

NICU-2-HOME: Using Health IT to Support Parents of NICU Graduates Transitioning to Home

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Summary: Transitioning to home from a neonatal intensive care unit (NICU) with a very low birth weight (VLBW) infant can be stressful for parents. VLBW infants who are discharged, or “graduate,” from the NICU have complicated home and outpatient care needs well into the first year of life and beyond. Many are discharged from the hospital with special health care needs, including home oxygen and monitoring, gastrostomy tube feeds, and complex medication regimens. These infants have a high rate of morbidity and frequent re-hospitalizations. Little research has been done on the factors that support parents in the successful transition of their VLBW infant from the NICU to the home, although research indicates that parents feel anxious and unprepared for discharge.

In an effort to support parents of VLBW NICU graduates, this project is developing a health information technology (IT) intervention known as the NICU-2-Home Service. This patient-and caregiver-centered service uses IT, including smart phones and tablets, to provide an informational and communication lifeline to parents as they move from the NICU to their homes and eventually establish a medical home with their pediatrician. The service is intended to empower parents, increase their self-efficacy and competency, and reduce their stress in caring for their NICU graduates. Mobile communication technologies and digital media content will provide parents with supportive guidance on the discharge process and post-discharge care; easy access to information and enhanced communication; tools, such as a care calendar and a care diary, to streamline the transition from the NICU to home; and links between the NICU, home, and the community pediatrician after discharge.

The NICU-2-Home system is being developed in collaboration with researchers at Northwestern University’s Feinberg School of Medicine and the technology company Motorola Mobility, Inc. Appropriate clinical, educational, and medical history information such as patient clinical information, immunization history, and growth data will form the foundation of the system. Smart phones with NICU-2-Home mobile applications, a bedside tablet, and a NICU-2-Home server will allow immediate delivery of necessary information to the appropriate person. An iterative development process is being used to build and refine the system. Focus groups have been conducted to collect qualitative data from primary users of the service—parents, neonatologists, and pediatricians. The data will help inform the development of the content, format, and interface of the system. A prototype will be developed and subsequent focus groups will provide additional feedback and assessment. Once final content and design decisions are made, the NICU-2-Home system will be pilot tested and its impact on outcomes such as parental self-efficacy,

involvement, and stress levels will be evaluated. The final component of this project involves a feasibility test in which parents of 100 VLBW NICU graduates will be randomized to a 1-month intervention of the NICU-2-Home Service or a control group.

Specific Aims:

- Design a novel health IT intervention, NICU-2-Home, using qualitative methods that will support both mothers and fathers of VLBW NICU graduates as they transition to home. **(Ongoing)**
- Implement NICU-2-Home in the NICU and during the transition to home. **(Upcoming)**
- Conduct a feasibility study with randomization in the NICU to test the ability of NICU-2-Home to: improve mothers' and fathers' self-efficacy and confidence in caring for their VLBW infants; decrease mothers' and fathers' stress as measured by self-report and salivary cortisol sampling; and enhance mothers' and fathers' involvement as measured using standardized tools with their VLBW infants as compared to controls. **(Upcoming)**

2011 Activities: Activities related to the development of the NICU-2-Home Service are well underway. Focus groups have been conducted with three groups of stakeholders: 1) mothers and fathers of VLBW infants in the NICU; 2) neonatologists; and 3) pediatricians. The data collected from the focus groups are currently being transcribed, coded, and analyzed.

As last self-reported in the AHRQ Research Reporting System, project progress and activities are mostly on track and the project budget funds are somewhat underspent. As staff were in process of being hired, personnel costs were less than projected for the first quarter of the project.

Preliminary Impact and Findings: This project has no findings to date.

Target Population: Children with Special Health Care Needs (CSHCN), Pediatric*

Strategic Goal: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

Business Goal: Implementation and Use

* This target population is one of AHRQ's priority populations.