

Strategies for Engaging Patients and Families as Stakeholders

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



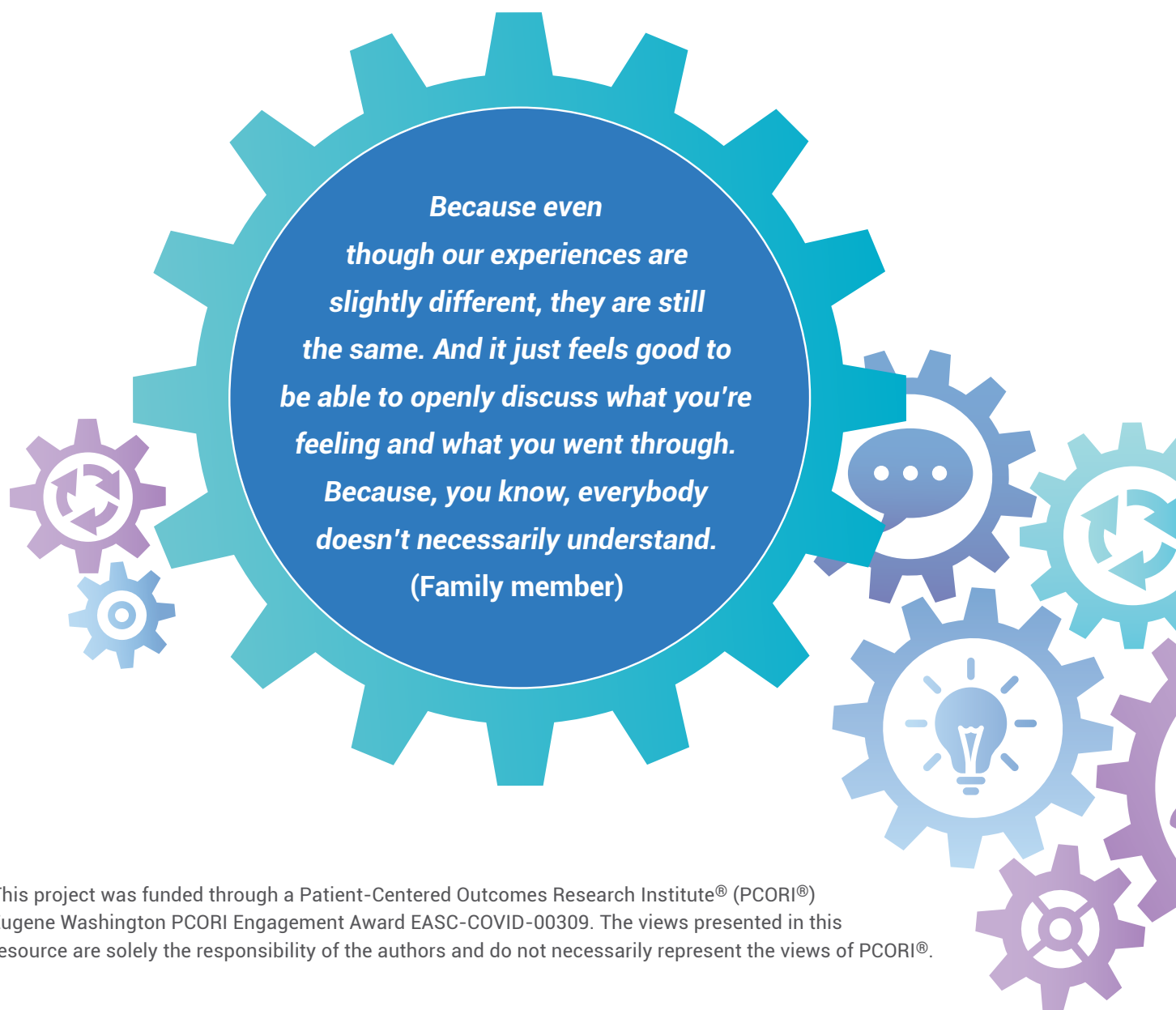
INSTITUTE FOR PATIENT- AND
FAMILY-CENTERED CARE®

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, clinicians, and staff – and to learn their perspectives about the impact of approaches to family presence during the pandemic in order to inform future research. More information about the project and the findings are included in the appendices.

The following summary of our experience shares what we learned and offers guidance and strategies to researchers and others about meaningful engagement of patients and families, including those from underserved communities.



