CRANE

CLEFT REGISTRY & AUDIT NETWORK

Promoting excellence in cleft care

Cleft Registry and Audit NEtwork Database
Part of the Clinical Effectiveness Unit, of the Royal College of Surgeons of England

2021 Annual Report: Appendices
Results of the audit in England, Wales and Northern Ireland for children
born with a cleft between January 2000 and December 2020

On behalf of the Cleft Development Group

Appendices

Documents related to this product, for reference, published separately:

Document	Published
CRANE 2021 Annual Report	December 2021
2021 Annual Report: Responses to outlier process	December 2021
2021 Annual Report: Methods	December 2021

Appendix 1: CRANE Project Team

Members of CRANE Project Team

Craig Russell	Clinical Project Lead / Consultant Surgeon	Clinical Effectiveness Unit / NHS Greater Glasgow and Clyde
Jibby Medina	Research Fellow	Clinical Effectiveness Unit
Kate Fitzsimons	Research Fellow	Clinical Effectiveness Unit (on maternity leave from August 2021)
Sophie Butterworth	Clinical Research Fellow	Clinical Effectiveness Unit (maternity cover from August 2021)
Hussein Wahedally	Data Manager	Clinical Effectiveness Unit
Jan van der Meulen	Clinical Epidemiologist	Clinical Effectiveness Unit / London School of Hygiene and Tropical Medicine
Min Hae Park	Assistant Professor	Clinical Effectiveness Unit
Catherine Foster	CEU Research Coordinator	Clinical Effectiveness Unit

Appendix 2: Governance and funding

Ownership

The database is funded by the National Health Service through the National Specialised Commissioning Group for England, the Wales Specialised Health Services Committee, and the Northern Ireland Specialist Services Commissioning Team; who have responsibility for the delivery of care to children born with cleft lip and palate in England, Wales and Northern Ireland. An independent body, the Cleft Development Group UK, which represents patient representative groups, clinicians and commissioners, has the overall responsibility for running the database.

Cleft Development Group

The Cleft Development Group is a body with two distinct roles. Firstly, it is responsible for making arrangements for the running and commissioning of the CRANE Database.

Secondly, it is responsible for providing guidance on all aspects of the delivery of cleft care in England, Wales, and – when asked – by Northern Ireland. It includes representatives from all the stakeholders in cleft care in the UK, including commissioners, public health consultants/regional cleft leads, specialists in the provision of cleft care, and parents and patients. It also has representatives from the health services in Wales, Scotland and Northern Ireland, as well as a representative from the Republic of Ireland cleft service.

The Cleft Development Group CRANE web page provides detail on the CDG Membership and Terms of Reference.

Funding

Funding of the CRANE Database is currently coordinated and agreed by representatives of the National Specialised Commissioning Group for England, the Wales Specialised Health Services Committee, and the Northern Ireland Specialist Services Commissioning Team. Funds are raised through a levy calculated on a weighted per capita basis from the commissioning bodies in England, Wales and Northern Ireland. The levy is currently collected by Specialised Commissioning (East Midlands).

Appendix 3: Description of the CRANE core set of indicators

Key: A – Audit (function); BCLP – Bilateral Cleft Lip and Palate; CAPS-A - ; Cleft Audit Protocol for Speech; CP – Cleft Lip; CP – Cleft Palate; dmft – decayed, missed or filled teeth; HES – Hospital Episode Statistics; O – outcome indicator (type); P – process indicator (type); R – Registry (function); UCLP – Unilateral Cleft Lip and Palate.

Core set of indicators (n=14)

Pathway	Function : Type	#	Indicator	Denominator	Numerator	Consideration
Diagnosis	Registry (R) : Process indicator	1	Timely detection of Cleft Palate (CP), within 24/72 hours from birth	Children diagnosed with a CP	Children diagnosed with a CP within 24/72 hours from birth	
Diagnosis	R : P	2	Antenatal diagnosis for CL, UCLP and BCLP	Children diagnosed with a CL, UCLP and BCLP antenatally	Children diagnosed with a CL, UCLP and BCLP within 24 hours from birth	
Referral and contact	R : P	3	Referral to a cleft care team within 24 hours of birth	Patients diagnosed with cleft lip and/or palate who have records on the CRANE Database system	Families were referred to a cleft care team within 24 hours of birth	Related to CLP01: % parents contacted by a cleft team Clinical Nurse Specialist (CNS) within 24 hrs of referral with an antenatal diagnosis of CLP
Referral and contact	R : P	4	Contact with a cleft care team within 24 hours of referral	Patients diagnosed with cleft lip and/or palate who have records on the CRANE Database system	Families were contacted by a cleft care team within 24 hours of referral	Related to CLP02: % parents, of infants diagnosed with CLP, who receive a visit from a cleft team CNS within 24 hrs of first referral (following birth)
Referral and contact	R : P	5	Consent verification undergone with all families of children with an orofacial cleft recorded in the CRANE Database (Participation in audit is a mandatory requirement of service provision contract > cannot audit without consent)	Patients diagnosed with cleft lip and/or palate who have records on the CRANE Database system	Families approached for consent verification – who have reached the decision to accept or decline consent to records being shared with CRANE for follow-up / audit purposes.	

Pathway	Function : Type	#	Indicator	Denominator	Numerator	Consideration
Outcomes / Treatment:: Nursing	A : Outcome indicator (O)	6	Healthy Body Mass Index (BMI) at 5 years of age	All consented children, without submucous cleft palates, alive at the age of 5 years – with child growth data	Patients with a healthy BMI at 5 years of age	
Outcomes / Treatment: Dental	A : O	7	Dental decay at 5 years of age	All consented children, without submucous cleft palates, alive at the age of 5 years – with dental health data	Patients with at least one dmft (dmft >0) at 5 years of age	
Outcomes / Treatment: Dental	A : O	8	Dental treatment index at 5 years of age	All consented children, without submucous cleft palates, alive at the age of 5 years – with dental health data	Patients with treatment indices of 1 (no untreated disease) at 5 years of age	Mirrors CLP06: % of 5 year old children with CLP, who have had a treatment index recorded by a calibrated paediatric dentist (dmft scores)
Outcomes / Treatment: Orthodontic	A : O	9	Facial growth at 5 years of age	All consented children with complete UCLP, without submucous cleft palates, alive at the age of 5 years – with Five Year Old Index scores	Patients with Five Year Old Index scores reflecting 'good' dental arch relationships	Mirrors CLP09: % of five year old children, with complete UCLP who have good maxillary growth as determined by the 5 Year Growth Index
Outcomes / Treatment: Speech and language therapy	A : O	10	Speech within the normal range at 5 years of age	All consented children with CP, UCLP and BCLP, without submucous cleft palates, without diagnosed syndromes, alive at the age of 5 years – with speech data (all 16 Cleft audit protocol for speech (CAPS-A) data items)	Patients achieving speech within the normal range at 5 years of age	
Outcomes / Treatment: Speech and language therapy	A : O	11	Speech without difficulties resulting from existing or previous structural anomalies at 5 years of age	All consented children with CP, UCLP and BCLP, without submucous cleft palates, without diagnosed syndromes, alive at the age of 5 years – with speech data (CAPS-A data items)	Patients achieving speech without difficulties resulting from existing or previous structural anomalies at 5 years of age	

