of life-threatening illness (acute, convalescent, and dying) described by Brown and colleagues (5). During acute illness, healthcare practitioners strive to attain physiological stabilization, provide decisional support, and address goals of care (including palliation). Throughout convalescence, efforts focus on recovery and rehabilitation (5). During the dying process, clinicians aim to relieve suffering, honor the patient's wishes, and

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provide emotional support to families. To be relevant, engagement activities should reflect the states of critical illness, acknowledge that critical illness is one part of the illness continuum, and be sensitive to the unique needs of participants in each phase.

Defining Engagement

Engagement is about patients, families, and healthcare providers actively working together to promote and support patient and family involvement and influence in health and healthcare decision-making (1). Specifically, engagement shifts the focus from “taking action to improve health and healthcare for people” to “taking action with people” (6). Recognizing the diverse ways to operationalize healthcare engagement, Carman and coworkers positioned engagement along axes reflecting different levels of engagement (direct care, organizational design, and policy making) and intensity of engagement (consultation, involvement, partnership, and shared leadership) (7). They acknowledged that engagement can be influenced by patients (health literacy, beliefs, education, and experiences), organizations (policy, practices, and culture), and society (norms, regulations, and policy) (7). To support patient care, research, and quality improvement in the ICU, Brown and colleagues refined the definition of patient and family engagement to include “active partnership between health professions and patients and families working at every level of the healthcare system to improve health and the quality, safety, and delivery of health care including but not limited to direct care, communication of patients’ values and goals, and transformation of care processes to promote and protect individual respect and dignity” (5). This definition embodies five core concepts (collaboration, respect and dignity, activation and participation, information sharing, and decision-making), and designates “family” as individuals whom the patient wishes to be involved in her/his care (5, 8, 9). Patient and family engagement is distinguished from patient- and family-centered care, which is an approach to health care that respects and responds to individual families’ values and needs (10). In this regard, patient- and family-centered care is one of many

possible outcomes of patient and family engagement, where engagement may be viewed as a mechanism to achieve patient- and family-centered care.

Mandate for Greater Patient and Family Engagement in Patient Care and Research

The call for meaningful patient and family engagement in health care and research is increasing (7). It emanates from increased expectations of patients and families to participate in shared decision-making, greater emphasis on patient- and family-centered care as a healthcare objective, and the democratization of medical knowledge through information technology, which provides patients and families with access to ever-increasing communication about health matters (11–17). Increasing emphasis on patient- and family-centered care in critical care and awareness that patients’ and families’ experiences in the ICU have long-term effects on their health and well-being have incited interest in engagement as a means to improve their experiences and outcomes (18–24).

The Patient Centered Outcomes Research Institute (PCORI) through the United States Congress and the Strategy for Patient-Oriented Research of the Canadian Institutes of Health Research fund engagement research designed to improve outcomes and aid stakeholders in making informed health decisions (26–28). These institutes foster the science behind engagement and the capacity to engage. Increasingly, clinical research proposals must demonstrate meaningful engagement in study design, implementation, and/or knowledge translation to be eligible for funding. By providing new insights into research design and implementation, ensuring a strong patient and family focus in research, and rendering research investments more accountable, engagement is increasingly moving from niche methodology to a prerequisite for the conduct of meaningful clinical research (28).

Current State of Engagement in ICU Patient Care and Research

Engagement in critical care is a relatively recent phenomenon, but there is a growing

body of literature on this topic. Olding and colleagues systematically reviewed 124 studies of patient and family engagement in ICU care (61 quantitative, 61 qualitative, and 2 mixed-methods) and identified cross-sectional surveys (45 [73.8%]) to be the most common study design (29). Studies were published in nursing ($n = 79$) and critical care ($n = 32$) journals and primarily characterized family involvement by five facets: being present, being supported, participating in communication, contributing to care, and sharing in decision-making. Studies typically explored families as “recipients of care” rather than as “active participants in care” and focused on the relationship between families and nurses (29). Six qualitative studies directly evaluated the experiences or perspectives of nurses or patients (30–35). In a related systematic review, Haines and colleagues identified only four critical care studies that described either an organizational model of engagement or partnering with patients and families within organizations (education, infrastructure, or in a manner consistent with the highest intensity of engagement, “partnership and shared leadership” proposed by Carman and colleagues) (5, 36). On balance, the literature suggests support and enthusiasm for engagement; however, most studies of critical care engagement have focused on individual encounters (vs. involvement at an organization level), and direct assessments of patient experiences are scarce in number.

