



## ELECTRONIC SUPPLEMENTARY MATERIAL

### **Foster JR *et al.*: A survey of pediatric intensive care unit clinician impact and experience with restricted family presence during COVID-19**

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\*Response to question: for future pandemic waves, what should go into a policy related to family visitation and presence in the PICU?

**eAppendix 1** A Consensus-based checklist for Reporting of Survey Studies (CROSS)

| Section/topic           | Item  | Location   |
|-------------------------|---|--|
| Title                   | State the word “survey” along with a commonly used term in title or abstract to introduce the study’s design  | Title page, page 1   |
| Abstract                | Provide an informative summary in the abstract, covering background, objectives, methods, findings/results, interpretation/discussion, and conclusions  | Page 3–4   |
| <b>Introduction</b>     |   |  |
| Background              | Provide a background about the rationale of study, what has been previously done, and why this survey is needed   | Page 5   |
| Purpose/aim             | Identify specific purposes, aims, goals, or objectives of the study.  | Page 6   |
| <b>Methods</b>          |   |  |
| Study design            | Specify the study design in the “Methods” section with a commonly used term (e.g., cross-sectional or longitudinal).  | Cross sectional survey, page 6   |
| Data Collection Methods | Describe the questionnaire (e.g., number of sections, number of questions, number and names of instruments used).   | Data sources, pages 7–8  |
|                         | Describe all questionnaire instruments that were used in the survey to measure particular concepts. Report target population, reported validity and reliability information, scoring/classification procedure, and reference links (if any).  | Methods, data sources, pages 7–8   |
|                         | Provide information on pretesting of the questionnaire, if performed (in the article or in an online supplement). Report the method of pretesting, number of times questionnaire was pre-tested, number and demographics of participants used for pretesting, and the level of similarity of demographics between pre-testing participants and sample population. | Methods, data sources, page 8  |
|                         | Questionnaire, if possible, should be fully provided (in the article, or as appendices or as an online supplement).   | Additional file 2  |
| Sample characteristics  | Describe the study population (i.e., background, locations, eligibility criteria for participant inclusion in survey, exclusion criteria).  | HCPs from Canadian PICUs at the bedside between March and June, 2020, Setting and Sample, page 6 |

|                        |  |   |
|------------------------|--|---|
|                        | Describe the sampling techniques used (e.g., single stage or multistage sampling, simple random sampling, stratified sampling, cluster sampling, convenience sampling). Specify the locations of sample participants whenever clustered sampling was applied | Non-probability voluntary response sampling, page 6   |
|                        | Provide information on sample size, along with details of sample size calculation.   | N/A   |
|                        | Describe how representative the sample is of the study population (or target population if possible), particularly for population-based surveys  | Page 6  |
| Survey administration  | Provide information on modes of questionnaire administration, including the type and number of contacts, the location where the survey was conducted (e.g., outpatient room or by use of online tools, such as SurveyMonkey).                                | Methods, setting and sample, page 6   |
|                        | Provide information of survey's time frame, such as periods of recruitment, exposure, and follow-up days.  | Methods, setting and sample, page 6   |
|                        | Provide information on the entry process:<br>→For non-web-based surveys, provide approaches to minimize human error in data entry.<br>→For web-based surveys, provide approaches to prevent "multiple participation" of participants.                        | No prevention of multiple participation; used untraceable web link. Methods, setting and sample, page 6 |
| Study preparation      | Describe any preparation process before conducting the survey (e.g., interviewers' training process, advertising the survey).  | Methods, setting and sample, page 6   |
| Ethical considerations | Provide information on ethical approval for the survey if obtained, including informed consent, institutional review board [IRB] approval, Helsinki declaration, and good clinical practice [GCP] declaration (as appropriate).                              | Methods, study design, page 6.  |
|                        | Provide information about survey anonymity and confidentiality and describe what mechanisms were used to protect unauthorized access   | Methods, setting and sample, page 6   |
| Statistical analysis   | Describe statistical methods and analytical approach. Report the statistical software that was used for data analysis.   | Methods, data analysis, page 8  |
|                        | Report any modification of variables used in the analysis, along with reference (if available).  | Methods, data analysis, page 8  |
|                        | Report details about how missing data was handled. Include rate of missing items, missing data mechanism (i.e., missing completely at random [MCAR], missing at random [MAR], or missing not   | Methods, data analysis, page 8  |

