Themes, Topics, Questions, and Recommendations

Learning from Experience:
Exploring the Impact of
Approaches to Family Presence
in Hospitals During COVID-19

INSTITUTE FOR PATIENT- AND
FAMILY-CENTERED CARE®

Transforming health care through partnerships
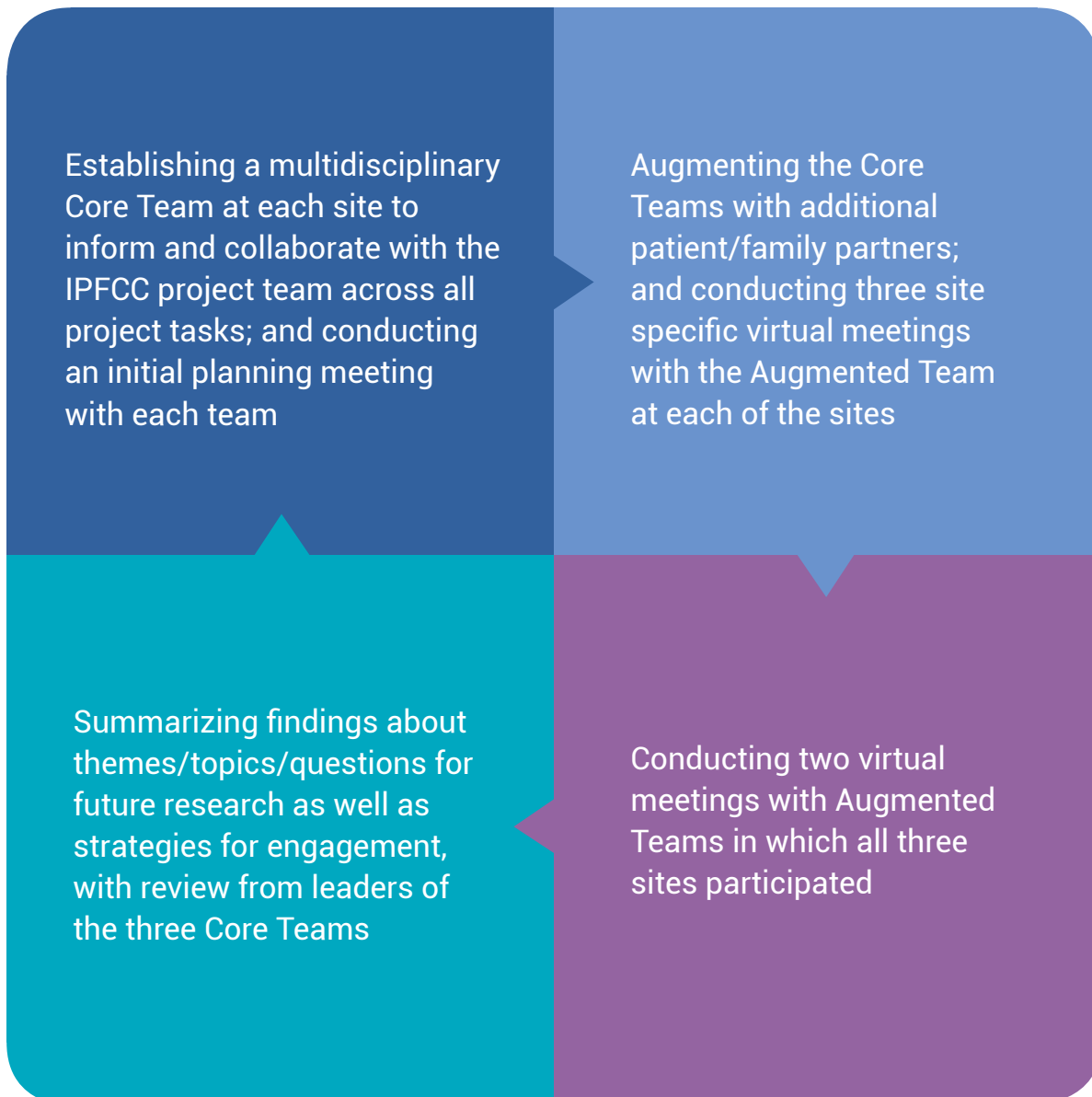
INTRODUCTION

The Institute for Patient- and Family-Centered Care (IPFCC) partnered with three health systems on the project, *"Learning from Experience: Exploring the Impact of Approaches to Family Presence in Hospitals During COVID-19,"* funded through a Eugene Washington PCORI Engagement Award. The project's purpose was to engage key stakeholders – patients, families, staff and clinicians – and to learn their perspectives about the impact of approaches to family presence during the pandemic in order to inform future research. The following summary of our experience shares what we learned and offers guidance to researchers, leaders and staff of hospitals/health systems, patient/family partners, and others.