As early as 2001, Hanley and coworkers demonstrated that many clinical research centers in the United Kingdom involved citizens (patients and potential patients, caregivers, organizations representing consumers) in research (23 of 62 [37.1%]), or planned to in the future (17/62 [27.4%]) (37). They underscored the value of this input in refining research questions, improving the quality of information provided to patients, and ensuring that trials were relevant to patients’ needs (37). Notwithstanding, most engagement in ICU research has focused on establishing research priorities from the perspectives of research personnel and organizations (38–47). A systematic review of 70 studies evaluating stakeholder engagement in research noted that half of the studies engaged stakeholders as consultants and one-third engaged them as coinvestigators or coworkers (53). Stakeholders were engaged through surveys or interviews (15–20%) or as members of focus groups or

panels (20–30%) (53). The roles and activities of stakeholders were highly variable (53). Other authors found that stakeholder activities infrequently involve research evaluation and evidence dissemination and rarely include evidence synthesis or evidence integration or interpretation (53–55). Despite international guidance documents on engagement in research, few studies report how patients and families were engaged or demonstrated impact on the conduct and quality of the study (48–52).

Opportunities for Engagement to Improve ICU Patient Care and Research

We identify ways in which patient and family engagement may improve patient care and research in the ICU.

Promoting Patient and Family Involvement in Care Delivery

Engaging families in care can improve health literacy, self-care in chronic disease management, clinical decision-making, and patient safety (56). In the ICU, this has been associated with improved caregiver psychological recovery and well-being (57), reduced post-traumatic stress disorder and depression (58), and increased satisfaction with care (59, 60). However, ICU clinicians may underestimate family interest in participating in the delivery of care. In one survey, 97% of families reported a high level of interest in participating in bedside rounds, including shared decision-making. Conversely, less than one-third of clinicians predicted this response (61). A survey of 78 French ICUs found that roughly one-third of family members would be willing to assist the ICU team in bedside care (62). These findings, however, may not be generalizable to all families or reflect the views of clinicians in different practice settings. Furthermore, not all families may be empowered to request to participate in patient care. To address this disparity, some ICUs have developed activity menus to guide family engagement in patient care (63).

Supporting Patients' and Families' Involvement and Influence in Decision-Making

At the individual level, patients and families most often engage with healthcare providers by stating their preferences, goals, and

values during shared decision-making (64). Recognizing the complex relationships and dynamics that exist between patients, families, and the multiprofessional ICU staff involved in patient care, special consideration is needed to ensure that patients and families have a clear understanding of the available care options to engage in decision-making (65). By imparting medical information in a nonthreatening manner when requesting and integrating patients' and families' preferences, decision aids have emerged as tools that may facilitate shared decision-making (66, 67).

At a system level, patient and family advisory councils, in which patients and families formally partner with healthcare teams on practice and policy decisions, have emerged to increase patient and family influence on ICU organization and policies (5, 36, 68). Many of these groups have published their accounts of these experiences to foster stakeholder engagement in other ICU settings (5, 68–70). Depending on the scope of the mandate of a patient and family advisory council, patient and family engagement in decision-making may require resources and a significant advisory time commitment (approximately 4–15 h/mo) (53, 69). By addressing gaps in the process, decision aids and patient and family advisory councils may enable shared decision-making.

Providing Novel Ideas in Patient Care and Research

Patients and families can provide innovative ideas about care and research. Experience-based codesign provides strategies to partner with patients and families for quality improvement in clinical care (71). In contrast to patient and family advisory councils, evidence-based codesign collects a broad range of experiences within a health service, often through discovery interviews with important stakeholders, identifies key moments that affect their experiences, and engages stakeholders in designing new strategies to improve their experiences (71, 72). As opposed to functioning in a more passive advisory role, codesign ensures that patients and families actively develop novel solutions with healthcare teams. Toolkits for evidence-based codesign have been developed and adapted for specific settings, including the Emergency Department (73) and ICU (74). As an alternative approach, two British ICUs have identified 48 service improvements

at 40% of the cost of traditional evidence-based codesign using a national audio and video archive of patient experiences in place of discovery interviews with local patients (74).

