



Patient and family engagement in patient care and research in Canadian intensive care units: a national survey

Engagement des patients et des familles dans les soins aux patients et la recherche dans les unités de soins intensifs canadiennes : un sondage national

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Abstract

Purpose While patient and family engagement may improve clinical care and research, current practices for engagement in Canadian intensive care units (ICUs) are unknown.

Methods We developed and administered a cross-sectional questionnaire to ICU leaders of current engagement practices, facilitators, and barriers to engagement, and whether engagement was a priority, using to an ordinal Likert scale from 1 to 10.

Results The response rate was 53.4% (124/232). Respondents were from 11 provinces and territories,

mainly from medical surgical ICUs (76%) and community hospitals (70%). Engagement in patient care included bedside care (84%) and bedside rounds (66%), presence during procedures/crises (65%), and survey completion (77%). Research engagement included ethics committees (36%), protocol review (31%), and knowledge translation (30%). Facilitators of engagement in patient care included family meetings (87%), open visitation policies (81%), and engagement as an institutional priority (74%). Support from departmental (43%) and hospital (33%) leadership was facilitator of research engagement. Time was the main barrier to engagement in any capacity. Engagement was a higher priority in patient

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care vs research (median [interquartile range], 8 [7–9] vs 3 [1–7]; $P < 0.001$) and in pediatric vs adult ICUs (10 [9–10] vs 8 [7–9]; $P = 0.003$). Research engagement was significantly higher in academic vs other ICUs (7 [5–8] vs 2 [1–4]; $P < 0.001$), and pediatric vs adult ICUs (7 [5–8] vs 3 [1–6]; $P = 0.01$).

Conclusions Organizational strategies and institutional support were key facilitators of engagement. Engagement in patient care was a higher priority than engagement in research.

Résumé

Objectif Bien que l'engagement des patients et des familles puisse améliorer les soins cliniques et la recherche, les pratiques actuelles en matière d'engagement dans les unités de soins intensifs (USI) canadiennes sont inconnues.

Méthode Nous avons élaboré et administré un questionnaire transversal à l'intention des dirigeants des USI portant sur les pratiques d'engagement actuelles, les facilitateurs et les obstacles à l'engagement, ainsi que la priorisation de l'engagement, en utilisant une échelle de Likert ordinale de 1 à 10.

Résultats Le taux de réponse était de 53,4 % (124/232). Les répondants provenaient de 11 provinces et territoires, principalement d'USI médico-chirurgicales (76%) et d'hôpitaux communautaires (70%). L'engagement dans les soins aux patients comprenait les soins au chevet du patient (84%) et les tournées au chevet (66%), la présence pendant les interventions ou les crises (65%), et la complétion des questionnaires (77%). La participation à la recherche comprenait les comités d'éthique (36%), l'examen des protocoles (31%) et le transfert des connaissances (30%). Les facilitateurs à l'engagement dans les soins aux patients comprenaient les réunions familiales (87%), les politiques de visites ouvertes (81%) et l'engagement en tant que priorité institutionnelle (74%). Le soutien des directions de département (43%) et d'hôpital (33%) a été un facilitateur de l'engagement en recherche. Le temps était le principal obstacle à l'engagement à quelque titre que ce soit. L'engagement était une priorité plus élevée dans les soins aux patients qu'en recherche (médiane [écart interquartile], 8 [7–9] vs 3 [1–7]; $P < 0,001$) et dans les USI pédiatriques vs adultes (10 [9–10] vs 8 [7–9]; $P = 0,003$). L'engagement en matière de recherche était significativement plus élevé dans les USI universitaires vs autres (7 [5–8] vs 2 [1–4]; $P < 0,001$), et pédiatriques vs pour adultes (7 [5–8] vs 3 [1–6]; $P = 0,01$).

Conclusion Les stratégies organisationnelles et le soutien institutionnel ont été des facilitateurs clés de l'engagement. L'engagement dans les soins aux patients était une priorité plus élevée que l'engagement dans la recherche.

