FAMILY PRESENCE DURING A PANDEMIC: GUIDANCE FOR DECISION-MAKING

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The **Institute for Patient- and Family-Centered Care** (IPFCC), a non-profit organization founded in 1992, takes pride in providing essential leadership to advance the understanding and practice of patient- and family-centered care. By promoting collaborative, empowering relationships among patients, families, and health care professionals, IPFCC facilitates patient- and family-centered change in all settings where individuals and families receive care and support. IPFCC also serves as a central resource for policy makers, administrators, program planners, direct service providers, educators of health care professionals, researchers, design professionals, and patient and family leaders.

Since the beginning of COVID-19, IPFCC has been creating new resources and networking opportunities for the field focused on maintaining patient- and family-centered care and its fundamental partnerships during the pandemic. For further information: www.ipfcc.org/bestpractices/covid-19/index.html

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BACKGROUND

Whether the family member is a parent trying to support a child or an adult child trying to support a parent, he or she is an essential care partner who should not be excluded from the bedside . . . Starting with hospital admission . . . clinicians are stretched to triage patients and accurately assess their symptoms, pain levels, and mental health status without communication from a family caregiver. Providers are further challenged at the time of patient discharge, without the critical partnership with a family caregiver, as they work to ensure at-home care will be both appropriate and thorough. (Reinhard, et al., 2020)

Although families may be defined in different ways and different terminology may be used (e.g., caregiver, care partner), their presence is essential to the care of patients in hospitals and other settings of care – and their role is distinct from that of visitors.[1]

For years, the Institute for Patient- and Family-Centered Care (IPFCC) has championed family presence and participation, most notably through its ***Better Together*** campaign, launched in 2014 and expanded across Canada through IPFCC's partner, the Canadian Foundation for Healthcare Improvement (CFHI). The campaign made significant progress in 1) changing the concept of families as "visitors" to recognizing their importance to the quality, experience, safety, and outcomes of health care, and 2) reducing restrictions on the presence and participation of family members in health care settings (Dokken et al., 2015; Dokken et al., 2020).

However, in March 2020, faced with the overwhelming COVID-19 pandemic, hospitals, health systems, outpatient settings, and nursing homes in the United States, Canada, and other countries around the world felt it was necessary to restrict "visitors" and family members to stop the spread of the virus and ensure the safety of staff, patients, families, and communities. Generally, families were not allowed to be present with loved ones; their ability to participate in care, care planning, and decision-making was severely limited. While this initial response is understandable given the significant clinical uncertainty which existed at the beginning of the pandemic, it is crucial to revisit it now that we know so much more about the clinical context. Serious consequences or harms of these restrictions for patients, for their families, and for health care professionals are increasingly coming to light. For example, articles in the *New York Times* reported:

> "Clinicians and hospital staff said keeping families away had been among the darkest experience of their professional lives. The restrictions run counter to a hospital's desire to keep patients and families together, not only for the salutary effect of something as simple as a hand held, or a chair pulled close to a bed, but because having a relative present can ease the workload of the medical team. It can also provide crucial information that a confused patient may not be able to offer." (Hafner, 2020)
>
> A critical care physician shared, "A hospital without loved ones is slowly becoming our new normal, a reality that threatens to upend the role of the family in the care of our hospitalized patients . . .Unless we focus on hospital visitor policies with real urgency, regularly and openly revisiting these rules as the coronavirus caseloads change in a given region, I can see our gains slipping away." (Lamas, 2020)

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[1] For the purposes of this document, we are using definitions modified from the report, *Sick, Scared & Separated from Loved Ones* (2019). The term "family member, caregiver, or care partner" is used to describe individuals, whether related to the patient or not, who have been identified by the patient as support persons whom hospitals and other settings should consider to be partners in care for the patient. The term "visitor" refers to other family members or friends who have not been designated by the patient to play such an involved role but nevertheless are individuals the patient would like to see from time to time while in a health care setting.

As reflected in quotes like the ones above, COVID-19 and the response of health care systems across North America and across the world have highlighted family presence in health care settings as a critical issue that must be re-addressed. For example:

- Stories and interviews like the ones excerpted above have appeared in the media.
- Emerging best practices for health care organizations since the beginning of the COVID-19 pandemic have been documented and new resources developed.
- Collaborative initiatives have created initial responses and recommendations:
  - *Person-Centered Guidelines for Preserving Family Presence in Challenging Times* (2020); led by Planetree International and the Pioneer Network
  - *Re-Integration of Family Caregivers as Essential Partners in Care* (2020, July), led by CFHI. CFHI together with the Canadian Patient Safety Institute built on this report with *Policy Guidance for the Reintegration of Caregivers as Essential Care Partners* (2020, November) and, subsequently, launched a new program, *Essential Together,* with practical resources to support implementation of the guidance. These resources include pre-entry preparation for families (essential care partners), a screening process, and education for staff about roles and safety protocols for essential care partners.
- A research report, *Experiences of Nursing Home Residents During the Pandemic: What We Learned from Residents About Life Under Covid-19 Restrictions and What We Can Do About It* (Montgomery et al., 2020), released by Altarum offers recommendations for protecting the health and well-being of residents in nursing homes.