PCORI-funded researchers have also shown that patients and families can provide novel ideas and observations that inform study design, methods, and outcome selection (25). At PCORI, members of the public can also identify important research questions through a web portal. These questions are subsequently filtered through a process that can influence projects that are ultimately funded (75). Reports detailing how patient and family advisory councils have contributed to randomized trial design and implementation in the ICU are beginning to emerge (76).

Aligning Care and Research Agendas with Patients' and Families' Needs

Patient and family engagement in research is a clear mandate of funding agencies such as PCORI and Canadian Institutes of Health Research—Strategy for Patient-Oriented Research as a mechanism to enhance the accountability of research investments (28, 77). Traditionally, researchers have posed questions that address clinical issues and report metrics relevant to the scientific community. With research funded by taxpayer dollars, investigators are increasingly being challenged to demonstrate that their proposals address research questions that are important to patients and families and report outcomes that are meaningful to them. By ensuring relevance to the patient and family, engagement is one strategy that may facilitate reform of our current critical care research paradigm.

Practical and standardized processes for bringing patients, families, and researchers together have been described by PCORI and the James Lind Alliance (JLA) (25, 28, 78). Priority setting aims to ensure that research questions are both relevant to and driven by patient needs and interests. The JLA approach to priority setting focuses on identifying uncertainties in clinical care (as opposed to specific research questions), assists stakeholders to find common ground, and reduces the technical and methodologic expertise required of participants (44, 79). Using JLA methodology, a priority-setting partnership engaged 21 clinicians, patients, and family members over 15 months to establish

priorities for future ICU research in the United Kingdom (80). This approach contrasts with processes that retain “expert panels” (excluding patients and family members) and decision-making authority (38–41, 43). Engagement in priority setting may also occur at the local level. To identify opportunities to improve ICU research, investigators in Alberta, Canada hosted a 3-hour Cafe Scientifique at a public venue with members of the public, patients, families, and healthcare providers (47). Stakeholders identified three areas of concern, including ICU provider well-being, communication, and the need for greater public engagement in healthcare decisions (47). This process showed that consensus-building activities can also integrate patient and provider priorities into health care and identify areas for future quality-improvement work (47, 78).

Patient and family engagement may also enhance accountability by improving the conduct, transparency, and efficiency of clinical research. To this end, a systematic review found that engaging patients in research improved patient enrollment and retention in clinical studies (81). Enhanced recruitment and retention rates, in turn, increase study feasibility, efficiency, and the probability that research investments yield useful knowledge (82, 83). Despite increased focus on standards for patient and family engagement in research, there is little guidance regarding which engagement strategies have the greatest potential to favorably affect research processes (5, 84).

Challenges

Willingness to Engage

“Willingness to engage” can be considered from the perspective of patients, families, and ICU practitioners. One study found that visitors of pediatric (vs. adult) patients were more confident that their involvement would impact care and research and were more likely to engage (85). These findings suggest that a gap exists between the perceived importance of engagement in care and research and willingness to participate and that this gap may be larger in the adult (vs. the pediatric) ICU context. There are several plausible explanations for this finding. First, engagement may require that the topic be familiar or personally meaningful to participants. For this reason, engagement is both better developed and

more active in areas of health services research with which patients have greater familiarity, such as mental health, physical and learning disabilities, pediatrics, pregnancy, child birth and care, cancer, geriatrics, and palliative care (86, 87). In contrast, most citizens are not familiar with the ICU. Even for individuals acquainted with the ICU, it typically does not have a continued presence in their lives. Second, physical and cognitive deficits and comorbidities that exist after ICU discharge may impede participation of ICU survivors and their family members (18, 19). Third, patients and families may suffer emotional or psychological sequelae and may be reluctant to revisit their experiences while striving to distance themselves from the ICU (20, 85) or may not wish to engage (65). Patients’ and families’ prior healthcare experiences, and comfort with and ability to participate, likely exist on a spectrum with regard to the novel circumstances induced by patient and family engagement, and clinicians should strive to use a personalized (patient and family centered) approach when engaging them. Clinicians may also hold differing views regarding engagement. In a cross-sectional study of the attitudes of healthcare providers toward family presence at bedside rounds, nurses, especially more senior, expressed the greatest reservation (88). McConnell and colleagues identified multiple factors (attitude toward engagement, experience, the need to be perceived as doing their job, reluctance to perform care duties in front of relatives) that influence nurses’ willingness to have family members participate in care (89).

