

Improving Neonatal Follow-up: A Quality Improvement Study Analyzing In-hospital Interventions and Long-term Show Rates

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Abstract

Introduction: Neonatal follow-up (NFU) clinics play an essential role in the multidisciplinary care of preterm patients. Despite the inherent value of NFU clinics, many clinical programs report poor compliance with follow-up visits. Preterm infants followed with difficulty in the long-term have higher rates of disability and lower IQ scores, even after adjustment of significant perinatal and socio-demographic variables. This quality improvement study aimed to improve the show rate for preterm infants from 60% to 80% at the initial 6-month adjusted age visit by implementing a multilevel education bundle. **Methods:** Participants included neonatal intensive care unit (NICU) physicians, physician extenders, registered nurses, and parents of preterm patients admitted to the NICU who qualified for NFU. Our 75-bed NICU is the regional perinatal center within an urban free-standing children's hospital. Our bundle included NICU provider education, discharge planning, and parent education. A tracking system was developed to identify qualifying patients to streamline workflow. **Results:** The monthly first visit show rate improved from 60% to 76% during the intervention period. Seventy-five percent of families who received parent education presented for their initial visit, compared to 51% of families who did not receive parent education. In anonymous surveys of families who presented for their initial visits, 95% indicated that bedside education played the most important role in appointment attendance. Interdisciplinary rounds are crucial for reaching all families before discharge. **Conclusion:** Implementing a multidimensional in-hospital education bundle and tracking system is feasible and can improve NFU clinic show rates, but may require dedicated personnel for sustainability. (*Pediatr Qual Saf* 2020;6:e363; doi: 10.1097/pq9.0000000000000363; Published online October 23, 2020.)

INTRODUCTION

Advances in medicine have led to an increasing population of preterm infants surviving with complex medical needs. Neonatal follow-up (NFU) clinics play an essential role in the multidisciplinary care of these patients. They provide parent support after discharge, aid in early identification

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of developmental disabilities and referral to appropriate services, and act as liaisons with community physicians and agencies.^{1,2}

NFU clinics can also obtain valuable information on these children's outcomes to enhance the care of current and future patients in the neonatal intensive care unit (NICU). Preterm infants followed with difficulty in the long-term have higher rates of disability and lower IQ scores, even after adjustment of significant perinatal and socio-demographic variables.³⁻⁵ The American Academy of Pediatrics and the Committee on Fetus & Newborn acknowledge that periodic developmental evaluation of the high-risk infant is crucial to facilitate early intervention services; however, the evaluation schedule is left to the discretion of individual centers.⁶ At our institution, the initial clinic visit is scheduled for 6 months post-discharge to accommodate all qualifying patients and to better assess development based on expected milestones.

Despite the inherent value of NFU clinics, many clinical programs report poor compliance with follow-up visits.⁷⁻¹³ At our institution, the baseline show rate for preterm infants from June 2015 to June 2016 was 60%. Several studies have examined barriers to follow-up after NICU discharge, noting that nonattendance leads to less access to required ancillary services, and in underreporting of developmental outcomes of high-risk infants.¹⁴⁻¹⁹

Barriers to referral include inconsistent or inappropriate referrals to NFU clinic, difficulties reaching families after discharge, scheduling difficulties, and perceived low importance of long-term neurodevelopmental follow-up. One such study examined post-discharge practices in contacting families and changes to clinic structure that increased NFU clinic attendance and decreased parent-reported disinterest in attendance.²⁰

It is essential to implement strategies earlier during an infant's stay in the NICU to provide an optimal transition to outpatient follow-up.¹² Our quality improvement (QI) study investigated the impact of an in-hospital intervention bundle, targeting both providers and families in improving NFU clinic attendance. We aimed to increase the initial visit show rate from a baseline of 60% to 80% over 12 months.

METHODS

The NICU at the Morgan Stanley Children's Hospital of NewYork-Presbyterian is a regional perinatal center with 75 beds. There are approximately 1000 admissions per year, with 90% being inborn. Forty percent of our NICU population has public insurance.

We refer all preterm infants less than 29 weeks of gestation and infants who are less than 32 weeks with a birth weight less than or equal to 1250g to our institution's Follow-up Program. We focused on preterm infants for this project because subspecialty services also follow the other high-risk populations followed in our program, such as infants with congenital heart disease or hypoxic-ischemic encephalopathy. Families of inborn patients who met our preterm follow-up criteria between July 1, 2016 and December 31, 2017 were included. Provider participants included physicians (attendings, fellows, residents, and house physicians), physician extenders (neonatal nurse practitioners and pediatric physician assistants), nurses, and care coordinators.