> *When COVID was hitting initially, nobody knew anything… You didn't really know what it did or how to not get it and so it was just this awful kind of cloudy experience.* (Physician)

KEY PROJECT ACTIVITIES

The IPFCC project team engaged teams, including patient and family partners, from three health systems to learn their perspectives about family presence during the pandemic and to develop themes/topics/questions to inform future research. The following graphic presents the key project activities.

Establishing a multidisciplinary Core Team at each site to inform and collaborate with the IPFCC project team across all project tasks; and conducting an initial planning meeting with each team

Augmenting the Core Teams with additional patient/family partners; and conducting three site specific virtual meetings with the Augmented Team at each of the sites

Summarizing findings about themes/topics/questions for future research as well as strategies for engagement, with review from leaders of the three Core Teams

Conducting two virtual meetings with Augmented Teams in which all three sites participated

An Analysis of Meeting Discussions and Findings is included as an Appendix.

IPFCC developed a companion resource offering guidance about meaningful engagement of patients and families. See *Strategies for Engaging Patients and Families as Stakeholders.*

THEMES AND TOPICS

1

Restrictions negatively impacted communication and information-sharing

When families were restricted from being at the bedside, there were negative impacts on communication and information-sharing. For example, information about patients' prior use of or problems with medications might not be known if families were not present to share this information or confirm.

I wasn't allowed to have anybody come in with me (ER). It was just not having somebody in the room that was able to communicate what I had been dealing with over the past months. (Non-COVID patient hospitalized during COVID)

Only one parent, only one caregiver was allowed to be with [patient]. And so my husband decided to go during the surgery... Just not knowing what was going on, not knowing when he [son] was going to be taken back. I was really having to rely on my husband to give me constant updates. (Family member, pediatric non-COVID patient)

Communication was via telephone, which could be difficult in a unit that was locked down with fans blowing to create the negative pressure environment that we had. So it was really hard to talk to families over the phone. (RICU nurse)

2

Restrictions negatively impacted patient care

Restrictions on family presence adversely impacted patient care. For example, families could not advocate for their loved ones or provide direct care (e.g., bathing), support, and comfort (e.g., providing food).

A big thing that happened was I was allergic to a lot of medication. And because of the lack of communication, they had given me medications that I was allergic to. And my husband kept trying to get fax numbers to fax them the medications and stuff. So I think medical care lost, too. (COVID patient)

I did struggle a little bit with pain and kind of emotional reactions post C-section. I think if my mom had been there, she would have noticed the change in my mental state a lot sooner. So I think I would have been able to get that medical attention for me sooner. (Non-COVID L&D patient)

3

Restrictions negatively impacted decision-making

Without families at the bedside, patients did not have input into critical decisions. These decisions were delayed because families either had to participate through technology, or lacked the direct experience of the patient's condition needed to make decisions.

Whenever anything needed to be done, instead of me being right there and saying, "Okay, let's get it done!" There was a phone call that needed to be made. And, then, I would conference in whoever needed to make that decision with me. And, we would have that conversation over the phone. So, there probably was a delay. (Mother of COVID patient)

It was hard to explain to family members how critically ill patients were because family members dropped them off and then hadn't seen them. Family member(s) hadn't been at the bedside and hadn't seen what was going on. And so I think in that aspect, it was hard for them to make those critical decisions not being there and not seeing the way that their disease had progressed. (Frontline staff)

When I was at the hospital, they allowed me to speak with them over the phone. And the doctor stayed in touch with my family over the phone as well but I wanted them to come and visit so they could also provide their opinions. (COVID patient, Spanish-speaking, through interpreter)

4

Restrictions negatively impacted the emotional well-being of staff and clinicians

Staff missed the role that families can play, found it difficult to limit access to families, and knew that they could not fulfill two roles: both provide clinical care to the patient and be their care partner. Staff and clinicians felt distressed that they could not communicate with families or provide care in ways they had before COVID.