Keywords clinical care · engagement · research · survey

Meaningful patient and family engagement requires health practitioners and researchers to actively partner with patients, families, and organizations to advance care and research.¹ Although engagement may have positive effects on health outcomes,² patient safety,³ quality of care,⁴ and healthcare costs^{5,6} in other settings, limited data exist to show whether similar benefits can be realized in the intensive care unit (ICU).^{3,7}

Institutes such as the Strategy for Patient-Oriented Research of the Canadian Institutes of Health Research and the Patient-Centered Outcomes Research Institute fund engagement research to foster the science behind engagement, enhance the capacity of researchers to engage, and aid stakeholders in making informed decisions about engagement.^{8,9} Increasingly, to be eligible for funding, clinical research proposals must show meaningful engagement in study design, implementation, and knowledge translation. Engagement can provide new insights into research design and implementation, ensure a strong patient and family focus in research, and render research investments more accountable.^{10,11} It has even been shown that patients and families can become primary researchers with the ability to identify and improve understanding of the issues most important to them.¹²

The Canadian Critical Care Trials Group (CCCTG) is a multidisciplinary, investigator-led clinical research consortium dedicated to improving the care of critically ill patients through collaborative clinical research.¹³ One of the CCCTG's strategic directions is to proactively engage and partner with stakeholder groups, including patients and family members in Canadian adult and pediatric ICUs. In January 2015, members of the CCCTG, alongside ICU survivors and family members, formed the Patient and Family Partnership Committee (PFPC). The PFPC's purpose was to better understand current engagement practices in patient care, research, and knowledge translation; to identify opportunities for improved patient and family engagement within CCCTG; and, ultimately, to improve the health outcomes and experiences of patients and families in the ICU and pediatric intensive care unit (PICU). One gap identified by the PFPC was the lack of information on how patients and families are engaged in patient care and research in the 253 ICUs across Canada. To address this gap, the PFPC designed and conducted a cross-sectional survey to learn about current practices in engaging patients and families in ICUs across Canada.

Methods

Participant identification

We aimed to develop an exhaustive list of Canadian ICUs and PICUs, including academic and community hospitals. Two individuals (M. P.-A., M. V.) developed lists of ICU leads across Canada using a multimodal strategy (email, internet searches, and telephone with local, regional, and provincial colleagues in critical care). When identifying ICU leads, we sought individuals with a significant administrative/leadership role in the ICU, who would be able to speak to current clinical and research practices. In some instances, these self-reported individuals were physicians; in other cases, they were administrators from varied backgrounds.

Survey development

We used a systematic approach to questionnaire design and reporting.^{14–16} Research ethics approval was sought, but waived, by the Hamilton Integrated Research Ethics Board (Hamilton, Ontario, Canada).

Item generation, reduction, and formatting

Five investigators (K. B., S. O., E. M., S. D., O. S.) generated questions in two domains of patient and family engagement (patient care and research), in addition to demographic data depicting characteristics of hospitals, ICUs, and research personnel. The same investigators reduced items within domains to retain relevant items and reduce respondent burden.¹⁴ A research assistant formatted the questionnaire in both national languages (English and French) prior to administration. We included two gift cards of CAD 2 for a national coffee franchise (one for each of the patient care and research sections) as an incentive for survey completion with each questionnaire administered.

Questionnaire pilot and sensibility testing

We pilot tested the questionnaire with five intensivists (department heads or clinicians) to identify poorly worded or redundant questions and responses, and to assess questionnaire flow, salience, and acceptability.¹⁴ Subsequently, we assessed the clinical sensibility (comprehensiveness, clarity, and face validity) using a clinical sensibility tool customized for this questionnaire and the time required to complete the questionnaire (20 min) with four intensivists.¹⁴ We sought to achieve diverse responses (French, English, men, women, academic, community, pediatric, and adult intensivists) among pilot and clinical sensibility testers. The final questionnaire was

formatted in English and French and included 11 questions plus nine demographic questions with nominal, ordinal, and interval response formats (available as Electronic Supplementary Material [ESM] eAppendix).