In our NFU clinic, we see preterm infants for their first visit (V1) at 6 months adjusted age (AA); second visit at 12 months AA; third visit at 18–24 months AA; and fourth visit at 30 months chronological age (CA). If only 1 infant of a multiple gestation pregnancy qualifies for follow-up based on weight criteria, then all infants are seen at the first visit. For this study, we included all children who received appointments at discharge in our analysis.

Baseline V1 show rate (June 2015 to June 2016) before we started our in-hospital interventions was 60%. Historical data for our institution showed that those families who presented for the initial clinic visit had higher follow-up rates at subsequent clinic visits over 2 years. Therefore, we aimed to increase the V1 show rate to 80% over 12 months.

We used the Institute for Healthcare Improvement (IHI) Model for Improvement as a framework for this project.²² During the study period from July 1, 2016 to

February 28, 2018, we implemented a multilevel bundle targeting in-hospital education for care providers and families. Our interventions targeted 3 major key drivers: NICU provider education, family education, and care coordination (Fig. 1). We developed a centralized qualifying patient database and educated NICU providers through scheduled sessions and with just-in-time teaching about eligibility criteria for the NFU clinic. We held parent information sessions regularly and conducted 1:1 parent education sessions at the patient bedside before discharge.

Parent education included a bedside meeting with the families following a standardized outline (see Supplemental Digital Content 1, <http://links.lww.com/PQ9/A220>) to discuss criteria for long-term developmental follow-up; the differences between CA and AA for developmental evaluation; the members of the Follow-Up team; the structure of the first visit; and how it would be different from their pediatrician appointments. We also recorded contact information from the families at this time (see Supplemental Digital Content 2, <http://links.lww.com/PQ9/A220>). These education sessions were completed at 33–34 weeks of gestational age, a time when most preterm infants are beginning oral feeding and weaning off respiratory support. The goal was to meet with the parents during a time separate from the acuity of their early days in the NICU, and from the likely overwhelming discharge process after a lengthy hospitalization. One of the 2 neonatologists in the clinic, the developmental psychologist, or our clinic coordinator conducted these parent education sessions. If multiple attempts to meet the family were unsuccessful, we attempted to contact the family by phone. In general, 2 attempts were required to reach families for one-on-one education sessions. We improved this process by scheduling appointments with parents and by coordinating these sessions around times when parents were at the bedside to provide routine care.

Parent education included monthly Follow-Up clinic staff attendance at the family groups coordinated by our NICU psychologist. We gave personalized invitations to families of patients who qualified for the NFU clinic, but these groups were open to all NICU families. We discussed the transition from NICU to home, focusing on developmental care, navigating Early Intervention, and the importance of parents being advocates for their children.

Finally, discharge planning involved 3 major components—contact with the pediatrician, redesign of discharge processes with our unit's discharge nurses, and coordination of care at our weekly interdisciplinary rounds (IDR). We formatted a letter to the child's pediatrician stating why the patient qualified for the NFU clinic, when the child's appointment would be, and the contact information for the clinic if the pediatrician had developmental concerns earlier than the scheduled V1 visit (see Supplemental Digital Content 3, <http://links.lww.com/PQ9/A220>). This letter was distributed to the family with

