The Contribution of Newborn Health to Child Mortality across England

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NCMD

National Child Mortality Database

Knowledge, understanding and learning to improve young lives

NCMD National Child Mortality Database

NCMD Thematic Report on the link between newborn health and child mortality

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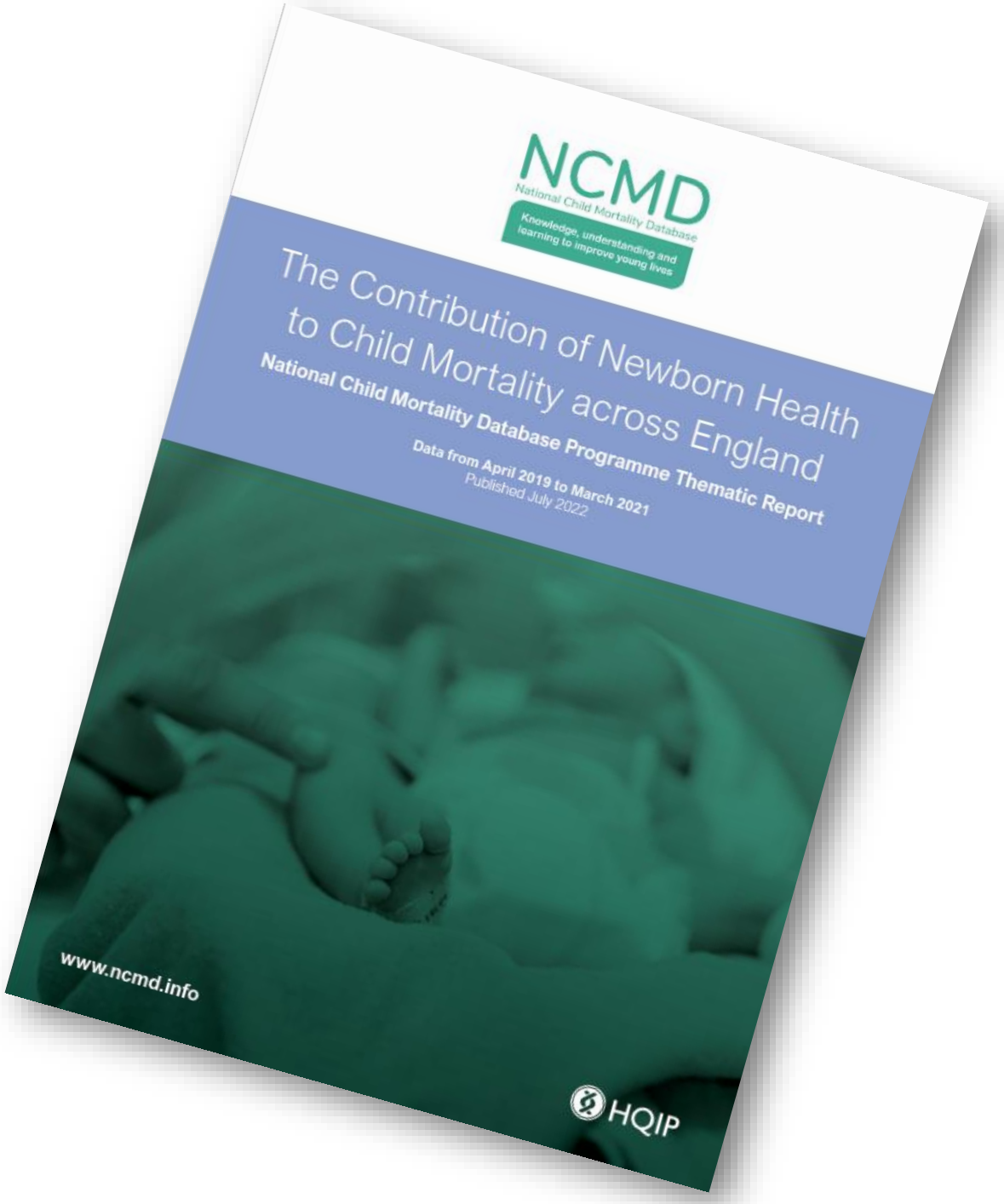
www.ncmd.info/perinatal



The National Child Mortality Database

- Commissioned by HQIP on behalf of NHS England
- Led by University of Bristol in collaboration with partners
- The Lullaby Trust, Sands and Child Bereavement UK are our partner charities
- Started collecting data on 1 April 2019

Our Aim

To collate and analyse information nationally to ensure that deaths are learned from, that learning is widely shared and that actions are taken, locally and nationally, to reduce the number of children who die.