And so it was, it was really, really, really hard to stand there as people would pass away or people would get sicker. And then you're like standing with this iPad, showing this person their family member and they're just devastated and there's absolutely nothing I can do besides stand there with an iPad. (Frontline staff)

It was just so hard to be the kind of physician you wanted to be. And I felt so bad for all of our patients. And, you know, it was an awful time. (Physician)

5

Restrictions especially impacted vulnerable populations*

For patients and families with certain barriers and challenges related to socio-economic status, language, geography, and/or technology – the lack of family presence was even more burdensome. Some patients and families felt distrust of the health care system and did not want to be hospitalized without a family member present.

I was hospitalized in November the next day after Thanksgiving in 2020. When I went to the hospital, I understood when they said that there's no beds, no rooms, but also they had no interpreters. (COVID patient, Spanish-speaking, through interpreter)

There were some rumors that everybody that was getting hospitalized was going to be killed. So we were afraid. Although he had a lot of the symptoms, we just decided to stay home. (COVID patient and family member, Spanish-speaking, through interpreter)

* Vulnerable populations are those who are diverse in race and ethnicity, gender, age, language, and socioeconomic and educational backgrounds.

6

Changes and inconsistencies in policies

Family presence policies changed over time and were inconsistent, causing confusion and stress. For example, the restrictions were not the same from one hospital to another – or even from one unit to another in the same hospital. Individual clinicians and staff "interpreted" the policies differently or made exceptions.

Every visit was a different update. At first, it was like, "Yeah, you can have one person but they can never leave." And, then, it was, "You can have one person but they can alternate." (Non-COVID patient)

We used to have family members in the ED and then all of the policies changed like as the wind blew in a different direction. (Physician)

7

Restrictions negatively impacted the emotional well-being of patients and families

For patients, it was frightening to be alone and not to have families there to "ground them" and advocate for them. Families felt powerless that there was so little they could do for their loved ones.

I was depressed (while in the hospital). Yeah, I hated it. You know, it's a time in my life that I don't want to experience again. I mean, I questioned myself for going to the hospital at all. (COVID patient)

It was devastating. Because like I said, I could not be there for my mom. There was not one time that she had been sick that I was not by her side. So to have to really trust these medical professionals to take care of her the way that I had always taken care of her like that was…hard. That was very, very hard. (Family member of non-COVID patient)

8

Use of technology had limitations

Technology provided some connection between patients and their families but had limitations. For example, technology was not the same experience as actual contact/presence. It was not useful for patients who did not know how to use it, were uncomfortable with technology, or who were very sick.

I had the shakes really bad from the drugs. So I couldn't like text or type. Like do anything on the phone. So that was really hard because, of course, all I wanted was to FaceTime my kids and my husband and my friend. I couldn't communicate and there was nobody there to help communicate with my words. (COVID patient)

My brother is not a tech person. So, there was not going to be any zooming or anything with him (in the hospital). Even if it had been offered, it wouldn't have been taken advantage of. (Family member of COVID patient)

There's something about seeing that person…versus seeing them on a video screen or, or talking to them or talking to the doctor. There's that piece of being in the space with them. (Friend of patient)

9

Staff and clinicians understood the burden of the restrictions on patients and families

Staff and clinicians recognized the harm of isolating patients from their families, especially in cases like intensive care and end-of-life.

But looking back from this perspective, I definitely wish all those times I would have had every single family member there for every patient. I hated having to see them go through this thing alone. (Nurse on COVID unit)

10

Patients and families understood the burden of the restrictions on staff and clinicians

Patients and families (who were at the bedside) witnessed and understood the stress staff was under and appreciated their efforts to provide "connection" when families could not be present.

I could tell that many of the staff, the nurses, were exhausted. And emotionally, I think almost overwhelmed at times, especially as they would lose patients, usually through the night.
(COVID patient, long stay)

It was all this extra burden (for the staff). The extra anxiety was there for them as well. So they were learning as well every day how to react to the issues. (Husband of non-COVID L&D patient)

QUESTIONS TO INFORM FUTURE RESEARCH

1 Restrictions negatively impacted communication and information-sharing

What tools or strategies are effective to help care partners receive and understand information related to their loved ones' care?

