Factors Associated with Successful First High-Risk Infant Clinic Visit for Very Low Birth Weight Infants in California

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Objectives To determine rates of at least 1 high-risk infant follow-up (HRIF) visit by 12 months corrected age, and factors associated with successful first visit among very low birth weight (VLBW) infants in a statewide population-based setting.

Study design We used the linked California Perinatal Quality of Care Collaborative and California Perinatal Quality of Care Collaborative–California Children's Services HRIF databases. Multivariable logistic regression examined independent associations of maternal, sociodemographic, neonatal clinical, and HRIF program factors with a successful first HRIF visit among VLBW infants born in 2010-2011.

Results Among 6512 VLBW children referred to HRIF, 4938 (76%) attended a first visit. Higher odds for first HRIF visit attendance was associated with older maternal age (OR, 1.48; 95% CI, 1.27-1.72; 30-39 vs 20-29 years), lower birth weight (OR, 2.11; 95% CI, 1.69-2.65; ≤750 g vs 1251-1499 g), private insurance (OR, 1.65; 95% CI, 1.19-2.31), a history of severe intracranial hemorrhage (OR, 1.61; 95% CI, 1.12-2.30), 2 parents as primary caregivers (OR, 1.18, 95% CI 1.03-1.36), and higher HRIF program volume (OR, 2.62; 95% CI, 1.88-3.66; second vs lowest quartile); and lower odds with maternal race African American or black (OR, 0.65; 95% CI, 0.54-0.78), and greater distance to HRIF program (OR, 0.69; 95% CI, 0.57-0.83). Rates varied substantially across HRIF programs, which remained after risk adjustment.

Conclusions In a population-based California VLBW cohort, maternal, sociodemographic, and home- and program-level disparities were associated with HRIF non-attendance. These findings underscore the need to identify challenges in access and resource risk factors during hospitalization in the neonatal intensive care unit, provide enhanced education about the benefits of HRIF, and create comprehensive neonatal intensive care unit-to-home transition approaches. *(J Pediatr 2019;210:91-8)*.

Survival and short-term outcomes have dramatically improved for preterm and very low birth weight (VLBW; <1500 g) infants, but they remain at high risk for neurodevelopmental, behavioral, and medical sequelae.[1,2] The American Academy of Pediatrics Committee on Fetus and Newborn and other expert groups have emphasized the critical need to integrate high-risk infant follow-up (HRIF) into the neonatal intensive care unit (NICU) discharge plan.[3,4] HRIF programs provide a range of multidisciplinary evaluations and ensure early identification and referral to appropriate community supports and therapies, including early intervention.[5,6] Participation in HRIF may improve outcomes for children born preterm and high risk through the facilitation of preventive and early developmental intervention programs.[7-9]

However, even the first step of initial referral to HRIF at NICU discharge is not ensured.[10] Furthermore, among those referred, studies have demonstrated variable compliance with scheduled HRIF visits, programmatic barriers, and family challenges to HRIF attendance.[11-14] In addition, those lost or followed with great difficulty are more likely to have severe disability, cognitive impairment, or adverse sensorineural outcomes.[15,16] Therefore, in addition to potential bias introduced to outcomes studies owing to non-random losses, the children who may benefit from multidisciplinary support and programs available through attendance at HRIF visits may be missing crucial opportunities.

Identification of factors associated with loss to HRIF would help to recognize and address potential barriers to quality follow-up care, and to develop interventions to improve access and attendance. The California Perinatal Quality of Care Collaborative (CPQCC), which maintains a population-based dataset of perinatal variables and short-term outcomes for infants discharged from NICUs in California, partnered

BW	Birth weight
CCS	California Children's Services
CPQCC	California Perinatal Quality of Care Collaborative
HRIF	High-risk infant follow-up
NICU	Neonatal intensive care unit
VLBW	Very low birth weight

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with California Children's Services (CCS) to create the CPQCC-CCS HRIF Quality of Care Initiative. These large, linked CPQCC and HRIF databases allow for a deep understanding of the challenges and successes across the continuum of care in a diverse California cohort of VLBW infants. Our objectives for this study were to determine follow-up rates to at least 1 HRIF visit by 12 months corrected age, and identify factors associated with attendance among VLBW infants born in 2010 and 2011.