Child Death Reviews

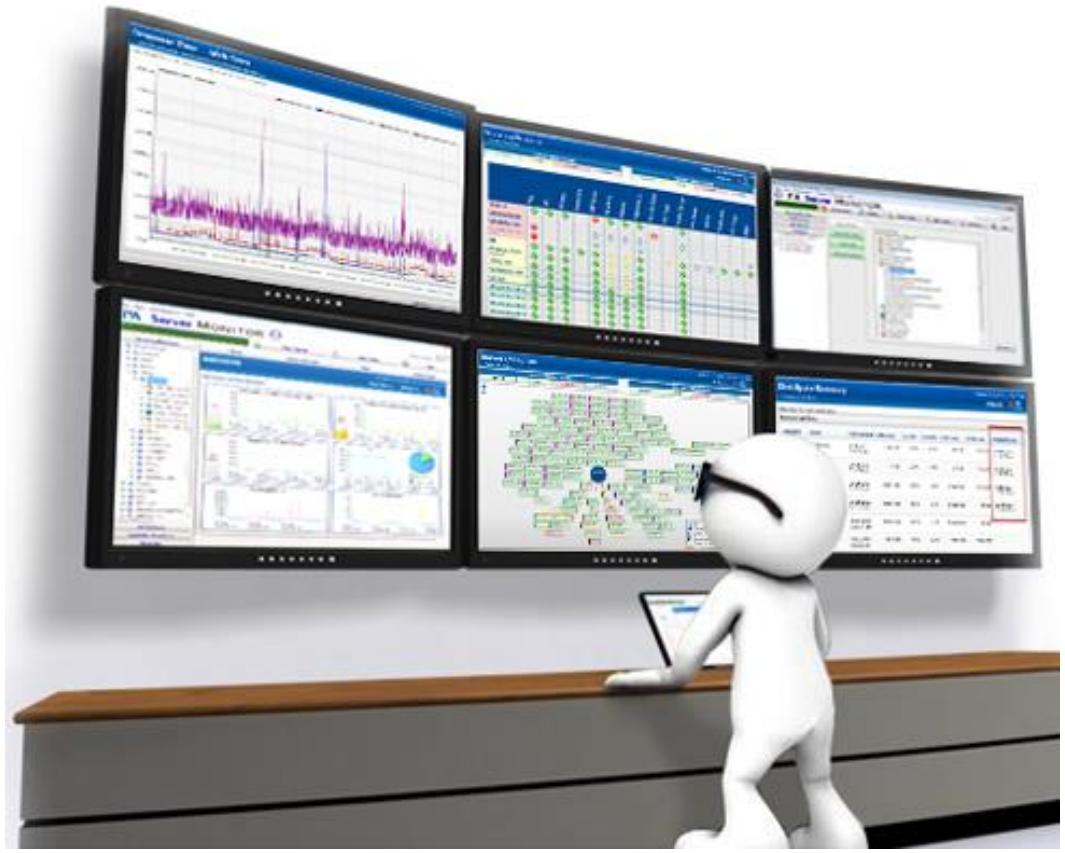
- Child Death Overview Panels (CDOPs) are tasked with reviewing deaths of children resident in their area
- There is a legal requirement to notify deaths to NCMD within 48 hours
- Following this a comprehensive, multi-agency information gathering process is carried out
- Information is collected on statutory forms and includes the views of families

NCMD Analysis

There are two ways in which data is analysed by NCMD. Real-time surveillance and analysis of reviewed data

Real-time surveillance includes data from the 48 hour notification

Analysis of reviewed data includes the full dataset after review by CDOP (often not available until many months after death)

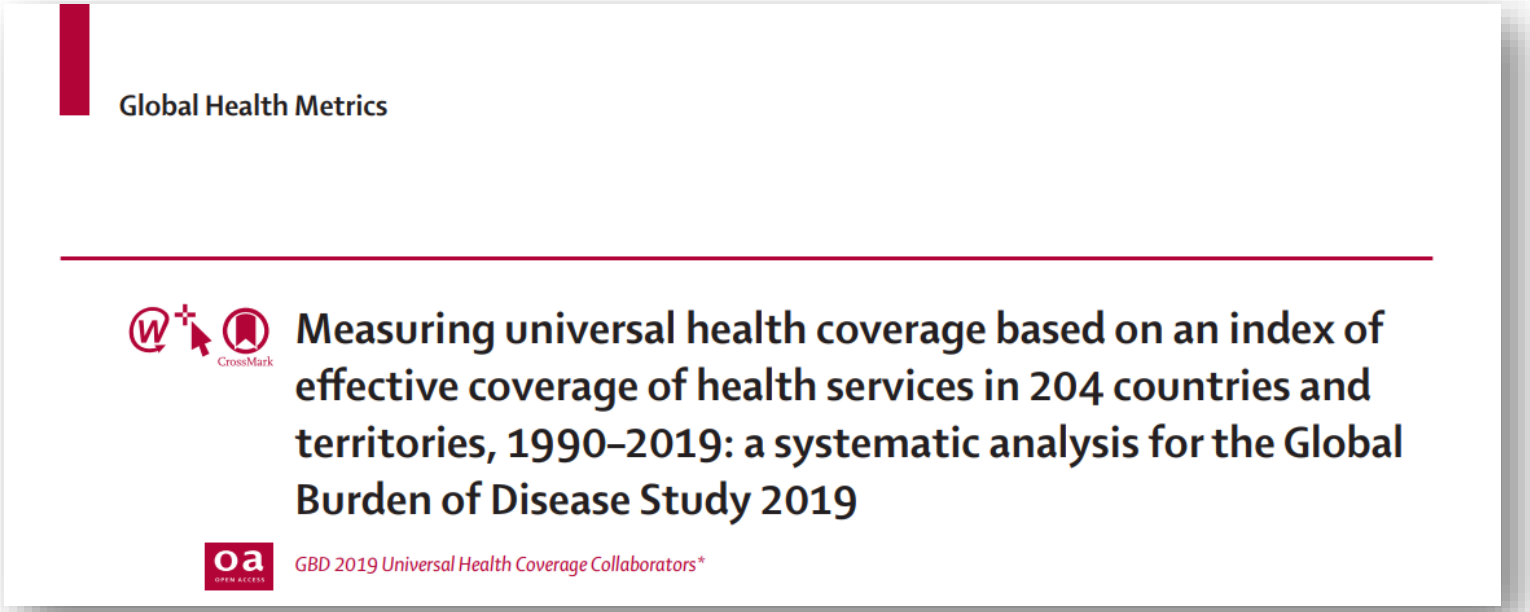


NCMD National Child Mortality Database

Perinatal events

“With children who had a neonatal illness being 14 times more likely to die all the way up to their 10th birthday, it’s clear that a whole-system approach will be central to tackling mortality. Across agencies, across health, education, social care and justice, we need to work together to consider every opportunity to improve. I am convinced that collectively we can make a difference.” – Dr Camilla Kingdon, President of the RCPCH

