



California Perinatal  
Quality Care Collaborative

# NICU Family Advisory Council Toolkit

A CPQCC Quality Improvement Toolkit

A close-up photograph of a young child with a medical ventilator mask on, looking upwards. The child has dark skin and is wearing a light blue hospital gown. The background is blurred, showing medical equipment and a blue wall.

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# NICU Family Advisory Council Toolkit

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# Introduction

*“I strongly believe that NICU families deserve and need more support than our hospital was offering. I supported and encouraged the NICU to shift from baby-centric care to including and supporting the families. My role as a parent mentor made me realize the families needed more than a mentor, they needed a program to help them through the journey.”*

— CPQCC California NICU FAC Member

This guide is both a resource and a message from families who have supported their infants through neonatal intensive care. Our goal is to offer a comprehensive toolkit to support neonatal intensive care unit (NICU) staff and families in establishing and maintaining a family advisory council (FAC).

An FAC can improve communication between families and hospital staff. Family perspectives can drive systemic improvements in patient care, health outcomes, and quality improvement, and promote the development of support programs for families in the NICU.

In these sections, you will find evidence-based research, best practices, realistic advice, personal stories, and actionable strategies to help create an FAC that will work to bridge the gap between families and their NICU healthcare providers. California Perinatal Quality Care Collaborative (CPQCC) believes collaboration between hospital staff and NICU families is essential for creating mutual respect, improving communication, and enhancing the overall care experience.

## PURPOSE OF THIS TOOLKIT

This toolkit is designed to help NICU staff and families create successful FACs in their units, whether starting from scratch or working to enhance an existing council. Drawing from both research and lived experience, this resource bridges theory and practice in family engagement.

## HOW TO USE THIS TOOLKIT

This toolkit is a practical, step-by-step guide for establishing a new FAC or enhancing an existing one. The content is organized into four sequential sections that mirror the FAC development process: assessing organizational readiness, recruiting a variety of members, creating meaningful engagement, and ensuring long-term sustainability. Each section includes evidence-based guidance, real-world examples from the CPQCC California NICU FAC, and practical tools that can be customized to fit an institution's needs and resources. For those ready to begin immediately, the **Quick Start Guide** (page 27) provides a condensed overview of essential steps. The toolkit can also be used flexibly to focus on specific areas where an FAC

needs the most support. Throughout the implementation journey, refer to the **Resource Library** (page 29) for additional training opportunities and expert guidance.

*“Having a robust FAC improves the overall care of families and helps them to achieve their goals of having healthy, happy children who grow up showing limited or no evidence of having been NICU children.”*

— CPQCC California NICU FAC Member

## FAC IMPACT

FACs can participate in a wide range of activities that improve NICU care and family interaction, including family support, quality improvement, organizational enhancement, and community engagement. FACs add value by providing a family perspective on NICU matters, such as what is needed to best support non-English language of preference (NELP) families. Incorporating family perspectives into NICU operations can create more responsive, effective, and compassionate care environments. This systematic approach to family engagement ensures that family-centered care moves beyond concept to daily practice.

FACs can initiate or participate in the following types of programs:

### FAMILY SUPPORT PROGRAMS

- Peer-to-peer mentoring systems for current NICU families
- Resource coordination for practical needs (transportation, meals)
- Multilingual information and support materials
- Navigation assistance for hospital services

### QUALITY IMPROVEMENT

- Input on NICU environment and equipment
- Participation in disaster planning and safety protocols
- Contribution to family education programs
- Guidance on family-centered policy development

### ORGANIZATIONAL ENHANCEMENT

- Advisory role in quality improvement projects
- Input on family-centered policies
- Participation in staff education
- Contribution to research initiatives



## COMMUNITY ENGAGEMENT

- NICU outreach and advocacy
- Family support program development
- Public education and awareness
- Resource network development

The positive impact of FACs on NICU quality has been measured across three key areas:

<h3>Clinical Outcomes<sup>1</sup></h3>	<ul style="list-style-type: none"> <li>• Reduced length of stay for complex cases</li> <li>• Increased breastfeeding rates</li> <li>• Improved adherence to developmental care practices</li> <li>• Better discharge planning and follow-up care</li> </ul>
<h3>Patient Satisfaction and Experience<sup>2</sup></h3>	<ul style="list-style-type: none"> <li>• Higher patient satisfaction scores</li> <li>• Improved communication between families and providers</li> <li>• Enhanced family preparedness for discharge</li> <li>• Stronger support systems for NICU families</li> </ul>
<h3>Organizational Benefits and Revenue Impact<sup>3</sup></h3>	<ul style="list-style-type: none"> <li>• Increased patient retention and loyalty</li> <li>• Higher referral rates through positive word-of-mouth</li> <li>• Better resource utilization</li> <li>• Enhanced hospital reputation in the community</li> <li>• Improved staff satisfaction and retention</li> </ul>

In addition, Macdonell et al. (2021) notes, "Family advisory councils create tangible improvements in care delivery and outcomes through the meaningful integration of family perspectives into quality improvement efforts."<sup>4</sup> Successful improvements enhance the development of FAC infrastructure, increase FAC membership, and lead to engagement in further quality improvement initiatives.

Helpful frameworks for presenting the value proposition to hospital leaders may include:

- Cost-benefit analysis frameworks
- Quality metric impact data
- Patient satisfaction correlations
- Resource utilization improvements
- Staff retention benefits

## TOOLS FOR FAC IMPLEMENTATION

Use this toolkit to implement a NICU family advisory council and join a growing movement toward more family-centered, quality-driven care. **Resources to develop an FAC are noted throughout the toolkit and available in the Tools & Templates section (page 30).** These include:

- Readiness assessment guides
- Recruitment templates
- Meeting facilitation tools
- Evaluation frameworks
- Sustainability planning resources

### Tools & Templates

Creating Patient and Family Advisory Councils (Tool, Institute for Patient- and Family-Centered Care)

Bylaws for NICU Patient Family Advisory Council (Template, Children's Mercy Kansas City)

[Patient & Family Advisory Council Charter](#)



# Section I: Assess Readiness

*“We were in the NICU for three months and it became my second home. I felt comfortable and safe there. This may not be everyone’s experience but it was mine. I never really left the NICU, I would come back and visit all the time after we were discharged and I have always wanted to give back in any way that I could. The first year after the NICU was a whirlwind but I stayed connected because it’s such a deep part of our story. After the first year I felt strong and confident, and I was ready.”*

— CPQCC California NICU FAC Member

Before starting an FAC, it’s important to assess whether NICU staff are ready for such an initiative. A well-established FAC requires support from both leadership and staff and adequate resources to ensure its success.

## ESSENTIAL ELEMENTS FOR FAC SUCCESS

### LEADERSHIP SUPPORT

Success begins with committed leadership support. Hospital leadership, including department leaders, NICU managers, and executive leadership, must be fully committed to supporting the FAC. Their buy-in is critical for ensuring the FAC is taken seriously and has the resources it needs to be successful. The value of an FAC can be justified by highlighting the benefits for both families and the NICU, including improved patient satisfaction and better family outcomes.

### FAC CHAMPION IDENTIFICATION

It’s vital to have at least one champion on staff who is passionate about the idea of the FAC and can be the main point of contact between the hospital and the FAC. A champion should:

- Demonstrate passion for family engagement
- Hold a position of influence within the organization
- Have time allocated for FAC responsibilities
- Possess strong communication and facilitation skills

## ADMINISTRATIVE INFRASTRUCTURE

- **FAC administrative support:** Designate someone to handle logistics, including scheduling meetings, sending out agendas and minutes, ensuring that all necessary resources are available, and maintaining a system for documentation and communication.
- **Time and resources for staff involvement:** NICU staff must have allotted time to engage with the FAC, such as dedicating a staff member to act as the FAC liaison or having flexible schedules to ensure staff participation.
- **Meeting space:** Provide a dedicated space for regular meetings, where parents and staff can discuss ideas privately without distractions. This space should include storage space for materials and supplies and access to technology for virtual meeting options.

## STAFF READINESS AND ENGAGEMENT

Staff readiness is essential for FAC success and requires thoughtful assessment and preparation. The FAC Readiness Assessment Checklist will help evaluate current attitudes toward family engagement and identify professional development needs.

Key assessment areas include:

- Understanding of family-centered care principles
- Communication skills and cultural competency
- Willingness to partner with families
- Previous experience with family collaboration

The results of these assessments can identify which training opportunities will be most useful to prepare staff for meaningful partnership with families. Regular reassessment helps track progress and identify ongoing support needs.

## BUDGET PLANNING AND RESOURCE ALLOCATION

Establishing appropriate funding for an FAC is crucial for success and sustainability. Financial support for FAC members reduces barriers to engagement and increases representation of a variety of families.

- Member compensation
- Course fees for FAC member training
- Honoraria for regular participation
- Stipends for special projects and leadership roles
- Professional development opportunities
- Support services
- Childcare during meetings (including medical complexity needs)
- Transportation assistance (parking, transit, mileage)

- Interpretation services and technology support
- Meeting supplies and refreshments

Regular budget reviews should reflect evolving program growth and family needs. Leadership support for appropriate funding demonstrates organizational commitment to meaningful family engagement while ensuring program sustainability.

## DEFINING AN FAC

### SETTING FOUNDATION AND EXPECTATIONS

Before launching an FAC, establish clear structure and expectations to ensure sustainable success. Focus on the following key areas:

#### COUNCIL OBJECTIVES AND ACTIVITIES

FAC objectives should align with both organizational goals and family needs. Common objectives include:

- Quality improvement collaboration
- Policy and procedure review
- Family support program development
- Communication enhancement initiatives
- Staff education and awareness

*Example: A NICU FAC aims to increase the percentage of NICU families who report feeling adequately informed about their infant's medical condition and treatment plan by 20% within six months by implementing a standardized, family-centered communication tool.*

### ROLES AND RESPONSIBILITIES

Clearly define commitments and expectations to ensure effective collaboration.

