

Disparities and Early Engagement Associated with the 18- to 36-month High-risk Infant Follow-up Visit among Very Low Birthweight Infants in California

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Objective To determine follow-up rates for the high-risk infant follow-up (HRIF) visit at 18-36 months among infants with very low birthweights and identify factors associated with completion.

Study design We completed a retrospective cohort study using linked California Perinatal Quality of Care Collaborative neonatal intensive care unit, California Perinatal Quality of Care Collaborative California Children's Services HRIF, and Vital Statistics Birth Cohort databases. We identified maternal, sociodemographic, neonatal, clinical, and HRIF program level factors associated with the 18- to 36-month follow-up using multivariable Poisson regression.

Results From 2010 to 2015, among 19 284 infants with very low birthweight expected to attend at least 1 visit at 18-36 months, 10 249 (53%) attended. On multivariable analysis, factors independently associated with attendance at an 18- to 36-month visit included estimated gestational age (relative risk [RR], 1.21; 95% CI, 1.15-1.26; <26 weeks vs ≥31 weeks), maternal education (RR, 1.09; 95% CI, 1.06-1.12; college degree or more vs high school), distance from clinic (RR, 0.92; 95% CI, 0.89-0.97; fourth quartile vs first quartile), and Black non-Hispanic race vs White race (RR, 0.88; 95% CI, 0.84-0.92). However, completion of an initial HRIF visit within the first 12 months was the factor most strongly associated with completion of an 18- to 36-month visit (RR, 6.47; 95% CI, 5.91-7.08).

Conclusions In a California very low birthweight cohort, maternal education, race, and distance from the clinic were associated with sustained HRIF participation, but attendance at a visit by 12 months was the most significantly associated factor. These findings highlight the importance of early engagement with all families to ensure equitable follow-through for children born preterm. (*J Pediatr* 2022; ■:1-9).

Although survival has improved, infants born weighing less than 1500 grams (very low birthweight) remain vulnerable to health and developmental challenges.¹⁻³ One way to optimize infant outcomes is participation in high-risk infant follow-up (HRIF) programs.^{4,5} Recommendations regarding timing, quality benchmarks, and developmental assessments for HRIF have been published.⁵⁻⁸ However, sociodemographic, clinical, caregiver, and programmatic characteristics are associated with variable HRIF attendance.⁹⁻¹²

In the California Perinatal Quality Care of Collaborative (CPQCC), disparities existed at referral and persisted through the first and second visits.^{9,10,13} The New England Neonatal Follow-Up Network cohort identified disparities at 18-24 months.¹² Moreover, in a single-center cohort study, neighborhood equity as measured by the Child Opportunity Index was associated with variable rates of HRIF participation.¹⁴ Identifying predictors of sustained follow-up is crucial to improving participation and equity of care in HRIF programs. The timing of the 18- to 36-month visit is often aligned with the end of participation in HRIF and early intervention services (Part C of the Individuals with Disabilities Education Act), and a critical time point to transition to other services such as individualized education plans with local school districts and community-based services. Participation in this early childhood visit is important to identify challenges and opportunities during this transition.^{15,16} The objective of this study was to

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CCS	California Children's Services
CPQCC	California Perinatal Quality Care of Collaborative
HRIF	High-risk infant follow-up
NICU	Neonatal intensive care unit
RR	relative risk

determine follow-up rate to the final HRIF visit at 18-36 months corrected age and the factors associated with successful completion of this visit among infants with very low birthweight in a California statewide setting.

Methods

We conducted a retrospective cohort analysis using the CPQCC neonatal intensive care unit (NICU), the CPQCC California Children's Services (CCS) HRIF, and the Vital Statistics Birth Cohort databases. These 3 parallel databases each have their own web-based data reporting system and were linked using probabilistic methods providing a unique and broad range of sociodemographic, parental, neonatal to developmental, and institutional information. The CCS mandates that all CCS-approved NICUs be members of the CPQCC. These NICUs are responsible for identifying and referring eligible infants, which includes any infant with very low birthweight or born at less than 32 weeks of gestation, to one of the CPQCC-CCS HRIF clinics across the state. The CPQCC CCS HRIF Program provides for 3 standard visits, recommended to be performed at 4-8 months, 12-16 months, and 18-36 months corrected age (final visit). During each standard visit, HRIF teams perform medical examinations, neurologic and developmental assessments, identify child and family resource use and needs, and parent or caregiver-identified concerns.¹⁷ There is no financial eligibility requirement for inclusion in the program.

We included infants born between January 2010 and December 2015 who were registered and referred to CPQCC CCS HRIF at NICU discharge. Infants who had died, moved out of California, or whose parents withdrew before completion of the program were excluded. Maternal, paternal, sociodemographic, neonatal clinical, NICU and HRIF program-related, and parent nativity data were obtained from linked NICU-HRIF-Birth Cohort data files. Maternal and paternal age were defined categorically. Nativity was defined dichotomously as US born or not. Maternal and paternal race and ethnicity were self-assigned and grouped as African American or Black, Asian/Pacific Islander, Hispanic, multiracial/alternative category not listed, Native American, or White. Parental Hispanic ethnicity was further subcategorized as Central/South American, Cubano, Mexican/Mexican American/Chicano, not Spanish/Hispanic, Puerto Rican or other non-US Hispanic, and other Spanish/Hispanic (born in the US). Maternal education was classified as less than high school General Educational Development, high school or some college, college degree or graduate degree, and unknown. Primary language spoken at home was grouped as English, Spanish, and other. We also defined a dichotomous factor variable indicating completion of at least 1 standard visit by 12 months corrected age. Other factors assessed were defined as previously described.^{9,10}

