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# Two-year neurodevelopmental data for preterm infants born over an 11-year period in England and Wales, 2008–2018: a retrospective study using the National Neonatal Research Database

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## ABSTRACT

**Objective** United Kingdom guidelines recommend all infants born <30 weeks' gestation receive neurodevelopmental follow-up at 2 years corrected age. In this study, we describe completeness and results of 2-year neurodevelopmental records in the National Neonatal Research Database (NNRD).

**Design** This retrospective cohort study uses data from the NNRD, which holds data on all neonatal admissions in England and Wales, including 2-year follow-up status.

**Patients** We included all preterm infants born <30 weeks' gestation between 1 January 2008 and 31 December 2018 in England and Wales, who survived to discharge from neonatal care.

**Main outcome measures** Presence of a 2-year neurodevelopmental assessment record in the NNRD, use of standardised assessment tools, results of functional 2-year neurodevelopmental assessments (visual, auditory, neuromotor, communication, overall development).

**Results** Of the 41 505 infants included, 24 125 (58%) had a 2-year neurodevelopmental assessment recorded. This improved over time, from 32% to 71% for births in 2008 and 2018, respectively. Of those with available data: 0.4% were blind; 1% had a hearing impairment not correctable with aids; 13% had <5 meaningful words, vocalisations or signs; 8% could not walk without assistance and 9% had severe (≥12 months) developmental delay.

**Conclusions** The proportion of infants admitted to neonatal units in England and Wales with a 2-year neurodevelopmental record has improved over time. Rates of follow-up data from recent years are comparable to those of bespoke observational studies. With continual improvement in data completeness, the potential for use of NNRD as a source of longer-term outcome data can be realised.

## BACKGROUND

Very preterm-born infants have increased risk of later life complications including adverse neurodevelopmental outcomes compared with their term-born peers. Two-year outcomes are predictive of long-term functional outcomes.<sup>1,2</sup> Providing this high-risk group with enhanced developmental surveillance at 2 years may permit earlier

## WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ The National Neonatal Research Database (NNRD) holds 2-year outcome data for all babies admitted to neonatal units in England and Wales since 2007, but completeness and results over time have not been evaluated previously.
- ⇒ Routine data have previously been used to supplement bespoke collection in interventional trials.
- ⇒ Using routinely recorded outcome data for research has the potential to reduce costs and burden on participating centres and families.
- ⇒ Understanding the completeness of routine data is necessary to assess its suitability as a source of information on neurodevelopmental outcomes.

## WHAT THIS STUDY ADDS

- ⇒ Between 2008 and 2018, the proportion of included infants with 2-year neurodevelopmental assessment records in the NNRD increased over time, to over 70% in recent years.
- ⇒ The majority (≥87%) of infants reviewed were assessed using functional (non-validated) neurodevelopmental tools; however, only half had an assessment using a validated, standardised tool.
- ⇒ Rates of impairment were higher for the earlier gestation group across all domains, and there was no improvement seen over time.

detection of developmental problems and provision of support.

In the UK, the National Institute for Health and Care Excellence (NICE) recommends all infants born before 30+0 weeks' gestation receive a 'detailed face-to-face developmental assessment' at 2 years corrected age.<sup>3</sup> The neonatal unit that discharges the baby home is responsible for this.

Data from 2-year follow-up are held in the National Neonatal Research Database (NNRD). Two-year neurodevelopment data in the NNRD is sourced from a clinician-entered electronic patient record, which includes standardised and functional

**HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY**

- ⇒ This cohort is larger than comparable studies, and the continuous 11-year period covered has afforded us the opportunity to examine functional outcomes longitudinally at population level.
- ⇒ Completeness of 2-year records from routine electronic patient records in England and Wales has improved over time and is comparable to that of outcome data in bespoke observational research studies, demonstrating the potential role and validity of using this routinely recorded data as source of outcome data for research.
- ⇒ We identified factors associated with missing 2-year neurodevelopmental assessment data.
- ⇒ Our findings suggest that there is opportunity for improvements in data completeness by targeting populations and neonatal units with a higher likelihood for missing data: babies born at later gestations, those with lower socioeconomic status, younger mothers and lower-level units.