|                            |   |  |
|----------------------------|---|--|
|                            | at random [MNAR]), and methods used to deal with missing data (e.g., multiple imputation).  |  |
|                            | State how non-response error was addressed  | Page 8   |
|                            | For longitudinal surveys, state how loss to follow-up was addressed   | N/A  |
|                            | Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for non-representativeness of the sample.   | N/A  |
|                            | Describe any sensitivity analysis conducted   | N/A  |
| <b>Results</b>             |   |  |
| Respondent characteristics | Report numbers of individuals at each stage of the study. Consider using a flow diagram, if possible.   | Results, page 9  |
|                            | Provide reasons for non-participation at each stage, if possible.   | Results, respondent demographics, page 9   |
|                            | Report response rate, present the definition of response rate or the formula used to calculate response rate.   | Results, respondent demographics, page 9. Definition in methods, data analysis, page 8 |
|                            | Provide information to define how unique visitors are determined. Report number of unique visitors along with relevant proportions (e.g., view proportion, participation proportion, completion proportion).                    | Page 8   |
| Descriptive results        | Provide characteristics of study participants, as well as information on potential confounders and assessed outcomes  | Results all sections , table 1, Additional file 3                                      |
| Main findings              | Give unadjusted estimates and, if applicable, confounder-adjusted estimates along with 95% confidence intervals and <i>p</i> values.  | Table 3  |
|                            | For multivariable analysis, provide information on the model building process, model fit statistics, and model assumptions (as appropriate).  | Methods, data analysis, page 8. Results, page 10. Table 4                              |
|                            | Provide details about any sensitivity analysis performed. If there are considerable amount of missing data, report sensitivity analyses comparing the results of complete cases with that of the imputed dataset (if possible). | N/A  |
| <b>Discussion</b>          |   |  |
| Limitations                | Discuss the limitations of the study, considering sources of potential biases and imprecisions, such as non-representativeness of sample, study design, important uncontrolled confounders.                                     | Discussion, page 17  |

|                       |  |  |
|-----------------------|--|--|
| Interpretations       | Give a cautious overall interpretation of results, based on potential biases and imprecisions and suggest areas for future research. | Discussion, pages 14–15                |
| Generalizability      | Discuss the external validity of the results   | Discussion, pages 15–16                |
| Other sections        |  |  |
| Funding source        | State whether any funding organization has had any roles in the survey’s design, implementation, and analysis.                       | Declarations, Funding sources, page 18 |
| Conflicts of interest | Declare any potential conflict of interest   | Declarations, Conflicts, page 18       |
| Acknowledgements      | Provide names of organizations/persons that are acknowledged along with their contribution to the research.                          | Acknowledgements, page 19              |

*Sharma A, Minh Duc NT, Luu Lam Thang T, et al. A Consensus-Based Checklist for Reporting of Survey Studies (CROSS). J Gen Intern Med 2021; 10.1007/s11606-021-06737-1.*

## eAppendix 2 RFP-PICU Healthcare Provider IMPACT Survey

### Information Letter of Implied Consent

#### UNIVERSITY OF ALBERTA STOLLERY CHILDREN'S HOSPITAL PEDIATRIC INTENSIVE CARE UNIT

**Title of the study:** Impact of Restricted Family Presence Policies on Bedside Healthcare Providers in the PICU During the COVID-19 Pandemic (Study Pro 00102535)

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Jamie Seabrook, PhD, Bresicia College, Western University

**Invitation to Participate:** You are invited to participate in this research study on the impact of restricted family presence (RFP) policies during COVID-19 pandemic, because you have worked during the period of pandemic RFP at your hospital.

**Purpose of the Study:** From this research we wish to learn the personal impact of this policy and your experience with it during the pandemic period.

**Participation:** If you wish to participate in this study, please complete the attached survey. The survey should take you approximately 15-20 min to complete. You do not have to answer any questions that you do not want to answer. Once you have completed the survey, please press submit on your device/computer and it will be finished.

We would appreciate receiving it before October 1/2020. If we do not receive it by said date, we will send a notice of reminder to your unit director, to be announced via email/ post notes.

**Benefits:** There will be no direct benefit to you when you respond to this survey, beyond the fact that you will be able to openly share your opinion and your experience in writing.

There may be significant benefit to the community at large since we hope to influence further policies regarding visitation during pandemics.

**Risks:** We do not anticipate any risks to you, but if participation in this research brings back memories and stressful moments you can **a.** interrupt and not submit the form **b.** contact the principal investigator (DG), who is trained in critical incident stress management and will gladly

talk to you in private at a time of your choosing to attempt to alleviate any stress that it may have caused to you. He may also help you to find support within close reach for you.

**Confidentiality and Anonymity:** The information that you share will remain strictly confidential and will be used solely for the purposes of this research. The only people who will have access to the research data are the investigators listed above. Your answers to open-ended questions may be used verbatim in presentations and publications but neither you nor your organization or hospital will be identified. Results will be published in pooled (aggregate) format. Anonymity for the survey is guaranteed since you are not being asked to provide your name or any personal information.

In order to minimize the risk of security breaches and to help ensure your confidentiality we recommend that you use standard safety measures such as signing out of your account, closing your browser and locking your screen or device when you are no longer using them / when you have completed the study. The data collected will remain in servers in Canada. At the end of the survey, after you hit submit, you will be asked if you would like to volunteer to participate in a follow-up in depth interview. If you volunteer for this, any information you provide to allow the researchers to contact you will not be connected or able to be connected to the answers in this survey. We will contact you separately, with another consent form for the interview.