Our primary outcome for this study was completion of at least 1 standard visit during 18-36 months among expected cases. We also examined caregiver concerns reported at a visit before the 18- to 36-month visit or at the 18- to 36-month

visit if they had not attended a previous visit and determined whether these were associated with completion of a visit at 18-36 months. Because information about caregiver concerns is only obtained at the standard visit, it was necessary to limit the analysis to those who had at least 1 visit after HRIF referral. We examined caregiver concerns queried at standard visits, which included questions about behavioral concerns, frequent illness, medications, sensory processing, sleeping/napping, calming/crying, gastrointestinal, motor skills/movement, speech/language, stress, and vision. We then compared participants by number of caregiver concerns (none, 1 or 2, and ≥ 3) between those who completed a visit between 18 and 36 months and those who did not.

Associations of maternal, neonatal, and hospital characteristics with successful follow-up to at least 1 visit during the 18- to 36-month period were explored by unadjusted analyses using a χ^2 test for categorical variables and the Student *t* test for continuous variables. A multivariable robust Poisson regression model was then constructed to identify factors independently associated with completion of at least 1 standard visit between 18 and 36 months pairwise by including variables from maternal, infant, and HRIF clinic center factors.^{18,19} Covariates were included based on statistical significance at 5% and the previous literature. The final model included maternal age, nativity, maternal race, maternal education, primary home language, birth weight small for gestational age, estimated gestational age, at least 1 completed HRIF visit in the first 12 months, and caregiver distance to the HRIF clinic. We included race in the model because previous work has demonstrated significant disparities in follow-up by race/ethnicity.^{9,10,13} Paternal factors, parental race/ethnicity, and select infant and NICU characteristics were not significant in early modeling and removed in the final model.

We then compared median first standard visit rates (percent, IQR) versus at least 1 standard visit between 18 and 36 months across HRIF clinics. Pearson correlation coefficients were used to assess degree of correlation. All statistical analyses were computed using SAS, 9.4 (SAS). Missing data were excluded; the amount of missing data was too great for imputation. The study was approved by the Stanford University Institutional Review Board.

Results

During birth years 2010-2015, there were 21 207 infants with very low birthweight referred to HRIF at NICU discharge; 1923 were excluded (**Figure 1**). Of the 19 284 infants expected, 10 249 (53%) attended at least 1 visit at 18-36 months (**Figure 1**). Of note, of the patients who withdrew before completion of the program, the frequencies of patient and family characteristics were similar to the cohort analyzed (**Table I**; available at www.jpeds.com). Maternal, sociodemographic, neonatal clinical, and program factors among children with and without a completed visit at 18-36 months are shown in **Table II**. In unadjusted bivariate analyses, multiple sociodemographic characteristics including maternal age of 19 years or less

