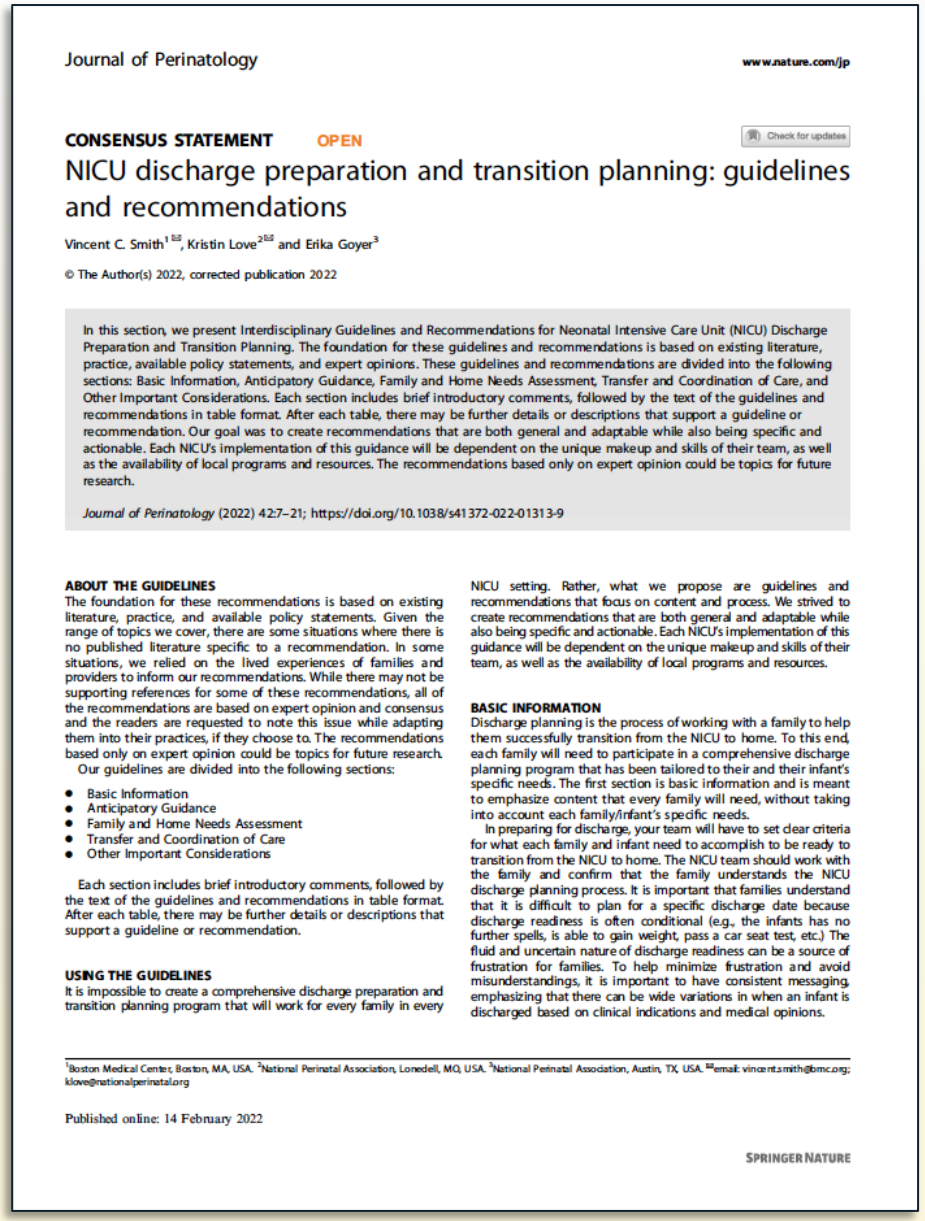
Bridging the NICU to Home:
A Team-Based Approach to Infant Discharge and Follow-Up Care