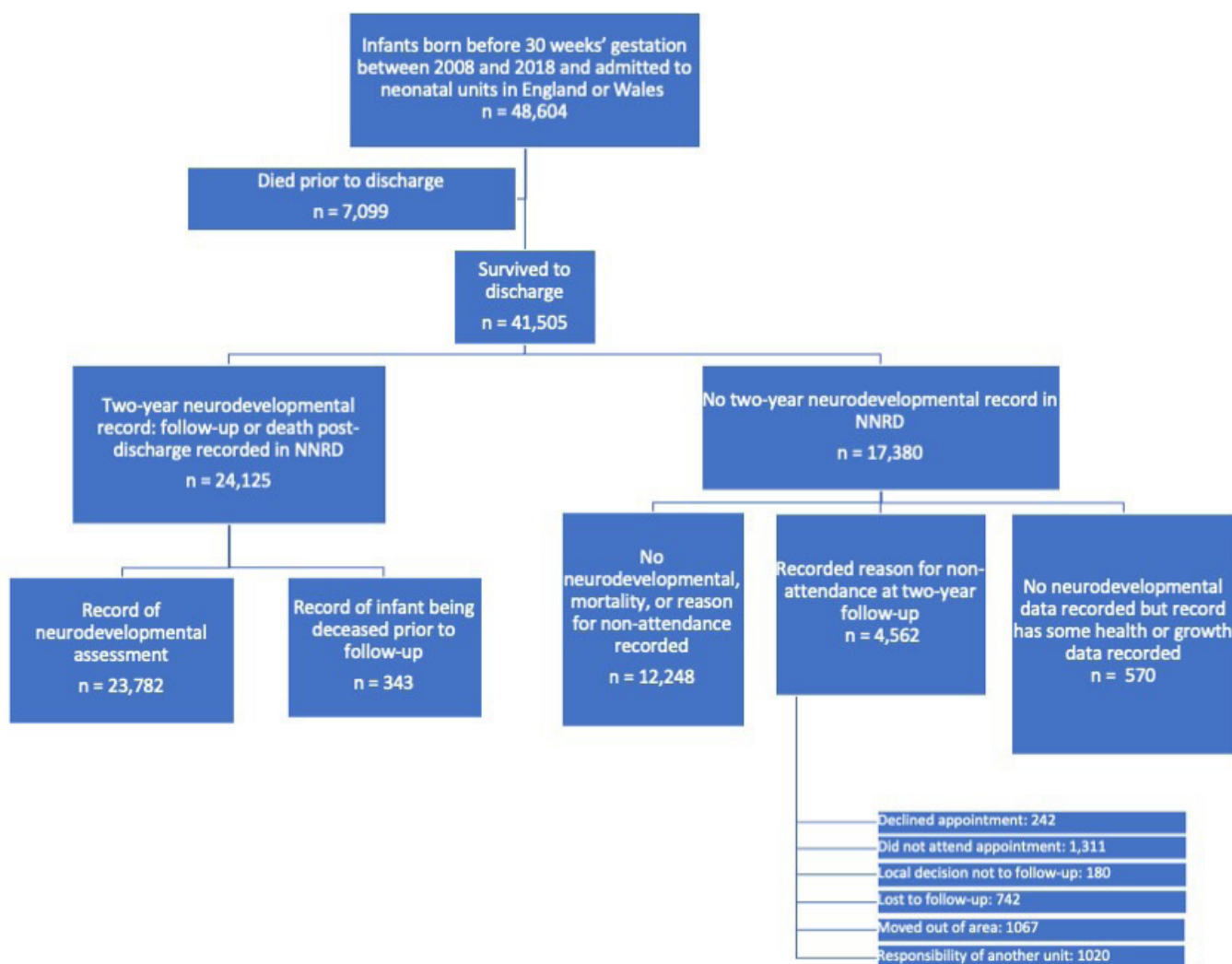
developmental outcomes. ‘Standardised’ outcomes refer to those obtained using validated neurodevelopmental assessment tools. The name of the tool is recorded, and scores can be entered for

Bayley Scales of Infant and Toddler Development 3rd edition, the Schedule of Growing Skills, and the Griffiths Mental Development Scales.