How can communication be improved to keep care partners updated on their loved ones' progress when they are not present?

What strategies are effective to help clinicians listen and respond to patient and family concerns?

2 Restrictions negatively impacted patient care

How did restrictions on family presence negatively affect patients' medical outcomes?

How does the presence of an advocate (care partner) impact patient care?

3 Restrictions negatively impacted decision-making

What tools can be developed and utilized so patients can better communicate with their families to elicit input for decision-making, when needed?

How does the presence of family members affect decision-making?

How does the absence of family members affect decision-making?

4 Restrictions negatively impacted the emotional well-being of staff and clinicians

What organizational systems can be put in place to better support the emotional well-being of clinicians and staff, especially during a public health crisis?

What kind of work environments can be created that will better protect against staff burnout, in a time of public health crisis?

How did restrictions on family presence affect clinicians' mental health (e.g., stress and trauma)?

How does mental trauma and stress affecting clinicians impact the quality of patient care?

5 Restrictions especially impacted vulnerable populations

How can the use of technology be improved so that non-English-speaking patients and families can actively participate in decision-making?

How can better approaches be developed and utilized for making decisions about restrictions on "visitors" so that vulnerable populations are not disproportionately impacted?

How can better information be developed and utilized for making decisions about restrictions on "visitors" so that vulnerable populations are not disproportionately impacted?

What factors and considerations can be used to minimize the disproportionate impact of the restrictions on vulnerable populations?

What factors and considerations can be used to minimize the disproportionate impact of restrictions on seniors?

6 Changes and inconsistencies in policies

What crisis management processes could be put in place to reduce the inconsistencies in, and changes to policies?

How can changes to policies and restrictions be effectively communicated to everyone and especially those who do not speak English?

In a time of public health crisis, how can policies be made more uniform across health systems, states, and regions?

7 Restrictions negatively impacted the emotional well-being of patients and families

What can hospitals do in the future to make sure patient and family support is available even in a time of crisis/pandemic?

How did restrictions on family presence negatively affect patients and their family members as a unit including their mind, body, and soul?

How did the emotional stress of not having family members present affect patients' medical outcomes?

What degree of risk are family members willing to take to see their loved ones, even during the time of a pandemic?

8 Use of technology had limitations

How can technology be improved to promote transparency and clarity in communication between clinicians, and patients and families?

How can technology and its use be improved to minimize the impact of any restrictions on family presence in the future?

In a time of crisis, how can technology be made more readily accessible to patients and their families?

In a time of crisis, how can technology be made more reliable for use by patients, families, and clinicians?

9 Staff and clinicians understood the burden of the restrictions on patients and families

What is best practice about developing therapeutic relationships during a time of crisis?

- How can experiences during COVID-19 inform that best practice?

- How can sample templates and protocols be developed to integrate that experience?

10 Patients and families understood the burden of the restrictions on staff and clinicians

What is best practice about developing therapeutic relationships during a time of crisis?

- How can experiences during COVID-19 inform that?

- How can sample templates and protocols be developed to integrate that experience?

RECOMMENDATIONS FOR HOSPITALS AND HEALTH SYSTEMS

These recommendations are derived from the themes, topics, and questions developed in the project by patients, families, clinicians, and staff.

Improve Communication and Information Sharing

- Develop and use effective tools and strategies to help families and care partners receive and understand information related to their loved ones' care.

- Improve communication to keep families and care partners updated on their loved ones' progress when they are not present.

- Educate clinicians and staff on effective ways to listen and respond to patient and family concerns.

Improve Decision-Making

- Develop new strategies and improve existing ones for patients to better communicate with their families and care partners to elicit input for decision-making.

- Develop tools and protocols for clinicians and staff to better communicate with families and care partners to support their participation in decision-making.

Support Vulnerable Populations

- Provide interpreters and translate patient information materials for non-English speakers.

- Improve the use of technology to better support the participation of patients and their families and care partners in information sharing and decision-making.

- Identify how vulnerable patients and families can be supported and respond with appropriate resources.