Patient, Family, and Organizational Barriers to Participation

Several authors have highlighted the mismatch that exists between espousing favorable attitudes toward participation and actual participation (65, 90, 91). In a study of 2,754 caregivers and 544 family members in 78 ICUs, Azoulay and colleagues identified several predictors of family participation in care, including factors related to the patient (lower illness severity, longer ICU stay), burden experienced by families (depressive symptoms), and their desire for information (more time for information) (62). In a mixed-methods study of 70 ICU nurses in Australia, McConnell and coworkers identified several barriers to family involvement in care, including patient-related (patient status,

use of invasive technology, privacy, ICU length of stay), family-related (personality traits, vulnerability), environment-related (space, workflow interruption, difficulty explaining care delivery processes), and legal (injury to relatives) barriers (89). Others have identified the negative impact that anxiety (58.5%) and depression (26.2%) can have on family participation (91) and highlighted the potential role for “supported participation,” especially by bedside nurses, to favorably influence participation in care (92). In an interviewer-administered questionnaire of 202 visitors to three adult ICU and one pediatric ICU waiting room, Burns and coworkers found that, although visitors in both settings identified similar facilitators (enhancing care of current/future patients, opportunity to give back and to communicate with healthcare providers) and barriers (personal/family/professional commitments, distance, coordinating meetings, knowledge) to participation in care and research, they prioritized them differently (85).

Risks to Patients, Families, and Clinicians

Engagement is not without risks (4, 36). These include the psychological risks to patients and families related to sharing or reflecting on personal experiences (e.g., embarrassment, feeling that time and effort are wasted, disappointment if recommendations are not acted on, post-traumatic stress disorder, and depression) and risks to the physician–patient relationship (e.g., being critical of the care received) (4, 36, 53, 93, 94). Some patients and families may feel pressured to participate in engagement activities as a way of expressing their gratitude to clinicians for the care they received and may be willing to accept a mild degree of personal discomfort or inconvenience to contribute to the welfare of others (36). Others may be overwhelmed by technical terms or have difficulty overcoming cultural differences between stakeholders and researchers (53). For clinicians, engaging families in bedside rounds has the potential to alter communication practices within interprofessional teams in both positive (e.g., focusing on the patient and his/her goals) and negative ways (e.g., reducing the medical education provided to the team, prolonging rounds, and constraining delivery of undesirable information) (88).

Engagement may also pose risks to research. Patients and family members

typically lack proficiency in physiology, pathology, therapeutics, and knowledge related to processes of care and research, and tensions may arise from the asymmetry in expertise and experience that exists between clinical and nonclinical stakeholders. These tensions raise questions regarding how researchers can best acknowledge, respect, and integrate the views of nonclinical stakeholders while simultaneously respecting clinicians' training and knowledge during study design and implementation. Institutional review boards may also have concerns regarding the potential risks posed to stakeholders by engagement in research, and these concerns may hinder the approval process (53).

Avoiding Tokenism

Tokenism is the practice of making perfunctory or symbolic efforts to engage patients or communities (95). A common practice in this field, tokenism creates a new obstacle to studies of the value and impact of patient and family engagement (96). Publications have highlighted the need for early stakeholder involvement to ensure meaningful impact (97), sincerity on the part of healthcare providers to enhance participant retention and satisfaction (98), and longitudinal interaction to translate findings into practice (95). Hahn and colleagues collated and compared engagement practices using the collective experiences of approximately 50 patients,

clinicians, and academic researchers into three domains (methods, structure of engagement, and intent/relationship building) (95). Genuine (versus tokenistic) engagement was characterized by sincerity of intent, a desire to build trusting and enduring relationships, and a commitment to seek and use patients' experiences.