Pathway	Function : Type	#	Indicator	Denominator	Numerator	Consideration
Outcomes / Treatment: Speech and language therapy	A : O	12	Speech without significant cleft-related articulation difficulties at 5 years of age	All consented children with CP, UCLP and BCLP, without submucous cleft palates, without diagnosed syndromes, alive at the age of 5 years – with speech data (CAPS-A data items)	Patients achieving speech without significant cleft-related articulation difficulties at 5 years of age	
Treatment / Process: Psychology	A : P	13	Psychology screening (at least one) before the age of 6 years	All consented children, without submucous cleft palates, without diagnosed syndromes, alive at the age of 5 years – with date of psychological screen data	Families screened at least once before the age of 6 years	
Outcomes / Treatment: Psychology	A : O	14	Psychological concerns identified at the age of 5	All consented children, without submucous cleft palates, alive at the age of 5 years – with Strengths and Difficulties Questionnaires (SDQ) scores	Patients with 'high' or 'very high' SDQ scores	

Notes: (1) Case ascertainment and surgical indictors require HES linkage so not added here.
(2) We are piloting data quality indicators in 2021.

Because adding data to CRANE is a requirement – additional Data Quality indicators being piloted in 2021

Pathway	Function : Type	#	Indicator	Denominator	Numerator	Consideration
Data Quality / Process: Diagnosis	A : P	8a	Gestational age and birth weight recorded for all eligible children	All live births registered in CRANE	Patients with a gestational age and birth weight data recorded in CRANE	
Data Quality / Process: Nursing	A : P	9a	Child growth at 5 years recorded for all eligible children	All consented children, without submucous cleft palates, alive at the age of 5 years	Patients with child growth (height & weight) data at 5 years of age recorded in CRANE	
Data Quality / Process: Dental	A : P	10a	dmft at 5 years recorded for all eligible children	All consented children, without submucous cleft palates, alive at the age of 5 years	Patients with recorded dmft scores at 5 years of age recorded in CRANE	
Data Quality / Process: Orthodontic	A : P	12a	Facial growth at 5 years recorded for all eligible children	All consented children with UCLP, without submucous cleft palates, alive at the age of 5 years	Patients with recorded Five Year Old Index scores at 5 years of age recorded in CRANE	

Data Quality / Process: Speech and language therapy	A : P	13a	Speech scores at 5 years recorded for all eligible children	All consented children with CP, UCLP and BCLP, without submucous cleft palates, without diagnosed syndromes, alive at the age of 5 years	Patients with CAPS-A scores (all 16) at 5 years of age recorded in CRANE	
Data Quality / Process: Psychology	A : P	16a	Psychology data at 5 years recorded for all eligible children	All consented children, without submucous cleft palates, alive at the age of 5 years	Patients with psychology screening information and SDQ scores at 5 years of age recorded in CRANE	

References

Standards / guidelines – described in the individual summary tables / sections of the report.

Appendix 4: Cleft Services

The CRANE Database covers England, Wales and Northern Ireland. Cleft care is currently delivered by the following cleft services.

Cleft Services – in England, Wales and Northern Ireland	Host Hospital(s)
Newcastle	Newcastle Hospitals NHS Foundation Trust
Leeds	Leeds Teaching Hospitals NHS Trust
Liverpool*	Liverpool Alder Hey Children's Hospital
Manchester*	Royal Manchester Children's Hospital
Trent	Nottingham University Hospitals NHS Foundation Trust
West Midlands	Birmingham Children's Hospital
Cleft Net East	Cambridge University Hospitals NHS Foundation Trust
North Thames**	Great Ormond Street Hospital (GOSH), jointly with Broomfield Hospital in Essex
The Spires***	Salisbury District Hospital, jointly with John Radcliffe Hospital, Oxford
South Wales	Swansea Bay University Health Board
South West	University Hospitals Bristol NHS Foundation Trust
Evelina London	Guy's and St Thomas' NHS Foundation Trust
Northern Ireland	Royal Belfast Hospital for Sick Children

Notes:
*The North West, Isle of Man and North Wales Cleft Lip and Palate Network.
**Data for GOSH and Broomfield cleft care teams combined upon request by the Spires' Clinical Director (January 2017).
***Data for Oxford and Salisbury cleft care teams combined upon request by the Spires' Clinical Director (June 2016).

More information on this can be found on the Cleft Lip & Palate Association (CLAPA) website
https://www.clapa.com/treatment/nhs-cleft-teams/

Appendix 5: Diagnosis and Procedure Codes, Hospital Episode Statistics (HES)

International classification of Disease 10th Revision (ICD-10) diagnostic codes for cleft lip and/or palate.

Code	Description
Q35	Cleft palate
Q36	Cleft lip
Q37	Cleft palate with cleft lip

Classification of Surgical Operations and Procedures 4th Revision (OPCS-4) codes for cleft lip and cleft palate repairs.

Code	Description
F031	Correction of deformity to lip
F291	Correction of deformity to palate

International classification of Disease 10th Revision (ICD-10) diagnostic codes for syndromes and malformations used to identify 'syndromic' cleft patients in CRANE-HES linked research work (Chapter 5). A patient was defined as 'syndromic' if there was a record of any of the following codes in any of the fourteen diagnosis code fields for any of their HES episodes.

