Participation in postpartum cCMV screening research

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INTRODUCTION

- Congenital cytomegalovirus (cCMV) disproportionately impacts Black and multiracial infants (9.5 and 7.8 per 1,000 live births, respectively) compared to infants that are non-Hispanic (NH) White, Hispanic, or Asian (1.0-3.0 per 1,000 live births).
- These disproportionately impacted populations are underrepresented in biomedical research in the US.

OBJECTIVES

- This study examined whether patient characteristics differ by enrollment decision in cCMV newborn screening research and whether the enrollment decision varied by timepoint (pre/post COVID-19 pandemic).

METHODS

- This retrospective study used electronic medical record data and screening forms from a large, prospective, universal cCMV screening study in Minnesota.
- The sample included two timepoints of data: T1: January 1-December 31, 2019, and T2: July 1, 2021-June 30, 2022, reflecting pre/post COVID-19 pandemic.
- Measures included: enrollment decision (enrolled/declined), maternal age, race/ethnicity, preferred language, interpreter need, insurance type, number of living children, and recruitment timepoint.

Figure 1. Study sample identification process
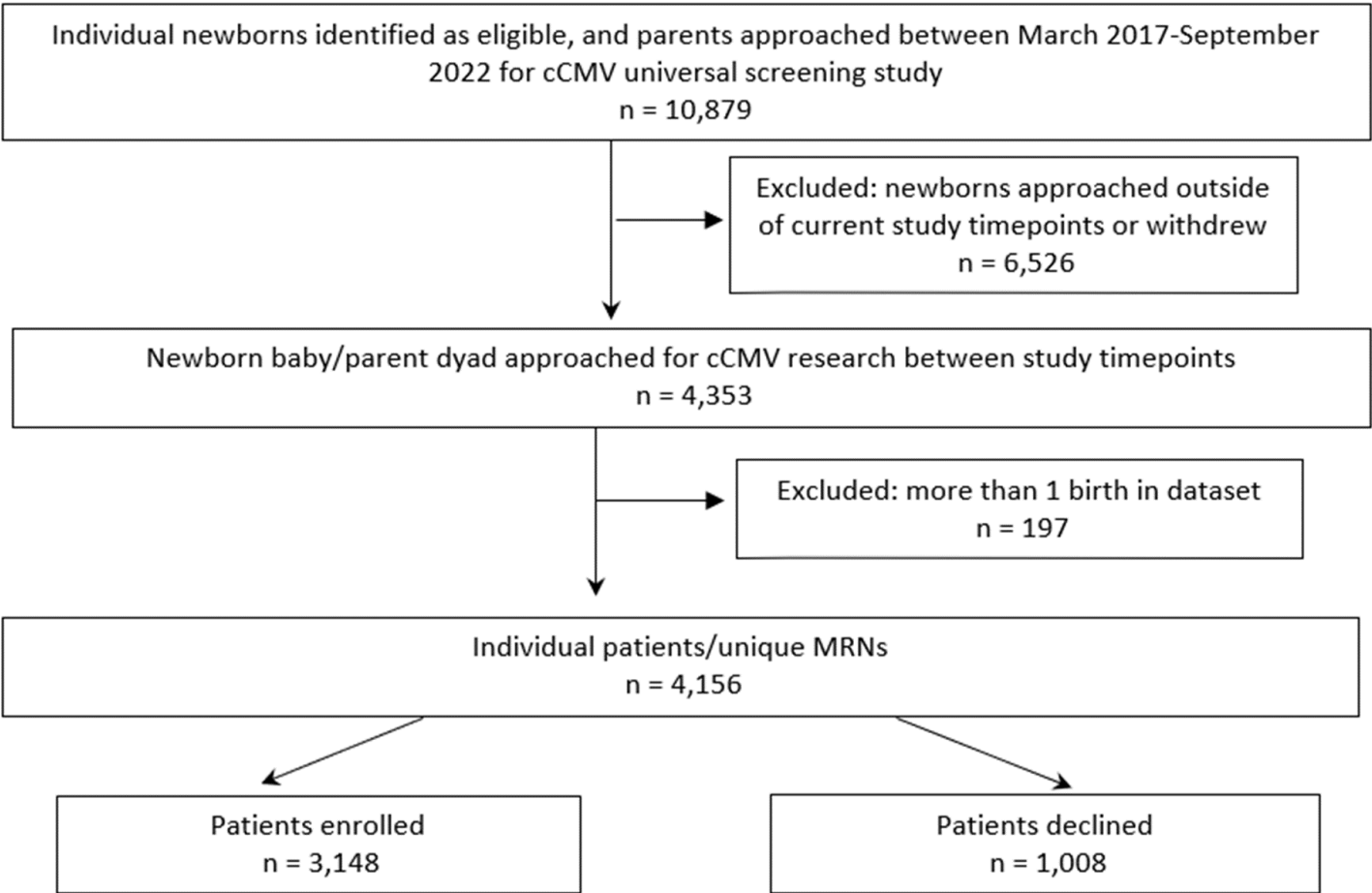
- Patients who had more than one birth during the study period were represented just once in the dataset (first birth).
- Differences between patients who enrolled and declined were examined using frequencies and chi-square tests, and univariate and multivariate logistic regression.

RESULTS

- 4,156 unique patients were included in the final sample (3,148 enrolled/ 1,008 declined).
- In univariate analysis, NH Black and NH multiracial patients were significantly more likely to decline study participation.
- Univariate analysis showed patients who were approached with an interpreter were more likely to decline study participation, as were those with Medicaid/Medicare.