**Data Storage:** The survey is done on the Qualtrics Platform, which is licensed to the University of Calgary. Electronic copies of the survey results will be encrypted and stored on a password protected computer in the department of Pediatrics, Division of Critical Care, at the University of Alberta. The data from the survey will only be downloaded by the researcher at the University of Alberta. This data will be retained for 5 years after publication of the results.

**Voluntary Participation:** You are under no obligation to participate and if you choose to participate, you may refuse to answer questions that you do not want to answer. Should you choose to withdraw midway through the electronic survey simply close the link and no responses will be included. Given the anonymous nature of the survey, once you have submitted your responses it will no longer be possible to withdraw them from the study.

**Information about the Study Results:** The results to the study will be available in the Pediatric Critical Care literature in approximately 1 years' time.

**Contact Information:** If you have any questions or require more information about the study itself, you may contact the researcher (*DG*) at the numbers mentioned herein.

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have any questions regarding your rights as a research participant or how the research is being conducted you may contact the Research Ethics Office at 780-492-2615.

Please keep this form for your records, if you so desire by printing a PDF copy.

Completion and submission of the survey means your consent to participate.

## Start of Survey

### Part 1: Demographics

Q1 What is your role in the PICU:

- Attending physician
  - Nurse
  - Nurse practitioner
  - Rotating resident
  - PICU fellow or subspecialty resident
  - Clinical assistant / associate
  - Social worker
  - Respiratory therapist
  - Other (please specify): \_\_\_\_\_
- 

Q2 How many years of experience do you have working in the PICU?

- Less than 1 year
  - 1-5 years
  - 5.1-10 years
  - Greater than 10 years
- 

Q3 What is your gender?

- Woman
  - Man
  - Another gender identity, please specify: \_\_\_\_\_
  - I prefer not to respond
-



Q4 In which hospital do you work?

- Janeway Children's Health and Rehabilitation Hospital
- IWK Health Centre
- Centre Hospitalier de l'Universite Laval
- CHU Sainte-Justine
- Montreal Children's Hospital
- CHU Sherbrooke
- Kingston Health Sciences Centre
- Children's Hospital of Eastern Ontario
- Hospital for Sick Children - Medical/Surgical PICU
- Hospital for Sick Children - Cardiac/Cardiac Surgical PICU
- McMaster Children's Hospital
- Children's Hospital London Health Sciences Centre
- Children's Hospital of Winnipeg
- Jim Pattison Children's Hospital
- Stollery Children's Hospital - Pediatric ICU
- Stollery Children's Hospital - Pediatric Cardiac ICU
- Alberta Children's Hospital
- BC Children's Hospital
- Victoria General Hospital

## Part 2: Baseline PICU policy and culture

The following questions refer to your PICU before the COVID-19 pandemic.

-----

Q5 **Prior** to the COVID-19 pandemic, how would you describe your PICU's **approach to the family** in the PICU? Please select **all** that apply.

- Family centered
- Family seen as part of the care team
- Family encouraged to be present with their child
- Family seen as visitors
- Limitation imposed on bedside parental presence
- Specific family visitation hours
- Other, please specify: \_\_\_\_\_

Q6 **Prior** to the COVID-19 pandemic, how would you describe **family access** to the PICU? Please select **all** that apply.

- Parents/care-providers allowed 24/7
  - Parents/care-providers had specific visitation hours
  - Only one parent/caregiver allowed at the bedside at a time
  - Family movement around the hospital was unlimited
  - Parent caregiver required/encouraged to stay in the patient room at all times
  - Parents provided with in-room sleeping arrangements, single family room care
  - Parents provided with local (parent room, Ronald McDonald House, Hotel) sleeping arrangements
  - Family provided with badge/code for accessing PICU at their convenience
  - Family calls/buzzes into unit to gain access
  - Other, please specify: \_\_\_\_\_
- 

Q7 **Prior** to the COVID-19 pandemic, how would you describe **participation of families in PICU activities**? Please select **all** that apply.

- Encourage family involvement in routine patient care activities
  - Family presence at resuscitation encouraged or enabled
  - Family presence at procedures encouraged or enabled
  - In Person family participation in rounds encouraged
  - Family not permitted to attend rounds in person
  - Family required to leave patient room for procedures
  - Other, please specify: \_\_\_\_\_
-

Q8 **Prior** to the COVID-19 pandemic, how would you describe your PICU's **approach to non-caregivers** in the PICU (e.g. siblings, non-parent family members)? Please select **all** that apply.

- Siblings allowed to visit any time
- Siblings allowed to visit with restricted visitation hours
- Siblings allowed to visit **only** during end of life care
- No visitors allowed other than parent/caregiver
- Always only 2 people allowed at the bedside at one time regardless of their relationship to the patient, except for end of life period
- Unlimited parent/caregiver visiting, but limited number of non-parent/caregivers allowed at the bedside
- There was no limit to the number of non-parent/caregiver visitors at the bedside
- Non-parent/caregiver visitors had restricted visiting hours
- Non-parent/caregiver visitors were allowed 24/7
- Other, please specify: \_\_\_\_\_

---

Q9 If your unit had different policies at certain times of the year/in certain circumstances that are not covered by the above questions, please describe:

\_\_\_\_\_ Free text space \_\_\_\_\_

---

Q10 Did you work in the PICU with patients and families during a period when there were restricted family presence policies in place (mid-March to early June in most centres)?

