HOMEWARD BOUND INITIATIVE: TOOLKIT

Florida Perinatal Quality Collaborative

The Florida Perinatal Quality Collaborative (FPQC) is excited for the Homeward Bound Initiative and the potential for quality impact on NICU infants, their families, and the teams that serve them. FPQC provides this Homeward Bound toolkit to help guide neonatal teams to develop individualized policies, guidelines, activities, best practices, and materials to 1) transform their family engagement culture to achieve discharge preparedness, 2) help families meet their health-related social needs while providing respectful care 3) coordinate with community healthcare partners to safely transfer the comprehensive care of the infant. The toolkit is not to be construed as a standard of care; rather it is a collection of resources that may be adapted by local institutions to develop and implement their quality improvement initiative. This toolkit will be updated throughout the initiative as additional resources become available.

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INTRODUCTION

The vision of the Homeward Bound Initiative is to integrate NICU families into a "Family-Centered" discharge process that encompasses Dignity & Respect, Participation, Communication, and Information Sharing. The process begins on admission, empowering families to collaborate with the clinical interdisciplinary team throughout their baby's transition from NICU admission to discharge home.

The overall goals of the Homeward Bound Initiative are:

1. To assist hospitals and providers in transforming their culture and environment to integrate families into the discharge readiness process for a smooth and safe transition to home.

2. To guide and support hospitals to implement a multidisciplinary team approach, that improves the transition to home through excellent clinical care, comprehensive education, and coordination of continued care with the community, including families with Social Determinants of Health (SDOH) challenges, or Health Related Social Needs (HRSN).

How to Use This Toolkit

This toolkit is intended to provide guidance and core concepts for hospital QI teams and includes practice, education, and administrative components. Hospitals have an obligation to patients, families, providers, and the community to assure patient safety, competent care, education, and referral. Likewise, providers have an obligation to patients, families, and the hospital to practice competent and evidence-based neonatal care. Care should be provided respectfully to all infants and families. 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 primary care providers, other healthcare professionals (e.g., social work, behavioral health treatment providers, etc.), as well as community partners. There is a responsibility to coordinate efforts to screen NICU families and/or caregivers for health-related social needs, arrange appropriate follow-up care, engage and educate patients in their care, engage and educate the spectrum of clinicians and other providers, and report on the outcomes for future improvements.

Hospitals are encouraged to have interdisciplinary teams in place with the necessary skill sets and designated roles to provide screening, neonatal care, education, and follow-up for families of NICU infants to help prepare them for the transition to home while addressing technical readiness, emotional readiness, and Health-related Social Needs (HRSN) or SDOH challenges. Administration, nursing, neonatology, social work/case managers, community providers, and others are all critical partners of the interdisciplinary team approach that is necessary for continuous process improvement and the provision of quality care. In addition, teams are encouraged to include community and family representatives in discharge planning as they provide valuable input and are essential to success. These teams need to train together and practice together to maintain and gain new competencies. Because each hospital and care team has varying resource sets, it is important to develop individualized protocols, guidelines, and processes for each facility. A comprehensive multi-disciplinary QI team is encouraged to review current practices and data, prioritize drivers for improvement, and develop an action plan to address their unique needs.

Disclaimer

This toolkit 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 toolkit is a working draft and living document. As more recent evidence-based strategies become available, hospitals and providers are encouraged to update their guidelines and protocols accordingly. The FPQC will communicate updates as well as revise materials. Please note the version number in the footer.

BACKGROUND

Comprehensive NICU care includes multidisciplinary, family-centered transition, and discharge guidelines to ensure that discharge readiness and outcomes are optimized. Discharge readiness is defined as the "attainment of technical skills and knowledge, emotional comfort, and confidence with infant care by the infant's primary caregivers at the time of discharge" (Smith, 2022). However, known social, environmental, economic, and mental health challenges impact NICU discharge readiness (Vohr, 2022). Neonatal intensive care unit (NICU) families can become overwhelmed by the discharge process and transition to home. Lack of parental emotional comfort and confidence can inhibit learning and contribute to poor infant outcomes and increased healthcare utilization after discharge. The quality of the discharge preparation is a strong predictor of discharge readiness (Balasundaram et al., 2021). Therefore, it is invaluable that NICUs develop a comprehensive multidisciplinary, family-centered discharge preparation program. This includes 1) educating, equipping, and enabling new parents in the care of their premature or sick newborn, 2) addressing health-related social needs of the caregivers and family through referral and coordination with community resources, and 3) arranging for the infant health care and support services families will need once discharged. Comprehensive, consistent, and early discharge preparation can lead to an effective and efficient NICU discharge and transition to home as well as improve caregiver and family satisfaction. The Florida Perinatal Quality Collaborative (FPQC) aims to achieve the outcome of discharge readiness by improving the discharge preparation process through this quality improvement initiative.