In hindsight, we know that the early responses of health care systems and the resulting restrictions on family presence and participation were implemented quickly in an environment of uncertainty and chaos. As a result, it is important now to carefully re-consider the decisions in a fuller context, including:

1. Learnings about restrictions on family presence during SARS and H1N1;
2. Evidence about the benefits of family presence, data showing lack of association between family presence and infection spread, and growing evidence about the harms caused by the restrictions;
3. Core concepts of patient- and family-centered care (PFCC), i.e., dignity and respect, information-sharing, participation, and collaboration; and
4. Key ethical principles, i.e., respect for autonomy (grounded in respect for persons) (Jonsen, Siegler, & Winslade, 2015), beneficence, non-maleficence, justice (Beauchamp & Childress, 2019).

This paper provides a broad context with guidance for decision-making in the future – whether for additional surges in COVID-19 or for other public health crises. It will (1) summarize the evidence and history as well as relevant concepts and principles from PFCC and bioethics and (2) based on that, provide new tools for collaborative decision-making, with the goal of achieving a **balance** between benefits and harms among different groups impacted in the short and longer term.

CONTEXT FOR DECISION-MAKING

Learnings from SARS and H1N1

Like the recent reaction to COVID-19, during SARS, the first pandemic of the 21st century, health officials and hospital leaders leaders in some parts of the world restricted the presence of family members as part of their initial response. With the "wisdom of hindsight," especially for the experience in Canada, the impact of these restrictions were looked at more carefully, harms were more clearly identified, and recommendations were made to not restrict family presence and participation so drastically in response to future pandemics.

- In Markwell's and Godkin's (2004) "Visitor Restrictions During a Public Health Emergency: Ethical Issues and Guidelines for Policy Development," thematic analysis of SARS related documents, the authors identified several recurring issues related to the restrictions: detrimental psychological impact in which staff, patients, residents and families struggled with issues related to loneliness and isolation; communication breakdowns which contributed to a sense of chaos and distress, and wide and varied interpretation and implementation of directives from the Ontario Ministry of Health and Long-Term Care – viewed by some as overly restrictive and by others as too lenient.

- In "Privileged Presence: Personal Stories of Connections in Health Care," (2006; 2014) authors Liz Crocker and Bev Johnson in a chapter titled, "It Was as Hard as It Gets: The Impact of a Global Crisis on Family-Centered Care," powerfully describe the "lockdown mentality" of the SARS restrictions and urged the healthcare field to learn from the past.

- With the arrival of H1N1, a Working Group, convened by IPFCC in October 2009, created a set of guidelines titled, "Pandemic Planning and Patient- and Family-Centered Care." The introduction to the guidelines cautioned decision-makers to **balance** containment of an infectious disease with recognition that "family members are integral to the healing of loved ones."

- In May 2020, IPFCC Board Member Liz Crocker wrote a commentary titled, "We've Been Here Before: Learning from the Lessons of the Past," urging that the past (SARS, H1N1) serve as a "teacher" about the "profound emotional side effects of family separation and patient isolation."

Evidence About Family Presence

Organizations from the Joint Commission to the American Association of Critical-Care Nurses support family presence and participation in patient care across all health care settings. For example, when the Society of Critical Care Medicine released its *Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU* (Davidson et al., 2017), lead author Judy Davidson commented: "Family presence, improved communication and family engagement in care may reduce post-intensive care syndrome for both patients and their family members, ultimately improving the health of our community" (Society of Critical Care Medicine, 2018). Given the nature of treatment for patients most severely affected by the COVID-19 pandemic, this information is particularly important.

Past studies have indicated that family presence in adult critical care is **not** associated with increased infection rates; in fact, the rate may decrease (Bishop & Walker, 2013; Fumagalli et al., 2006). Data also exist about the importance of family presence for elderly patients – a population especially vulnerable to the effects of COVID-19. For those patients, hospitalization for acute or critical illness is often associated with reduced cognitive function (Ehlenbach et al., 2010). Family caregivers/care partners may be much more keenly aware of a change in cognitive function and can provide valuable information to hospital staff.

