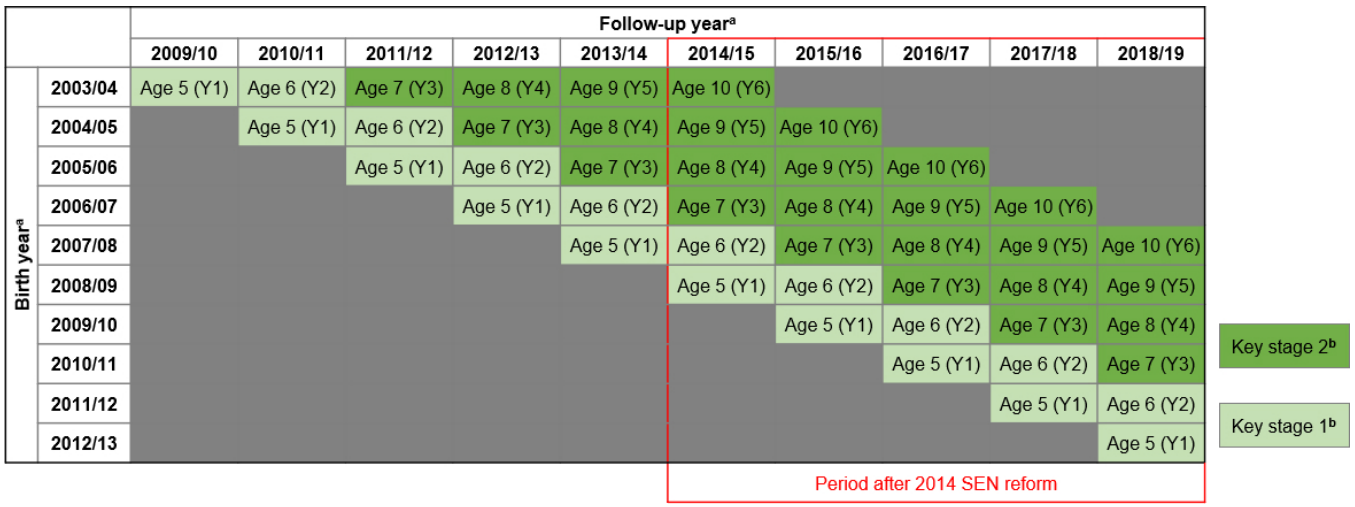
Supplementary Appendix 1

Supplementary Table 1: Pupil-level national pupil database censuses and school types included in this study

Census name (collection frequency)	School type	Examples of school type[a]	Dates of inclusion in study	Included in specialist provision[b]
School census (termly)	Mainstream schools: provide education for students with a wide range of abilities and aptitudes	Maintained, academy and free schools	2009/10–2018/19	No
	Special schools[c]: provide education specifically for students with special educational needs	Maintained and non-maintained special schools, including hospital special schools and academy special schools	2009/10–2018/19	Yes
	Pupil referral units (a type of alternative provision[d]): cater for children who aren't able to attend a mainstream school, often for reasons related to their behaviour	Maintained pupil referral units, alternative provision academies, alternative provision free schools	2013/14–2018/19	Yes
Pupil referral unit census (annual collection)	Pupil referral units (a type of alternative provision[d]): cater for children who aren't able to attend a mainstream school, often for reasons related to their behaviour	Maintained pupil referral units, alternative provision academies, alternative provision free schools	2009/10–2012/13	Yes
Alternative provision census (annual collection)	Alternative provision[d]: provision outside of school due to reasons such as exclusion from school on a permanent or fixed term basis, unable to attend school for medical reasons, or awaiting placement in a maintained school	Schools not maintained by an authority for whom the local authority is paying full tuition fees; including some independent schools, hospitals and non-maintained special schools	2009/10–2018/19	Yes

[a]School descriptors: maintained = local authority run schools (also known as community schools), academies and free schools = not-for-profit schools that are independent from the local authority; [b]Specialist provision is a category of recorded SEN provision in this study, encompassing establishments that provide an alternative educational environment for pupils who, for a variety of reasons, cannot attend mainstream school; [c]Special schools are tailored towards children with healthcare needs (including palliative care) and disabilities. Almost all children attending special school have an EHCP. Provision at special school differs from provision in a mainstream school due to availability of medical staff, teaching assistants, facilities (for example, padded classrooms, hoists and an on-site aqua therapy room), class sizes as well as alternative assessments and qualifications. In this study, 0.72% of children attended special school in Year 1 (rising to 1.34% of children in Year 6). [d]Alternative provision (including pupil referral units) provides an educational and social environment for pupils who for a variety of reasons cannot attend mainstream school, for example behavioural challenges in a mainstream setting that could disrupt other students. That vast majority of pupils at alternative provision have either a record of SEN support or an EHCP. In this study, 0.25% of children attended alternative provision in Year 6. In this study, 0.07% of children attended alternative provision in Year 1 (rising to 0.34% of children in Year 6).

Supplementary Figure 1: Expected age at entry into primary school years 1 to 6, by birth year and follow-up year



SEN = special educational needs, Y = year; [a]defined according to the academic calendar, i.e. from 1 September to 31 August; [b]key stages represent blocks of set subjects and standards (the 'national curriculum') followed by, and the basis of examinations for, most pupils in state-funded schools in England and Wales.

Supplementary Table 2: ICD-10 codes used to define major congenital anomalies[a], by system-specific subgroup and selected conditions

Subgroup Condition	Definition (ICD-10 codes)[b]	
	Include	**Exclude**
Nervous system anomalies		
Any nervous system anomaly	Q00-07	Q0461[c], Q0780[c], Q0782[c]
Microcephaly	Q02	
Hydrocephaly	Q03	
Spina Bifida	Q05	
Eye anomalies		
Any eye anomaly	Q10-15	Q101-103, Q105, Q135,
Anophthalmos/Microphthalmos	Q110-112	
Congenital cataract	Q120	
Congenital glaucoma	Q150	
Ear, face, and neck anomalies		
Any ear, face, and neck anomaly	Q16-18	Q170-175, Q179, Q180-182, Q184-187, Q1880[c], Q189
Cardiac anomalies		
Any cardiac anomaly	Q20-26	Q2111[c], Q246, Q2541[c], Q250 if gestational age <37 weeks, Q256 if gestational age <37 weeks, Q261
Severe cardiac anomaly	Q200-201, Q203-204, Q212-213, Q220, Q224-226, Q230, Q232-234, Q251-252, Q262	
Respiratory anomalies		
Any respiratory anomaly	Q300, Q32-34	Q320, Q322, Q3300[c], Q331, Q336
Choanal atresia	Q300	
Orofacial anomalies		
Any orofacial anomaly	Q35-37	Q357
Cleft lip	Q36	
Cleft palate	Q350-356, Q358-359	
Cleft lip and palate	Q37	
Digestive anomalies		
Any digestive system anomaly	Q38-Q45, Q790	Q381-382, Q3850[c], Q400-401, Q4021[c], Q430, Q4320[c], Q4381[c], Q4382[c], Q444, Q4583[c]
Oesophageal atresia	Q390, Q391	
Small intestine atresia	Q410-418	
Hirschsprung's disease	Q431	
Biliary atresia	Q442	
Anorectal malformation	As defined in Ford *et al.* (2022) [1]	
Congenital diaphragmatic hernia	As defined in Peppa *et al.* (2022) [2]	
Abdominal wall anomaly		
Any abdominal anomaly	Q792, Q793, Q795	
Omphalocele	Q792	
Gastroschisis	Q793	
Urinary system anomalies		
Any urinary system anomaly	Q60-64, Q794	Q610, Q627, Q633
Bladder exstrophy	Q640-641	
Genital anomalies		
Any genital anomaly	Q50-52, Q54-56	Q501-502, Q505, Q523, Q525, Q527, Q544, Q5520[c], Q5521[c]
Hypospadias	Q540, Q541-543, Q548, Q549	
Indeterminate sex	Q56	

Continued

Supplementary Table 2: Continued

Subgroup Condition	Definition (ICD-10 codes)[b]	
	Include	**Exclude**
Limb anomalies		
Any limb anomaly	Q65-74	Q653-656, Q658-Q659, Q661-669, Q670-678, Q680, Q6810[c], Q6821[c], Q683-685, Q7400[c]
Limb reduction defect	Q71-73	
Chromosomal anomalies[d]		
Any chromosomal anomaly	Q90-93, Q96-99	
Down syndrome	Q90	
Turner syndrome	Q96	
Other anomalies[e]	Q271-274, Q278-279, Q28, Q301-303, Q308-313, Q318-319, Q750-751, Q754-755, Q758-759, Q761-764, Q766-767, Q768-769, Q77, Q78, Q791, Q796, Q798-799, Q80, Q81, Q820-824, Q828-829, Q83, Q840-844, Q846, Q848-849, Q85, Q86, Q87, Q890-894, Q897-898, Q952-955, Q958-959	

ICD-10=International Classification of Diseases 10th Revision; [a]children without any such codes in hospital or mortality records during the first year of life were defined as not having any MCA; [b]definitions based on 'European Network of Population-based Registries for Congenital Malformations' (EUROCAT) Guide 1.5 [3], unless specified; [c]we were unable to exclude these ICD-10 codes in our dataset; [d]subset of the EUROCAT "genetic disorders sub-group"; [e]included in the definition of "any MCA" alongside the 12 system-specific anomalies.