‘Functional’ outcomes refer to those derived from a questionnaire on functional abilities, developed through regional group consensus.<sup>4</sup> These questions were designed for use by clinicians without additional training or expertise in neurodevelopmental assessment. When compared against assessments using the Bayley Scales of Infant and Toddler Development, 3rd edition, they were found to identify children with no impairment with high validity, but lack sensitivity in the identification of impairment.<sup>5</sup>

The NNRD contains quality-assured data from the electronic patient records of infants admitted to UK neonatal units since 2007. In addition to 2-year data, the dataset includes demographic, clinical and organisational data from neonatal inpatient admissions. All units in England and Wales have contributed data since 2012 and 2013, respectively, providing whole population coverage for very preterm-born infants admitted to neonatal units.<sup>6,7</sup>

There is growing interest in the use of routinely recorded data to provide a more cost-efficient and less burdensome method to obtain outcome data for observational and interventional studies. However, the validity and generalisability of these data are dependent on the population attrition rates and data quality.



**Figure 1** Flow chart for the population eligible for 2-year neurodevelopmental follow-up. NNRD, National Neonatal Research Database

Table 1 Characteristics of cohort

Characteristics	All eligible infants (N=41 505)	Neurodevelopmental record or death post-discharge in NNRD (N=24 125)	No neurodevelopmental record in NNRD (N=17 380)
Gestational age at birth (weeks)			
Median (IQR)	28 (26–29)	27 (26–29)	28 (26–29)
Maternal ethnicity, n (%)			
Asian	4824 (11.6)	2935 (12.2)	1889 (10.9)
Black	4130 (10.0)	2257 (9.4)	1873 (10.8)
Mixed	720 (1.7)	401 (1.7)	319 (1.8)
White	26 521 (63.9)	15 402 (63.8)	11 119 (64.0)
Other	656 (1.6)	370 (1.5)	286 (1.7)
Missing or unknown	4654 (11.2)	2760 (11.4)	1894 (10.9)
IMD decile, n (%)			
1	6776 (16.3)	3941 (16.3)	2835 (16.3)
2	5703 (13.7)	3289 (13.6)	2414 (13.4)
3	4877 (11.8)	2785 (11.5)	2092 (12.0)
4	4160 (10.0)	2445 (10.1)	1715 (9.9)
5	3638 (8.8)	2169 (9.0)	1469 (8.5)
6	3172 (7.6)	1903 (7.8)	1269 (7.3)
7	2957 (7.1)	1776 (7.4)	1181 (6.8)
8	2681 (6.5)	1658 (6.9)	1023 (5.9)
9	2393 (5.8)	1463 (6.1)	930 (5.4)
10	2076 (5.0)	1317 (5.5)	759 (4.4)
Missing or unknown	3072 (7.4)	1379 (5.7)	1693 (9.7)
Maternal age (years)			
Median (IQR)	30 (26–35)	31 (26–35)	30 (25–35)
Missing, n (%)	346 (0.8)	133 (0.6)	213 (1.2)
Number of different neonatal units that provided care, n (%)			
1	21 800 (52.5)	12 662 (52.5)	9138 (52.6)
2	15 351 (37.0)	9054 (37.5)	6297 (36.2)
3	3788 (9.1)	2104 (8.7)	1684 (9.7)
4 or more	566 (1.4)	305 (1.3)	261 (1.5)
Level of unit of discharge, n (%)			
Special care baby unit (lowest level)	5711 (13.8)	2863 (11.9)	2848 (16.4)
Local neonatal unit	18 301 (44.1)	10 574 (43.8)	7727 (44.5)
Neonatal intensive care unit (highest level)	17 493 (42.2)	10 688 (44.3)	6805 (39.2)

NNRD, National Neonatal Research Database.

It is known that infants who are lost to follow-up often differ from those who are not.<sup>8</sup> Understanding completeness and quality of routinely recorded data is necessary to assess suitability for its use in research.

In this study, we examine the completeness and results of 2-year neurodevelopmental records in the NNRD and report the applied assessment tools.

## METHODS

Preterm infants born below 30 weeks' gestation between 1 January 2008 and 31 December 2018, admitted to National Health Service (NHS) neonatal units in England and Wales and survived to discharge from neonatal care, were included. Babies with missing gestational age or birth year were excluded. For analyses of assessment results, infants known to be deceased post-discharge, prior to assessment, were excluded.

SAS V.9.4 and Stata V.16.0 software were used for data extraction and analysis. The following data were extracted from the NNRD: maternal, pregnancy and infant characteristics, and geographical region of birth responsible for coordinating the care pathway of the baby (known as the Operational

Delivery Network (ODN)). We determined the designation of the discharging neonatal unit responsible for 2-year follow-up: special care baby unit being the lowest level, neonatal intensive care unit (NICU) being the highest and local neonatal units sitting between these.<sup>9</sup> We derived the Index of Multiple Deprivation (IMD) decile, a socioeconomic measure, using maternal postcode at the time of delivery.