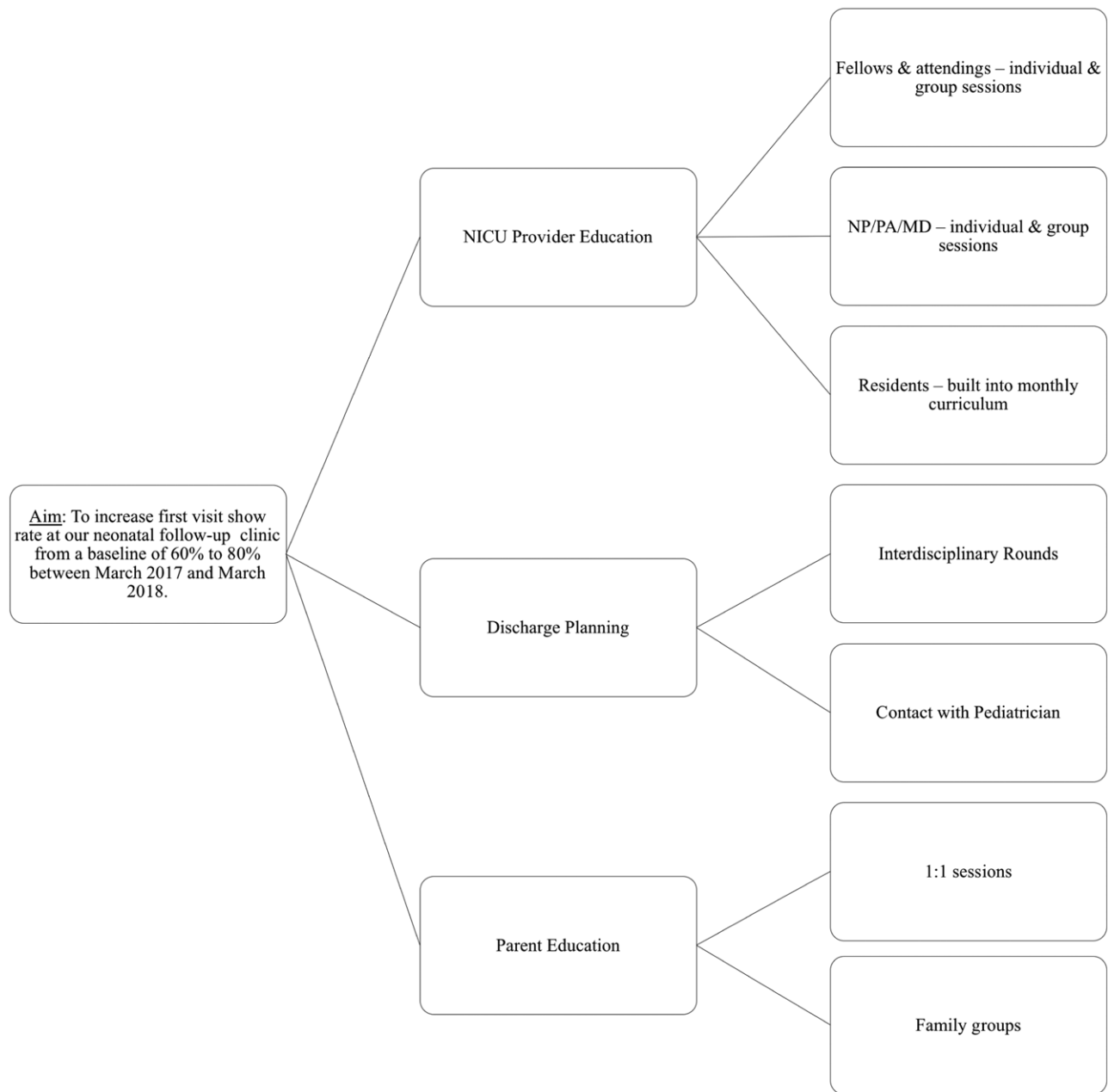


Fig. 1. Key drivers for improving NFU.

a copy of the discharge summary to give to the pediatrician. We worked with care coordinators to ensure that all qualifying infants received NFU clinic appointments before discharge. This appointment was confirmed when the discharge nurses called families to check-in 1–2 weeks post-discharge. Finally, members of the Follow-Up team attended our unit’s weekly IDR to discuss qualifying patients approaching discharge with the primary team.

Our primary outcome—monthly patient show rate at the initial visit at 6-months AA—was assessed by manual review in the electronic medical record. This review was done in 3-month segments to appropriately track patients who presented for their appointments due to the possibility of rescheduled visits. Process measures included

percentages of families receiving appointments, information packets, and parent education before discharge. We reviewed changes in clinic utilization as our balancing measure.

We maintained patient information in a coded Excel database, which included demographic information, tracked which in-hospital interventions the family received, whether the family presented for the initial visit, and notes about post-discharge contact by the clinic coordinator.

When families presented for their initial visits, we collected anonymous surveys at the end of the visit that asked them about what motivated them to come to the visit, whether they found the visit helpful, how we could

improve their experience in clinic, and whether they planned on returning for future visits (see Supplemental Digital Content 4, <http://links.lww.com/PQ9/A220>). We also contacted families scheduled for an initial 6-month AA visit but failed to present to the appointment to identify factors that may impact this population’s compliance with NFU. These were families who would be routinely contacted by our follow-up clinic coordinator to reschedule appointments.