#### STAFF COMMITMENTS

- Dedicating time for FAC activities
- Sharing of professional expertise
- Supporting project implementation
- Maintaining ongoing communication

#### MEMBER EXPECTATIONS

- Attending monthly meetings
- Committing to a two-year term
- Participating in projects
- Maintaining confidentiality

## EVALUATION FRAMEWORK

Establish metrics to track FAC impact using the Impact Scorecard Template for meeting attendance and engagement, including:

- Project completion rates
- Member satisfaction levels
- Patient outcome improvements

### Tools & Templates

FAC Readiness Assessment Checklist (Tool, CPQCC)

Fact Sheet: A Guide to Establishing Effective Hospital Family Advisory Councils (Tool, Lucile Packard Foundation for Children's Health)

FAC Budget Planning Template (CPQCC)

FAC Interpretation Services and Technology Support Guide (Tool, CPQCC)

*“For [parents] to have had their experiences with less incidence of trauma helps them recover and become the parents they hope to be for their children.”*

*— CPQCC California NICU FAC Member*



# Section 2: Recruit Members

*“I started volunteering in the NICU about a year after my daughter was discharged as a parent mentor. I found it to be extremely rewarding and wanted to fill a gap in patient support. For many, it can be triggering to be back in the NICU, or even the hospital; for me, it has brought healing and closure. By the time they established a FAC, I was mentoring multiple parents weekly, as well as weekly cuddle shifts.”*

— CPQCC California NICU FAC Member

## UNDERSTANDING THE FAC COMMUNITY

Successful recruitment begins with understanding the hospital’s NICU community. A variety of FAC members will bring unique perspectives and provide a variety of insights based on individual lived experiences.

### SETTING MEMBERSHIP PARAMETERS

Create a guideline for member selection with consideration of the following parameters:

#### TIME SINCE NICU EXPERIENCE

Consider recruiting family members who are at least one-year post-discharge, allowing them time to:

- Process their NICU experience
- Address potential mental health needs
- Establish post-NICU routines
- Develop an advocacy perspective

However, maintain flexibility in these guidelines as recent NICU experiences can provide valuable insights for current improvements.

#### REPRESENTING DIFFERENT TYPES OF FAMILIES

An FAC that represents different types of families ensures comprehensive input for improving NICU practices and supporting all families through their journeys.

- Different NICU experiences
- Varied lengths of stay
- Alternative family structures

- Variable socioeconomic settings
- Multiple cultural and language backgrounds
- Bereaved family members

## RECRUITMENT STRATEGIES

A comprehensive recruitment strategy employs multiple approaches to reach potential members. Direct outreach through surveys during NICU stays and at discharge provides an immediate connection with families and helps identify those who may be candidates for future FAC participation. Follow-up communication post-discharge and engagement at NICU graduate events can further explore interest in FAC involvement. Social media platforms offer additional channels for reaching a variety of family groups.

FAC members should also be encouraged to include recruitment as a part of their duties. Connecting to and referring other NICU families will improve sustainability.

Staff engagement proves crucial in identifying potential members. NICU staff often develop strong relationships with families and can recognize those who might be particularly suited for FAC participation. Encourage staff to nominate families who have shown interest in improvement or provided constructive feedback during their NICU stay.

Community partnerships enhance recruitment reach. Consider connecting with:

- Local parent support groups
- Cultural community organizations
- Family resource centers
- NICU graduate networks
- Social media NICU parent groups
- Peer buddy/mentor programs

## RECRUITMENT AND ENGAGEMENT INTERVENTIONS

A survey was distributed to CPQCC California NICU FAC members for improvement opportunities related to family engagement and recruitment. Their ideas included:

- Contacting family members while they are still in the NICU
- Supporting family members with a guidebook to help them navigate the NICU stay, including questions to ask providers and staff
- Creating a post-discharge, peer-buddy program
- Engaging parents with others who have had similar experiences
- Conducting FAC introductions with discharge follow-up care/support
- Sending a “Welcome Home” card to baby and family from the NICU’s FAC
- Introducing the FAC at the NICU graduation/reunion ceremonies

- Producing personal FAC invitation letters for the NICU family members
- Providing resources for NICU families in the area, such as support groups
- Helping NICU families to understand that they are not alone in their journey

## APPLICATION PROCESS

The application process serves as the foundation for identifying committed and prepared people to be NICU family representatives. The NICU FAC Member Application Form template gathers comprehensive information from all potential members.

Key application components should include:

- NICU experience details
- Personal readiness assessment
- Interests and skills
- Prior patient advisory/advocacy experience

## INTERVIEW PROCESS

Interviews provide an opportunity to assess readiness while building rapport with potential members. The NICU FAC Interview Guide and Questions template provides a structured approach that maintains sensitivity to family experiences.

## ONBOARDING PROCESS

A comprehensive onboarding program ensures new members feel prepared and supported in their roles. The onboarding process should be flexible enough to accommodate different learning styles and schedules while ensuring all members receive essential information and training. (*Please reference the chart on the next page for suggested onboarding topics and sample elements.*)

## PLANNING FOR SUCCESS

Recruitment requires ongoing attention and flexibility. Plan to recruit more members than the target number, anticipating natural attrition as family circumstances change. Document successful recruitment strategies and maintain an ongoing pipeline of potential members. Regular evaluation of the recruitment process helps ensure continued success in building and maintaining an engaged council that represents many different NICU experiences and families.

Available tools in this section will assist and guide the recruitment process, and include an application template, interview guide, and feedback survey. These resources provide a foundation for developing a robust recruitment program tailored to the NICU FAC's needs.

Onboarding Topics	Sample Elements
<b>PROGRAM OVERVIEW</b>	<ul style="list-style-type: none"> <li>FAC mission and objectives</li> <li>Meeting procedures and expectations</li> <li>Communication protocols</li> <li>Available resources and support</li> </ul>
<b>LEGAL AND COMPLIANCE REQUIREMENTS</b>	<ul style="list-style-type: none"> <li>Confidentiality agreement</li> <li>HIPAA compliance training</li> <li>Privacy laws</li> <li>Organizational information security guidelines</li> <li>Documentation requirements</li> </ul>
<b>TRAINING OPPORTUNITIES</b>	<ul style="list-style-type: none"> <li>Quality improvement basics</li> <li>Trauma-informed care</li> <li>Patient and family advocacy</li> </ul>
<b>AVAILABLE RESOURCES</b>	<ul style="list-style-type: none"> <li>FAC handbook and guidelines</li> <li>Contact information for leadership</li> <li>Meeting schedules and materials</li> <li>Support resources and references</li> </ul>

## Tools & Templates

NICU FAC Recruitment Flyer (Sample in English and Spanish, CPQCC)

NICU FAC Member Application Form (Template, CPQCC)

NICU FAC Interview Guide & Questions (Template, CPQCC)

NICU Feedback Survey About FAC (Template, CPQCC)



# Section 3: Engage and Involve

*"I just want to recognize how amazing you all are at being tireless advocates for your children. Your strength and perseverance are truly commendable. Your experiences and advice are so valuable for NICU families."*

*— CPQCC California NICU FAC Leader*

## CREATING A CULTURE OF ENGAGEMENT

Establishing a successful FAC requires more than just member recruitment—it demands ongoing attention to engagement and inclusion. Healthcare organizations must create an environment where family members feel valued as essential partners in improving NICU care. This section outlines how to create a supportive, and safe environment that encourages the participation of many different families in an FAC.

### INTEGRATION AND INCLUSION STRATEGIES

#### BUILD AN INCLUSIVE CULTURE

Schedule consistent check-ins with members between meetings to maintain connection and identify potential concerns early. Structure meetings to ensure equal participation opportunities. Consider using round-robin discussion techniques, small group breakouts, and rotating presentation responsibilities. Ensure that every member feels valued.

- Acknowledge each member's contributions
- Ensure that everyone's voice is heard during meetings
- Check in regularly with members to ensure they feel supported

#### IDENTIFY EACH MEMBER'S STRENGTHS

Match members with projects that align with their interests and experiences. Each family member has unique skills and perspectives. Take time to discover their passions and strengths and assign them to projects or roles that align with their interests. This will help keep members engaged and motivated.

Initial FAC engagement is supported by the NICU FAC Member Connection and Priority Setting Activity tool. This structured 60-minute exercise helps new FAC members build relationships while identifying group priorities and individual strengths. Through guided story sharing, strength mapping, and collaborative priority setting, the activity creates a foundation for meaningful engagement while generating concrete project ideas. The template includes facilitation guidelines, documentation frameworks, and follow-up recommendations to ensure productive outcomes. This tool may be effective during early FAC meetings for

helping establish the collaboration essential for long-term success.

## PROFESSIONAL EDUCATION

Providing specialized education helps ensure members can contribute effectively to quality improvement efforts.

### QUALITY IMPROVEMENT

Providing FAC members with basic quality improvement (QI) knowledge will help them understand how to contribute to improving NICU care processes and policies, and equip them to advocate for change. Some recommended trainings for clinical staff to use when working with FACs include:

- [Institute for Healthcare Improvement's Open School](#) for courses on basic QI concepts
- [CPQCC's Quality Improvement Fundamentals Course](#) (CPQCC QI collaborative teams only)
- [Family-Centered Care Taskforce webinars](#)

### TRAUMA-INFORMED CARE

Educating FAC members about trauma-informed care can help them approach their FAC role with sensitivity, provide compassionate support to NICU families, and collaborate with NICU staff. Essential training in trauma-informed approaches is available through:

- [Caring Essentials Collaborative](#)
- [Gold Learning](#)

### PATIENT AND FAMILY ADVOCACY

These organizations use advocacy approaches that can be shared with FAC members:

- [MoMMAs Voices: Maternal Mortality & Morbidity Advocates](#)
- [Once Upon A Preemie, Inc.](#)
- [Family Voices of California](#)

## PROJECT MANAGEMENT

### BRAINSTORM AND TRACK PROJECTS

Facilitate regular brainstorming sessions to generate ideas for improvement projects. Identify a group leader/liaison to coordinate communication with the NICU and hospital leadership regarding institutional priorities. Once feasible improvement projects are agreed upon by the FAC and the institution, assign responsibilities to track the progress of each project.