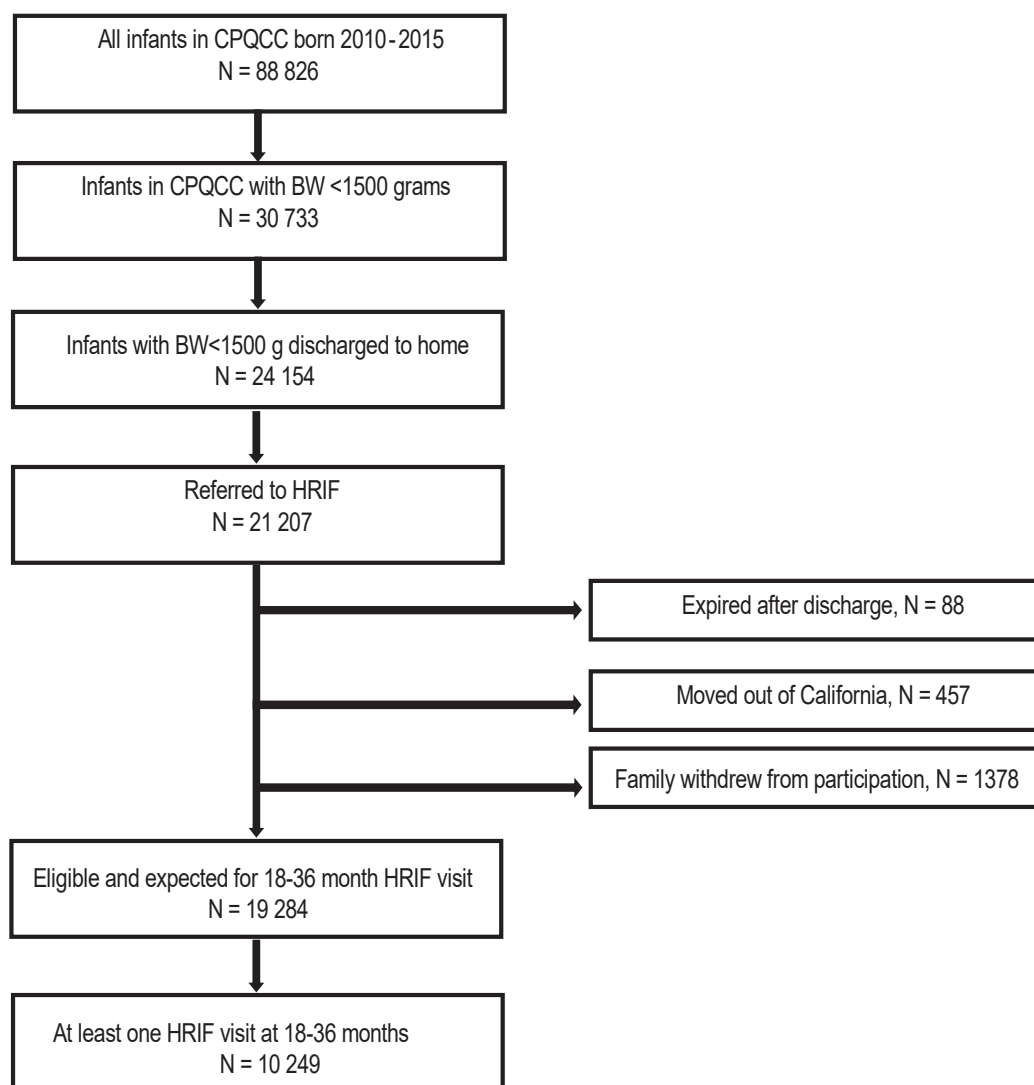


Figure 1. Flow diagram of participant inclusion and exclusion. *BW*, birth weight.

and Black race were associated with lower 18- to 36-month visit rates, whereas maternal foreign birth, having both parents as caregivers, higher maternal education, and Spanish as a primary language were associated with higher visit rates. Neonatal clinical morbidities were associated with higher 18- to 36-month visit rates on unadjusted analyses. Shorter patient distance to HRIF clinic and higher HRIF volume were associated with higher 18- to 36-month visit rates in unadjusted analyses.

We explored caregiver concerns reported at a previous HRIF visit for both those who did and did not complete an 18- to 36-month HRIF visit. In unadjusted bivariate analyses, we found that, among those who did not return for an 18- to 36-month visit, more than one-third of caregivers (35%) had reported some concern about the child, whereas among those who did return, more than 40% had reported some concern ($P < .0001$) (Table III; available at www.jpeds.com). Specific areas of caregiver concern included behavioral concerns and

speech and language for those who both did and did not return to the 18- to 36-month visit (Table III). One to 2 caregiver concerns were reported by 36% of those who returned for the 18- to 36-month visit, compared with 32% among those who did not return ($P = .0003$) (Figure 2; available at www.jpeds.com).

Results from robust Poisson multivariable analysis are shown in Table IV. Completion of an HRIF visit within 12 months was most significantly associated with participation in the 18- to 36-month visit (relative risk [RR], 6.47; 95% CI, 5.91–7.08). Other sociodemographic and program-level factors were independently associated with nonparticipation in the 18- to 36-month visit including maternal age (RR, 0.93; 95% CI, 0.88–0.99; <20 years of age vs 20–29 years), nativity (RR, 0.94; 95% CI, 0.91–0.97; US born vs non-US born), and race (RR, 0.88; 95% CI, 0.83–0.92; Black vs White). Mothers with a college degree or graduate degree were more likely to complete the visit, as

Table II. Selected sociodemographic characteristics among very low birthweight infants with and without at least 1 standard visit between 18 and 36 months corrected age

