Potentially Better Practices for Follow Through in Neonatal Intensive Care Units

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abstract

OBJECTIVE: To ascertain how NICU teams are undertaking action to follow through, involving teams, families, and communities as partners to address health-related social needs of infants and families.

METHODS: Nineteen potentially better practices (PBPs) for follow through first published in 2020 were reported and analyzed as a sum, overall, and by safety-net hospital status, hospital ownership, and NICU type, among US NICUs that finalized Vermont Oxford Network data collection in 2023.

RESULTS: One hundred percent of 758 eligible hospitals completed the annual membership survey, of which 57.5% reported screening for social risks. Almost all NICUs offered social work, lactation support, and translation services, but only 16% included a lawyer or paralegal on the team. Overall, 90.2% helped families offset financial costs while their infants were in the hospital, either with direct services or vouchers. At discharge, 94.0% of NICUs connected families with appropriate community organizations and services, 52.9% provided telemedicine after discharge, and 11.7% conducted home visits. The median number of PBPs at each hospital was 10 (25th percentile: 8, 75th percentile: 12). The number of PBPs reported differed by hospital control or ownership and level of NICU care. There were no differences by safety-net hospital status.

CONCLUSIONS: Despite concerns about time and resources, a diverse set of US NICUs reported adopting potentially better practices for follow through. However, the marked variation among NICUs and the lower rates at for-profit and lower-level NICUs suggest there is substantial opportunity for improvement.

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WHAT'S KNOWN ON THIS SUBJECT: NICU teams are reporting efforts to improve follow through and achieve health equity, but the extent to which potentially better practices for follow through have permeated units throughout the United States is unknown.

WHAT THIS STUDY ADDS: A diverse set of US neonatal intensive care units report addressing follow through with potentially better practices while infants are hospitalized. Follow through after the hospital is an area for improvement.

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In America, race, ethnicity, income, immigration status, and neighborhood of residence play a large role in shaping a person's health and well-being.[1,2] These effects are pronounced for infants requiring neonatal intensive care because of long-term morbidities, increased risk for neurodevelopmental disabilities, and need for specialized services.[3,4] Disparities by race and ethnicity exist both during[5–8] and after[9–11] infants' initial birth hospitalizations.

In 2020, Vermont Oxford Network (VON) introduced the concept of follow through, a comprehensive approach that begins before birth and continues into childhood involving health professionals, families, and communities as partners to address the social and medical needs of infants and families and improve health equity.[12] We call it "follow through" to distinguish it from the more typical practice of "follow-up," which is focused on medical and neurodevelopmental outcomes after discharge. Instead, follow through addresses families' health-related social needs during and after the hospital stay, as well as equity and social justice, to ensure that every newborn and family achieves their fullest potential.

With the introduction of follow through, VON offered a list of potentially better practices (PBPs) for follow through in 6 domains: promote a culture of equity; identify social risks of families and provide interventions to prevent and mitigate those risks; take action to assist families after discharge during the transition to home; maintain support for families through infancy; develop robust quality improvement efforts to ensure equitable, high-quality hospital and follow-through care; and advocate for social justice. These improvement ideas are "potentially better" instead of "better" or "best" practices because it is not known whether a practice is better or best until it is adapted, tested, and shown to work in the local context.

To measure follow through, the 2023 VON annual membership survey completed by NICU teams included 19 items measuring various PBPs, recognizing that some centers may have had these practices in place before 2020. We evaluated the PBPs individually and as a sum, by safety-net hospital status, hospital control or ownership, and NICU type.

METHODS

VON is a voluntary worldwide community of practice dedicated to improving the quality, safety, and value of newborn care through a coordinated program of data-driven quality improvement, education, and research.[13] VON members complete a membership survey annually. US hospitals that finalized infant data collection in 2023 and completed the annual membership survey were eligible for this study.