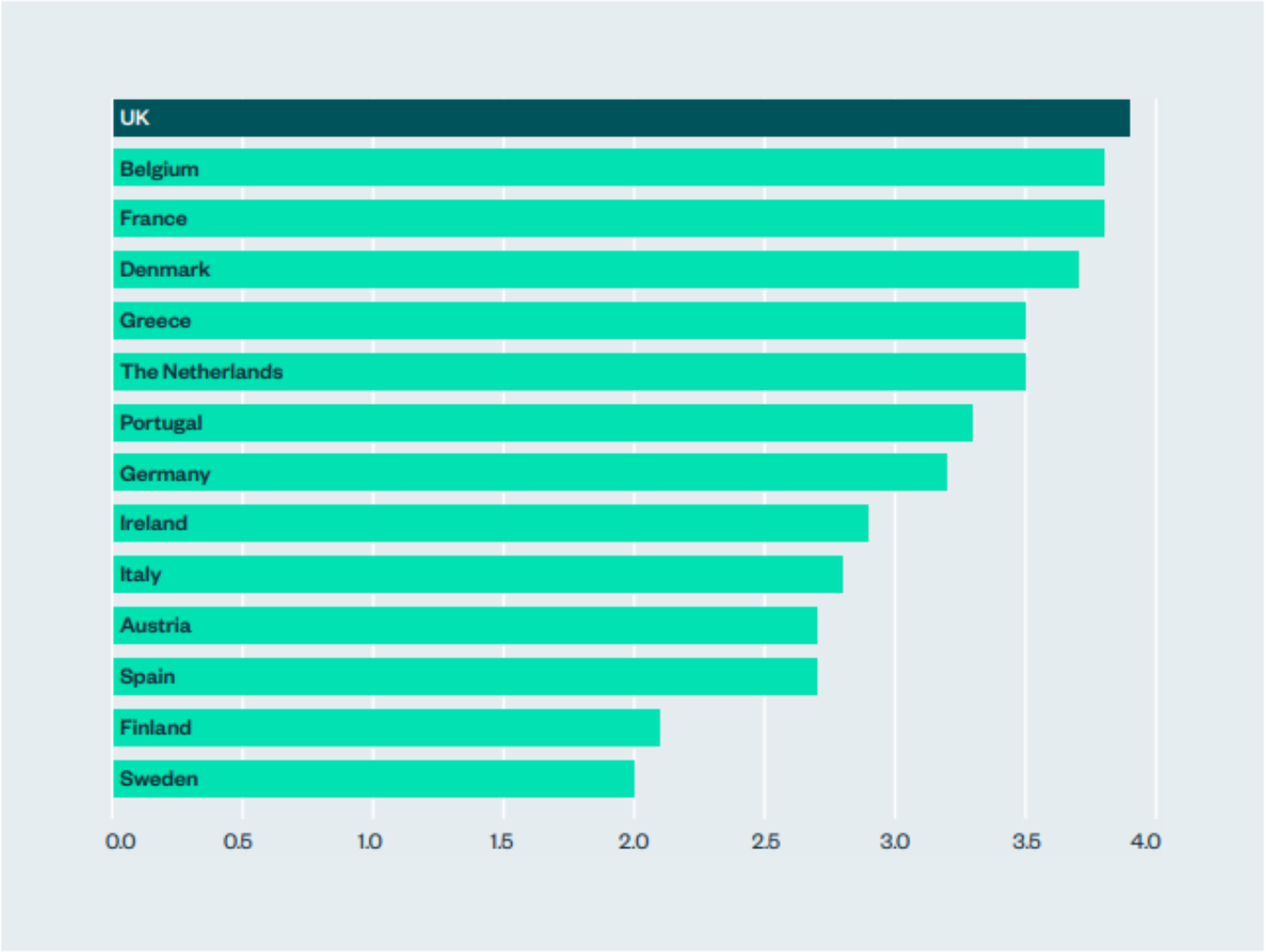
THE LANCET



The Global Burden of Disease Study reported the under 5 mortality rate in the UK in 2019 as 4.1 per 1000, the second highest amongst the 23 countries in Western Europe (average 3.4 per 1000), after Malta.

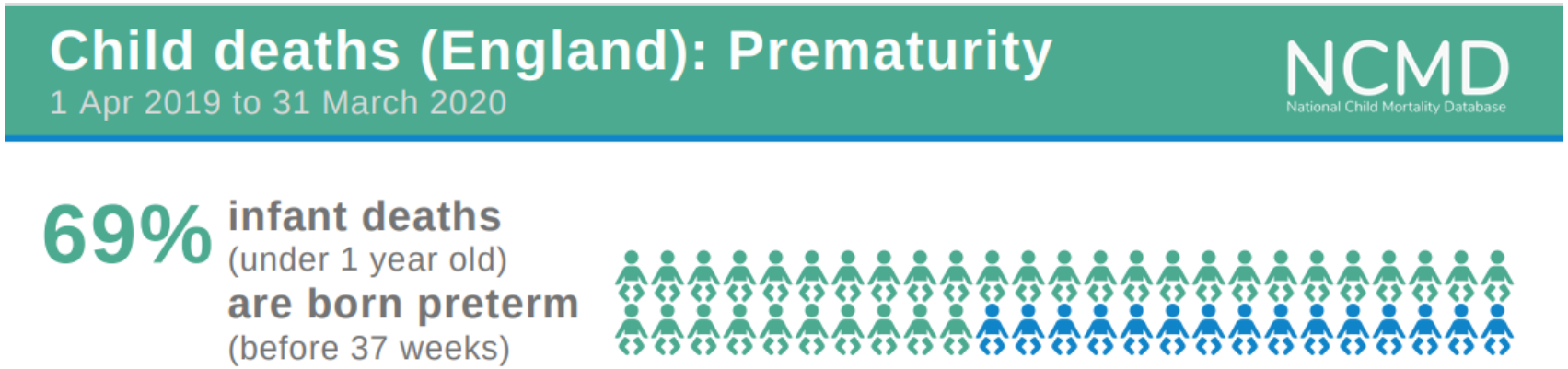
GBD 2019 Universal Health Coverage Collaborators. Measuring universal health coverage based on an index of effective coverage of health services in 204 countries and territories, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. Lancet. 2020 Oct 17;396(10258):1250-1284. doi: 10.1016/S0140-6736(20)30750-9. Epub 2020 Aug 27. PMID: 32861314; PMCID: PMC7562819.