For many decades, health care professionals have often believed that families were the major source of infections. However, research revealed that lack of handwashing or non-compliance with infection control protocols by staff and clinicians are the major sources of infections in hospitals, not families. Emerging data about the COVID-19 restrictions also suggest that family presence may **not** increase infection rates. Initial findings from a study in the Netherlands to "open" nursing homes showed no new infections in 26 participating facilities (Verbeek et al., 2020). Given the increased risk for COVID-19 in nursing homes and long-term care facilities, this is compelling data. Research in the hospital setting supports the conclusion that: "At present there is limited evidence to support visitors having an important role in hospital-related transmission of COVID-19" (Munshi et al., 2020).

Conversely, other new data are beginning to highlight some of the harms caused by the restrictions, especially the impact on the mental health of clinicians, patients, and families. Recent articles are documenting the moral distress experienced by clinical staff who feel that it is not right to separate patients and their families (Morley et al., 2020). A study of ICUs in 49 Michigan hospitals, conducted in April/May 2020, looked specifically at restrictions to visitation policies and the impact on patients. "For patients, early reports of COVID-19 described high rates of delirium and sedation requirements…" – conditions found in other studies to be reduced by access to family members (Valley et al., 2020). And, family members who cannot be with their loved ones also suffer emotional harm that may have long term effects, as Montauk and Kuhl noted, "The psychological impact of COVID-related separation on ICU families will reverberate for years and likely result in high numbers of people needing trauma-related services" (2020).

A comprehensive essay in the *Journal of Law and the Biosciences* also addresses the issue of harm to mental health. It looks at the recent restrictions on the presence of support persons for women in labor in the broader context of legal protection of women's rights during childbirth – and urges better understanding of the harms on the "emotional and physical well-being of birthing women and their families" (Gan-Or, 2020).

A recent study in the UK and the US looked at the impact of restrictions on family presence in newborn intensive care. Sixty-two percent of respondent parents found the stricter policies to be "restrictive." Forty-one percent reported that they were not able to bond enough with their infants (Muniraman et al., 2020). Another recent article in *Pediatric Nursing,* written by Family Faculty with the Vermont Oxford Network, summarized, "Increased anxiety and stress, decreased care and learning opportunities for families, and interrupted bonding may all have a lasting impact on long-term outcomes for babies, as well as on the mental health of family members" (Bainter et al., 2020).

Patient- and Family-Centered Care (PFCC) Core Concepts

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It is based on the following four core concepts:

- **Dignity and respect** for patients and their families and for all staff and clinicians
- **Information sharing** with patients and families in ways that are useful and affirming
- **Participation** of patients and families in care, care planning, and decision-making
- **Collaboration** with patients and families as key stakeholders at all levels in health care organizations, including policy changes and communication about the changes

Grounded in respect for patients and their families, the remaining three PFCC concepts then suggest ways to "operationalize" respect in health care. All four concepts are consistent with fundamental principles of bioethics – and together must be foundational to decision-making about family presence during a pandemic.

Ethical Principles

Like the core concepts of PFCC, the four fundamental principles of bioethics begin with respect for persons and focus on maximizing benefits and reducing harm.

- Respect for persons
- Beneficence, i.e., do good
- Non-maleficence, i.e., avoid harm
- Justice (In this context, an example of justice would be to avoid disproportionate harm done to the most vulnerable patients and populations, including those with cognitive impairments, infants and children, women in labor, patients at the end-of-life. According to the United Nations Office for the Coordination of Humanitarian Affairs, "Vulnerable groups, such as the elderly, indigenous people, those with disabilities, adolescents, and refugees and migrants face a greater risk from COVID-19") (Krubiner et al., 2020).

Ethicists, including a pandemic working group from the University of Toronto Joint Centre for Bioethics, have also highlighted additional ethical values to influence decision makers who are trying to balance competing benefits in public health emergencies (Pandemic Influenza Working Group, 2005). The ten "substantive values" are: individual liberty, protection of the public, proportionality, privacy, duty to provide care, reciprocity, equity, trust, solidarity, and stewardship.

The direct application of these ethical principles to the role of family members in health care is not new, for example:

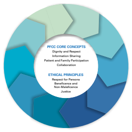
- Markwell's and Godkin's SARS work in 2004 described earlier on page 6.

- United Hospital Fund's ethical framework, developed in 2006, to guide public policy that recognized family caregivers as partners in family members' care and as clients in their own right. This framework was intended to "spell out the standards by which specific regulations, policies, and programs" could be measured (United Hospital Fund, 2006).