- Yes
- No

*Skip To: End of Survey If "no".*

### Part 3: COVID-19 PICU policy and culture

The following questions refer to your PICU during the early part of the COVID pandemic (mid-March to early June).

Q11 During the early COVID-19 pandemic response, how would you describe your PICU's **approach to the family** in the PICU? Please select **all** that apply.

- Family-centered
  - Family seen as part of the care team
  - Family encouraged to be present with their child
  - Family seen as visitors
  - Limitation imposed on bedside parental presence
  - Specific family visitation hours
  - Other, please specify: \_\_\_\_\_
- 

Q12 **During** the early COVID-19 pandemic response, how would you describe **family access** to the PICU? Please select **all** that apply.

- Parents/care-providers allowed 24/7
  - Parents/care-providers had specific visitation hours
  - Only one parent/caregiver allowed at the bedside at a time
  - Family movement around the hospital was unlimited
  - Parent/caregiver required/encouraged to stay in the patient room at all times
  - Parents provided with in-room sleeping arrangements, single family room care
  - Parents provided with local (parent room, Ronald McDonald House, Hotel) sleeping arrangements
  - Family provided with badge/code for accessing PICU at their convenience
  - Family calls/buzzes into unit to gain access
  - Other, please specify: \_\_\_\_\_
-

Q13 **During** the early COVID-19 pandemic response, how would you describe **participation of families in PICU activities**? Please select **all** that apply.

- Encourage family involvement in routine patient care activities
  - Family presence at resuscitation encouraged or enabled
  - Family presence at procedures encouraged or enabled
  - Family participation in rounds encouraged
  - Family not allowed to leave patient room to join rounds in isolated patients
  - Family required to leave patient room for procedures
  - Other, please specify: \_\_\_\_\_
- 

Q14 **During** the early COVID-19 pandemic response, how would you describe your PICU's **approach to non-caregivers** (e.g. siblings, non-parent family members) in the PICU? Please select **all** that apply.

- Siblings allowed to visit any time
- Siblings allowed to visit with restricted visitation hours
- Siblings only allowed to visit ***only*** during end of life care
- No visitors allowed other than parent/caregiver
- Always only 2 people allowed at the bedside at one time regardless of their relationship to the patient, except for end of life period
- Unlimited parent/caregiver visiting, but limited number of non-parent/caregivers allowed at the bedside
- There was no limit to the number of non-parent/caregiver visitors at the bedside
- Non parent/caregiver visitors had restricted visiting hours
- Non-parent/caregiver visitors were allowed 24/7
- Other please specify: \_\_\_\_\_

**Part 4: Restriction rules - experience and opinions**

All questions in this section refer to your experience with and opinions about the restricted family visitation and presence policies in the PICU during the COVID-19 pandemic, rather than any other changes that occurred as a result of the pandemic.

Q15 Indicate your level of agreement with the following statements below:

|   | Strongly disagree        | Somewhat disagree        | Disagree                 | Agree | Somewhat agree           | Strongly agree           |
|---|--------------------------|--------------------------|--------------------------|-------|--------------------------|--------------------------|
| I was not consulted prior to implementation of the restricted family presence policies.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| I received training or written information on how to consistently inform families about the specific restricted family presence rules and the reasons for it. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| I felt that the hospital/PICU valued my opinion as a healthcare provider when implementing the restricted family presence policies.                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| I felt that the hospital/PICU valued my health when implementing the restricted family presence policies.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| The restricted visitation policies implemented during the COVID-19 pandemic were for the benefit of healthcare providers.                                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| The restricted family presence policies are congruent with our PICU's values.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| The restricted family presence made it easier to do my job.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| My experience with the restricted family presence was mainly positive.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |

Q16 When you cared for individual patients, did the restricted family presence policies result in an increase in your work load?

- Yes
- No

*If 16 = Yes, display the following*

Q17 Please indicate the ways in which the restricted family presence **increased** your work load/flow. Select **all** that apply.

- Negotiating for exceptions/exemptions to the restricted family presence policies
  - More time comforting/entertaining patients
  - More time comforting/talking to the parent who was with the child
  - More time updating the family member(s) who could not be present
  - I had to do more patient care activities that parents would normally do
  - I had to give patients more sedative/analgesic medications or muscle relaxants
  - More time finding food for parents
  - More time helping parents get internet access
  - Trying to enable facetime between patients/support person in hospital and other family
  - Other, please specify: \_\_\_\_\_
-