Code	Description
D821	Di George's syndrome
Congenital malformations of the nervous system (Q00-Q07)	
Q00	Anencephaly and similar malformations
Q01	Encephalocele
Q02	Microcephaly
Q03	Congenital hydrocephalus
Q04	Other congenital malformations of brain
Q05	Spina bifida
Q06	Other congenital malformations of spinal cord
Q07	Other congenital malformations of nervous system
Q16	Congenital malformations of ear causing impairment of hearing
Q18	Other congenital malformations of face and neck
Congenital malformations of the circulatory system (Q20-Q28)	
Q20	Congenital malformations of cardiac chambers and connections
Q21	Congenital malformations of cardiac septa
Q22	Congenital malformations of pulmonary and tricuspid valves
Q23	Congenital malformations of aortic and mitral valves
Q24	Other congenital malformations of heart
Q25	Congenital malformations of great arteries
Q26	Congenital malformations of great veins
Q27	Other congenital malformations of peripheral vascular system
Q28	Other congenital malformations of circulatory system
Q380	Congenital malformations of lips, not elsewhere classified
Q75	Other congenital malformations of skull and face bones
Q86	Congenital malformation syndromes due to known exogenous causes, not elsewhere classified
Q87	Other specified congenital malformation syndromes affecting multiple systems
Chromosomal abnormalities, not elsewhere classified (Q90-99)	
Q90	Down's syndrome
Q91	Edwards' syndrome and Patau's syndrome
Q92	Other trisomies and partial trisomies of the autosomes, not elsewhere classified
Q93	Monosomies and deletions from the autosomes, not elsewhere classified
Q95	Balanced rearrangements and structural markers, not elsewhere classified
Q96	Turner's syndrome
Q97	Other sex chromosome abnormalities, female phenotype, not elsewhere classified
Q98	Other sex chromosome abnormalities, male phenotype, not elsewhere classified
Q99	Other chromosome abnormalities, not elsewhere classified

Appendix 6: Registrations – raw data

Sex and cleft type

Table A. Distribution of CRANE-registered[1] children born in 2017-2019, by cleft types and sex, according to each cleft service.

Cleft Services	Children with specified cleft type[2]	CP		CL		UCLP		BCLP		Children with specified sex[3]	Female		Male	
	N	n	(%)	n	(%)	n	(%)	n	(%)	N	n	(%)	n	(%)
Newcastle	147	59	40.1%	36	24.5%	36	24.5%	16	10.9%	163	65	39.9%	98	60.1%
Leeds	184	76	41.3%	45	24.5%	35	19.0%	28	15.2%	188	62	33.0%	126	67.0%
Liverpool	145	72	49.7%	24	16.6%	33	22.8%	16	11.0%	185	84	45.4%	101	54.6%
Manchester	181	72	39.8%	39	21.5%	47	26.0%	23	12.7%	219	96	43.8%	123	56.2%
Trent	277	127	45.8%	64	23.1%	66	23.8%	20	7.2%	280	111	39.6%	169	60.4%
West Midlands	310	139	44.8%	69	22.3%	72	23.2%	30	9.7%	326	149	45.7%	177	54.3%
Cleft Net East	203	86	42.4%	46	22.7%	47	23.2%	24	11.8%	202	101	50.0%	101	50.0%
North Thames	369	155	42.0%	85	23.0%	85	23.0%	44	11.9%	400	192	48.0%	208	52.0%
Spires	234	97	41.5%	59	25.2%	52	22.2%	26	11.1%	245	110	44.9%	135	55.1%
South Wales	108	53	49.1%	25	23.1%	18	16.7%	12	11.1%	108	49	45.4%	59	54.6%
South West	159	80	50.3%	39	24.5%	25	15.7%	15	9.4%	180	85	47.2%	95	52.8%
Evelina London	353	151	42.8%	88	24.9%	77	21.8%	37	10.5%	372	169	45.4%	203	54.6%
Northern Ireland	96	50	52.1%	11	11.5%	25	26.0%	10	10.4%	102	39	38.2%	63	61.8%
National[1]	2,766	1,217	44.0%	630	22.8%	618	22.3%	301	10.9%	2970	1312	44.2%	1658	55.8%

[1] Registered in CRANE by 30 June 2021. [2] Children with unspecified cleft type are excluded. [3] Children with missing data for sex are excluded.

Table B. Distribution of CRANE-registered[1] children born in 2020, by cleft types and sex, according to each cleft service.

Cleft Services	Children with specified cleft type[2]	CP		CL		UCLP		BCLP		Children with specified sex[3]	Female		Male	
	N	n	(%)	n	(%)	n	(%)	n	(%)	N	n	(%)	n	(%)
Newcastle	36	15	41.7%	8	22.2%	6	16.7%	7	19.4%	47	20	42.6%	27	57.4%
Leeds	56	30	53.6%	7	12.5%	16	28.6%	3	5.4%	56	27	48.2%	29	51.8%
Liverpool	53	22	41.5%	14	26.4%	13	24.5%	4	7.5%	67	18	26.9%	49	73.1%
Manchester	46	25	54.3%	12	26.1%	6	13.0%	3	6.5%	54	28	51.9%	26	48.1%
Trent	73	28	38.4%	19	26.0%	20	27.4%	6	8.2%	75	28	37.3%	47	62.7%
West Midlands	96	30	31.3%	32	33.3%	25	26.0%	9	9.4%	100	55	55.0%	45	45.0%
Cleft Net East	55	19	34.5%	17	30.9%	13	23.6%	6	10.9%	54	22	40.7%	32	59.3%
North Thames	101	45	44.6%	24	23.8%	21	20.8%	11	10.9%	111	47	42.3%	64	57.7%
Spires	79	36	45.6%	20	25.3%	11	13.9%	12	15.2%	80	36	45.0%	44	55.0%
South Wales	36	15	41.7%	11	30.6%	8	22.2%	2	5.6%	35	14	40.0%	21	60.0%
South West	27	10	37.0%	13	48.1%	2	7.4%	2	7.4%	56	22	39.3%	34	60.7%
Evelina London	115	53	46.1%	29	25.2%	20	17.4%	13	11.3%	120	49	40.8%	71	59.2%
Northern Ireland	33	17	51.5%	7	21.2%	4	12.1%	5	15.2%	34	12	35.3%	22	64.7%
National[1]	806	345	42.8%	213	26.4%	165	20.5%	83	10.3%	889	378	42.5%	511	57.5%

[1] Registered in CRANE by 30 June 2021. [2] Children with unspecified cleft type are excluded. [3] Children with missing data for sex are excluded.

