

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

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| Principal Investigator: | Garfield, Craig, F.M.D., M.A.P.P. |
| Organization: | Northwestern University |
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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 has developed a health information technology (IT) intervention known as the NICU-2-Home Service. This patient-and caregiver-centered service uses IT to provide parents with information and a means of communication as they move from the NICU to their homes and eventually establish a medical home with their pediatrician. The NICU-2-Home system was developed in collaboration with researchers at Northwestern University’s Feinberg School of Medicine and the technology company Motorola Mobility, Inc. Appropriate clinical, educational, and patient medical information such as immunization history and growth data form the foundation of the system.

Smart phones with NICU-2-Home mobile applications and a NICU-2-Home server allow immediate delivery of necessary information to the appropriate person. An iterative development process was used to build and refine the system. Focus groups and interviews were conducted to collect qualitative data from primary users of the service—parents, neonatologists, and pediatricians—to inform the development of the content, format, and interface of the system. A prototype was developed and tested with subsequent focus groups to provide additional feedback and assessment. Once final content and design decisions were made, the NICU-2-Home system was pilot tested and its impact on outcomes such as parental self-efficacy, involvement, and stress levels were 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. **(Achieved)**

- Implement NICU-2-Home in the NICU and during the transition to home. **(Ongoing)**
- 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. **(Ongoing)**

2012 Activities: Development of the NICU-2-Home prototype was completed and evaluated among six sets of parents. The prototype application was installed on study smart phones. The project team described the goals of the application to the parents and walked them through the features of the application. Their feedback was incorporated into the prototype. The evaluation also indicated a need for and guided the development of an orientation manual of the NICU-2-Home application for parents. The revised prototype was then pilot tested among three sets of parents and findings were integrated into the final prototype. Enrollment for the feasibility study of the final NICU-2-Home prototype will start in January 2013. The study will recruit parents of VLBW NICU graduates.

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. Funds budgeted for the feasibility study, including participant fees and cell phone and data service, will be accrued during 2013, bringing the budget spending back on track.

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

Target Population: Children with Special Health Care Needs, 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.*