Activity 1

Implementing a NICU Discharge Planning Program: Evidence - Based Guidelines



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CONSENSUS STATEMENT OPEN

NICU discharge preparation and transition planning: guidelines and recommendations

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In this section, we present Interdisciplinary Guidelines and Recommendations for Neonatal Intensive Care Unit (NICU) Discharge Preparation and Transition Planning. The foundation for these guidelines and recommendations is based on existing literature, practice, available policy statements, and expert opinions. These guidelines and recommendations are divided into the following sections: Basic Information, Anticipatory Guidance, Family and Home Needs Assessment, Transfer and Coordination of Care, and Other Important Considerations. Each section includes brief introductory comments, followed by the text of the guidelines and recommendations in table format. After each table, there may be further details or descriptions that support a guideline or recommendation. Our goal was to create recommendations that are both general and adaptable while also being specific and actionable. Each NICU's implementation of this guidance will be dependent on the unique makeup and skills of their team, as well as the availability of local programs and resources. The recommendations based only on expert opinion could be topics for future research.

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ABOUT THE GUIDELINES

The foundation for these recommendations is based on existing literature, practice, and available policy statements. Given the range of topics we cover, there are some situations where there is no published literature specific to a recommendation. In some situations, we relied on the lived experiences of families and providers to inform our recommendations. While there may not be supporting references for some of these recommendations, all of the recommendations are based on expert opinion and consensus and the readers are requested to note this issue while adapting them into their practices, if they choose to. The recommendations based only on expert opinion could be topics for future research.

Our guidelines are divided into the following sections:

- Basic Information
- Anticipatory Guidance
- Family and Home Needs Assessment
- Transfer and Coordination of Care
- Other Important Considerations

Each section includes brief introductory comments, followed by the text of the guidelines and recommendations in table format. After each table, there may be further details or descriptions that support a guideline or recommendation.

USING THE GUIDELINES

It is impossible to create a comprehensive discharge preparation and transition planning program that will work for every family in every NICU setting. Rather, what we propose are guidelines and recommendations that focus on content and process. We strived to create recommendations that are both general and adaptable while also being specific and actionable. Each NICU's implementation of this guidance will be dependent on the unique makeup and skills of their team, as well as the availability of local programs and resources.

BASIC INFORMATION

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. The first section is basic information and is meant to emphasize content that every family will need, without taking into account each family/infant's specific needs.

In preparing for discharge, your team will have to set clear criteria for what each family and infant need to accomplish to be ready to transition from the NICU to home. The NICU team should work with the family and confirm that the family understands the NICU discharge planning process. It is important that families understand that it is difficult to plan for a specific discharge date because discharge readiness is often conditional (e.g., the infants has no further spells, is able to gain weight, pass a car seat test, etc.) The fluid and uncertain nature of discharge readiness can be a source of frustration for families. To help minimize frustration and avoid misunderstandings, it is important to have consistent messaging, emphasizing that there can be wide variations in when an infant is discharged based on clinical indications and medical opinions.

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NICU Discharge Preparation and Transition Planning: Guidelines and Recommendations

CONSENSUS STATEMENT

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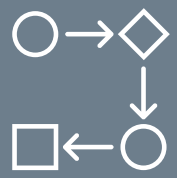
Introduction and Background

Evidence Base

Founded on existing literature, clinical practice, available policy statements, and expert consensus across an interdisciplinary workgroup

Scope

Covers every family transitioning from NICU to home—from infant care skills and family readiness through community coordination and follow-up care



Implementation

Designed to be both general and adaptable. Each NICU should tailor implementation to their team makeup, family needs, and local resources

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A Framework for Discharge Preparation

Five interdisciplinary pillars guide every family's transition from NICU to home:

1

Basic Information

Discharge education, planning tools, team roles & process

2

Anticipatory Guidance

Home life, infant behavior, emergency planning, mental health, finances & medical bills

3

Family & Home Needs Assessment

Social determinants, housing, transport, parental well-being

4

Transfer & Coordination of Care

Primary care contact, community referrals, follow-up care, peer-to-peer support

5

Special Considerations

Language proficiency, military families, LGBTQIA+, parents with disabilities, cultural expectations

Guiding principle: No single program works for every family. These guidelines are designed to be **both adaptable and actionable**—tailored to each NICU's team, resources, and the unique needs of each family.