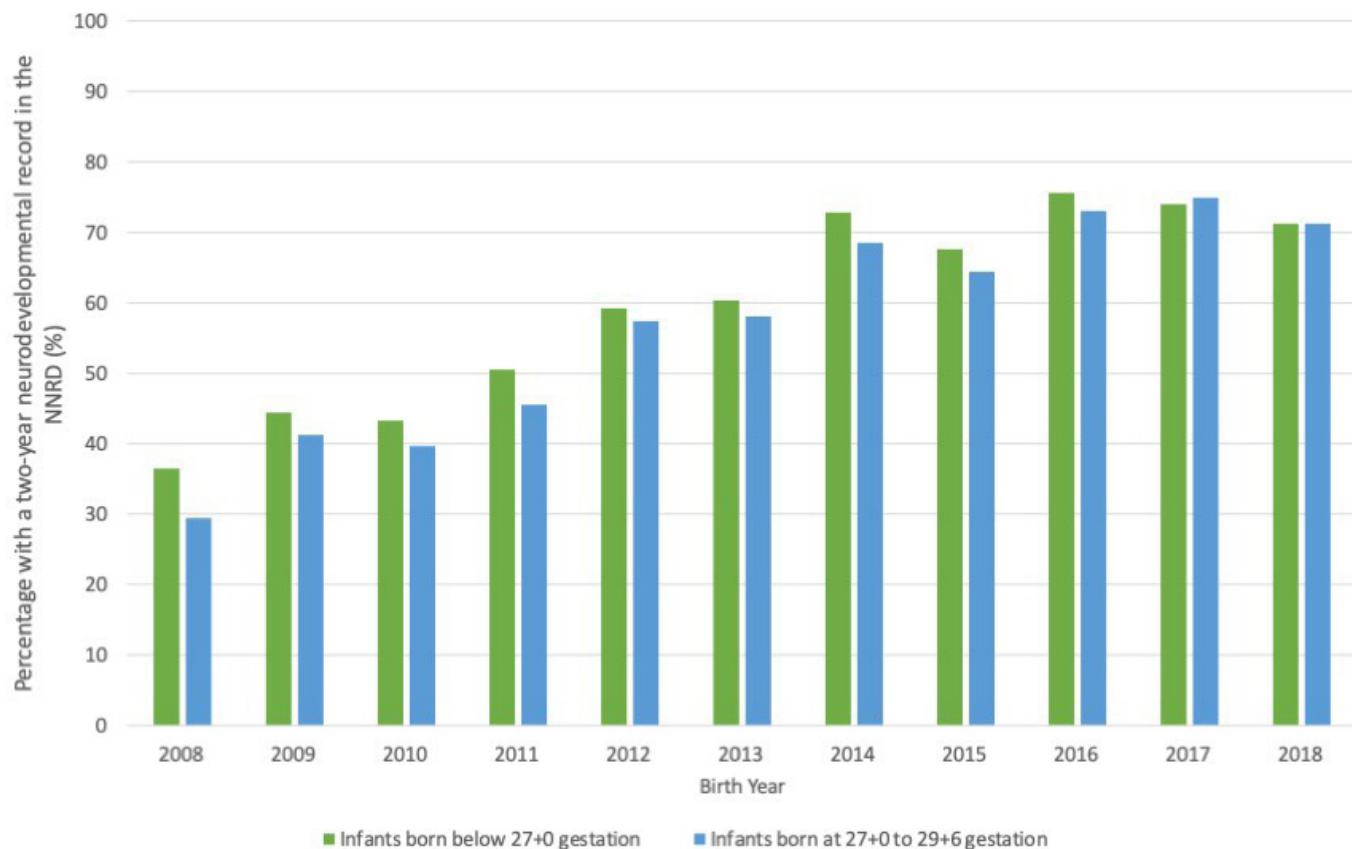
## We report the following

### Presence of 2-year neurodevelopmental record

We determined the number and proportion of eligible infants with a 2-year neurodevelopmental record, defined as present if any 2-year neurodevelopmental assessment results fields were completed or if death prior to 2-year follow-up was recorded. We report reasons recorded for non-attendance.

