Follow-up after very preterm birth in Europe

Follow-up programmes aim to detect neurodevelopmental and health problems and enable early interventions for children born very preterm (<32 weeks of gestational age (GA)). Although the importance of postdischarge follow-up is widely acknowledged, recommendations differ regarding eligibility criteria, frequency, duration and content, especially for follow-up beyond early childhood.[1–3] We used data from a European cohort of children born very preterm to describe the use of routine follow-up services until 5 years of age.

The data were collected for the Effective Perinatal Intensive care in Europe and Screening to Improve Health in Very Preterm Infants studies, which constituted and followed up an area-based cohort of children born very preterm in 2011/2012 in 19 regions across 11 European countries.[4] Perinatal data were collected from obstetric and neonatal records, and parents completed questionnaires at 2 and 5 years of age. Out of 7900 live births, 6792 were discharged from neonatal care, of whom 6759 were alive at 5 years and 3635 (53.8%) participated in the study.

Based on a question on the use of routine follow-up services for children born very preterm in the 5-year parental questionnaire, we classified children as having never used follow-up, no longer using follow-up or still using follow-up services. We described associations with family sociodemographic characteristics and perinatal risks and estimated adjusted risks using multinomial regression models with robust variance estimators for clustered samples and inverse probability weights using baseline characteristics to account for study attrition bias.[4]

Of all children, 90.3% had used follow-up services, and 27.3% (10.9 to 58.4% by country) were still doing so at 5 years of age (table 1). Never using follow-up services was associated with maternal sociodemographic characteristics (younger age, low educational level and being born outside Europe) and lower perinatal risk. Continued follow-up at 5 years of age was related to perinatal risk factors (low GA, small for GA, bronchopulmonary dysplasia and male sex). Children with mothers born outside of Europe were less likely to continue follow-up. Adjustments for social and perinatal characteristics failed to explain differences between countries.

Table 1 Family sociodemographic and perinatal factors associated with routine follow-up for children born very preterm, at 5 years of age