Gestational age and birth weight

Table C. Percentage of premature and normal births among CRANE-consented[1] children born in 2017-2019, compared to 2020 cohort, according to each cleft service.

| | 2017-19 | | | | | 2020 | | | | |
| | Eligible children with gestation data[1] | Premature births | | Normal births | | Eligible children with gestation data[1] | Premature births | | Normal births | |
Cleft Services	N	n	%	n	%	N	n	%	n	%
Newcastle	131	26	19.8%	105	80.2%	23	2	8.7%	21	91.3%
Leeds	170	26	15.3%	144	84.7%	50	4	8.0%	46	92.0%
Liverpool	4	1	25.0%	3	75.0%					
Manchester	135	18	13.3%	117	86.7%	34	5	14.7%	29	85.3%
Trent	6	1	16.7%	5	83.3%					
Cleft Net East	76	9	11.8%	67	88.2%	2	0	0.0%	2	100.0%
North Thames	121	14	11.6%	107	88.4%	21	2	9.5%	19	90.5%
Spires	6	2	33.3%	4	66.7%	7	1	14.3%	6	85.7%
South Wales	86	17	19.8%	69	80.2%	31	5	16.1%	26	83.9%
South West	112	7	6.3%	105	93.8%	19	4	21.1%	15	78.9%
Evelina London	95	9	9.5%	86	90.5%	41	3	7.3%	38	92.7%
Northern Ireland	81	11	13.6%	70	86.4%	25	4	16.0%	21	84.0%
National[2]	1,023	141	13.8%	882	86.2%	253	30	11.9%	223	88.1%

[1] Registered in CRANE by 30 June 2021 and children without consent and gestation data are excluded. [2] National average for 2017-19 excludes West Midlands as they did not submit gestation data between 2017 and 2019. National average for 2020 excludes Liverpool, Trent and West Midlands as they did not provide gestation data in 2020.

Table D. Percentage of CRANE-consented[1] children born in 2017-2019 with low and high birth weight, compared to 2020 cohort, according to each cleft service – **for children born at term only**.

| | 2017-19 | | | | | | | 2020 | | | | | | |
| | Eligible children born at term[1] | Low Birthweight (<2500g) | | Healthy Birthweight (2500g-4000g) | | High Birthweight (>=4000g) | | Total | Low Birthweight (<2500g) | | Healthy Birthweight (2500g-4000g) | | High Birthweight (>=4000g) | |
Cleft Services	N	n	%	n	%	n	%		n	%	n	%	n	%
Newcastle	99	10	10.1%	82	82.8%	7	7.1%	21	0	0.0%	18	85.7%	3	14.3%
Leeds	141	12	8.5%	112	79.4%	17	12.1%	44	3	6.8%	36	81.8%	5	11.4%
Liverpool	2	0	0.0%	2	100.0%	0	0.0%							
Manchester	116	8	6.9%	98	84.5%	10	8.6%	29	2	6.9%	25	86.2%	2	6.9%
Trent	4	0	0.0%	4	100.0%	0	0.0%							
Cleft Net East	67	5	7.5%	57	85.1%	5	7.5%	2	0	0.0%	2	100.0%	0	0.0%
North Thames	105	5	4.8%	95	90.5%	5	4.8%	19	0	0.0%	18	94.7%	1	5.3%
Spires	4	0	0.0%	4	100.0%	0	0.0%	5	0	0.0%	4	80.0%	1	20.0%
South Wales	66	4	6.1%	58	87.9%	4	6.1%	26	1	3.8%	24	92.3%	1	3.8%
South West	99	4	4.0%	88	88.9%	7	7.1%	14	1	7.1%	12	85.7%	1	7.1%
Evelina London	84	9	10.7%	70	83.3%	5	6.0%	38	2	5.3%	26	68.4%	10	26.3%
Northern Ireland	70	3	4.3%	59	84.3%	8	11.4%	21	1	4.8%	19	90.5%	1	4.8%
West Midlands														
National[2]	857	60	7.0%	729	85.1%	68	7.9%	219	10	4.6%	184	84.0%	25	11.4%

[1] Registered in CRANE by 30 June 2021. Children without consent, gestation data and birth weight are excluded. [2] National average for 2017-19 exclude West Midlands as they did not submit birth weight data between 2017 and 2019. National average for 2020 excludes Liverpool, Trent and West Midlands cleft services as they did not provide birth weight data in 2020.

Referral time and contact time

Table E. Percentage of children[1] referred to a cleft team within 24 hours after birth and 24 hours after birth in 2017-2019 and 2020, by cleft services and national percentage for 2017-19 and 2020.

	2017-19							2020						
	Total number of children[1]	Number of children with referral time[2]		Referred within 24 hours of birth		Referred 24 hours after birth		Total number of children[1]	Number of children with referral time[2]		Referred within 24 hours of birth		Referred 24 hours after birth	
Cleft Services	N	n	%	n	%	n	%	N	n	%	n	%	n	%
Newcastle	163	142	87.1%	122	85.9%	20	14.1%	47	27	57.4%	25	92.6%	2	7.4%
Leeds	188	169	89.9%	134	79.3%	35	20.7%	56	45	80.4%	42	93.3%	3	6.7%
Liverpool	199	147	73.9%	118	80.3%	29	19.7%	71	44	62.0%	37	84.1%	7	15.9%
Manchester	220	145	65.9%	125	86.2%	20	13.8%	55	39	70.9%	32	82.1%	7	17.9%
Trent	281	241	85.8%	195	80.9%	46	19.1%	75	69	92.0%	62	89.9%	7	10.1%
West Midlands	330	193	58.5%	165	85.5%	28	14.5%	100	13	13.0%	12	92.3%	1	7.7%
Cleft Net East	211	132	62.6%	115	87.1%	17	12.9%	55	34	61.8%	32	94.1%	2	5.9%
North Thames	404	188	46.5%	148	78.7%	40	21.3%	112	21	18.8%	19	90.5%	2	9.5%
Spires	247	190	76.9%	167	87.9%	23	12.1%	80	46	57.5%	38	82.6%	8	17.4%
South Wales	110	92	83.6%	81	88.0%	11	12.0%	36	32	88.9%	26	81.3%	6	18.8%
South West	180	149	82.8%	114	76.5%	35	23.5%	57	14	24.6%	11	78.6%	3	21.4%
Evelina London	372	116	31.2%	101	87.1%	15	12.9%	120	51	42.5%	43	84.3%	8	15.7%
Northern Ireland	102	76	74.5%	56	73.7%	20	26.3%	34	15	44.1%	10	66.7%	5	33.3%
National	3,007	1,980	65.8%	1,641	82.9%	339	17.1%	898	450	50.1%	389	86.4%	61	13.6%

[1] Registered in CRANE by 30 June 2021. [2] Children without referral time are excluded.