And, currently, in the US and in Canada, many health care organizations have ethicists on staff and/or ethics committees who regularly employ ethical frameworks for decision-making. They have been involved in the process of developing policies/guidelines on family presence. One example is the Saskatchewan Health Authority (SHA), which like some other organizations in Canada, views open family presence as being foundational at the provincial level. As a result, SHA has developed three levels of policy directives for family presence depending on prevalence and rates of infection during COVID-19; for example, for patients at end-of-life, two family members can be present.

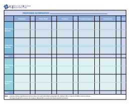
TOOLS FOR GUIDING DECISION-MAKING FOR FAMILY PRESENCE AND PARTICIPATION WITHIN A PATIENT- AND FAMILY-CENTERED ETHICAL FRAMEWORK

Integrating both the core concepts of PFCC and fundamental principles of bioethics, three tools, with instructions for their use, have been developed to facilitate decision-making moving forward. They are intended to be used "in tandem" and by a collaborative decision-making team of key stakeholders, including patient and family advisors.



1. The initial tool is a graphic outlining a 10-step **iterative,** collaborative, decision-making process (Appendix 1, page 17)

2. The second tool outlines key questions for each of the 10 steps (Appendix 2, pages 18 – 20)



3. The third tool, a matrix, supports the decision-making team in considering the relative **balance** of benefits and burdens/harms to key groups in both the short- and the longer-term (Appendix 3, page 21)

Note: Instructions for using the tools are outlined on page 16

CONCLUSION

Despite the promise of vaccines, every indication suggests that North America and other parts of the world will be impacted for additional months – or even years – by COVID-19. Patients in hospitals, health systems, outpatient settings, and nursing homes cannot continue to be separated from family members and caregivers. The essential role of families in contributing to the quality, experience, safety, and outcomes of care cannot continue to be restricted.

Thoughtful recent articles about family presence during the pandemic emphasize that public health concerns and patient- and family-centered care can "co-exist" and be "compatible," even during a pandemic (Voo, 2020; Curley, 2020). Joining other recommendations to "preserve family presence," a January 2021 consensus statement issued by three professional associations calls on staff and leaders to "**balance** the risks and benefits of specific policies, such as visitation guidelines, with respect to the holistic needs of the family" (AWHONN, NANN, & NPA, 2021).

These recommendations are positive signs and, as a result, we agree with the conclusion of an editorial in *Pediatric Nursing* journal:

> *At the beginning of the pandemic, decisions were often made in crisis mode to quickly protect safety. Restricting family presence is one example. However . . . creative and caring individuals – clinicians and patient/family advisors – have begun to re-visit earlier decisions and are finding new ways to keep patients and families connected. These are hopeful signs.* (Dokken & Ahmann, 2020)

Please use the tools included in the Appendices to establish a collaborative process to make and continually "revisit" your institution's decisions about family presence and participation.

To help organizations identify, prepare, and support care partners in their roles in health care and to guide implementation, the Canadian Foundation for Healthcare Improvement, in partnership with the Canadian Patient Safety Institute, developed a set of online resources, *Essential Together.* These practical resources can serve as a complement to the decision-making tools.

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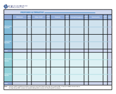
For more information and resources visit IPFCC's website section, *PFCC and COVID-19* at https://www.ipfcc.org/bestpractices/covid-19/index.html

APPENDICES

1. **An Iterative Process for Decision-Making Within a Patient- and Family-Centered Ethical Framework**



2. **Implementation of the Ten-Step Iterative Process**
3. **A Matrix for Decision-Making: Consideration of the Balance of Benefits and Harms**

Instructions for Use of Decision-Making Tools

- Leaders charged with decision-making for family presence designate a preliminary decision-making team.

- Note: Reviewing the membership of that team to see if any key perspectives/groups are missing will be one of the 1st tasks of the team when it meets.

- Circulate the guidance document and tools in the appendices beforehand and schedule a first meeting. Ask that all members review the guidance document and tools prior to this first meeting.