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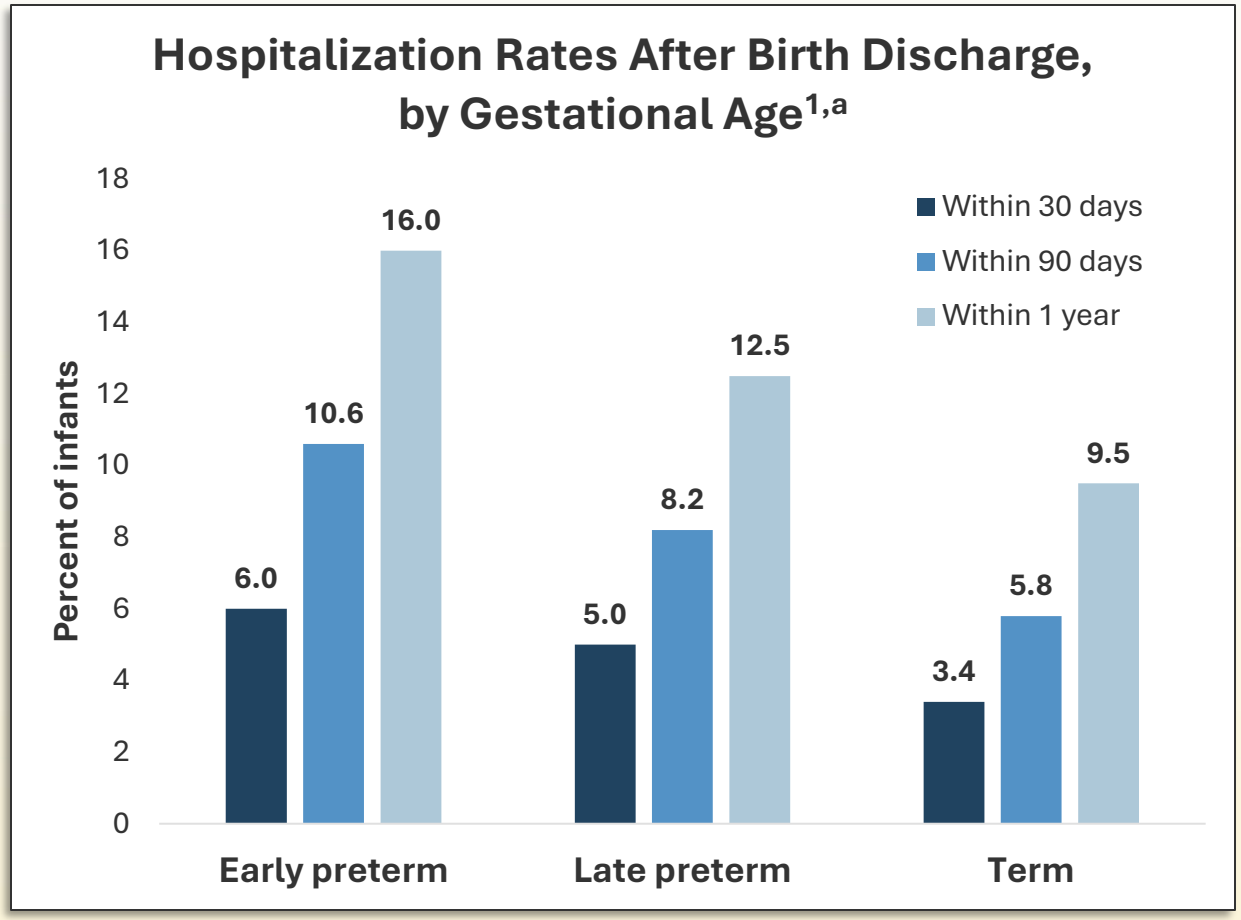
Post–NICU Discharge Readmission Is Common for Preterm Infants



