

A Quality Improvement Tool Kit for the
PAIRED Initiative

Family-Centered Care in the NICU



Florida Perinatal
Quality Collaborative



The Family-Centered Care PAIRED Initiative tool kit is intended to provide guidance to hospitals and neonatal providers in the development of individualized policies and protocols related to promoting family-centered care. It is not to be construed as a standard of care; rather it is a collection of resources that may be adapted by local institutions in order to develop standardized approaches to family-centered care. The tool kit will be updated as additional resources become available.

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About the Tool Kit



This document is a working draft that reflects a review of clinical, scientific and patient safety recommendations. The information presented here should not be used as a standard of care. Rather, it is a collection of resources that may be adapted by local institutions in order to develop standardized protocols and processes for implementing and improving family-centered care.

The overall goal of the Family-Centered Care PAIRED Initiative Tool Kit is to provide tools to apply evidence-based interventions (such as prompt skin-to-skin care) and other potentially better FCC practices to improve care for infants and their families in Florida hospitals.

This tool kit will provide neonatal and infant healthcare providers, staff at healthcare facilities and families with the resources to locally develop their own family-centered care policies and protocols with a focus on safe practices and optimizing care and outcomes.

Every U.S. NICU facility should develop and implement a policy to address family-centered care that is specific to the resources and needs of the individual institution. The policy will need to address the multidisciplinary care required for these infants and families involving standards of care, communication, collaboration, and coordination of care. The policy should also include protocols and resources to support staff's goals of safe and healthy outcomes. Ideally, there should be a reporting mechanism with debriefing and analysis to identify system(s) improvement opportunities to optimize care for infants and education and engagement of their families.

Another important element is having multi-disciplinary teams in place with necessary skill sets and identified roles in implementing family-centered care. Administration, nursing, obstetrics providers, neonatology, and others are all critical partners in the multidisciplinary team approach necessary for QI. These teams need to train together and practice together in order to maintain and gain new competencies. Because each hospital and care team has differing resource sets, it is important to develop individualized protocols for each facility. A QI team composed of a core set of team members from the involved disciplines must review current policies and data, determine the priorities for improvement, and develop a work plan to address their needs.

How to Use This Tool Kit

This tool kit is intended to provide guidance and core concepts for the QI team to include practice and administrative components. Hospitals have an obligation to patients, providers and others to assure patient safety and competent care, and likewise providers have an obligation to patients and the hospital to practice in a competent, evidence-based manner. These obligations are closely tied together and supportive of the multi-disciplinary team including the immediate neonatal care team and the extended team to include obstetric providers, nurses, primary caregiver(s), and other

healthcare professionals (e.g., occupational therapy, social work). It is everyone's responsibility to coordinate efforts to assess and treat infants, engage families in their care, and to report on the outcomes for future improvements. This guide offers the concepts and tools which may be adopted or adapted for local use.

The Family-Centered Care PAIRED Tool Kit is designed as a working draft to be modified as new information and strategies are identified. All levels of hospitals who provide care to infants can utilize the tool kit and modify the strategies to fit their local resources and needs. The continuum of care beyond the hospital setting is important when caring for infants and families experiencing NICU stays. It is important that all providers working with families with infants in the NICU provide appropriate treatment, actively involve families in care, and maintain reporting mechanisms that allow tracking of outcomes and improvements in care.

Disclaimer

This tool kit is considered a resource. 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 to not rely solely on the guidelines presented here. This tool kit is a working draft. As more recent evidence-based strategies become available, hospitals and providers should update their guidelines and protocols accordingly; the FPQC will also send out updates as well as revise these materials. Please note the version number in the footer.

Background

Family-centered care (FCC)¹ is defined as a shared approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnership among health care professionals, patients, and families. FCC places an emphasis on collaborating with people of all ages and backgrounds, at all levels of care, and in all health care settings. FCC assures that health care is responsive to priorities, preferences, and values of patients and their families. FCC recognizes that families are essential partners for health care quality and safety during the direct care of the patient within the family but also in the effort to improve health care for all.

FPQC hopes to improve the provision of FCC in partnership with hospitals through this initiative. The initiative's name, PAIRED, reflects the initiative's emphasis on the need for paired care between the medical team and families, by recognizing and utilizing the key elements of the core domains of FCC. In support of this concept, PAIRED was developed with by a PAIRED Advisory Council as well as participating family advisory group members.

The FCC topic is all-encompassing and represents an entire culture change in the methodology of providing healthcare. Despite evidence of the importance of caring for a family unit in addition to the specific medical care required for an infant during a NICU stay, there are currently no validated metrics focused solely on FCC. We plan to outline key processes to

welcome parents and families into a paired care team model that encourages them to begin graduated participation in their infant's care starting at admission, to assist them to recognize and respond to their infant's individual personality, to improve processes of communication with the medical team, and to educate families throughout the NICU stay about their infant's medical care so that they become competent and confident independent family caregivers by the time of discharge. We also

Core domains of Family-Centered Care include²:

- (1) **P**Articipation in care and decision-making;
- (2) dignity and respect in identifying every infant and family as **I**ndividuals;
- (3) **R**espectful collaboration with families; and
- (4) information sharing regarding **E**Ducation for families on medical care.