### Characteristics of the cohort and factors affecting completeness

We report characteristics of all babies eligible for follow-up and of those with and without a 2-year neurodevelopmental record separately. We explored factors associated with having this



**Figure 2** Percentage of eligible infants with a 2-year neurodevelopmental record over time. NNRD, National Neonatal Research Database.

record using univariate and multiple logistic regression models. The models included the following variables: birth year, gestation, maternal age at birth, IMD decile, the number of different neonatal units to which the baby was admitted and level of unit of discharge. The multiple model adjusted only for these variables; infants with missing data for any of these variables were excluded. Gestational age at birth, birth year, IMD decile and maternal age were treated as continuous variables. The number of neonatal units was grouped into 'one' (reference category), 'two' and 'three or more'. The reference category for level of unit of discharge was NICU.

#### Completeness over time and by geographical region (ODN)

We report the number and proportion of infants with a 2-year neurodevelopmental record across birth epochs (2008–2010, 2011–2014, 2015–2018), by gestation group (<27+0 and 27+0–29+6)<sup>10</sup> and by ODN. The Cochran-Armitage test was used to test for a linear association between completeness and birth year.

#### Completeness of neurodevelopmental assessments at 2 years

We report completeness of functional and standardised neurodevelopmental assessments as a proportion of infants with a 2-year neurodevelopmental record who were not deceased.

#### Choice of standardised neurodevelopmental assessment tool

We report the name of the standardised neurodevelopmental assessment tool used.

#### Results of neurodevelopmental assessments at 2 years

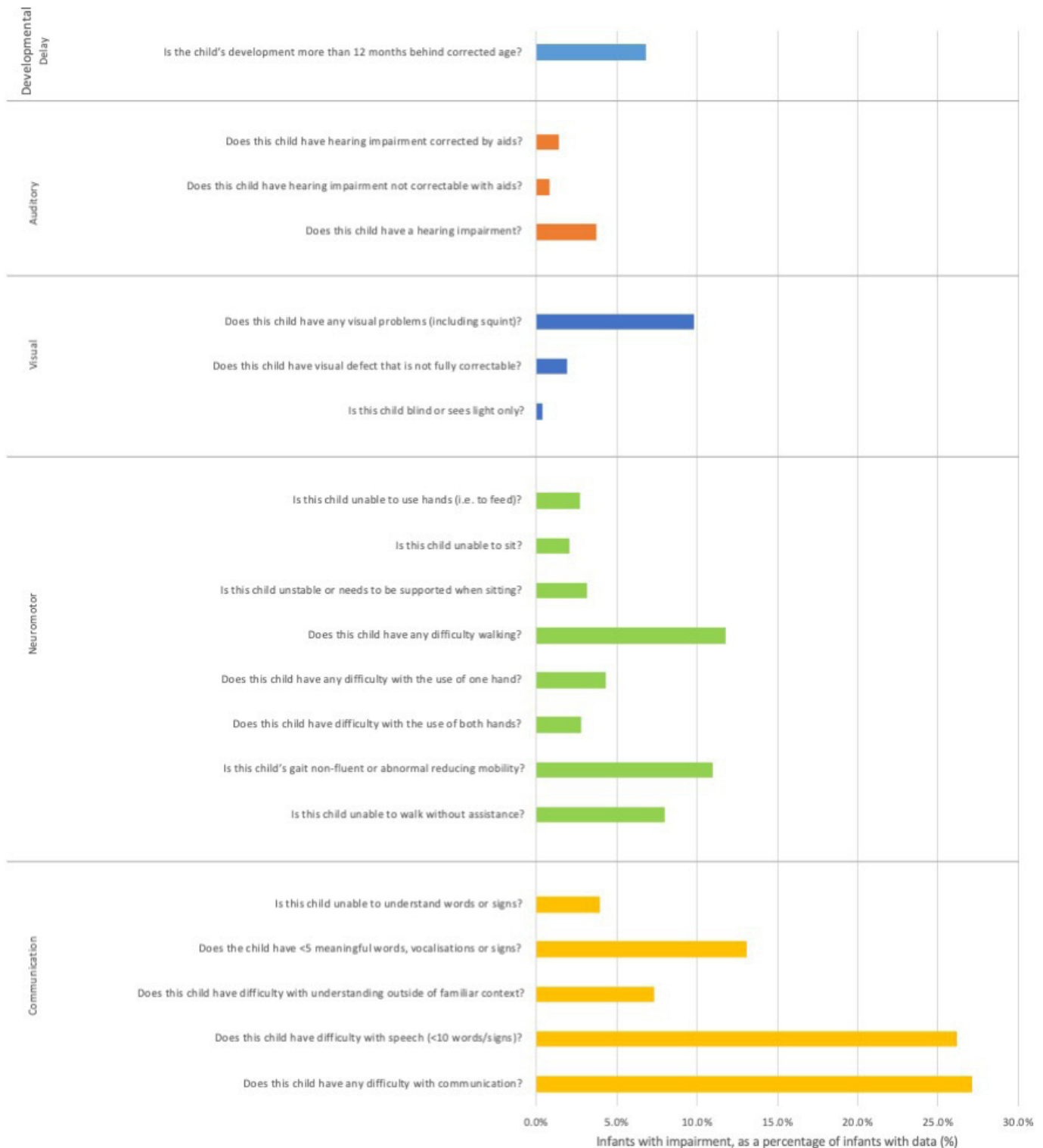
We report results of neurodevelopmental assessments. Possible outcomes for functional assessments of visual, auditory, communication and neuromotor neurodevelopmental domains were 'impairment' or 'no impairment'. For overall development, possible outcomes were: 'normal' (<3 months delay), 'mild' (3–6 months delay), 'moderate' (6–12 months delay) and 'severe' (>12 months delay).