Because even though our experiences are slightly different, they are still the same. And it just feels good to be able to openly discuss what you're feeling and what you went through. Because, you know, everybody doesn't necessarily understand.
(Family member)

This project was funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award EASC-COVID-00309. The views presented in this resource are solely the responsibility of the authors and do not necessarily represent the views of PCORI®.

STRATEGIES FOR ENGAGING PATIENTS AND FAMILIES

Although these strategies are not “novel” or unique, they were critical to the success of our project in engaging patients and families. We hope they offer guidance to researchers and others in the future. Appendix A includes a tool for planning to implement the strategies.

Partnering with Core Teams at project sites

The success of the project, including the engagement of Patient and Family Partners, depended upon the effectiveness of partnerships created between IPFCC staff and project teams at the three participating health systems.

- **Utilize prior working relationships, if possible**

IPFCC had previously worked with each of the three sites in some way, primarily with one of the team leaders. This strengthened every aspect of the project, from beginning to end, and ensured effective communication.

- **Clarify expectations and roles up front**

The Letter of Agreement (LOA) executed with each site outlined the roles and responsibilities for the site team and for IPFCC as well as timelines and payment schedules.

- **Provide resources to the organization to support engagement**

Each site received a stipend to provide funding to support their work in engaging Patient and Family Partners.

- **Hold initial planning meetings**

Although the team at each project site engaged Patient and Family Partners as key stakeholders, IPFCC staff initially held meetings with smaller Core Teams at each site to discuss expectations and plan operational details of the project, including selection of Patient and Family Partners.

- **Jointly develop Facilitator Guides for project meetings**

For four of the five virtual team meetings during the project, IPFCC staff drafted Facilitator Guides and shared them with team leaders at each of the sites for review and feedback.

- **Co-facilitate meetings**

All virtual meetings were co-facilitated with team leaders from the sites. This not only highlighted our partnership with the sites but also facilitated engagement of participants. Because the team leaders were familiar to the Patient and Family Partners, their presence provided reassurance and resulted in more active engagement and richer discussions.

- **Develop final reports/resources jointly**

As part of the ongoing partnership with the sites, IPFCC staff drafted the final project reports/resources and shared them with the site leaders for review and feedback.

Identifying Patient and Family Partners, including those from underserved communities

Patient and Family Partners, who had the lived experience of hospitalization during COVID, were included as key stakeholders. Identifying and engaging them was an essential component of the project.

- **Use pre-existing structures at project sites for identification**

Each site had a different, but equally relevant, structure for identifying patients and families:

- (1) a center that provides services for Latinxs, (2) a post-COVID clinic for patients, and
- (3) an engagement studio where patients and families were already involved in research.

- **Specify that identification is a responsibility of Core Team**

One of the specific roles outlined in the LOA for each site was the identification of Patient and Family Partners. The Core Team and its leaders had personal knowledge of patients and families with whom they had worked. More importantly, they had established trust with the patients and families and, therefore, could encourage involvement in the project.

- **Request that the Core Team contacts Patient and Family Partners about participation**

Again, building on established trust, team leaders from the project sites invited people to participate in the project. Team leaders shared background materials with the patients and families to build their understanding of the project goals and process. For those who were non-English-speaking, the team leader engaged an interpreter to communicate.



Supporting Patient and Family Partners

Meaningful participation of Patient and Family Partners depended upon the partnership between IPFCC staff and the site team leaders. It also required knowledge of support that might be needed, allocation of budgetary resources for that support, and the capability to provide the support, in various ways, throughout the project.

- **Communicate with Patient and Family Partners through the Core Team**

Because of their established trust, team leaders at project sites invited Patient and Family Partners to participate and reached out to them with important messages throughout the project, including reminders about upcoming meetings.

- **Provide materials describing both the project and the role**

The IPFCC team developed a description of the role of Patient and Family Partners in the project. This was distributed by the team leaders along with a short project summary.

- **Request signed Patient and Family Partner Confirmation Agreements**

Following the invitation to participate, each Patient and Family Partner received a Confirmation Agreement that they signed and returned. This both formalized and validated the importance of their role.

- **Co-facilitate key meetings with leaders of Core Teams**

Co-facilitation of virtual meetings was an important aspect of partnership with project sites and their leaders. It brought new perspectives to the project and provided support to participants, especially Patient and Family Partners. It also modeled partnership between the project team and the site teams.