Support the Emotional Well-Being of Patients and Families

- Develop policies that ensure that families and care partners are not restricted from being present at the bedside.

- Ensure that protocols are in place for families and care partners to understand the risks and to follow safe guidelines in order for them to be present.

- Dedicate and prepare staff to provide support to patients when families and care partners are not able to be present.

- Ask patients and their family members how staff can support their emotional well-being.

Support the Emotional Well-Being of Clinicians and Staff

- Identify the stress and emotional burdens that clinicians and staff experience in their work.

- Dedicate staff to provide support to address the emotional needs of clinicians and staff.

- Develop systems and provide resources to protect clinicians and staff from burnout.

- Foster an environment/culture that supports the emotional well-being of clinicians and staff.

Understand the Impact of Restrictions on Patient Care

- Identify through data how restrictions on family presence affected patients' medical outcomes (e.g., outcome data, surveys, interviews).

- Identify through data how the presence of a family member or care partner affected patient care (e.g., surveys, interviews, listening sessions).

Employ Consistent Policies

- Identify crisis management processes to put in place to minimize the number of changes and inconsistencies in family presence policies.

- Ensure that family presence policies are uniformly adhered to across the hospital and across the health system.

- Develop communication strategies to inform patients, families, clinicians, and staff about policy changes.

- Translate materials related to policies and changes in appropriate languages and reading levels.
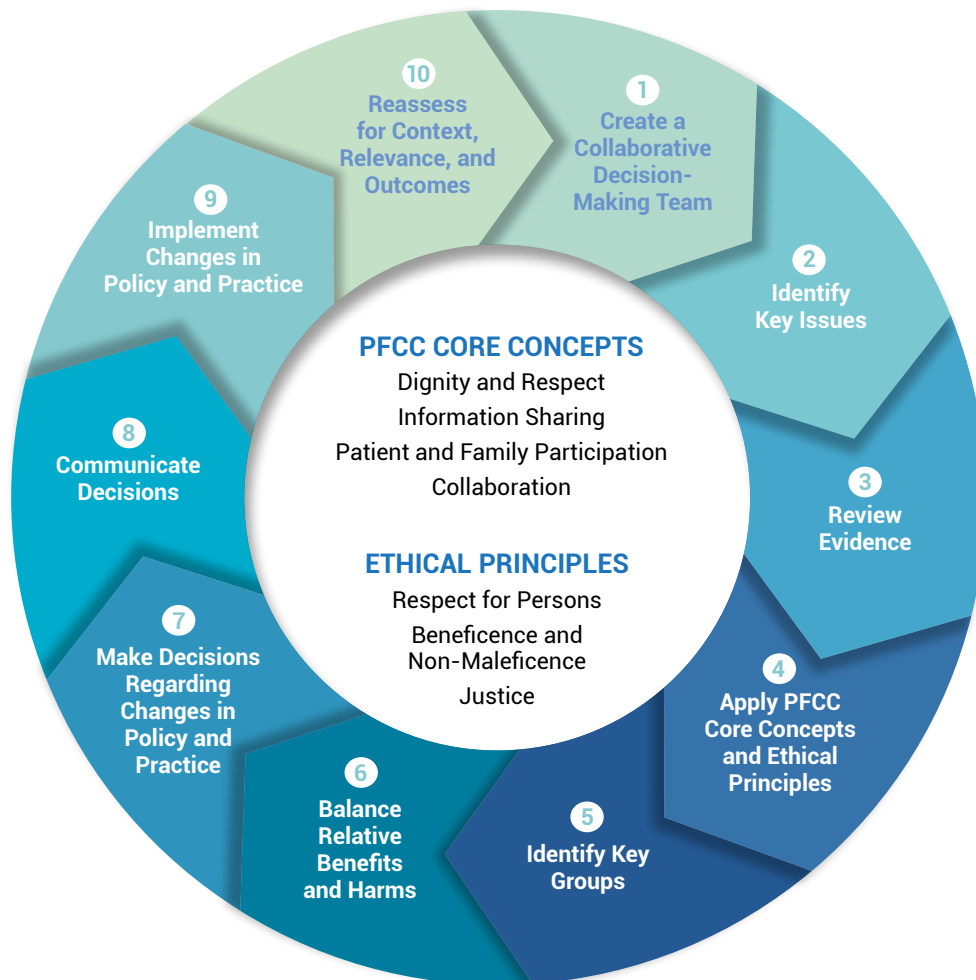
NEXT STEPS: REVISITING RESTRICTIONS ON FAMILY PRESENCE

Faced with the overwhelming COVID-19 pandemic, hospitals, health systems, outpatient settings, and long-term care communities 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. This initial response was understandable given the significant clinical uncertainty which existed at the beginning of the pandemic. However, now, it is crucial to continue to study the impact of that response and to engage those most affected by COVID-19 in the research process.