Through the initiative, FPQC will partner with Florida's Level 2, 3, and 4 NICUs to promote comprehensive discharge preparation and ensure an optimized discharge and transition of the NICU baby to home through using three Key Drivers for improvement:

1. Family Engagement and Preparedness
2. Health-Related Social Needs
3. Transfer and Coordination of Care

Homeward Bound was developed with direct input and support of a Homeward Bound Advisory group consisting of health care team professionals, community leaders, and family members. The initiative's programs, trainings, materials, and data tracking are evidence-based or potentially best practices using the recently published national interdisciplinary guidelines on NICU discharge preparation and transition planning (Smith et al., 2022).

Homeward Bound Aim:

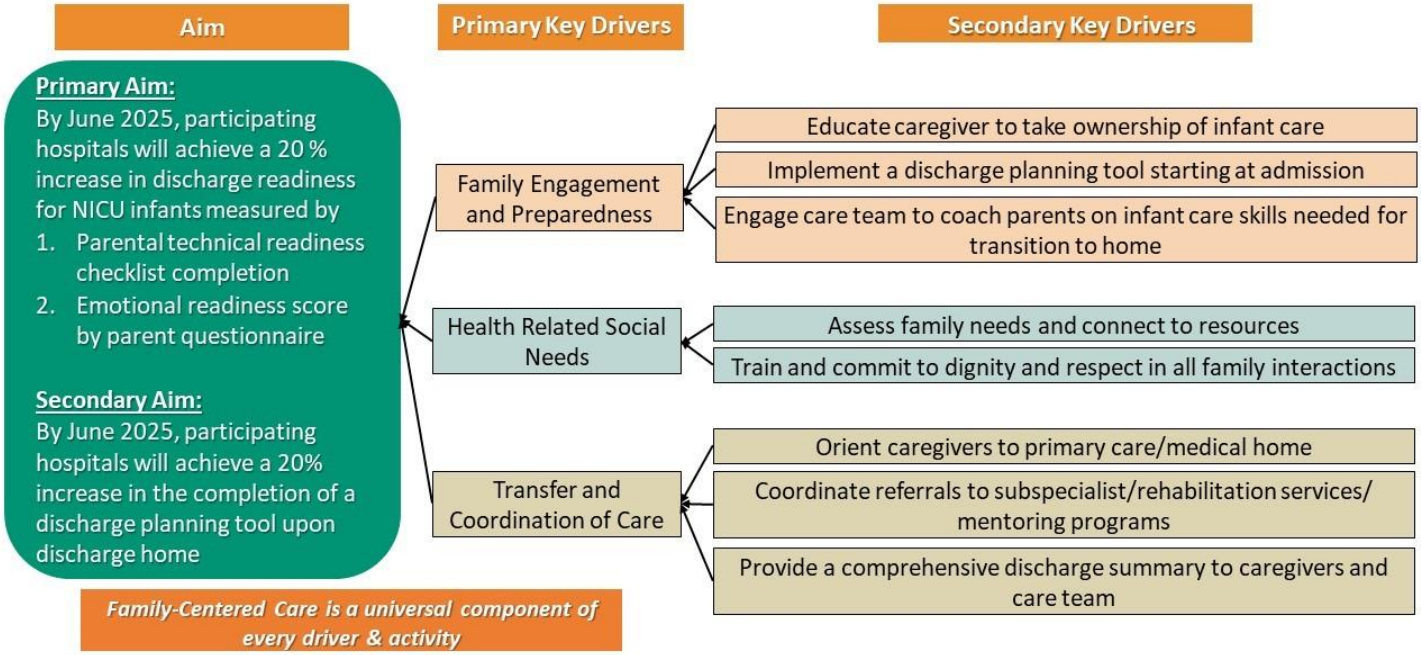
1. By June 2025, participating hospitals will achieve a 20% increase in discharge readiness for NICU infants measured by
    - Parental technical readiness checklist completion
    - Emotional readiness score by parent survey

2. By June 2025, participating hospitals will achieve a 20% increase in the completion of a discharge planning tool upon discharge home.

