

1 **Title:** Family presence in Canadian PICUs pre- and during the COVID-19 pandemic: A cross-
 2 sectional survey of policy and practice

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31 Canadian Institutes of Health Research to examine the impact of restricted family presence policies in
32 pediatric intensive care units and strategies for optimizing policies and practices in the future.

33 **Keywords for Indexing:** 1. intensive care units, pediatric; 2. COVID-19/prevention and control; 3. visitors
34 to patients; 4. Caregivers; 5. Method, survey

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Confidential

37 ABSTRACT

38 **Background:** Despite broad adherence to values of family-centeredness, children's hospitals and the
39 pediatric intensive care units (PICUs) within them restricted family presence during the COVID-19
40 pandemic. The aim of this study was to describe the initial restricted family presence policies and
41 practices enacted in Canadian PICUs during the COVID-19 pandemic.

42 **Methods:** Cross-sectional survey of the clinical/operations manager and/or physician chief of all 19
43 administratively separate PICUs in Canada. Researchers administered the structured questionnaire in a
44 semi-structured manner via telephone or virtual technology to enable elaboration and allow for wide
45 variation in practice.

46 **Results:** All 19 Canadian PICUs were represented by 15 chiefs and 9 managers who participated from
47 August to December 2020. Reported pre-COVID-19 and pandemic-related policies and practices varied
48 between units, by patient COVID-19 status, and between manager and chief reports. Most pandemic-
49 related restrictions were designed and implemented in a top-down manner (89%) without input from
50 PICU stakeholders (70%). Pre-pandemic, all units reported 2 or more family members and a high degree
51 of flexibility for siblings, extended family, and visitors. Reported initial pandemic practices limited
52 presence to 1 (88% COVID-19 negative, 96% COVID-19+/suspect), or 2 adult support people with no
53 siblings (100%). Support person switches and in-hospital mobility were restricted, as was participation in
54 patient care rounds. All respondents noted the need for policy exceptions during end-of-life care; 58%
55 identified no initial policy/process for this. Reported policies and practices demonstrated responsiveness
56 during the study period.

57 **Interpretation:** Both pre- and COVID-19-related family presence policies in Canadian PICUs were
58 variable between centres. Restrictive, top-down policies limited family-centeredness of care, though
59 demonstrated responsiveness.

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61 INTRODUCTION

62 In response to the COVID-19 pandemic, hospitals worldwide implemented sweeping changes to
63 visitation policies. Although less restrictive than their adult counterparts, the impacts felt in children's
64 hospitals and pediatric intensive care units (PICUs) are likely still significant (1–3). The PICU is a
65 frightening environment for children and their parents, where the risk of death and long term morbidity
66 are ever-present (4,5) and the majority of deaths in Canadian children's hospitals occur (6). Recognizing
67 that family is central to a child's journey through critical illness (7), Canadian children's hospitals and
68 their PICUs have traditionally advocated for and broadly adopted family-centered care (8–13), though
69 policy and practice has not been previously described. From typical PICU practices of family participation
70 in care and 24/7 presence (14,15), the emergence of COVID-19 led to the rapid and prolonged adoption
71 of restricted family presence, following a largely utilitarian approach (16). While ethically justifiable at
72 the pandemic's outset (17,18), in the longer term these policies have potential for significant harm (19–
73 21).

74 As part of a national research program exploring the impacts of pandemic-related restricted family
75 presence we sought to understand the design, implementation, and practice of these policies. We
76 initially performed an environmental scan of hospital and PICU pre-pandemic and early pandemic
77 (March to May, 2020) websites that addressed family presence and visitation. The publicly accessible
78 information tended to be cursory and occasionally difficult to find. Although pre-pandemic information
79 often addressed sibling presence and sometimes sleeping arrangements, information early in the
80 pandemic tended to be distilled down to the number of family members enabled at one time; findings
81 supported by a recent study of the websites of 239 US children's hospitals (22). However, day-to-day
82 operations involve complex situations and decision-making beyond the number and type of enabled

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3 83 family members. Thus, we designed this study to describe the initial restricted family presence policies
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5 84 and practices enacted during the COVID-19 pandemic in PICUs across Canada. Our secondary objectives
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7 85 were to ascertain 1) pre-pandemic family presence policies, 2) the processes used to create and
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9 86 disseminate initial restricted family presence policies, 3) the processes used to determine need for and
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11 87 grant exceptions, and 4) policy and practice evolution.
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16 88 METHODS

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18 89 The Research Ethics and Institutional Review Board of IWK Health approved this study (REB #1025836).

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20 90 **Design:** Cross sectional survey with researcher-administered questionnaire using structured interviews.