Figure 3: International comparisons of infant mortality rate per 1,000 live births, 2018. *Source: Eurostat 2021.*



UK has the highest infant mortality rate in Western Europe

Number of infant death notifications received by CDOPs by gestational age at birth in weeks and age group at death, year ending 31 March 2020 (NCMD England)



1 in 3 deaths under 1 year born extremely preterm (22-27+6 wks)

Source: National Child Mortality Database; Second Annual Report NCMD_2nd_Annual_Report_June-2021_web-FINAL.pdf

Aim

- The aim of this work was to investigate how many deaths in the 1st 10 years of childhood are associated with neonatal illness
- The specific neonatal conditions involved
- The reasons the children died.

Exposure: Likely neonatal illness

All children who had received care in a neonatal unit after birth

+

Those who died in the first day of life prior to admission

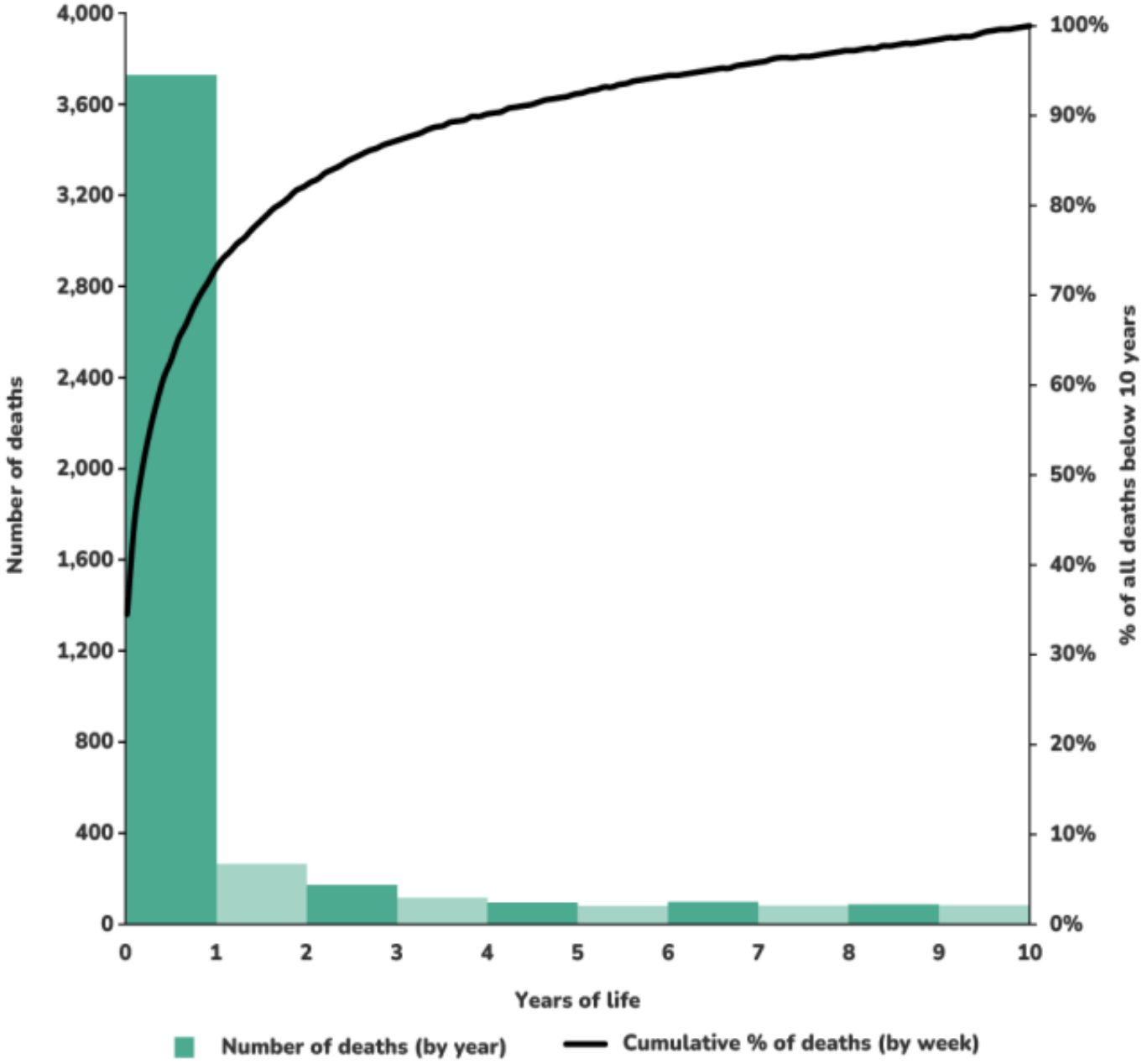
Population

- All deaths between the 1st April 2019 to the 31st March 2021 (24 months)
- Child death review data were matched with Neonatal records on BadgerNet.
- Evidence of specific neonatal conditions were identified from text in the BadgerNet or NCMD record.

The contribution of perinatal events to child mortality: Notified deaths

- For babies born alive, at or after 22 weeks gestation, who subsequently died before 10 years of age, half of the deaths occurred in children over one month old.
- Children who received additional care after birth made up 83% of children who died before their 1st birthday, 38% of deaths in the next 4 years, and 27% of deaths between the ages of 5 and 9.
- There is a clear association between childhood death following neonatal illness and learning disabilities. Over half of the children who died also had learning disabilities.
- From a public health perspective, it is possible that neonatal illness contributes to 72% of all deaths under 10 years of age.