The sections of the toolkit are organized by primary drivers shown in the Homeward Bound Initiative Key Driver Diagram (KDD) below. Each primary driver section includes additional information related to the secondary drivers in the diagram.

Homeward Bound

Vision: Integrate family into a "Family Centered" discharge process that encompasses Dignity & Respect, Participation, Communication, and Information Sharing. The process begins on admission, empowering families to collaborate with the clinical interdisciplinary team throughout their baby's transition from NICU admission to discharge home.



Primary Driver #1: Family Preparedness and Engagement

Family engagement and preparedness is the cornerstone for improved outcomes in the important transition from the NICU. Engaged and well-prepared parents are more likely to successfully care for their infants at home and mitigate the risks of re-admission.

The family perspective is important when defining a successful discharge from the NICU and transition to home. Including families in the QI process helps identify opportunities for improving the neonatal care provided. Cultivating a supportive culture receptive to family input can foster family engagement in QI. Families can be empowered through resource provision, training, and clearly defined roles. Recognizing their contributions and offering support or incentives can further encourage active family participation in QI initiatives and can increase positive outcomes.

Mental health and psychosocial support encompass all forms of assistance provided to safeguard or enhance individuals' mental well-being and psychosocial welfare. Parental mental health in the NICU is a significant and often overlooked element of the care provided to families with premature or critically ill newborns. The NICU experience can be stressful, emotionally taxing, and overwhelming for parents.

Family preparedness and engagement in the NICU offer a range of benefits, such as strengthened parent-infant bonding, reduced parental stress, improved long-term parental well-being, enhanced decision-making capabilities, the development of a more robust support network, and enhanced long-term neurobehavioral outcomes for children, among others.

Resources:

2022 Interdisciplinary NICU Discharge Guidelines and Recommendations

Canadian Paediatric Society Position Statement on Discharge Planning of the Preterm Infant

Secondary driver 1a: *Educate caregivers to take ownership of infant care*

Effective family engagement and preparedness provide sufficient education and support to families to help them successfully transition to home. Prior to discharge, primary caregivers must consistently participate in their infant's care, receive education on infant care, and demonstrate readiness and competence to provide home care.

FPQC Recommends:

- Begin preparing the family for discharge early in the NICU stay and repeat regularly to fully engage family.
- Communicate to the family the technical skills that need to be mastered prior to discharge and the expected timing of discharge, including having families demonstrate proficiency of these skills.
- Invite family members' questions. Communicate clearly that you expect they will have questions now and in the future. Let them know who can help answer those questions.
- Establish that the family feels comfortable with their ability to provide care at discharge.
- Families' technical infant care skills and knowledge of discharge preparation occurs based on the family's availability, regardless of time of day. When possible, ensure that at least two caregivers are knowledgeable about infant care skills and discharge planning.
- Supplement discharge skill demonstrations and discharge education in the family's preferred learning style and language (i.e., written, visual, live demonstration, or recorded) to reinforce instruction and increase knowledge retention.

- Allow multiple educational opportunities and skill demonstrations. Give families adequate time to process information and ask questions.

Resources:

- Baby Steps to Home: A step-by-step educational tool for NICU nurses and parents, featuring customizable resources to prepare parents for their baby's transition home.
- NICU to Home: Recommendations of a comprehensive NICU discharge preparation program. Includes discharge education resources, planning tools, planning team, and an educational philosophy.
- Discharge Education: Comprehensive list of discharge education curriculum from the Interdisciplinary Guidelines and Recommendations for NICU Discharge Preparation and Transition Planning. Includes infant care skills demonstration, family comprehension assessment, timing of discharge education, and some elements to support family education.
- NICU Discharge Parent Education Videos: AAP YouTube playlist in Spanish and English.
- Recommendations for Families with Limited English Proficiency: Guidelines for engaging and supporting families with limited English proficiency.
- Hand to Hold: A free smartphone app endorsed by the NPA that offers support groups, counseling, educational content, and other resources to NICU families and providers.

Secondary driver 1b: *Implement a discharge planning tool starting at admission*

Tools for discharge preparation and transition planning include resources that help support the family's discharge preparation. Resources include a NICU course roadmap, a discharge worksheet for both providers and parents, and a dedicated discharge planning folder.

FPQC Recommends:

- NICUs use evidence-based tools to assess technical components of readiness for discharge, including understanding feeding, infant care, and equipment.
- NICUs use evidence-based tools to assess emotional readiness of families for discharge.
- NICUs engage parents throughout their stay in planning for discharge using roadmaps, checklists, or other tools to track readiness.