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22 91 **Questionnaire development and content:** The study team (PICU clinicians, parent partners, healthcare
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24 92 administrator, PICU leadership, biostatistician) developed the questionnaire to understand policy and
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26 93 practice pre-pandemic, during the initial pandemic (March-May, 2020), and in evolution to the time of
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28 94 the interview through the following domains: family presence policy and practice; pandemic policy
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30 95 creation and dissemination; patient care rounds (“rounds”); intra-hospital mobility; and personal
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32 96 protective equipment (Questionnaire, Supplemental file 1). We developed items addressing each
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34 97 domain through an iterative process of creation, team feedback, and reduction/revision. We pre-tested
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36 98 the questionnaire with professionals adjacent to our target population (Supplemental file 2). Each
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38 99 interviewer practiced administering the questionnaire with 1-2 colleagues.
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42 100 **Participants:** JRF invited the physician chief/medical director (“chief”) and clinical/operations manager
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44 101 (“manager”) for all 19 administratively-separate PICUs in Canada to participate without incentive. We
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46 102 identified participants through professional networks, hospital directories, and personal
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48 103 communications and sent an e-mail invitation followed by 1 telephone and up to 3 e-mail reminders. All
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50 104 participants provided informed consent.
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53 105 **Structured Interviews:** JRF and LAL conducted and audio recorded the telephone or virtual interviews
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55 106 from August to December 2020 using the structured questionnaire in a semi-structured manner to
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3 107 enable elaboration and clarification. We hand-transcribed responses onto a data collection form
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5 108 without participant- or hospital-identifying information, sent participants their completed data
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7 109 collection form for response verification, then entered data into Microsoft Excel for analysis.

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10 110 **Analysis:** We used descriptive statistics to describe participants and PICUs. We reported nominal-level
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12 111 data with percentages. Where perceptions rather than actual or verifiable policy were solicited, we
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14 112 presented results for all respondents followed by the % agreement for the units with chief/manager
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16 113 dyad response.

17 18 19 114 RESULTS

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23 115 Fifteen chiefs (79%, 4 non-respondents) and 9 managers (47%, 10 non-respondents) from 19 (100%)
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25 116 Canadian PICUs in 17 hospitals agreed to participate (Table 1). For 5 (26%) units, both the chief and
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27 117 manager responded (interviewed within 2 weeks of one another).

28 29 118 **Pandemic Policy Creation:**

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32 119 *“Early on, this was not driven from the ground up, this was top-down.”*

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34 120 Most restricted family presence policies for pediatrics were designed at a hospital level (n=15, 79%),
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36 121 with 9 (47%) aligning with provincial mandates. Two hospitals followed regionally-generated policies
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38 122 (e.g., health zone, municipality) but enabled adaptation for pediatric units. PICU-specific policies were
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40 123 consistent with those of their children’s hospital in 17 units (89%), and were designed by PICU
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42 124 leadership in the remainder.

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44 125 The majority of PICU leaders did not perceive that they were consulted for hospital (79%) or PICU-
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46 126 specific (70%) policies. Four respondents (17%) from 4 different institutions (chief-manager agreement
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48 127 60%) perceived that families were consulted during design and implementation of overall children’s
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50 128 hospital policies. Regarding PICU-specific policies, two respondents (8%) from 2 institutions (chief-
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52 129 manager agreement 80%) perceived that PICU families were consulted.

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3 **130 Policy Dissemination:**
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5 **131** *“A big problem at the beginning was these e-mail changes – we would get changes*

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7 **132** *and updates on visitor restrictions – it was a big flurry at the beginning...”*
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10 **133** PICU leadership received policy information through one or a combination of leadership meetings (46%),
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12 **134** e-mails (46%), direct communication from hospital leadership (21%), or direct involvement in the
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14 **135** decision-making process (17%), though 8% reported learning about policies through media, websites, or
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16 **136** word of mouth.
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19 **137** PICU managers (47%), charge nurses (32%), and bedside staff (32%) generally bore responsibility for
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21 **138** informing families about the new policies at the pandemic outset. Ongoing communication to newly
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23 **139** admitted families occurred through posters, letters, and websites (79%); the PICU bedside nurse (67%);
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25 **140** and the point of first contact (e.g., emergency department or transport teams) (33%).
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28 **141 Policy and practice elements:**
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30 **142** *“You can’t just have a 3-year-old talking to their parent with an iPad. I mean, it’s not*

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32 **143** *going to work.”*
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34 **144** *“We are in a high risk environment. We need to protect our patients from each other. We*

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36 **145** *need to protect our families from each other And we need to protect our staff to ... be*

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38 **146** *able to show up to work.”*
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41 **147** Table 2 provides perceived policies and practices.
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43 **148** Pre-COVID-19 pandemic: All respondents conveyed that family presence was enabled 24/7, though 2
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46 **149** units did not allow family members to sleep at the bedside, and 3 units reported asking family members
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48 **150** to leave for rounds and handover discussions on children not their own. All units allowed non-family
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50 **151** member presence.
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52 **152** COVID-19 pandemic: Early in the pandemic (March to May 2020), all units enabled 1 to 2 support
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55 **153** persons at the bedside, though presence was limited to designated individuals with varying ability to
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3 154 switch with one another for all patients in all units, irrespective of COVID-19 status. Presence was
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5 155 enabled 24/7 in all but one unit, in which family presence was not allowed overnight. Restrictions
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7 156 changed through the pandemic as disease understanding and local epidemiology fluctuated.