*Project example: Discharge Education Enhancement*

*Goal: Improve family preparation for NICU discharge*

*Timeline: Six months*

*Components:*

- *Family survey development*

- *Current process review*
- *Recommendation development*
- *Implementation plan*
- *Outcome measurement*

***Project tracking to document:***

- *Project milestones*
- *Assignment of responsibilities*
- *Timeline adherence*
- *Outcome metrics*

## **CELEBRATE MILESTONES**

Celebrate the success of the FAC! Recognize milestones—whether big or small—and share updates with staff and other families. Consider implementing:

### **Regular Recognition**

- Monthly FAC member spotlight in hospital newsletter
- Annual appreciation event
- Project completion celebrations
- Public acknowledgment of contributions

### **Documentation of Impact**

Track and share concrete outcomes such as:

- Revised institutional or unit policies
- Developed family education materials
- Enhanced staff training programs
- Improved NICU family/patient experiences

## **LESSONS LEARNED**

Document successful strategies as well as areas for quality improvement. Some of the lessons learned in creating the CPQCC California NICU FAC:

- **Family members have varying experiences and varying expectations for change in the NICU.** It's important to listen to everyone's voice, but also to plan carefully based on what projects will be impactful and possible. Ensure that the initial project for a new FAC is straightforward and can be a "quick win" to develop agency and enthusiasm.
- **Recruiting takes a lot of planning, time, and attention—plan ahead and leave at least a couple of months to find and attract members.** Plan for members who may require additional accommodations, such as an interpreter or travel support.

- **Family members face complex demands on their time.** Scheduling meetings and retaining active members can be challenging. One option is to hold meetings on an alternating basis, perhaps one in the evening followed by one during the day, to accommodate members with small children as well as members with full-time jobs.
- **Having a consistent point of contact for the FAC members is important to build trust.** Make sure that the staff member has sufficient time protected to develop authentic relationships with the members.

### Tools & Templates

NICU FAC Standard Meeting Agenda (Template, CPQCC)

NICU FAC Member Connection and Priority Setting Activity (Tool, CPQCC)



# Section 4: Sustain, Evaluate, and Improve

*"As a parent who spent 90 days in the NICU, I know firsthand the importance of having someone to talk to—someone who understands what you're going through. Our family advisory council gave us a platform to share our experiences and make meaningful changes in the NICU. It felt empowering to know that our voices could help improve the experience for other families."*

*— CPQCC California NICU FAC Member*

## SUSTAIN ENGAGEMENT

Keeping FAC members engaged over time requires recognition and support for flexibility.

### RECOGNIZE CONTRIBUTIONS

Regularly celebrate the efforts of FAC members through formal recognition, thank-you notes, or small tokens of appreciation.

### SUPPORT FLEXIBLE INVOLVEMENT

Allow for flexibility in participation, as family members' availability and needs may change over time. Offering short-term roles or project-based involvement can help members stay engaged without becoming overwhelmed.

*"We all have different lived experiences at the NICU....and they are all important! Whether they had a good NICU experience or a not-so-good NICU experience, their voice matters. FACs are vital to support families going through an extremely challenging time, and the more voices, the better. It is a chance to really make a difference for the families who come after you. It is an opportunity to share your feedback and support, and hopefully, impact positive changes. It is truly one of the most rewarding experiences."*

*— CPQCC California NICU FAC Member*

## EVALUATE AND IMPROVE

### COLLECT AND USE FEEDBACK TO REFINE PROCESSES

Analyze feedback collected to adjust processes, ensuring the FAC continues to evolve and improve. Use regular surveys or check-ins to gather feedback from:

- FAC members
- NICU staff
- Hospital leadership

This feedback can help identify areas where the FAC is excelling and where there's room for improvement.

### REVIEW FUND ALLOCATIONS

Develop a budget that includes funds for honoraria to recognize FAC member time and contributions. This strategy may enable a broader representation of families on the FAC and foster long-term engagement. CPQCC recognizes that NICU FAC participation is a meaningful exchange that enhances QI work, and has committed to compensating family members for their time.

### ATTRITION

When members leave or disengage from the council, it can be challenging to maintain continuity, expertise, and representation of diverse family perspectives. Several factors could contribute to attrition:

#### LIFE CHANGES

- Family members may experience changes in their personal lives, such as moving to a new location, work commitments, loss of a loved one, or health issues which can interfere with their ability to attend meetings or participate actively.

#### TIME COMMITMENT

- Serving on an FAC often requires a significant time commitment, including attending meetings, reviewing materials, and sometimes engaging in additional tasks or subcommittees. For many families, balancing this responsibility with work, caregiving, and other duties can be difficult.
- If council meetings or activities conflict with family members' schedules, they may not be able to participate.

#### LACK OF ENGAGEMENT OR IMPACT

- Family members may disengage if they feel their contributions aren't making a difference or if there is insufficient follow-through on initiatives. Emotional exhaustion can also lead to burnout, especially when dealing with sensitive healthcare topics.
- Tensions within the group, poor communication, or unclear goals can create dissatisfaction, while the absence of recognition can make members feel undervalued.

## ATTRITION PREVENTION

It is crucial to ensure meaningful engagement by acting on recommendations, providing emotional support, fostering clear communication, offering recognition, and implementing proper training. The NICU FAC Member Experience Survey is a helpful tool to support retention and can be used to check in regularly with members to assess their satisfaction and needs, ensuring they feel valued and equipped to contribute meaningfully.

## ANNUAL FAC EVALUATION

Evaluation should include an open-ended survey and focus group interview after each year.

## PLAN FOR THE FUTURE

After an FAC is established and has been in place for at least a year, conduct a comprehensive review to plan future FAC goals. This is a time to celebrate FAC successes: learnings from starting an FAC, positive impact on NICU family experience, connections with the local community, and collaborations between NICU staff and families. An FAC may not achieve significant change immediately and may require more time to grow and develop. Regardless of the level of progress, a NICU must affirm its commitment to the valuable work achieved by the FAC. Identify future areas for FAC improvement and advancement to enhance the NICU family experience. Ultimately, the true value of an FAC is in creating a NICU environment that welcomes all NICU families, and a strong partnership with NICU staff to achieve ongoing change.

### Tools & Templates

NICU FAC Feedback Survey Package (Template, CPQCC)

FAC Impact Measurement Scorecard (Tool, CPQCC)

Project Impact Survey (Template, CPQCC)



# Conclusion

*“I have watched the evolution of our NICU to include a more family-centric environment and promote and encourage family participation, and there is still more to do! Through my involvement in CPQCC, I have enjoyed learning about other members’ FACs and getting great ideas to bring back to my FAC.”*

— CPQCC California NICU FAC Member

Creating and maintaining a successful FAC requires planning, commitment, and ongoing support.

By assessing readiness, recruiting members with a variety of lived experiences, engaging them effectively, and ensuring sustainability, NICUs can create a supportive environment where families and staff work together to improve care.

An FAC in the NICU can connect healthcare providers and families, improving communication, patient care, and family experience during a stressful time. Involving families in the decision-making process helps ensure that NICU care is more responsive to their needs and empowers them to be active participants in their child’s care journey. The insights provided by an FAC can drive improvements that benefit everyone involved, leading to better outcomes for both NICU patients and their families.

## FINAL THOUGHTS

Congratulations on taking the first steps toward creating a formal FAC for your NICU! You’ve embarked on an impactful journey that will make a difference for your staff, providers, and families. This work may not be easy, but it will be rewarding, and you are already making great strides. Start by assessing readiness, recruiting members, and integrating family voices into your NICU’s decision-making processes. By doing so, you’ll help create a NICU environment that values family input and improves care for all. The possibilities for your FAC are vast, and the positive impact on your NICU is just beginning!

*“I think as families we have a unique opportunity to personalize the NICU experience. We have a unique opportunity to create both policy change and structural change within hospitals, as well as opportunities to impact the education of medical practitioners.”*

*— Sylvia, with NICU Graduate Felix  
CPQCC California NICU FAC Member (2023-2024)*



# NICU Family Advisory Council Toolkit

## Quick Start Guide

This Quick Start Guide summarizes the important points in the NICU Family Advisory Council Toolkit. A family advisory council (FAC) can improve communication between families and hospital staff. Family perspectives can drive systemic improvements in patient care, health outcomes, and quality improvement, and promote the development of support programs for families in the NICU. The toolkit is designed to help NICU staff and families create successful FACs in their units, whether starting from scratch or working to enhance an existing council.

### ASSESS READINESS

#### ESSENTIAL ELEMENTS FOR FAC SUCCESS

- Leadership support
- FAC champion identification
- Administrative infrastructure
- Staff readiness and engagement
- Budget planning and resource allocation

#### DEFINING A FAMILY ADVISORY COUNCIL

- Establish a strong foundation and clear expectations
- Align objectives and activities with organizational goals and family needs
- Clearly define roles and responsibilities for NICU staff and FAC members
- Establish metrics to track FAC impact

#### RECRUIT MEMBERS

- Understand the hospital's NICU community
- Set membership parameters with consideration for time since NICU experience and representing different types of families
- Strategize recruitment using NICU follow-up surveys, social media platforms, staff engagement, and community partnerships

- Review applications and conduct interviews focusing on NICU experience, personal readiness, interests/skills, and prior advisory/advocacy experience

Onboard and prepare members using a comprehensive process that includes:

- Program overview
- Legal and compliance requirements
- Training opportunities
- Distribution of handbooks, guides, and resources

## ENGAGE AND INVOLVE

### CREATING A CULTURE OF ENGAGEMENT

- Build a culture that supports all members
- Identify member strengths and interests

### PROFESSIONAL EDUCATION

- Includes quality improvement and trauma-informed care

### PROJECT MANAGEMENT

- Brainstorm project ideas and track progress
- Celebrate and recognize milestones
- Document impact of outcomes

## SUSTAIN, EVALUATE, AND IMPROVE

- Recognize contributions of FAC members
- Support flexible involvement, including short-term roles or projects
- Collect feedback from FAC members, NICU staff, and hospital leadership
- Review fund allocations, including honoraria for FAC members
- Refine processes based on feedback
- Anticipate and prevent attrition
- Perform annual evaluations
- Plan future FAC goals

**Disclaimer:** This toolkit is considered a resource but does not define the standard of care in California. Readers are advised to adapt the guidelines and resources based on their local facility's level of care and patient populations served and are also advised not to rely solely on the guidelines presented here. The examples provided in Tools & Templates, as well as links for additional information or training, should not be viewed as exclusive or preferred.