Characteristics	No visit between 18 and 36 months corrected age (n = 9208)			At least 1 visit between 18 and 36 months corrected age (n = 10 249)			P value
	n	n/N	%	N	n/N	%	
Sociodemographic							
Maternal age (years)							
≤19	858	858/1427	60.1	569	569/1427	39.9	<.0001
20-29	3947	3947/7844	50.3	3897	3897/7844	49.7	
30-39	3685	3685/8680	42.5	4995	4995/8680	57.6	
≥40	541	541/1325	40.8	784	784/1325	59.2	
Father's age (years)							
≤19	245	245/389	63	144	144/389	37	<.0001
20-29	1994	1994/3916	50.9	1922	1922/3916	49.1	
30-39	5135	5135/11 432	44.9	6297	6297/11 432	55.1	
≥40	810	810/1951	41.5	1141	1141/1951	58.5	
Prenatal care							
No	376	376/636	59.1	260	260/636	40.9	<.0001
Yes	8639	8639/18 608	46.4	9969	9969/18 608	53.6	
US-born mother							
No	2816	2816/6893	40.9	4077	4077/6893	59.2	<.0001
Yes	6084	6084/12 133	50.1	6049	6049/12 133	49.9	
Maternal race/ethnicity							
Asian or Pacific Islander	965	965/2395	40.3	1430	1430/2395	59.7	<.0001
Black	1463	1463/2456	59.6	993	993/2456	40.4	
Hispanic	4014	4014/8912	45	4898	4898/8912	55	
Native American or multiracial or alternative category not listed	254	254/497	51.1	243	243/497	48.9	
White	2311	2311/4962	46.6	2651	2651/4962	53.4	
Paternal race/ethnicity							
Asian or Pacific Islander	582	582/1444	40.3	862	862/1444	59.7	<.0001
Black	818	818/1393	58.7	575	575/1393	41.3	
Hispanic	5420	5420/11 784	46	6364	6364/11 784	54	
Native American or multiracial or alternative category not listed	35	35/70	50	35	35/70	50	
White	1239	1239/2793	44.4	1554	1554/2793	55.6	
Maternal nativity							
Central/South American	424	424/1040	40.8	616	616/1040	59.2	<.0001
Mexican/Mexican American/Chicano	2995	2995/6789	44.1	3794	3794/6789	55.9	
Not Spanish/Hispanic	4484	4484/9270	48.4	4786	4786/9270	51.6	
Other Spanish/Hispanic (born in the US)	625	625/1182	52.9	557	557/1182	47.1	
Puerto Rican or Cuban or other non-US-born Hispanic	72	72/149	48.3	77	77/149	51.7	
Paternal nativity							
Central/South American	292	292/680	42.9	388	388/680	57.1	.0057
Mexican/Mexican American/Chicano	4762	4762/10 398	45.8	5636	5636/10 398	54.2	
Not Spanish/Hispanic	2677	2677/5708	46.9	3031	3031/5708	53.1	
Other Spanish/Hispanic (born in the US)	315	315/599	52.6	284	284/599	47.4	
Puerto Rican or Cuban or other non-US-born Hispanic	51	51/107	47.7	56	56/107	52.3	
Primary caregiver							
Foster/adopter (CPS)	226	226/454	49.8	228	228/454	50.2	<.0001
Both parents	4660	4660/10 715	43.5	6055	6055/10 715	56.5	
One parent	3708	3708/7470	49.6	3762	3762/7470	50.4	
Other	73	73/143	51.1	70	70/143	49	
Maternal education							
Less than high school GED (<9th grade or some high school)	1779	1779/3633	49	1854	1854/3633	51	<.0001
High school or some college	4491	4491/8967	50.1	4476	4476/8967	49.9	
College degree or graduate degree	2098	2098/5384	39	3286	3286/5384	61	
Unknown	539	539/1055	51.1	516	516/1055	48.9	
Primary languages							
English	6680	6680/14 018	47.7	7338	7338/14 018	52.4	<.0001
Spanish	1313	1313/3408	38.5	2095	2095/3408	61.5	
Others	813	813/1581	51.4	768	768/1581	48.6	
At least 1 visit during first 12 months							
No	4249	4299/4674	90.9	425	425/4674	9	<.0001
Yes	4547	4547/14 002	32.5	9455	9455/14 002	67.5	

(continued)

Table II. Continued

Characteristics	No visit between 18 and 36 months corrected age (n = 9208)			At least 1 visit between 18 and 36 months corrected age (n = 10 249)			P value
	n	n/N	%	N	n/N	%	
Infant characteristics							
Sex							
Male	4578	4578/9539	48	4961	4961/9539	52	.0017
Female	4456	4456/9743	45.7	5287	5287/9743	54.3	
Small for gestational age							
Yes	2727	2727/5549	49.1	2822	2822/5549	50.9	<.0001
No	6306	6306/13 733	45.9	7427	7427/13 733	54.1	
Congenital anomalies							
No	8204	8204/17 441	47	9237	9237/17 441	53	.1243
Yes	830	830/1838	45.1	1008	1008/1838	54	
Bronchopulmonary dysplasia							
No	7048	7048/14 439	48.8	7391	7391/14 439	51.2	<.0001
Yes	1925	1925/4750	40.5	2825	2825/4750	59.5	
Late sepsis							
No	8570	8570/18 192	47.1	9622	9622/18 192	52.9	.0038
Yes	463	463/1087	42.6	624	624/1087	57.4	
Necrotizing enterocolitis							
No	8751	8751/18 610	47	9859	9859/18 610	53	.0151
Yes	284	284/672	42.3	388	388/672	57.7	
Severe intraventricular hemorrhage							
No	8241	8241/17 620	46.8	9379	9379/17 620	53.2	<.0001
Yes	362	362/925	39.1	563	563/925	60.9	
Any surgery during NICU stay							
No	8183	8183/17 143	47.7	8960	8960/17 143	52.3	<.0001
Yes	852	852/2141	39.8	1289	1289/2141	60.2	
HRIF clinic characteristics							
Distance from HRIF program (miles)							
First quartile (≤ 4.8)	2113	2113/4803	44	2690	2690/4803	56	<.0001
Second quartile (4.81-9.9)	2099	2099/4638	45.3	2539	2539/4638	54.7	
Third quartile (9.91-21.0)	2225	2225/4728	47.1	2503	2503/4728	52.9	
Fourth quartile (≥ 21.1)	2335	2335/4752	49.1	2417	2417/4752	50.9	
HRIF volume							
First quartile (≤ 35)	610	610/1210	50.4	600	600/1210	49.6	<.0001
Second quartile (36-65)	1286	1286/2730	47.1	1444	1444/2730	52.9	
Third quartile (66-125)	1876	1876/4510	41.6	2634	2634/4510	58.4	
Fourth quartile (≥ 126)	5263	5253/10 834	48.6	5571	5571/10 834	51.4	

CPS, child protective services; GED, General Educational Development.

were those who were primarily Spanish speaking compared with English speaking. Infants with lower gestational age were significantly more likely to complete the visit and those born small for gestational age were less likely, independent of gestational age. Greater caregiver distance from the HRIF clinic was associated independently with a lower RR for visit completion.