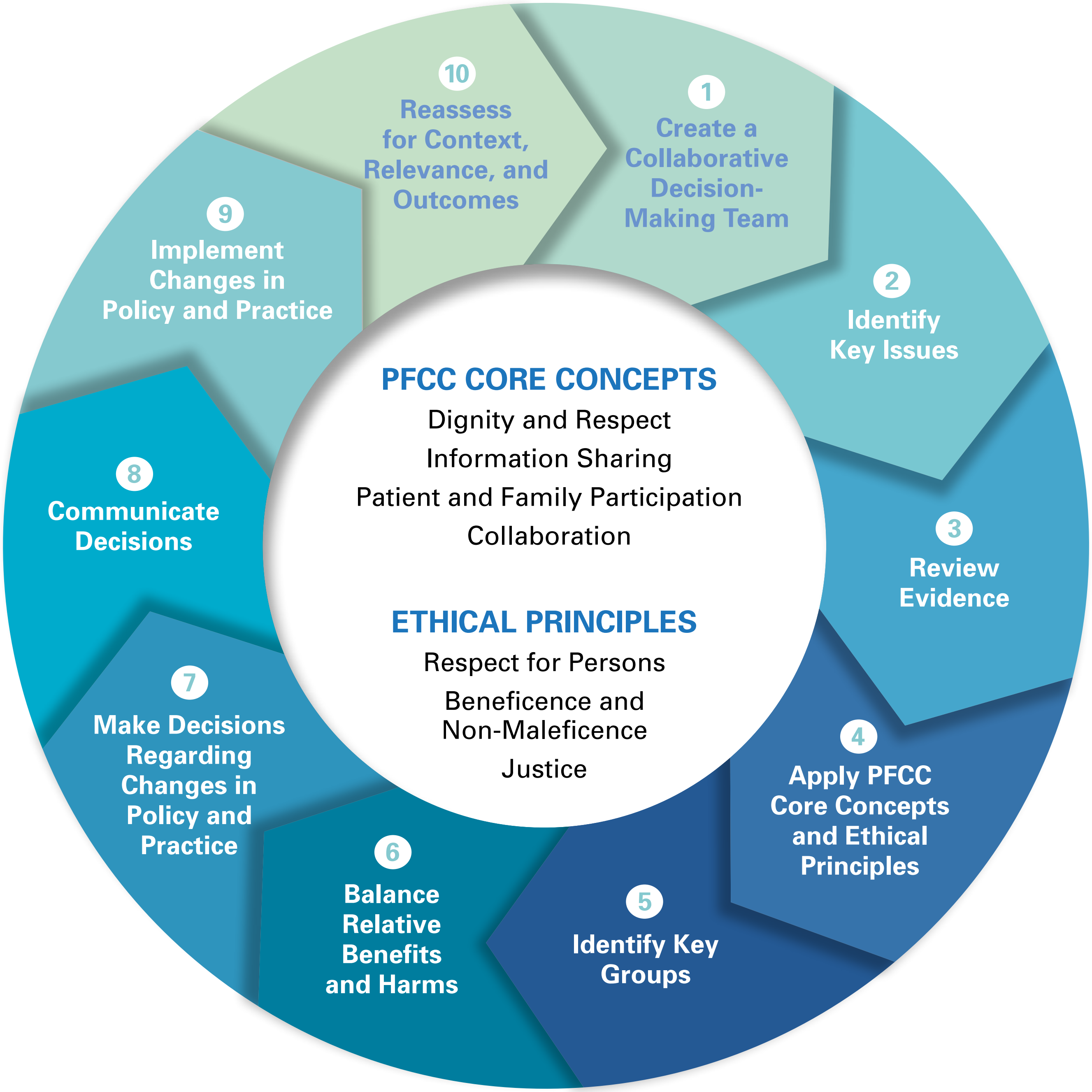
- At the first meeting:
  - Review **An Iterative Process for Decision-Making Within a Patient- and Family-Centered Ethical Framework** (Appendix 1), emphasizing that the proposed decision-making process is iterative.
  - Turn to **Implementation of the Ten-Step Iterative Process** (Appendix 2) and focus on Step 1, i.e., creating the collaborative team.
    Note: When completing Step 1, if it is determined that members need to be added, it may be necessary to "pause" in the process and schedule a second meeting when they can join the team as full members.

- At subsequent meeting(s):
  - Using Steps 2-5 in the iterative process, complete background information.
    Note: The guidance document accompanying the tools will provide help.
  - To complete Step 6: Utilize the **Matrix for Decision-Making** (Appendix 3)) to identify policy/practice alternatives. See separate instructions for use of the matrix on page 21. The matrix begins on page 22.
  - Complete Steps 7-10, including communication about any decisions made about changes in policy and practice.
  - Establish a date for the group to re-convene and re-assess the context, relevance, and outcomes of the changes.

- At subsequent meeting(s), continue this iterative process as appropriate with changes in the pandemic.