Results for principal neurodevelopmental outcomes from each domain are reported by gestation in weeks, gestation group (as above) and birth epoch (as above). These principal outcomes are: blindness or light perception only (vision), hearing impairment not correctable with aids (auditory), having fewer than five meaningful words, vocalisations or signs (communication); being unable to walk without assistance (neuromotor); 'mild', 'moderate' or 'severe' developmental delay.

## RESULTS

### Presence of 2-year neurodevelopmental records

Among 48 604 infants born before 30 weeks' gestation between 2008 and 2018, admitted to neonatal units in England or Wales, 41 505 survived to neonatal discharge (figure 1). Of these, 58% (24 125/41 505) had a record of 2-year neurodevelopmental assessment or death post-discharge. After discounting 343 records of death post-discharge, the eligible population for 2-year assessment was 41 162, of which 58% (23 782/41 162) had neurodevelopmental data recorded. Of the 17 380 infants without a 2-year neurodevelopmental record, 4562 (26%) had a reason for non-attendance recorded.



**Figure 3** Impairment rates at 2-year follow-up, as a proportion of infants with available data.

### Characteristics of the cohort and factors affecting completeness

Table 1 describes characteristics of infants who survived to neonatal discharge, and those with and without a 2-year neurodevelopmental record.

Results of univariate analyses are given in online supplemental table 1. 38,243 infants were included in the multiple logistic regression model. Following adjustment, later birth year, earlier gestation, greater maternal age, higher IMD decile and higher level of unit

at discharge increased the probability of having a 2-year neurodevelopmental record (online supplemental table 2). Compared with receiving care in one unit, receiving care in three or more units increased the probability, but receiving care in two units did not.

### Completeness over time and by geographical region (ODN)

The proportion of patients with a 2 year neurodevelopmental record increased over time from 32% to 71% (births in 2008 and 2018 respectively) (online supplemental figure 1). The



**Table 2** Principal neurodevelopmental outcomes by gestation group and epoch for children with a record of neurodevelopmental assessment at 2 years, excluding those known to have died prior to 2-year follow-up

Gestation group	Birth epoch	Developmental delay				Neuromotor: is this child unable to walk without assistance?			Communication: does this child have <5 meaningful words, vocalisations or signs?			Vision: is this child blind or sees light only?			Auditory: does this child have hearing impairment not correctable with aids?		
		Data available, n	Mild*, n (%)	Moderate*, n (%)	Severe*, n (%)	Data available, n	Impairment, n (%)	Data available, n	Impairment, n (%)	Data available, n	Impairment, n (%)	Data available, n	Impairment, n (%)	Data available, n	Impairment, n (%)		
<27	2008–2010	1188	190 (16)	153 (13)	129 (11)	1326	173 (13)	1279	221 (17)	1276	<5 (<0.4)	1267	31 (2.4)				
	2011–2014	2644	481 (18)	363 (14)	262 (10)	2902	304 (10)	2816	466 (17)	2765	21 (0.8)	2753	34 (1.2)				
	2015–2018	2996	525 (18)	450 (15)	331 (11)	3406	353 (10)	3335	722 (22)	3286	26 (0.8)	3255	31 (1.0)				
27+0–29+6	2008–2010	2346	286 (12)	180 (7.7)	87 (3.7)	2613	200 (7.7)	2530	173 (6.8)	2535	9 (0.4)	2506	19 (0.8)				
	2011–2014	5170	744 (14)	464 (9.0)	258 (5.0)	5818	403 (6.9)	5643	561 (9.9)	5528	16 (0.3)	5500	27 (0.5)				
	2015–2018	6299	867 (14)	551 (8.7)	335 (5.3)	7244	418 (5.8)	7076	823 (12)	7019	16 (0.2)	6974	44 (0.6)				