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10 157 *“We had families in rooms in the very beginning while we did resuscitations, while*
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12 158 *we did procedures. We had them behind a screen wearing headphones....”*

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14 159 Family members, particularly for COVID-19+/suspected patients, experienced restrictions in ability to
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16 160 leave their PICU room or the hospital. Mobility restrictions resulted in novel problems including: 1.
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18 161 Support persons having to use a commode in patient rooms or a designated “COVID” bathroom 2.
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20 162 Support person unable to leave for cigarette breaks resulting in nicotine withdrawal, aggression to staff,
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22 163 and hospital provision of nicotine patches; 3. Lack of sleeping provisions requiring the support person to
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24 164 sleep in chairs; 4. Challenges with food provision for support persons resulting in hospital-supplied
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26 165 meals, bedside staff picking up delivery orders, and lack of access to culturally appropriate options.

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30 166 **Rounding practices:**

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32 167 Pre-pandemic, patient care rounds were universally adjacent to the bedside with active family
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34 168 participation. Pandemic-era rounding changes are outlined in Figures 1 and 2. Perceived early pandemic
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36 169 family participation changed for both non-COVID (42%, agreement 80%) and COVID+/suspected (74%,
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38 170 agreement 50%) patients (see Figures 1 and 2). Although some teams used alternate methods of
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40 171 communication (telephones, intercoms, and virtual technology), respondents from some units perceived
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42 172 that family members were unable to participate in rounds (26% non-COVID-19 [100% agreement] and
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44 173 43% COVID-19+/suspected [75% agreement]). Although 39% reported using virtual technology, it was
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46 174 not consistently to enable family member involvement. Despite evolution through the pandemic, 27% of
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48 175 participants reported that families of COVID-19+/suspected patients remained non-participatory (25%
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50 176 agreement) at the time of interview, though it is notable that there was poor agreement between the 4
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52 177 chief-manager pairs who provided a response.

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3 **178 Policy Exceptions:**
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5 179 *“COVID threw a wrench in our usual decision-making. It was almost like we didn’t know*
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7 *how to make any decisions for ourselves. And part of that was the reporting structure*
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9 *completely changed...I was asking questions of my director that I would normally make*
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11 *myself, but I had to get permission...”*
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14 183 All leaders expressed a need for policy exceptions during extenuating circumstances and at end of life. In
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16 184 the early pandemic, 42% of respondents indicated that exceptions were enabled by policy, while 17%
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18 185 stated that processes were understood though not formalized. Seven respondents (29%) described an
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20 186 evolving process as the need for exceptions was realized. Three (12%) respondents indicated no policy
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22 187 or formal process for exceptions at any time, with decision-making taken at the PICU level (agreement
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24 188 100%). Although most respondents were not aware of a list of acceptable reasons for exceptions (75%),
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26 189 all indicated that exceptions would be granted at the end of life. Reasons provided for granting
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28 190 exceptions are outlined in Figure 3.
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32 191 The process for granting exceptions varied between units. While bedside staff identified the need for
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34 192 individual exceptions in all units, final decision-making was perceived to be held outside the PICU - by
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36 193 hospital directors (n=8, 35%), infection prevention and control or emergency operations (n=6, 26%), and
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38 194 hospital executive (n=2, 9%) – more often than within (n=7, 30%) (agreement = 100%). However, 42%
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40 195 described the ability for PICU personnel to grant urgently needed exceptions (agreement = 80%).
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44 **196 INTERPRETATIONS**
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48 197 We present the first description of restricted family presence in PICUs during the COVID-19 pandemic.
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50 198 Though all Canadian critically ill children had at least one parent’s present, there were significant
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52 199 restrictions to family member presence and threats to family centered care. Inter-hospital policy
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54 200 variation existed pre-pandemic and marked variation in development, communication, implementation,
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3 201 and practice of pandemic-related policies existed even within the same hospital, city, or province.
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5 202 Importantly, there was clear consensus that families need access to critically ill children who are at end-
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7 203 of-life or high risk of death. While not all PICUs began the pandemic with such an approach in place,
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9 204 there was a high degree of responsiveness from healthcare organizations to the need for these
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11 205 exceptions.
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14 206 Though pediatric patients were spared the extreme restrictions faced by adult patients (23), restriction
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16 207 to 1-2 parents and exclusion of siblings and other members of a child's support circle is a deviation from
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18 208 the family centeredness of pre-pandemic Canadian children's hospitals (24). This has potential for
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20 209 negative impacts on mental health, decision-making, family functioning, and sibling adjustment
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22 210 (5,20,25–27). In models of FCC embraced by Canadian PICUs, family are seen as core members of the
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24 211 healthcare team, as well as vulnerable individuals experiencing trauma who are in need of care
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26 212 themselves (28). Mobility restrictions were a significant deviation from usual practices, and introduced
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28 213 novel issues around caring for family members; issues that, to our knowledge, have not been addressed
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30 214 in the existing literature. Several PICU leaders spoke of family members being restricted to their child's
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32 215 room, unable to leave even during traumatic events. PICU literature suggests that the rates of acute and
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34 216 post-traumatic stress in family members is already high (29,30); these practice changes may have
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36 217 worsened this morbidity. The widely implemented removal of family presence at rounds is in clear
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38 218 opposition to FCC principles (31) and may have impacted the ability of families to participate in
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40 219 decision-making and care; although a family member was allowed at bedside, they were no longer part
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42 220 of the team. Examination of the impacts of these practices on family members are needed.
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44 221 We revealed a concerning lack of participation of families, bedside healthcare providers, and PICU
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46 222 leadership in policy design and implementation. Such circumstances can create a situation of moral
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48 223 hazard, in which those who are empowered to parse risk and fashion responses (decision makers) are
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50 224 not those who suffer its burdens (decision bearers) (32). Most decisions regarding exceptions were
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3 225 made outside the PICU. This denotes a centralized approach that does not acknowledge the local and
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5 226 specialized needs of critically ill children and their families. Multiple chief-manager discrepancies were
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7 227 noted across eras. These discrepancies in the interpretation of multi-faceted family presence policies
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9 228 may be due to differences between leaders who do and do not work at the bedside – thus, policy and
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11 229 practice – or may reflect communication breakdowns, and underscore a need within organizations to
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13 230 ensure alignment between policy and practice. PICU leadership need a shared mental model with
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15 231 ongoing evaluation of family presence practice at the bedside within each unit (33,34). Inconsistency
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17 232 seen between leaders and between Canadian PICUs means families have unequal access to their
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19 233 critically ill child both at a baseline and during periods of restriction. Consensus on the essential
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21 234 elements of family presence policies, which can be used to guide policy in any context, should be a
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23 235 priority for the pediatric critical care community.
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27 236 Design and application of a family presence policy in PICUs requires balancing risks and benefits for the
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29 237 patient, their family, and the healthcare team. Thoughtful consideration of numbers, timing, mobility,
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31 238 access of extended family (e.g., siblings, grandparents), and access for family members with infectious
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33 239 symptoms must be balanced against infection control practices to protect both staff and other patients.
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35 240 Attention must be paid to provisions for sleeping, eating, and self-care (35–37). Centres require an
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37 241 upfront and flexible approach to policy exceptions (38) with provisions for deviation in extenuating
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39 242 circumstances from the outset (38,39). While the demands of the early pandemic required rapid policy
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41 243 change, it is imperative that future and ongoing policy be designed and implemented in a manner that is
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43 244 inclusive of stakeholder input (40) with an aim to optimize family centeredness.
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47 245 Study strengths include performing interviews during the pandemic to minimize recall bias, and
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49 246 representation from all Canadian PICUs creating a geographically diverse and complete sample.
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51 247 Interviewing allowed a more accurate and nuanced understanding of policy application and practice
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53 248 than would a paper/web-based survey. Our study was limited by self-report and perceptions of the PICU
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3 249 leadership. Lack of participation from all chiefs and managers limited interpretations of disparity. The
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5 250 level of disagreement in some responses may reflect variability in healthcare provider practice or
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7 251 discrepancies between actual versus reported implementation.
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10 252 *Conclusions:* Both pre- and pandemic-related family presence policies in Canadian PICUs were variable
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12 253 between centres. Initial COVID-19 restrictions universally limited family presence, and often restricted
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14 254 mobility and participation in decision-making and care activities without provision for extenuating
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16 255 circumstances, thus limiting family-centeredness of care, but showed responsiveness through the
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18 256 pandemic.
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22 23 24 258 ACKNOWLEDGEMENTS