Questionnaire administration

We sampled all identified Canadian ICUs (convenience sample) without formal sample size estimation. Prior to questionnaire administration, we sent prenotification e-mails (on 26 September 2019, and again on 12 November 2019, for e-mails that bounced back). We administered the initial questionnaire to critical care site leads on 25 November 2019, by post. Three volunteers (M. D. S., S. D., W. D. S.) created survey packages including a cover letter, paper questionnaire, prepaid addressed return envelope, and gift cards. Subsequently, we administered one electronic reminder to critical care site leads with a fillable PDF version of the questionnaire identical in appearance to the paper questionnaire (separated by approximately four weeks). We requested that the critical care site leads identify one individual in each ICU who could complete the patient care section (e.g., practice leaders, clinical lead managers, physician, or nurse leaders) and a second individual who could complete the research section (e.g., research manager/coordinator, physician, or nurse leader). We acknowledged that in certain clinical settings, the same individual may be best suited to complete both sections. The ICU demographic data section could be completed by either the individual completing the domain pertaining to engagement in patient care or research or the critical care chief/lead. Participation was voluntary and questionnaire completion implied consent to participate.

Statistical analyses

Using our list of potential respondent adult and pediatric ICUs in Canada, we planned to administer 232 questionnaires and aimed for a 50% response rate.^{17,18} We summarized binary and continuous data using counts, percentages, and medians with interquartile ranges [IQRs], where appropriate. Surveys with missing items were excluded from the denominator for that response. We used the Mann–Whitney U test to compare nonparametric continuous or ordinal data.

In subgroup analyses, we compared whether engagement was a priority in clinical care and research (responses to Q1 and Q6, respectively), based on practice setting (academic and community hospital with a university affiliation *vs* community hospital without a university affiliation), type of ICU (adult *vs* pediatric), presence of dedicated research personnel (full- or part-

time), and presence of a dedicated individual for promoting and supporting engagement. We used the rank biserial correlation test to identify factors associated with engagement as a priority in patient care and research, wherein Somers' delta (range, -1 to +1) provides the strength of the correlation between each factor (dichotomous variable) and engagement priority (ordinal variable). For example, an independent variable that had a statistically significant *delta* of 0.44 on engagement in research improves the accuracy of predicting engagement in research as a priority by 44%. All analyses were conducted in IBM SPSS Statistics for Windows, Version 26.0. (IBM Corp., Armonk, NY, USA).

Results

We analyzed results from 124 questionnaires for a response rate of 124/232 (53.4%). Table 1 presents the characteristics of the respondent ICUs.

Patient and family engagement in patient care

Respondents rated patient and family engagement to be a strong priority (median [IQR], 8 [3–10]), especially in pediatric *vs* adult ICUs (Figure). With regard to individual patient experiences, engagement activities most often included family participation in care activities (103/124; 83%), family access to tools to help staff learn about patients (95/124; 77%), experience surveys (95/124; 77%), participation in medical rounds (82/124; 66%), and family presence during procedures/crises (81/124; 65%). Less frequently, patients and families were invited to participate in post-ICU support groups (24/124; 19%). Beyond the individual patient experience, engagement activities included committee participation (58/124; 47%), feedback on policies or procedures (55/124; 44%), participation in focus groups or community consultation panels (53/124; 43%), and creation/review of educational materials (50/124; 40%). Less often, these activities included participation in space planning/design (39/124; 31%), staff education (15/124; 12%), and staff hiring panels (15/124; 12%).

Routine family meetings (103/119; 87%), open visitation policies (99/122; 81%), and engagement as an institutional priority (89/120; 74%) were identified as key facilitators of engagement in patient care. Conversely, availability of time (53/121; 44%), nurse staffing levels (46/120; 38%), multidisciplinary staffing levels (43/121; 36%), and the physical layout of the ICU (38/122; 31%) were key barriers to patient care. We present facilitators and barriers to patient and family engagement in patient care in Table 2.

Patient and family engagement in research

Respondents rated patient and family engagement in research to be a significantly lower priority than engagement in patient care (median [IQR], 3 [1–10] *vs* 8 [7–9]; $P < 0.001$). Only a quarter of sites (33/124; 27%) surveyed had research projects underway in their ICU/PICU and few sites (33/124; 27%) acknowledged having dedicated research personnel. Engagement in research most involved participation on research ethics boards (43/124; 36%), protocol development/review (37/124; 31%), knowledge transfer activities (36/124; 30%), development/review of research materials (33/124; 27%), community consultation panels (31/124; 26%), teleconferences (29/124; 24%), and development/review of consent forms (26/124; 22%). Less often, research engagement involved patient and/or family members as steering committee members (25/124; 21%), in priority setting (23/124; 19%), in data collection/analysis (21/124; 17%), as research committee members (19/124; 16%), as coapplicants on grants or ethics applications (10/124; 8%), or as coauthors on manuscripts (7/124; 6%) (Figure).