Deaths through the first 9 years



Neonatal Conditions

Figure 4: Proportion of deaths, by the presence of any neonatal condition, by year of death

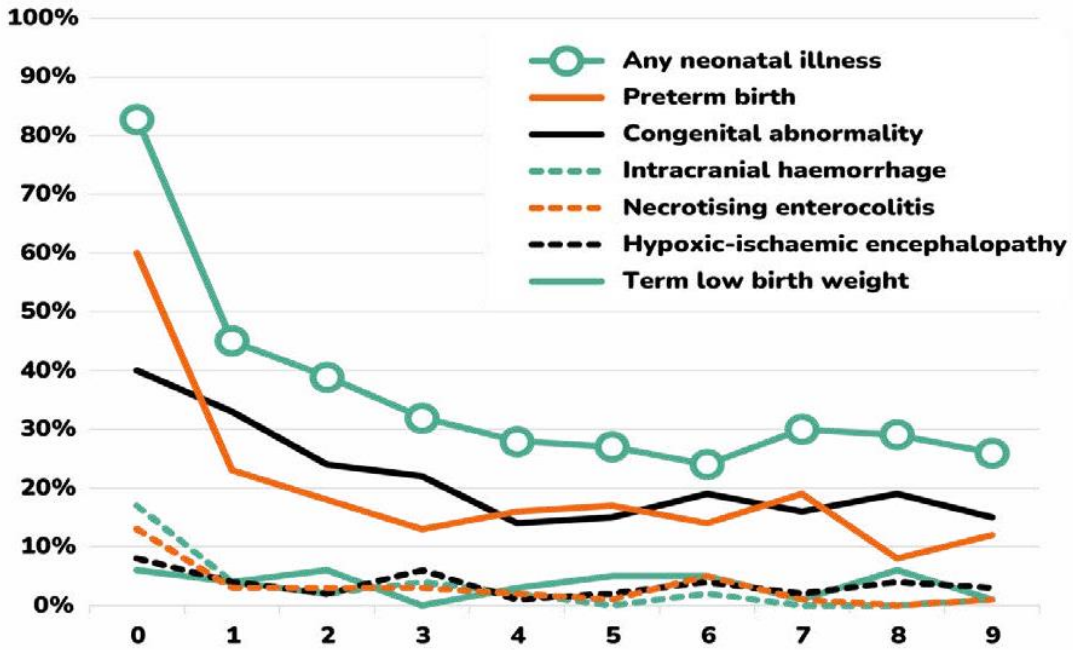


Table 8: Neonatal conditions of all deaths of children aged less than 10 years in England, 1 April 2019 to 31 March 2021, split by their age at death

Characteristic	Age at death			p-value**
	<1 year	1-4 years	5-9 years	
All deaths	3730	659	440	-
Any Evidence of Neonatal Illness	3083 (82.7%)	253 (38.4%)	120 (27.3%)	<0.001
Specific Neonatal Conditions*				
Low Birthweight (Term births only)	223 (6.0%)	24 (3.6%)	16 (3.6%)	0.011
Preterm	2244 (60.2%)	124 (18.8%)	61 (13.9%)	<0.001
Hypoxic-Ischaemic Encephalopathy	304 (8.3%)	18 (2.7%)	14 (3.2%)	<0.001
Congenital Abnormality	1503 (40.3%)	171 (26.0%)	75 (17.1%)	<0.001
Intracranial Haemorrhage	600 (16.1%)	19 (2.9%)	-	<0.001
NEC	401 (10.8%)	19 (2.9%)	-	<0.001

Number are n (%)

* Children without evidence were assumed to not have the characteristic

** A p-value is a measure of the probability that an observed difference could have occurred just by random chance. The lower the p-value, the greater the statistical significance of the observed difference.