We used statistical process control with our monthly show rates displayed on a p-chart and used the Aggregate Point Rule to justify special cause because our data were collected monthly.²¹ We compared the differences in show rates between families receiving caregiver education versus those discharged without caregiver education during the study period using χ^2 tests.

Careful analysis of barriers to NFU in our institution was essential to improving processes to ensure adequate referral to ancillary services for high-risk neonates. We received a “Not Human Subjects Research” designation from our Institutional Review Board for this project.

RESULTS

Based on our eligibility criteria during the study period, 109 patients qualified for NFU clinic appointments. Of these patients, 72 (66%) received parent education pre-discharge, and 73 (67%) patients presented to their initial appointments. The control chart (Fig. 2) displays our monthly show rate. Our mean monthly show rate before the institution of our intervention bundle was 60%. We were able to demonstrate a shift in our process between March 2017 and December 2017 using the Aggregate Point Rule because our data were collected monthly. It allowed us to show a valuable change in our

process earlier than the standard “eight-point rule” would allow.^{21,22} We calculated upper and lower control limits for our data based on these mean show rates and sample size per month. We hypothesize that we had one point near the lower control limit in June 2018 because 2 of the patients who did not present to their initial appointment had been transferred to our institution from centers that had their own follow-up programs.

Further analysis revealed that 54 patients who received parent education presented to their first NFU clinic appointment, compared to 19 patients who did not receive parent education (75% vs. 51% overall show rate, $P < 0.05$). Anonymous surveys were offered at the V1 visit so that families could indicate factors that aided or impeded their ability to come to NFU clinic appointments. Of the surveys completed ($n = 20$), 95% indicated that the bedside session played the most important role in their coming to their follow-up appointment. Furthermore, a retrospective review of our data showed that approximately one-fifth of qualifying patients in 2015 and 2016 were lost to follow-up because they were never scheduled for a clinic visit before discharge. In comparison, only 3% of patients were missed during the study period.

Our clinic coordinator made multiple attempts via phone to reach families who did not present to their initial appointment. They offered an opportunity to reschedule the visit and understand why the family did not present for the initial appointment. Unfortunately, these phone calls did not yield a high response rate because these were often the same families who did not answer their phones when our clinic coordinator contacted them to remind them of their appointment.

Clinic utilization, our balancing measure, was defined as the number of patients seen divided by the number of available appointment slots. The number of patients seen

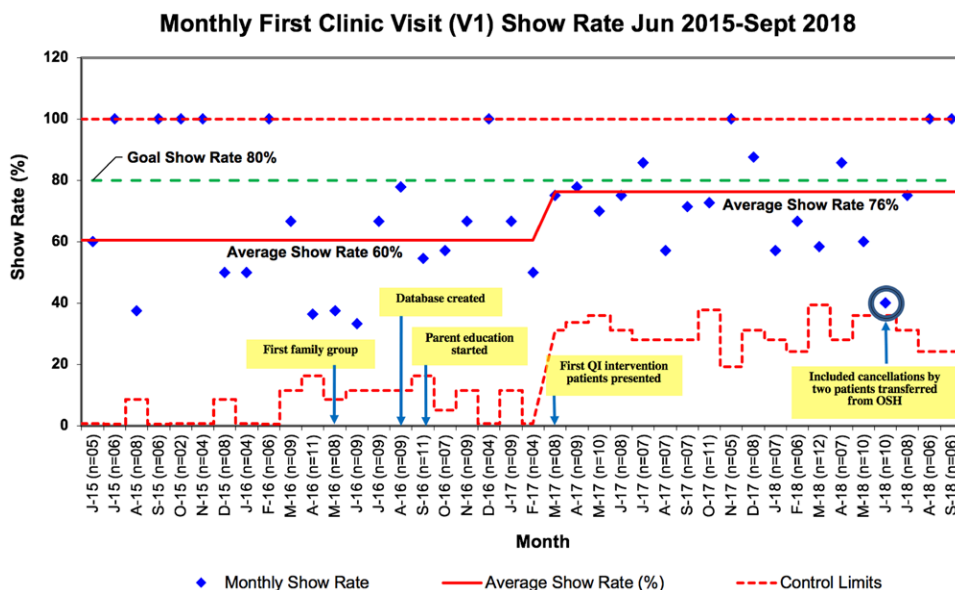


Fig. 2. Control p-chart—monthly first visit show rate before and during the study period, annotated with relevant interventions; x-axis—month, y-axis—monthly show rate (%).