Support from department leadership (52/120; 43%) and hospital leadership (39/120; 33%) was identified as key factor that facilitated research engagement. Conversely, availability of time (63/119; 53%), resources to reimburse participants for engagement activities (51/120; 43%), availability of personnel to engage with patients and families (49/120; 41%), and staff knowledge of “how to engage” (37/120; 31%) were identified as key barriers to research engagement. We depict facilitators and barriers to patient and family engagement in research in Table 3.

Subgroup analyses

Engagement in patient care was a significantly higher priority in pediatric *vs* adult ICUs (median [IQR], 10 [9–10] *vs* 8 [7–9]; $P = 0.003$). Engagement in research was significantly higher in academic *vs* other ICUs (7 [5–8] *vs* 2 [1–4]; $P < 0.001$), pediatric *vs* adult ICUs (7 [5–8] *vs* 3 [1–6]; $P = 0.01$), community ICUs affiliated *vs* not affiliated with a university (3 [1–7] *vs* 2 [1–3]; $P = 0.04$), and in ICUs with dedicated research personnel *vs* no dedicated research personnel (8 [5–8] *vs* 2 [1–4]; $P < 0.001$).

Rank biserial correlation analyses

We identified several engagement activities and strategies that were associated with patient care being perceived as a priority at participating ICUs (ESM eTable 1). Delta scores were highest for seven engagement practices in patient care, comprising family presence in medical rounds (0.33;

Table 1 Respondent ICU characteristics

ICU characteristics (<i>N</i> = 124)	<i>n</i> /total <i>N</i> (%)
Location	British Columbia, 16/124 (13%) Alberta, 8/124 (6%) Saskatchewan, 9/124 (7%) Manitoba, 4/124 (3%) Ontario, 45/124 (36%) Quebec, 20/124 (16%) New Brunswick, 6/124 (5%) Nova Scotia, 5/124 (4%) Prince Edward Island, 2/124 (2%) Newfoundland and Labrador, 8/124 (6%) Territories, 1/124 (1%)
Hospital type	Community hospital with university affiliation, 61/124 (49%) Community hospital without university affiliation, 26/124 (21%) Academic hospital, 37/124 (30%)
ICU type	Medical surgical, 93/122 (76%) Pediatric, 10/122 (8%) Step-down ICU, 3/122 (2%) Trauma/neurotrauma, 2/122 (2%) Other (medical only, cardiovascular only, neurosciences only), 14/122 (12%)
ICU collects patient experience measures	Yes, 89/123 (72%) No, 30/123 (24%) Don't know, 4/123 (3%)
Individual responsible for supporting engagement?	Yes, 26/122 (21%) No, 90/122 (74%) Don't know, 6/122 (5%)
Dedicated research personnel	Yes, 33/121 (27%) No, 88/121 (73%)
Funding to support engagement in patient care	No, 99/121 (82%) Foundations or donations or charities, 15/121 (12%) Health care institution, 7/121 (6%) Local funds, 7/121 (6%) Federal/provincial research funding agency, 3/121 (2%) Research center, 3/121 (2%)
Funding to support engagement in research	No, 103/124 (84%) Foundations or donations or charities, 8/124 (7%) Federal/provincial research funding agency, 7/124 (6%) Research center, 7/124 (6%) Health care institution, 4/124 (3%) Local funds, 3/124 (2%) Industry, 1/124 (1%)

ICU = intensive care unit

$P = 0.007$), patient and family participation in education for staff and in space planning and design (0.46; $P = 0.005$ and 0.40; $P < 0.001$), patient and family feedback on policies or procedures (0.35; $P = 0.001$), engagement as an institutional priority (0.33; $P = 0.04$), ICU culture (0.40;

$P < 0.001$), and existence of an open visiting policy (0.35; $P = 0.01$). We identified many research engagement activities and strategies that were significantly associated with research being perceived as a priority in the ICU (ESM eTable 2).