Resources:

- Discharge Roadmap for Families: A NICU Roadmap is the visual schematic that outlines the time span from NICU admission to NICU discharge with tasks, education goals, milestones, and care needs to complete.
- NICU Discharge Planning Worksheet: A discharge worksheet allows hospital staff to engage families in discharge planning.
- Discharge Planning Tools: Includes essential elements of the discharge summary and recommendations for different planning tools from the Interdisciplinary Guidelines and Recommendations for NICU Discharge Preparation and Transition Planning.

Secondary driver 1c: *Engage care team to coach parents on infant care skills needed for transition to home admission*

A well-prepared care team can provide parents with the knowledge and confidence needed to navigate the often daunting shift from hospital care to home care. Equipping healthcare professionals with the expertise and resources to coach parents enhances the safety and health of infants and empowers parents to take an active role in their child's care journey. Staff should feel encouraged and capable of coaching parents early in the NICU admission and throughout the entire NICU stay.

FPQC Recommends:

- Within 72 hours of admission (and before delivery, if possible), hospital NICU teams should implement a process to educate parents on what to expect during a NICU admission, from care of the infant to how the family will be part of the care team.
- Before discharge, the NICU team should work with families to assure that they understand key components of care following discharge, ranging from maintaining the infant's body temperature to obtaining community resources, or using a standard tool. A selection of tools can be found in the Homeward Bound Toolbox with links below in the resource section.
- At discharge, NICU teams should complete standard clinical elements for discharge, including a comprehensive physical examination, clear understanding of growth parameters, and a plan for follow visits according to the infant's needs.

Resources:

- Recommendations for NICU Discharge Planning: Recommended discharge planning checklist elements from the Canadian Paediatric Society.
- Caring for Kids: This website provided by the Canadian Paediatric Association provides information on keeping children safe around the home.
- AAP Safe Sleep Guidelines: This article explains the AAP safe sleep policy for families.
- Getting Ready to Go Home From the NICU: Families and providers can use this March of Dimes website to reinforce discharge teaching and families can access it from home.

Primary Driver #2: Health-Related Social Needs

Implementing a standardized, universal screening process for health-related social needs is considered standard evidence-based practice supported by medical professional organizations including AAP, NANN, and AWHONN.

Definitions:

Social determinants of Health (SDOH) – the conditions in the environments where people are born, live, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks (Healthy People 2030, n.d.).

Health-Related Social Needs (HRSN) – People that live in a community share similar SDOH but have varying social needs. There are five social needs domains prioritized by CMS:

1. Housing instability
2. Food insecurity
3. Transportation problems
4. Utility help needs
5. Interpersonal safety

Resources:

- CMS Screening Tool: The Tool can help providers find out patients' needs in the 5 core CMS domains.
- TJC: Assess Health-Related Social Needs: This document from The Joint Commission includes resources on how organizations can assess health-related social needs.

Secondary driver 2a: *Assess family needs and connect to resources*

Screening for HRSN is vital to a smooth discharge transition to home. Those who have adverse health determinants need to be connected to resources while in the hospital. Ensuring that caregivers' screens are either communicated to the NICU from the Labor and Delivery Unit, or completed while in the NICU, will help bridge the gap in care when transitioning to home.

FPQC Recommends:

- Know professional organizational standards for addressing SDOH (AWHONN, NANN, AANP, ACNM, ACOG, and AAP).
- Assess current HRSN screening and referral workflow and regularly keep current to ensure essential steps are standardized for all patients admitted for care.
- Ensure that HRSN screening completion for NICU infant's primary caregivers is documented in infant's chart. If screening is completed on the parent while an OB patient, then create a process to communicate screen to the NICU team.
- Adapt care plan for families that screen positive for HRSN by providing needed resources to prevent a delayed discharge transition to home.
- Repeat screening if HRSN change during NICU stay.
- Provide the applicable resources and referrals to ensure a family-centered transition to home.
- Supply breastfeeding trays and breast pumps to facilitate optimal feeding and growth of the infant.
- Practice Shared Decision-Making with the family to promote completion of the referral process.