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34 355 SUPPLEMENTAL DIGITAL CONTENT LEGEND

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37 357 **Supplemental File 1:** Questionnaire administered to PICU leadership virtually or by telephone
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39 358 **Supplemental File 2:** Survey development process
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Table 1: Description of Canadian PICUs

| Characteristic | Number (%) |
|---|------------|
| Hospital Type | |
| Stand-alone children's hospital | 5 (26%) |
| Children's Health within a larger, mixed hospital | 11 (58%) |
| Women's and Children's | 3 (16%) |
| PICU type | |
| Medical-surgical | 11 (58%) |
| Level 2 medical-surgical | 2 (11%) |
| Cardiac | 2 (11%) |
| Mixed medical surgical-cardiac | 6 (32%) |
| Bed number | |
| <10 | 5 (26%) |
| 10-19 | 10 (53%) |
| ≥20 beds | 4 (21%) |
| Ages admitted | |
| Birth to 16 | 2 (11%) |
| Birth to 17 | 3 (16%) |
| Birth to 18 | 14 (74%) |

Table 2: Reported family presence policy (all results in % respondents)

| Characteristic | Pre-pandemic practice | Initial pandemic practice | | Evolved pandemic practice at interview | |
|---|-----------------------|---------------------------|----------------------|--|----------------------|
| | | Non-COVID | COVID+/ suspected | Non-COVID | COVID+/ suspected |
| # at bedside | | | | | |
| One | 0 | 83% | 96% | 26% | 74% |
| Two strict | 25% | 17% | 4% | 74% | 26% |
| Two by policy, flexible practice | 50% | 0 | 0 | 0 | 0 |
| Unlimited | 25% | 0 | 0 | 0 | 0 |
| Agreement (% , number of pairs) | 40%, 5 | 80%, 5 | 100%, 5 | 100%, 5 | 60%, 5 |
| Switches to enable other parent's presence | | | | | |
| Unnecessary | 100% | 13% | 4% | 44% | 30% |
| Not allowed | N/A | 26% | 57% | 0 | 26% |
| Any time | N/A | 17% | 9% | 30% | 13% |
| At restricted times | N/A | 43% | 30% | 26% | 30% |
| Agreement (% , number of pairs) | 100%, 5 | 50%, 4 | 75%, 4 | 50%, 4 | 50%, 4 |
| Non-parent family and visitors may switch in | | | | | |
| Unnecessary as family and visitors unlimited | 25% | 0 | 0 | 0 | 0 |
| Not allowed | 0 | 92% | 92% | 58% | 88% |
| Any time | 54% | 4% | 4% | 25% | 8% |
| At restricted times | 21% | 4% | 4% | 17% | 4% |
| Agreement (% , number of pairs) | 40%, 5 | 100%, 5 | 100%, 5 | 40%, 5 | 80%, 5 |
| Sibling presence | | | | | |
| Unrestricted | 50% | 0 | 0 | 0 | 0 |
| Not allowed or only end of life | 4% | 100% | 100% | 80% | 100% |
| With restrictions (time, age) | 38% | 0 | 0 | 20% | 0 |
| At RN discretion | 8% | 0 | 0 | 0 | 0 |
| Agreement (% , number of pairs) | 100%, 5 | 100%, 5 | 100%, 5 | 80%, 5 | 100%, 5 |
| Ability to leave PICU room | | | | | |
| Unrestricted | 100% | 96% | 8% | 100% | 8% |
| Not allowed to leave | N/A | 0% | 29% | 0 | 29% |
| Restricted- Toilet | N/A | 4% | 46% | 0 | 50% |
| Restricted- Eating | N/A | 0 | 8% | 0 | 8% |
| Restricted-Stress/procedures | N/A | 0 | 17% | 0 | 29% |
| Agreement (% , number of pairs) | 100%, 5 | 100%, 5 | 80%, 5 | 100%, 5 | 80%, 5 |
| Ability to leave hospital | | | | | |
| Unlimited | 100% | 88% | 12% | 96% | 17% |
| Restricted frequency (e.g. 1/shift, 1/day, for switches only) | 0 | 8% | 25% | 4% | 21% |
| Restricted – smoking | 0 | 0 | 25% | 0 | 25% |

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|---------------------------------|---------|--------|--------|---------|--------|
| Never | 0 | 4% | 38% | 0% | 38% |
| Agreement (% , number of pairs) | 100%, 5 | 80%, 5 | 60%, 5 | 100%, 5 | 60%, 5 |

number of pairs = number of physician chief/medical director + clinical/operations manager pairs from the same unit for which each provided an answer to the given variable

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Figure 1: Patient care rounding practices for non-COVID-19 patients and COVID-19-positive or suspected (COVID-19+/suspected) patients. Reported for pre-COVID-19, early (first practice in mid-March, 2020), and late (most recent practice at interview time, August to December, 2020) in the pandemic.