Table 1. Patient characteristics stratified by cCMV study enrollment status (n = 4,156)

	Total (n = 4,156)	Enrolled (n = 3,148)	Declined (n = 1,008)	p-value
Maternal Age, mean±SD	31.4 (5.4)	31.5 (5.3)	31.0 (5.7)	0.008
≤ 24	11.3% (469)	10.7% (336)	13.2% (133)	<0.001
25-29	21.8% (906)	20.6% (649)	25.5% (257)	
30-34	37.8% (1571)	39.2% (1233)	33.5% (338)	
≥ 35	29.1% (1210)	29.5% (930)	27.8% (280)	
Race/Ethnicity				
NH White	60.4% (2509)	67.2% (2114)	39.3% (395)	<0.001
NH Black	19.1% (791)	13.3% (418)	37.1% (373)	
NH Asian	7.3% (301)	7% (221)	8% (80)	
NH American Indian	1% (41)	1% (31)	1% (10)	
NH Multiracial	2% (81)	1.8% (55)	2.6% (26)	
NH Native Hawaiian	0.1% (6)	0.1% (4)	0.2% (2)	
Hispanic	7.1% (293)	6.7% (210)	8.3% (83)	
Unknown	3.1% (130)	3% (93)	3.7% (37)	
Preferred Language				
English	96.3% (4001)	97.5% (3067)	92.8% (934)	<0.001
Somali	0.8% (35)	0.7% (21)	1.4% (14)	
Spanish	1.6% (67)	1% (30)	3.7% (37)	
Other	1.2% (50)	0.9% (28)	2.2% (22)	
Interpreter Needed				
No	97.4% (4045)	98.3% (3092)	94.6% (953)	<0.001
Yes	2.6% (108)	1.7% (54)	5.4% (54)	
Insurance Type				
Private	70.7% (2939)	76.9% (2422)	51.3% (517)	<0.001
Medicaid/Medicare	29.3% (1217)	23.1% (726)	48.7% (491)	
Number of Living Children				
1	47% (1955)	49% (1543)	40.9% (412)	<0.001
2	30% (1247)	31.3% (984)	26.1% (263)	
3	13.8% (572)	12.8% (403)	16.8% (169)	
4+	9.2% (382)	6.9% (218)	16.3% (164)	
Recruitment Timepoint				
T1: Pre-COVID 2019	56.5% (2349)	58.9% (1854)	49.1% (495)	<0.001
T2: Post-COVID 2021-2022	43.5% (1807)	41.1% (1294)	50.9% (513)	

Data are %(n) unless otherwise specified

- The characteristics that remain significant in a multivariate analysis examining patient decline were age (≤ 24), race/ethnicity (NH Black, NH Asian, NH multiracial, and Hispanic), insurance type (Medicaid/Medicare), number of living children (3+) and recruitment timepoint (T2).

Table 2. Factors associated with declining cCMV study participation

	Univariate models			Multivariate model		
	OR	[95% CI]	p-value	OR	[95% CI]	p-value
Race/Ethnicity	(n = 4,146)			(n = 4,144)		
NH White	Ref.			Ref.		
NH Black	4.78	[4.00, 5.70]	0.000	3.14	[2.53, 3.90]	0.000
NH Asian	1.94	[1.47, 2.56]	0.000	1.88	[1.42, 2.49]	0.000
NH American Indian	1.73	[0.84, 3.55]	0.138	1.17	[0.55, 2.46]	0.683
NH Multiracial	2.53	[1.57, 4.08]	0.000	2.22	[1.35, 3.64]	0.002
Hispanic	2.12	[1.61, 2.79]	0.000	1.66	[1.23, 2.22]	0.001
Unknown	2.13	[1.43, 3.16]	0.000	1.84	[1.23, 2.75]	0.003
Maternal Age						
30-34	Ref.			Ref.		
≤ 24	1.44	[1.14, 1.82]	0.002	0.74	[0.56, 0.98]	0.036
25-29	1.44	[1.20, 1.74]	0.000	1.11	[0.90, 1.36]	0.321
≥ 35	1.10	[0.92, 1.31]	0.307	1.04	[0.86, 1.26]	0.672
Interpreter Needed						
No	Ref.					
Yes	3.24	[2.21, 4.76]	0.000			
Insurance Type						
Private	Ref.			Ref.		
Medicaid/Medicare	3.17	[2.73, 3.68]	0.000	1.81	[1.48, 2.22]	0.000
Number of Living Children						
1	Ref.			Ref.		
2	1.00	[0.84, 1.19]	0.991	0.93	[0.78, 1.12]	0.472
3	1.57	[1.27, 1.94]	0.000	1.26	[1.00, 1.59]	0.049
4+	2.82	[2.24, 3.55]	0.000	1.45	[1.11, 1.9]	0.006
Recruitment Timepoint						
T1: Pre-COVID 2019	Ref.			Ref.		
T2: Post-COVID 2021-2022	1.48	[1.29, 1.71]	0.000	1.39	[1.20, 1.62]	0.000

CONCLUSIONS

- Patients who declined participation in cCMV screening research differed from patients who enrolled by age, race/ethnicity, interpreter need, insurance type, number of living children and timepoint they were approached.
- NH Black and NH multiracial patients were most likely to decline, the same groups with the highest prevalence of cCMV reported by other studies.
- Differential participation in cCMV research could result in underreported or biased estimates of prevalence and outcomes.