We summed the number of the following PBPs implemented by each hospital: screen all families for social risk; include a social worker on the team; include a paralegal on the team; provide mental health services for families during the hospital stay; provide housing, meals, and transportation for families; provide housing, meals, and transportation vouchers for families; provide sibling care; practice family-integrated care tailored to the capabilities and needs of families; provide language support and culturally appropriate translation services for families; provide discharge education and planning tailored to each family's needs; connect families with appropriate community organizations and services; provide high-risk infant follow-up; facilitate parent support groups and peer counseling that extend beyond the stay; conduct home visits before discharge and at intervals after discharge; provide telehealth support after discharge; establish a reach out and read program for patients and siblings; launch a fruit and vegetable prescription program; establish measurable improvement aims related to social determinants of health; develop strategies to support quality improvement (QI) participation by parents; and provide salary support for family advisors. The possible sum ranged from 0 to 19.

We analyzed the PBP sum by whether the hospital was a safety-net provider, by hospital control or ownership, and by NICU type. A safety-net hospital was defined as a 1 in the upper quartile of the distribution of uncompensated and unreimbursed care as a share of total operating expense based on the 2019 Centers for Medicare and Medicaid Services Healthcare Cost Report Information System data.[14] Hospital control or ownership came from the 2021 American Hospital Association Annual Survey Database[15] and was defined as government, nonprofit, and for-profit. NICU type definitions were derived from responses to the VON membership survey. Type A NICUs are required to transfer infants who need assisted ventilation. Type B1 centers do not perform the following surgeries: omphalocoele repair; ventriculo-peritoneal shunt; tracheoesophageal fistula or esophageal atresia repair; bowel resection or renanastomosis; meningomyelocele repair; cardiac catheterization; patent ductus arteriosus ligation; cardiac surgery requiring bypass. Type B2 centers perform at least 1 of the listed surgeries except cardiac surgery requiring bypass. Type C centers perform cardiac surgery requiring bypass. Type A centers are similar to the American Academy of Pediatrics level II classification,[16] type B1 and B2 centers are similar to level III, and type C centers are similar to level IV. We tested statistical differences in medians by safety-net providers using the Wilcoxon rank sum test and between hospital ownership and NICU types using Friedman's test.

RESULTS

Of the 758 eligible hospitals, 100% completed the survey, of which 98 (12.9%) were Type A, 315 (41.6%) were Type B1, 244 (32.2%) were Type B2, and 101 (13.3%) were Type C. Information on uncompensated care was available for 736 hospitals, of which 129 (17.7%) were safety-net providers. Overall, 94 (12.4%) were government controlled,

563 (74.3%) had nonprofit ownership, and 101 (13.3%) had for-profit ownership; 9.2% of the hospitals were free-standing children's hospitals and 50.3% were teaching hospitals; 14.9% were in the northeast, 20.3% were in the Midwest, 36.9% were in the south, and 27.9% were in the west.

In the domain "Identify social risks of families and provide interventions to prevent and mitigate those risks" (Table 1), 57.5% of NICUs reported screening for social risks and social support. Almost all NICUs offered social work support, whereas 16% of NICUs reported including a paralegal or attorney on the team. Ninety percent of NICUs offered financial support for families while their infants are receiving care; two-thirds of NICUs reported offering meals, transportation, or parking support for families, either directly or through vouchers, whereas 39.1% offered housing, and 17.4% reported having an on-site food pantry. Nearly all NICUs offered lactation support, language support, and culturally appropriate translation services for families. In the area of family-centered care, 89.7% of NICUs had a written policy or guideline that supports the bedside presence of family members at all times of day and 86.9% had proactive care conferences with families and multidisciplinary teams, whereas 32.1% of NICUs reported having a formal family advisory council. NICUs were less likely to report assigning a primary physician or advanced practice provider, or primary nurse or nursing care team, within the first week after admission.

In the domains "Take action to assist families after discharge during the transition to home" and "Maintain support for families through infancy" (Table 2), 94.0% of NICUs reported connecting families with appropriate community organizations and services, 84.1% have a follow-up clinic that they routinely refer infants for neurodevelopmental evaluation after hospital discharge, and 76.6% provide discharge summaries as part of discharge education and planning tailored to each family's needs. Overall, 52.9% of NICUs reported providing telehealth support after discharge, whereas 11.7% reported conducting home visits and 38.0% of NICUs offered parent

TABLE 1 NICUs Reporting Services That Correspond With Potentially Better Practices for Follow Through in the Domain "Identify Social Risks of Families and Provide Interventions to Prevent and Mitigate Those Risks"