Q18 Indicate your level of agreement with the following statements below:

|  | Strongly disagree        | Somewhat disagree        | Disagree                 | Agree | Somewhat agree           | Strongly agree           |
|--|--------------------------|--------------------------|--------------------------|-------|--------------------------|--------------------------|
| When I had a patient whose family member needed to “have a break” they were allowed to leave the patient room as needed.                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| I knew the process for requesting an exception to the restricted visitation rules.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| When I had a patient who needed an extra family present, I felt that the hospital/administration listened to my reasons.                     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| The response to requests for exceptions to the restricted visitation rules seemed consistent, no matter which person in charge was deciding. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| The restricted family presence policies protected patients and their families.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| The children in PICU for whom I cared did not notice the restrictions in family members.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| The restricted family presence policies added to the stress of families with a child in the PICU.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |
| Families with a child in the PICU generally coped well with the restrictions in visitation/presence.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |       | <input type="checkbox"/> | <input type="checkbox"/> |

Q19 Do you feel that certain groups or types of families were more significantly impacted by the restricted family presence policies and rules?

- Yes. Please describe: \_\_\_\_\_
- No



Q20 Please share any other opinions you may have about the restricted family presence policies or your experience with them.

\_\_\_\_\_Free Text here\_\_\_\_\_

\_\_\_\_\_

### Part 5: Impact of Restricted Family Presence on Healthcare Providers

We know that front line healthcare providers are often the people who tell families about new rules or restrictions, enforce the rules, and who experience their impact day to day, good or bad.

In this section we will assess some of the impacts that restricted family presence policies may have had on you at the time and long term, and any moral distress you may have experienced.

-----

Q21 The COVID-19 pandemic introduced many new challenges to PICU politics and care. To what degree do you feel that the restricted family presence policies altered your stress during this time?

- Significantly decreased my stress
- Decreased my stress
- No change in my stress
- Increased my stress
- Significantly increased my stress

*Display This Question:*

*If 21 = Increased my stress OR Significantly increased my stress, ask question 22*

Q22 How did the restricted family presence policies increase your stress at the time?

\_\_\_\_\_Free text here\_\_\_\_\_

-----

*Display This Question:*

*If 21 = Decreased my stress OR Significantly decreased my stress, ask question 23*

Q23 How did the restricted family presence policies decrease your stress at the time?

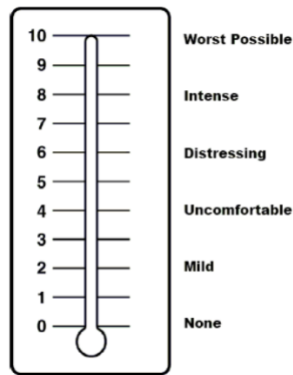
\_\_\_\_\_Free text here\_\_\_\_\_

### Tool 1: Moral Distress Evaluator

DEFINITION: MORAL DISTRESS occurs when you believe you know the ethically correct thing to do, but someone or something restricts your ability to pursue the right course of action.

---

Q24 Please indicate the number on the Moral Distress Thermometer that best describes how much moral distress you have experienced related to restricted family presence during the COVID 19 pandemic.



0 1 2 3 4 5 6 7 8 9 10

---

Q25 Do you have any added comments, thoughts, or experiences you wish to share related to moral distress or situations that caused you moral distress?

\_\_\_\_\_Free text here\_\_\_\_\_

## Tool 2: Impact of event scale

We are considering **restriction of family presence at the bedside in PICU during the COVID-19 pandemic** a possible stressful event, and we are interested in the ongoing impact of that event on you. You may have 1 particular experience or event that you were most touched by, and you can answer the questions related to that event. Otherwise, please answer for the entire experience of restricted family presence in PICU related to COVID-19.

---

Q26 If there was a **particular experience/event** during the period of restricted visitation that will be the basis of your answers about the impact of restricted visitation, please describe here in your own words. If the **whole experience of restricted visitation** was the event for you, describe it in your own words.

\_\_\_\_\_ Free text here \_\_\_\_\_

---

Q27 Below is a list of comments made by people after stressful life events. Please indicate how frequently these comments were true for you during the past seven days by selecting from the following options: Often, sometimes, rarely or not at all. Select only one answer per row.

|   | Not at all               | Rarely                   | Sometimes                | Often                    |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| I thought about it when I didn't mean to.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I avoided letting myself get upset when I thought about it or was reminded about it.                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I tried to remove it from memory.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I had trouble falling asleep or staying asleep because of pictures or thoughts about it that came to my mind. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I had waves of strong feelings about it.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I had dreams about it.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I stayed away from reminders about it.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I felt as if it hadn't happened or was unreal.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I tried not to talk about it.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Pictures about it popped into my mind.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other things kept making me think about it.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I was aware that I still had a lot of feelings about it, but I didn't deal with them.                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I tried not to think about it.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Any reminder brought back feelings about it.  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| My feelings about it were kind of numb.   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**Part 6: Future Restriction Policies**

Q28 For future pandemic waves, what should go into a policy related to family visitation and presence in the PICU?

\_\_\_\_\_ Free text here \_\_\_\_\_

### **eAppendix 3** Pediatric Intensive Care Unit-Family Presence Index (PICU-FPI)

The PICU-FPI was created to measure HCP perceptions of two key components of Family Centered Care (FCC) in the PICU: family presence and participation.