¹ Family centered care (FCC) is defined as a shared approach to the planning, delivery, and evaluation of healthcare that is based upon a partnership between healthcare professionals and families of patients. There are four essential domains of FCC: 1) family participation in care, 2) dignity and respect, 3) family collaboration, and 4) information sharing.

will provide participating NICUs with metrics to track and measure their improvement in the delivery of FCC in their own unit.

Through extensive discussions, literature searches and input from the Family Advisory Council, the PAIRED Advisory Group identified a large number of potentially better practices that all contribute toward an improvement in overall FCC. Many of these potentially better practices will be included in the toolkit for hospital teams to review and possibly implement in their units.

Skin-to-skin care will be the centerpiece of PAIRED and is a recommended practice for every participating NICU.

Skin-to-skin care has been shown repeatedly in the literature to promote optimal outcomes for the infants and their families. In addition, it is an initiative that is easily instituted and measured with minimal costs to the hospitals. The initiative will be enhanced by a robust modular educational program on the FCC evidence base and potentially better practices for implementation of skin-to-skin care as well as the other identified better practices.



Initiative Goals

PRIMARY Aim Statement:

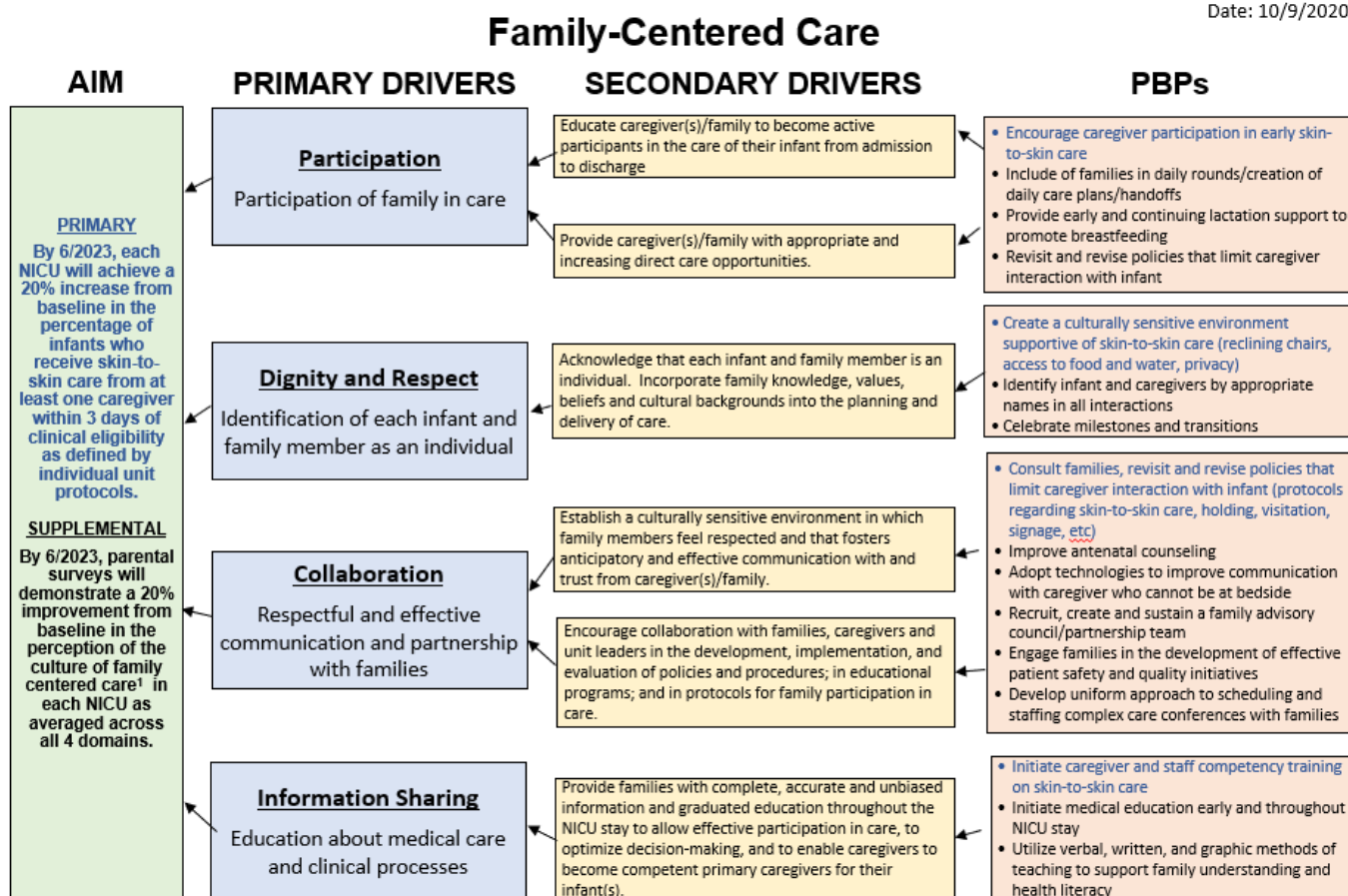
By 6/2023, each NICU will achieve a 20% increase from baseline in the percentage of infants who receive skin-to-skin care from a least one family caregiver within 3 days of clinical eligibility as defined by individual unit protocols.