	N	*No.*	*%*
Screen all families for social risks and social support using a standardized tool	700	403	57.6
Of those that did screening:			
Housing screening	392	388	99.0
Food insecurity screening	393	377	95.9
Transportation needs screening	393	392	99.7
Utility needs screening	392	352	89.8
Interpersonal safety screening	391	381	97.4
Results are recorded in medical record	395	384	97.2
Include a social worker or other social health professional on the team	723	709	98.1
Include a paralegal or attorney on the team	689	110	16.0
Provide mental health services for families during the hospital stay	711	333	46.8
Adult psychologist	715	337	47.1
Child psychologist	715	249	34.8
Provide housing, meals, and transportation for families directly or with vouchers			
At least 1 of the following:	714	644	90.2
Housing	701	275	39.2
Meals	706	465	65.9
Transportation	703	470	66.9
Parking	699	458	65.5
On-site food pantry	697	121	17.4
Provide sibling care	700	46	6.6
Practice family-integrated care tailored to the capabilities and needs of families			
At least 1 of the following:	751	731	97.3
Written policy or guideline that supports the bedside presence of family members at all hours of the day	707	634	89.7
Assign a primary physician or advanced practice provider within first week after admission	698	228	32.7
Assign a primary nurse or nursing team within first week after admission	693	180	26.0
Proactive care conferences with families and multidisciplinary teams	711	618	86.9
Families have access to the medical record while infants are in the hospital	708	558	78.8
Formal NICU family advisory council	739	237	32.1
Provide lactation support using peer counselors and other approaches	722	695	96.3
Provide language support and culturally appropriate translation services for families	707	692	97.9

TABLE 2 NICUs Reporting Services That Correspond With Potentially Better Practices for Follow Through in the Domains "Take Action to Assist Families After Discharge During the Transition To Home" and "Maintain Support for Families Through Infancy"			
	N	*No.*	*%*
Provide discharge education and planning tailored to each family's needs	706	540	76.5
Connect families with appropriate community organizations and services	703	661	94.0
Provide high-risk infant follow-up	729	613	84.1
Facilitate parent support groups and peer counseling that extend beyond the stay	697	265	38.0
Conduct home visits before discharge and at intervals after discharge	683	80	11.7
Provide telehealth support after discharge	688	364	52.9
Establish a reach out and read program for patients and siblings	699	299	42.8
Launch a fruit and vegetable prescription program	693	83	12.0

support groups and peer counseling that extend beyond the NICU stay.

In the domain "Develop robust quality improvement efforts to ensure equitable, high-quality hospital and follow-through care" (Table 3), 54.1% of NICUs reported establishing measurable improvement aims related to social determinants of health, whereas 34.7% reported including families in quality improvement and 10% reported having a paid family advisor.

The median number of PBPs at each hospital was 10 (25th percentile: 8; 75th percentile: 12; Fig 1). There was no difference in the median number of PBPs by whether the hospital was a safety-net provider (Supplemental Fig 2; $P < .53$). The median number of PBPs was 11 (9–13) at government hospitals, 10 (8–12) at nonprofit hospitals and 9 (7–11) at for-profit hospitals (Supplemental Fig 3; $P < .0001$). The median was 9 (7–10) at Type A hospitals, 9 (7–11) at Type B1 hospitals, 10 (9–12) at Type B2 hospitals, and 13 (10–15) at Type C hospitals (Supplemental Fig 4; $P < .0001$). Tables of individual PBPs by safety-net provider status, hospital ownership, and NICU type are in Supplemental Tables 4 through 6.

DISCUSSION

A diverse set of NICUs in the United States report working to meet the social needs of infants and families by enacting PBPs for follow through. Half of NICUs had 10 or more programs or services that addressed PBPs, but there was marked variation overall, with some NICUs enacting none of the PBPs, as well as by NICU type and hospital control or ownership.

We hear 2 concerns from NICU teams about follow through. The first is lack of time. However, 57.5% of NICUs reported screening for social risks, the first step in follow through. In a randomly selected set of hospitals surveyed in 2021, only 23% of NICUs reported screening.[17] It is hard to explain the difference between the proportion reported on our survey compared with previous findings, although the Center for Medicaid and Medicare Services mandate to screen all adult inpatients starting in 2024[18] could have sparked an uptake across all hospital units, including NICUs.