Table F. Percentage of children[1] contacted by a cleft team within 24 hours after referral and 24 hours after referral in 2017-2019 and 2020, by cleft services and national percentage for 2017-19 and 2020.

	2017-19							2020						
	Total number of children[1]	Number of children with contact time[2]		Contacted within 24 hours of referral		Contacted 24 hours after referral		Total number of children[1]	Number of children with contact time[2]		Contacted within 24 hours of referral		Contacted 24 hours after referral	
Cleft Services	N	n	%	n	%	n	%	N	n	%	n	%	n	%
Newcastle	163	159	97.5%	158	99.4%	1	0.6%	47	45	95.7%	45	100%	0	0.0%
Leeds	188	175	93.1%	173	98.9%	2	1.1%	56	51	91.1%	51	100%	0	0.0%
Liverpool	199	172	86.4%	171	99.4%	1	0.6%	71	62	87.3%	60	96.8%	2	3.2%
Manchester	220	177	80.5%	176	99.4%	1	0.6%	55	49	89.1%	48	98.0%	1	2.0%
Trent	281	272	96.8%	272	100%	0	0.0%	75	75	100%	75	100%	0	0.0%
West Midlands	330	314	95.2%	290	92.4%	24	7.6%	100	97	97.0%	78	80.4%	19	19.6%
Cleft Net East	211	205	97.2%	203	99.0%	2	1.0%	55	54	98.2%	54	100%	0	0.0%
North Thames	404	131	32.4%	110	84.0%	21	16.0%	112	57	50.9%	54	94.7%	3	5.3%
Spires	247	241	97.6%	224	92.9%	17	7.1%	80	77	96.3%	69	89.6%	8	10.4%
South Wales	110	108	98.2%	108	100%	0	0.0%	36	35	97.2%	34	97.1%	1	2.9%
South West	180	163	90.6%	161	98.8%	2	1.2%	57	36	63.2%	35	97.2%	1	2.8%
Evelina London	372	368	98.9%	349	94.8%	19	5.2%	120	119	99.2%	113	95.0%	6	5.0%
Northern Ireland	102	86	84.3%	76	88.4%	10	11.6%	34	15	44.1%	13	86.7%	2	13.3%
National	3,007	2571	85.5%	2471	96.1%	100	3.9%	898	772	86.0%	729	94.4%	43	5.6%

[1] Registered in CRANE by 30 June 2021. [2] Children without contact time after referral are excluded.

Timely diagnoses of all clefts

Table G. Number (%) of CRANE-registered children born in 2017-19 with **all clefts**, according to the timing of diagnosis and cleft service.

Cleft service	Antenatal		At birth		<72 hours		<1 week		<1 month		<6 months		>6 months		All
					Diagnosis time n (%)										
Newcastle	67	41.9%	66	41.3%	3	1.9%	8	5%	7	4.4%	7	4.4%	2	1.3%	160
Leeds	92	48.9%	67	35.6%	11	5.9%	8	4.3%	5	2.7%	5	2.7%	0	0%	188
Liverpool	64	35.6%	84	46.7%	17	9.4%	4	2.2%	6	3.3%	3	1.7%	2	1.1%	180
Manchester	107	54.0%	61	30.8%	12	6.1%	6	3%	6	3%	3	1.5%	3	1.5%	198
Trent	124	44.6%	103	37.1%	19	6.8%	11	4%	5	1.8%	11	4%	5	1.8%	278
West Midlands	122	37.5%	187	57.5%	4	1.2%	5	1.5%	6	1.8%	1	0.3%	0	0%	325
Cleft Net East	104	50.7%	76	37.1%	13	6.3%	6	2.9%	3	1.5%	3	1.5%	0	0%	205
North Thames	192	50.5%	151	39.7%	11	2.9%	11	2.9%	5	1.3%	10	2.6%	0	0%	380
Spires	114	46.5%	107	43.7%	11	4.5%	2	0.8%	5	2%	3	1.2%	3	1.2%	245
South Wales	53	49.1%	44	40.7%	3	2.8%	0	0%	4	3.7%	4	3.7%	0	0%	108
South West	73	44.5%	78	47.6%	5	3%	5	3%	3	1.8%	0	0%	0	0%	164
Evelina London	177	48.0%	127	34.4%	29	7.9%	10	2.7%	14	3.8%	10	2.7%	2	0.5%	369
Northern Ireland	35	36.1%	48	49.5%	5	5.2%	1	1%	4	4.1%	0	0%	4	4.1%	97
All	1324	45.7%	1199	41.4%	143	4.9%	77	2.7%	73	2.5%	60	2.1%	21	0.7%	2,897

Note: Recording of 'timing of diagnosis' within 72 hours commenced in May 2014 to align CRANE data collection with NIPE standards[1].

Table H. Number (%) of CRANE-registered children born in 2020 with **all clefts**, according to the timing of diagnosis and cleft service.

Cleft service	Antenatal		At birth		<72 hours		<1 week		<1 month		<6 months		>6 months		All
					Diagnosis time n (%)										
Newcastle	22	48.9%	17	37.8%	3	6.7%	0	0%	1	2.2%	2	4.4%	0	0%	45
Leeds	26	46.4%	24	42.9%	1	1.8%	3	5.4%	2	3.6%	0	0%	0	0%	56
Liverpool	26	40.0%	30	46.2%	5	7.7%	3	4.6%	0	0%	1	1.5%	0	0%	65
Manchester	21	40.4%	15	28.8%	10	19.2%	3	5.8%	1	1.9%	2	3.8%	0	0%	52
Trent	39	52.0%	29	38.7%	3	4%	2	2.7%	0	0%	2	2.7%	0	0%	75
West Midlands	43	43.0%	49	49%	2	2%	2	2%	1	1%	3	3%	0	0%	100
Cleft Net East	37	67.3%	14	25.5%	2	3.6%	2	3.6%	0	0%	0	0%	0	0%	55
North Thames	44	43.1%	53	52%	3	2.9%	0	0%	0	0%	1	1%	1	1%	102
Spires	22	28.2%	38	48.7%	9	11.5%	4	5.1%	0	0%	4	5.1%	1	1.3%	78
South Wales	19	54.3%	15	42.9%	0	0%	0	0%	1	2.9%	0	0%	0	0%	35
South West	6	46.2%	5	38.5%	1	7.7%	1	7.7%	0	0%	0	0%	0	0%	13
Evelina London	52	43.3%	49	40.8%	9	7.5%	3	2.5%	4	3.3%	3	2.5%	0	0%	120
Northern Ireland	15	51.7%	11	37.9%	0	0%	0	0%	1	3.4%	0	0%	2	6.9%	29
All	372	45.1%	349	42.3%	48	5.8%	23	2.8%	11	1.3%	18	2.2%	4	0.5%	825