SUPPLEMENTAL Aim Statement:

By 6/2023, parental surveys will demonstrate a 20% improvement from baseline in the perception of the culture of family centered care¹ in each NICU as averaged across all 4 domains.

Figure 1: PAIRED Initiative Key Driver Diagram

Date: 10/9/2020



Family-centered care is defined as a shared approach to the planning, delivery, and evaluation of healthcare that is based upon a partnership between healthcare professionals and families of patients. There are four essential domains of FCC: 1) family participation in care, 2) dignity and respect, 3) family collaboration, and 4) information sharing.



Primary Drivers

In order to fully address the complex culture of family-centered care, the PAIRED Initiative is utilizing four primary domains or drivers which are essential components to implementation of FCC. These four essential domains of FCC are 1) family participation in care, 2) dignity and respect, 3) family collaboration, and 4) information sharing.

PARTICIPATION OF FAMILY IN CARE

An emphasis on family participation in a paired model of care in the NICU is an essential component of family-centered care. Drivers for improvement in family participation in care include:

1. Educate family caregivers to become active participants in the care of their infant from *admission* to discharge.
2. Provide family caregivers with appropriate and increasing direct care opportunities.

DIGNITY AND RESPECT

In order to treat families and patients with dignity and respect, we must identify each infant and each family member as an individual. Drivers for improvement in this domain include:

1. Acknowledge that each infant and family member is an individual.
2. Incorporate family knowledge, values, beliefs, and culture backgrounds into the planning and delivery of care.

FAMILY COLLABORATION

A culture of FCC requires respectful and effective communication and partnership with families. Drivers for improvement in this domain include:

1. Establish a culturally sensitive environment in which family members feel respected and that fosters anticipatory and effective communication with and trust from family caregivers.
2. Encourage collaboration with families, caregivers, and unit leaders in the development, implementation, and evaluation of policies and procedures, in educational programs, and in protocols for family participation in care.

INFORMATION SHARING

Family education about medical care and clinical processes is a key domain of FCC as it establishes trust with families and allows them to become independent caregivers.

Drivers for improvement in this domain include:

1. Provide families with complete, accurate, and unbiased information and graduated education throughout the NICU stay to allow effective participation in care, to optimize decision-making, and to enable family caregivers to become competent and confident primary caregivers for their infant(s).

Skin-to-skin care has been identified as the PAIRED Initiative centerpiece and will be recommended for every participating NICU. The primary aim for this initiative is focused on improvement in skin-to-skin care.

Empirical evidence has identified the importance of early skin-to-skin touch to optimize newborns' neurodevelopmental outcomes later in life. Gentle skin-to-skin contact is especially important for the brain development of preterm infants who often spend their first days or weeks of life in neonatal intensive care units (NICUs).

Additionally, there are physiologic benefits to newborns when they are held skin-to-skin, such as stabilization of heart rate, breathing patterns and blood oxygen levels, gains in sleep time and weight, decreased crying, greater breastfeeding success, and earlier hospital discharge. Ongoing research has also identified benefits to the family caregivers that skin-to-skin contact can provide: decrease of parental stress that can interfere with bonding, health and emotional wellness, and the interpersonal relations of parents, as well as breastfeeding rates (Maitre 2020).

Leading organizations recommend skin-to-skin contact, among them the World Health Organization, American Academy of Pediatrics, Academy of Breastfeeding Medicine and the Neonatal Resuscitation Program. Because skin-to-skin is a simple technique, has been so well studied, and has demonstrated benefits for both the family caregiver and the infant, it was clear that skin-to-skin care should be the centerpiece for the initiative.

The primary aim of this initiative is for each participating NICU to achieve a 20% increase from baseline in the percentage of infants who receive skin-to-skin care from at least one family caregiver within 3 days of clinical eligibility as defined by individual unit protocols by June 2023.

In order to aid participating centers in this aim, we have provided potentially better practices (PBPs) related to the primary drivers of FCC and suggested metrics to track improvement. This list of PBPs is not meant to be comprehensive but rather a source of ideas for your unit to consider as you work toward the primary aim of improving skin-to-skin care. Additionally, many national and international groups have worked to create resources and guidelines for improving skin-to-skin care (or kangaroo care), and we have included some of these as resources for centers to utilize in their quality work.

Skin to Skin Potentially Better Practices

1. Encourage family caregiver participation in early skin-to-skin care
2. Create a culturally sensitive environment support of skin-to-skin care (reclining chairs, access to food and water, privacy, etc.)
3. Consult families and revisit/revise policies that limit family caregiver interaction with infant (protocols regarding skin-to-skin care, holding, visitation, signage, etc.)
4. Initiate family caregiver and staff competency training on skin-to-skin care



Resources

1. Kangaroo Mother Care: <http://kangaroomothercare.com/>
 - Information on the importance of kangaroo care/skin-to-skin care for both preterm and term infants
 - Tips on techniques for performing safe skin-to-skin care
 - Specific section of website devoted to fathers and skin-to-skin care
 - Personal articles and testimonials
2. Hand to Hold: <https://handtohold.org/kangaroo-care-benefits/>
 - Details the benefits of skin-to-skin care/kangaroo care
 - Inspirational quotes from family caregivers
3. March of Dimes: <https://www.marchofdimes.org/baby/kangaroo-care.aspx>
 - Information on what is kangaroo care/skin-to-skin care and how it can help your baby

Additional resources for are found in the Appendices and the PAIRED Online Tool Box:
www.fpqc.org/paired/toolbox

Metrics

Included below are metrics in brief that we would like participating units to collect. Detailed definitions of each of these metrics in the Appendix.