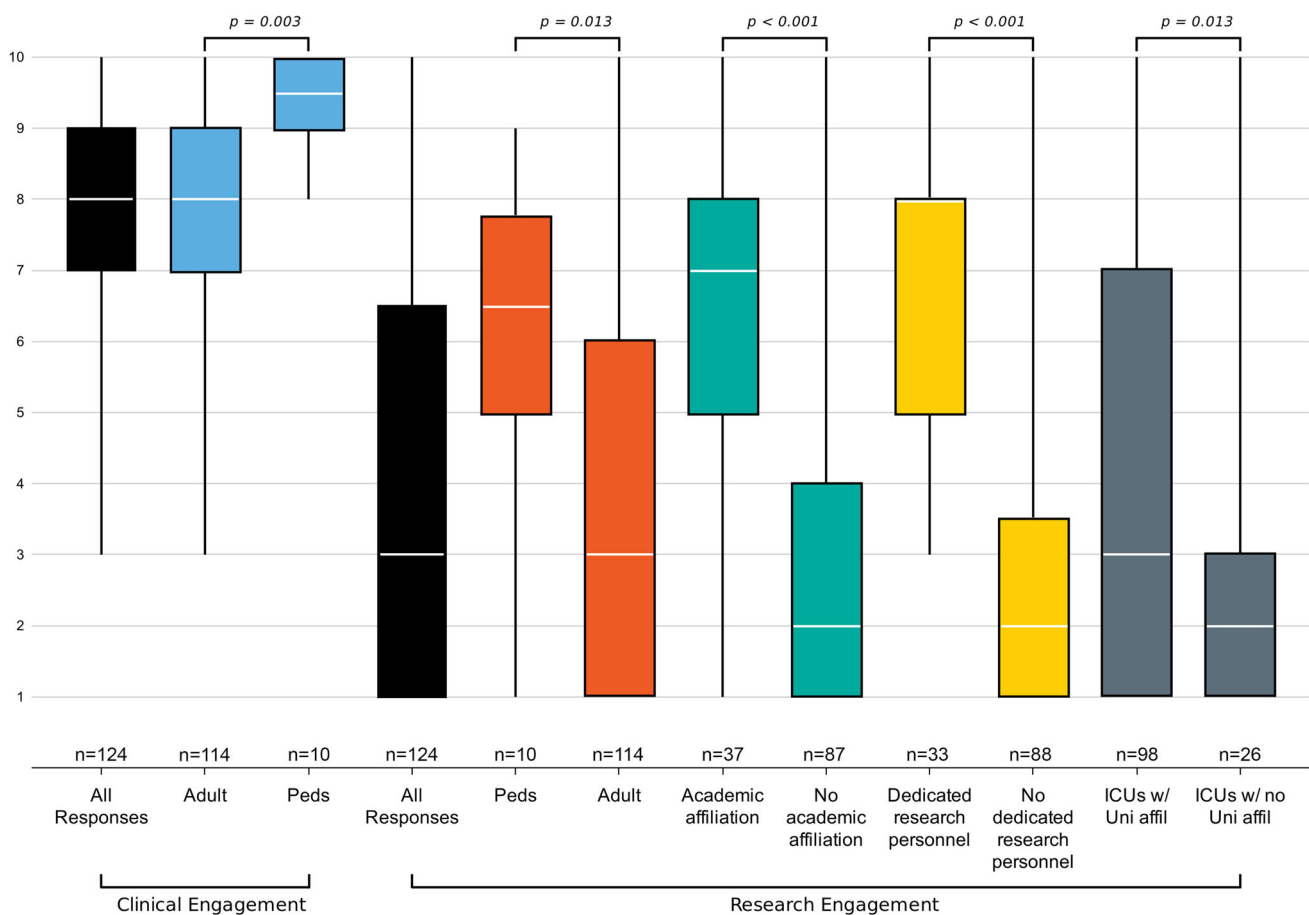


Figure Difference in engagement practices in patient care and research. The Likert scale for priority is depicted on the y-axis. The overall priority scores for engagement in patient care and research are illustrated in black candlesticks. The colored candlesticks represent engagement in patient care in adult vs pediatric ICU (light blue) and engagement in research in adult vs pediatric ICU (orange), ICUs with academic affiliation vs no academic affiliation (teal), ICUs with dedicated research personnel vs none (yellow), and ICUs with

university affiliations vs none (gray). The white line traversing each candlestick represents the median, the body represents the interquartile range, and the wicks denote the minimum and maximum.