References

1. Ford K, Peppa M, Zylbersztejn A, Curry JI, Gilbert R. Birth prevalence of anorectal malformations in England and 5-year survival: a national birth cohort study. Arch Dis Child. 2022;107: 758. https://doi.org/10.1136/archdischild-2021-323474

2. Peppa M, De Stavola BL, Loukogeorgakis S, Zylbersztejn A, Gilbert R, De Coppi P. Congenital diaphragmatic hernia subtypes: Comparing birth prevalence, occurrence by maternal age, and mortality in a national birth cohort. Paediatric and Perinatal Epidemiology. 2022;n/a. https://doi.org/10.1111/ppe.12939

3. EUROCAT. EUROCAT Guide 1.5: Chapter 3.3 EUROCAT Subgroups of Congenital Anomalies. 2022 [cited 18 Jul 2022]. Available: https://eu-rd-platform.jrc.ec.europa.eu/system/files/public/eurocat/Guide_1.5_Chapter_3.3.pdf.

Supplementary Table 3: Prevalence of major congenital anomalies identified in this study compared with data from five England-based registries[a]

	This study[b]: prevalence per 10,000 live births (95% CI)	**Registry data[a]: prevalence per 10,000 live and still births (95% CI; all values rounded to the nearest 0.5)**
Total population of children (N)	**6,180,400 births between 1 September 2003 to 31 August 2013**	**2,000,000–2,020,000 births between 2004 and 2014**
Any MCA	354.7 (353.3–356.2)	185.5 (183.5–187.0)
Nervous system anomalies		
Any nervous system anomaly	19.4 (19.0–19.7)	11.0 (10.5–11.5)
Isolated nervous system anomaly	11.8 (11.6–12.1)	[c]
Microcephaly	3.8 (3.6–4.0)	1.5 (1.9–1.5)
Hydrocephaly	4.2 (4.0–4.3)	3.5 (3.5–4.0)
Spina Bifida	2.2 (2.1–2.3)	1.5 (1.5–2.0)
Eye anomalies		
Any eye anomaly	7.1 (6.9–7.3)	3.0 (2.5–3.0)
Isolated eye anomaly	4.6 (4.4–4.8)	[c]
Anophthalmos/Microphthalmos	1.1 (1.0–1.2)	0.5 (0.5–0.5)
Congenital cataract	2.1 (1.9–2.2)	1.0 (0.5–1.0)
Congenital Glaucoma	0.7 (0.7–0.8)	0 cases registered
Ear, face, and neck anomalies		
Any ear, face, and neck	2.7 (2.6–2.8)	1.5 (1.0–1.5)
Isolated ear, face, and neck	1.6 (1.5–1.7)	[c]
Cardiac anomalies		
Any cardiac anomaly	87.0 (86.2–87.7)	53.0 (52.0–54.0)
Isolated cardiac anomaly	60.0 (59.4–60.6)	[c]
Severe cardiac	23.1 (22.7–23.5)	21.0 (20.5–22.0)
Respiratory anomalies		
Any respiratory anomaly	6.4 (6.2–6.6)	3.5 (3.5–4.0)
Isolated respiratory anomaly	3.4 (3.3–3.6)	[c]
Choanal atresia	1.3 (1.2–1.4)	<5 cases registered
Orofacial anomalies		
Any orofacial anomaly	15.6 (15.2–15.9)	14.0 (13.5–14.5)
Isolated orofacial anomaly	10.5 (10.3–10.8)	[c]
Cleft lip	4.2 (4.0–4.4)	[c]
Cleft palate	7.9 (7.7–8.1)	6.0 (5.5–6.0)
Cleft lip and palate	5.9 (5.7–6.1)	[c]
Digestive system anomalies		
Any digestive anomaly	26.0 (25.6–26.5)	15.5 (15.0–16.5)
Isolated digestive anomaly	15.1 (14.8–15.4)	[c]
Oesophageal atresia	2.7 (2.6–2.8)	2.0 (2.0–2.5)
Small intestine atresia	3.1 (3.0–3.3)	<5 cases registered
Hirschsprung's disease	2.4 (2.3–2.6)	1.5 (1.5–1.5)
Biliary atresia	0.7 (0.6–0.8)	0 cases registered
Anorectal malformation	2.5 (2.3–2.6)	[c]
Congenital diaphragmatic hernia	2.8 (2.6–2.9)	2.5 (2.0–2.5)
Abdominal wall anomalies		
Any abdominal wall anomaly	6.7 (6.4–6.9)	6.0 (6.0–6.5)
Isolated abdominal wall anomaly	4.6 (4.5–4.8)	[c]
Omphalocele	2.1 (2.0–2.2)	1.5 (1.5–2.0)
Gastroschisis	4.1 (4.0–4.3)	4.5 (4.0–4.5)

Continued

Supplementary Table 3: Continued

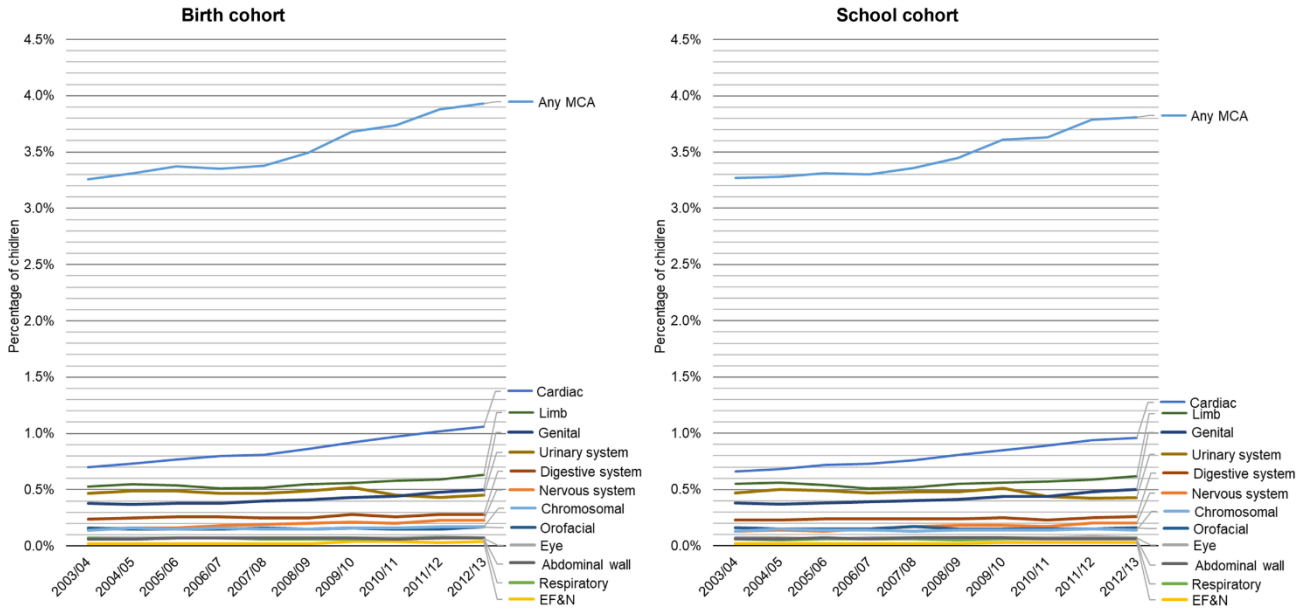
	This study[b]: prevalence per 10,000 live births (95% CI)	Registry data[a]: prevalence per 10,000 live and still births (95% CI; all values rounded to the nearest 0.5)
Total population of children (N)	**6,180,400 births between 1 September 2003 to 31 August 2013**	**2,000,000–2,020,000 births between 2004 and 2014**
Urinary system anomalies		
Any urinary system anomaly	47.2 (46.6–47.7)	23.5 (22.5–24.0)
Isolated urinary system anomaly	40.0 (39.5–40.5)	[c]
Bladder exstrophy	1.1 (1.1–1.2)	0.5 (0.5–0.5)
Genital anomalies		
Any genital anomaly	41.9 (41.4–42.4)	19.0 (18.5–19.5)
Isolated genital anomaly	36.0 (35.5–36.5)	[c]
Hypospadias	28.7 (28.3–29.1)	15.0 (14.5–15.5)
Indeterminate sex	1.7 (1.6–1.8)	0.5 (0.5–1.0)
Limb anomalies		
Any limb anomaly	55.6 (55.0–56.2)	28.5 (27.5–29.0)
Isolated limb anomaly	46.8 (46.2–47.3)	[c]
Limb reduction defect	3.5 (3.4–3.7)	4.0 (3.5–4.5)
Chromosomal anomalies		
Any chromosomal anomaly	15.8 (15.4–16.1)	[c]
Isolated chromosomal anomaly	5.4 (5.2–5.6)	[c]
Down syndrome	10.1 (9.9–10.4)	11.5 (11.0–12.0)
Turner syndrome	0.6 (0.6–0.7)	1.0 (1.0–1.5)

MCA = major congenital anomaly;[a]combined average of the prevalence per 10,000 live births and still births across five England-based registries from 2004 to 2013, inclusive (including genetic anomalies): East Midlands & South Yorkshire (data gap in 2013), Northern England, South West England, Thames Valley, Wessex [1]; [b]MCAs identified in hospital and mortality records before the age of 1 year among children born in NHS-funded hospitals in England between 1 September 2003 to 31 August 2013; [c]comparator data not available.