increased by 10% during the study period; however, we had also increased available appointment slots by 7% due to clinic restructuring, so our effective clinic utilization increased by 2%. While we did not track other effects of increased show rates, such as longer wait times for established patients to get an appointment due to this increase in clinic utilization, we had preemptively made additional changes to our clinic structure, including increasing the number of neonatologists who see patients in the clinic, changing to a preceptor work model with attendings and fellows, and having our developmental psychologist work full time to evaluate older children who present to the clinic.

DISCUSSION

Our QI study improved the NFU clinic monthly show rate at 6 months AA through the implementation of a multilevel education bundle targeting providers and families of qualifying preterm patients from a baseline of 60% to 76%. We had a 75% overall show rate for families who received parent education, compared to 51% for families who did not receive parent education ($P < 0.05$).

Due to the long-term nature of our primary outcome, we did not see the immediate effects of our in-hospital interventions until patients presented approximately 6 months after hospital discharge for their initial NFU clinic visit. The first families received parent education in September 2016, and they presented for their initial appointments in March 2017. We collected monthly show rate data until September 2018, a period during which we showed sustained improved show rates except for June 2018 when we had a single point near the lower control limit. Presumably, this deviation was because 2 of the patients who canceled their appointments that month were transferred to our institution from centers that had established follow-up programs.

Our in-hospital interventions targeted NICU provider education, parent education, and discharge care coordination. The improved workflow also required creating a database to identify qualifying patients so that bedside education sessions and invitations to group sessions could be coordinated ahead of time. This database also decreased the number of patients lost to follow up because they did not receive a follow-up appointment before NICU discharge.

Many studies highlight barriers affecting NFU show rates,^{7–13,23} but limited studies investigate the impact of programs to improve attendance at NFU clinics. Studies investigating mothers' and healthcare providers' perspectives on barriers and facilitators to attendance at NFU programs identified family-focused interventions and a sense of partnership as positive contributors to promoting clinic attendance.^{8,9} A population-based study from the California Perinatal Quality of Care Collaborative identified maternal and sociodemographic factors, home- and

program-level disparities associated with nonattendance, and highlighted the importance of identifying barriers and providing family education during hospitalization to promote an appropriate transition to home from the NICU.^{23,24}

No published studies have assessed the impact of in-hospital education on improving clinic show rates. We believe that our QI study highlights the importance of implementing an in-hospital parent education program and the need for personnel and a workflow model to sustain this practice.

Our results support a need for personnel focused on bedside education so that families are aware of the critical need for long-term follow-up by dedicated specialists. Individual NFU program and NICU culture and workflow will determine whether dedicated NFU staff or NICU front line clinical staff with protected time can accomplish this role.

Figure 3 displays a value-stream map for our current workflow and barriers to implementation with proposed solutions. Our next steps involve creating a model for parent education that more directly involves front-line inpatient providers. We continue to identify families eligible for parent education and have a consistent presence of NFU clinic providers at the weekly IDR. Front-line providers will be provided NFU clinic information packets and letters to the pediatrician to distribute to these families. We believe that inpatient providers will be more likely to coordinate meeting the families because of their front-line presence. One strategy may involve standardizing a family meeting with the primary NICU team when an infant reaches 33–34 weeks of gestation to discuss general post-discharge needs. We also believe that this will alleviate the clinic providers' daily workflow so that they do not have to coordinate, leaving the clinic to come to the inpatient unit to meet with families. Finally, we have transitioned to Research Electronic Data Capture, a secure, web-based software platform designed to support data capture for clinical/operational use and research studies through integration with our inpatient electronic medical record to more easily identify patients who qualify for follow up at our NFU clinic.^{25,26}

As with all QI projects, many components may affect our primary outcome beyond our tested interventions, especially given the long-term nature of when we were able to study our primary outcome, many months after our inpatient intervention. Our value-stream map also identifies many areas for ongoing improvement in our described process. However, given that we observed a sustained increase in show rates after implementation of in-hospital interventions, and that we had a statistically significant difference between show rates for families who did and did not receive inpatient education during our study period, we believe that this particular intervention was a major contributing factor for the improvement in clinic attendance.