\* Definitions for developmental delay: 'mild' (3 to 6 months delay), 'moderate' (6 to 12 months delay), 'severe' (over 12 months delay). Numbers below 5 are masked.

Cochran-Armitage test showed an association between birth year and presence of a 2-year neurodevelopmental record ( $p < 0.001$ ). Infants born <27 weeks had higher rates than those born 27+0–29+6 weeks (figure 2). The proportion of infants with a 2-year neurodevelopmental record ranged from 53% to 67% across ODNs (online supplemental table 3).

### Completeness of functional and standardised assessments at 2 years

Of the 23782 children with a 2-year neurodevelopmental record, individual functional outcomes were  $\geq 87\%$  complete (online supplemental table 4). Half, 11 777/23 782 (50%), had a standardised developmental assessment. The majority (61%) used Bayley Scales of Infant and Toddler Development (online supplemental figure 2).

### Results of neurodevelopmental assessments at 2 years

Functional neurodevelopmental outcomes and outcomes by gestation group and birth epoch are shown in figure 3 and table 2, respectively. Rates of impairment were higher for the earlier gestation group across all domains. Blindness or light perception only and hearing impairment not correctable with aids were relatively uncommon (<3%). Impairments in other domains were more common. 7% to 22% had fewer than five meaningful words, vocalisations or signs; 6–13% could not walk without assistance. Mild developmental delay (12–18%) was more common than moderate (8–15%) or severe (4–11%) delay. Rates of impairment do not appear to improve over time. Online supplemental tables 5,6 show functional outcomes by gestation and birth epoch, respectively.

Due to low rates of completeness, and variety in assessment tools used, results from standardised assessments are not reported.

### DISCUSSION

In this whole population study, 24 125 of an eligible population of 41 505 had a 2-year record of neurodevelopmental assessment or death. Completeness improved over time to above 70% in recent years. Our regression analysis showed that 2-year records were not missing at random, suggesting opportunity for improving completeness by targeting groups with higher likelihoods for missing data. These include babies born at later gestations, those with lower socioeconomic status, younger mothers and lower-level units. We speculate that the association between gestational age and likelihood of a follow-up record may be due to higher rates of morbidities seen at earlier gestations and increased need for medical care following discharge. Most children had functional assessments. Higher rates of impairment were seen in the earlier gestation group, as expected. We did not find improvement in impairment rates over time. We speculate this may be due to a changing population, with increasing numbers of infants surviving at lower gestations.<sup>11</sup> Only half received a standardised assessment, likely due to their being time-consuming and requiring a trained assessor.

Availability of 2-year data in the NNRD in recent years (>70%) exceeds that seen in some large prospective observational cohort studies of very preterm infants that used bespoke outcome data collection. EPICure-2, an English prospective national cohort study, evaluated 576/1031 (55%) of their cohort in face-to-face assessments at 3 years.<sup>12</sup> The Effective Perinatal Intensive Care in Europe (EPICE) study, a European population-based prospective cohort study, had 2-year corrected outcome

data (obtained by questionnaire) for 4426/6792 (66%).<sup>13</sup> Unlike these examples, our study used routine data extracts.