References

1. European Platform on Rare Diseases Registration. Prevalence charts and tables. 2023 [cited 3 Jun 2023]. Available: https://eu-rd-platform.jrc.ec.europa.eu/eurocat/eurocat-data/.

Supplementary Figure 2: Prevalence of any identified MCAs and MCA subgroups in the birth and school cohorts, by birth year[a]



EF&N = ear, face and neck anomalies, MCA = major congenital anomaly; [a]defined according to the academic calendar (i.e. 2003/04 includes 1 September 2003 to 31 August 2004, inclusive).

Supplementary Table 4: Number and proportion of children in the birth cohort (and alive at age five years) and the school cohort, by birth characteristics

		School cohort		Not in the school cohort[a]	
	Birth cohort survivors N (%)	N	% of birth cohort survivors	N	% of birth cohort survivors
Total	6,150,877	5,189,922	84.4	960,955	15.6
Birth year[b]					
2003/04	563,921	451,420	80.1	112,501	19.9
2004/05	576,193	476,102	82.6	100,091	17.4
2005/06	587,269	490,098	83.5	97,171	16.5
2006/07	597,539	499,899	83.7	97,640	16.3
2007/08	626,003	506,763	81.0	119,240	19.0
2008/09	624,394	527,775	84.5	96,619	15.5
2009/10	638,738	554,159	86.8	84,579	13.2
2010/11	652,799	567,194	86.9	85,605	13.1
2011/12	649,787	566,420	87.2	83,367	12.8
2012/13	634,234	550,092	86.7	84,142	13.3
Sex					
Female	3,146,768	2,668,336	84.8	478,432	15.2
Male	2,993,216	2,521,586	84.2	471,630	15.8
Missing	10,893	0	0.0	10,893	100.0
Region of residence					
North East	235,861	219,524	93.1	16,337	6.9
North West	650,383	572,635	88.0	77,748	12.0
Yorkshire and the Humber	476,208	438,161	92.0	38,047	8.0
East Midlands	378,006	343,111	90.8	34,895	9.2
West Midlands	463,163	417,085	90.1	46,078	9.9
East of England	464,822	412,577	88.8	52,245	11.2
London	799,122	639,527	80.0	159,595	20.0
South East	726,273	630,998	86.9	95,275	13.1
South West	438,393	396,149	90.4	42,244	9.6
Missing	1,518,646	1,120,155	73.8	398,491	26.2
Ethnic group					
White	4,193,153	3,632,233	86.6	560,920	13.4
Black	307,350	251,723	81.9	55,627	18.1
Asian	600,823	491,680	81.8	109,143	18.2
Mixed/multiple	219,785	182,998	83.3	36,787	16.7
Other	166,433	128,282	77.1	38,151	22.9
Missing	663,333	503,006	75.8	160,327	24.2
IMD groups					
1 Most deprived	1,129,032	1,026,359	90.9	102,673	9.1
2	881,819	792,960	89.9	88,859	10.1
3	730,658	652,110	89.2	78,548	10.8
4	652,141	576,170	88.4	75,971	11.6
5 Least deprived	639,392	557,453	87.2	81,939	12.8
Missing	2,117,835	1,584,870	74.8	532,965	25.2

IMD = index of multiple deprivation, MCA = major congenital anomaly; [a]these children do not appear in the school cohort for a variety of reasons, including attendance at a non-state-funded school, missed links between their hospital and school records, emigration and death before school entry; [b]defined according to the academic calendar (i.e. 2003/04 includes 1 September 2003 to 31 August 2004, inclusive).

Supplementary Table 5: Number and proportion of children from birth cohort present in school cohort, by MCA, system-specific subgroup[a] and selected conditions

	Birth cohort N	Birth cohort survivors at age 5[b] N	Present in any school year 1–6		
			N	% of birth cohort	% of birth cohort survivors
No MCA	5961151	5942586	5008598	84.0	84.3
Any MCA	219249	208558	181324	82.7	86.9
Nervous system anomalies					
Any nervous system anomaly	11971	9877	8676	72.5	87.8
Isolated nervous system anomaly	7322	6452	5656	77.2	87.7
Microcephaly	2349	1871	1659	70.6	88.7
Hydrocephaly	2574	2111	1883	73.2	89.2
Spina Bifida	1343	1169	1022	76.1	87.4
Eye anomalies					
Any eye anomaly	4404	4028	3599	81.7	89.3
Isolated eye anomaly	2849	2826	2510	88.1	88.8
Anophthalmos/ Microphthalmos	672	553	506	75.3	91.5
Congenital cataract	1271	1183	1069	84.1	90.4
Congenital Glaucoma	448	428	390	87.1	91.1
Ear, face, and neck anomalies					
Any ear, face, and neck anomaly	1663	1572	1336	80.3	85.0
Isolated ear, face, and neck anomaly	993	987	829	83.5	83.7
Cardiac anomalies					
Any cardiac anomaly	53741	47691	41857	77.9	87.8
Isolated cardiac anomaly	37080	34065	29745	80.2	87.3
Severe cardiac	14260	11676	10337	72.5	88.5
Respiratory anomalies					
Any respiratory anomaly	3941	3448	2997	76.0	86.9
Isolated respiratory anomaly	2121	2038	1755	82.7	86.1
Choanal atresia	804	722	647	80.5	89.6
Orofacial anomalies					
Any orofacial anomaly	9611	9131	7993	83.2	87.5
Isolated orofacial anomaly	6503	6474	5653	86.9	87.3
Cleft lip	2589	2538	2242	86.6	88.3
Cleft palate	4891	4591	4030	82.4	87.8
Cleft lip and palate	3656	3473	3051	83.5	87.8
Digestive anomalies					
Any digestive anomaly	16098	14367	12544	77.9	87.3
Isolated digestive anomaly	9343	8825	7657	82.0	86.8
Oesophageal atresia	1664	1464	1297	77.9	88.6
Small intestine atresia	1934	1767	1545	79.9	87.4
Hirschsprung's disease	1508	1448	1298	86.1	89.6
Biliary atresia	440	395	346	78.6	87.6
Anorectal malformation	1524	1019	896	58.8	87.9
Congenital diaphragmatic hernia	1713	1540	1363	79.6	88.5
Abdominal wall anomalies					
Any abdominal wall anomaly	4110	3818	3352	81.6	87.8
Isolated abdominal wall anomaly	2854	2757	2398	84.0	87.0
Omphalocele	1286	1131	968	75.3	85.6
Gastroschisis	2539	2400	2141	84.3	89.2
Urinary system anomalies					
Any urinary system anomaly	29158	27958	24203	83.0	86.6
Isolated urinary system anomaly	24703	24234	20949	84.8	86.4
Bladder exstrophy	704	699	596	84.7	85.1

Continued

Supplementary Table 5: Continued

	Birth cohort N	Birth cohort survivors at age 5[b] N	Present in any school year 1–6		
			N	% of birth cohort	% of birth cohort survivors
Genital anomalies					
Any genital anomaly	25914	25426	21923	84.6	86.2
Isolated genital anomaly	22252	22152	19093	85.8	86.2
Hypospadias	17727	17492	15243	86.0	87.1
Indeterminate sex	1044	925	637	61.0	68.9
Limb anomalies					
Any limb anomaly	34366	33381	28951	84.2	86.7
Isolated limb anomaly	28911	28752	24911	86.2	86.6
Limb reduction defect	2180	2038	1783	81.8	87.5
Chromosomal anomalies					
Any chromosomal anomaly	9734	8122	7208	74.0	88.7
Isolated chromosomal anomaly	3330	2983	2626	78.9	88.0
Down syndrome	6260	5768	5157	82.4	89.4
Turner syndrome	381	349	305	80.1	87.4

MCA = major congenital anomaly; [a]*any* groups contain children with and without additional anomalies in other system-specific subgroups, *isolated* groups do not contain children with anomalies in other system-specific subgroups; [b]a random number of deaths between 1 and 7 is imputed for isolated ear, face, and neck anomaly and bladder exstrophy groups due to suppressed death count (see Table 1).