Participant Remuneration

To demonstrate the value of engagement, clinicians and researchers may compensate participants for their time. Several authors have noted that funding constraints (limited funding mechanisms, compensation for time and workload) pose a barrier to engagement for patients, families, and

Table 1. Strategies for Optimizing Patient and Family Engagement in the ICU

Consideration	Guidance from the Literature
Who should be engaged?	<p>Consider the 7 Ps Framework for Stakeholder Engagement, including patients (or the public), providers, purchasers, payers, policy makers, product makers, and principal investigators (55). For research, determine who should be involved by asking four questions: 1) What topic(s) does the research address? 2) What healthcare decision(s) is the research meant to inform? 3) Who are the decision-makers responsible for these decision(s)? 4) Who are the individuals and groups affected by these decisions? (55)</p> <p>Avoid limiting engagement to those who are self-selected, exclusively white, or from one culture or linguistic background (104). Intentionally engage individuals of different ages, sexes, and socioeconomic backgrounds (36, 80).</p> <p>Recognize that ICU survivors may have limited recall and that both ICU survivors and family members are "hard to reach" populations that may not be broadly representative (79, 80).</p> <p>Recognize that preference during engagement may be given to cooperative, "favorite," or previously/currently engaged patients, which may skew input (4).</p>
In what way should we engage?	<p>Consider several mechanisms for engaging stakeholders, including focus groups, surveys, computer games, electronic portals, a modified Delphi process, concept mapping, and asynchronous web-based input (105, 106).</p> <p>Align the mechanisms of engagement with stakeholder preferences (55).</p> <p>Recognize that some stakeholders may prefer more time-sensitive activities (e.g., completing electronic surveys, comment cards, and questions on a website), whereas others may desire more in-depth engagement activities (e.g., committees that meet regularly) (85).</p>
How do we prepare for engagement?	<p>On the basis of the engagement mechanism being considered, assess the potential barriers for all involved parties. These may not be evident to clinicians or investigators (4, 89).</p> <p>Ask patients and families what they need to feel comfortable with engagement and to participate fully and how their needs could be addressed. For example, for conference attendees assign ambassadors to aid with preparation, use checklists for travel and appropriate accommodation, and conduct debriefing sessions (4).</p> <p>Consider microlevel mediators (e.g., development of people skills, development and management of team dynamics) and macrolevel mediators (e.g., quality of organizational infrastructures to support engagement) of successful engagement (96).</p> <p>Ensure researcher flexibility, trust between researchers and stakeholders, and a commitment from researchers and stakeholders to maintain contact and participation (53).</p>
How will we engage?	<p>Consider using a tool developed to facilitate and guide engagement activities (107, 108). Review features of successful engagement strategies (96) (Table 2).</p>
How will we determine if engagement is successful?	<p>Measure and report the impact of patient and family engagement on patient- and process-related outcomes (109–120).</p>
How will we report our engagement efforts?	<p>Describe how patients were engaged, the processes used to engage them, and engagement activities (48–53).</p>

clinicians (86, 99). This barrier may be particularly important in the early phase of research, when engagement may be most impactful (96). Recent publications suggest that even small amounts of remuneration can favorably impact engagement (100, 101). In a scoping review of 10 studies focused on parental engagement in health research, Shen and colleagues identified reimbursement and childcare provision as enablers of participation (102). For projects with limited funding, organizers may be challenged by balancing the need to provide sufficient remuneration to facilitate engagement while ensuring the feasibility of the project as a whole.

“Engagement Science” in the ICU

Despite the call for increased patient and family engagement, the science behind “how to engage” patients and families is not well developed. In one study, ICU visitors preferred to participate using time-efficient and convenient methods, including completing electronic surveys or comment cards and answering questions on a website, and few respondents wanted to participate as members of committees that met regularly (85). Moreover, visitors preferred to engage in specific activities (e.g., sharing experiences, interpreting change from their perspective) that were more intuitive and less factual or

intimidating. They prioritized engagement in preselected care activities (presence during rounds, communication) and research topics (prevention and recovery from critical illness) that were familiar and meaningful to them (85). Although adult visitors to ICUs preferred to engage in research by sharing personal experiences, pediatric visitors prioritized identifying outcomes of importance to patients and families (85). Outcomes research may be particularly important in pediatric critical care given the high prevalence of chronic illnesses and disabilities, the paucity of studies evaluating longitudinal outcomes, and greater uncertainty regarding recovery after critical illness (85, 103). In Tables 1 and 2, respectively, we provide an overview of how to engage patients and families and highlight strategies for successful patient and family engagement (96).