# Resource Library

## ESSENTIAL RESOURCES FOR FAC NICU DEVELOPMENT AND OPERATION

- [California Perinatal Quality Care Collaborative](#)
- [Family-Centered Care Taskforce](#)
- [Institute for Patient- and Family-Centered Care \(IPFCC\)](#)
- [Agency for Healthcare Research and Quality](#)
- [Lucile Packard Foundation for Children's Health](#)
- [Vermont Oxford Network for Health Equity—Potentially Better Practices for Follow Through](#)
- [March of Dimes NICU Family Support](#)

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Bylaws for NICU Patient Family Advisory Council

[Patient & Family Advisory Council Charter](#)

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Fact Sheet: A Guide to Establishing Effective Hospital Family Advisory Councils

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NICU FAC Recruitment Flyer, English and Spanish

NICU FAC Member Application Form

NICU FAC Interview Guide & Questions

NICU Feedback Survey About FAC

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NICU FAC Standard Meeting Agenda

NICU FAC Member Connection and Priority Setting Activity

## TOOLS & TEMPLATES

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NICU FAC Feedback Survey Package

FAC Impact Measurement Scorecard

Project Impact Survey

## CREATING PATIENT AND FAMILY ADVISORY COUNCILS



**INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®**

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## CREATING PATIENT AND FAMILY ADVISORY COUNCILS

### ▼ Purpose/responsibility of the advisory council

- Serves as advisory resource to administration and staff of the organization or one of its programs
- Promotes improved relationships between patients, families, and staff
- Provides a vehicle for communication between patients, families, and staff
- Provides a venue for patients and families to provide input into policy and program development
- Provides an opportunity for patients and families to review recommendations referred to the council by staff or administration and provide input
- Provides an opportunity for patients and families to actively participate in improving quality, safety, equity, and the experience of care
- Channels information, needs, and concerns to staff and administration
- Actively helps implement changes
- Provides input into educational programs for staff
- Collaborates as partners with staff, physicians, and administration in the planning and operation of specific programs
- Provides opportunities for staff to learn from the perspectives of patients and families
- Provides a safe venue for patients and families to provide input in a setting where they are receiving care

### ▼ Benefits of an advisory council

- Provides an effective mechanism for receiving and responding to feedback
- Results in more efficient planning to ensure that services address the needs and priorities of patients and families
- Leads to increased understanding and partnership between patients and families and clinicians and staff
- Promotes respectful, effective partnerships between patients and families and health care professionals
- Offers a forum for developing creative, cost-effective solutions to problems and challenges faced by the program or organization

## CREATING PATIENT AND FAMILY ADVISORY COUNCILS

- Assists the organization in achieving its safety, quality, equity, and experience of care outcomes
- Provides a link between the organization, its surrounding community, and community groups

**Note:** The council should not be seen as a place where an individual council member brings their personal grievances about clinic/ hospital experiences to be dealt with and solved. Personal experiences should be used as examples when discussing a program or service. Council members should also bring experiences and perceptions of other patients and families to the discussion. The council should not be seen as a support group. Patients or families who are grieving over a loss should be directed to a support group.

### ▼ Representing the patients and families served

Seek patients and families who represent a variety of clinical experiences such as type of condition, illness, and programs utilized. Seek a broad range of experiences. Include patients and families who have both positive as well as negative perspectives of experiences.

Seek patients and families who reflect the diversity of those served by the hospital or clinic—racial, cultural, religious, gender, socioeconomic, age, educational background, and a variety of family structures.

### ▼ Qualities and skills of patient and family advisors

Identify patients, families, staff, and community organizations that can recommend potential members. Patient experience personnel, physicians, nurses, managers, social workers, child life personnel, and volunteer coordinators as well as other professionals can recommend candidates.

Seek individuals and families who are able to:

- Share insights and information about their experiences in ways that others can learn from them
- See beyond their own personal experiences
- Show concern for more than one issue or agenda
- Listen well
- Respect the perspectives of others
- Speak comfortably in a group with candor
- Interact well with many different kinds of people
- Work in partnership with others

### ▼ Recruitment

- Ask staff for suggestions
- Post and advertise within the units or clinics
- Put notices in websites, social media platforms, and publications
- Send direct mail to present and former patients

## CREATING PATIENT AND FAMILY ADVISORY COUNCILS

### ▼ Developing the council

Consider developing a patient and family workgroup as a precursor to a more formal council. A workgroup is a quick way to get patient and family participation in activities. The informal structure of a workgroup may be less threatening to staff. Someone internal or external to the organization can facilitate the workgroup. The latter provides an opportunity for staff, patients, and families to become comfortable over time with new ways of working together. A workgroup is a place where staff, patients, and families can learn and practice new collaborative skills and a place to gain confidence in the collaborative process. It provides an opportunity for natural leaders to emerge. A workgroup can provide invaluable information to staff until a permanent council and/ or a variety of other collaborative endeavors are established.

### ▼ Council structure

Determine structure, size, meeting frequency, operating procedures, and guidelines/bylaws.

#### Size

Smaller groups encourage greater discussion and participation by all members. Most people are more comfortable speaking in a smaller group. It is more challenging to facilitate larger groups and obtain input from everyone. Larger groups will provide a wider range of experiences and input. They also are able to have broader representation of diverse populations. Consider availability of meeting sites to accommodate various sizes of groups. Twelve to eighteen patient and family members is usually considered a manageable size.

#### Staff membership

No more than 3-4 staff should have a permanent place on the council. Other staff can attend depending on topics for discussion. Staff should have easy access to the council. Too many staff will result in patients/ families not feeling it is their council.

#### Terms of membership

Consider length of term with rotation being intermittent rather than everyone turning over at once. Suggested term is 2-3 years to maintain some consistency. When their term ends they can serve as advisors in other ways such as faculty for staff education or on board level committees.

#### Compensation/reimbursement

Plan for compensation of time, expertise, and expenses for patients and families. Consider remuneration for patients and families in the form of a small amount to cover transportation expenses, internet or data plans, child or respite care, or other costs that might be incurred. Some patients and families may have difficulty joining the council if they are not given some assistance. Consider providing child care during meetings if needed. Designate one staff member from the organization to be responsible for reimbursement and other practical or logistical issues for family advisors.

#### Officers

Co-chairs and a secretary are the essential officers. If possible provide organizational support to assist with mailing or emailing materials, distributing minutes. Co-chairs could be two patient or family advisors or a staff person and patient/ family advisor. Suggest selecting one new co-chair each year so there is carryover to the next year.

## CREATING PATIENT AND FAMILY ADVISORY COUNCILS

### Committees

You may want to create some permanent committees that could include membership of patients/ family members who are not on the council. Task forces or ad hoc committees might be identified to work on a specific issue or short-term project. Patients and family members who are not on the council would be encouraged to participate—this will increase the number of patients and family members who participate and provide input as well as help in recruiting long-term advisors.

### Guidelines/Bylaws

Operating guidelines/bylaws need to be developed by the council. These are important because they provide the framework for perceived goals and objectives. They also legitimize the group and help promote a feeling of an established, well-organized group. Developing guidelines/bylaws can be time consuming, however, reviewing examples from existing advisory councils can save you time. They can be adapted and amended to suit your group's specific needs.

Select a small core group from the council to develop the guidelines/bylaws. Among the issues that should be addressed in the bylaws are:

- Purpose of the council
- Vision or mission statement
- Goals and responsibilities
- Structure of the council
- Size of the council
- Membership qualifications
- Nominations and elections of members and officers
- Duties of members and officers
- Committees and task forces
- Voting procedures
- Meetings including options for participation (e.g., virtually)
- Agendas
- Expectation for annual assessment of members and council
- Guidelines of authority
- Confidentiality and Privacy
- Leave of absence and termination policies

After developing your group's guidelines/bylaws, present them to administration for approval. All council members should review, discuss, and amend if necessary and give final approval. The guidelines/bylaws should be reviewed annually and revised as necessary.

## CREATING PATIENT AND FAMILY ADVISORY COUNCILS

### ▼ Meetings schedule

Frequency - monthly is highly recommended. When meetings are less frequent, members lose momentum and involvement and less work can be accomplished. When they are too frequent, members will have trouble attending.

Days/ times - let the council members select but may be dependent on room availability if meeting in-person. Consider what is convenient for patients/ families and staff.

### Agenda

The council should develop a list of issues they wish to work on and “own” the agenda. Staff or other patients/ families can add to the agenda. Keep in mind that effective and productive councils are those that align their goals with the strategic priorities of the organization.

### Minutes

Minutes should be kept and distributed widely so the activities of the council are made aware to as much of the organization as possible.

### ▼ Orientation of new council members

Orientation should include:

- Introductions and the sharing of personal and family stories of health care experiences
- The vision and goals of the organization
- The role of the council, how its fits within the organization’s structure, and how it can assist the organization in achieving its vision and goals
- The roles and responsibilities of members
- The roles and responsibilities of officers
- HIPAA and expectations for honoring privacy and confidentiality
- Meeting attendance expectations of members
- The roles and responsibilities of staff on the council
- How to be an effective council member
- How to present issues effectively
- How to be most effective in collaborating with organizational leaders, clinicians, and staff.

### ▼ Maintaining history

It is important to track accomplishments and disseminate widely. Track issues the council is working on so they do not get lost.

## CREATING PATIENT AND FAMILY ADVISORY COUNCILS

### ▼ Sustaining the council

- Invest in building leadership skills of council members
- Select patients and families wisely
- Ensure that the council is representative of patients and families served
- Maintain balance between new members and committed members with longevity of service
- Devote time to planning and evaluation of council efforts and impact
- Set priorities and focus efforts on meaningful collaborative projects

### ▼ Resources

For a more comprehensive resource see: Minniti, M. M., & Abraham, M. R. (2013). *Essential Allies—Patient, Resident, and Family Advisors: A Guide for Staff Liaisons*. Bethesda, MD: IPFCC.

For guidance to help patient and family members prepare to be an advisor see: Abraham, M., Ahmann, E., & Dokken, D. (2013). *Words of Advice: A Guide for Patient, Resident, and Family Advisors*. Bethesda, MD: IPFCC.

Available for download on IPFCC's website are the following resources:

*Diverse Voices Matter: Improving Diversity in Patient and Family Advisory Councils* at [www.ipfcc.org/resources/Diverse-Voices-Matter.pdf](http://www.ipfcc.org/resources/Diverse-Voices-Matter.pdf)

*Key Learnings for Strengthening Partnerships: Recommendations from a National Study of Patient and Family Advisory Councils in U.S.* at [www.ipfcc.org/resources/IPFCC\\_Key\\_Learnings.pdf](http://www.ipfcc.org/resources/IPFCC_Key_Learnings.pdf)

*Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals* at [www.ipfcc.org/bestpractices/NYSHF\\_2018\\_PFAC\\_Online\\_v3.pdf](http://www.ipfcc.org/bestpractices/NYSHF_2018_PFAC_Online_v3.pdf)

## BYLAWS FOR NICU PATIENT FAMILY ADVISORY COUNCIL



### Bylaws for NICU Patient Family Advisory Council

**PFAC Mission:** The NICU PFAC serves to enhance family centered care in the Neonatal Intensive Care Unit by identifying education, supportive programming, and creative activities for development and unit implementation; and provides the perspective of families and the community into the care experience.