3- to 4-fold increased risk
for NICU readmission in preterm vs term infants[2]

Respiratory and feeding complications
are the most common reasons for NICU readmission.[2]

Strategies to optimize NICU discharge planning are needed to reduce postdischarge complications.

a. In an observational cohort study of >6.6 million Californian infants.

1. Ray KN, Lorch SA. *Hosp Pediatr*. 2013;3(3):194-203. 2. Hannan KE et al. *Semin Perinatol*. 2020;44(4):151245.

What Is Discharge Planning?

Discharge planning is "the process of working with a family to help them successfully transition from the NICU to home."

Although specific discharge planning procedures will vary based on the family and NICU setting, shared components of successful discharge planning programs include:

- Multidisciplinary team involvement
- Anticipatory guidance provision
- Predischarge family and home needs assessments
- Transfer and coordination of care for both the patient and family

Key Principle: Discharge planning begins at admission!

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SECTION 1

Basic Information

Discharge Education and Planning

Education content

- Infant care skills: feeding, bathing, safe sleep, medications
- Recognizing illness; when to call pediatrician vs 911
- CPR, tummy time, infection prevention, vaccinations

Planning tools

- Discharge summary: diagnoses, meds, follow-up, community referrals
- NICU roadmap: individualized milestones & educational goals
- Discharge folder, written materials (plain language, family's language)

Planning team

- Nurses, physicians, social workers, psychologists, case managers
- Primary caregivers identified early; consistent bedside nursing
- Siblings, extended family & support network included as appropriate

Planning process

- Planning begins at admission and continues throughout the stay
- Family included in all discharge meetings; flexible scheduling
- Family-Centered Care: dignity, information sharing, participation

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SECTION 2

Anticipatory Guidance

Infant Care and Behavior

Help families understand what they can realistically expect their lives to be like with their infant, both immediately postdischarge and in the future

Home & Family Life

- Expected clinic visits for routine care, acute illness, or specialty care

Infant Behavior

- Infant developmental milestones and expected age range
- Potential developmental and/or growth-related challenges
- Recommendations to facilitate physical and behavioral growth over the first year
- Distinguishing typical and atypical infant behaviors

Soothing Strategies

- Strategies for soothing crying infants
- Coping skills for when infants are difficult to soothe

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SECTION 2

Anticipatory Guidance

Supporting Family Well-Being

Support families and caregivers in recognizing mental health issues and addressing the financial burden associated with NICU stays and ongoing care

Emergency Planning

- Who to call and when: pediatrician vs EMS vs waiting for next visit
- Prepare a written emergency contact plan before discharge

Parental Mental Health

- Common mental health issues, including posttraumatic stress disorder
- Strategies for coping in the moment with mental health stressors
- Support resources (eg, support groups, referrals)

Financial Guidance

- Social worker or case manager referral to discuss financial burden of at-risk infant
- Financial counseling resources

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SECTION 3

Family and Home Needs Assessment

Definition and Overview

- Process for **assessing the medical**, **physical**, **psychosocial**, and **mental health needs of families** and **connecting them** with appropriate community resources
- Conducted by NICU staff within the **first days of admission** and **before discharge**
  - Preferably involves a multidisciplinary team
  - Staff should be trained and aware of their own explicit or implicit biases
- Process should be **collaborative with the family**

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SECTION 3

Family and Home Needs Assessment

Families Should Be the Drivers and Owners of the Process

- Before the assessment, **explain to families:**
  - What is being assessed
  - The assessment process
  - How the results will be used
- Begin the assessment by **asking families for permission**
- As much as possible, **maintain family confidentiality** and **limit sharing assessment results** only with those who need to know