Given our finding that an early HRIF visit was strongly associated with 18- to 36-month visit completion, we evaluated HRIF clinics with respect to their follow-up rates by 12 months compared with follow-up rates at 18-36 months (Figure 3). The relationship between early HRIF visit completion and sustained HRIF participation was highly correlated (Figure 4; available at www.jpeds.com) ($r = 0.81$; $P < .0001$).

Discussion

In a population-based California very low birthweight cohort, we found that 53% of infants completed a visit between 18 and 36 months of age, which was similar to other cohorts.¹² Completion of a first HRIF visit by 12 months was the factor most significantly associated with completion

of the 18- to 36-month visit. Maternal, sociodemographic, and HRIF program-level factors were also independently associated with completion of the 18- to 36-month visit. These findings underscore the potential adverse impact of gaps in comprehensive care coordination and communication for children and families after NICU discharge. We propose that the foundation for success after discharge must begin with robust family engagement and support in the NICU; identifying and mitigating barriers to transition to home, educating parents and healthcare provider partners in the value of HRIF, and connecting families with and actively advocating for wrap-around community services that promote equitable support through childhood.

We identified that completion of an early HRIF visit was strongly and independently associated with sustained HRIF participation. There may be numerous reasons why families are unable to complete the first visit and for attrition after the first visit. Systems-based issues such as a lack of support for single caregivers and caregivers who face substance use disorders and distance from follow-up programs are associated with lower likelihood to attend HRIF visit.^{4,20} Descriptive work found that mothers often felt isolated and have limited

Table IV. Modified Poisson multivariable model analysis for completion of at least 1 visit between 18-36 months corrected age

Characteristics	Levels	RR	95% CI	P value
Sociodemographics				
Maternal age (years)	<20	0.93	(0.88-0.99)	.0316
	20-29	Reference		Reference
	30-39	1.04	(1.02-1.07)	.0016
	≥40	1.05	(1.0-1.1)	.0523
US-born mother	No	1.06	(1.03-1.09)	.0002
	Yes	Reference		Reference
Maternal race	Asian or Pacific Islander	1.04	(0.99-1.08)	.018
	Black	0.88	(0.84-0.92)	<.0001
	Hispanic	1.01	(0.97-1.04)	.5697
	Native American or multiracial or alternative category not listed	0.93	(0.86-1.02)	.0734
	White	Reference		Reference
Maternal education	Less than high school GED (<9th grade or some high school)	0.97	(0.93-1.01)	.0928
	High school GED or some college	Reference		Reference
	College degree or graduate degree	1.09	(1.06-1.12)	<.0001
	Unknown	1	(0.94-1.05)	.8971
Primary home language	Other	0.94	(0.89-0.98)	.0072
	Spanish	1.09	(1.05-1.14)	<.0001
	English	Reference		Reference
Infant characteristics				
Small for gestational age	No	0.94	(0.91-0.97)	.0002
	Yes	Reference		Reference
Gestational age (weeks)	≤26	1.21	(1.15-1.26)	<.0001
	27-30	1.12	(1.07-1.16)	<.0001
	≥31	Reference		Reference
At least 1 visit during first 12 months	Yes	6.47	(5.91-7.08)	<.0001
	No	Reference		Reference
HRIF program characteristics				
Caregiver distance to HRIF clinic (miles)	First quartile (≤4.8)	Reference		Reference
	Second quartile (4.81-9.9)	0.97	(0.93-1.00)	.0363
	Third quartile (9.91-21.0)	0.95	(0.91-0.98)	.0033
	Fourth quartile (≥21.1)	0.92	(0.89-0.97)	<.0001

support and resources to attend clinic or did not want to hear bad news that may be presented at a follow-up appointment.²⁰ Our prior research also revealed similar themes when families were trying to connect with early intervention programs, such as isolation and a lack of resources and support.²¹ Identifying families who may require additional support to participate in postdischarge visits is critical to proactively directing resources. Some simple solutions may include offering families a rideshare to their appointments, which has been shown to be effective for publicly insured patients in primary care settings.²² Also, many large regional NICUs have developed satellite clinics in an attempt to offer families visits closer to their communities. However, that measure may not be adequate for many families to attend the visit; thus, home visits may be more optimal. Other innovative solutions include mobile HRIF programs such as Curbside Care for Moms and Babies at Boston Medical Center, which provides mother-infant dyadic care with a mobile visit during the first 6 weeks.²³ Many HRIF programs have also adopted telehealth models during the coronavirus disease 2019 pandemic. An audit of the Vermont Oxford Network Extremely Low Birth Weight Follow Up Study group identified that although the ability to identify infant medical and developmental needs were offered via telehealth, connectedness with families was

preserved and accessibility improved.²⁴ Similarly, Panda et al identified via surveys that only 56% of programs were able to offer multidisciplinary telehealth visits during the coronavirus disease 2019 pandemic.²⁵