Resources:

- Poverty and Child Health in the United States: Policy statement from AAP recommending universal social risk screening and referral to community resources in pediatric clinical care.
- Current State of HRSN Screening in NICU: Reviews the current state of HRSN screening in NICU's across America.
- The SHARE Approach: The Agency for Healthcare Research and Quality developed a five-step process on shared decision-making that includes a training curriculum and tools.
- Implementing Social Risk Screening and Referral to Resources in the NICU: Shows a QI methodology to implement Social Risk Screening and referral in the NICU and provides an example of a screening tool.
- Approaches to Addressing Social Determinants of Health in the NICU: A Mixed Methods Study: Provides an overview of why it is important to have a standardized screening process for HRSN in the NICU.
- Association of Social Factors and Time Spent in the NICU for Mothers of Very Preterm Infants: Shows that social factors are associated with maternal time spent in the NICU.

Secondary driver 2b: *Train and commit to dignity and respect in all family interactions*

Dignity and respect are core principles of Family-Centered Care. Assessments of family needs and connections to resources should be carried out in a culturally responsive, inclusive, and non-judgmental manner. When respectful care is prioritized by the care team, families may feel more compelled to engage in the discharge process and better prepared to return home.

FPQC Recommends:

- Educating all members of the NICU care team about respectful care and its components and strategies to enhance family interactions.
- Developing a hospital commitment on family dignity and respect for providers and staff support.
- Adopting and committing to appropriate Respectful Care Practices to best serve the identified needs in their communities.
- Creating a strategy for sharing expected respectful care practices with the NICU clinical team and families.

FPQC Resources:

- Respectful Care Commitment for NICU Families

Resources:

- A 4-Step Framework for Shared Decision-Making in Pediatrics
- NICU Discharge Preparation and Transition Planning: Guidelines and Recommendations
- Parental Satisfaction with Neonatal Intensive Care Units: A Quantitative Cross-Sectional Study
- Tip Sheet 10 ideas FFC Diversity Disparities (CPQCC): Examines the experiences and perceptions of health care providers caring for new immigrant families in the NICU.
- Parents' and Nurses' Experiences of Partnership in Neonatal Intensive Care Units: A Qualitative Review and Meta-Synthesis
- Caring for Indigenous Families in the Neonatal Intensive Care Unit
- When a Common Language is Missing: Nurse–Mother Communication in the NICU. A Qualitative Study
- Implementing the New ANA Standard 8: Culturally Congruent Practice: Records the history of the revised scope and standards and new Standard 8, the reasoning behind this standard and its impact on nursing practice, education, and research.
- Racism and Quality of Neonatal Intensive Care: Voices of Black Mothers: A qualitative study showing racism impacts quality of NICU care and ideas for interventions.
- Disparities in NICU Quality of Care: A Qualitative Study of Family and Clinician Accounts: A qualitative study describing disparities in NICU quality of care.
- Former NICU Families Describe Gaps in Family-Centered Care: A qualitative study describing family-centered care experiences.

Primary Driver #3: Transfer and Coordination of Care

The Transfer and Coordination of Care Primary Driver of the Homeward Bound initiative is focused on the infant's discharge from the NICU to home and to the community for continued care. In addition to educating and training the caregivers, a successful transition process includes a comprehensive discharge summary, personalized care plan, arrangement of needed services and equipment, and appropriate follow-up.

"Discharge planning is the process of working with a family to help them successfully transition from the NICU to home. To this end, each family will need to participate in a comprehensive discharge planning program that has been tailored

to their and their infant's specific needs" (Smith et al., 2022). Discharge from the NICU is a vulnerable period for infants and families. Well-coordinated transitions improve health care quality and safety and positively impact the family's experience.

Resources:

2022 Interdisciplinary NICU Discharge Guidelines and Recommendations

2013 NICU Discharge Preparation

2008 AAP Statement on Hospital Discharge of the High-Risk Neonate

Secondary driver 3a: *Orient caregivers to primary care/medical home*

The AAP and the NPA both recommend that every high-risk infant receive primary care in a medical home. A medical home is a multidisciplinary team of providers and community partners dedicated to coordinating the needs of the infant and family. The infant's primary care pediatrician should have experience managing NICU graduates and be made aware of the infant's specific care needs and follow-up plans prior to discharge, thus enhancing continuity of care. In many cases, families will benefit from assistance in choosing an appropriate provider, especially one that accepts their health insurance coverage.

FPQC Recommends:

- Provide the caregivers with a list of pediatricians who can manage NICU graduates and which Medicaid plans they accept.
- Call the selected pediatrician prior to patient discharge to discuss the infant and their special care plan based on unit criteria.
- Recommend risk-appropriate hospital PICUs and ERs based on the infant's needs and unit criteria prior to patient discharge and after consulting with their selected pediatrician.