Contribution of children with perinatal illness to overall mortality

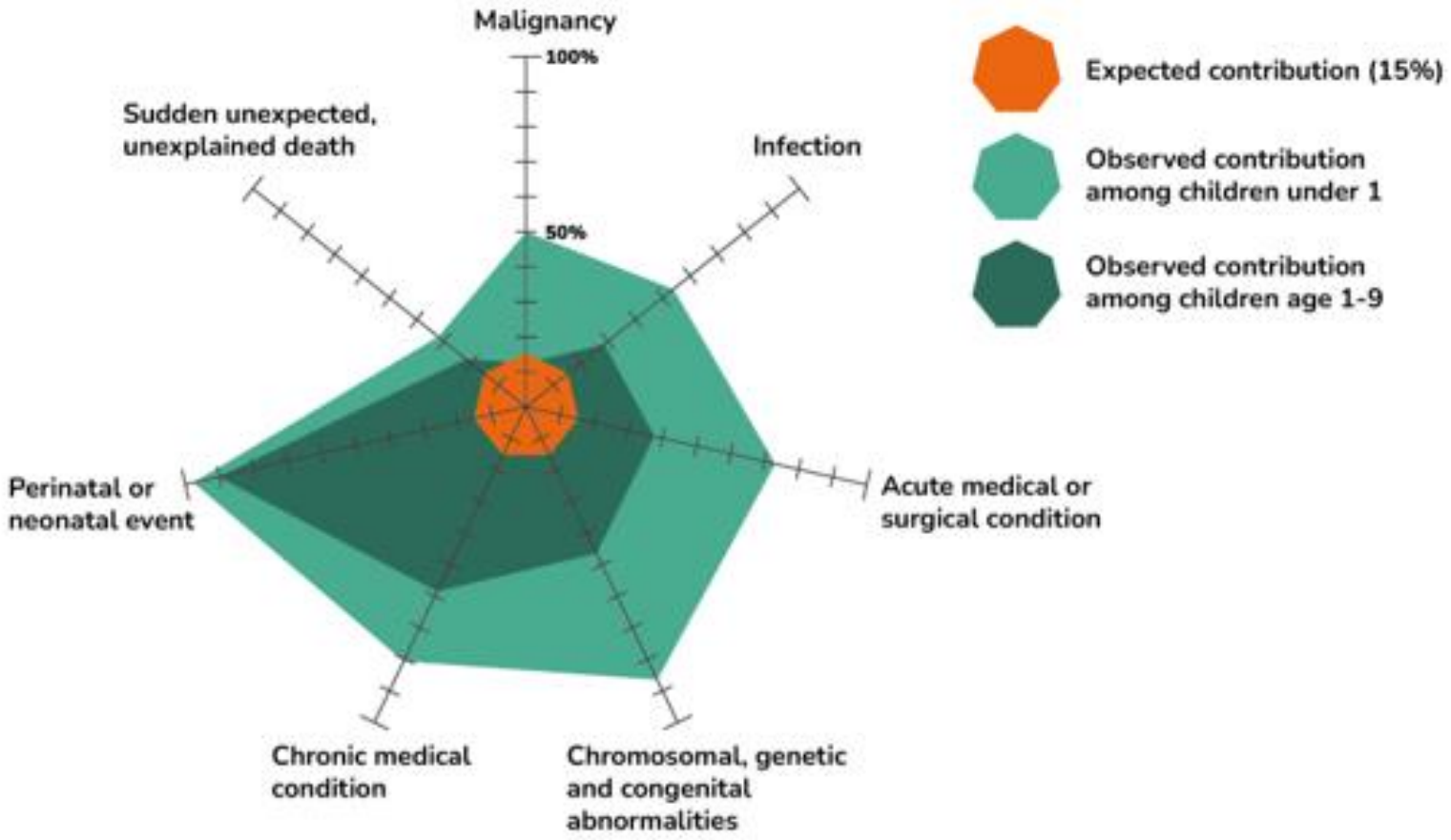


Table 7: Relative Risk of death, and estimated population impact, of neonatal illness on all cause child mortality before 10 years, over a 2 year period of 1 April 2019 to 31 March 2021

Age at death	Neonatal Illness		No Neonatal Illness		Relative Risk (95% CI)	Population Attributable Risk Fraction (95% CI)
	Deaths	Est Population at risk*	Deaths	Population		
All ages (0-9 years)	3456	1,874,997	1373	19,296,082	13.82 (13.00-14.71)	66.4% (64.9% to 67.9%)
<1 year	3083	190,478	647	1,030,532	25.78 (23.69-28.06)	79.4% (78.0% to 81.8%)
1-4 years	253	749,049	406	4,118,801	3.69 (3.12-4.37)	29.3% (24.3% to 33.9%)
5-9 years	120	935,470	320	5,146,749	2.08 (1.72-2.52)	14.3% (9.7% to 18.6%)

*Derived from ONS 2019 Population Estimates, and estimated for number of children at risk over 24 months.

Link with learning disabilities

Table 6: Proportion of deaths with learning disabilities or other developmental impairment or disability, split by age and neonatal illness

Disabilities identified during Review	Age at death		
	<1 year	1-4 years	5-9 years
Learning disabilities identified			
Neonatal Illness	-	-	71/120 (59.2%)
No evidence of Neonatal Illness	-	-	107/320 (33.4%)
p-value*	-	-	<0.001
Learning disabilities or other developmental impairment or disability			
Neonatal Illness	209/3083 (6.8%)	140/253 (55.3%)	82/120 (68.3%)
No evidence of Neonatal Illness	30/647 (4.6%)	93/406 (22.9%)	134/320 (41.9%)
p-value	0.043	<0.001	<0.001

* A p-value is a measure of the probability that an observed difference could have occurred just by random chance. The lower the p-value, the greater the statistical significance of the observed difference.

Regional disparities

	All Ages (0-9 years)	p-value*	Age at death		$P_{interaction}$**
			<1 year	1-9 years	
Region		**0.022**			**0.008**
East Midlands	284 (73.0%)		252 (82.1%)	32 (39.0%)	
East of England	325 (70.5%)		282 (81.7%)	43 (37.1%)	
London	651 (73.4%)		599 (86.4%)	52 (26.8%)	
North East	144 (68.3%)		127 (82.5%)	17 (29.8%)	
North West	493 (71.4%)		437 (80.9%)	56 (37.1%)	
South East	443 (69.4%)		399 (83.1%)	44 (27.9%)	
South West	250 (69.3%)		214 (79.6%)	36 (39.1%)	
West Midlands	496 (76.8%)		445 (84.6%)	51 (42.5%)	
Yorkshire and Humber	370 (67.9%)		328 (78.9%)	42 (32.6%)	