Studies using national registries or databases as their source for outcome data have completeness similar to or exceeding that of the NNRD. The Extremely Preterm Infants-Dutch Analysis on Follow-up (EPI-DAF) Study, a national cohort study using registry data, had 2-year data available for 554/651 (85%) of the eligible cohort.<sup>14</sup> A Belgian population-based cohort study using a national database had 2-year data for 1089/1783 (61%) of their eligible cohort.<sup>15</sup> In both studies, higher proportions of children followed up were assessed using standardised developmental tools (79–89% and 96%, respectively).<sup>14 15</sup>

Rates of 2-year data in the NNRD in recent years approach, but remain below, completeness seen in large interventional trials. The Speed of Increasing Milk Feeds Trial (SIFT) had 88% available 2-year outcome data.<sup>16</sup> The Caffeine for Apnoea of Prematurity (CAP) trial had 93% adequate outcome data.<sup>17</sup>

Our study has key strengths. The NNRD has whole population coverage for neonatal care of very preterm infants. Our study uses only routinely recorded data, reducing costs, workload and the burden imposed on families by duplication of assessments. Our cohort is larger than comparable studies; 6792 infants were eligible for follow-up in the largest aforementioned study (EPICE)<sup>13</sup> versus 41 505 in our study. Our cohort covers a longer time-period than comparable studies. EPIPAGE-2 (a French national cohort study) and EPICure-2 both compare cohorts born in two 1-year periods.<sup>12 18</sup> The continuous 11-year period covered allowed us to examine functional outcomes longitudinally at population level.

Our study has several limitations. Missing data may not represent non-attendance; an assessment may occur without being entered into the correct system. Possible explanations include lack of awareness or resources to support health professionals. This may in part explain the poorer completeness in lower-level units, which we speculate may have fewer resources. Second, due to low rates of standardised assessments and variety of tools used, we did not report these results. Third, there is variation in follow-up practices between units.<sup>19</sup> In exploring factors influencing completeness, we were unable to include important local factors, such as follow-up co-ordinators, as this information was not available. It is likely that unmeasured factors influenced the likelihood of follow-up. Fourth, although practical and easy to use, functional assessments are not gold standard and may underestimate the prevalence of impairment.<sup>20</sup>

The improvement in completeness over time is likely multifactorial and reflects introduction of formal guidance, incentives and greater data visibility over the period of interest, facilitated by the National Neonatal Audit Programme (NNAP). In 2014, NNAP identified 2-year follow-up as an important quality improvement opportunity.<sup>21</sup> Changes to ameliorate data completeness included reporting by hospital versus network level and allocating responsibility for follow-up to discharging units. Some ODNs introduced 2-year follow-up targets in their payment framework.<sup>20</sup> In their 2017 guideline for developmental follow-up of preterm infants, NICE recommended assessment at 2-year corrected age for children born before 30 weeks.<sup>3</sup>

Unit and network-level insights provided by NNAP are crucial to informing quality improvement efforts. Ongoing efforts to improve follow-up rates include the recent introduction of ODN-level discharge coordinators.<sup>22</sup>

Using routine data for research improves feasibility and reduces costs. Two-year outcomes are commonly reported in research, balancing improved predictive accuracy at older ages with increasing risk of attrition over time.<sup>23</sup> The quality of 2-year data

in the NNRD, as examined in this study, is crucial to understand its potential for use in research. Routinely recorded 2-year data has previously been used to supplement study-specific collection in interventional studies. Outcome data for 10% of the patients enrolled in the SIFT trial were sourced from the same electronic patient records, which populate the NNRD.<sup>16</sup> Using a database to avoid duplicative data collection for interventional studies has been shown to be feasible and acceptable in the UK.<sup>24</sup>

The low rate of standardised assessments likely reflects the challenge of undertaking time-consuming validated assessments. Improving completeness of standardised assessments in the NNRD would enhance its potential for use in research. The Parent Report of Children's Abilities-Revised (PARCA-R) is a validated, cost-effective parent-completed questionnaire used for developmental screening<sup>25 26</sup> and has been used in interventional trials.<sup>27</sup> The increase in 'other' standardised assessments used for infants born in 2018 (online supplemental figure 2) may reflect increased use of PARCA-R. A recent revision of the neonatal dataset enables capture of PARCA-R assessments in the NNRD, and systematic capture of an electronic version has been piloted successfully (ePARCA-R).<sup>28</sup> Practicality of this tool may improve completeness of 2-year standardised assessments sufficiently for use of this routinely recorded data for research.

## CONCLUSIONS

In recent years, two-year neurodevelopmental outcomes are available for over two-thirds of survivors born before 30 weeks in England and Wales. Those born to younger mothers, from lower socioeconomic status, at later gestations and discharged from a lower-level unit have a higher chance of missing data and offer opportunity for targeted improvements in 2-year follow-up programmes nationally. Continual improvements in 2-year outcome data will support the use of routinely recorded records as a more cost-efficient and practical source of outcome data.

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