Families who identified as Spanish speaking versus English speaking were more likely to complete the 18- to 36-month visit. This finding is in contrast with some studies that identified non-English-speaking participants were less likely to participate in HRIF visits.¹⁴ Nevertheless, this finding is consistent with prior work using California statewide linked datasets, which found that Spanish-speaking families were more likely to receive influenza vaccines and complete preventive visits and more likely to complete a HRIF visit in the first 12 months compared with English-speaking families.^{10,26} This positive adherence to recommendations and follow-up might be attributable to cultural health factors, social networks among immigrant communities, and normative cultural values.²⁷ We also found that infants of Black non-Hispanic mothers were less likely to complete the visit. A number of factors may be contributing to this finding, including implicit bias, structural racism, a history of oppression, lower perceived efficacy of voice with doctors, and lack of trust in the medical system.^{28,29} Racism, segregation, and inequality contribute to disparities across the life course.³⁰

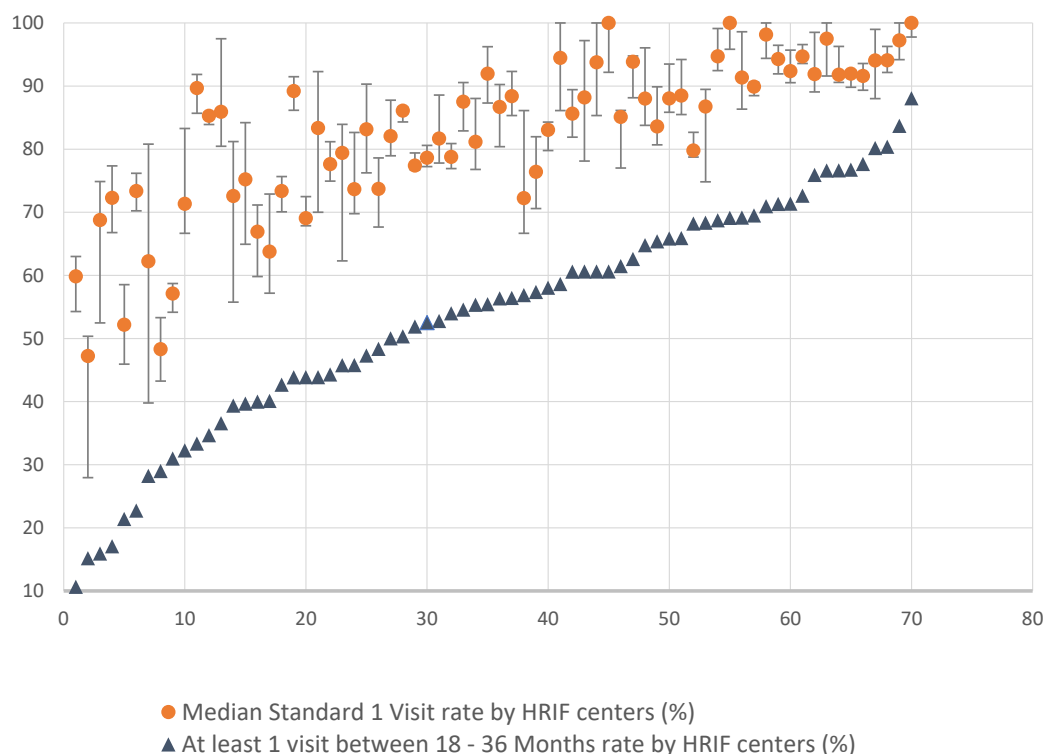


Figure 3. Rate of successful first HRIF visit by 12 months (median and IQR) shown with rate of at least 1 visit at 18-36 months among infants with very low birthweight across high risk infant follow-up centers.

Moreover, systemic quality of care is a modifiable factor that can contribute disparities. For example, Horbar et al demonstrated that Black infants with very low birthweight receive care in a concentrated set of hospitals with higher mortality rates.³¹ Some families also experience low-quality interactions with NICU staff, which may affect effective discharge planning and family readiness.^{32,33} The negative impact of these early experiences for parents and families may influence limited postdischarge engagement.

This study highlights the importance of considering caregiver concerns. More than one-third of caregivers expressed concerns about their child at an HRIF visit. A higher proportion of those who expressed concerns completed the third visit. By investing in areas of value to families, HRIF teams will be able to engage with these families early and address their concerns promptly. In a recent systematic review, improved patient-provider communication in the NICU was associated with higher parent satisfaction.³⁴ HRIF teams have the opportunity for broad connections with families; understanding their concerns may facilitate a partnership to address those concerns. For example, if a family is worried about their child's speech and language development, the HRIF team may be able to better engage the family on the child's progress in that area, which may lead to the family seeing sustained participation in follow-up visits and the program as valuable.