Table 1: Skin to Skin Measures

#	Outcome Measures	Frequency
1	Percentage of infants receiving prompt initiation of skin-to-skin care	Monthly
2	Average day of life when skin-to-skin care was first provided by family caregiver(s)	Monthly
3	Number (percent) of eligible inpatient days where any family caregiver provided at least one hour of skin-to-skin care	Monthly
4	Scores on family caregiver surveys on skin-to-skin care	Quarterly
5	Percent of infants receiving any breastmilk feedings at the time of initial disposition	Monthly
#	Structural Measures	Frequency
1	Use of standardized documentation of skin-to-skin care in the electronic medical record or use of a case report form designed to capture key information for each episode of skin-to-skin care	Monthly
2	Development and implementation of an NICU policy promoting skin-to-skin care for all eligible infants and family caregivers.	Monthly
#	Process Measures (Some process measures will be reported on individual infants, and some will be reported on individual hospitals.)	Frequency
1	Percentage of providers, nursing and respiratory therapy staff educated about all of skin-to-skin care (didactic instruction about the benefits of skin-to-skin care, followed by clinical training via simulation, bedside observation, or direct assistance with infant transfers)	Monthly
2	Percentage of family caregivers who received education about and competency training in skin-to-skin care	Monthly
#	Balancing Measures	Frequency
1	Percentage of unplanned extubations associated with skin-to-skin care among skin-to-skin care episodes	Monthly
2.	Percentage of other documented unplanned events* associated with skin-to-skin care among skin to skin episodes *Significant desaturation/apnea/bradycardia; hypothermia or line dislodgement	Monthly



Potentially Better Practices

PAIRED-Plus: PBPs to Improve Family Centered Care

Robust discussion within the Advisory Council and Family Advisors Group led to a large number of PBPs that could all potentially improve the culture of family-centered care in the NICU. In order to prioritize those PBPs to be focused on in this PAIRED initiative, both the Advisory Council and Family Advisors Group were asked to rank the proposed PBPs in order of importance. These results can be seen below in tabular format.

TABLE 2: POTENTIALLY BETTER PRACTICES FOR FCC

	Potentially Better Practice for FCC	Family Advisors		Advisory Council	
		Raw Score	Score %	Raw Score	Score %
1	Daily rounds including families	199	90.0%	94	72.3%
2	Develop complex care conferences with families	141	63.8%	67	51.5%
3	Early and continuing medical education of families	136	61.5%	91	70.0%
4	Use appropriate infant and family caregiver names	134	60.6%	78	60.0%
5	Create family advisory council	133	60.2%	64	49.2%
6	Policies on family caregiver-infant interactions	132	59.7%	82	63.1%
7	Early and continuing lactation support	129	58.4%	88	67.7%
8	Improve antenatal counseling	115	52.0%	73	56.2%
9	Technologies to improve communications	114	51.6%	63	48.5%
10	Engage families in QI and safety initiatives	106	48.0%	58	44.6%
11	Celebrate milestones and transitions	101	45.7%	62	47.7%
12	Multiple methods to support health literacy	90	40.7%	56	43.1%
13	Other (please explain)	17	7.7%	34	26.2%

The green highlighted cells indicate the top 6 PBPs for both the Family Advisory Group and the Advisory Council. There was a good degree of consensus between these two advisory groups so these 8 PBPs were chosen to be included in the PAIRED Initiative toolkit. All of the PBPs listed are considered important by the PAIRED Initiative and this is not meant to represent a comprehensive list of PBPs to enhance FCC culture.

I. Family Inclusion in Daily Rounds

Definition & Rationale

Family caregivers are not visitors to the NICU; rather they are partners with the health care team and can be allies and advocates for safe, quality care for the infants. (Griffin,2013). Including family

caregivers in bedside rounds is integral to the concept of family centered care. Family caregivers who participate in bedside rounds are overwhelmingly positive, report a decrease in their anxiety and have increased confidence in the health care team overall (Davidson 2013; Grzyb, Coo, Ruhland, & Dow 2014). The success of family caregiver presence on bedside rounds should include a thoughtful, systematic approach to mitigate concerns regarding privacy, time management, and teaching opportunities. Providing staff education on family centered care and the importance of family presence during rounds, introducing the family to the idea of rounds, providing options for attendance, and addressing privacy concerns will all aid in optimizing participation.