Appendix 1

An Iterative Process for Decision-Making Within a Patient- and Family-Centered Ethical Framework



1 Create a Collaborative Decision-Making Team

2 Identify Key Issues

3 Review Evidence

4 Apply PFCC Core Concepts and Ethical Principles

5 Identify Key Groups

6 Balance Relative Benefits and Harms

7 Make Decisions Regarding Changes in Policy and Practice

8 Communicate Decisions

9 Implement Changes in Policy and Practice

10 Reassess for Context, Relevance, and Outcomes

PFCC CORE CONCEPTS

Dignity and Respect
Information Sharing
Patient and Family Participation
Collaboration

ETHICAL PRINCIPLES

Respect for Persons
Beneficence and Non-Maleficence
Justice

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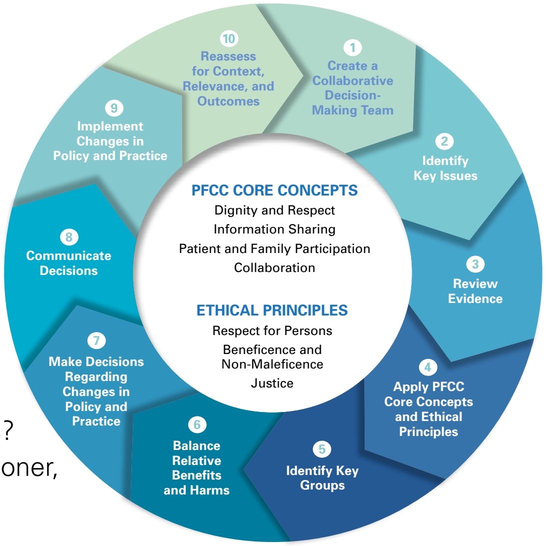
Catholic Health Association of Canada. (2000). *Health ethics guide* (2nd ed.).

Center for Clinical Ethics. (2016). *Decision-making framework: YODA.* https://ccethics.com/ethics-service/decision-making-framework/

Appendix 2



Implementation of the Ten-Step Iterative Process[2]

1. Create a Collaborative Decision-Making Team

- Who are the relevant stakeholders?
- Are the "right" people involved in the decision-making process:
  - Patients, residents in long-term care, and families/care partners?
  - Frontline staff, clinicians, an ethicist, an infection control practitioner, and managers/leaders?
  - Community members?
- Do the people involved represent the diversity of the community served?
- Do we need to involve others in the conversation?
- Have we ensured that individuals who serve on patient and family advisory councils, resident and family councils, and other partnership committees are full members of the team?
- How do we ensure that power is shared among all participants in the discussions?
- How are we being intentional in building trust about the process among all participants?

2. Identify Key Issues

- Prior to the pandemic, what was our organization's policy or guidelines about family presence and participation?
- How did we change our organization's policy or guidelines in 2020?
- What are the principal factors "pushing" for change now?
- What is the current impact of the pandemic in our geographic area?

3. Review the Evidence

- How have similar issues been resolved in the past (e.g., SARS) and what were the outcomes?
- What is the evidence about the benefits of family presence to patient safety and outcomes?
- What do government leaders and agencies, laws, and public health advisories say about the issues?
- How have other organizations addressed the issue of family presence?

4. Apply PFCC Core Concepts and Ethical Principles

- How do the foundational values of the organization inform our decision-making?
- Have we ensured that patient- and family-centered core concepts and ethical principles are centrally involved in the decision-making?

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[2] Embedded in this iterative process is recognition of procedural values, including empowerment, relevance, publicity/transparency, and compliance (Daniels & Sabin, 2002).

Appendix 2

Implementation of the Ten-Step Iterative Process *continued*

4. Apply PFCC Core Concepts and Ethical Principles *continued*

- Are the concepts and principles in conflict with other values?
- Are there any other relevant values that should be considered?
- How can we balance public health standards for infection control with patient safety, quality of life, and other concerns like the emotional and mental health needs of patients, families, staff, and leaders?

5. Identify the Key Groups Impacted

- What are concerns, values, and priorities of the key groups who will be impacted:
    - Patients, residents in long-term care, and families/care partners?
    - Frontline staff, clinicians, and managers/leaders?
    - The community?
- Are their concerns in conflict with those of the hospital, health system, or long-term care facility? If so, how?

6. Balance the Relative Benefits and Harms (short- and longer-term) of Different Alternatives (Utilize the matrix in Appendix 3):

- What alternatives are we considering?
- How do we balance benefits and burdens for the key groups impacted?
- How can we minimize potential burdens or harms for each group?
- How do we address issues of justice and equity?
- How have we addressed the needs of the most vulnerable?
- Have we disregarded any viable alternatives?
- Based on patient- and family-centered core concepts and ethical principles, what alternative has the strongest justification?

7. Make Decisions Regarding Changes in Policy and Practice

- Have we clearly stated the changes in policy and practice?
- Have we documented the issues, decision-making process, and outcomes sufficiently?
- What is the process for step-by-step implementation?
- Has an appeals process been outlined?
- Have the resources and support needed by each key group for implementation been identified?
- Is there flexibility so that policy and practice can be modified in response to changes in clinical and public health needs?