Methods

We analyzed prospectively collected data of VLBW infants in the CPQCC born in 2010 and 2011 and referred to CPQCC-CCS HRIF at NICU discharge. The CPQCC collects data for neonates born at member hospitals throughout California. During the study period, >95% of California's VLBW infants were cared for in the 127 CPQCC hospitals. The CCS partnered with CPQCC to restructure the existing statewide NICU Follow-Up program, creating a completely web-based reporting system to collect data for the CPQCC-CCS HRIF Program, which was launched in 2009. During the study period, there were 64 CPQCC-CCS HRIF programs in California. All VLBW infants, regardless of gestational age, are eligible for HRIF. The CPQCC-CCS HRIF provides a series of standard visits at recommended ages of 4-8 months, 12-16 months (corrected for gestational age), and 18-36 months. Additional HRIF visits as necessary are supported by the CCS. Owing to the longitudinal nature of this dataset, final data closure for the HRIF data did not occur during the study period until approximately 8 months after the third birthday of the final child enrolled in the given birth year. Annual statewide training sessions for both the CPQCC and the CPQCC-CCS HRIF personnel promote accuracy and uniformity in data reporting and abstraction.

The CCS program standards require that each CCS-approved NICU ensure the follow-up of infants discharged from the NICU who are at high risk for neurodevelopmental delay or disability. The CCS mandates that all CCS-approved NICUs are a part of the CPQCC and responsible for identifying and referring eligible infants to CPQCC-CCS HRIF, which is completed through a web-based system. The individual HRIF clinics are CCS Special Care Centers with required team members to perform diagnostic services, including neurologic and developmental assessments. More than 1 NICU may refer to 1 HRIF clinic, including interconnected NICUs under the same health care systems or managed by the same institution. The CPQCC and the CPQCC-CCS HRIF Reporting System Databases operate independently, and the databases were linked for this analysis. The linkage process matches cases on the CPQCC NICU Record ID number, then by a matching algorithm based on patient and maternal data.

Success to ≥1 HRIF visit was defined as having completed ≥1 standard or additional visit by 12 months of age, corrected for prematurity (corrected age). We evaluated factors potentially associated with successful completion of the first HRIF visit for VLBW infants. Maternal, sociodemographic, neonatal clinical, HRIF program-related, and California regional data were obtained through linked CPQCC and HRIF records.[17,18] Prenatal care was defined categorically. Maternal age was grouped as <20 years, 20-29 years, 30-39 years, and ≥40 years. Maternal race and ethnicity was categorized according to CCS guidelines (black or African American, Hispanic, white, Asian/Pacific Islander, Native American, or other). Other factors included neonatal morbidities that may have contributed to severity of illness, as defined in a previous publication.[10,19] NICU level of care was based on CCS guidelines, which classify NICUs into 3 levels—regional, community, and intermediate NICUs—according to the services provided at each center, with designations based on the American Academy of Pediatrics' definitions in place during the study period.[20] The annual HRIF program volume was based on the average number of VLBW children seen for birth years 2010 and 2011 in each HRIF clinic, grouped according to quartile of annual VLBW visit volume. Information regarding insurance, primary language spoken at the home, primary caregiver(s), education of caregiver, and distance of child residence to the HRIF program were collected from the CPQCC-CCS HRIF Referral/Registration form. Options for insurance coverage could have multiple responses, including private insurance such as a health maintenance organization or preferred provider organization, MediCal (California's Medicaid program), and CCS. Medical eligibility for the statewide CCS HRIF program includes all VLBW infants or infants born <32 weeks of gestation who are discharged from a CCS-approved NICU. There is no financial eligibility requirement for inclusion in the CCS HRIF program. Therefore, all infants considered in this analysis were eligible for HRIF. To capture reasons for visit non-attendance, the staff at the HRIF clinics were expected to complete a web-based form ("Client not seen" form) for cases in which children were scheduled but did not show for a visit, or if children were referred to HRIF but staff were unable to contact the family to establish an initial visit.

The rates of success to first visit by HRIF program were calculated by dividing the number of children returning for ≥1 HRIF visit by 12 months of corrected age by the number of children expected. A multivariable logistic regression model was then constructed to identify factors independently associated with successful first HRIF visit using backward selection with an exit criterion of a P value of > .15, which included variables prospectively identified as relevant, and factors determined to be significant in unadjusted analyses. Because birth weight (BW) and gestational age are highly correlated, the final model included BW only. Small for gestational age was included in the model. For unadjusted analyses, categorical variables were analyzed by a χ^2 test, and continuous variables by the Student t test. Additional potential correlations were explored through Pearson or Spearman correlations. Risk-adjusted ORs were obtained and expected and risk-adjusted referral rates were computed. Statistical analyses were computed using SAS 9.4 (SAS, Cary,

North Carolina). This study was approved by the Stanford University Institutional Review Board.