Supplementary Table 6: Number and proportion of children in the school cohort with SEN provision recorded during years 1 and/or 2 (key stage 1), by category of recorded SEN provision, MCA, system-specific subgroups[a] and selected conditions

	School cohort[b]	Any recorded SEN	SEN support in mainstream school	EHCP in mainstream school	Specialist provision
	N	N (%)	N (%)	N (%)	N (%)
No MCA	4,977,468	1022149 (20.5)	919893 (18.5)	62007 (1.2)	40249 (0.8)
Any MCA	180,308	66134 (36.7)	44795 (24.8)	11429 (6.3)	9910 (5.5)
Nervous system anomalies					
Any nervous system anomaly	8,646	6072 (70.2)	2254 (26.1)	1433 (16.6)	2385 (27.6)
Isolated nervous system anomaly	5,634	3648 (64.7)	1544 (27.4)	802 (14.2)	1302 (23.1)
Microcephaly	1,652	1407 (85.2)	290 (17.6)	232 (14.0)	885 (53.6)
Hydrocephaly	1,876	1476 (78.7)	511 (27.2)	392 (20.9)	573 (30.5)
Spina Bifida	1,022	766 (75.0)	345 (33.8)	297 (29.1)	124 (12.1)
Eye anomalies					
Any eye anomaly	3,580	2240 (62.6)	1125 (31.4)	540 (15.1)	575 (16.1)
Isolated eye anomaly	2,497	1341 (53.7)	890 (35.6)	285 (11.4)	166 (6.6)
Anophthalmos/Microphthalmos	504	414 (82.1)	155 (30.8)	115 (22.8)	144 (28.6)
Congenital cataract	1,061	704 (66.4)	393 (37.0)	145 (13.7)	166 (15.6)
Congenital Glaucoma	388	272 (70.1)	147 (37.9)	70 (18.0)	55 (14.2)
Ear, face, and neck anomalies					
Any ear, face, and neck anomaly	1,328	638 (48.0)	383 (28.8)	115 (8.7)	140 (10.5)
Isolated ear, face, and neck anomaly	827	291 (35.2)	236 (28.5)	33 (4.0)	22 (2.7)
Cardiac anomalies					
Any cardiac anomaly	41,647	19964 (47.9)	11392 (27.4)	4578 (11.0)	3994 (9.6)
Isolated cardiac anomaly	29,589	11202 (37.9)	8373 (28.3)	1603 (5.4)	1226 (4.1)
Severe cardiac	10,278	5387 (52.4)	2874 (28.0)	1344 (13.1)	1169 (11.4)
Respiratory anomalies					
Any respiratory anomaly	2,983	1452 (48.7)	833 (27.9)	327 (11.0)	292 (9.8)
Isolated respiratory anomaly	1,746	594 (34.0)	459 (26.3)	74 (4.2)	61 (3.5)
Choanal atresia	647	370 (57.2)	158 (24.4)	102 (15.8)	110 (17.0)
Orofacial anomalies					
Any orofacial anomaly	7,950	4059 (51.1)	2963 (37.3)	575 (7.2)	521 (6.6)
Isolated orofacial anomaly	5,617	2474 (44.0)	2103 (37.4)	229 (4.1)	142 (2.5)
Cleft lip	2,227	788 (35.4)	649 (29.1)	74 (3.3)	65 (2.9)
Cleft palate	4,015	2290 (57.0)	1525 (38.0)	391 (9.7)	374 (9.3)
Cleft lip and palate	3,031	1708 (56.4)	1332 (43.9)	207 (6.8)	169 (5.6)
Digestive anomalies					
Any digestive anomaly	12,487	5313 (42.5)	3397 (27.2)	1022 (8.2)	894 (7.2)
Isolated digestive anomaly	7,615	2421 (31.8)	1959 (25.7)	268 (3.5)	194 (2.5)
Oesophageal atresia	1,292	647 (50.1)	421 (32.6)	151 (11.7)	75 (5.8)
Small intestine atresia	1,541	723 (46.9)	365 (23.7)	198 (12.8)	160 (10.4)
Hirschsprung's disease	1,291	591 (45.8)	358 (27.7)	124 (9.6)	109 (8.4)
Biliary atresia	342	156 (45.6)	111 (32.5)	23 (6.7)	22 (6.4)
Anorectal malformation	895	325 (36.3)	230 (25.7)	49 (5.5)	46 (5.1)
Congenital diaphragmatic hernia	1,360	714 (52.5)	466 (34.3)	155 (11.4)	93 (6.8)
Abdominal wall anomalies					
Any abdominal wall anomaly	3,339	1143 (34.2)	924 (27.7)	130 (3.9)	89 (2.7)
Isolated abdominal wall anomaly	2,389	699 (29.3)	616 (25.8)	47 (2.0)	36 (1.5)
Omphalocele	965	365 (37.8)	256 (26.5)	68 (7.0)	41 (4.2)
Gastroschisis	2,133	686 (32.2)	607 (28.5)	51 (2.4)	28 (1.3)
Urinary system anomalies					
Any urinary system anomaly	24,044	7592 (31.6)	5822 (24.2)	949 (3.9)	821 (3.4)
Isolated urinary system anomaly	20,804	5677 (27.3)	4857 (23.3)	487 (2.3)	333 (1.6)
Bladder exstrophy	592	224 (37.8)	166 (28.0)	36 (6.1)	22 (3.7)