Note: Recording of 'timing of diagnosis' within 72 hours commenced in May 2014 to align CRANE data collection with NIPE standards[2].

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[1] UK National Screening Committee Newborn and Infant Physical Examination (NIPE) Standards and Competencies 1 document (2008) – setting out the standard for 95% newborn to be screened by 72 hours after birth (page 13 of the document found at http://newbornphysical.screening.nhs.uk/getdata.php?id=10639).

[2] UK National Screening Committee Newborn and Infant Physical Examination (NIPE) Standards and Competencies 1 document (2008) – setting out the standard for 95% newborn to be screened by 72 hours after birth (page 13 of the document found at http://newbornphysical.screening.nhs.uk/getdata.php?id=10639).

Table I. Number (%) of CRANE-registered children born in 2017-19 with a **cleft involving the lip**, according to the timing of diagnosis and cleft service.

Cleft service	Antenatal		At birth		<72 hours		<1 week		<1 month		<6 months		>6 months		All
Newcastle	64	73.6%	18	20.7%	1	1.1%	2	2.3%	1	1.1%	1	1.1%	0	0%	87
Leeds	89	82.4%	13	12%	2	1.9%	1	0.9%	2	1.9%	1	0.9%	0	0%	108
Liverpool	55	75.3%	18	24.7%	0	0%	0	0%	0	0%	0	0%	0	0%	73
Manchester	97	89.8%	8	7.4%	1	0.9%	0	0%	0	0%	1	0.9%	1	0.9%	108
Trent	122	81.9%	21	14.1%	3	2%	0	0%	0	0%	2	1.3%	1	0.7%	149
West Midlands	117	70.1%	50	29.9%	0	0%	0	0%	0	0%	0	0%	0	0%	167
Cleft Net East	102	87.9%	13	11.2%	1	0.9%	0	0%	0	0%	0	0%	0	0%	116
North Thames	181	85.8%	27	12.8%	1	0.5%	2	0.9%	0	0%	0	0%	0	0%	211
Spires	104	75.9%	32	23.4%	1	0.7%	0	0%	0	0%	0	0%	0	0%	137
South Wales	52	94.5%	1	1.8%	0	0%	0	0%	1	1.8%	1	1.8%	0	0%	55
South West	61	80.3%	15	19.7%	0	0%	0	0%	0	0%	0	0%	0	0%	76
Evelina London	168	83.6%	28	13.9%	2	1%	0	0%	3	1.5%	0	0%	0	0%	201
Northern Ireland	33	71.7%	13	28.3%	0	0%	0	0%	0	0%	0	0%	0	0%	46
All	1245	81.2%	257	16.8%	12	0.8%	5	0.3%	7	0.5%	6	0.4%	2	0.1%	1,534

Note: Recording of 'timing of diagnosis' within 72 hours commenced in May 2014 to align CRANE data collection with NIPE standards[3].

Table J. Number (%) of CRANE-registered children born in 2020 with a **cleft involving the lip**, according to the timing of diagnosis and cleft service.

Cleft service	Antenatal		At birth		<72 hours		<1 week		<1 month		<6 months		>6 months		All
Newcastle	16	84.2%	3	15.8%	0	0%	0	0%	0	0%	0	0%	0	0%	19
Leeds	26	100.0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	26
Liverpool	21	67.7%	10	32.3%	0	0%	0	0%	0	0%	0	0%	0	0%	31
Manchester	18	85.7%	3	14.3%	0	0%	0	0%	0	0%	0	0%	0	0%	21
Trent	37	82.2%	6	13.3%	0	0%	1	2.2%	0	0%	1	2.2%	0	0%	45
West Midlands	43	65.2%	21	31.8%	0	0%	0	0%	0	0%	2	3%	0	0%	66
Cleft Net East	36	100.0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	36
North Thames	40	75.5%	12	22.6%	0	0%	0	0%	0	0%	0	0%	1	1.9%	53
Spires	21	48.8%	19	44.2%	0	0%	1	2.3%	0	0%	1	2.3%	1	2.3%	43
South Wales	18	90.0%	2	10%	0	0%	0	0%	0	0%	0	0%	0	0%	20
South West	6	100.0%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	6
Evelina London	50	80.6%	12	19.4%	0	0%	0	0%	0	0%	0	0%	0	0%	62
Northern Ireland	14	93.3%	1	6.7%	0	0%	0	0%	0	0%	0	0%	0	0%	15
All	346	78.1%	89	20.1%	0	0%	2	0.5%	0	0%	4	0.9%	2	0.5%	443

Note: Recording of 'timing of diagnosis' within 72 hours commenced in May 2014 to align CRANE data collection with NIPE standards[4].

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[3] UK National Screening Committee Newborn and Infant Physical Examination (NIPE) Standards and Competencies 1 document (2008) – setting out the standard for 95% newborn to be screened by 72 hours after birth (page 13 of the document found at http://newbornphysical.screening.nhs.uk/getdata.php?id=10639).

[4] UK National Screening Committee Newborn and Infant Physical Examination (NIPE) Standards and Competencies 1 document (2008) – setting out the standard for 95% newborn to be screened by 72 hours after birth (page 13 of the document found at http://newbornphysical.screening.nhs.uk/getdata.php?id=10639).

Table K. Number (%) of CRANE-registered children born in 2020 with a **cleft palate**, according to the timing of diagnosis and cleft service.