**Membership:** Members will consist of parents and caregivers of child/children who have received care in the NICU at Children's Mercy. All members will become official Children's Mercy volunteers and must comply with the requirements set forth by Volunteer Services.

**Application Process:** To help achieve a diverse representation and work towards the PFAC's mission, Children's Mercy has created the following application process for potential members.

- All applicants complete an [ONLINE APPLICATION](#).
- Applications are shared with the clinic team and/or the PFAC Staff Facilitator to confirm membership recommendation.
- Applicants are interviewed by the PFAC Chair or Co-Chair; with recommendations forwarded to the Patient and Family Engagement liaison.
- When necessary, the PFAC Chair will seek additional input from current PFAC members and staff about potential candidate's acceptance to the PFAC.
- Upon acceptance, the new member will receive the PFAC Orientation Manual after completing the hospital's Volunteer Services onboarding requirements and be invited to and introduced at the next PFAC meeting.

**Size:** The PFAC will strive for membership of between 8-18 family members and at least one active and consistent Children's Mercy staff member from the related unit or department. Children's Mercy staff are non-voting members.

**Diversity in Membership:** Diverse representation is a vital component in gathering comprehensive feedback. Membership representing different races, ethnicities, diagnoses, lengths of stay, medical outcomes, ranges in socioeconomic status, levels of education, religions, genders, ages, and sexual orientations is encouraged.

**Terms:** PFAC members commit to serve for a minimum of 2 years, with additional 2-year terms if members have met the membership and attendance requirements.

## BYLAWS FOR NICU PATIENT FAMILY ADVISORY COUNCIL



**Attendance:** Consistent and active attendance is vital to the purpose of the PFAC. Each member is strongly encouraged to attend and participate in all PFAC meetings, either in-person or via the Microsoft Teams virtual platform. PFAC members are required to attend 50% of the PFAC meetings within a 12-month period. PFAC meetings are scheduled at the same day and time on a recurring calendar invite. It will be assumed all members will be in attendance. If a member cannot attend, out of courtesy for the group he/she will notify the PFE Liaison as soon as possible. A quorum of 50% of the total membership, either in person or electronically (or a combination), is required to vote on issues. All decisions that require a vote need a simple majority to pass.

**Officer Leadership and Elections:** The PFAC Leadership Team consists of a Parent Chair, Parent Co-Chair, Staff Facilitator, and a Liaison from the Patient and Family Engagement Team. PFAC members can nominate themselves or other members for leadership roles; PFAC members can decline a leadership nomination. Leadership terms will run from July 1 to June 30 following the Children's Mercy fiscal year. Election will be held every June as and terms will be limited to a year with a one-time renewal option.

- **Chair:** Organize and lead meetings. The Chair will be the PFAC representative at official meetings when needed, including the FAB Annual Meeting in January. The chair will also distribute meeting agendas and minutes and maintain council communications.
- **Co-Chair:** Support the Chair in their duties, including serving as acting Chair during the Chair's absence; may record meeting minutes.
- **Staff Facilitator:** Act as the connection between parents/caregivers and the unit or department. Schedule and participate in the planning meeting prior to each PFAC meeting; attend all PFAC meetings as an active and consistent member and provide a hospital update during each meeting; may record meeting minutes; inform the unit or department about the PFAC's accomplishments, goals, and projects; may be PFE Liaison.
- **PFE Liaison:** Acts as a bridge between the PFAC and the hospital, sharing project goals and successes of the PFAC with the appropriate hospital teams. May also serve as Staff Facilitator. Will track member volunteer hours associated with the NICU PFAC.

**Member Expectations:** The PFAC is an action-oriented group with expectations of time investment outside of the meetings. It is important to note that the PFAC will not meet the needs and capacity of a diagnosis-specific support group. Typical agendas of PFAC meetings may include reviewing and improving existing processes; co-designing parent education; and reporting summaries from the sub-committees.

## BYLAWS FOR NICU PATIENT FAMILY ADVISORY COUNCIL



Members will:

- Serve as an advisory resource to unit leadership and staff.
- Advocate to improve the quality and accessibility of care.
- Assist in the development and review of educational materials.
- Respectfully listen and tactfully discuss ideas, issues, and concerns.
- Respect the privacy and confidentiality of council members, their families, and all staff.
- Actively participate with expectations of time investment outside of the meetings.

**Sub-Committees:** The purpose of a sub-committee is to obtain rapid, real-time, feedback from a smaller group of PFAC members, beyond the regularly scheduled PFAC meeting. Subcommittees may be utilized for a short-term project (3-6 months), specific to the needs of the related unit or department, or they may be an ongoing group looking at a long-term goal. Subcommittees are led by a Lead Parent/Caregiver who will report project updates to the larger group during PFAC meetings.

**Patient and Family Engagement Team:** The Patient and Family Engagement Team provides support and oversight for all PFACs at Children's Mercy. This team serves as a liaison between PFACs and the healthcare system. They produce an annual report denoting accomplishments of each PFAC.

**Bylaw changes:** Any articles of these guidelines may be added, deleted, or amended by majority of the vote of at least 2/3 of the PFAC membership.

Guidelines Approved 10/16/24

## FAC READINESS ASSESSMENT CHECKLIST

CPQCC created this scoring system to help you identify potential resources in your unit. However, it is optional as most centers have successfully implemented an FAC and collaborated with families without relying upon a scoring system.

Check all that apply for your hospital's NICU. Each check = 1 point. Review the score at the end.



### LEADERSHIP SUPPORT

- Executive leadership endorsement
- Department head buy-in
- Budget allocation
- Staff time commitment
- Clear reporting structure

### INFRASTRUCTURE

- Dedicated meeting space
- Administrative support
- Technology for virtual meetings
- Document storage system
- Communication channels

### STAFFING & RESOURCES

- FAC coordinator identified
- Staff liaison designated
- Clinical team representatives
- Training resources available
- Volunteer services support

### Scoring Guide

13-15 items checked: Ready to proceed

8-12 items checked: Some preparation needed

0-7 items checked: Significant groundwork required

# FACT SHEET:

## A GUIDE TO ESTABLISHING EFFECTIVE HOSPITAL FAMILY ADVISORY COUNCILS



### Fact Sheet

September 2015

#### A Guide to Establishing Effective Hospital Family Advisory Councils

When families partner with their children's health care providers the quality of care improves and parents' fears and anxieties are reduced. This is especially important when the health of children with chronic, complex conditions depends on hospital care. Creating effective Family Advisory Councils (FACs) in children's hospitals is one proven approach to ensuring that families have a strong voice regarding how health care is delivered to their children. To promote such Councils, the Lucile Packard Foundation for Children's Health provided grant funding for the formation of the *California Patient & Family Centered Care Network*, a statewide collaborative composed of parents and providers representing 15 pediatric hospitals and clinics. Network members shared their experiences with FACs and developed a checklist for establishing effective Councils.

Family Advisory Council Checklist	
<b>1. FAC Function</b>	
<input type="checkbox"/>	Determine function of Council (advise; implement; hybrid)
<input type="checkbox"/>	Identify resource needs to proceed with identified function (Advising—do you have diverse representation? Implementing—do you have capacity to plan and implement?)
<input type="checkbox"/>	Set clear expectations regarding function with Council members
<input type="checkbox"/>	Clarify function with hospital administration and staff
<input type="checkbox"/>	Incorporate FAC function into member orientation
<input type="checkbox"/>	Intervene when Council work veers from stated function
<b>2. FAC Authority</b>	
<input type="checkbox"/>	Develop co-agreement of Council authority (advice; recommendation; binding recommendation) with hospital administration
<input type="checkbox"/>	Set clear expectations with Council members
<input type="checkbox"/>	Maintain parent as leader or co-leader to model expected "authority level"
<input type="checkbox"/>	Incorporate FAC authority definition into member orientation
<input type="checkbox"/>	Create feedback loops from initiatives, projects and policies to determine effectiveness of FAC input
<input type="checkbox"/>	If staff members are part of Council membership, clarify their role in giving input
<input type="checkbox"/>	Make sure hospital staff understands FAC authority prior to work with Council

A Strong Voice for Parents: How to Establish Effective Family Advisory Councils in Pediatric Settings

Wayman, K. I. (2015, September). A guide to establishing effective hospital family advisory councils (Fact sheet). Lucile Packard Children's Hospital Stanford. [https://lpfch.org/wp-content/uploads/2024/02/a\\_guide\\_to\\_establishing\\_effective\\_hospital\\_family\\_advisory\\_councils.pdf](https://lpfch.org/wp-content/uploads/2024/02/a_guide_to_establishing_effective_hospital_family_advisory_councils.pdf)