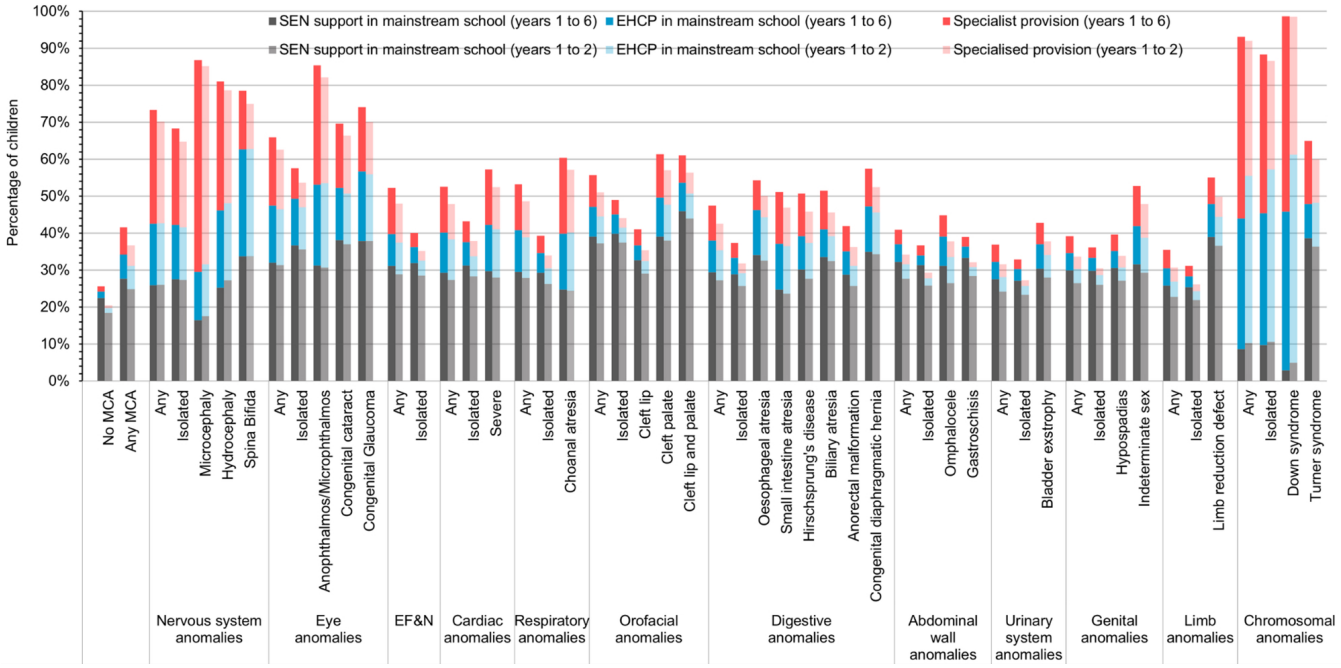
Continued

Supplementary Table 6: Continued

	School cohort[b]	Any recorded SEN	SEN support in mainstream school	EHCP in mainstream school	Specialist provision
	N	N (%)	N (%)	N (%)	N (%)
Genital anomalies					
Any genital anomaly	21,817	7351 (33.7)	5783 (26.5)	822 (3.8)	746 (3.4)
Isolated genital anomaly	18,996	5792 (30.5)	4946 (26.0)	502 (2.6)	344 (1.8)
Hypospadias	15,164	5144 (33.9)	4119 (27.2)	545 (3.6)	480 (3.2)
Indeterminate sex	635	304 (47.9)	186 (29.3)	60 (9.4)	58 (9.1)
Limb anomalies					
Any limb anomaly	28,769	8832 (30.7)	6547 (22.8)	1211 (4.2)	1074 (3.7)
Isolated limb anomaly	24,747	6464 (26.1)	5425 (21.9)	596 (2.4)	443 (1.8)
Limb reduction defect	1,770	882 (49.8)	647 (36.6)	140 (7.9)	95 (5.4)
Chromosomal anomalies					
Any chromosomal anomaly	7,173	6603 (92.1)	736 (10.3)	3242 (45.2)	2625 (36.6)
Isolated chromosomal anomaly	2,611	2260 (86.6)	277 (10.6)	1217 (46.6)	766 (29.3)
Down syndrome	5,130	5055 (98.5)	253 (4.9)	2891 (56.4)	1911 (37.3)
Turner syndrome	305	183 (60.0)	111 (36.4)	36 (11.8)	36 (11.8)

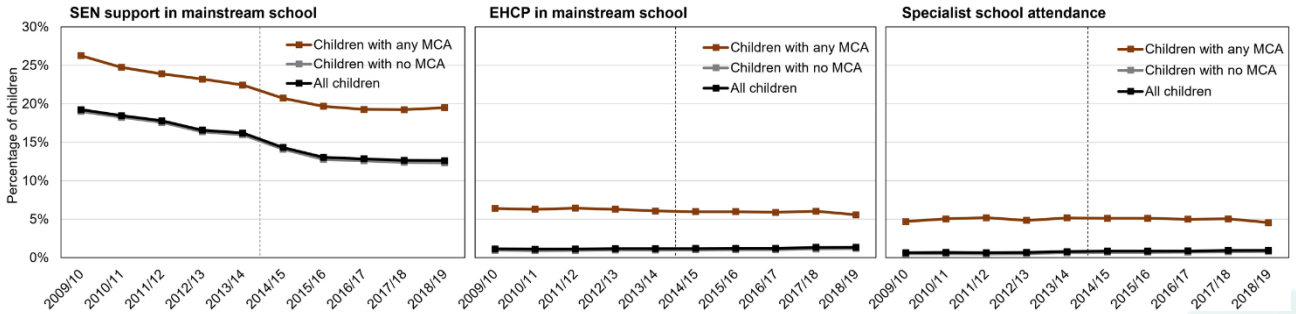
EHCP = education, health and care plan, MCA=major congenital anomaly, SEN= Special Educational Needs; [a]*any* groups contain children with and without additional anomalies in other system-specific subgroups, *isolated* groups do not contain children with anomalies in other system-specific subgroup; [b]Children in the school cohort that are present in year 1 and/or year 2 of the education data.

Supplementary Figure 3: Percentage of children in the school cohort with different categories of recorded SEN provision, by MCA, system-specific subgroup and selected conditions: comparing results for years 1 to 6 with years 1 to 2 (key stage 1 only)



EF&N = ear, face, and neck anomalies, EHCP = education, health and care plan, MCA = major congenital anomaly, SEN = special educational needs.

Supplementary Figure 4: Prevalence of recorded SEN provision in year 1, by academic year and MCA status: split by category of SEN provision (dotted line represents approximate timing of the SEN reforms)



EHCP = Education, health and care plan, MCA = major congenital anomaly, SEN = special educational needs.

Supplementary Table 7: Prevalence of (a) any recorded SEN provision, (b) SEN support, (c) EHCP and (d) specialist provision attendance in year 1 before and after 2014 SEN reforms, by MCA, system-specific subgroup[a] and selected conditions

	Before reforms[b]		After reforms[c]		
S7(a) Any recorded SEN	**Total N**	**Any recorded SEN provision N (%)**	**Total N**	**Any recorded SEN provision N (%)**	**Absolute % difference (99% CI)**
No MCA	2311628	437223 (18.9)	2643436	388885 (14.7)	−4.23 (−4.32, −4.15)
Any MCA	79242	28023 (35.4)	99965	30777 (30.8)	−4.83 (−5.40, −4.25)
Nervous system anomalies					
Any nervous system anomaly	3519	2487 (70.7)	5069	3387 (66.8)	−5.11 (−7.72, −2.50)
Isolated nervous system anomaly	2383	1558 (65.4)	3230	1945 (60.2)	−6.01 (−9.35, −2.66)
Microcephaly	759	665 (87.6)	892	736 (82.5)	−7.00 (−11.57, −2.44)
Hydrocephaly	793	625 (78.8)	1068	820 (76.8)	−4.13 (−9.17, 0.91)
Spina Bifida	426	324 (76.1)	592	424 (71.6)	−5.62 (−12.79, 1.54)
Eye anomalies					
Any eye anomaly	1660	1010 (60.8)	1893	1126 (59.5)	−2.29 (−6.52, 1.94)
Isolated eye anomaly	1192	623 (52.3)	1283	622 (48.5)	−4.23 (−9.40, 0.93)
Anophthalmos/Microphthalmos	209	164 (78.5)	290	239 (82.4)	1.73 (−7.70, 11.17)
Congenital cataract	497	318 (64.0)	557	354 (63.6)	−1.11 (−8.74, 6.53)
Congenital Glaucoma	191	129 (67.5)	191	127 (66.5)	−2.41 (−14.80, 9.98)
Ear, face, and neck anomalies					
Any ear, face, and neck anomaly	484	207 (42.8)	834	377 (45.2)	1.79 (−5.48, 9.07)
Isolated ear, face, and neck anomaly	308	92 (29.9)	513	156 (30.4)	0.19 (−8.30, 8.67)
Cardiac anomalies					
Any cardiac anomaly	17094	8156 (47.7)	24146	10218 (42.3)	−6.06 (−7.33, −4.78)
Isolated cardiac anomaly	12282	4634 (37.7)	17122	5280 (30.8)	−7.14 (−8.58, −5.70)
Severe cardiac	4518	2320 (51.4)	5668	2657 (46.9)	−5.25 (−7.81, −2.70)
Respiratory anomalies					
Any respiratory anomaly	1382	658 (47.6)	1567	658 (42.0)	−6.25 (−10.95, −1.55)
Isolated respiratory anomaly	804	271 (33.7)	921	226 (24.5)	−9.33 (−14.95, −3.70)
Choanal atresia	282	144 (51.1)	365	218 (59.7)	7.70 (−2.41, 17.80)
Orofacial anomalies					
Any orofacial anomaly	3777	1848 (48.9)	4143	1878 (45.3)	−3.92 (−6.81, −1.04)
Isolated orofacial anomaly	2718	1137 (41.8)	2872	1046 (36.4)	−5.53 (−8.88, −2.17)
Cleft lip	1043	361 (34.6)	1173	319 (27.2)	−7.49 (−12.54, −2.43)
Cleft palate	1947	1066 (54.8)	2049	1080 (52.7)	−2.60 (−6.66, 1.45)
Cleft lip and palate	1453	769 (52.9)	1577	802 (50.9)	−2.42 (−7.09, 2.25)
Digestive anomalies					
Any digestive anomaly	5655	2307 (40.8)	6737	2449 (36.4)	−4.90 (−7.15, −2.65)
Isolated digestive anomaly	3651	1136 (31.1)	3922	904 (23.0)	−8.21 (−10.83, −5.59)
Oesophageal atresia	596	274 (46.0)	677	325 (48.0)	0.66 (−6.51, 7.82)
Small intestine atresia	703	319 (45.4)	816	341 (41.8)	−4.64 (−11.16, 1.89)
Hirschsprung's disease	617	264 (42.8)	667	276 (41.4)	−2.02 (−9.09, 5.05)
Biliary atresia	153	70 (45.8)	187	61 (32.6)	−13.30 (−26.91, 0.30)
Anorectal malformation	418	147 (35.2)	475	135 (28.4)	−6.98 (−15.00, 1.03)
Congenital diaphragmatic hernia	594	322 (54.2)	756	336 (44.4)	−10.29 (−17.29, −3.28)
Abdominal wall anomalies					
Any abdominal wall anomaly	1503	492 (32.7)	1822	450 (24.7)	−8.18 (−12.24, −4.13)
Isolated abdominal wall anomaly	1112	300 (27.0)	1268	249 (19.6)	−7.40 (−11.87, −2.93)
Omphalocele	450	162 (36.0)	511	162 (31.7)	−4.54 (−12.40, 3.31)
Gastroschisis	993	305 (30.7)	1128	232 (20.6)	−10.29 (−15.16, −5.42)
Urinary system anomalies					
Any urinary system anomaly	11476	3257 (28.4)	12455	3287 (26.4)	−2.13 (−3.61, −0.64)
Isolated urinary system anomaly	10143	2479 (24.4)	10578	2251 (21.3)	−3.23 (−4.73, −1.73)