Results

During birth years 2010-2011, 8070 VLBW infants survived to discharge home from CPQCC NICUs. A referral to the CPQCC-CCS HRIF was received for 6512 (81% of survivors to discharge). At least 1 HRIF visit was completed by 12 months corrected age by 4938 (61% of survivors to discharge, and 76% of those referred; 2369 of 3143 for birth year 2010 and 2569 of 3369 for birth year 2011). The majority of first HRIF visits occurred during the recommended range of 4-8 months corrected age (n = 4079 [83%]). Among the 1574 children who did not attend a first HRIF visit by 12 months corrected age, a client not seen form was not filed for 82 (5%). Of those with a form and a reason for non-attendance recorded, the majority were documented as "no show/reason unknown" or "lost" (33%), and "unable to contact" (27%). Other reasons recorded included family moved or referred to another program (13%), parent refusal (6%), and insurance authorization concerns (7%).

Maternal, sociodemographic, neonatal clinical, and HRIF program-related factors among children born VLBW with successful HRIF first visit by 12 months corrected age and those lost to follow-up are shown in **Table I**. In unadjusted analyses, higher gestational age and BW were associated with decreased rates of a successful first HRIF visit ($P < .0001$; **Figure 1** [available at www.jpeds.com]). Attendance at the first HRIF visit varied across many factors (**Table I**). On unadjusted analyses, the rates of a successful HRIF visit differed significantly by maternal age and race factors, as well as primary caregiver characteristics. The evaluation of neonatal clinical factors and characteristics did not uniformly demonstrate differences in rates of successful follow-up, although there were overall low rates of many of the NICU-based morbidities. Of note, for caregiver education, data were available for only 3946 of 6512 referred children (60%). The rates of a successful first visit also varied significantly on unadjusted analyses by HRIF program factors, including lower rates of attendance among lower volume HRIF clinics, and for those children and families at greater distance from the HRIF clinic.

The results of multivariable logistic regression analysis are reported in **Table II**, showing factors independently associated with the outcome of successful first HRIF visit by 12 months of corrected age. Compared with children born to women 20-29 years of age, those born to women 30-39 years of age at the time of delivery had higher odds for successful first HRIF visit, as did those whose mothers had prenatal care. Maternal African American race was associated with significantly lower odds for successful HRIF visit, whereas primary Spanish language was associated with significantly higher odds. Compared with those reporting only CCS or MediCal as health insurance support, a health maintenance organization or a preferred provider organization with CCS was associated with significantly higher odds for a successful first HRIF visit, whereas those with other insurance, including self-pay, was associated with lower odds. Those identifying 2 parents as primary caregivers had higher odds for successful first HRIF visit compared with 1 parent. Very few neonatal clinical characteristics and severity of illness factors were independently associated with successful first HRIF visit in multivariable regression analysis after adjustment for confounders. Infants with BW of <1250 g and those with severe intracranial hemorrhage had higher odds of a successful first HRIF visit. HRIF program-level factors were also associated with successful first HRIF visit. HRIF clinic volume was independently associated with attendance at HRIF visit, with those in second quartile and third quartile volume programs associated with 2.6-fold and 1.5-fold greater odds, respectively, for successful follow-up compared with the lowest volume programs. The distance from the HRIF also impacted success, with those in the highest mileage quartiles associated with significantly lower odds for a first HRIF visit.

Using the logistic regression model, observed and risk-adjusted rates of successful first HRIF visit were calculated for the 54 HRIF programs with at least 20 VLBW children annually (**Figure 2**). Of these programs, 7 had observed successful first HRIF visit rates of >95%, whereas 17 had rates of <75%. There was variability in observed successful first HRIF visit rates, ranging from 54.7% to 97.9%, which remained after risk adjustment.