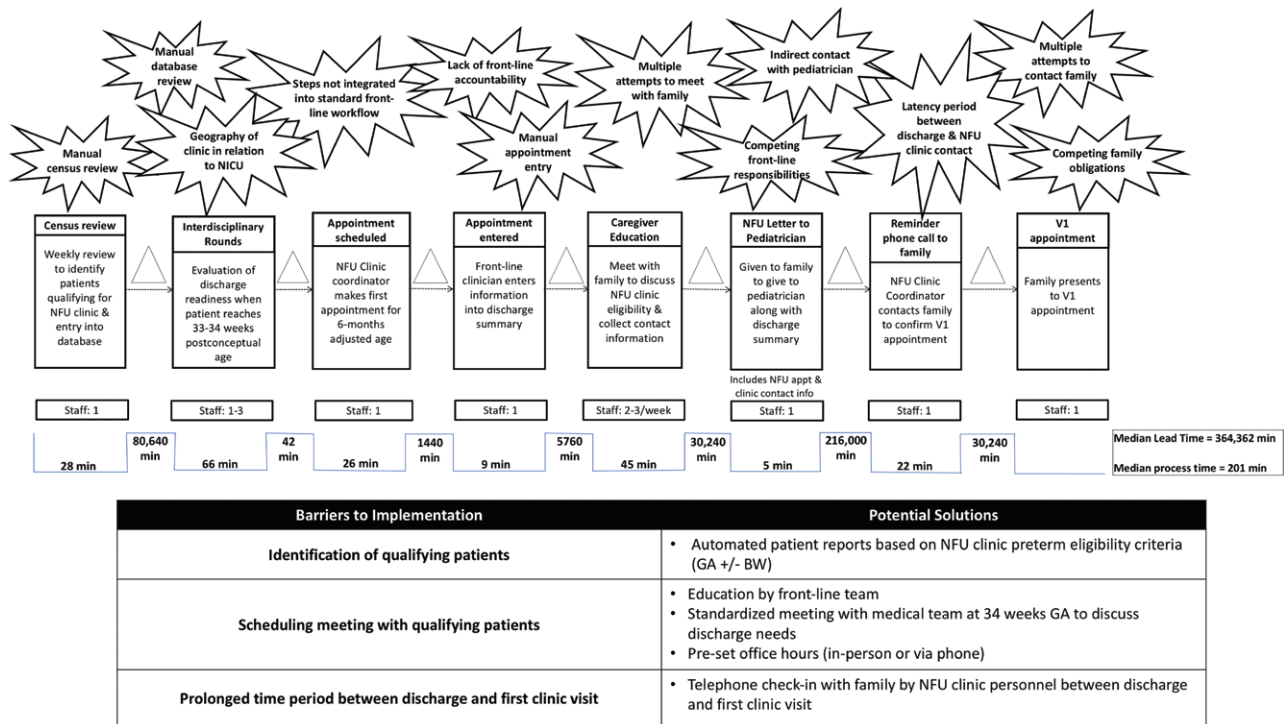


Fig. 3. Value-stream map for follow up of qualifying preterm infants and table with barriers to implementation and proposed solutions.

CONCLUDING SUMMARY

NFU clinics provide an invaluable service to high-risk neonates. They offer providers an opportunity to learn about the long term medical and developmental needs of the high-risk neonate. Participation in NFU clinics is also a requirement of neonatal-perinatal medicine fellowship training. Despite the inherent value of NFU clinics, many clinical programs report poor compliance with follow-up visits.⁶⁻¹² Poor access leads to less access to required ancillary services and underreporting of the developmental outcomes of high-risk infants.¹³⁻¹⁸ Our study highlights the impact of strategies implemented earlier during an infant’s stay in the NICU to provide an optimal transition to outpatient follow up of these children.

Our QI study increased the monthly show rate for the initial visit at 6 months AA for qualifying preterm patients from a baseline of 60% to 76% through implementing a multilevel in-hospital education bundle. Further analysis revealed that 75% of families who received education presented to this initial visit, compared to 51% of families who did not receive education ($P < 0.05$). Therefore, we believe that an inpatient model for education can improve outpatient clinic attendance. In the future, we will be working to develop a model to sustain consistent parent education and collect patient data from streamlining inpatient and outpatient practices to provide optimum patient care for this high-risk population.

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DISCLOSURE

The authors have no financial interest to declare in relation to the content of this article.

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