A new paradigm in caring for infants beyond the NICU has been proposed that focuses on follow-through rather than follow-up.^{30,35} Follow-through expands on the transactional

HRIF visit by integrating providers, families, and the community into a comprehensive model to care for a child from before birth to early childhood, facilitating bidirectional engagement of families with HRIF teams. Our analysis found that the completion of the first HRIF visit was associated with completion of the 18- to 36-month visit independent of other factors, which may point to success of this kind of engagement. However, a more beneficial approach would be to operationalize family connections with HRIF early in the NICU course and facilitate process improvement that spans NICU to home and community. For example, Brachio et al outlined a parent education initiative that began in the NICU that involved a bedside meeting with HRIF staff, appointment scheduling and, a warm handoff to the primary care provider; first visit rates improved from 60% to 76% during the intervention period.³⁶ Other successful program such as the Transition Home Plus Program and the Family Integrated Care model emphasize interdisciplinary and family-focused care before and after discharge.^{37,38} These studies and others have highlighted the need to address disparities in follow-through, enhancing communication with staff and families, creating a community-hospital partnership and a community resources team that can educate partners about health problems and the healthcare personnel that can create a resource list to foster communication. This phenomenon has been especially apparent during the coronavirus disease 2019 pandemic as families navigate the healthcare system without usual supports.³⁹

Our study should be viewed in light of its design. The population-based nature of the study is a strength in minimizing selection bias. Misclassification bias should be low given the low proportion of missing data, but we acknowledge that the data collected in the CPQCC do not currently include information regarding patient and family perspectives of discrimination, quality of life, stress and anxiety, alcohol or drug use, and other potentially important factors that may be related to nonattendance at the 18- to 36-month visit. We collect quantitative NICU and HRIF program-level data, but we do not routinely explore nuanced issues related to approaches to patient engagement or site-specific challenges in tracking and follow-up. Moreover, there may be variation in ascertainment and under-reporting of caregiver concerns. Also, it may be argued that these results are not generalizable because data were from a single state; however, California is one of the nation's most populous states, with diversity in geography, residents, and societal factors.

We propose that sustained participation in recommended follow through programs begins with early family engagement strategies focused on cultural humility and fostering family partnerships and self-agency. Logistical recommendations include improved educational models for families and providers, robust outpatient care coordination, mitigation of transitional barriers, and facilitated connections to community-based services.

In a very large California very low birthweight cohort, completion of a first HRIF visit by 12 months of age was strongly and independently associated with sustained HRIF, whereas nonparticipation was associated with sociodemographic and program-level factors. These findings characterize the chasms that may occur in the care of children discharged from the NICU and their families. Tailored equitable interventions will prime children and their families for success. ■

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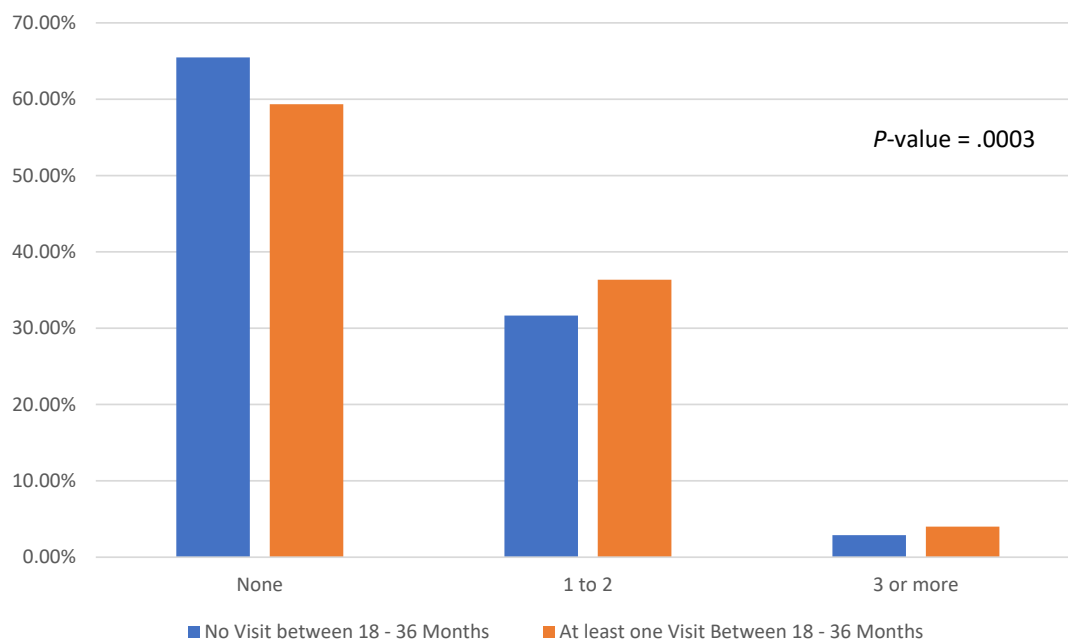


Figure 2. Prevalence of number of reported caregiver concerns during a standard visit at a prior (if any) visit among those who did and did not complete 18- to 36-month visit.