Discussion

In a large, population-based California cohort of VLBW infants born in 2010-2011, using linked statewide NICU and HRIF data, we found that just 76% of those referred to HRIF at NICU discharge had at least 1 HRIF visit before 12 months corrected age. We found that maternal, sociodemographic, home, and HRIF program-level disparities and factors were associated with attendance at first HRIF visit, whereas neonatal clinical characteristics and morbidities were not independently associated with this outcome, with the exception of a lower BW and severe intracranial hemorrhage. These findings present opportunities for improving education about the benefits of HRIF, identifying resource and access challenges that families may be facing during hospitalization in the NICU, and creating more comprehensive transition from NICU to home approaches. Our findings also underscore the need to evaluate HRIF program variability, which may be impacted by resource and infrastructure limitations, and to identify best performing HRIF program practices with a goal of attaining sustained HRIF involvement.

Recognizing clinical predictors of HRIF visit non-attendance in the NICU, as well as gaining a deeper understanding

Table I. Selected maternal, sociodemographic, neonatal clinical, and HRIF program-level characteristics among VLBW with successful first HRIF visit and those lost to follow-up

Factors	N	Not seen by 12 months corrected age (n = 1574)		Successful first HRIF visit by 12 months corrected age (N = 4938)		*P* value
Maternal, sociodemographic, family factors						
Maternal age, y						
<19	583	194/583	33.3%	389/583	66.7%	<.0001
20-29	2718	725/2718	26.7%	1993/2718	73.3%	
30-39	2755	565/2755	20.5%	2190/2755	79.5%	
≥40	452	90/452	19.9%	362/452	80.1%	
Prenatal care						
Yes	6312	1501/6312	23.8%	4811/6312	76.2%	<.0001
No	176	65/176	36.9%	111/176	63.1%	
Maternal race						
African American or Black	758	223/758	29.4%	535/758	70.6%	<.0001
Hispanic	2781	595/2781	21.4%	2186/2781	78.6%	
Asian	678	129/678	19.0%	549/678	81.0%	
American Indian	32	5/32	15.6%	27/32	84.4%	
Other	145	36/145	24.8%	109/145	75.2%	
White	1598	353/1598	22.1%	1245/1598	77.9%	
Primary caregiver						
One parent	2507	674/2507	26.9%	1833/2507	73.1%	<.0001
Two parents	3614	736/3614	20.4%	2878/3614	79.6%	
Foster/adoptive	124	29/124	23.4%	95/124	76.6%	
Other	54	13/54	24.1%	41/54	75.9%	
Primary caregiver education						
<9th grade	211	28/211	13.3%	183/211	86.7%	<.0001
Some high school	577	144/577	25.0%	433/577	75.0%	
High school degree	993	220/993	22.2%	773/993	77.8%	
Some college	901	154/901	17.1%	747/901	82.9%	
College degree	855	117/855	13.7%	738/855	86.3%	
Graduate school	358	45/358	12.6%	313/358	87.4%	
Other	51	6/51	11.8%	45/51	88.2%	
Primary language spoken at home						
English	4721	1132/4721	24.0%	3589/4721	76.0%	<.0001
Spanish	1133	204/1133	18.0%	929/1133	82.0%	
Other	293	46/293	15.7%	247/293	84.3%	
Neonatal and clinical characteristics*						
Sex						
Male	3328	772/3328	23.2%	2556/3328	76.8%	.0587
Female	3182	802/3182	25.2%	2380/3182	74.8%	
Multiple gestation						
Yes	1788	408/1788	22.8%	1380/1788	77.2%	.1159
No	4723	1166/4723	24.7%	3557/4723	75.3%	
SGA*						
Yes	1841	494/1841	26.8%	1347/1841	73.2%	.0015
No	4642	1078/4642	23.2%	3564/4642	76.8%	
Congenital anomalies						
Yes	658	149/658	22.6%	509/658	77.4%	.3324
No	5852	1425/5852	24.3%	4427/5852	75.7%	
BPD*						
Yes	1644	327/1644	19.9%	1317/1644	80.1%	<.0001
No	4824	1235/4824	25.6%	3589/4824	74.4%	
Late sepsis*						
Yes	749	158/749	21.1%	591/749	78.9%	.0366
No	5763	1416/5763	24.6%	4347/5763	75.4%	
NEC*						
Yes	255	54/255	21.2%	201/255	78.8%	.2534
No	6255	1520/6255	24.3%	4735/6255	75.7%	
Severe ICH*						
Yes	328	53/328	16.2%	275/328	83.8%	.0006
No	5976	1460/5976	24.4%	4516/5976	75.6%	
Surgery during NICU stay*						
Yes	908	147/908	16.2%	761/908	83.8%	<.0001
No	5604	1427/5604	25.5%	4177/5604	74.5%	
HRIF program factors						
HRIF program CCS level						
Regional	3345	868/3345	26.0%	2477/3345	74.0%	<.0001
Community	3039	662/3039	21.8%	2377/3039	78.2%	
Intermediate	127	43/127	33.9%	84/127	66.1%	
Non-CCS	1	1/1	100.0%	0/1	0%	