Appendix 2

Implementation of the Ten-Step Iterative Process *continued*

8. Communicate the Decisions

- Who are the best people or groups to communicate the decisions?
- What is the best process for ensuring that decision-making is transparent, i.e., all key groups understand the reasons for the decisions and the steps for implementation?
- Is the communication understandable to all key groups, e.g., health literacy, dominant language of communication?

9. Implement Changes in Policy and Practice

- Who are the best people or groups to lead implementation of changes in policy and practice?
- When is the appropriate timeframe in which to implement these changes?
- When do we want to first assess the impact of the changes?

10. Reassess for Context, Relevance, and Outcomes

- What went well as the changes were implemented?
- Were there any harms that were not anticipated?
- What feedback have we received from the key groups such as:
    - Patients, residents in long-term care, and families/care partners?
    - Frontline staff, clinicians, and managers/leaders?
    - The community?
- Has the situation with the pandemic changed in our geographic area?
- In light of the feedback and/or the pandemic itself, are the changes still relevant or do we need to further modify current policies, guidelines, procedures, etc.?

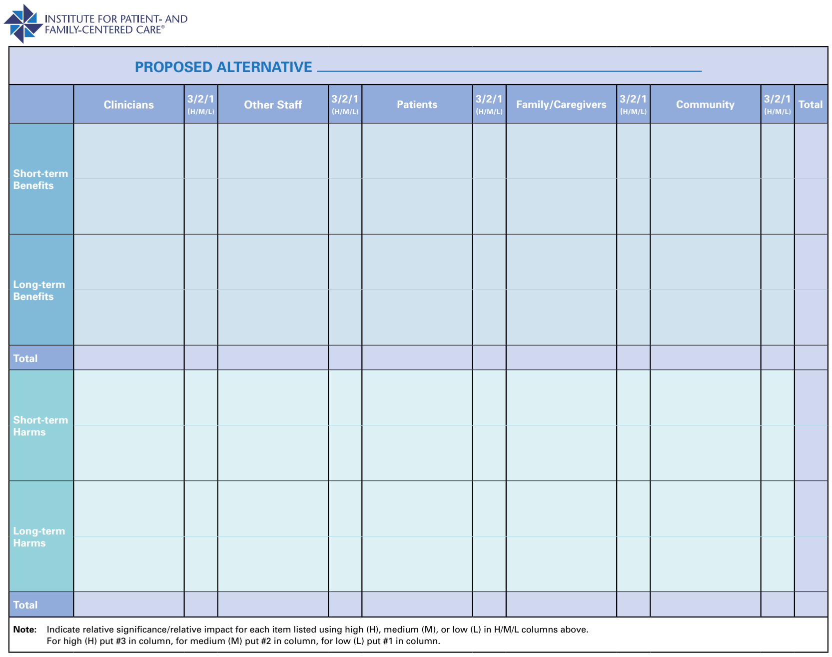
Adapted with permission from the Catholic Health Alliance of Canada in Ottawa and the Centre for Clinical Ethics at Unity Health Toronto.

Catholic Health Association of Canada. (2000). *Health ethics guide* (2nd ed.).

Center for Clinical Ethics. (2016). *Decision-making framework: YODA.* https://ccethics.com/ethics-service/decision-making-framework/

Appendix 3

A Matrix for Decision-Making: Consideration of the Balance of Benefits and Harms



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PROPOSED ALTERNATIVE ______________________________

	Clinicians	3/2/1 (H/M/L)	Other Staff	3/2/1 (H/M/L)	Patients	3/2/1 (H/M/L)	Family/Caregivers	3/2/1 (H/M/L)	Community	3/2/1 (H/M/L)	Total
Short-term Benefits											
Long-term Benefits											
Total											
Short-term Harms											
Long-term Harms											
Total											

Note: Indicate relative significance/relative impact for each item listed using high (H), medium (M), or low (L) in H/M/L columns above.
For high (H) put #3 in column, for medium (M) put #2 in column, for low (L) put #1 in column.

Instructions for Use of the Matrix

As a tool for decision-making, the matrix provides an opportunity for the collaborative group to carefully consider the relative **balance** of benefits and harms to key groups in both the short and the longer-term. The matrix begins on the following page. **You must use a designated PDF Reader to utilize the interactive, built-in, features of the matrix.**