It is also crucial for hospitals, health systems, and other settings to revisit their approaches to family presence.

Integrating both the core concepts of patient- and family-centered care and fundamental principles of bioethics, IPFCC developed three tools to facilitate decision-making moving forward – to revisit the restrictions and to recommit to family presence. The tools are included in the resource, *Family Presence During a Pandemic: Guidance for Decision-Making.*

10 Reassess for Context, Relevance, and Outcomes

1 Create a Collaborative Decision-Making Team

9 Implement Changes in Policy and Practice

2 Identify Key Issues

8 Communicate Decisions

3 Review Evidence

7 Make Decisions Regarding Changes in Policy and Practice

4 Apply PFCC Core Concepts and Ethical Principles

6 Balance Relative Benefits and Harms

5 Identify Key Groups

PFCC CORE CONCEPTS
Dignity and Respect
Information Sharing
Patient and Family Participation
Collaboration

ETHICAL PRINCIPLES
Respect for Persons
Beneficence and Non-Maleficence
Justice

APPENDIX

Analysis of Meeting Discussions and Findings

Three meetings were held with each of the three Augmented Teams. Each meeting included breakout groups in order to support active engagement of the participants. The first meeting focused on discussion of general perspectives of the impact of family presence restrictions. The second meeting captured more detail about the impact of restrictions on care, decision-making, and well-being. All discussions were recorded and transcribed. Transcripts were carefully reviewed individually by the IPFCC project team and potential themes were identified. The team worked together to compare their individual analyses and develop a cohesive set of themes and topics.

The themes and topics were presented to the Augmented Teams in the third meeting at which they were asked to provide input about whether the themes and topics aligned with what they shared in the previous meetings and if there were any missing items. The themes and topics were further refined with the feedback.

A final meeting was held with all three Augmented Teams together to hear their perspectives about important topics to be studied in the future. Participants were assigned to one of five small groups and

a Facilitator Guide was used to lead discussions. Participants were asked to prioritize 10 themes and topics that they generated in previous meetings. After the prioritization activity, participants were asked to share potential ideas and questions for future research related to the themes and topics.

Discussions were recorded and transcribed. Transcriptions were reviewed by the IPFCC project team. Five themes and topics were rated as high priority and five as lower priority but important. The IPFCC project team members analyzed the findings from the ideas and questions for future research and coded them to the appropriate themes and topics. A document summarizing the potential ideas and questions for research was developed.

The summary of the analysis was reviewed by all IPFCC project team members to check for inconsistencies or inaccurate coding. The Core Team members reviewed and provided input about the summary document to ensure that it adequately captured the discussions and perspectives shared by the participants.

ACKNOWLEDGEMENTS

We are so grateful to the patients, families, staff and clinicians who participated in this project. Thank you for sharing your powerful personal stories of being in the hospital during the COVID-19 pandemic – and for supporting others in sharing theirs. Also, thank you to the team leaders at our three project sites. Without your experience, insights and commitment to partnership, this project could not have happened.

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RESOURCES

Simultaneous with this project, IPFCC conducted another project, ***"Building Capacity for Long-Term Care Stakeholders in COVID-Related Patient-Centered Outcomes Research/Comparative Effectiveness Research (PCOR/CER)."*** Two resources emerging from this project might be of interest to readers. Access the resources here.

Throughout the pandemic, IPFCC remained firmly committed to advancing patient- and family-centered approaches that adhere to the safest guidelines and pose the least burden on health care professionals. Several resources were developed that relate directly to family presence and partnerships during a pandemic. https://www.ipfcc.org/bestpractices/covid-19/index.html