(*continued*)

Table I. Continued

Factors	N	Not seen by 12 months corrected age (n = 1574)		Successful first HRIF visit by 12 months corrected age (N = 4938)		*P* value
Distance from HRIF program†						
Lowest quartile	1573	316/1573	20.1%	1257/1573	79.9%	<.0001
Second quartile	1607	333/1607	20.7%	1274/1607	79.3%	
Third quartile	1613	392/1613	24.3%	1221/1613	75.7%	
Highest quartile	1595	443/1595	27.8%	1152/1595	72.2%	
HRIF program VLBW volume‡						
Lowest quartile	497	165/497	33.2%	332/497	66.8%	<.0001
Second quartile	999	160/999	16.0%	839/999	84.0%	
Third quartile	1371	270/1371	19.7%	1101/1371	80.3%	
Highest quartile	3618	952/3618	26.3%	2666/3618	73.7%	

SGA, small for gestational age; *BPD*, bronchopulmonary dysplasia (oxygen use at 36 weeks postmenstrual age); *late sepsis*, culture-proven sepsis or meningitis after day 3; *NEC*, necrotizing enterocolitis; *severe ICH*, grade 3 or 4 intracranial hemorrhage; *surgery during NICU stay*, surgery for NEC, patent ductus arteriosus and/or retinopathy of prematurity.
*See **Figure 1** for rates of attendance at first HRIF visit by BW and EGA.
†Quartile for miles of child residence from HRIF program: lowest quartile, <4.7 miles; second quartile, 4.7-10.0 miles; third quartile, 10.0-21.4 miles; highest quartile, >21.4 miles.
‡Quartile for HRIF program volume is based on average annual number of children born VLBW for birth years 2010 and 2011: lowest quartile, <45; second quartile, 46-80; third quartile, 81-136; highest quartile, >139.

of the associated family factors, sociodemographic disparities, and HRIF program factors are crucial to developing strategies to improve follow-up. In multivariable analyses, we found that, although some clinical descriptors such as lower BW were independently associated with a successful first HRIF visit, the majority of neonatal clinical morbidities were not. Instead, factors with the most significant impact on HRIF visit attendance were sociodemographic, home and environment, and program based. These findings reveal concerning disparities in the access to and use of HRIF, which may be associated with limited resources and supports for patients and families after discharge, and need for enhanced education regarding eligibility and value of HRIF.

Our statewide, population-based results are consistent with those of other investigators who have noted similar findings in single-center or regional studies.[11,12,21,22] In a study of 3 Canadian tertiary NICUs referring to 2 HRIF clinics,[11] no infant clinical factors were found to be associated with missing HRIF appointments, but mothers parenting alone and those at greater distances from clinics were less likely to attend. In a single regional center NICU study, Nehra et al found that children of older mothers were more likely to attend HRIF, and that neonatal clinical morbidities did not impact attendance.[21] In another single-center study, Harmon et al found greater distance to be independently associated with non-attendance, as well as male sex and multiple gestation.[12] Neonatal severity of illness factors were associated with HRIF attendance only on unadjusted analyses. Even among preterm infants with BPD, clearly at extremely high risk, Brady et al found that attendance at HRIF is far from assured, with logistical, access, and time-related barriers frequently reported.[14] In a single-site study, Patra et al found several risk factors for early HRIF non-attendance in unadjusted analyses, including maternal black or African American race.[22] In multivariable analyses, however, only lower gestational age and provision of breast milk at discharge were independently associated with HRIF attendance. Previous studies exploring challenges to postdischarge breast milk feeding have also pointed to social and environmental stressors, need to return to work, and a lack of social support, which in turn may be linked to economic and educational disparities.[23,24] Similarly, mothers who identify themselves as the sole primary caregiver and parent alone are more likely to be impacted by economic and educational disparities and to experience more limited social supports as compared with 2-parent families.