Does child have routine check-ups for children born very preterm at 5 years?	N	No, never %	Not anymore %	Yes, still %	Reference: still in follow-up at 5 years: No, never aRRR	95% CI	Not anymore aRRR	95% CI
Mother's age at delivery (years)								
≤24	422	17.3	55.2	27.5	2.0	1.2 to 3.5	1.1	0.8 to 1.6
25–34	2057	9.2	63.0	27.8	ref		ref	
≥35	1098	6.8	67.2	26.0	0.7	0.5 to 1.2	1.0	0.8 to 1.3
Parity at delivery								
Multiparous	2156	8.3	63.6	28.1	ref		ref	
Nulliparous	1390	11.2	62.7	26.1	1.1	0.7 to 1.6	1.0	0.8 to 1.2
Multiple birth								
No (singleton)	2531	10.6	62.0	27.4	ref		ref	
Yes (twins or more)	1056	7.5	65.4	27.1	0.5	0.3 to 0.9	1.0	0.7 to 1.2
Mother's educational level								
Lower (ISCED levels 0–2: lower secondary or lower)	589	13.7	58.9	27.4	2.0	1.1 to 3.5	0.9	0.7 to 1.3
Intermediate (ISCED levels 3–5: upper or post-secondary, non-tertiary or short cycle tertiary)	1474	9.7	64.0	26.3	1.4	0.9 to 2.2	0.8	0.7 to 1.1
Higher (ISCED levels 6–8: bachelor degree or higher)	1478	6.3	66.3	27.4	Ref		Ref	
Country of birth								
Native	2857	8.9	63.5	27.6	Ref		Ref	
European born	238	7.7	63.9	28.4	0.9	0.4 to 2.0	0.8	0.5 to 1.2
Born outside Europe	476	13.3	61.9	24.9	2.5	1.4 to 4.2	1.4	1.0 to 1.9
GA, completed weeks								
<26	305	5.5	53.9	40.6	0.2	0.1 to 0.4	0.3	0.2 to 0.5
26–27	657	6.0	54.2	39.9	0.2	0.1 to 0.4	0.5	0.4 to 0.6
28–29	937	6.3	66.1	27.6	0.3	0.2 to 0.5	0.7	0.6 to 0.9
30–31	1688	13.8	66.2	20.0	Ref		Ref	
Small for GA**								
<3 centile	766	7.7	62.0	30.2	0.5	0.3 to 0.7	0.7	0.5 to 0.9
3–9 centile	417	11.0	59.3	29.6	1.0	0.6 to 1.6	0.7	0.5 to 0.9
≥10 centile	2404	10.2	63.8	26.0	Ref		Ref	
Severe neonatal morbidity††								
No	3141	10.4	63.5	26.1	Ref		Ref	
Yes	365	5.0	57.7	37.3	0.5	0.2 to 1.1	0.9	0.7 to 1.3
Bronchopulmonary dysplasia								
No	3034	10.7	64.4	24.9	Ref		Ref	
Yes	466	3.8	53.8	42.4	0.4	0.2 to 0.8	0.6	0.5 to 0.9
Congenital anomaly								
No	3292	9.9	62.7	27.4	Ref		Ref	
Yes	295	8.5	65.5	26.0	0.6	0.3 to 1.2	0.9	0.6 to 1.2
Child sex								
Male	1914	10.0	59.3	30.7	0.9	0.6 to 1.3	0.7	0.6 to 0.9
Female	1673	9.4	67.1	23.5	Ref		Ref	
Country (region)					(ref sample mean)		(ref sample mean)	
Portugal (Lisbon, Northern Region)	425	4.8	36.8	58.4	0.6	0.3 to 1.2	0.2	0.1 to 0.2
Belgium (Flanders)	259	12.8	40.5	46.7	3.6	2.0 to 6.3	0.3	0.2 to 0.4
Netherlands (Central Eastern)	146	6.3	52.2	41.5	1.7	0.7 to 4.1	0.5	0.3 to 0.7
France (Burgundy, Ile-de-France, Northern Region)	770	10.3	58.6	31.2	3.0	1.9 to 4.6	0.6	0.5 to 0.8
Denmark (Eastern Region)	151	10.8	62.5	26.7	6.3	2.9 to 13.8	0.9	0.6 to 1.4
Sweden (Greater Stockholm)	141	2.8	70.7	26.6	1.1	0.2 to 6.3	1.0	0.7 to 1.5
UK (East Midlands, Northern, Yorkshire and the Humber)	419	13.6	69.4	17.0	10.9	6.1 to 19.4	1.9	1.4 to 2.7
Germany (Hesse, Saarland)	266	21.5	65.4	13.0	21.1	11.3 to 39.4	1.9	1.2 to 3.1
Estonia (entire country)	133	0.0	87.2	12.8	0.0	0.0 to 0.0	2.6	1.6 to 4.2
Italy (Emilia-Romagna, Lazio, Marche)	691	4.5	83.2	12.3	4.5	2.3 to 8.7	2.5	1.9 to 3.3
Poland (Wielkopolska)	186	13.4	75.7	10.9	18.9	9.4 to 38.3	2.9	1.8 to 4.8

Inverse probability weights after multiple imputation were used for all analyses.
*Using intrauterine charts modelled for the Effective Perinatal Intensive care in Europe cohort.
†Intraventricular haemorrhage grades III and IV, cystic periventricular leucomalacia, retinopathy of prematurity stages III–V or necrotising enterocolitis needing surgery.
aRRR, adjusted relative risk ratio; GA, gestational age; ISCED, International Standard Classification of Education.

This study provides novel data on use of routine follow-up services after preterm birth based on a population-based design and standardised questions on follow-up from diverse European regions. Limits are reliance on parental recall and study attrition.

Children from socially disadvantaged families were more likely to never use follow-up services, corroborating previous

studies.[5] This is concerning, as these children are more vulnerable to the adverse neurodevelopmental consequences of preterm birth, and may benefit most from interventions. Variation between European countries in the percentage of children continuing follow-up at five persisted after accounting for perinatal risk factors, such as lower GA and neonatal morbidities. While differences are expected, given the heterogeneity in follow-up policies and programmes, the magnitude of these cross-country disparities, in tandem with marked social inequalities at follow-up entry, underscore the need for better evidence on optimal follow-up organisation and duration.

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