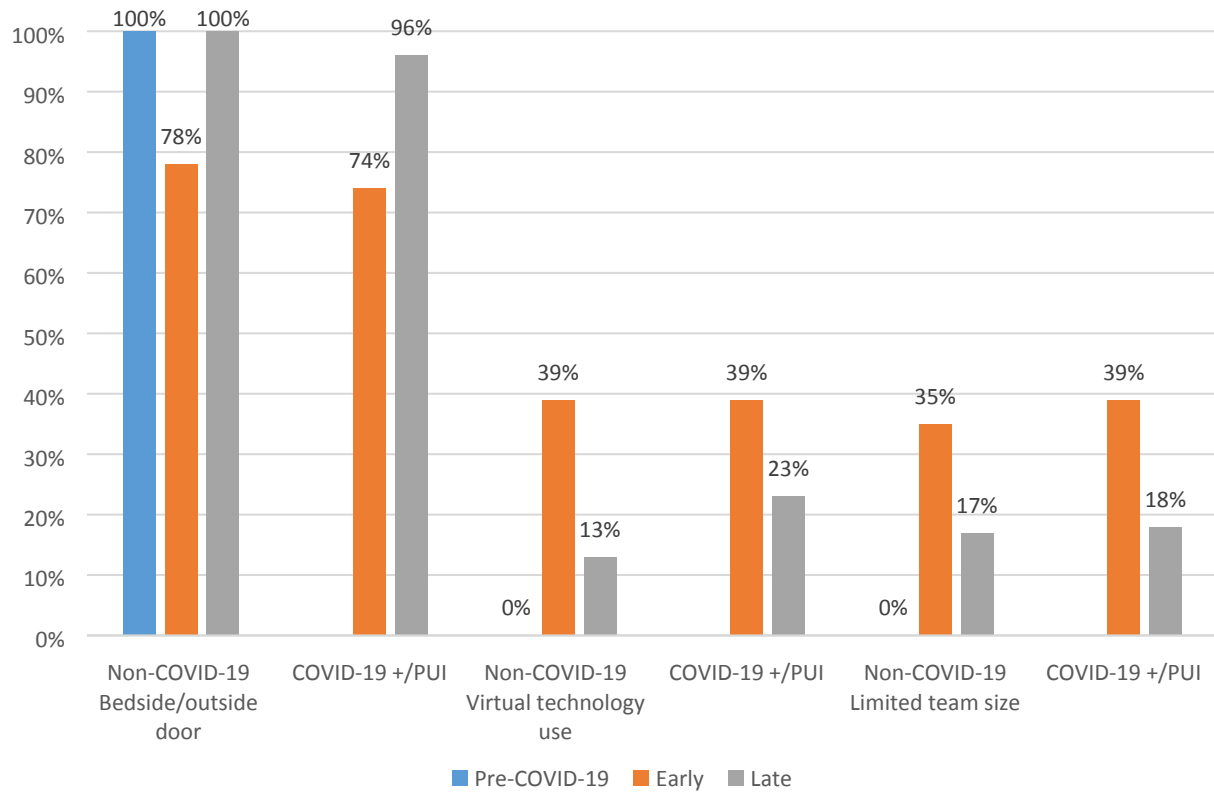
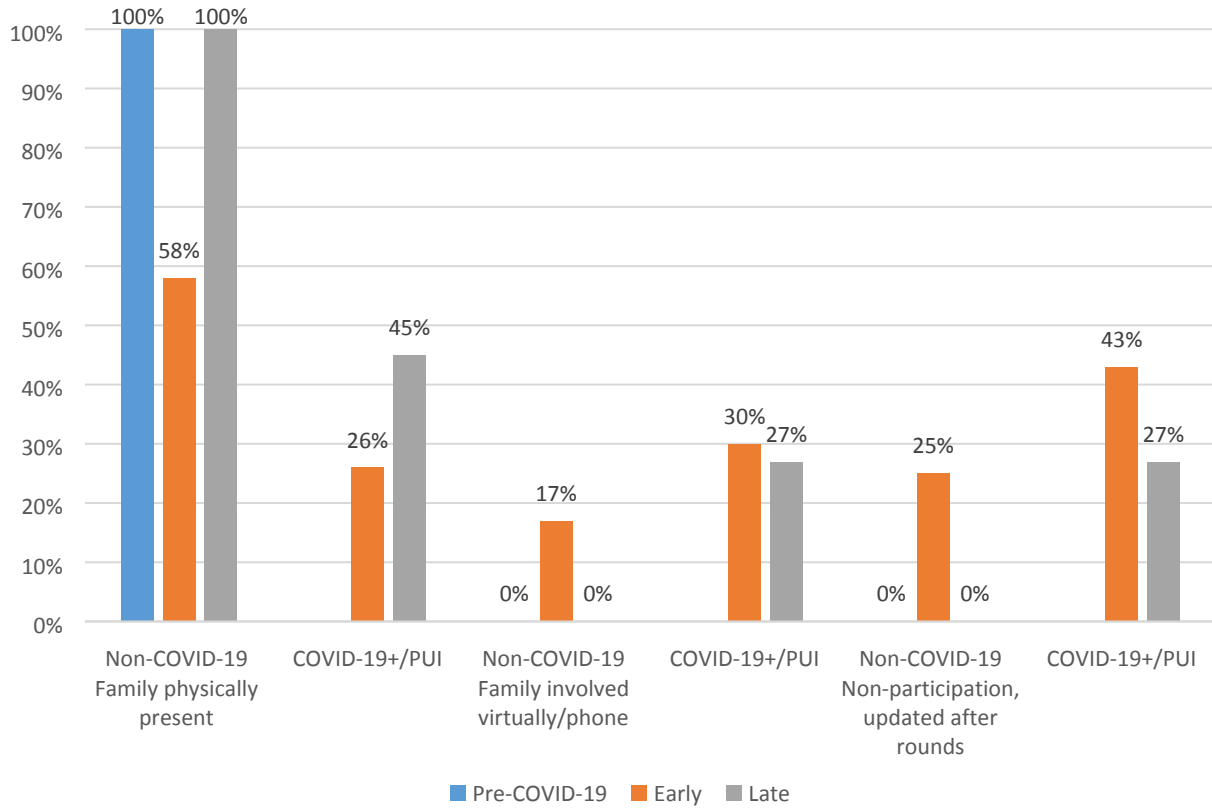