1. Begin by typing a descriptive title for your identified **Alternative #1** at the top of the matrix.
2. Click inside each box to start typing. There are two sections within each of the benefit boxes and the harm boxes.
   Note: There is no text limit. Each box will automatically change to "scroll mode" to accommodate your text. The overall size of the box will not change. However, the full text will auto-populate on subsequent Summary pages (see 6.a. and b. below).
3. After you describe a benefit or harm for a particular group, rank it (3, 2, 1) in the narrow column to the right of the box. A ranking of 3 is for highest benefit or harm, 2 is moderate, and 1 is for the lowest.
   Note: All ranking totals will auto-populate as you fill out the matrix.
   Continue to another set of two boxes and repeat the process until the matrix is completed.
4. Proceed to your identified **Alternative #2** on the next page and repeat the process of describing and ranking benefits and harms.
5. If your group has identified an **Alternative #3,** continue to page 3 of the tool and repeat the process.
6. Upon completion of pages for each Alternative:
   a. You may print the completed matrix pages for the alternatives but the scrolled text will not appear.
   b. If you want to view and print the full text of benefits and harms for each alternative, subsequent Summary pages will be auto-populated as you complete each matrix. Therefore, **you do not need to re-type any text yourself.**

PROPOSED ALTERNATIVE #1 ______________________________

	Clinicians	3/2/1 (H/M/L)	Other Staff	3/2/1 (H/M/L)	Patients	3/2/1 (H/M/L)	Family/Caregivers	3/2/1 (H/M/L)	Community	3/2/1 (H/M/L)	Total
Short-term Benefits											0
											0
Long-term Benefits											0
											0
Total		0		0		0		0		0	0
Short-term Harms											0
											0
Long-term Harms											0
											0
Total		0		0		0		0		0	0

Note: Indicate relative significance/relative impact for each item listed using high (H), medium (M), or low (L) in H/M/L columns above.
For high (H) put #3 in column, for medium (M) put #2 in column, for low (L) put #1 in column.

PROPOSED ALTERNATIVE #2 ____

	Clinicians	3/2/1 (H/M/L)	Other Staff	3/2/1 (H/M/L)	Patients	3/2/1 (H/M/L)	Family/Caregivers	3/2/1 (H/M/L)	Community	3/2/1 (H/M/L)	Total
Short-term Benefits											0
											0
Long-term Benefits											0
											0
Total		0		0		0		0		0	0
Short-term Harms											0
											0
Long-term Harms											0
											0
Total		0		0		0		0		0	0

Note: Indicate relative significance/relative impact for each item listed using high (H), medium (M), or low (L) in H/M/L columns above.
For high (H) put #3 in column, for medium (M) put #2 in column, for low (L) put #1 in column.

PROPOSED ALTERNATIVE #3 ____________________

	Clinicians	3/2/1 (H/M/L)	Other Staff	3/2/1 (H/M/L)	Patients	3/2/1 (H/M/L)	Family/Caregivers	3/2/1 (H/M/L)	Community	3/2/1 (H/M/L)	Total
Short-term Benefits											0
											0
Long-term Benefits											0
											0
Total		0		0		0		0		0	0
Short-term Harms											0
											0
Long-term Harms											0
											0
Total		0		0		0		0		0	0

Note: Indicate relative significance/relative impact for each item listed using high (H), medium (M), or low (L) in H/M/L columns above.
For high (H) put #3 in column, for medium (M) put #2 in column, for low (L) put #1 in column.

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Summary: Proposed Alternative 1 Short-term Benefits

Clinicians

Other Staff

Patients

Family/Caregivers

Community

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Summary: Proposed Alternative 1 Long-term Benefits

Clinicians

Other Staff

Patients

Family/Caregivers

Community

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Summary: Proposed Alternative 1 Short-term Harms

Clinicians

Other Staff

Patients

Family/Caregivers

Community

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

Summary: Proposed Alternative 1 Long-term Harms

Clinicians

Other Staff

Patients

Family/Caregivers

Community

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Summary: Proposed Alternative 2 Short-term Benefits

Clinicians

Other Staff

Patients

Family/Caregivers

Community

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Summary: Proposed Alternative 2 Long-term Benefits

Clinicians

Other Staff

Patients

Family/Caregivers

Community

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

Summary: Proposed Alternative 2 Short-term Harms

Clinicians

Other Staff

Patients

Family/Caregivers

Community

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

Summary: Proposed Alternative 2 Long-term Harms

Clinicians

Other Staff

Patients

Family/Caregivers

Community

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

Summary: Proposed Alternative 3 Short-term Benefits

Clinicians

Other Staff

Patients

Family/Caregivers

Community

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

Summary: Proposed Alternative 3 Long-term Benefits

Clinicians

Other Staff

Patients

Family/Caregivers

Community

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

Summary: Proposed Alternative 3 Short-term Harms

Clinicians

Other Staff

Patients

Family/Caregivers

Community

Summary: Proposed Alternative 3 Long-term Harms

Clinicians

Other Staff

Patients

Family/Caregivers

Community