- **Request that group assignments be done by leaders of Core Teams**

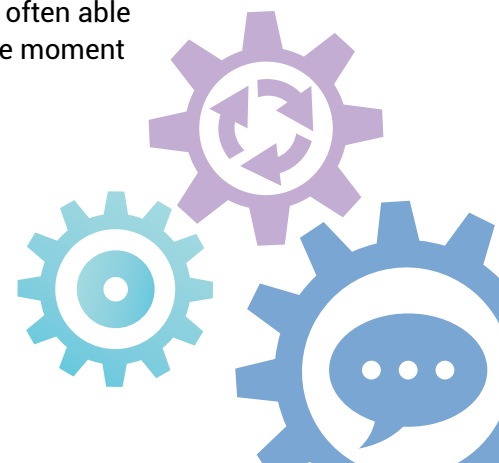
Four of the virtual meetings during the project relied on small group discussions and, therefore, participants were assigned to small breakout rooms. Team leaders were asked to make those assignments since they had prior knowledge of the participants and could create discussion groups that were both comfortable and productive.

- **Provide honoraria to participants**

A visible way of formalizing and validating the importance of the role of Patient and Family Partners was to provide honoraria for participation. However, providing alternatives for honoraria and issuing and tracking payments to multiple participants required significant staff time.

- **Respond to planned and “as needed” supports**

Over the course of the project, individual Patient and Family Partners sometimes needed support, especially for participation in virtual meetings. Team leaders were often able to identify these supports in advance. However, some needs occurred at the moment and required real-time project staff support.



Supporting non-English-speaking participants

A key purpose of the project was to engage patients and families, including some representing underserved communities. Among the Patient and Family Partners who participated were Latinxs who spoke only Spanish and had additional needs for support.

- **Identify needs for additional resources**

Engaging Patient and Family Partners, especially those from underserved communities, requires identifying what support (e.g., interpretation, technology) they need for meaningful participation and allocating resources to provide that support.

- **Use interpretation and translation services**

Through Language Access Services at one of the sites, the project had access to interpreters and translators for the Spanish-speaking Patient and Family Partners. However, providing these services required additional resources: (1) allocated funds to pay for the services, (2) lead time before meetings to engage the services, (3) time to translate meeting materials, and (4) project staff time to brief the multiple interpreters and share meeting materials with them. A consistent interpreter would have been helpful.

- **Assist with access to technology or alternatives**

From the time of the first project meeting, it was clear that the Spanish-speaking participants did not have good access to or comfort with technology, other than cell phones. Therefore, alternatives were found to engage with them, e.g., calls were made by a Spanish-speaking staff member to remind them about upcoming meetings vs. sending emails.

- **Provide alternatives for payment of honoraria**

Because payment via bank check was not an option for some Patient and Family Partners, gift cards were sent via mail instead.

Themes	Temas
Policies differed from pre-COVID	Las políticas diferían de las anteriores a COVID
Restrictions negatively impacted:	Restricciones impactadas negativamente:
Patient care	- Atención al paciente
Communication	- Comunicación
Decision-making	- Toma de decisiones
Emotional well-being of patients and families	- Bienestar emocional de pacientes y familiares
Vulnerable populations were impacted more by restrictions	Las restricciones tuvieron un impacto especial en poblaciones específicas
Use of technology had limitations	El uso de la tecnología tenía limitaciones



Utilizing technology

In identifying themes and topics for future research, participants highlighted both the pros and the cons of the use of technology. Technology provided connection for patients and families but was not equally accessible nor comfortable for all patients. The same was true in the project itself, i.e., technology made it possible to engage stakeholders from diverse backgrounds and geographic locations but use of technology also presented challenges and, potentially, created inequities.

- **Assess participants' access to technology and comfort in using it**

Because the project relied on virtual meetings, it was important to know if participants needed access to technology or help in using it. Team leaders were invaluable in providing that information.

- **Anticipate and plan for “glitches”**

With increased use of technology (e.g., breakout rooms, polling) during the virtual meetings, the project staff anticipated that problems would occur and planned ahead for solutions.

- **Dedicate a technical support person to assist during meetings**

Recognizing the complexities of technology and potential “glitches,” the project staff did not want to divert the attention of the meeting co-facilitators. Instead, an additional staff person served in the technical support role.



Recognizing the value of shared experience

An auxiliary, but important, learning from the project, articulated several times by participants themselves, was the power and the value of shared experience – and its ability to transcend other differences or boundaries.