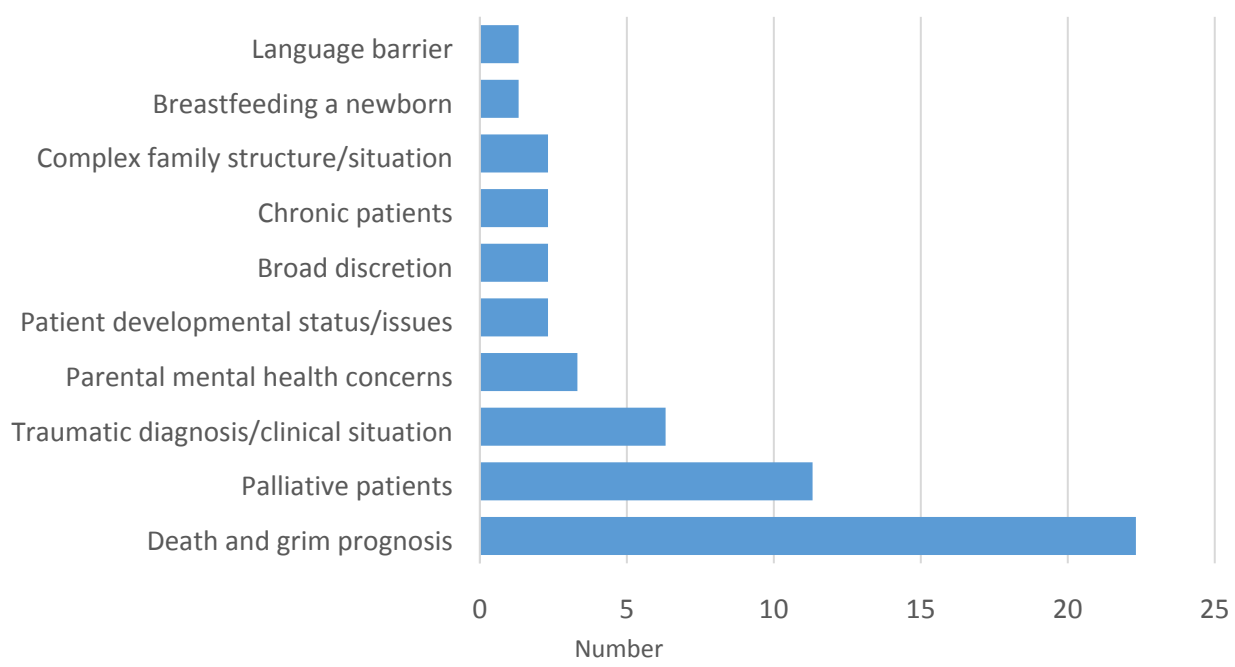