Continued

Supplementary Table 7: Continued

S7(a) Any recorded SEN	Before reforms[b] Total N	Before reforms[b] Any recorded SEN provision N (%)	After reforms[c] Total N	After reforms[c] Any recorded SEN provision N (%)	Absolute % difference (99% CI)
Bladder exstrophy	248	91 (36.7)	339	107 (31.6)	−5.22 (−15.43, 4.99)
Genital anomalies					
Any genital anomaly	9239	2862 (31.0)	12474	3436 (27.5)	−3.58 (−5.19, −1.97)
Isolated genital anomaly	8118	2250 (27.7)	10801	2590 (24.0)	−3.82 (−5.48, −2.16)
Hypospadias	6471	2022 (31.2)	8630	2387 (27.7)	−3.73 (−5.66, −1.80)
Indeterminate sex	269	120 (44.6)	359	148 (41.2)	−3.73 (−13.98, 6.53)
Limb anomalies					
Any limb anomaly	12829	3702 (28.9)	15769	4039 (25.6)	−3.37 (−4.73, −2.01)
Isolated limb anomaly	11218	2779 (24.8)	13406	2705 (20.2)	−4.65 (−6.03, −3.27)
Limb reduction defect	755	361 (47.8)	1001	448 (44.8)	−3.55 (−9.72, 2.63)
Chromosomal anomalies					
Any chromosomal anomaly	3285	2991 (91.1)	3682	3587 (97.4)	0.38 (−1.34, 2.11)
Isolated chromosomal anomaly	1344	1151 (85.6)	1201	1083 (90.2)	−0.63 (−4.20, 2.93)
Down syndrome	2389	2356 (98.6)	2543	2709 (106.5)	−0.54 (−1.45, 0.37)
Turner syndrome	145	82 (56.6)	157	86 (54.8)	−2.80 (−17.48, 11.88)

S7(b) SEN support in mainstream school	Before reforms[b] Total N	Before reforms[b] SEN support N (%)	After reforms[c] Total N	After reforms[c] SEN support N (%)	Absolute % difference (99% CI)
No MCA	2311628	402204 (17.4)	2643436	340095 (12.9)	−4.56 (−4.64, −4.48)
Any MCA	79242	19074 (24.1)	99965	19844 (19.9)	−4.38 (−4.89, −3.87)
Nervous system anomalies					
Any nervous system anomaly	3519	878 (25.0)	5069	1297 (25.6)	0.16 (−2.28, 2.59)
Isolated nervous system anomaly	2383	607 (25.5)	3230	876 (27.1)	1.27 (−1.77, 4.31)
Microcephaly	759	128 (16.9)	892	167 (18.7)	1.43 (−3.38, 6.24)
Hydrocephaly	793	227 (28.6)	1068	287 (26.9)	−2.49 (−7.85, 2.88)
Spina Bifida	426	143 (33.6)	592	195 (32.9)	−1.18 (−8.85, 6.50)
Eye anomalies					
Any eye anomaly	1660	516 (31.1)	1893	547 (28.9)	−2.64 (−6.59, 1.31)
Isolated eye anomaly	1192	420 (35.2)	1283	411 (32.0)	−3.50 (−8.38, 1.38)
Anophthalmos/Microphthalmos	209	63 (30.1)	290	82 (28.3)	−2.63 (−13.17, 7.92)
Congenital cataract	497	181 (36.4)	557	196 (35.2)	−1.61 (−9.20, 5.99)
Congenital Glaucoma	191	66 (34.6)	191	72 (37.7)	2.37 (−10.19, 14.93)
Ear, face, and neck anomalies					
Any ear, face, and neck anomaly	484	117 (24.2)	834	226 (27.1)	2.54 (−3.82, 8.90)
Isolated ear, face, and neck anomaly	308	70 (22.7)	513	130 (25.3)	2.32 (−5.54, 10.18)
Cardiac anomalies					
Any cardiac anomaly	17094	4732 (27.7)	24146	5548 (23.0)	−5.07 (−6.18, −3.95)
Isolated cardiac anomaly	12282	3520 (28.7)	17122	3859 (22.5)	−6.30 (−7.63, −4.97)
Severe cardiac	4518	1248 (27.6)	5668	1348 (23.8)	−4.24 (−6.47, −2.00)
Respiratory anomalies					
Any respiratory anomaly	1382	396 (28.7)	1567	345 (22.0)	−6.97 (−11.08, −2.86)
Isolated respiratory anomaly	804	206 (25.6)	921	177 (19.2)	−6.53 (−11.70, −1.35)
Choanal atresia	282	64 (22.7)	365	94 (25.8)	2.64 (−6.02, 11.31)
Orofacial anomalies					
Any orofacial anomaly	3777	1392 (36.9)	4143	1319 (31.8)	−5.25 (−7.99, −2.50)
Isolated orofacial anomaly	2718	979 (36.0)	2872	886 (30.8)	−5.27 (−8.51, −2.02)
Cleft lip	1043	296 (28.4)	1173	260 (22.2)	−6.27 (−11.03, −1.51)
Cleft palate	1947	757 (38.9)	2049	675 (32.9)	−6.29 (−10.18, −2.40)

Continued

Supplementary Table 7: Continued

S7(b) SEN support in mainstream school	Before reforms[b] Total N	Before reforms[b] SEN support N (%)	After reforms[c] Total N	After reforms[c] SEN support N (%)	Absolute % difference (99% CI)
Cleft lip and palate	1453	601 (41.4)	1577	621 (39.4)	−2.26 (−6.84, 2.33)
Digestive anomalies					
Any digestive anomaly	5655	1522 (26.9)	6737	1441 (21.4)	−5.79 (−7.78, −3.81)
Isolated digestive anomaly	3651	926 (25.4)	3922	704 (18.0)	−7.52 (−9.95, −5.09)
Oesophageal atresia	596	188 (31.5)	677	201 (29.7)	−2.71 (−9.31, 3.90)
Small intestine atresia	703	167 (23.8)	816	154 (18.9)	−5.36 (−10.74, 0.03)
Hirschsprung's disease	617	165 (26.7)	667	150 (22.5)	−4.59 (−10.75, 1.58)
Biliary atresia	153	50 (32.7)	187	43 (23.0)	−9.81 (−22.36, 2.75)
Anorectal malformation	418	102 (24.4)	475	84 (17.7)	−6.87 (−13.89, 0.16)
Congenital diaphragmatic hernia	594	215 (36.2)	756	214 (28.3)	−8.22 (−14.80, −1.64)
Abdominal wall anomalies					
Any abdominal wall anomaly	1503	416 (27.7)	1822	331 (18.2)	−9.62 (−13.39, −5.85)
Isolated abdominal wall anomaly	1112	280 (25.2)	1268	201 (15.9)	−9.38 (−13.64, −5.11)
Omphalocele	450	117 (26.0)	511	103 (20.2)	−6.00 (−13.00, 1.00)
Gastroschisis	993	279 (28.1)	1128	196 (17.4)	−10.84 (−15.52, −6.17)
Urinary system anomalies					
Any urinary system anomaly	11476	2568 (22.4)	12455	2371 (19.0)	−3.44 (−4.79, −2.09)
Isolated urinary system anomaly	10143	2164 (21.3)	10578	1866 (17.6)	−3.75 (−5.17, −2.33)
Bladder exstrophy	248	70 (28.2)	339	79 (23.3)	−4.99 (−14.42, 4.44)
Genital anomalies					
Any genital anomaly	9239	2300 (24.9)	12474	2623 (21.0)	−3.98 (−5.47, −2.49)
Isolated genital anomaly	8118	1967 (24.2)	10801	2184 (20.2)	−4.08 (−5.66, −2.51)
Hypospadias	6471	1636 (25.3)	8630	1875 (21.7)	−3.67 (−5.47, −1.87)
Indeterminate sex	269	76 (28.3)	359	88 (24.5)	−3.94 (−13.09, 5.21)
Limb anomalies					
Any limb anomaly	12829	2842 (22.2)	15769	2814 (17.8)	−4.40 (−5.62, −3.17)
Isolated limb anomaly	11218	2377 (21.2)	13406	2212 (16.5)	−4.73 (−6.02, −3.44)
Limb reduction defect	755	278 (36.8)	1001	320 (32.0)	−5.20 (−11.08, 0.68)
Chromosomal anomalies					
Any chromosomal anomaly	3285	362 (11.0)	3682	440 (12.0)	0.20 (−1.72, 2.11)
Isolated chromosomal anomaly	1344	149 (11.1)	1201	133 (11.1)	−0.65 (−3.77, 2.47)
Down syndrome	2389	137 (5.7)	2543	183 (7.2)	0.89 (−0.84, 2.62)
Turner syndrome	145	47 (32.4)	157	56 (35.7)	2.59 (−11.36, 16.54)