Tool development: Items were generated utilizing a review of the current literature, including a scoping review,<sup>1</sup> experience of PICU clinician team members (RT, RN, NP, MD), and experience of parent and a patient partners (MW, CS, NM). Potential tool items proceeded through two rounds of testing: first by 2 PICU clinicians and 2 PICU family members not initially involved in the item development where they provided item by item feedback on face validity, redundancy, comprehensiveness, readability, and comprehension; and secondly by 5 multidisciplinary PICU clinicians for readability and flow. This resulted in 30 potential items, which were grouped into four themes: 1) PICU approach to family; 2) Family access to PICU; 3) Participation of parents/caregivers in PICU activities; and 4) Approach to non-caregivers (e.g., siblings, grandparents). Eight independent raters (3 patient/family partners and 5 PICU clinicians) assigned scores to each item (-1 = non-family centered, 0 neither, +1 family centered) to assess content validity and quantify the score. Where agreement between the independent scores was  $\geq 75\%$  and included agreement of equivalence or a higher (more family centered) rating by the patient partners, the assigned score was accepted. If the patient partners scored the item lower than the clinical raters the item was resolved by consensus discussion. Equivalence was assumed for agreement of 50% and a score of 0 was assigned. For agreement between 50-75% a 9<sup>th</sup> expert clinician reviewer provided an additional vote. Items that received a final score of 0 were not included in the final tool as they neither added to nor subtracted from a unit's family presence practices. The resulting tool, the PICU-FPI, consists of 20 items with scores ranging from -8 to +12 and is presented in Additional File 4: Figure 1.

Validity: Construct validity was established through the development process and through assessment of perceived association with family centered care. The PICU-FPI was included in a cross-sectional survey of Canadian clinicians working in PICUs during COVID-19-related RFP. Respondents completed the tool during the COVID-19 pandemic. They were asked to score, using recall, for the period prior to the implementation of RFP and during the pandemic-related RFP.

Statistical Analysis: Data were analyzed using IBM SPSS Statistics, version 25.0 (Armonk, NY). The independent samples t-test was used to compare mean differences in PICU-FPI scores between the clinician agree/disagree responses to the statement, "The unit is family centered", as well as to compare the difference in mean RFP-FPI score before and during restricted presence. Inter-rater reliability was assessed using an intraclass correlation coefficient for all PICUs with at least 15 respondents (n=10 PICUs that had at least 15 respondents), with a cut-off of 0.90 for excellent reliability.<sup>2</sup> A p-value  $< 0.05$  was considered statistically significant.

### **Results**

The PICU-FPI was completed for the pre-COVID (n=386) and early-COVID (n=345) periods by respondents from 15 PICUs in 13 hospitals, with 344 respondents completing both assessments. The mean [standard deviation (SD)] score was significantly higher prior to widely implemented COVID-19-related restrictions at 6.8 (2.4) versus 1.3(2.8) early in the pandemic, with a mean

(95% Confidence Interval) paired difference of -5.5 (5.2-5.8),  $p < 0.001$ . The mean PICU-FPI score differed significantly between those that did and did not describe their unit as family centered, both pre-pandemic (7.0 [2.3] versus 5.4 [2.6] respectively,  $p < 0.001$ ) and during the pandemic (2.3 [2.6] versus 0.3 [2.7] respectively,  $p < 0.001$ ). An interclass correlation of 0.97 (95%CI: 0.94-0.99) indicates excellent interrater reliability across all 15 PICUs.

## References

1. Miller L, Richard M, Krmpotic K, Kennedy A, Seabrook J, Slumkoski C, et al. Parental presence at the bedside of critically ill children in the pediatric intensive care unit: A scoping review. *Eur J Pediatr* [Internet]. 2021;181(2):823–31. Available from: <https://doi.org/10.1007/s00431-021-04279-6>
2. Koo TK, Li MY. A Guideline of Selecting and Reporting Intraclass Correlation Coefficients for Reliability Research. *J Chiropr Med* [Internet]. 2016;15(2):155–63. Available from: <http://dx.doi.org/10.1016/j.jcm.2016.02.012>