Referral to and longitudinal follow-up in HRIF are critical components of comprehensive quality care for preterm and other high-risk infants discharged from NICUs. In California, HRIF is considered among the special care centers within the CCS, which are composed of multidisciplinary, multispecialty providers who evaluate specific conditions and develop a family-centered health care plan to facilitate the provision of coordinated treatment. Regular and repeated evaluation by the HRIF team allows for skilled assessments at different timepoints to identify medical, developmental, and behavioral needs as they evolve, and thereby allow referral to appropriate services and therapies, including early intervention and many others. Although high-risk infants are expected to receive regular pediatric care, routine clinical assessment may poorly identify emerging impairments, particularly in the cognitive and communication domains.[25] Focused specialty assessment results in timely referral to needed interventions that otherwise could have been missed,[6,26] which in turn been shown to be associated with improved motor, developmental, and cognitive outcomes for high-risk infants.[7-9] However, such benefits can accrue only to those who are routinely followed in an HRIF setting. Therefore, it is important to attempt to achieve as robust follow-up rates as possible through early childhood, both to better understand outcomes of high-risk infants and their families and to improve access and timeliness of referral to needed services and interventions.

Our findings offer numerous opportunities for process and quality improvement to increase HRIF attendance. Such efforts will require engagement throughout the

Table II. Results of multivariable logistic regression for successful first HRIF visit by 12 months corrected age for VLBW infants in California born 2010 and 2011*

	Adjusted OR	95% CI	*P* value
Prenatal care			
Yes	1.92	1.34-2.77	.0004
No		Reference	
Maternal age, y			
<20	0.84	0.67-1.06	.149
20-29		Reference	
30-39	1.48	1.27-1.72	<.0001
≥40	1.28	0.97-1.7	.083
Maternal race			
African American or Black	0.65	0.54-0.78	<.0001
Non-African American or Black		Reference	
BW, g			
<750	2.11	1.69-2.65	<.001
751-1000	1.81	1.51-2.17	<.0001
1001-1250	1.34	1.14-1.58	.0005
1251-1499		Reference	
Severe ICH			
Yes	1.61	1.12-2.3	.0093
No		Reference	
Insurance category			
HMO/PPO, no CCS	1.03	0.87-1.22	.710
HMO/PPO, with CCS	1.65	1.19-2.31	.003
Other including self-pay	0.46	0.30-0.56	<.0001
CCS or MediCal only		Reference	
Primary caregiver			
Two parents	1.18	1.03-1.36	.019
One parent		Reference	
Primary language			
English		Reference	
Spanish	1.26	1.03-1.53	.022
Other language	1.52	1.05-2.21	.027
Distance from HRIF program†			
Lowest quartile		Reference	
Second quartile	0.98	0.8-1.21	.883
Third quartile	0.79	0.65-0.96	.018
Highest quartile	0.69	0.57-0.83	.0002
HRIF program volume‡			
Lowest quartile		Reference	
Second quartile	2.62	1.88-3.66	<.0001
Third quartile	1.55	1.15-2.10	.0045
Highest quartile	1.10	0.83-1.44	.506

HMO, Health maintenance organization; *PPO*, preferred provider organization.
*Educational level attained by the primary caregiver is not included in final model owing to volume of missing data.
†Quartile for miles of child residence from HRIF program: lowest quartile, <4.7 miles; second quartile, 4.7-10.0 miles; third quartile, 10.0-21.4 miles; highest quartile, >21.4 miles.
‡Quartile for HRIF program volume is based on average annual number of children born VLBW for birth years 2010 and 2011: lowest quartile, <45; second quartile, 46-80; third quartile, 81-136; highest quartile, >139.

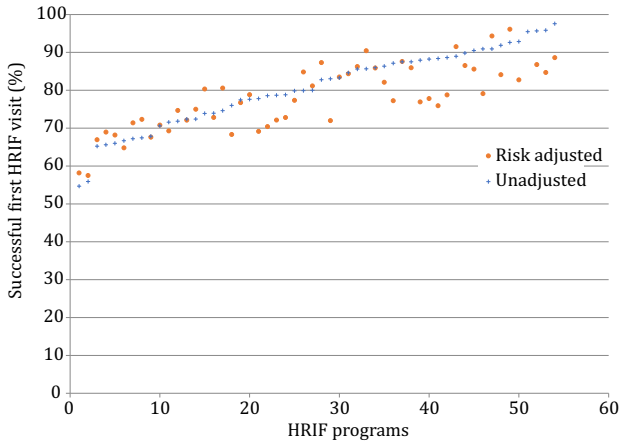

Figure 2. Observed (*crosses*) and risk-adjusted (*dots*) rates of successful first HRIF visit by 12 months corrected age for VLBW infants in California by HRIF program.