# FACT SHEET:

## A GUIDE TO ESTABLISHING EFFECTIVE HOSPITAL FAMILY ADVISORY COUNCILS

Lucile Packard Foundation for Children's Health

<b>3. Scope</b>	
<input type="checkbox"/>	Brainstorm potential internal and external projects and individuals who would benefit from FAC input
<input type="checkbox"/>	Prioritize projects and individuals for highest impact
<b>4. Member Management</b>	
<input type="checkbox"/>	<p>Create a recruitment process that includes:</p> <ul style="list-style-type: none"> <li>■ a set of member characteristics that are aligned with Council goals</li> <li>■ an interview process to determine goodness-of-fit</li> <li>■ opportunities for potential parent participants to observe FAC prior to committing</li> </ul>
<input type="checkbox"/>	<p>Screening: List of member characteristics identified by Network—a beginning list</p> <ul style="list-style-type: none"> <li>■ good communication skills</li> <li>■ able to speak in broad terms as well as specific terms about health care experience</li> <li>■ child not in active disease process (not hospitalized or in diagnostic phase)</li> <li>■ interested in change</li> </ul>
<input type="checkbox"/>	<p>Training:</p> <ul style="list-style-type: none"> <li>■ should be ongoing (more than a one-time orientation)</li> <li>■ a brief debriefing should occur after each Council meeting</li> <li>■ facilitate respect for varying opinions</li> <li>■ provide strategies to tell an effective story</li> <li>■ identify strategies for providing "solutions" to issues</li> </ul>
<input type="checkbox"/>	Feedback: Facilitate Council members agreement on approach to give feedback that promotes partnership and respects differing opinions
<input type="checkbox"/>	Feedback: FAC facilitator develop set of communication strategies to enhance parent feedback; some suggestions: <ul style="list-style-type: none"> <li>■ "That's a powerful story—what would have improved your experience?"</li> <li>■ "What would you like to see changed based on your story?"</li> <li>■ "Let's pull out the key elements of your story and think of recommendations for change."</li> </ul>
<input type="checkbox"/>	<p>Feedback: Assure that all Council members are provided the opportunity to give input at every meeting</p> <ul style="list-style-type: none"> <li>■ Suggestion: Provide written notification (table card) asking, "Has everyone been heard?" as a reminder to let everyone have input</li> </ul>
<b>5. Meeting Management (Sustaining FACs)</b>	
<input type="checkbox"/>	<p>Mix up type of Council work</p> <ul style="list-style-type: none"> <li>■ short-term focus group</li> <li>■ ongoing project input</li> <li>■ environmental "walk-about"</li> <li>■ meet and greets</li> <li>■ policy input</li> <li>■ document review</li> <li>■ special Council project</li> <li>■ variety of topics (customer service; patient safety; new construction)</li> </ul>
<input type="checkbox"/>	Tap into member interests and passion (arrange for feedback in an area of member interest)
<input type="checkbox"/>	To help plan (or expand) the FAC agenda—reflect on the following: <ul style="list-style-type: none"> <li>■ Does FAC work reflect the institution's strategic goals?</li> <li>■ Does the agenda include presentations from both ongoing staff champions as well as staff unfamiliar with the FAC?</li> </ul>

A Strong Voice for Parents: How to Establish Effective Family Advisory Councils in Pediatric Settings

# FACT SHEET:

## A GUIDE TO ESTABLISHING EFFECTIVE HOSPITAL FAMILY ADVISORY COUNCILS

Lucile Packard Foundation for Children's Health

	<ul style="list-style-type: none"> <li>■ Which hospital-based change initiatives would benefit from parent input?</li> </ul>
<input type="checkbox"/>	<ul style="list-style-type: none"> <li>Pre-meeting protocol with provider-presenter           <ul style="list-style-type: none"> <li>■ interview health care provider prior to presentation to clarify function and authority of FAC</li> <li>■ get "homework" or pre-materials to prepare Council members to give input</li> </ul> </li> </ul>
<input type="checkbox"/>	<ul style="list-style-type: none"> <li>Post-meeting protocol with provider-presenter           <ul style="list-style-type: none"> <li>■ send thank-you to provider</li> <li>■ check in with provider to determine if additional input is needed</li> <li>■ determine next steps or date of return</li> <li>■ periodically check in with provider to determine additional input needs</li> </ul> </li> </ul>
<input type="checkbox"/>	<ul style="list-style-type: none"> <li>Post-meeting debrief with Council members           <ul style="list-style-type: none"> <li>■ discussion generates thoughts-feelings-concerns?</li> <li>■ what was the quality of Council input?</li> <li>■ was everyone heard?</li> <li>■ need for more training?</li> <li>■ describe how issues/questions/input fits into hospital operations</li> </ul> </li> </ul>
<b>6. Accountability/Messaging</b>	
<input type="checkbox"/>	Periodic newsletters to list accomplishments of FAC
<input type="checkbox"/>	Presentations to hospital leadership to describe Council function and accomplishments
<input type="checkbox"/>	Ongoing list of FAC agenda items
<input type="checkbox"/>	Content analysis of FAC input to trend type and frequency of work

*Report prepared by Karen I. Wayman, PhD, Director of Family-Centered Care, Lucile Packard Children's Hospital Stanford.*

See [Creating and Sustaining Effective Hospital Family Advisory Councils: Findings from the California Patient and Family Centered Care Network of Pediatric Hospitals](#) for a full report on the work of the Network.

**ABOUT THE FOUNDATION:** The Lucile Packard Foundation for Children's Health is a public charity, founded in 1997. Its mission is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. The Foundation works in alignment with Lucile Packard Children's Hospital Stanford and the child health programs of Stanford University School of Medicine.

The Foundation encourages dissemination of its publications. A complete list of publications is available at <http://lpfch.org/publications>

**CONTACT:** The Lucile Packard Foundation for Children's Health, 400 Hamilton Avenue, Suite 340, Palo Alto, CA 94301  
[cshen@lpfch.org](mailto:cshen@lpfch.org) (650) 497-8365

**A Strong Voice for Parents: How to Establish Effective Family Advisory Councils in Pediatric Settings**

## FAC BUDGET PLANNING TEMPLATE

### ANNUAL BUDGET WORKSHEET

CPQCC created this worksheet to help you allocate funds if your FAC is supported by a large grant. Please customize the worksheet to fit your specific needs and resources.



#### MEMBER SUPPORT

Category	Annual Estimate	Notes
Member Honorariums	\$	Quarterly/annual payments
Special Project Compensation	\$	Additional involvement
Leadership Role Stipends	\$	For chair/co-chair positions
Training Participation	\$	For required courses/sessions

#### MEETING SUPPORT SERVICES

Category	Annual Estimate	Notes
Childcare Services	\$	During meetings/events
Transportation Support	\$	Parking/transit/mileage
Meal Provisions	\$	For extended meetings
Interpretation Services	\$	As needed for meetings

#### OPERATIONAL EXPENSES

Category	Annual Estimate	Notes
Meeting Materials	\$	Supplies/printing
Technology Resources	\$	Virtual meeting platforms
Professional Development	\$	Training/conferences
Administrative Support	\$	Coordination time

#### BUDGET JUSTIFICATION GUIDE

##### Member Compensation Calculation:

- Regular meetings: (# of members × hourly rate × hours per meeting × # of meetings)
- Special projects: (Estimated hours × project rate)
- Leadership roles: (Additional responsibility compensation)

##### Support Services Estimation:

- Childcare: (Average rate × hours needed × # of meetings)
- Transportation: (Average cost per member × # of meetings)
- Meals: (Per person cost × # of attendees × # of meetings)

## FAC BUDGET PLANNING TEMPLATE

### ROI Considerations:

- Patient satisfaction improvements
- Quality improvement outcomes
- Family engagement metrics



### IMPLEMENTATION NOTES

1. Review budget quarterly
2. Track actual vs. estimated expenses
3. Document impact of expenditures
4. Adjust based on program growth

# FAC INTERPRETATION SERVICES AND TECHNOLOGY SUPPORT GUIDE

This guide provides practical steps for implementing interpretation services and technology support to ensure that all NICU families can participate meaningfully in FAC activities, regardless of their language preference or technical barriers.



## INTERPRETATION SERVICES ASSESSMENT

### IDENTIFY LANGUAGE NEEDS

- Review NICU demographics from the past 12 months
- Survey current FAC interest among non-English language of preference (NELP) families
- Document the primary languages spoken by families

### IDENTIFY AVAILABLE RESOURCES

- Review your hospital's existing interpretation services contract
- Survey staff interpreter availability during FAC meeting time
- Assess current hospital video remote interpretation (VRI) technology
- Review budget allocated for interpretation services

### PRE-MEETING PREPARATION

- Provide interpreters with meeting agendas and materials 24-48 hours in advance
- Brief interpreters on NICU terminology and FAC context
- Establish ground rules for interpretation breaks and clarifications

## TECHNOLOGY SUPPORT ASSESSMENT

### IDENTIFY TECHNOLOGY NEEDS

- Assess family members' device access (smartphone, computer, tablet)
- Evaluate internet connectivity quality
- Identify comfort level with video conferencing platforms
- Document preferred communication methods

### IDENTIFY INFRASTRUCTURE RESOURCES

- Select a reliable virtual meeting platform (Zoom, Teams, WebEx)
- Ensure IT support is available during meeting times
- Prepare technical training resources
- Identify backup communication methods

# FAC INTERPRETATION SERVICES AND TECHNOLOGY SUPPORT GUIDE



## PRE-MEETING PREPARATION

- Provide instructions for joining the meeting (link, dial-in options)
- Explain basic platform navigation (mute/unmute, video on/off)

If applicable:

- Demonstrate use of the chat function
- Explain use of screen sharing for viewing documents
- Brief interpreters on NICU terminology and FAC context
- Establish ground rules for interpretation breaks and clarifications

## QUALITY ASSURANCE AND EVALUATION

### INTERPRETATION SERVICES

- Track number of sessions that provided interpretation
- Document interpreter availability, reliability, and rates/cost per interpreted session

### TECHNOLOGY SUPPORT

- Track number of technical assistance requests
- Document family comfort level with technology (pre-/post-session surveys)
- Log meeting participation rates for remote attendees

## FEEDBACK COLLECTION TOOLS

### FAMILY SATISFACTION SURVEY QUESTIONS

- How would you rate the quality of interpretation services? (1-5 scale)
- Did interpretation allow you to fully participate in discussions? (Yes/No)
- Were technical issues resolved quickly? (Yes/No)
- What improvements would you suggest for remote participation?
- Would you recommend virtual meeting options to other families? (Yes/No)

### STAFF FEEDBACK ASSESSMENT

- How well did interpretation services support meeting objectives?
- What were the most common technical challenges?
- How can we improve the remote participation experience?
- What additional training would be helpful?

## NICU FAC RECRUITMENT FLYER (ENGLISH)



Did you have a NICU baby?

Are you passionate about making the NICU journey better for families?

### Join CPQCC's 2025 California NICU Family Advisory Council

CPQCC has led statewide improvements in NICU care quality and racial and health equity since 1997. We believe all babies and families deserve equitable, high-quality care, and we know that family-centered care helps babies thrive.

The Council brings together diverse families with valuable lived experience to guide CPQCC in prioritizing, developing and putting into action tools for healthcare teams to expand family-centered care. Following statewide NICU data, the 2025 Council will focus on addressing social determinants of health, the needs of families who prefer a non-English language, making the NICU discharge process better for all babies and families, and more.

**Apply by January 31, 2025**



**CPQCC**  
california perinatal  
quality care  
collaborative



## NICU FAC RECRUITMENT FLYER (SPANISH)



# Consejo Asesor para Familias de la NICU en California



¿Tuvo uno o más bebés  
en la unidad de cuidados intensivos neonatales (NICU)? ¿Le interesa mejorar  
la experiencia en la NICU para todas las familias?