### Pediatric Intensive Care Unit – Family Presence Index (PICU-FPI) final tool

| <b>PICU Family Presence Index (PICU-FPI)</b>   |   | Points assigned if item selected |
|--|---|----------------------------------|
| <b>The following questions refer to your PICU</b>  | ✓ |                                  |
| <b>How would you describe your PICU's approach to the family? (Check all that apply)</b>                 |   |                                  |
| Family seen as part of the care team   |   | +1                               |
| Family encouraged to be present with their child   |   | +1                               |
| Family seen as visitors  |   | -1                               |
| Specific family visitation hours   |   | -1                               |
| <b>How would you describe Family access to PICU? (Check all that apply)</b>                              |   |                                  |
| Parents/care providers allowed 24/7  |   | +1                               |
| Parents/care providers had specific visitation hours   |   | -1                               |
| Only one parent/care-provider allowed at the bedside at a time   |   | -1                               |
| Parents provided with in-room sleeping arrangements, single room care                                    |   | +1                               |
| Family given badge/code to get into PICU   |   | +1                               |
| <b>How would you describe participation of families in PICU activities? (Check all that apply)</b>       |   |                                  |
| Encourage family involvement in routine patient care activities  |   | +1                               |
| Family presence at resuscitation encouraged or enabled   |   | +1                               |
| Family presence at procedures encouraged or enabled  |   | +1                               |
| Family required to leave room for procedures   |   | -1                               |
| In person family participation in rounds encouraged  |   | +1                               |
| Family not permitted to attend rounds in person  |   | -1                               |
| <b>How would you describe your PICU's approach to non-caregivers in the PICU? (Check all that apply)</b> |   |                                  |
| Siblings allowed to visit any time   |   | +1                               |
| Siblings allowed to visit <i>only</i> during end of life care  |   | -1                               |
| No visitors other than parents/care-giver  |   | -1                               |
| There was no limit to the number of non-parent/caregiver visitors at the bedside                         |   | +1                               |
| Non-parent/caregiver visitors were allowed 24/7  |   | +1                               |
| <b>Total Score (Range -8 to +12)</b>   |   |                                  |

**eAppendix 4** Comparison of demographics for respondents who experienced restrictions and were included in the complete analysis and those who did not experience restrictions and were not included in the full analysis. Demographic variables are consolidated to preserve cell sizes  $\geq 5$ .

|  | Worked under RFP policies<br><i>N</i> = 368 | Did not work under RFP policies<br><i>N</i> = 20 |
|--|---|--|
| Profession, <i>n</i> (%)   |   |  |
| Registered Nurse (bedside)   | 240 (65.2%)                                 | 13 (65%)   |
| Non-nurse respondent (MD, RT, SW, PT, Child Life, Unit aide, Ward Clerk, Manger) | 128 (34.8%)                                 | 7 (35%)  |
| Geographic location, <i>n</i> (%)  |   |  |
| Province of Ontario  | 146 (39.7%)                                 | 11 (55%)   |
| Rest of Canada   | 222 (60.3%)                                 | 9 (45%)  |
| Years' experience  |   |  |
| 0-5 years  | 128 (34.7%)                                 | 8 (40%)  |
| 5.1-10 years   | 84 (22.8%)                                  | 5 (25%)  |
| >10 years  | 156 (42.4%)                                 | 7 (35%)  |
| Gender, <i>n</i> (%)   |   |  |
| Female   | 333 (90.7%)                                 | 17 (89.5%)                                       |
| Language in which survey completed, <i>n</i> (%)                                 |   |  |
| English  | 338 (91.8%)                                 | 19 (95%)   |

PT = physiotherapist; RN = Registered Nurse; RT = Respiratory Therapist; SW = Social Worker

## eAppendix 5 PICU clinician opinions about future policy\*

| <b>Theme 1: Policy-making priorities (n=35)</b>  | <b>Exemplar quotes</b>   |
|--|--|
| <p><b>Balancing priorities</b> (n=20). Safety of patients and clinicians (n=12) must be weighed against need for optimized family presence and commitment to family centered care (n=8).</p>   | <ul style="list-style-type: none"> <li>• “As a general rule, if the risk is not significant family visitation should be allowed and encouraged in the PICU.” (HCP-360)</li> <li>• “Minimizing the risk to patients, families and healthcare workers while balancing the commitment and principles of family centered care.” (HCP-070)</li> </ul>   |
| <p><b>Family-centered approach</b> (n=13). Approach to families should continue to recognize families as a unit.</p>   | <ul style="list-style-type: none"> <li>• “True family-centred care. Recognizing the family as a whole unit that shouldn’t be separated and recognizing that a family that is all together sharing germs poses very little additional risk by allowing a sibling or second parent.” (HCP-029)</li> </ul>  |
| <p><b>Built-in flexibility</b> (n=18).</p> <ul style="list-style-type: none"> <li>• Adaptable and responsive (n=11)</li> <li>• Avoid one-size-fits-all (n=5)</li> <li>• Consider issues of equity (n=4)</li> <li>• Empathetic approach (n=7)</li> </ul>  | <ul style="list-style-type: none"> <li>• “A more flexible and inclusive approach would be kind given the acuity and the changing status of our patients.” (HCP-111)</li> <li>• “...the decisions should be evidence based, or if unable to do so, needs to be revised as soon as evidence allows” (HCP-332)</li> <li>• “Blanket visitation rules for an entire healthcare organization are not appropriate for the unique family centered care approach in pediatrics. There should be a separate policy for pediatric facilities.” (HCP-138)</li> <li>• “Consideration of equity and equality.” (HCP-070)</li> <li>• “Put yourself in the position of the family- think how awful it would be to have a sick child and not be able to be there as a couple to support your child and each other. So so hard for these families.” (HCP-315)</li> </ul> |
| <b>Theme 2: Policy development (n=120)</b>   | <b>Exemplar quotes</b>   |
| <p><b>Number of people</b> (n=64)</p> <ul style="list-style-type: none"> <li>• Two (n=50)</li> <li>• One (n=10)</li> <li>• More than two (n=4)</li> </ul>  | <ul style="list-style-type: none"> <li>• “2 caregivers. 1 is not reasonable. People need support. Children need their parents/caregivers.” (HCP-009)</li> <li>• “One visitor at a time, screened. Not necessarily a parent.” (HCP-317)</li> </ul>  |
| <p><b>Who is enabled</b> (n=75)</p> <ul style="list-style-type: none"> <li>• Primary caregivers/parents (n=43)</li> <li>• Only healthy individuals (n=15)</li> <li>• Only those compliant with rules (n=15)</li> <li>• Siblings (n=14)</li> <li>• More than nuclear family (n=7)</li> <li>• Assess case by case (n=6)</li> </ul> | <ul style="list-style-type: none"> <li>• “Les 2 parents puisse rester au chevet de leur enfant.” Translation – “Both parents can remain at their child’s bedside.” (HCP-006)</li> <li>• “Restrict visitation that is unnecessary. One caregiver at all times. If caregivers are ill, then NO visitors unless child is dying. We as care providers DO NOT need covid positive parents in the room with their covid positive child.” (HCP-298)</li> <li>• “I wouldn't care how many adults visits [sic] providing they wear masks &amp; follow other guidelines when in common areas to protect anyone else.” (HCP-123)</li> <li>• “A sibling allowed to visit along with the two parent rule.” (HCP-243)</li> <li>• “Parents should also be able to designate non-family if they were a big part of the child's life.” (HCP-147)</li> </ul>             |