Figure 2: Family member involvement in patient care rounds. Presented for pre-COVID-19 pandemic, early (first practice mid-March of 2020) and late (at time of interview, August to December, 2020) in the pandemic.



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Figure 3: Stated reasons for granting exceptions to restrictions in numbers of family present at one time or frequency of switches. Twenty-two respondents answered this question.



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Structured Questionnaire and Data recording

PICU Information:

1. Hospital type:
 - Stand-alone children's hospital
 - Children's hospital within a hospital
 - Women's and Children's

2. ICU type:
 - Med-surg
 - Cardiac
 - Mixed

3. Patient age range: _____

4. # Beds: _____

5. What is your role in the PICU?
 - PICU physician chief
 - Pediatric intensivist (not physician head)
 - PICU Operations manager
 - Broader hospital director
 - Other _____

Baseline Family Presence Policy

6. In the period BEFORE the COVID-19 pandemic, what were the **PICU** visitation policies?:

Number, type: _____

Family vs visitor rules: _____

Times: _____

If limited, when: _____

7. In the period Before the COVID-19 pandemic, did the Children's Hospital and your PICU within it have the same family presence policies with respect to family presence, number of visitors, visitation times, and mobility of visitors around the hospital? Yes / no / unsure

(If they were the same, skip question 8. If different, go to question 9)

8. In the period BEFORE the pandemic, what were the **hospital** visitation policies?:

Number, type: _____

Family vs visitor rules: _____

Times: _____

If limited, when: _____

COVID-ERA Policy Design:

9. Did your PICU follow the hospital-wide policies for family presence and visitation with children during the pandemic, or did they have a different set of rules?

10. How much variation was there in the rules for different areas or units of the hospital?

a. If there were differences, what accounted for these?

11. Once COVID started, how were **Hospital wide** policies about parental presence and visitation for your children's hospital determined? (Provincially, regionally, locally, within the hospital?)

12. Were PICU leaders consulted when determining the **hospital-wide policies** and practices? (circle one) Yes / no If YES, what was the input? _____

13. Were PICU families consulted when determining the **hospital-wide policies** and practices? (circle one) Yes / no If YES, what was the input? _____

14. Was PICU leadership consulted about the **PICU-specific** family presence policies during the beginning of the Covid-19 pandemic? Yes / no If YES, what was the role/input of PICU leadership? _____

15. Were PICU families consulted about the **PICU-specific** family presence policies during the beginning of the Covid-19 pandemic? Yes / no If YES, what was the role/input of PICU families? _____

16. How were you informed of the new visitation policies?

Safety Measures:

17. What was the screening or testing process for visitors and family members staying with children in the PICU?

- COVID test before allowed to visit
- Screening questions at admission
- Screening questions asked regularly
- Daily screening for symptoms
- Screening for fever on entrance

18. Were visitors or family members required to wear PPE? Yes / no

a. If yes, what PPE and in what circumstances? (e.g. in the room, wandering the hospital?)

b. Was this different for covid or non-covid patients? yes / no If yes, explain:

Initial Restrictive Policy and Practice

19. Was the initial pandemic visitation policy in your PICU the same for COVID-19 presumed/suspected/proven and non-COVID-19 patients? (if different, need to ask these questions twice, once for COVID-19 and once for non-COVID-19) (yes / no)

20. What was the initial pandemic visitation policy in your PICU?

COVID (or All if same)

Non-COVID (if different)

1. Number of visitors at one time:

None

One

Two

No limit

Other: _____

None

One

Two

No limit

Other: _____

2. Timing of support person/people staying with the child

24/7

Restricted to a certain # hours per day. Describe:

Other: _____

24/7

Restricted to a certain # hours per day. Describe:

Other: _____

3. If only one/two visitors allowed, were families allowed to "switch out"?

Yes / no

yes / no

i. If so, how often?

ii. When switching out happened (either it was allowed or because of an exception), how was it managed (i.e. could parents switch out in the hospital or did one have to leave before the other could enter?)