**Súmese al Consejo Asesor para Familias de la NICU en California  
de 2025 del CPQCC**

El CPQCC ha llevado a cabo mejoras a nivel estatal en la calidad de la atención en la NICU y en la equidad racial y de la salud desde 1997. Creemos que todos los bebés y las familias merecen una atención justa y de alta calidad, y sabemos que la atención centrada en la familia ayuda en el crecimiento de los bebés.

El Consejo reúne diversas familias con valiosas experiencias de vida para orientar al CPQCC para priorizar, desarrollar e implementar herramientas para los equipos de atención médica, y así ampliar la atención centrada en la familia. Con la información estatal sobre la NICU, el Consejo del 2025 se concentrará en abordar los factores sociales determinantes de la salud, satisfacer las necesidades de las familias que prefieren un idioma que no sea el inglés, mejorar el proceso de alta de la NICU para todos los bebés y las familias, y más.

**Envíe una solicitud para postularse antes del 31 de enero de 2025**





**CPQCC**  
california perinatal  
quality care  
collaborative



## NICU FAC MEMBER APPLICATION FORM



### PERSONAL INFORMATION

(Please customize this section based on your institution's practices.)

### DEMOGRAPHIC INFORMATION

(Please customize this section based on your institution's practices.)

### NICU EXPERIENCE

When was your NICU stay? \_\_\_\_\_

Length of stay: \_\_\_\_\_ Child's current age: \_\_\_\_\_

### ABOUT YOU

1. What interests you about joining the Family Advisory Council?
2. What unique perspectives would you bring to the Council?
3. Please describe any volunteer or committee experience.
4. What aspects of the NICU experience would you most like to help improve?

### AVAILABILITY & COMMITMENT

- Meetings are held monthly for 2 hours
- Additional time may be needed for special projects
- Initial commitment is one year

Can you regularly attend monthly meetings?

Yes

No

What are your preferred meeting times? (Check all that apply.)

- Weekday mornings
- Weekday afternoons
- Weekday evenings
- Weekend mornings
- Weekend afternoons

### REFERENCES

Please provide one reference (healthcare provider, employer, or volunteer coordinator):

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

## NICU FAC MEMBER APPLICATION FORM

Contact Information: \_\_\_\_\_



### ADDITIONAL INFORMATION

1. Are you comfortable sharing your NICU story with others? Yes/No
2. Are you willing to maintain confidentiality of sensitive information? Yes/No
3. Do you have any special skills or expertise you'd like to share?

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### SIGNATURE

I understand the commitment required and will do my best to fulfill these responsibilities if selected.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## NICU FAC INTERVIEW GUIDE & QUESTIONS



CPQCC created this interview guide to support with recruitment efforts for family advisory councils (FACs). There are a variety of questions included to illustrate the range of topics that can be addressed during interviews. Please feel free to choose questions that are most relevant for your FAC. Interviews can be brief, and even asking as few as five questions can be sufficient to provide good insights.

### INTRODUCTION SCRIPT

"Thank you for your interest in joining our NICU Family Advisory Council. This interview will help us learn more about you and ensure the council is a good fit for both of us. We'll discuss your NICU experience, what brings you to the FAC, and how you hope to contribute. Please feel free to ask questions throughout our conversation."

### BACKGROUND & MOTIVATING QUESTIONS

#### NICU EXPERIENCE

1. How long has it been since your NICU experience?
2. What aspects of your NICU journey stand out most to you? (*Looking for: Emotional readiness, ability to reflect constructively*)

#### MOTIVATION & INTEREST

1. What interested you in joining the Family Advisory Council?
2. What do you hope to accomplish as a council member? (*Looking for: Focus on helping others, broader perspective beyond personal experience*)

#### PREVIOUS EXPERIENCE

1. Have you served on any committees or advisory groups before?
2. What experience do you have working in group settings? (*Looking for: Teamwork abilities, understanding of group dynamics*)

### SKILLS & QUALITIES ASSESSMENT

#### COMMUNICATION STYLE

1. How would you share feedback about a difficult experience in a constructive way?
2. Can you tell me about a time when you had to explain a complex situation to others? (*Looking for: Diplomatic communication, ability to articulate clearly*)

#### PERSPECTIVE TAKING

1. How do you handle situations where others have different opinions than yours?
2. What would you do if another council member shared an experience very different from yours? (*Looking for: Openness to different viewpoints, respect for a variety of experiences*)

# NICU FAC INTERVIEW GUIDE & QUESTIONS



## PROBLEM SOLVING

1. Can you share an example of how you've helped improve a situation or process?
2. How do you approach challenges when working with others? (*Looking for: Solution-oriented thinking, collaborative approach*)

## PRACTICAL CONSIDERATIONS

### TIME & COMMITMENT

1. Our meetings are [specify time/date]. How would this fit with your schedule?
2. What other commitments might impact your participation? (*Looking for: Realistic understanding of time commitment*)

### CONTRIBUTION AREAS

1. What specific skills or experiences could you bring to the council?
2. Are there particular areas of NICU care you're most interested in helping improve? (*Looking for: Potential contribution areas, specific interests*)

## SCENARIO-BASED QUESTIONS

### SCENARIOS

1. "If you heard about a family struggling with [specific NICU challenge], how would you advise addressing this at the council level?"
2. "If hospital staff proposed a change you disagreed with, how would you handle that?" (*Looking for: Strategic thinking, professional approach*)

## CLOSING QUESTIONS

### FINAL THOUGHTS

1. What questions do you have about the Family Advisory Council?
2. Is there anything else you'd like us to know about you? (*Opportunity to address concerns and gauge enthusiasm*)

## INTERVIEW EVALUATION CRITERIA

Rate candidates on a scale of 1-5 (1=Needs Development, 5=Excellent) in these areas:

- Emotional Readiness
- Communication Skills
- Team Orientation
- Commitment Level
- Strategic Thinking

## NICU FAC INTERVIEW GUIDE & QUESTIONS

- Cultural Sensitivity
- Time Availability
- Overall Fit



### RED FLAGS TO WATCH FOR

- Still processing significant trauma from NICU experience
- Focused solely on personal grievances
- Inflexible viewpoints
- Unable to maintain confidentiality
- Unrealistic time commitment
- Difficulty working in groups

### GREEN FLAGS TO WATCH FOR

- Balanced perspective on NICU experience
- Constructive approach to feedback
- Strong listening skills
- Commitment to improving care for all families
- Realistic understanding of role
- Experience with teamwork
- Cultural sensitivity

### POST-INTERVIEW NOTES TEMPLATE

Candidate Name: \_\_\_\_\_ Interview Date: \_\_\_\_\_

Strengths:

- 1.
- 2.
- 3.

Areas of Concern:

- 1.
- 2.
- 3.

## NICU FAC INTERVIEW GUIDE & QUESTIONS

Overall recommendation:

- Highly Recommend
- Recommend
- Consider with Reservations
- Do Not Recommend

Additional notes:

Interviewer: \_\_\_\_\_ Signature: \_\_\_\_\_



## NICU FEEDBACK SURVEY ABOUT FAC

### FOR CURRENT NICU FAMILIES

#### AWARENESS & ENGAGEMENT

- Are you aware of the Family Advisory Council? Yes/No
- Have you interacted with FAC initiatives? Yes/No
- Would you be interested in joining the FAC when you are eligible? Yes/No (Note: Some families are ready to join an FAC sooner than others. The timing is personal to the specific family. If your child/children have a longer NICU stay such as four months, we would recommend having at least four months post discharge before you join an FAC.)

#### IMPACT ASSESSMENT

(1=Least Achievement, 5=Highest Achievement)

- Rate the family-centeredness of care
- Rate family inclusion in decision-making
- Rate family support resources
- Rate communication effectiveness

### FOR HOSPITAL STAFF WHO INTERACT WITH AN FAC

Check all that apply for your hospital's NICU. Each check = 1 point. Review the score at the end.

#### COLLABORATION ASSESSMENT

This should be completed after the FAC has been established and the staff has been working with them for 6-18 months.

- FAC input is valuable to my work.
- FAC members are professional and constructive.
- The process for getting FAC input is clear.
- FAC feedback is timely.
- Working with the FAC has improved my understanding of family needs.

#### IMPACT EVALUATION

This should be completed each year after the first successful year of the FAC implementation.

- FAC recommendations are practical.
- Changes influenced by FAC have been positive.
- FAC helps improve family-centered care.

## NICU FEEDBACK SURVEY ABOUT FAC

- FAC represents a variety of different family perspectives and lived experiences.
- I would recommend involving FAC in future projects.



### Scoring Guide

4-5 items checked: Good

2-3 items checked: Some quality improvement is needed

0-1 items checked: Significant improvement required

## NICU FAC STANDARD MEETING AGENDA

**Date:** [Insert Date]

**Time:** [Start Time - End Time]

**Location:** [Room/Virtual Link]



### 5:30-5:45 pm: Welcome & Check-In

- Welcome new members
- Member spotlight/sharing moment
- Review meeting objectives

### 5:45-6:15 pm: Main Topic Discussion

Presenter: [Name & Title]

Topic: [Topic Title]

Goals:

- [Goal 1]
- [Goal 2]
- [Goal 3]

Discussion Questions:

- [Question 1]
- [Question 2]
- [Question 3]

### 6:15-6:45 pm: Project Updates

- Project A Status Update (10 min)
- Project B Status Update (10 min)
- New Project Proposals (10 min)

### 6:45-7:00 pm: Wrap Up

- Action items review
- Next meeting preview
- Member announcements

## NICU FAC MEMBER CONNECTION AND PRIORITY SETTING ACTIVITY



This 60-minute activity helps new FAC members:

- Build relationships through shared experiences
- Identify individual and collective priorities
- Discover members' unique strengths
- Generate initial project ideas

### MATERIALS NEEDED

- Large sticky notes (3 colors)
- Markers
- Whiteboard or large paper
- Timer
- Member notebooks
- Name tags

### ACTIVITY STRUCTURE

#### OPENING (10 MINUTES)

Facilitator introduces the activity: "Today we'll explore our NICU experiences and how they can help shape our FAC's priorities. Everyone's story and perspective is valuable as we work together to improve NICU care."