|  |   |
|--|---|
| <p><b>Input into decisions and policy development</b> (n=22)</p> <ul style="list-style-type: none"> <li>• Family (n=6)</li> <li>• Many stakeholders (n=3)</li> <li>• PICU staff (n=14)</li> </ul>                                | <ul style="list-style-type: none"> <li>• “family / patient input, more healthcare provider input.” (HCP-001)</li> <li>• “Consultation with front line staff and discussion about what we need to support parents at bedside.” (HCP-277)</li> <li>• “allowing front line RNs to have a voice in policy development. Allow charge RNs to make decisions instead of always having to escalate through unit managers to senior management.” (HCP-271)</li> </ul>  |
| <p><b>Theme 3: Implementation (n=84)</b></p>   | <p><b>Exemplar quotes</b></p>   |
| <p><b>Exceptions to the rules</b> (n=49)</p> <ul style="list-style-type: none"> <li>• Palliative patients and end-of-life care (n=22)</li> <li>• Transparent process (n=22)</li> <li>• Fewer/limited exceptions (n=3)</li> </ul> | <ul style="list-style-type: none"> <li>• “Access to end of life patients (non-pandemic causes) should not be restricted.” (HCP-028)</li> <li>• “Clear guidelines regarding exceptions to the visitation policy to try and reduce bias and inconsistencies.” (HCP-073)</li> <li>• “Have more support for nights and weekend for bedside staff/ families who are trying to get exceptions.” (HCP-140)</li> <li>• “fewer exemptions. I felt like anyone could get an exemption for anything they wanted.” (HCP-203)</li> </ul> |
| <p><b>Provision of supports for families</b> (n=24)</p>  | <ul style="list-style-type: none"> <li>• “The hospital should invest in some ipads/phones to use so that people can see loved ones through skype etc.” (HCP-337)</li> <li>• “providing staff with more resources with how to help parents/guardians with coping outside the hospital be ideal.” (HCP-110)</li> <li>• “Support to enable parents to stay with child in room, meals provided, etc to avoid movement around the building” (HCP-223)</li> </ul>   |
| <p><b>Consistency</b> (n=17)</p>   | <ul style="list-style-type: none"> <li>• “There needs to be more consistency with policies and how they are implemented. It seemed that we were making certain exceptions in some cases and putting other patients/staff at risk.” (HCP-086)</li> <li>• “The same rules should apply to every single family.” (HCP-247)</li> </ul>  |
| <p><b>Communication</b> (n=14)</p>   | <ul style="list-style-type: none"> <li>• “information on how to convey this to families in a sensitive manner [...]” (HCP-001)</li> <li>• “Information pamphlet to be given to parents/caregiver of child with clear, specific guidelines and instances when modifications could be made followed with clear explanation as to why these rules are in place.” (HCP-359)</li> </ul>  |
| <p><b>Enforcement</b> (n=8)</p>  | <ul style="list-style-type: none"> <li>• “Training for staff who will have to enforce it.” (HCP-098)</li> <li>• “Ask administrators to enforce the rules when parents cannot understand the policy (this should not be part of the nursing role as it completely breaks down the therapeutic relationship).” (HCP-209)</li> </ul>   |

\*Response to question: For future pandemic waves, what should go into a policy related to family visitation and presence in the PICU?