Cordova-Ramos and colleagues at Boston Medical Center used a quality improvement framework to implement screening and referral.[19] They trained nurse champions, residents, and bedside nurses to do the screening and co-designed a new services referral guide with families. They also created relationships with community organizations so that families could contact a specific person for assistance. This work resulted in 49% of families screened, with 98% receiving referrals and 52% connecting with community resources. Travia and colleagues also used a quality improvement framework to implement screening for food insecurity, achieving a 95% screening rate over 9 months, with nearly 7% screening positive and 91% referred. At that institution, social workers screened families; screening added less than 5 minutes to the interview time and compiling resources took 15 to 30 minutes.[20] Families that screen positive for food insecurity can be helped during the hospital stay with an on-site food pantry[21] or a food prescription program[22] but only 17.4% and 12.0% of NICUs, respectively, reported having these programs.

Fewer NICUs reported taking steps to follow through after discharge. NICU teams may feel that they have less

TABLE 3 NICUs Reporting Services That Correspond With Potentially Better Practices for Follow Through in the Domains "Develop Robust Quality Improvement Efforts to Ensure Equitable, High-Quality Hospital and Follow-through Care"			
	N	*No.*	*%*
Establish measurable improvement aims related to social determinants of health	689	374	54.3
Develop strategies to support QI participation by parents	739	256	34.6
Provide salary support for family advisors	700	70	10.0

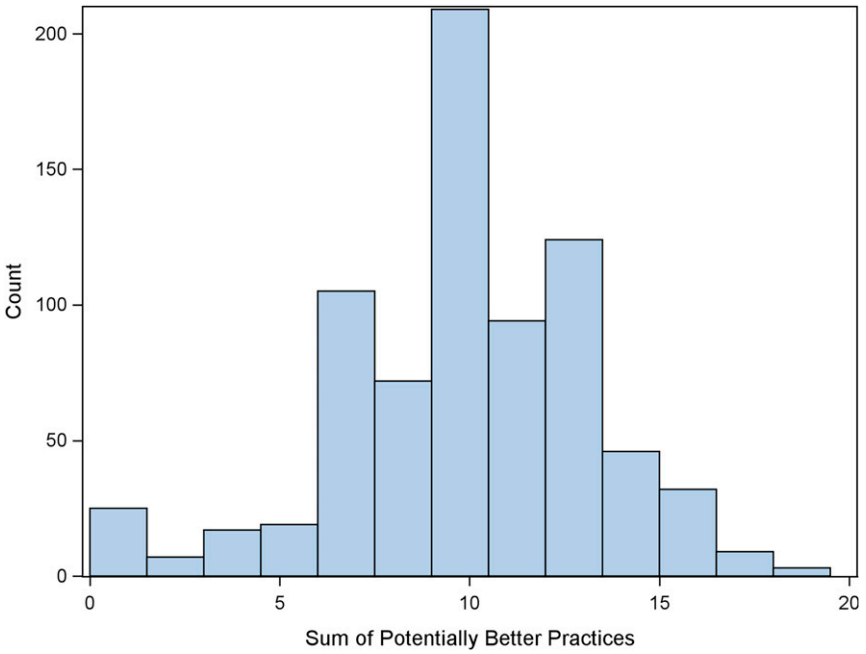

FIGURE 1
Count distribution of hospitals by the number of PBPs enacted.

control over what happens when infants leave the hospital and fewer resources to address emergent issues at home. Teams should partner with primary care and other providers, as well as community partners, to implement the PBPs related to discharge. Creating teams that specialize in postdischarge care may improve follow through after discharge.[23] NICU teams should also ensure discharge to a medical home, which provides family-centered primary care with providers who manage and facilitate all aspects of pediatric care.[24] Medical-legal partnerships can help address substandard housing, eviction threats, benefit denial, and ultimately may lower hospitalization rates.[25,26] Just 16% of NICUs reported having medical-legal partnerships, a clear opportunity for growth. Doernbecher Children's Hospital at Oregon Health and Science University developed a NICU-specific medical-legal partnership staffed by Oregon Health Justice center and contracted through the Medical Legal Partnership of Oregon.[27] The team handles civil legal needs identified through standardized screening; approximately 60% of families have more than 1 need. Center for Medicaid and Medicare Services also released guidance on how states can use Medicaid and the Children's Health Insurance Program to fund health-related social needs in a wide range of domains, including adapting the home environment, caregiver respite, home remediations, and nutrition including fruit and vegetable prescription programs,[28] all of which could aid the transition to home.