Cleft service	Time of diagnosis in relation to birth n (%)							All
	Antenatal	At birth	< 72 hours	≤1 week	≤1 month	≤6 months	>6 months	
Newcastle	1 6.7%	9 60%	3 20%	0 0%	1 6.7%	1 6.7%	0 0%	15
Leeds	0 0.0%	24 80%	1 3.3%	3 10%	2 6.7%	0 0%	0 0%	30
Liverpool	1 4.5%	13 59.1%	5 22.7%	2 9.1%	0 0%	1 4.5%	0 0%	22
Manchester	0 0.0%	11 44%	8 32%	3 12%	1 4%	2 8%	0 0%	25
Trent	1 3.6%	22 78.6%	3 10.7%	1 3.6%	0 0%	1 3.6%	0 0%	28
West Midlands	0 0.0%	24 80%	2 6.7%	2 6.7%	1 3.3%	1 3.3%	0 0%	30
Cleft Net East	1 5.3%	14 73.7%	2 10.5%	2 10.5%	0 0%	0 0%	0 0%	19
North Thames	1 2.6%	34 87.2%	3 7.7%	0 0%	0 0%	1 2.6%	0 0%	39
Spires	1 2.9%	19 54.3%	9 25.7%	3 8.6%	0 0%	3 8.6%	0 0%	35
South Wales	1 6.7%	13 86.7%	0 0%	0 0%	1 6.7%	0 0%	0 0%	15
South West	0 0.0%	4 66.7%	1 16.7%	1 16.7%	0 0%	0 0%	0 0%	6
Evelina London	2 3.8%	33 62.3%	8 15.1%	3 5.7%	4 7.5%	3 5.7%	0 0%	53
Northern Ireland	0 0.0%	10 76.9%	0 0%	0 0%	1 7.7%	0 0%	2 15.4%	13
All	9 2.7%	230 69.7%	45 13.6%	20 6.1%	11 3.3%	13 3.9%	2 0.6%	330

Note: Recording of 'timing of diagnosis' within 72 hours commenced in May 2014 to align CRANE data collection with NIPE standards[5].

For 2017-19 breakdown see section 3.3.2 of the report.

Consent verification

Table L. Number (%) of CRANE-registered children born in 2011-2013, according to consent status and cleft service.

Cleft service	Total cases*	Consented		Declined		Awaiting verification		Not possible to verify		Total cases verified
	N	n	(%)	n	(%)	n	(%)	n	(%)	(%)
Newcastle	192	186	96.9%	1	0.5%	5	2.6%	0	0.0%	97.4%
Leeds	198	195	98.5%	2	1.0%	1	0.5%	0	0.0%	99.5%
Liverpool	203	184	90.6%	1	0.5%	18	8.9%	0	0.0%	91.1%
Manchester	224	208	92.9%	8	3.6%	6	2.7%	2	0.9%	96.4%
Trent	293	270	92.2%	1	0.3%	22	7.5%	0	0.0%	92.5%
West Midlands	352	312	88.6%	11	3.1%	28	8.0%	1	0.3%	91.8%
Cleft Net East	235	190	80.9%	13	5.5%	29	12.3%	3	1.3%	86.4%
North Thames	472	396	83.9%	5	1.1%	71	15.0%	0	0.0%	85.0%
Spires	290	264	91.0%	2	0.7%	22	7.6%	2	0.7%	91.7%
South Wales	137	121	88.3%	6	4.4%	6	4.4%	4	2.9%	92.7%
South West	219	206	94.1%	1	0.5%	11	5.0%	1	0.5%	94.5%
Evelina London	333	227	68.2%	1	0.3%	103	30.9%	2	0.6%	68.5%
Northern Ireland	113	112	99.1%	0	0.0%	1	0.9%	0	0.0%	99.1%
All	3,261	2,871	88.0%	52	1.6%	323	9.9%	15	0.5%	89.6%

*Excluding those who died before 5 years and those with submucous cleft palates.

Grey column indicates data presented in funnel plot.

[5] UK National Screening Committee Newborn and Infant Physical Examination (NIPE) Standards and Competencies 1 document (2008) – setting out the standard for 95% newborn to be screened by 72 hours after birth (page 13 of the document found at http://newbornphysical.screening.nhs.uk/getdata.php?id=10639).

Table M. Number (%) of CRANE-registered children born in 2014, according to consent status and cleft service.

Cleft service	Total cases* N	Consented n	(%)	Declined n	(%)	Awaiting verification n	(%)	Not possible to verify n	(%)	Total cases verified (%)
Newcastle	57	53	93.0%	4	7.0%	0	0.0%	0	0.0%	100.0%
Leeds	62	61	98.4%	1	1.6%	0	0.0%	0	0.0%	100.0%
Liverpool	83	77	92.8%	0	0.0%	6	7.2%	0	0.0%	92.8%
Manchester	76	70	92.1%	5	6.6%	1	1.3%	0	0.0%	98.7%
Trent	83	77	92.8%	2	2.4%	4	4.8%	0	0.0%	95.2%
West Midlands	119	97	81.5%	3	2.5%	18	15.1%	1	0.8%	84.0%
Cleft Net East	71	54	76.1%	2	2.8%	15	21.1%	0	0.0%	78.9%
North Thames	147	131	89.1%	5	3.4%	11	7.5%	0	0.0%	92.5%
Spires	79	67	84.8%	4	5.1%	8	10.1%	0	0.0%	89.9%
South Wales	35	34	97.1%	1	2.9%	0	0.0%	0	0.0%	100.0%
South West	58	53	91.4%	0	0.0%	5	8.6%	0	0.0%	91.4%
Evelina London	126	72	57.1%	1	0.8%	51	40.5%	2	1.6%	57.9%
Northern Ireland	35	34	97.1%	0	0.0%	0	0.0%	1	2.9%	97.1%
All	1,031	880	85.4%	28	2.7%	119	11.5%	4	0.4%	88.1%

*Excluding those who died before 5 years and those with submucous cleft palates.