Resources:

- Considerations When Choosing a Provider: Questions to guide hospitals and parents in selecting an appropriate PCP.
- PCP Discussion Elements: Recommended discussion elements for handoff to PCP/medical home.
- Example List of Pediatricians – *coming soon.*
- Example PCP Discussion Agenda – *coming soon.*

Secondary driver 3b: *Coordinate referrals to subspecialist/rehabilitation services/mentoring programs*

In addition to their primary medical home, many NICU infants require subspecialty care, case management, rehabilitative services, Early Steps or early intervention services, medical equipment, and NICU follow up clinic care. Their families may desire and benefit from community services and support programs. To ease the transition and reduce the risk of poor outcomes, the AAP and NPA recommend that all these referrals be made prior to discharge, providing a clear actionable plan for the caregivers. Whenever possible, appointments should also be arranged prior to discharge. Maintaining a comprehensive community resource list that hospital staff can use in assisting NICU families is also helpful. The infant's personalized care plan should document the referrals made, appointments scheduled, and

remaining actions that are required. The infant's personalized care plan should be developed with input from the family, the chosen pediatrician, and the care team. The final plan should be agreed upon and supported by the caregivers.

FPQC Recommends:

- Start the referral process to Medicaid or other insurer case management services early during the NICU admission to actively engage them in the transition to home process.
- Create a patient-specific care plan with the family that includes subspecialists, ST, PT, OT, home health services, equipment, NICU developmental follow-up programs, and make appointments prior to discharge. The chosen pediatrician should also be consulted.
- Refer the patient/caregivers to Healthy Start, Early Steps, and other needed community services prior to discharge.
- Discuss and adapt the patient-specific care plan to meet caregiver approval and support including appointments, referrals, immunizations, medications, diet, special needs/instructions, and equipment arrangements and orientations.

Resources:

- Recommended Care Plan Elements: Recommended elements for a patient-specific care plan.
- NICU Community Resource Template: A template for hospitals to fill out with local resources to share with hospitals and contains general resources as well.
- Early Steps Eligibility and Screening: Children who have an established condition that places them at risk of developmental delay may be eligible for early intervention services through Early Steps. See toolbox for additional resources and information on Early Steps.
- Florida Birth Defects Surveillance Program Statewide Resource Guide: Lists resources by category and by region for families of children with special healthcare needs. See toolbox for additional resources from the Florida Birth Defects Surveillance Program, including brochures and emergency preparedness materials.
- Medicaid Health Plan Case Management Services Referral List – *coming soon.*
- Example of Patient-Specific Care Plan – *coming soon.*

Secondary driver 3c: *Provide a comprehensive discharge summary to caregivers and care team*

The infant's discharge summary is a way to communicate important health information to both the family and providers who will be caring for the infant after discharge. The NPA recommends that the discharge summary have a standardized format, be discussed with the family before discharge, and translated into the family's primary language. Multiple copies of the discharge summary should be provided for the family at discharge and available for any future provider or specialist. In addition, discharge summaries should be sent to the chosen pediatrician and any specialists and referrals based on unit criteria. After discharge, a NICU health care professional should follow-up by phone, virtually, or in person with the family within three days of discharge to assess how the transition home is going.

FPQC Recommends:

- Create a standardized format for the Discharge Summary including history and all care provided.
- Discuss the Discharge Summary verbally and use mixed teaching/learning approaches in the caregivers' primary language to assure understanding.
- Discuss patient and caregiver information in the family's primary language, using an interpreter and translating materials when needed.

- Provide multiple copies of the Discharge Summary to the family for them to take for each appointment, plus one extra just in case.
- Give a letter of necessity for community first responders, utilities, and officials based on unit criteria.
- Have a health care professional call the caregivers within 3 days after discharge based on unit criteria.

Resources:

- Neonatal Discharge Summary: Sample format of a discharge summary.
- Recommended Discharge Summary Elements: Recommended elements to include in a discharge summary, including general recommendations for how to format and distribute.
- NICU Discharge Planning Worksheet: See driver 1b for this resource.
- NICU Discharge Order Set: Recommended elements to be ordered by the provider for a comprehensive discharge and transition home.
- Recommended Follow-Up Call Elements: Recommendations for the 3-day follow-up call to families.
- Recommendations for Families with Limited English Proficiency: See driver 1a for this resource.
- Caregiver Education Approaches – *coming soon.*
- Example Letter of Necessity – *coming soon.*
- Example Follow-Up Phone Call Agenda or Worksheet – *coming soon*.

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