Change Ideas

- Address your unit's rounding process and maximize ability to include family caregivers
 - Review current process for rounds and examine how to include and partner with family caregivers during this daily routine.
 - Outline a process for rounds; ex. bedside nurse presents the 24-hour clinical updates, family caregivers add their observations/questions, team discusses plan for the day.
 - Round on those infants with families present first.
 - Set one time per week that all families have rounds.
 - Create a plan if family caregivers have additional questions and concerns that require a lengthy amount of time to discuss. Team may need to schedule a time to follow back up with family caregivers later in day to ensure they have time to round on other patients with family caregivers present.
- Develop a teaching strategy for family caregivers
 - Educate family caregivers on purpose and process of rounds, share outline for rounds, and gather feedback.
- NICU Process
 - Standardize the family caregiver introduction to the NICU, including a discussion of the rounding process and the potential to include family caregivers.
 - Identify the family's goals or expectations for rounds during the initial admission process.
- Utilize technology for multiple purposes that support family caregiver involvement in rounds:
 - To inform family caregivers of when rounds occur
 - To include family caregivers in rounds if they cannot be physically present
 - To track family engagement in rounds within your EMR
- Address language, cultural, educational barriers which may preclude family caregivers from participating in rounds (or knowing about rounds).
 - Investigate the availability of interpreting services for rounds.
 - If family caregivers are not present at bedside, discuss the reasons with them to see if it is a systems issue that can be addressed.
 - Utilize appropriate vocabulary and tailor explanations so they can be understood by family caregivers.

Resources

- Family centered rounds toolkit
 - <https://www.hipxchange.org/FamilyRounds>
- [Applying Patient and Family Centered Care Concepts to Bedside Rounds in Newborn Intensive Care](#). This document provides guidelines for conducting rounds to accomplish a variety of purposes successfully within a context of respect and support for families in the NICU.
- Existing models for rounds that include the families, such as [ISHAPED](#). The “ISHAPED” (I=Introduce, S=Story, H=History, A=Assessment, P=Plan, E=Error Prevention, and D=Dialogue) project focused on making bedside shift reports more patient- and family-centered. The goal was to always include patients/family in the ISHAPED nursing shift-to-shift handoff process at the bedside to add an additional layer of safety by enabling the patient/family to communicate potential safety concerns. The site contains several handouts that were successfully used in the project.
- Technology for families to be involved (cameras, FaceTime, etc.)

Potential Metrics

- % of parents attending rounds
- # of days of rounds with family present
- Quantify utilization of technology to contact families/involve in rounds.
- Length of time spent with parent/family.

II. Develop uniform approach to scheduling and staffing complex care conferences with families.

Definition

With long-term or complex NICU stays, there is often a need for formal, family care conferences. Some of these conferences may just involve the primary NICU medical team and the family, but often they require input from various other subspecialists or ancillary services in order to support the family in medical understanding, decision-making, and planning.

Rationale

There have been some small studies and QI initiatives focused on improving family satisfaction with care via standardization and formalization of these complex care conferences.

Change Ideas

- NICU Process
 - Standardized introduction to the NICU with discussion of care conferences

- Identify family's goals or expectations for regular meetings during initial admission process.
- Standardize complex care conference protocol.
 - Define criteria and timing.
 - Define other triggers for complex care conferences.
 - Guidelines for who should attend.
- Create of printed materials to be provided at time of complex care conference.
- Training on delivery of family care conferences with an emphasis on FCC
- Involvement of pediatrician in discharge-related care conferences to allow for enhanced transition of care.

Resources

- Many centers have developed their own complex care conference protocols to help standardize this process and ensure a family-centered approach.

Potential Metrics

- Compliance with care conference guidelines at your center (whether conferences occur at the recommended times, with recommended participants, with printed materials provided, etc.)
- Family satisfaction with care conference experience (likely survey-based)
- Staff comfort level with leading care conferences
 - Could be broken down by staff type based on who primarily participates in care conferences at individual institutions.
 - Most likely measured via survey

III. Identify infant and family caregivers by appropriate name in all interactions.

Definition

There is a tendency to address infants in the NICU as baby boy/girl or twin A/B rather than use their first name. Additionally, some families may not prefer an infant's first name as the name used by the medical team.

Rationale

When speaking with and/or updating family caregivers, the infant's preferred name should be utilized. Use of the infant's name, as opposed to 'your baby', 'baby boy/girl', or 'twin A/twin B' for example, shows the family that the healthcare provider (physician, APP, nurse, ancillary staff, etc.) is familiar with their child and invested in their child's care. The spelling of the infant's preferred name should be verified and the name should be posted clearly at bedside within 48 hours of admission so that all

providers can utilize the infant's preferred name. An exception to this would be if the family has cultural and/or family traditions around when to name their child. In those cases, the family caregivers should be asked their preference on using a name to refer to the infant. Additionally, many family caregivers do not prefer to be called 'mom' or 'dad' by unit staff. Families should also be asked if they have a preferred form of address. This may not be able to be displayed at bedside per unit policy and/or family preference; however, utilizing a family caregiver's preferred method of address demonstrates mutual respect.

Unfortunately, some of our families experience an infant demise and this can be particularly devastating for families when there are surviving infants from a multiple gestation. Units should have a procedure for acknowledging infants who have passed in interactions with families.

Change Ideas

- NICU Process
 - Include a discussion with families regarding preferred infant names as a standardized part of the initial admission process.
 - Develop a method of documenting this family preference.
 - Include the preferred infant name in rounds, documentation, and if possible, include in the EMR (different hospitals may have different restrictions on this).
- Create printed materials to be placed at bedside (signs, etc.). *These may need to be approved by your infection control team.
- Provide training for staff on the rationale of addressing infant's by preferred name and provide guidelines for when the name needs to be posted at bedside.