- **Engage individuals from different sites/geography**

Participants first engaged in three virtual meetings with their own site teams. Subsequently, the teams from all three sites met together for two meetings. Because of the sequencing, participants were comfortable meeting in the combined setting and, in fact, the discussion was enriched.

- **Learn from the different experiences of patients and families**

Among the stakeholders engaged in the project were both patients and families. Their clinical experiences differed, e.g., long and shorter hospitalizations, COVID and non-COVID. Some were experienced in the hospital setting before COVID; some were not. They also differed in other ways, including educational level and urban/rural living. But participants respected those differences in group discussions and learned from them.

- **Engage patients, families, clinicians and staff together**

Although concerns are often raised about bringing together patients, families, staff and clinicians in discussions about “difficult” topics, it has been shown to be a powerful way of learning¹ and of fostering mutual understanding and respect.

- **Highlight the commonality of experiences**

Despite differences of geography, role, and experience, participants in the project valued the opportunity to share what was common, i.e., the uncertainty and stress of being in the hospital setting during COVID – when family presence was restricted.



*I really enjoyed
having a space to express
my feelings and emotions
with a group of people who
could relate to what I had gone
through. I have really valued
this experience.
(Patient)*

¹ Solomon, M.Z., Browning, D., Dokken, D., Merriman, M., & Rushton, C.H. (2010). Learning that leads to action: Impact and characteristics of a professional education approach to improve the care of critically ill children and their families. *Arch. Pediatr. Adolesc. Med.*, 164(4), 315-322. DOI: [10.1001/archpediatrics.2010.12](https://doi.org/10.1001/archpediatrics.2010.12)

APPENDIX A: THEMES AND TOPICS

During the series of project meetings, the following themes and topics were identified and prioritized by participants/stakeholders. For more information, including questions for future research, see companion resource titled, [*Themes, Topics, Questions, and Recommendations*](#).

Listed in order of priority determined by project participants.

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.

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).

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.

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 both provide clinical care and be care partner. Staff and clinicians felt distressed that they could not communicate with families or provide care in ways they had before COVID.

5 Restrictions especially impacted vulnerable populations

For patients and families with certain barriers and challenges – socio-economic, language, geographic, technologic – 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.

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.

APPENDIX A: THEMES AND TOPICS (continued)

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.

8 Use of technology had limitations

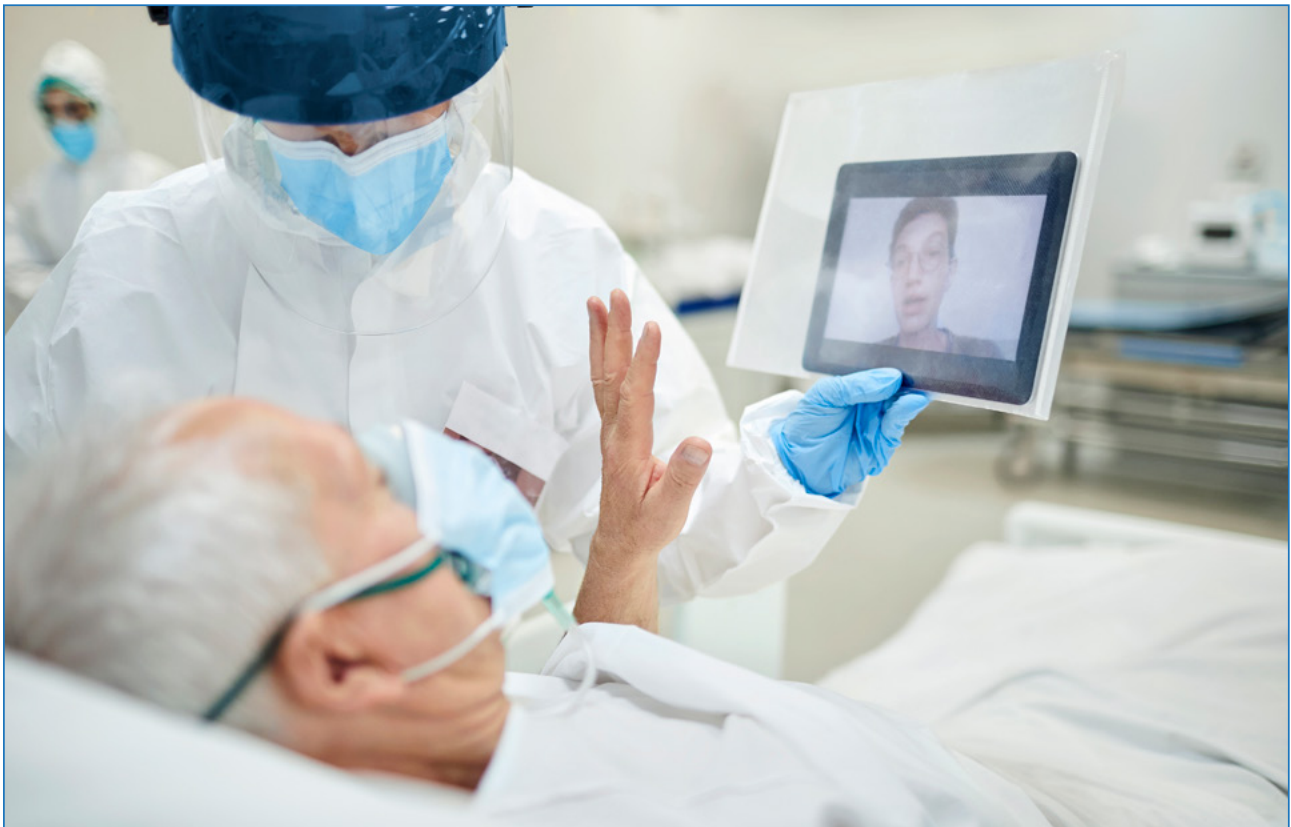
Technology provided some connection between patients and their families but had limitations. For example, technology was not the same experience as actual contact/presence. It was not useful for patients who did not know how to use it, were uncomfortable with technology, or who were very sick.