Recommendations for Family and Home Needs Assessments

- Family living arrangement
- Home supplies (eg, food, diapers, safe sleep environment, car seat)
- Home assessment
- Transportation
- Childcare needs
- Nutrition assistance
- Social support services
- Coping style
- Caregiver mental health

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SECTION 4

Transfer and Coordination of Care

Primary Care

Beginning of discharge planning

- Identify the primary care provider or practice that will be providing follow-up care
- If no provider has been identified, help the family identify a suitable option

At or within 48 hours of discharge

- Contact the primary care provider to make them aware of the infant's history and discharge plan
  - Invite ongoing communication
  - Include infant medical concerns, discharge medications, test results, follow-up appointment needs, and needed family resources (eg, translation services)
  - Provide discharge summary
- Consider a warm handoff for complex medical or social situations

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SECTION 4

Transfer and Coordination of Care

NICU Contact

Within 72 hours after discharge, a NICU representative should follow up with the family to assess and support

Key components of assessment and discussion:

- Discharge instructions and the family's understanding of them
- Feeding practices
- Medications and medications administration
- Follow-up appointments
- General well-being of infants and family
- Issues or challenges encountered

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SECTION 5

Individualizing Plans for Special Considerations

Selected Key Populations

Limited English Proficiency

- Eliminate language as a barrier by using a medical interpreter
- Limit computer-assisted translations to urgent situations

Military Families

- Provide copy of entire medical record (or, at minimum, discharge summary) to bring to next provider
- During deployment, facilitate inclusion of the deployed family member

LGBTQIA+

- Use inclusive language
- Ensure non-biological parent has necessary authorization to consent

Parents With Disabilities

- Ask about preferred methods for communicating discharge information
- Ensure facilities meet ADA standards
- Ask about and connect with resources for needed home modifications

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Developing Protocols and Procedures

- **Discharge educational content** forms the foundational curriculum for families in the NICU
  - Ensure consistent messaging within written materials and across all staff
  - Consider separating educational content into “basic information” that all families will need and ad hoc materials based on specific infant and family needs

- In developing a **discharge planning team**, consider the available NICU personnel and assign key functions
  - Train all staff on the discharge planning process and procedures

- **Develop resources individualized to your care setting** and organize them into folders or binders

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Key Concepts

- **Discharge planning is a process, not an event.** It begins at admission and continues until the family is safely connected to their community.
- **The family is the center of the team.** Every guideline should be tailored to the family's language, culture, structure, and circumstances.
- **Preparation goes beyond infant care skills.** Families also need guidance on mental health, finances, emergencies, and community resources.
- **A warm handoff matters.** Active coordination with the medical home and a postdischarge follow-up call significantly support transition success.
- **These guidelines are adaptable by design.** Implementation will look different in every NICU — what matters is that the content and intent reach every family.

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Appendix

SECTION 1

Basic Information

The Discharge Planning Team

- Caregiver(s) and family support people
- Nursing team
- Physicians
- Discharge coordinator/planner or case manager
- Social workers
- Psychologists or mental health providers

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SECTION 1

Basic Information

The Discharge Planning Process

Examples of the Progression of Educational Content Throughout the NICU Stay

Initial Educational Content

- Steps in the discharge planning process
- Medical criteria for infant discharge readiness
- Criteria for family and home readiness prior to discharge

↓

Educational Content Approaching Discharge

- Demonstrated technical infant care skills
- Safe home care of a high-risk infant
- Recognizing signs of illness, complications, and urgent concerns
- Family support resources

Resources and processes supporting discharge planning may include:

- In-person or remote discharge planning meetings with families
- NICU roadmap (ie, a visual aid that outlines the steps in a NICU stay)
- Printed materials written at a patient-appropriate level
- Supplemental materials (eg, folders, videos, website resources)

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