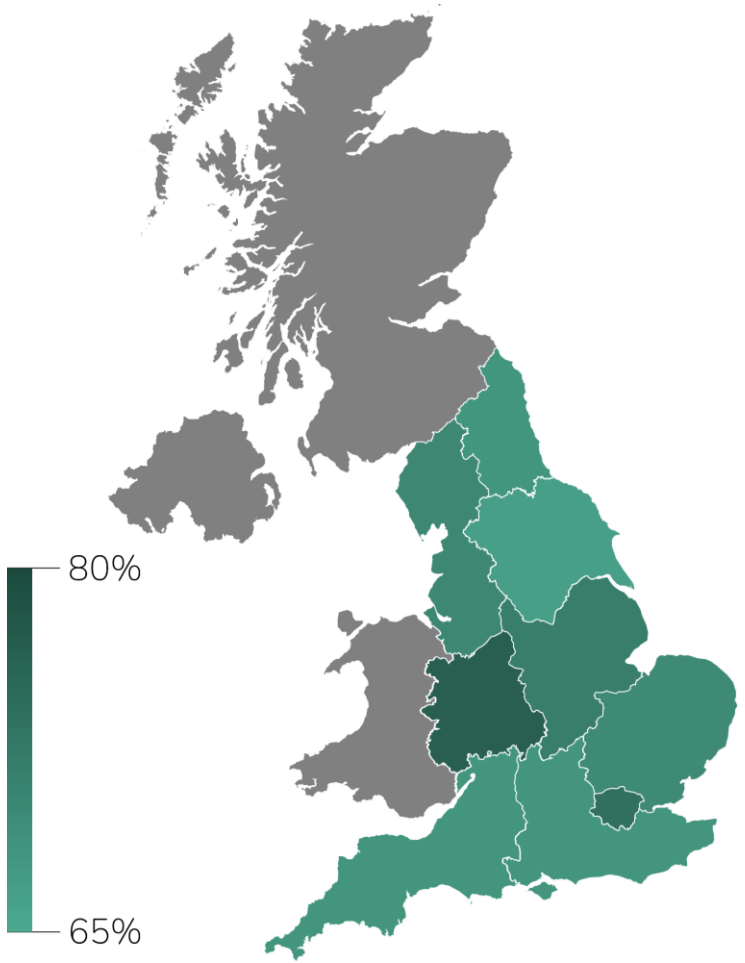


Table 2: Proportion of deaths in children aged less than 10 years in England linked to neonatal illness, 1 April 2019 to 31 March 2021, split by ethnicity

	All Ages (0-9 years)		Age at death		
			<1 year	1-9 years	
	Number (%)	p-value*	Number (%)	Number (%)	$P_{interaction}$**
Ethnicity*		0.008			0.003
Asian or Asian British	586 (74.6%)		511 (87.2%)	75 (37.5%)	
Black or Black British	271 (77.2%)		252 (88.7%)	19 (28.4%)	
Mixed	186 (70.5%)		167 (80.7%)	19 (33.3%)	
Other	73 (64.0%)		68 (86.1%)	5 (14.3%)	
White	1897 (70.5%)		1679 (81.1%)	218 (35.2%)	

Number are n (%). Due to small numbers, comparisons are between deaths under and over 1 year of age

* Ethnicity is grouped based on groupings used in the 2011 Census

* A p-value is a measure of the probability that an observed difference could have occurred just by random chance. The lower the p-value, the greater the statistical significance of the observed difference.

** Pinteraction .is the probability that the relationship between neonatal illness and age is different for different ethnic groups.

Table 4: Proportion of deaths in children aged less than 10 years in England linked to neonatal illness, 1 April 2019 to 31 March 2021, split by social deprivation decile

Characteristic	All Ages	p-value**	Age at death		$P_{interaction}$**
			<1 year	1-9 years	
IMD*		**0.131**			**0.054**
1-2 (Most deprived)	1224 (74.0%)		1083 (82.8%)	141 (40.8%)	
3-4	793 (70.9%)		720 (80.7%)	73 (32.2%)	
5-6	619 (70.8%)		554 (84.1%)	65 (30.2%)	
7-8	439 (70.9%)		388 (84.7%)	51 (31.7%)	
9-10 (Least deprived)	344 (68.9%)		304 (83.3%)	40 (29.9%)	

Number are n (%). Due to small numbers, comparisons are between deaths under and over 1 year of age

* Index of Multiple Deprivation (IMD)

** A p-value is a measure of the probability that an observed difference could have occurred just by random chance. The lower the p-value, the greater the statistical significance of the observed difference.

** Pinteraction is the probability that the relationship between neonatal illness and age is different for different measures of deprivation.

The contribution of perinatal events to child mortality: Reviewed deaths

- Immaturity/prematurity related conditions caused 78% of deaths, 13% were caused by perinatal asphyxia, 4% were caused by a perinatally acquired infection, and 4% were due to other causes.

- In 17% of deaths, there was planned palliative care, and, of these deaths, the majority (93%) occurred within a hospital trust.

- Modifiable factors were identified in 34% of deaths.

- Learning points or issues were identified in almost half (49%) of child death reviews.

Perinatal/Neonatal Events

Table 9: Number of reviews categorised as Perinatal/neonatal event by sub-category and age at death, where the review occurred between 1 April 2019 and 31 March 2021

	Number (%) of child death reviews that were completed between 1 April 2019 and 31 March 2021			
	0 – 27 days	28 – 364 days	Over 1 year	Total
Immaturity/prematurity related	1153	179	10	1342 (78%)
Perinatal asphyxia	192	13	15	220 (13%)
Perinatally acquired infection	68	*	*	72 (4%)
Other	54	9	*	64 (4%)
Total	**1490**	**208**	**28**	**1726 (100%)**

28 reviews were excluded where sub-category of death was not known or unclear

Place of Death

Table 10: Number of reviews categorised as Perinatal/neonatal event by place of death, where the review occurred between 1 April 2019 and 31 March 2021

Place of death	Number (%) of child death reviews that were completed between 1 April 2019 and 31 March 2021
Home	28 (2%)
Hospice	20 (1%)
Hospital trust	1644 (97%)
Emergency Department	32 (2%)
Hospital ward	67 (4%)
Labour ward/delivery suite	552 (32%)
Midwifery Unit	37 (2%)
Neonatal Unit	891 (52%)
PICU	59 (3%)
Other hospital area (Operating Theatre, AICU)	6 (<1%)
Other	8 (<1%)
Total	**1700 (100%)**