Resources

- Many centers have developed their own guidelines to help standardize this process and ensure a family centered approach.
- There are commercially produced products that are available from a variety of vendors:
 - As an example Every Tiny Thing: everytingthing.com

Potential Metrics

- % of admissions that have preferred infant name clearly posted at bedside at 48 hours after admission
- Family satisfaction with staff use of preferred infant's name (likely survey-based)
- % of admission notes or progress notes within one week using preferred infant name (if possible, within your hospital's EMR)

IV. Initiate medical education early and throughout the NICU stay

Definition

Family caregivers have the right to seek and receive all information necessary to understand their infant's medical situation, to know the name and specialty of the physicians and other healthcare providers who are responsible for their care, and to talk with these providers. Family caregivers are entitled to know about diagnoses and treatments, including an explanation of each day's procedures and tests, and the future medical course and prognosis. Family caregivers need to receive medical information that is current, consistent, accessible, understandable, reliable, and credible.

Rationale

The initiation of early medical education is a key component to family caregiver involvement in the care of their infant. Most families come into the NICU unfamiliar with babies who have been born prematurely or who have unique medical conditions and needs. Standardized parent education programs have shown benefits to family caregivers and also create efficiencies in healthcare provision. At a minimum, the following should be incorporated into early medical education:

- Family caregivers have the right to know who is providing medical services and who is responsible for their infant's care.
- Family caregivers have the right to know what patient support services are available, including whether an interpreter is available if the family caregivers do not feel proficient in the English language.
- Family caregivers have the right to know what they can and cannot do when they are on the unit.
- Family caregivers have the right to be given information concerning diagnoses, treatment courses, alternatives, risks, and prognosis by the healthcare provider.
- Family caregivers should be given the opportunity to express questions and concerns to the healthcare providers on a regular basis.
- Treatment plans should be developed through collaboration between the family caregiver and the healthcare provider, acknowledging the medical expertise of the healthcare provider but also the specific concerns and goals of the family caregivers.

Change Ideas

- Revisit and revise existing family caregiver educational materials to ensure that these are current.
- Create roadmaps or milestone achievements that emphasize need for education throughout admission
- Utilize multiple modalities to provide family caregiver education
 - Printed materials
 - Electronically accessible materials (ex. QR codes, websites, etc.)
 - Materials family caregivers can listen to

- Optimize family caregiver understanding of direct education
 - Use plain, understandable vocabulary in the preferred language of the family caregiver
 - If an interpreter is used, utilize a designated interpreter. Do not utilize other family members as interpreters.
 - Train healthcare providers and staff to utilize open-ended questions and teach-back methods to elicit responses from family caregivers during education.
- Initiate evaluations of health literacy upon admission
- Consider different means of communication, education, and teaching aids to accommodate for educational level, language barriers, and cultural needs.
- Designate a staff liaison to whom family caregivers can address concerns and questions. This may be a unique staff position if supported by your unit or may be a designated member of an infant's care team (i.e. primary nurse, physician, charge nurse) but regardless of who is chosen by your hospital, this should be explicitly communicated to family caregivers as their initial contact from the time of admission onward.

Resources

- NICU Parent Network (NPN): <https://nicuparentnetwork.org/>
- Educational materials may already exist for your unit and serve a basis for revision/modification. Visit www.fpqc.org/paired for resources.

Potential Metrics

- Measure of family caregiver readiness for discharge
 - Would be best to institute a serial assessment of family caregivers that occurs at designated intervals throughout admission, likely based on achievement of certain milestones (ex. 2 weeks of NICU stay, 1 week post-trach or GT placement, at time of open crib, at time of 50% PO feeds achieved, at time of room air trial, at time of car seat evaluation, etc.)
- Documentation of education completed at desired time period by family caregivers

V. Create Family Advisory Council

Definition

A Family Advisory Council (FAC) is made up of a diverse group of graduate NICU families that collaborate to assist NICU staff, integrating the views and needs of families into the delivery of family centered care to their infants and respective families. The main purpose of FACs is to include the perspectives of graduate NICU families directly into the planning, delivery, and evaluation of healthcare, supporting an environment where family members feel safe, respected, and empowered to be partners in their infant's care. The FAC aims to enhance patient and family centered care by collaborating with existing governance committees to better support the needs of the NICU's diverse patient populations, supporting staff and leadership in patient and family centered activities and

initiatives. The FAC acts as a sounding board for implementation of new programs and existing programs across the NICU delivery system.

Rationale

Working with NICU families is a critical part of family engagement and family centered care. Bringing the perspective of the family caregivers directly into the planning, delivery, and evaluation of care allows them to become valuable partners in efforts to improve the safety and quality of healthcare for their infants.