continuum of care from the NICU, through discharge and transition to home and community, to postdischarge follow-up. Among those referred to HRIF in our VLBW cohort, the follow-up rate to ≥1 HRIF visit by 12 months corrected age was just 76%. However, this is a clinically driven, statewide follow-up program, without the research-based and frequently incentivized infrastructures connected to multicenter prospective studies that typically achieve 85%-90% follow-up rates to 2 years.[27] Furthermore, our follow-up rate is consistent with or higher than other clinical programs that have explored factors related to HRIF compliance,[12,21,22] although we focused on an early follow-up visit. Nonetheless, the imperative to improve follow-up for high-risk infants is clear. We found that for the majority of cases of HRIF non-attendance in this analysis, either no lost to follow-up form was filed or the reasons provided were uninformative. To more deeply explore potential administrative and perceived patient barriers to follow-up, our group recently reported on results of a web-based survey of HRIF programs in California.[13] The findings delineate a broad variation in program and family resource challenges across the >50 responding sites, including limited NICU–HRIF interface in some programs, a need for greater physician and family education about HRIF services, challenges to follow-up owing to parent work schedules, and personnel staffing and clinic space difficulties faced by programs. The findings from our current study may suggest links with these administrative challenges, including potential struggles with more limited resources in smaller HRIF programs. Other investigators have also reported family obstacles to follow-up, such as distance from the clinic, length of HRIF appointment, multiple other appointments, and work and financial concerns, as well as aids to compliance such as calls from HRIF soon after NICU discharge.[14,21,22] Families and primary care providers may not understand the added value of HRIF above and beyond routine primary care, which may include developmental screening. In our previous survey,[13] we also found variation among clinics in HRIF provider composition and availability, which may point to further opportunities to explore the impact of physician–family connections and continuity on HRIF visit attendance. Leveraging knowledge of these and other factors presents opportunities for targeted interventions to improve follow-up through education to parents and physicians beginning in the NICU, consistent engagement with families before and after discharge, and

consideration for structural changes to the HRIF clinic construct.

Our study has both strengths and weaknesses. We report findings from a large, California population-based cohort of VLBW infants, with HRIF referral and visit data linked to NICU-based data. The majority of previous studies exploring factors related to follow-up were single-center studies. Our statewide capability allowed for a robust evaluation of a diverse population and the ability to highlight substantial variation among many HRIF clinics. Our analysis demonstrates sociodemographic and patient characteristics linked with access and follow-up challenges that can inform NICUs and HRIF teams statewide in local process improvement. As a part of the statewide database, we do not routinely collect data maternal alcohol or drug use and stress and anxiety measures during NICU hospitalization, shown to be associated with HRIF nonattendance in other studies.[11,12] Individual sites may have these protected data, which could be important in future improvement efforts to increase follow-up. However, supported by our findings and those of others, we do not believe that an intervention to improve HRIF attendance should narrowly target traditional risk groups only. For instance, Patra et al showed that public insurance was not associated with HRIF noncompliance, but rather private insurance nonauthorization or redirection of services may be increasingly problematic.[22] Similarly, we found that Spanish as a primary language was independently associated with a higher odds of successful first HRIF visit. This is consistent with Eneriz-Wiemer et al, who found that non-English parent language was associated with higher odds of completing preventative health visits before age 2, potentially related to cultural health values.[28] The impact of factors such as Spanish-speaking NICU and HRIF staff and rapid availability of interpreters is likely to be important and to vary by site. We were not able to include primary caregiver educational level in our multivariable analysis owing to the volume of missing data. We acknowledge this may be an additional independent factor related to HRIF attendance, and we have since implemented changes in our data collection to capture this variable more consistently. We also recognize that our initial practice of data finalization for all follow-up visits only after completion of the longitudinal 3-year program resulted in the delay of a timely evaluation of statewide data. We have, therefore, implemented changes to the visit closure process to require first visit data finalization earlier than previously required.