Affil = affiliation; ICU = intensive care unit; Uni = University

Discussion

Despite the call for increased patient and family engagement in patient care and research, the science behind how to engage patients and families is not well developed in critical care.¹⁹ Similar to a previous study, we found that engagement activities in patient care may be driven by ICU priorities (presence during rounds or procedures/crises, use of communication aids, and survey completion).²⁰ Similar to others, we noted substantial variation in engagement practices across ICUs.²¹ We also found that patient care engagement activities occurred at the patient level (as described above) and at the organizational level.¹⁹ Engagement activities at the organizational level included participation in focus groups or as members of community consultation panels, cocreation and review of educational materials, and

provision of feedback related to policies and procedures. We identified that patients and families were possibly less engaged in postdischarge support groups in adult (vs pediatric) ICUs. At the organizational level, we identified three key facilitators of engagement in patient care: routine family meetings, open visitation policies, and engagement being an institutional priority. Similar to others, we found that family presence in the ICU was a key facilitator of engagement in patient care²² and that patient and family time was an important barrier to participation in care.¹⁹ An international qualitative study of clinicians previously highlighted the importance of having a strong commitment from leadership to successful patient and family engagement.²³ Similarly, we identified that nurse and multidisciplinary staffing levels and the physical layout of the ICU were barriers to engagement in patient care, possibly because they reduced interactions between

Table 2 Facilitators and barriers to patient and family engagement in patient care

Variable	Facilitator	Neither facilitator nor barrier	Barrier	Unsure or N/A
Regular/routine family meetings, <i>n</i> /total <i>N</i> (%)	103/119 (87%)	10/119 (8%)	3/119 (3%)	3/119 (3%)
Existence of open visiting policy, <i>n</i> /total <i>N</i> (%)	99/122 (81%)	8/122 (7%)	10/122 (8%)	5/122 (4%)
Engagement is an institutional priority, <i>n</i> /total <i>N</i> (%)	89/120 (74%)	23/120 (19%)	1/120 (1%)	7/120 (6%)
Engagement practices of health disciplines, <i>n</i> /total <i>N</i> (%)	80/121 (66%)	32/121 (26%)	7/121 (6%)	2/121 (2%)
Family presence on rounds, <i>n</i> /total <i>N</i> (%)	80/124 (65%)	19/124 (15%)	8/124 (6%)	15/124 (12%)
Team-family dynamics, <i>n</i> /total <i>N</i> (%)	77/121 (64%)	31/121 (26%)	7/121 (6%)	6/121 (5%)
Engagement practices of attending physicians, <i>n</i> /total <i>N</i> (%)	76/121 (63%)	29/121 (24%)	16/121 (13%)	0/121 (0%)
Family participation in direct physical care of patients, <i>n</i> /total <i>N</i> (%)	75/120 (63%)	30/120 (25%)	4/120 (3%)	11/120 (9%)
Unit culture, <i>n</i> /total <i>N</i> (%)	73/122 (60%)	25/122 (20%)	22/122 (18%)	2/122 (2%)
Engagement practices of front line nurses, <i>n</i> /total <i>N</i> (%)	69/121 (57%)	30/121 (25%)	9/121 (7%)	13/121 (11%)
Existence of tools to convey personalized patient information, <i>n</i> /total <i>N</i> (%)	65/122 (53%)	21/122 (17%)	7/122 (6%)	29/122 (24%)
Institutional guidelines for engagement exist, <i>n</i> /total <i>N</i> (%)	63/120 (53%)	25/120 (21%)	4/120 (3%)	27/120 (23%)
Team morale, <i>n</i> /total <i>N</i> (%)	61/121 (50%)	44/121 (36%)	16/121 (13%)	0/121 (0%)
Family presence during procedures, <i>n</i> /total <i>N</i> (%)	60/122 (49%)	30/122 (25%)	13/122 (11%)	19/122 (16%)
Physical layout/space of ICU, <i>n</i> /total <i>N</i> (%)	58/122 (48%)	23/122 (19%)	38/122 (31%)	3/122 (2%)
Existence of organizational champions, <i>n</i> /total <i>N</i> (%)	56/118 (47%)	24/118 (20%)	3/118 (3%)	35/118 (30%)
Staff knowledge about engagement, <i>n</i> /total <i>N</i> (%)	51/117 (44%)	40/117 (34%)	26/117 (22%)	4/117 (3%)
Existence of unit-based champions, <i>n</i> /total <i>N</i> (%)	45/121 (37%)	25/121 (21%)	12/121 (10%)	39/121 (32%)
Physician staffing levels, <i>n</i> /total <i>N</i> (%)	41/120 (34%)	53/120 (44%)	22/120 (18%)	4/120 (3%)
Nurse staffing levels, <i>n</i> /total <i>N</i> (%)	37/120 (31%)	36/120 (30%)	46/120 (38%)	0/120 (0%)
Availability of time, <i>n</i> /total <i>N</i> (%)	36/121 (30%)	32/121 (26%)	53/121 (44%)	0/121 (0%)
Health disciplines staffing levels, <i>n</i> /total <i>N</i> (%)	31/121 (26%)	43/121 (36%)	43/121 (36%)	4/121 (3%)
Patient acuity levels, <i>n</i> /total <i>N</i> (%)	24/120 (20%)	68/120 (57%)	27/120 (23%)	1/120 (1%)
Availability of resources to reimburse patients and families, <i>n</i> /total <i>N</i> (%)	21/116 (18%)	14/116 (12%)	25/116 (22%)	56/116 (48%)