Change Ideas

- Educate and train staff about the importance of FACs
- Recruit and provide mentorship to volunteer family caregivers
- Provide both in-person and virtual meetings for the FAC
- Obtain hospital administration and staff buy-in for both the development of a FAC and involvement of the FAC in ongoing/future initiatives

Resources

- Your hospital may already have Family Advisory Council Charters/Bylaws
 - https://www.ipfcc.org/resources/Advisory_Councils.pdf
- Existing models for FACs
 - AHRQ Working with Patient and Families as Advisors Implementation Handbook: <https://www.ahrq.gov>
 - Effective Patient and Family Advisory Councils – Institute for Patient and Family Centered Care: ipecac.org

Potential Metrics

- Existence of a Family Advisory Council for your NICU
- # of members/volunteers in FAC
- # of meetings of FAC per year
- # of FAC recommendations implemented in your unit
- # of initiatives/projects/committees in which the FAC is involved in your unit

VI. Improve Antenatal Counseling

Definition

For many families, the NICU journey begins well before their infant is born. Many families must struggle with unexpected diagnoses early in pregnancy or with unforeseen health issues for the mother or fetus. In these instances, centers may attempt to have antenatal counseling provided by the NICU and subspecialist teams, in addition to the counseling given by the obstetrician. This emphasis

on creating a collaborative environment between the family and the NICU/subspecialist teams prior to delivery is an important milestone in developing a long term, mutually supportive, family centered relationship with expectant families. Antenatal counseling can even impact long-term goals in care, such as future provision of skin-to-skin care after admission to the NICU (Alenchery AJ, et al). The literature devoted to the topic of antenatal counseling is made up largely of expert opinion, observational studies, and retrospective reviews detailing the frequency of antenatal counseling occurring. There are many additional potential areas for improvement beyond just the existence of antenatal counseling; for example, standardized guidelines for counseling, accuracy and relevancy of content provided during the consult, provision of social work/case management support antenatally, standardization of training in antenatal counseling for trainees (fellows, residents, APPs), acknowledgment of family values/goals at time of antenatal counseling, etc. (Chiu HY; Feltman DM 2020; Guillen U; Kukora SK; Feltman DM 2017; Mehrotra A). Additionally, families express a desire to begin their positive relationship with the NICU during an antenatal consult through the use of empathetic interactions, genuine conversation, and preparation for the NICU stay.

Rationale

Often the first interaction between family caregivers and the NICU occurs antenatally and this is an opportunity to begin family centered care even prior to NICU admission.

Change Ideas

- Standardize your antenatal counseling
 - Create standardized content for antenatal counseling in your unit/outpatient setting which may be based on gestational age/estimated fetal weight or specific diagnoses
 - Standardize when antenatal counseling should occur and if/when it should be repeated during pregnancy
 - Create guidelines for who should be involved in antenatal counseling (NICU representative, subspecialists, social workers/case managers, etc.)
- Develop printed materials (ex. Brochures) to be utilized during antenatal counseling. These should have family caregiver input as they are being developed (excellent opportunity for involvement of your Family Advisory Council).
- Create a Fetal Care Center
- Design a training curriculum for fellows/residents/APPs to practice communication skills in antenatal counseling scenarios

Resources

- Training materials and literature on communication skills exist but may not be directly related to antenatal counseling
- Guidelines for antenatal counseling content are available in the PAIRED Online Tool Box: www.fpqc.org/paired/toolbox

Potential Metrics

- Existence of a Fetal Care Center
- % of qualifying families with a likely NICU admission receiving antenatal counseling prior to NICU admission
 - Qualifying families would be defined by unit
- % of antenatal consults where families receive printed materials/brochure
- % of qualifying antenatal consults that include relevant subspecialist
 - Qualifying antenatal consults would be defined by unit
- Staff comfort level with providing antenatal consultation (most likely via survey)
- Family satisfaction with antenatal consultation (most likely via survey)
- % of trainees completing formal antenatal counseling training

VII. Early and Continuing Lactation Support Throughout NICU Admission

Definition

It is well established that breastmilk is the ideal nutrition source, especially for preterm infants, with direct health benefits to both the mother and infant. Despite the widespread agreement, an evaluation in 2013 by the FPQC showed that less than 50% of very low birthweight (VLBW) infants in Florida NICUs received any breastmilk through discharge. This prompted a statewide FPQC initiative to increase the number of VLBW infants in Florida's NICUs who receive at least 50% of their feedings as mother's own milk at discharge called the MOM Initiative.

Rationale

Breastmilk feeds are a benefit for both the mother and infant and should be encouraged.

Change Ideas

- Discussion of breastfeeding goals during antenatal consultation
- Lactation and breastfeeding education provided to mothers at appropriate reading levels and available in language of preference
- Incorporation of lactation consultant on rounds

Resources

- FPQC Mothers Own Milk (MOM) Initiative: www.fpqc.org/mom

Potential Metrics

- Documentation of lactation assessment within 24 hours of admission to NICU
- Use of breast pump within 6 hours of birth (if mother is medically stable and desires to breastfeed)
- % of infants receiving any of mother's own milk at time of discharge

All participating centers will participate in the Skin-to-Skin component of the FPQC PAIRED Initiative with the aim to improve this very important aspect of family centered care (FCC) in the NICU. However, we acknowledge that there are many facets to family centered care and for units with the interest and resources to work toward other FCC-focused improvements, we have created a toolkit with a variety of potentially better practices, change ideas, resources, and potential metrics. If your unit decides to implement these other family centered care improvements, you do not need to report your progress or results to the FPQC but we encourage you to utilize this toolkit in your work.