26 reviews were excluded where place of death was not known/not stated

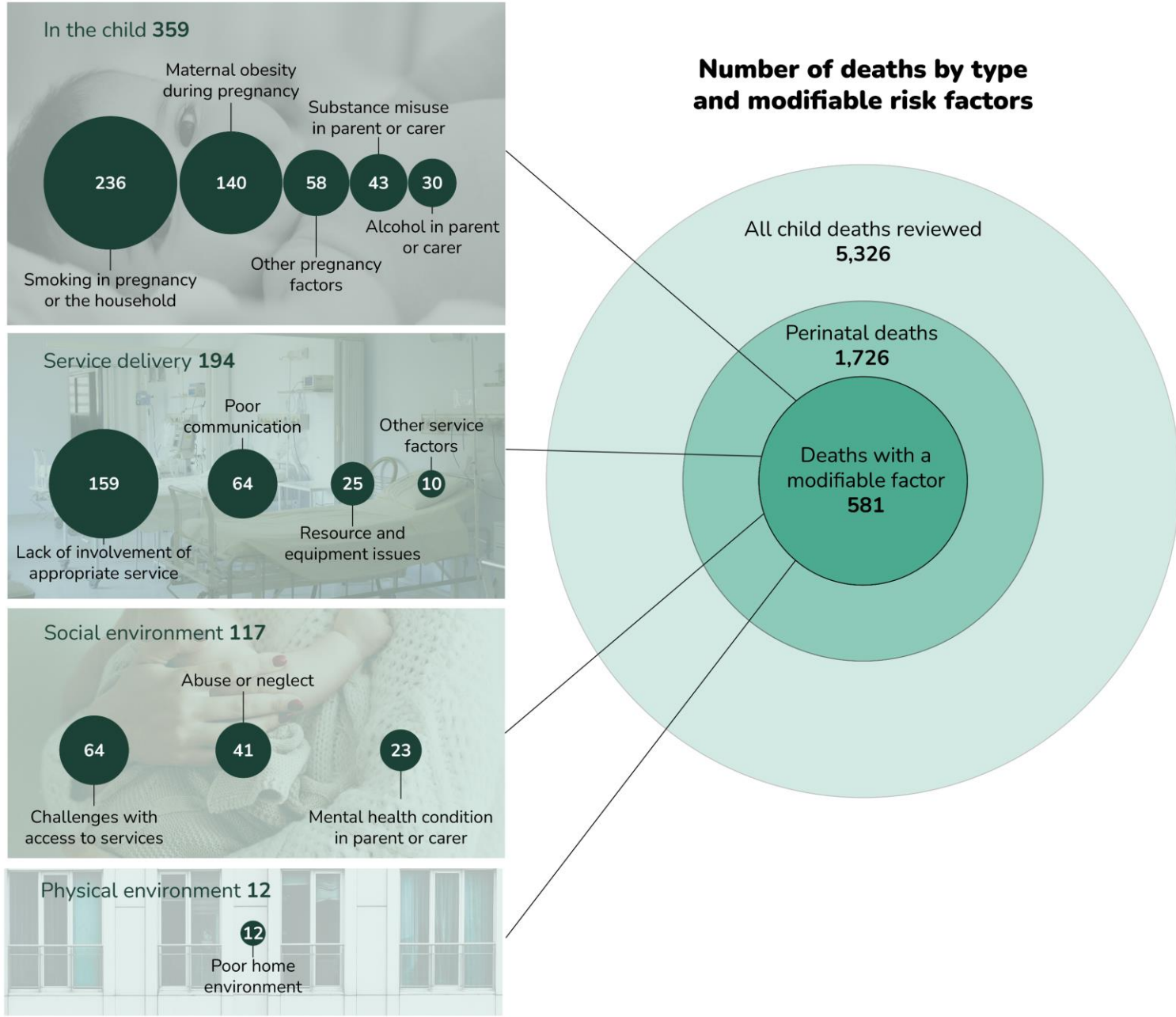
"Other" includes abroad and public place

Modifiable Factors

Table 13: Number of reviews categorised as Perinatal/neonatal event by sub-category and modifiable factors identified, where the review occurred between 1 April 2019 and 31 March 2021

	Number of child death reviews that were completed between 1 April 2019 and 31 March 2021	Number (%) of reviews that identified modifiable factors
Immaturity/prematurity related	1329	412 (31%)
Perinatal asphyxia	219	113 (52%)
Perinatally acquired infection	72	28 (39%)
Other	91	28 (31%)
Total	**1711 (100%)**	**581 (34%)**

15 reviews were excluded where the CDOP indicated that inadequate information was available to make a judgement on modifiable factors (see Section 5: Limitations for further details on these cases)


In the child 359
Maternal obesity during pregnancy
Substance misuse in parent or carer
236
140
58
43
30
Alcohol in parent or carer
Smoking in pregnancy or the household
Other pregnancy factors
Service delivery 194
Poor communication
Other service factors
159
64
25
10
Lack of involvement of appropriate service
Resource and equipment issues
Social environment 117
Abuse or neglect
64
41
23
Challenges with access to services
Mental health condition in parent or carer
Physical environment 12
12
Poor home environment
Number of deaths by type and modifiable risk factors
All child deaths reviewed
5,326
Perinatal deaths
1,726
Deaths with a modifiable factor
581

Learning Points from CDOPs

In Relation to:

- **Antenatal Care**
- **Labour and birth**
- **Neonatal period**
- **Postnatal period**
- **Cross cutting themes:**
  - **Communication and Language**
  - **Bereavement support and services**

Recommendations from the report

- **Predict and prevent preterm birth**
- **Optimise the baby prior to and following preterm birth**
- **Improve perinatal care to reduce mortality and brain injury after birth**
- **Community and Social Interventions**
- **Additional Data Collection and Processes**

The families who shared their stories for inclusion in this report so that we may learn, and improve services provided in the future

CDOPs and CDR Professionals
NCMD Support Team

Sarah Harris Child Bereavement UK
Caroline Lee-Davey Bliss
Charlotte Bevan Sands
Kate Fitch Tommy's
Robert Wilson Joint Sands/Tommy's Policy Unit
Nigel Simpson
Helen Mactier and Wendy Tyler BAPM
Camilla Kingdon RCPCH

Forget Me Not Children's Hospice
Greater Manchester's Smokefree Pregnancy programme
SW ODN – PERIPrem Case Study
Clevermed

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Sylvia Stoianova National Child Mortality Database, University of Bristol
Vicky Sleap National Child Mortality Database, University of Bristol
Nikki Glover UCL Partners
Peter Fleming National Child Mortality Database, University of Bristol
Grace Rossouw National Child Mortality Database, University of Bristol

Further information

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Perinatal events

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