ICU = intensive care unit; N/A = not applicable

clinicians and families. McConnell *et al.* identified classified barriers to engagement in care as being 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).²⁴ Our facilitators and barriers were similar to those noted in a national collaborative of 63 ICUs, which found that purposeful, sustained, multimodal approaches to patient and family engagement not only increased opportunities for family participation in care but also enhanced family satisfaction with quality of care and decision-making.²⁵ The association between engagement activities and the priority of engagement within the ICU may be two-way; while importance of engagement facilitates adoption of engagement practices, the visibility of engagement practice may enhance perceived importance.

Contrary to a previous study of ICU visitors, which identified that families preferred time-efficient and convenient engagement methods,¹⁹ we found that ICUs most often engaged patients and families in research through participation on research ethics boards, in protocol development/review, and knowledge translation—activities requiring substantial time and commitment. Intensive care units less often engaged patients and family members in priority setting, data collection, and analysis, as coapplicants on grants or authors on manuscripts, and as members of steering or research committees. These findings align with those of a systematic review of 70 studies evaluating stakeholder engagement in research, which found that while half of included studies engaged stakeholders as consultants, only a third of studies engaged stakeholders as coinvestigators or coworkers.²⁶ Others have noted that stakeholder activities infrequently involved research evaluation and dissemination, and rarely

Table 3 Facilitators and barriers to patient and family engagement in research

Variable	Facilitator	Neither facilitator nor barrier	Barrier	Unsure or N/A
Level of support for engagement from departmental leadership, <i>n</i> /total <i>N</i> (%)	52/120 (43%)	37/120 (31%)	10/120 (8%)	21/120 (18%)
Level of support for engagement from hospital leadership, <i>n</i> /total <i>N</i> (%)	39/120 (33%)	38/120 (32%)	21/120 (18%)	22/120 (18%)
Level of staff experience with engaging patients and families, <i>n</i> /total <i>N</i> (%)	30/120 (25%)	34/120 (28%)	34/120 (28%)	22/120 (18%)
Staff knowledge about how to engage with patients and families, <i>n</i> /total <i>N</i> (%)	26/120 (22%)	37/120 (31%)	37/120 (31%)	20/120 (17%)
Availability of patients and families to engage, <i>n</i> /total <i>N</i> (%)	26/120 (22%)	47/120 (39%)	25/120 (21%)	22/120 (18%)
Engagement as a priority in research in our department, <i>n</i> /total <i>N</i> (%)	22/120 (18%)	33/120 (28%)	31/120 (26%)	34/120 (28%)
Availability of personnel to engage patients and families, <i>n</i> /total <i>N</i> (%)	20/120 (17%)	29/120 (24%)	49/120 (41%)	22/120 (18%)
Administrative support for patient and family engagement, <i>n</i> /total <i>N</i> (%)	19/114 (17%)	33/114 (29%)	20/114 (18%)	42/114 (37%)
Availability of time, <i>n</i> /total <i>N</i> (%)	10/119 (8%)	25/119 (21%)	63/119 (53%)	21/119 (18%)
Availability of resources to reimburse for engagement activities, <i>n</i> /total <i>N</i> (%)	6/120 (5%)	16/120 (13%)	51/120 (43%)	47/120 (39%)