PAIRED Plus Gap Analysis Survey

For centers interested in pursuing additional FCC strategies, this survey may help you in determining what area of focus is best in your particular unit. It can also be used to survey participating families.

How Family-Centered is your NICU Culture Currently?

In our unit....	Yes	Rarely /No	# of 'Rarely/No' Answers
Family Inclusion in Daily Rounds			
Most families are present (physically or virtually) on daily rounds Families encouraged to attend and participate on daily rounds Family expectations for rounds are elicited as part of admission process We utilize technology to include families on daily rounds if they can't be in the unit Families are encouraged to attend and participate in nursing shift changes			
Uniform Approach to Long Term Care and Complex Care Conferences			
We have a set guideline for when complex care conferences are held We provide printed materials/documentation to families at the conclusion of complex care conferences We offer training for staff who lead complex care conferences			

<p>We involve pediatricians in discharge-related care conferences</p> <p>Family caregivers are considered equal members of the team</p> <p>Peer support program(s) are available to family caregivers</p>			
Identifying infants and families as individuals			
<p>We ask family caregivers what is their preferred name for their infant</p> <p>We use preferred infant name on rounds</p> <p>We use preferred infant name in documentation</p> <p>We post the preferred infant name at bedside</p> <p>We ask family caregivers for their preferred name/method of address</p> <p>We have palliative and bereavement services available to family caregivers when needed</p>			
Initiating Medical Education Early and Continuing Throughout NICU Stay			
<p>We begin family caregiver education early in admission</p> <p>We have family caregiver education available in both printed and electronic versions</p> <p>We have family caregiver education available in multiple languages</p> <p>We utilize teach-back methods in educating family caregivers</p> <p>We have a staff liaison for families</p> <p>Family caregivers have unlimited time to spend with their baby, learning to provide safe and confident care</p> <p>Family caregivers have access to their baby's medical records and a liaison to help them understand the records if needed</p>			
Creation and Utilization of a Family Advisory Council			
<p>We have a Family Advisory Council</p> <p>Our Family Advisory Council participates actively in our guidelines and initiatives</p>			
Improving the Antenatal Experience: Interactions and Counseling			
<p>We have guidelines for who receives an antenatal consult</p> <p>We have guidelines for what content is included in antenatal consults</p> <p>We include subspecialists in antenatal consults</p> <p>We provide printed materials at antenatal consults</p> <p>Our staff is formally trained to provide antenatal consultation</p>			

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Appendix A: Staff Resources

Additional resources are available in the [PAIRED Online Tool Box](#).

- [Clinical Guideline: Skin to Skin Care for the Newborn](#). This is an Evidence Based Clinical Guideline from The Royal Children’s Hospital in Melbourne Australia. The guideline is comprehensive and contains the following sections: Introduction, Aim, Definition of terms, Assessment, Management, Evidence Table, and References. It is a wonderful resource for staff to use when updating a unit’s policies and procedures.
- Advances in Neonatal Care: [A Clinical Guideline for Implementation of Kangaroo Care With Premature Infants of 30 or More Weeks' Postmenstrual Age](#) (Ludington-Hoe 2008). Clinical guideline for skin-to-skin care, Details of physiologic benefits for infant, Criteria for assessing infant, parental, and institutional readiness for skin-to-skin care, Sample protocol/policy that can be modified for unit use.
- [IFCDC: Recommendations for Skin-to-Skin Contact with Intimate Family Members](#). List of standards that should be adopted to promote skin-to-skin care, along with recommended competencies and evidence-based rationale.
- [United States Institute for Kangaroo Care](#). Excellent resource for training/lectures in provision of kangaroo care/skin-to-skin care. Competency checklist for kangaroo care. Educational videos on skin-to-skin care. Information on products that aid in provision of skin-to-skin care.
- The [National Perinatal Association](#) and the NICU Parent Network have partnered together to produce innovation online staff education.

Appendix B: Institutional Resources



Additional resources are available in the [PAIRED Online Tool Box](#).

- [Support for NICU parents](#). This website offers comprehensive resources for NICU Family Support.
- [Hand to Hold®](#) helps families before, during, and after a NICU stay and infant loss by providing powerful resources for the whole family, and most importantly, one-on-one mentoring from someone who has been there.
- [The Family Integrated Care \(FICare\)](#) model is an extension of the principles of Family Centered Care. It is an actionable model by which parents are true partners in their infant's care, even when in the NICU. This model was developed by a healthcare team that included parents who had previously been in the NICU (veteran parents). Integrating parents into the care team in Family Integrated Care goes well beyond merely allowing parents to be present and observe their infant's care. This site contains information on how to implement FICARE, a section for parents, a toolkit, a curated list of links and a video library to enhance learning.
- [NICU Design NICU Standards](#). In 1993 an open, multi-disciplinary conference on NICU design and care led to the creation of a multi-disciplinary committee of neonatologists, nurses, researchers, architects, and regulators. They convened to review current evidence on the physical environment of the NICU and this led to the First Recommended Standards of Newborn Intensive Care Unit Design. The Consensus Committee has continued to meet and update the recommended standards and produced the 9th edition.



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