#### PART 1: STORY CIRCLES (15 MINUTES)

1. Divide into groups of 3-4 members
2. Each person shares (2-3 minutes each):
  - One challenge from their NICU experience
  - One positive memory or helpful support received
  - One thing they wish had been different

#### PART 2: STRENGTH MAPPING (15 MINUTES)

1. Individual reflection (5 minutes) Write on sticky notes:
  - YELLOW: Personal strengths (skills, experiences, knowledge)
  - PINK: Areas of passion/interest in NICU improvement
  - BLUE: Resources or connections they can contribute
2. Group sharing (10 minutes)
  - Post notes on whiteboard
  - Look for patterns and connections
  - Identify potential project alignments

#### PART 3: PRIORITY SETTING (15 MINUTES)

1. As a full group, discuss:
  - Common themes from stories
  - Shared areas of concern
  - Potential quick wins
  - Long-term improvement goals
2. Create initial priority list:
  - Immediate concerns
  - Medium-term projects
  - Long-term vision

## NICU FAC MEMBER CONNECTION AND PRIORITY SETTING ACTIVITY



### CLOSING (5 MINUTES)

- Summarize key themes
- Identify next steps
- Schedule follow-up discussions

### DOCUMENTATION TEMPLATE

Date: \_\_\_\_\_ Facilitator: \_\_\_\_\_ Number of Participants: \_\_\_\_\_

### KEY THEMES IDENTIFIED

1. \_\_\_\_\_  
\_\_\_\_\_
2. \_\_\_\_\_  
\_\_\_\_\_
3. \_\_\_\_\_  
\_\_\_\_\_

### PRIORITY PROJECTS: IMMEDIATE (1-3 MONTHS)

1. \_\_\_\_\_  
\_\_\_\_\_
2. \_\_\_\_\_  
\_\_\_\_\_
3. \_\_\_\_\_  
\_\_\_\_\_

### MEDIUM TERM (3-6 MONTHS):

1. \_\_\_\_\_  
\_\_\_\_\_
2. \_\_\_\_\_  
\_\_\_\_\_

## NICU FAC MEMBER CONNECTION AND PRIORITY SETTING ACTIVITY



3. \_\_\_\_\_  
\_\_\_\_\_

### LONG-TERM (6+ MONTHS):

1. \_\_\_\_\_  
\_\_\_\_\_

2. \_\_\_\_\_  
\_\_\_\_\_

3. \_\_\_\_\_  
\_\_\_\_\_

### MEMBER RESOURCES

- Strength/Resource: \_\_\_\_\_ Member Name: \_\_\_\_\_
- Strength/Resource: \_\_\_\_\_ Member Name: \_\_\_\_\_

### NEXT STEPS:

1. \_\_\_\_\_  
\_\_\_\_\_

2. \_\_\_\_\_  
\_\_\_\_\_

3. \_\_\_\_\_  
\_\_\_\_\_

Follow up meeting date: \_\_\_\_\_

### TIPS FOR FACILITATORS

- Create a safe, supportive environment
- Manage time while remaining flexible
- Ensure all voices are heard
- Document insights and decisions
- Follow up with absent members
- Share summary with all members

## NICU FAC FEEDBACK SURVEY PACKAGE

### FAC MEMBER EXPERIENCE SURVEY

(To be administered annually to all FAC members.)



Please rate your agreement with the following statements.

(1=Strongly Disagree, 5=Strongly Agree)

#### MEETING EFFECTIVENESS

- Meetings are well organized
- Meeting time is used effectively
- My input is valued and respected
- Communication between meetings is adequate
- Meeting frequency is appropriate

#### PERSONAL IMPACT

- I feel I am making a meaningful contribution
- The time commitment is manageable
- I have received adequate training/support
- I understand my role and responsibilities
- I feel connected to other FAC members

#### COUNCIL EFFECTIVENESS

- The FAC has clear goals and objectives
- Projects and initiatives are well managed
- The FAC is making a positive impact
- Hospital leadership is responsive to FAC input
- The FAC represents a variety of family perspectives

#### OPEN-ENDED QUESTIONS

1. What has been most rewarding about your FAC participation?
2. What challenges have you experienced as an FAC member?
3. What suggestions do you have for improving the FAC?
4. What topics/projects would you like to see addressed?

## NICU FAC FEEDBACK SURVEY PACKAGE

### FAC MEMBER EXIT SURVEY

(To be administered when members depart the FAC.)



Thank you for your dedicated service as a family advisory council member. Your feedback is invaluable in shaping the future of our work and improving the experience for future FAC members. Please take a few moments to complete this exit survey.

#### GENERAL EXPERIENCE

1. How would you describe your overall experience as a member of the Family Advisory Council? (Please select one.)  
 Excellent  
 Good  
 Fair  
 Poor
2. What aspects of being part of the NICU FAC did you find most rewarding? (Please select all that apply.)  
 Making a difference in the community  
 Collaborating with family members who have had a variety of lived experiences  
 Providing input on programs/policies  
 Building connections with staff/leadership  
 Other (please specify) \_\_\_\_\_
3. What aspects of your experience did you find most challenging? (Please select all that apply.)  
 Time commitment  
 Limited impact or follow-up on suggestions  
 Balancing council work with personal/family obligations  
 Other (please specify) \_\_\_\_\_

#### COUNCIL ACTIVITIES & ENGAGEMENT

1. What specific activities, initiatives, or projects did you participate in during your term on the council? (Please list or describe any key projects or events you were involved with.)  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## NICU FAC FEEDBACK SURVEY PACKAGE

2. What did you find most valuable about these activities?

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---

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3. Were there any areas or initiatives where you felt your involvement could have been better supported or more impactful? If so, how?

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4. Did you feel the council's meetings and activities were well organized and productive?

Yes

Somewhat (please suggest areas for improvement) \_\_\_\_\_

---

---

---

No (please suggest areas for improvement) \_\_\_\_\_

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### FEEDBACK FOR THE FUTURE

1. What changes, improvements, or new initiatives would you suggest for the future of the NICU FAC?

---

---

---

2. Are there any areas or issues that the FAC should focus on more in the future?

---

---

---

3. What qualities or skills do you think the next group of council members should have to make the council more effective?

---

---

## NICU FAC FEEDBACK SURVEY PACKAGE

### STAYING CONNECTED

1. Would you be interested in staying connected for future family-related opportunities (e.g., continuing to serve on advisory groups, attending or facilitating family events, providing feedback on programs/policies, or participating in focus groups)?

Yes (please specify) \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Maybe (please specify) \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

No \_\_\_\_\_

### FINAL THOUGHTS

1. Looking ahead, what do you envision as the future of family involvement and the work of the NICU FAC?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

2. Do you have any additional comments or suggestions?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### PHOTOS/VIDEOS (OPTIONAL)

(CPQCC suggests asking outgoing NICU FAC members if they would like to share photos/videos for future use in NICU FAC marketing. Please ensure that your institution's policies around photos/videos are followed.)

### HIPAA AUTHORIZATION (AS NEEDED)

(If your organization is a HIPAA-covered entity, you will need to ensure NICU FAC Members provide HIPAA authorization for any protected health information that they have disclosed for future use, such as quotes, testimonials, or personal stories.)

# FAC IMPACT MEASUREMENT SCORECARD

## FAMILY ENGAGEMENT METRICS

### MEETING PARTICIPATION

- % Meeting attendance rate (Target: >80%)
- Number of active members (Target: 12-15)
- % Member retention rate (Target: >75%)
- Communication between meetings is adequate
- Meeting frequency is appropriate

### FAMILY INPUT

- Number of family suggestions submitted
- Number of suggestions implemented
- Family satisfaction with FAC (1-5 scale, with 1=least satisfied and 5=highly satisfied)

## PROJECT IMPACT

### PROJECT IMPLEMENTATION

- Number of projects initiated
- Number of projects completed
- Average project completion time (in months)

### QUALITY IMPROVEMENTS

- Number of policy changes influenced
- Number of process improvements
- % Staff adoption rate of changes

## HOSPITAL INTEGRATION

### STAFF ENGAGEMENT

- Number of staff presentations to FAC
- Number of departments engaged
- Staff satisfaction with FAC input (1-5 scale, with 1=least satisfied and 5=highly satisfied)

### RESOURCE UTILIZATION

- % of Allocated budget used
- Volunteer hours contributed
- Staff support hours

# FAC IMPACT MEASUREMENT SCORECARD

## COMMUNICATION EFFECTIVENESS

### INTERNAL COMMUNICATION

- Number of newsletters distributed, per year
- Updates given to hospital leadership, per quarter
- % Staff awareness of FAC, per internal survey

### EXTERNAL COMMUNICATION

- % Family awareness of FAC, per external survey
- Community presentations, per year
- Social media engagement, total interactions

## FAMILY EXPERIENCE IMPACT

### NICU FAMILY SATISFACTION

- Overall satisfaction (1-5 scale, with 1=least satisfied and 5=highly satisfied)
- Communication satisfaction (1-5 scale, with 1=least satisfied and 5=highly satisfied)
- Support services satisfaction (1-5 scale, with 1=least satisfied and 5=highly satisfied)

### LONG-TERM OUTCOMES

- Family preparedness at discharge (1-5 scale, with 1=least prepared and 5=highly prepared)
- % Follow-up appointment attendance
- Family engagement in care (1-5 scale, with 1=least engaged and 5=highly engaged)

## QUARTERLY REVIEW NOTES

Date: \_\_\_\_\_

### STRENGTHS

- 1.
- 2.
- 3.

### ACTION ITEMS

- 1.
- 2.
- 3.

### AREAS FOR IMPROVEMENT

- 1.
- 2.
- 3.

## PROJECT IMPACT SURVEY

(To be completed after each major FAC initiative.)



### PROJECT OUTCOMES

(1=Least Achievement, 5=Highest Achievement)

- Project goal achievement
- Timeline adherence
- Resource utilization
- Stakeholder satisfaction
- Impact sustainability

### PROCESS EVALUATION

(1=Least Achievement, 5=Highest Achievement)

- Communication was effective
- Roles were clear
- Resources were adequate
- Timeline was realistic
- Stakeholder engagement was sufficient

# References

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2. Institute for Patient and Family-Centered Care. Accessed February 27, 2025. <https://www.ipfcc.org>
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4. Macdonell K, Christie K, Robson K, Pytlik K, Lee SK, O'Brien K. Implementing Family-Integrated Care in the NICU: Engaging Veteran Parents in Program Design and Delivery. *Adv Neonatal Care.* 2013;13(4):262-269. doi:10.1097/ANC.0b013e31829d8319



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