N/A = not applicable

included evidence synthesis, integration, or interpretation.^{27,28} At the organizational level, we identified that staff knowledge of “how to engage” was a key barrier to engagement in research and that endorsement by departmental and hospital leadership was a key facilitator of research engagement. Similar to others, we noted that time, resources to reimburse participants for engagement activities,^{29–31} and availability of personnel to engage with patients and families were barriers to engagement in research. Publications suggest that even small amounts of remuneration^{32–34} and childcare provision³⁴ can favorably impact engagement.

Several additional findings from our survey warrant mention. Respondent ICUs in our study considered engagement in patient care to be higher priority than engagement in research. Most adult ICUs in Canada are community-based and are therefore likely to view patient and family engagement in research as a lower priority than engagement in patient care. These findings align with the current literature, which is heavily focused on engagement in patient care as opposed to research.¹⁹ Additionally, we identified that engagement in research was a higher priority in PICUs, academic ICUs, ICUs with dedicated research personnel, and community ICUs affiliated with a university. Research may be particularly important in pediatric ICUs because of the higher prevalence of chronic

illnesses, lack of longitudinal outcomes data, and greater uncertainty regarding outcomes.^{19,35} As well, PICUs in Canada are mostly affiliated with universities and thus have a mandate to conduct clinical research.

Our survey has several strengths. First, it is a large cross-sectional survey of patient and family engagement in community and academic ICUs, with responses that are well aligned with the composition of ICUs across Canada—nearly 70% of our respondents were from community ICUs, and we obtained responses from ICUs in ten Canadian provinces and one territory. Second, we identified separate facilitators and barriers to engagement in clinical care and research. Third, we had a satisfactory response rate for a multidisciplinary, cross-sectional survey.^{17,18} Our study also has limitations. First, our findings may not be generalizable to ICUs outside of Canada. Second, we administered our questionnaire prior to the COVID-19 pandemic, and the applicability of our findings to current practice is unknown. Notwithstanding, our study provides a baseline of engagement practices to which future studies can be compared. Third, the activities reported are “perceived” engagement, and there may be a disconnect between perceived and actual engagement, especially from the patient and family perspective. Lastly, as our sampling frame included all Canadian ICUs, we did not conduct any power calculations.

Statistically significant findings—especially in groups with very small numbers (e.g., PICUs), should be interpreted with caution.

Conclusions

In this national cross-sectional survey of ICUs, we found patient and family engagement in patient care was a higher priority than engagement in research, especially in pediatric vs adult ICUs. Research engagement was higher in academic ICUs, PICUs, ICUs with dedicated research personnel, and community ICUs affiliated with a university. Key facilitators of engagement in patient care included routine family meetings, open visitation policies, and identification of patient and family engagement as an institutional priority. Conversely, key barriers to engagement in patient care included time, staffing levels, and the physical layout of ICUs. Support from department and hospital leadership was identified as the main factor facilitating engagement in research. Conversely, time, resources to remunerate participants, availability of personnel to engage with patients and families, and staff knowledge were identified as key barriers to engagement in research.

Author contributions Karen Burns, Ellen McDonald, Sylvie Debigaré, and Simon Oczkowsky contributed to study design. Mikael Piche-Ayotte, Moises Vasquez, and Ellen McDonald contributed to the development of the respondent list. Karen Burns and Ellen McDonald contributed to questionnaire development and testing. Sylvie Debigaré, Ellen McDonald, Karen Burns, Mikael Piche-Ayotte, and Moises Vasquez contributed to questionnaire administration. Simon Oczkowsky contributed to data collection. Simon Oczkowsky and Nasim Zamir contributed to data analysis. Karen Burns, Ellen McDonald, Sylvie Debigaré, Simon Oczkowsky, and Nasim Zamir contributed to manuscript preparation. All authors approved the manuscript.

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