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.

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.



APPENDIX B: SELECTED STRATEGIES—PLANNING TOOL

A selected set of strategies was developed to assist you in engaging patients and families in planning research. Use the Planning column to record ideas for implementing the strategies.

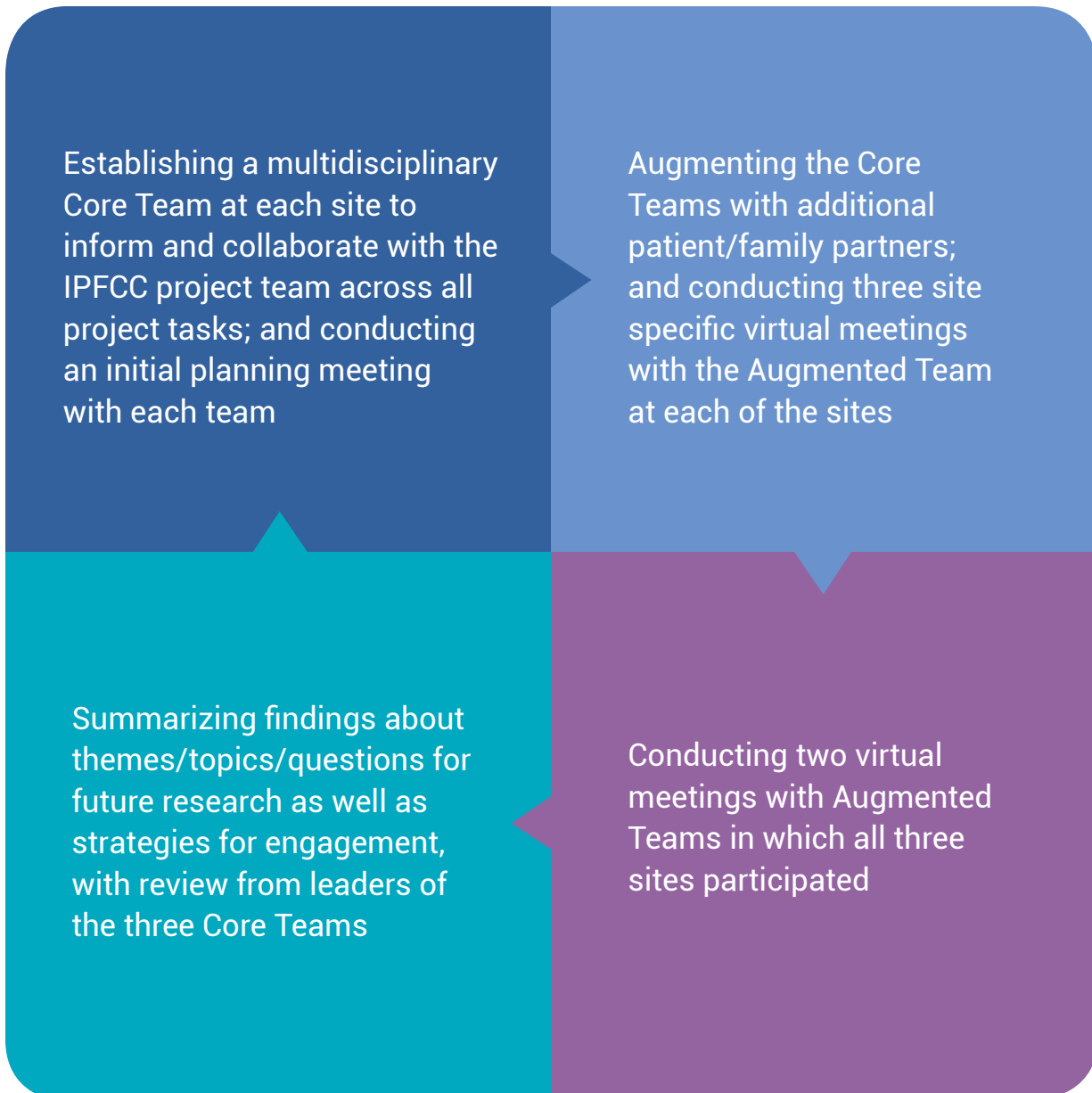
STRATEGIES	PLANNING
Establish productive working relationships with site teams	
Build on any prior working relationship you have had with the site you will be partnering with	
If there is none, create a process to develop a relationship with the site: <ul style="list-style-type: none"> • Identify a key contact • Share project information with the key contact • Plan and conduct a call to meet the key contact and others to review the project and answer questions 	
Develop materials that clearly describe the expectations and roles for the site team members and provide information about the project	
Develop, distribute, and obtain signed forms (e.g., Letters of Agreement, payment process) to confirm commitment of the site team to the expectations and roles	
Hold initial meetings with the site team to discuss the purpose, goals, and objectives of the project and responsibilities of the site team and project team	
Provide a stipend to the site to support project administration and the work of the site team	
Identify and recruit patient and family partners	
Make use of any pre-existing structures the site has in place to identify patient/family partners (e.g., patient and family advisory councils)	
If there are no structures in place, assist the site in using strategies to identify and recruit patient/family partners	
Ask that at least one site team member is designated as the key contact for the patient/family partners	
Partner with site teams throughout the project	
Hold regular meetings with the site team to plan for future meetings with participants	
Collaboratively develop facilitator guides with the site team to ensure that meetings achieve their goals and are consistent across facilitators	
With the site team, collaboratively develop meeting materials to share with participants	
With site team leaders, co-facilitate meetings held with patient/family partners	