4. Were/Are there different policies for patients of different ages? If yes describe.

Yes / no

yes / no

5. For what reasons are/were the visitor(s) allowed to leave the patient room:

- | | |
|---|---|
| <input type="checkbox"/> May not leave room | <input type="checkbox"/> May not leave room |
| <input type="checkbox"/> Unrestricted | <input type="checkbox"/> Unrestricted |
| <input type="checkbox"/> Toilet | <input type="checkbox"/> Toilet |
| <input type="checkbox"/> Food | <input type="checkbox"/> Food |
| <input type="checkbox"/> Smoking | <input type="checkbox"/> Smoking |
| <input type="checkbox"/> Sleeping | <input type="checkbox"/> Sleeping |
| <input type="checkbox"/> To leave building | <input type="checkbox"/> To leave building |
| <input type="checkbox"/> If overly distressed | <input type="checkbox"/> If overly distressed |
| <input type="checkbox"/> Other: | <input type="checkbox"/> Other: |

21. How were families informed of the new policies related to visitation and presence in the PICU?

Initially: _____

Ongoing: _____

22. What were your rounding practices related to family presence pre-pandemic?

23. What were your rounding practices related to family presence during the early part of the pandemic?

a. If the family was not involved in rounds directly, how did you ensure that families were updated on their child's status and care plans?

24. Has there been evolution in the rounding practices during the pandemic?

25. Did you use virtual technology in your rounding during COVID-19?

Policy Exceptions and Exemptions:

26. What was the process for requesting and deciding whether exemptions should be granted?

27. **For units that have a restriction in visitors**, please list reasons for which an exception would be made to the visitation policy

28. Since the beginning of the COVID-19 pandemic, have the family presence and visitation rules in your PICU changed? How so? When? Where do the rules stand today? (give exact dates where possible. Do

PICU-RFP: Administrator Questionnaire

all iterations of the rules.

PPE: _____

Rounds: _____

Caregivers present: _____

Caregiver role: _____

Switches: _____

Exceptions: _____

Hospital Restricted family presence policy

This section is additional recording space for HOSPITAL policies that are different than PICU (page with questions 17-20 and 26-28 repeated for the pediatric section of the HOSPITAL)

Scenarios:

Please consider how you, as a leader with some decision-making capacity, would have responded during the first phase of the COVID-19 Pandemic; does not reflect what you as a person would want to do, but what you would have been likely to do in your leadership role.

1. You have admitted a 3 year old with a new diagnosis of intracranial malignancy. Would you allow 2 parents/an increase in visitors for:

- Admission process
- Return from the OR post-surgically
- Delivering news of the diagnosis
- Child deteriorates and needs intubated
- Parent not coping well, becomes highly agitated and anxious
- Parent highly distressed/upset
- Child highly distressed
- Discussions of withdrawal of life support
- Visitation prior to WLS
- Withdrawal of Life Support

2. You have admitted a chronic, complex, medically fragile 8 year old with Covid-related pneumonia and ARDS who has been admitted to the PICU multiple times in the past. Would you allow any visitors from the same household? (yes/no) Would you allow an exception to the restricted visitation for:

- Admission process
- Child deteriorates and needs intubated
- Parent not coping well, becomes highly agitated and anxious
- Parent highly distressed/upset
- Child highly distressed
- Discussions of withdrawal of life support
- Visitation prior to WLS
- Withdrawal of Life Support

PICU-RFP: Administrator Questionnaire

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2
3 3. You have admitted a previously-well 3 year old with Covid-19-related cardiomyopathy (negative
4 swab now). Would you alter the rules (and how) for:

- 5
6 Admission process
7 Child deteriorates and needs intubated
8 Parent not coping well, becomes highly agitated and anxious
9 Parent highly distressed/upset
10 Child highly distressed
11 Peri-ECMO cannulation (if not offered in their centre “transfer to another institution”)
12 Delivering news of devastating stroke
13 Discussions of withdrawal of life support
14 Visitation prior to WLS
15 Withdrawal of Life Support
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Supplemental file 2: Survey development process

Pre-testing information:

Method 1: Paper review of questionnaire for question relevance, redundancy, readability

Pre-test #1 participants:

1. Director, Children's Health
2. Adult intensive care unit physician
3. Pediatric intensive care unit physician

Method 2: Telephone interview with discussion of question content, wording

Pre-test #2 participants:

1. Adult intensive care unit physician chief
2. Pediatric intensive care unit manager

Interviewer training:

Both interviewers were involved in all stages of questionnaire conception and development and were familiar with the survey content.

Each interviewer practiced the survey with health care professionals in fields adjacent to the target population (PICU physician, children's health manager).

Pilot testing:

Given the small population of Canadian PICU leadership, formalized pilot testing was not feasible, and the results of all participants were included. After the first two interviews performed by each interviewer, JRF and LAL met to discuss questionnaire flow and adjust the order of questions.