Demonstrating Impact and Effectiveness

Outside of the ICU, investigators have shown that research engagement can clarify objectives and trial design; develop research questions and user-friendly study information, recruitment strategies, and study summaries; and inform implementation and dissemination (109–111). In interviews with patients,

relatives, investigators, and managers (*n* = 48) involved in 28 trials, Dudley and colleagues found that engagement influenced how researchers thought about aspects of a trial. They highlighted two factors: early (vs. late) involvement and inclusion in capacities that were more likely to be impactful, such as a responsive (e.g., advisory groups) or managerial role (e.g., trial management) as opposed to an oversight role (e.g., Steering Committee) (112). Others also found that engagement improved the relevance of research to patient and family needs, enhanced mutual stakeholder learning, improved research adoption, and increased stakeholder trust in research and researchers (53).

Despite the apparent value of engagement, few practical data exist on how to measure its impact (109). Grading and coauthors proposed assessing the value of engagement using three metrics: 1) change/accountability, 2) effectiveness/quality/validity, and 3) partnership/respect/clarity (113). In a cross-case ethnographic comparison of experience-based codesign in two clinical pathways involving two trials, Boaz and colleagues identified a range of roles adopted by patients (*n* = 63) during and after four quality-improvement interventions. They noted that, although small in scale, patients and caregivers not only provided innovative ideas and solutions but also acted as catalysts for attitudinal and organizational change (114). Although engagement has been shown to have positive effects on health outcomes (115), patient safety (56, 116), quality of care (117), and healthcare costs (118, 119) in other settings, limited data exist to demonstrate whether similar benefits can be realized in the ICU (116, 120). Future ICU research should aim to explicate the impact that engagement activities have on both patient- and process-related outcomes.

Areas for Future Engagement Work in Critical Care

To advance patient and family engagement in the ICU, primary research is needed to:

1. Characterize current practices in patient and family engagement in ICU care and research and metrics for reporting its impact.

Table 2. Features of Successful Engagement Strategies

Level of Engagement	Successful Engagement Strategies
Individual level	Provide engagement support, education, and training for all team members, not limited to content but also including politics and policies Engage participants early in the process Prioritize, develop, and maintain team cohesion Enable personal development of participants, especially patient and family participants Provide appropriate education and support for participants Emphasize and support relationship development and building Promote clear reporting of engagement processes and outcomes
Organizational level	Are embedded into the culture of organizations and avoid tokenism Have intrinsic value Are proactive in integrating patients and families into policy, patient care, and research activities Are led by a clear vision (clear guidance on the purposes of engagement) and are supported by models of good practice and measurable standards Are supported by appropriate financial and nonfinancial resources from conception to completion Are endorsed and supported by institutions, research ethics committees, journals, and funders

2. Develop and validate tools and techniques to 1) support patient and family engagement in clinical care and research (53, 121), and 2) measure ICU-relevant engagement (7).
3. Develop strategies to personalize (identify families that do/do not wish to be engaged) and optimize engagement (maximize benefits and minimize risks).
4. Identify whether and what type of patient and family engagement activities inform decision-making and improve uptake of research evidence into practice (55).
5. Identify potential sources of bias (e.g., selection, recall, interpretation) and elucidate their impact on engagement processes and outcomes (122).
6. Assess the role of electronic communication portals and decision support tools in patient and family engagement (123, 124).
7. Optimize the balance between accessing digital health information to facilitate patient and family engagement and ensuring privacy (5, 125).
8. Expand the scope of engagement across the ICU care continuum, by including patients and families before ICU admission (e.g., outreach teams) and after discharge (e.g., rehabilitation and post-ICU care clinics).

Conclusions

The rationale for and mandate to strengthen engagement in ICU care and research is clear. Although associated with numerous opportunities, engagement in the ICU is encumbered by several challenges that are exacerbated by the unique experiences of critically ill patients and their families and the circumstances in which critical care clinicians provide care and conduct research. At present, enormous prospects remain to advance engagement across the continuum of ICU care and research. ■

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