S7(c) EHCP in mainstream school	Before reforms[b] Total N	Before reforms[b] EHCP N (%)	After reforms[c] Total N	After reforms[c] EHCP N (%)	Absolute % difference (99% CI)
No MCA	2311628	22500 (1.0)	2643436	29049 (1.1)	0.12 (0.10, 0.15)
Any MCA	79242	5014 (6.3)	99965	5956 (6.0)	−0.42 (−0.71, −0.12)
Nervous system anomalies					
Any nervous system anomaly	3519	604 (17.2)	5069	792 (15.6)	−1.83 (−3.92, 0.25)
Isolated nervous system anomaly	2383	354 (14.9)	3230	401 (12.4)	−2.61 (−5.00, −0.23)
Microcephaly	759	117 (15.4)	892	122 (13.7)	−2.05 (−6.50, 2.40)
Hydrocephaly	793	164 (20.7)	1068	209 (19.6)	−1.65 (−6.45, 3.15)
Spina Bifida	426	131 (30.8)	592	166 (28.0)	−3.18 (−10.60, 4.25)
Eye anomalies					
Any eye anomaly	1660	239 (14.4)	1893	283 (14.9)	0.32 (−2.72, 3.36)
Isolated eye anomaly	1192	128 (10.7)	1283	138 (10.8)	−0.08 (−3.28, 3.11)
Anophthalmos/Microphthalmos	209	45 (21.5)	290	72 (24.8)	2.63 (−7.09, 12.35)
Congenital cataract	497	66 (13.3)	557	70 (12.6)	−0.85 (−6.16, 4.46)

Continued

Supplementary Table 7: Continued

S7(c) EHCP in mainstream school	Before reforms[b] Total N	Before reforms[b] EHCP N (%)	After reforms[c] Total N	After reforms[c] EHCP N (%)	Absolute % difference (99% CI)
Congenital Glaucoma	191	36 (18.8)	191	34 (17.8)	−1.41 (−11.52, 8.69)
Ear, face, and neck anomalies					
Any ear, face, and neck anomaly	484	42 (8.7)	834	70 (8.4)	−0.40 (−4.50, 3.70)
Isolated ear, face, and neck anomaly	308	[d]	513	[d]	[d]
Cardiac anomalies					
Any cardiac anomaly	17094	1957 (11.4)	24146	2517 (10.4)	−1.19 (−1.99, −0.39)
Isolated cardiac anomaly	12282	648 (5.3)	17122	791 (4.6)	−0.69 (−1.36, −0.03)
Severe cardiac	4518	610 (13.5)	5668	739 (13.0)	−0.68 (−2.41, 1.05)
Respiratory anomalies					
Any respiratory anomaly	1382	142 (10.3)	1567	165 (10.5)	0.10 (−2.79, 2.98)
Isolated respiratory anomaly	804	34 (4.2)	921	28 (3.0)	−1.21 (−3.54, 1.12)
Choanal atresia	282	40 (14.2)	365	57 (15.6)	1.18 (−6.02, 8.38)
Orofacial anomalies					
Any orofacial anomaly	3777	242 (6.4)	4143	291 (7.0)	0.57 (−0.88, 2.01)
Isolated orofacial anomaly	2718	101 (3.7)	2872	102 (3.6)	−0.18 (−1.46, 1.11)
Cleft lip	1043	35 (3.4)	1173	32 (2.7)	−0.63 (−2.52, 1.25)
Cleft palate	1947	157 (8.1)	2049	204 (10.0)	1.79 (−0.53, 4.10)
Cleft lip and palate	1453	98 (6.7)	1577	98 (6.2)	−0.57 (−2.87, 1.73)
Digestive anomalies					
Any digestive anomaly	5655	447 (7.9)	6737	553 (8.2)	0.20 (−1.06, 1.46)
Isolated digestive anomaly	3651	126 (3.5)	3922	124 (3.2)	−0.31 (−1.37, 0.75)
Oesophageal atresia	596	59 (9.9)	677	80 (11.8)	1.58 (−2.85, 6.01)
Small intestine atresia	703	91 (12.9)	816	111 (13.6)	0.32 (−4.13, 4.76)
Hirschsprung's disease	617	57 (9.2)	667	71 (10.6)	1.25 (−3.02, 5.52)
Biliary atresia	153	[d]	187	[d]	[d]
Anorectal malformation	418	26 (6.2)	475	27 (5.7)	−0.58 (−4.66, 3.49)
Congenital diaphragmatic hernia	594	70 (11.8)	756	77 (10.2)	−1.72 (−6.13, 2.69)
Abdominal wall anomalies					
Any abdominal wall anomaly	1503	44 (2.9)	1822	77 (4.2)	1.27 (−0.37, 2.92)
Isolated abdominal wall anomaly	1112	10 (0.9)	1268	29 (2.3)	1.38 (0.08, 2.68)
Omphalocele	450	26 (5.8)	511	41 (8.0)	2.18 (−2.00, 6.36)
Gastroschisis	993	[d]	1128	[d]	[d]
Urinary system anomalies					
Any urinary system anomaly	11476	400 (3.5)	12455	484 (3.9)	0.38 (−0.25, 1.01)
Isolated urinary system anomaly	10143	203 (2.0)	10578	221 (2.1)	0.08 (−0.42, 0.59)
Bladder exstrophy	248	[d]	339	[d]	[d]
Genital anomalies					
Any genital anomaly	9239	289 (3.1)	12474	440 (3.5)	0.38 (−0.25, 1.01)
Isolated genital anomaly	8118	161 (2.0)	10801	247 (2.3)	0.30 (−0.25, 0.84)
Hypospadias	6471	201 (3.1)	8630	282 (3.3)	0.14 (−0.60, 0.89)
Indeterminate sex	269	18 (6.7)	359	32 (8.9)	2.15 (−3.34, 7.64)
Limb anomalies					
Any limb anomaly	12829	473 (3.7)	15769	647 (4.1)	0.40 (−0.19, 0.99)
Isolated limb anomaly	11218	237 (2.1)	13406	284 (2.1)	0.00 (−0.47, 0.47)
Limb reduction defect	755	53 (7.0)	1001	75 (7.5)	0.39 (−2.81, 3.59)
Chromosomal anomalies					
Any chromosomal anomaly	3285	1616 (49.2)	3682	1848 (50.2)	−2.09 (−5.13, 0.96)
Isolated chromosomal anomaly	1344	669 (49.8)	1201	642 (53.5)	0.62 (−4.42, 5.65)
Down syndrome	2389	1473 (61.7)	2543	1650 (64.9)	−1.92 (−5.43, 1.60)
Turner syndrome	145	16 (11.0)	157	14 (8.9)	−2.28 (−11.12, 6.55)