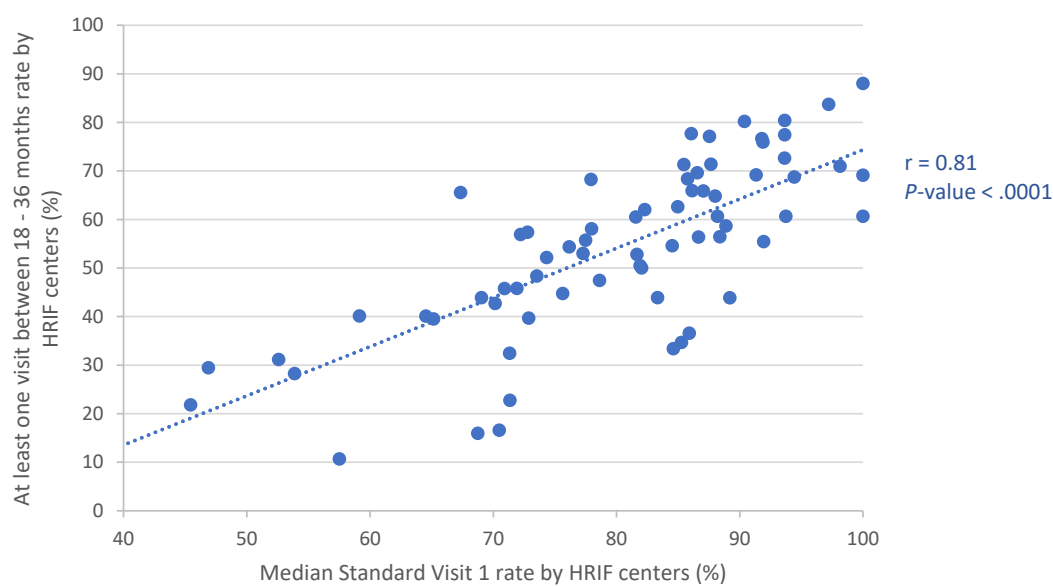


Figure 4. Correlation between median rate of successful first HRIF visit by 12 months and at least 1 visit at 18-36 months among infants born very low birthweight across HRIF centers.

Table 1. Description of patients who withdrew before completion of the program

Factors	Category	Frequency	Percent
Maternal age (years)	<20	57	4.15
	20-29	453	32.95
	30-39	722	52.51
	≥40	141	10.25
Maternal race	Asian and Pacific Islander	223	16.22
	Black	197	14.33
	Hispanic	387	28.15
	Native American or Multiracial or Alternative Category not listed	50	3.64
	White	513	37.31
Primary caregiver	Foster/adopter (CPS)	27	1.96
	Both parents	809	58.84
	One parent	482	35.05
	Other	16	1.16
Maternal education	<9th grade or some high school	15	1.09
	High school GED or some college	60	4.36
	College degree or graduate degree	68	4.95
	Unknown	4	0.29
Primary language	English	1124	81.75
	Spanish	108	7.85
	Other	117	8.51
Sex	Female	709	51.56
	Male	665	48.36
Any surgery during NICU stay	Yes	124	9.02
	No	1251	90.98
Any morbidity at discharge	Yes	317	23.07
	No	1057	76.93
Necrotizing enterocolitis	Yes	29	2.11
	No	1346	97.89
Late sepsis	Yes	60	4.36
	No	1315	95.64
Severe intraventricular hemorrhage	Yes	45	3.27
	No	1249	90.84
Bronchopulmonary dysplasia	Yes	266	19.35
	No	1105	80.36
Congenital abnormality	Yes	99	7.2
	No	1275	92.73
Prenatal care	Yes	1333	96.95
	No	42	3.05
Insurance	Commercial PPO/HMO—no CCS	673	48.95
	Commercial PPO/HMO—with CCS	69	5.02
	CCS or MEDI-CAL only	533	38.76
	Other, including self-pay, unknown	100	7.27
Small for gestational age	Yes	486	35.35
	No	889	64.65
Gestational age (weeks)	≤26	241	17.53
	27-30	686	49.89
	≥31	448	32.58

CPS, child protective services; GED, General Educational Development; HMO, health maintenance organization; PPO, preferred provide organization.

Table III. Caregiver concerns at a prior standard HRIF visit among those with and without HRIF visit between 18 and 36 months (n = 15 185)

	No visit between 18 and 36 months among those with at least 1 HRIF visit prior			At least 1 visit between 18 and 36 months among those with at least 1 HRIF visit prior			P value
	(n = 4936)*			(n = 10 249)			
	n	n/N	Proportion (%)	N	n/N	Proportion (%)	
Any caregiver concern reported about child	1668	1668/4831	34.53	4136	4136/10 219	40.47	<.0001
Specific concerns							
Behavioral concern	122	122/4871	2.50	612	612/10 247	5.97	<.0001
Frequent illness	88	88/4871	1.81	128	128/10 247	1.25	.007
Medication	15	15/4871	0.31	16	16/10 247	0.16	.0538
Sensory processing	24	24/4871	0.49	99	99/10 247	0.97	.0025
Sleeping/napping	67	67/4871	1.38	195	195/10 247	1.90	.0202
Calming/crying	54	54/4871	1.11	81	81/10 247	0.79	.052
Gastrointestinal	123	123/4871	2.53	170	170/10 247	1.66	.0003
Motor skills/movement	668	668/4871	13.71	1272	1272/10 247	12.41	.0255
Speech/language	318	318/4871	6.53	1630	1630/10 247	15.91	<.0001
Stress	19	19/4871	0.39	20	20/10 247	0.20	.0273
Vision	86	86/4871	1.77	149	149/10 247	1.45	.148

*Caregiver concerns are routinely collected during a standard visit. Of the 19 284 infants expected, 15 185 infants completed any standard visit and were included in the analysis; 4099 were excluded because they did not complete a standard visit. If a patient had a visit before 18-36 months, then caregiver concerns from that previous visit were used for the analysis. Otherwise, caregiver concerns at the 18- to 36-month visit were used for the analysis. Among patients with at least 1 visit between 18 and 36 months (n = 10 249), 182 had caregiver concern taken from their current visit. The N for each construct varies owing to missing data, which were excluded.