Ask for review and feedback for final project reports/resources	
Ask site teams to participate in dissemination activities	

APPENDIX B: SELECTED STRATEGIES—PLANNING TOOL (continued)

STRATEGIES	PLANNING
Support patient and family partners	
Ensure that site team leaders communicate regularly with the patient/family partners to: <ul style="list-style-type: none"> • Distribute and collect confirmation agreements • Share materials about the project and meetings • Remind them of upcoming meetings and how to join, if virtual • Identify any issues that may limit their participation • Follow up after meetings, as needed • Assist with honoraria payment process 	
Provide additional support (e.g., assisting in access or use of technology)	
Provide clear and concise education about research and how project activities will inform future research	
Provide honoraria and options for payment (e.g., gift cards in place of bank checks)	
Support non-English-speaking patient and family partners	
Include a budget item for resources needed to partner with non-English-speaking participants (e.g., translation, interpretation)	
Provide real-time interpreter services in meetings	
Translate all project and meeting materials into appropriate languages	
Utilize technology effectively	
Identify potential issues participants may have with using technology and plan strategies to address the issues	
Assess the participants' access to and comfort level in using technology	
Provide support to participants who need assistance using technology prior to meetings and during meetings	
Dedicate at least one technical support person to help navigating the technology and assisting during meetings	
Recognize and honor the value of participation	
Be open and committed to learn from the different lived experiences of patients, families, and staff	
Dedicate time in meeting agendas to summarize how the lived experiences of participants are informing the project	
Acknowledge and designate time to celebrate the efforts of all participants	

APPENDIX C: 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.



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. [Access the resources here.](#)

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