Continued

Supplementary Table 7: Continued

S7(d) Specialist provision attendance	Before reforms[b] Total N	Before reforms[b] Specialist provision	After reforms[c] Total N	After reforms[c] Specialist provision	Absolute % difference (99% CI)
No MCA	2311628	12519 (0.5)	2643436	19741 (0.7)	0.20 (0.19, 0.22)
Any MCA	79242	3935 (5.0)	99965	4977 (5.0)	−0.03 (−0.29, 0.24)
Nervous system anomalies					
Any nervous system anomaly	3519	1005 (28.6)	5069	1298 (25.6)	−3.43 (−5.94, −0.93)
Isolated nervous system anomaly	2383	597 (25.1)	3230	668 (20.7)	−4.66 (−7.58, −1.74)
Microcephaly	759	420 (55.3)	892	447 (50.1)	−6.38 (−12.68, −0.07)
Hydrocephaly	793	234 (29.5)	1068	324 (30.3)	0.00 (−5.47, 5.47)
Spina Bifida	426	50 (11.7)	592	63 (10.6)	−1.27 (−6.42, 3.87)
Eye anomalies					
Any eye anomaly	1660	255 (15.4)	1893	296 (15.6)	0.03 (−3.08, 3.14)
Isolated eye anomaly	1192	75 (6.3)	1283	73 (5.7)	−0.65 (−3.11, 1.80)
Anophthalmos/Microphthalmos	209	56 (26.8)	290	85 (29.3)	1.73 (−8.65, 12.11)
Congenital cataract	497	71 (14.3)	557	88 (15.8)	1.34 (−4.30, 6.99)
Congenital Glaucoma	191	27 (14.1)	191	21 (11.0)	−3.37 (−12.02, 5.29)
Ear, face, and neck anomalies					
Any ear, face, and neck anomaly	484	48 (9.9)	834	81 (9.7)	−0.34 (−4.71, 4.02)
Isolated ear, face, and neck anomaly	308	[d]	513	[d]	[d]
Cardiac anomalies					
Any cardiac anomaly	17094	1467 (8.6)	24146	2153 (8.9)	0.20 (−0.53, 0.92)
Isolated cardiac anomaly	12282	466 (3.8)	17122	630 (3.7)	−0.14 (−0.72, 0.43)
Severe cardiac	4518	462 (10.2)	5668	570 (10.1)	−0.34 (−1.88, 1.20)
Respiratory anomalies					
Any respiratory anomaly	1382	120 (8.7)	1567	148 (9.4)	0.62 (−2.09, 3.33)
Isolated respiratory anomaly	804	31 (3.9)	921	21 (2.3)	−1.59 (−3.75, 0.56)
Choanal atresia	282	40 (14.2)	365	67 (18.4)	3.87 (−3.55, 11.30)
Orofacial anomalies					
Any orofacial anomaly	3777	214 (5.7)	4143	268 (6.5)	0.76 (−0.62, 2.13)
Isolated orofacial anomaly	2718	57 (2.1)	2872	58 (2.0)	−0.08 (−1.06, 0.89)
Cleft lip	1043	30 (2.9)	1173	27 (2.3)	−0.58 (−2.32, 1.16)
Cleft palate	1947	152 (7.8)	2049	201 (9.8)	1.90 (−0.39, 4.19)
Cleft lip and palate	1453	70 (4.8)	1577	83 (5.3)	0.41 (−1.63, 2.45)
Digestive anomalies					
Any digestive anomaly	5655	338 (6.0)	6737	455 (6.8)	0.69 (−0.43, 1.82)
Isolated digestive anomaly	3651	84 (2.3)	3922	76 (1.9)	−0.37 (−1.23, 0.48)
Oesophageal atresia	596	27 (4.5)	677	44 (6.5)	1.78 (−1.45, 5.01)
Small intestine atresia	703	61 (8.7)	816	76 (9.3)	0.40 (−3.34, 4.15)
Hirschsprung's disease	617	42 (6.8)	667	55 (8.2)	1.32 (−2.44, 5.08)
Biliary atresia	153	[d]	187	[d]	[d]
Anorectal malformation	418	19 (4.5)	475	24 (5.1)	0.46 (−3.21, 4.14)
Congenital diaphragmatic hernia	594	37 (6.2)	756	45 (6.0)	−0.35 (−3.71, 3.02)
Abdominal wall anomalies					
Any abdominal wall anomaly	1503	32 (2.1)	1822	42 (2.3)	0.16 (−1.15, 1.48)
Isolated abdominal wall anomaly	1112	10 (0.9)	1268	19 (1.5)	0.59 (−0.55, 1.73)
Omphalocele	450	19 (4.2)	511	18 (3.5)	−0.73 (−3.94, 2.48)
Gastroschisis	993	[d]	1128	[d]	[d]
Urinary system anomalies					
Any urinary system anomaly	11476	289 (2.5)	12455	432 (3.5)	0.93 (0.37, 1.50)
Isolated urinary system anomaly	10143	112 (1.1)	10578	164 (1.6)	0.44 (0.03, 0.85)
Bladder exstrophy	248	[d]	339	[d]	[d]

Continued

Supplementary Table 7: Continued

S7(d) Specialist provision attendance	Before reforms[b] Total N	Before reforms[b] Specialist provision	After reforms[c] Total N	After reforms[c] Specialist provision	Absolute % difference (99% CI)
Genital anomalies					
Any genital anomaly	9239	273 (3.0)	12474	373 (3.0)	0.02 (−0.58, 0.62)
Isolated genital anomaly	8118	122 (1.5)	10801	159 (1.5)	−0.04 (−0.49, 0.42)
Hypospadias	6471	185 (2.9)	8630	230 (2.7)	−0.21 (−0.90, 0.49)
Indeterminate sex	269	26 (9.7)	359	28 (7.8)	−1.93 (−7.81, 3.95)
Limb anomalies					
Any limb anomaly	12829	387 (3.0)	15769	578 (3.7)	0.63 (0.08, 1.18)
Isolated limb anomaly	11218	165 (1.5)	13406	209 (1.6)	0.08 (−0.32, 0.49)
Limb reduction defect	755	30 (4.0)	1001	53 (5.3)	1.26 (−1.31, 3.83)
Chromosomal anomalies					
Any chromosomal anomaly	3285	1013 (30.8)	3682	1299 (35.3)	2.28 (−0.56, 5.11)
Isolated chromosomal anomaly	1344	333 (24.8)	1201	308 (25.6)	−0.60 (−4.93, 3.73)
Down syndrome	2389	746 (31.2)	2543	876 (34.4)	0.49 (−2.85, 3.83)
Turner syndrome	145	19 (13.1)	157	16 (10.2)	−3.10 (−12.56, 6.35)

CI = confidence interval, MCA=major congenital anomaly, SEN= Special Educational Needs; [a]any groups contain children with and without additional anomalies in other system-specific, isolated groups do not contain children with anomalies in other system-specific subgroups; [b]before reforms group includes children born between 2003/04 and 2007/08 (entering year 1 before 2014/15); [c]after reforms group includes children born between 2008/09 and 2012/13 (entering year 1 on and after 2014/15); [d]small numbers (<8) suppressed to prevent disclosure of identities.

Supplementary Appendix 2

The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Title and abstract					
	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found		RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract.	Title; Methods and findings section of the abstract Title Title
Introduction					
Background rationale	2	Explain the scientific background and rationale for the investigation being reported			Introduction paragraph 1
Objectives	3	State specific objectives, including any prespecified hypotheses			Introduction paragraph 3
Methods					
Study Design	4	Present key elements of study design early in the paper			Methods paragraph 2
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection			Methods paragraph 1, 2
Participants	6	*(a) Cohort study* - Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study* - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study* - Give the eligibility criteria, and the sources and methods of selection of participants *(b) Cohort study* - For matched studies, give matching criteria and number of exposed and unexposed *Case-control study* - For matched studies, give matching criteria and the number of controls per case		RECORD 6.1: The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided. RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided. RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.	Methods paragraph 2 Methods paragraph 3 Fig 1 (flowchart)
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.		RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	Code provided (GitHub link)
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group			Methods paragraphs 3-5
Bias	9	Describe any efforts to address potential sources of bias			Methods analysis section
Study size	10	Explain how the study size was arrived at			Fig 1 (flowchart)
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why			Methods paragraphs 3-5
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) *Cohort study* - If applicable, explain how loss to follow-up was addressed			

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
		Case-control study - If applicable, explain how matching of cases and controls was addressed *Cross-sectional study* - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses			Methods analysis section
Data access and cleaning methods		..		RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population. RECORD 12.2: Authors should provide information on the data cleaning methods used in the study.	Method analysis section, third paragraph Code provided (GitHub link)
Linkage		..		RECORD 12.3: State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided.	Methods paragraph 1
Results					
Participants	13	(a) Report the numbers of individuals at each stage of the study (*e.g.*, numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram		RECORD 13.1: Describe in detail the selection of the persons included in the study (*i.e.,* study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	Fig 1 (flowchart)
Descriptive data	14	(a) Give characteristics of study participants (*e.g.*, demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) *Cohort study* - summarise follow-up time (*e.g.*, average and total amount)			S4 table
Outcome data	15	*Cohort study* - Report numbers of outcome events or summary measures over time *Case-control study* - Report numbers in each exposure category, or summary measures of exposure *Cross-sectional study* - Report numbers of outcome events or summary measures			S3 Fig
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period			All results are unadjusted, 95% and 99% confidence intervals included
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses			Across all results
Discussion					
Key results	18	Summarise key results with reference to study objectives			Discussion paragraph 1
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias		RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported.	Discussion paragraph 4-6
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence			Discussion paragraph 2
Generalisability	21	Discuss the generalisability (external validity) of the study results			Discussion paragraph 5

	Item No.	STROBE items	Location in manuscript where items are reported	RECORD items	Location in manuscript where items are reported
Other Information					
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based			Funding information provided in paper
Accessibility of protocol, raw data, and programming code		..		RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	Link to code supplied in paper

*Reference: Benchimol EI, Smeeth L, Guttmann A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.