The second concern is lack of resources, particularly financial. In our survey, NICUs in government and nonprofit hospitals reported enacting more PBPs than NICUs in for-profit hospitals, and higher-level NICUs enacted more PBPs than lower-level NICUs, but there was no difference for safety-net hospitals. With infants' high risks and long lengths of stay[29] offering many opportunities for intervention, NICU teams at all types of hospitals and all levels of care must work with their senior leaders and accept that follow through is our shared responsibility. Hospitals and health systems are investing in programs to address social determinants of health like education, employment, food security, social and community context, and transportation.[30,31] However, there is building evidence, from a nationally representative survey of hospitals and health systems[32] as well as from the American Hospital Association annual survey[31] and our findings, that for-profit hospitals are less likely to invest in addressing health-related social needs.

Some have raised concerns that investments in health-related social needs divert resources to programs with little opportunity for success.[33] As hospitals and health care systems focus on population health, addressing social determinants of health may be in a hospital's best interest if doing so reduces high-cost readmissions and saves money in the long run. Infants born preterm are at higher risk for readmission than infants born at term,[34] and preterm infants born to mothers with health-related social risks have higher readmission rates than those born to mothers without health-related social risks.[35] Neonatal teams are well placed to address social determinants of health with screening and

referral to needed services, medical-legal partnerships to address civic issues, discharge preparation and planning, and strong community partnerships. NICUs can also lead by example in their hospitals by encouraging a culture of equity, fostering antiracism with training to address implicit bias.[36] Still, empirical evidence on investments in addressing health-related social needs and long-term outcomes for infants, families, and hospitals is needed.

Many NICUs are reporting services supporting family-centered care. The majority of NICUs offer help with housing, meals, transportation, or parking during the NICU stay, have policies that support the bedside presence of family members at all hours of the day, and have proactive care conferences with families and multidisciplinary teams during the stay. However, fewer NICUs conduct home visits or provide parent support groups and peer counseling that extend beyond the NICU stay. Helping families when they leave the NICU is an important part of the follow-through process, but it means that NICUs must accept that responsibility for infants and families extends beyond the hospital walls. Giving families a voice in the NICU in the form of a family advisory council, involvement in quality improvement, and paid family advisors is an important aspect of family-centered care. Unfortunately, only around 35% of NICUs reported having a family advisory council or family involvement in quality improvement, and only 10% had paid family advisors.

We observed that improvements in survival and major acute complications of NICU care have slowed, stalled, or reversed in recent years and suggest a 3-part strategy of research, quality improvement, and follow through to regain the progress of previous years.[37] Although many units have adopted potentially better practices for follow through, substantial opportunities for improvement remain. Despite progress toward follow through, there was marked variation overall, between certain groups (hospital control, NICU type), and within those subgroups. Opportunities to improve follow through can be developed using a quality improvement framework. Indeed, the PBPs are called "potentially better" because it is not known if the practice is "best" until it is tested and refined by applying the Model for Improvement or a similar quality improvement methodology. As teams adopt follow-through PBPs, we expect to see less variation.

This study does have limitations. Although these results represent responses from a diverse set of NICUs in the United States, respondents include Vermont Oxford Network members only and, therefore, the results are not generalizable to all NICUs in the United States. These data are self-reported and were not verified by VON and are open to positive response bias as well as potential misinterpretation. We were unable to measure how the PBPs were implemented; PBP adoption does not reflect that the practice has been adopted with fidelity or that coverage of a PBP reaches 100% of patients. Among centers with positive responses to PBP implementation, there are still opportunities for improvement to reach and serve all families.

CONCLUSIONS

Despite concerns about time and resources, a diverse set of US NICUs reported adopting potentially better practices for follow through. However, the marked variation among NICUs and the lower rates at for-profit and lower-level NICUs suggest there is substantial opportunity for improvement in following through for the infants and families that we serve.

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ABBREVIATIONS

PBP: potentially better practice
VON: Vermont Oxford Network

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