Our study revealed access disparities among an unquestioned high-risk patient group who are all eligible for California statewide services. The potential downstream effects of missed assessments include delayed subsequent referral to beneficial interventions, treatments, and services. We speculate that it is unlikely that a child who did not attend at least 1 HRIF visit within 12 months would attend serial visits thereafter. Without this early interface, the opportunity for multidisciplinary HRIF teams to respond to evolving and emerging neurodevelopmental and behavioral challenges will be lost. Because the survival of even the highest risk infants has improved, our focus must shift to after discharge, and to longer term endpoints for children and families. Our findings underscore the need to create comprehensive transition from NICU to home programs, as have been successfully launched within single centers or small regional areas, resulting in numerous benefits to children, families, and health care systems.[29-31] Deployed on a statewide scale, similar programs could have the potential to sustain engagement in HRIF, impact public policy, and ideally level the playing field for an increasingly diverse high-risk infant population. ■

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Data Statement

Data sharing statement available at www.jpeds.com.

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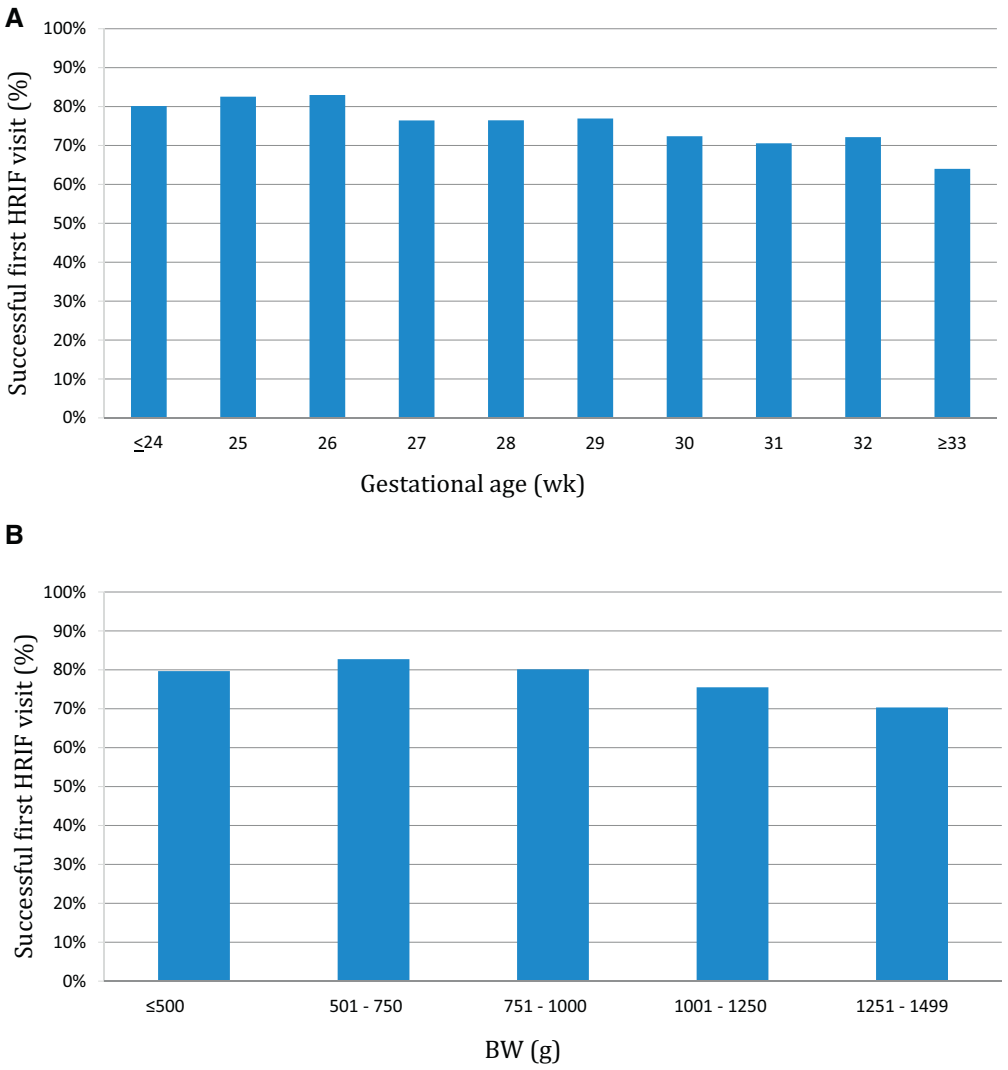

Figure 1. Rates of successful follow-up to first HRIF visit by 12 months corrected age for VLBW infants in California by **A**, gestational age and **B**, BW.