Appendix 7: Distribution of reasons provided for not collecting outcome data for CRANE-consented children at 5 years of age

Reason for not collecting speech data: 2011-13 births	Child growth		Dental health		Facial growth		Speech		Psychology	
	N	%	N	%	N	%	N	%	N	%
Patient deceased or emigrated	6	2.6	4	1.4	1	1.4	11	2.6	14	2.3
Patient transferred in or out of area	25	11.0	22	7.7	6	8.3	60	14.1	42	6.9
Syndromic diagnosis	11	4.8	10	3.5	2	2.8	6	1.2	8	1.3
Clinically contraindicated (non-syndromic)	5	2.2	2	0.7	5	6.9	82	19.0	7	1.1
Lack of staff facilities or equipment	48	21.1	97	34.3	9	12.5	39	9.2	279	45.7
Patient DNA / cancelled / did not consent / cooperate	80	35.1	83	29.2	30	41.7	123	28.9	148	24.2
Other	53	23.3	66	23.2	19	26.4	100	23.5	105	17.2
Specific to Psychology: Screen only partially completed	-	-	-	-	-	-	-	-	1	0.2
Specific to Psychology: Not completed due to language barriers	-	-	-	-	-	-	-	-	4	0.7
Specific to Psychology: Parents declined to complete	-	-	-	-	-	-	-	-	3	0.5
Specific to Speech: Not appointed before 6 years	-	-	-	-	-	-			-	-
Total	228	100	284	100	72	100	428	100	611	100

Reason for not collecting speech data: 2014 births	Child growth		Dental health		Facial growth		Speech		Psychology	
	N	%	N	%	N	%	N	%	N	%
Patient deceased or emigrated	3	2.46	5	2.1	0	0.0	2	0.8	4	1.8
Patient transferred in or out of area	7	5.74	9	3.8	3	18.8	17	7.1	11	4.8
Syndromic diagnosis	4	3.28	3	1.3	0	0.0	-	-	1	0.4
Clinically contraindicated (non-syndromic)	2	1.64	1	0.4	0	0.0	23	9.6	3	1.3
Lack of staff facilities or equipment	35	28.69	92	38.5	3	18.8	1	0.4	57	25.0
Patient DNA / cancelled / did not consent / cooperate	14	11.48	27	11.3	2	12.5	13	5.4	28	12.3
Other	57	46.72	102	42.7	8	50.0	182	76.2	109	47.8
Specific to Psychology: Screen only partially completed	-	-	-	-	-	-	-	-	1	0.4
Specific to Psychology: Not completed due to language barriers	-	-	-	-	-	-	-	-	0	0.0
Specific to Psychology: Parents declined to complete	-	-	-	-	-	-	-	-	14	6.1
Specific to Speech: Not appointed before 6 years	-	-	-	-	-	-			-	-
Total	122	100	239	100	16	100	240	100	228	100

Appendix 8: Child Growth – raw data

Table A. Number (%) of CRANE-registered[a] consented children born in 2011-2013 with growth data (height and weight) at the age of five or reasons this outcome was not collected at 5 years of age, according to cleft service.

Cleft Service	Consented eligible cases[b]	Height & Weight at 5 years reported		Height only reported		Weight only reported		Reason reported for not collecting outcome		Missing data	
	N	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Newcastle	186	148	79.6%	1	0.5%	3	1.6%	33	17.7%	1	0.5%
Leeds	195	148	75.9%	0	0.0%	1	0.5%	43	22.1%	3	1.5%
Liverpool	184	51	27.7%	0	0.0%	3	1.6%	9	4.9%	121	65.8%
Manchester	207	153	73.9%	2	1.0%	0	0.0%	25	12.1%	27	13.0%
Trent	264	129	48.9%	1	0.4%	1	0.4%	7	2.7%	126	47.7%
West Midlands	307	0	0.0%	0	0.0%	0	0.0%	3	1.0%	304	99.0%
Cleft Net East	190	96	50.5%	2	1.1%	2	1.1%	2	1.1%	88	46.3%
North Thames	396	192	48.5%	0	0.0%	9	2.3%	19	4.8%	176	44.4%
Spires	263	138	52.5%	2	0.8%	2	0.8%	56	21.3%	65	24.7%
South Wales	116	91	78.4%	2	1.7%	2	1.7%	10	8.6%	11	9.5%
South West	204	22	10.8%	0	0.0%	9	4.4%	6	2.9%	167	81.9%
Evelina London*	227	56	24.7%	0	0.0%	0	0.0%	7	3.1%	164	72.2%
Northern Ireland	111	29	26.1%	0	0.0%	1	0.9%	8	7.2%	73	65.8%
Total	2,850	1,253	44.0%	10	0.4%	33	1.2%	228	8.0%	1,326	46.5%
Revised total[c]	2,623	1,197	45.6%	10	0.4%	33	1.3%	221	8.4%	1,162	44.3%

[a] Registered in CRANE by 30 June 2021. [b] Exclusions (not mutually exclusive): Children who died before the age of 5 years, with submucous cleft palates, and those born with a diagnosed syndrome entered into the CRANE Database. [c] Revised totals have excluded Evelina London due to being an outlier for consent verification (2011-2013 births). The revised mean was used to calculate funnel plots.

Table B. Number (%) of CRANE-registered[a] consented children born in 2014 with growth data (height and weight) at the age of five or reasons this outcome was not collected at 5 years of age, according to cleft service.

Cleft Services	Consented eligible cases[b]	Height & Weight at 5 years reported		Height only reported		Weight only reported		Reason reported for not collecting outcome		Missing data	
	N	n	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Newcastle	53	30	56.6%	0	0.0%	0	0.0%	23	43.4%	0	0.0%
Leeds	61	30	49.2%	0	0.0%	0	0.0%	31	50.8%	0	0.0%
Liverpool	77	20	26.0%	0	0.0%	1	1.3%	3	3.9%	53	68.8%
Manchester	70	55	78.6%	0	0.0%	0	0.0%	2	2.9%	13	18.6%
Trent	76	36	47.4%	0	0.0%	0	0.0%	0	0.0%	40	52.6%
West Midlands	97	0	0.0%	0	0.0%	0	0.0%	1	1.0%	96	99.0%
Cleft Net East	54	20	37.0%	0	0.0%	2	3.7%	0	0.0%	32	59.3%
North Thames	130	66	50.8%	3	2.3%	4	3.1%	5	3.8%	52	40.0%
Spires	66	25	37.9%	0	0.0%	1	1.5%	20	30.3%	20	30.3%
South Wales	32	28	87.5%	1	3.1%	0	0.0%	3	9.4%	0	0.0%
South West	51	4	7.8%	0	0.0%	0	0.0%	2	3.9%	45	88.2%
Evelina London	71	17	23.9%	0	0.0%	0	0.0%	0	0.0%	54	76.1%
Northern Ireland	34	2	5.9%	0	0.0%	0	0.0%	32	94.1%	0	0.0%
Total	872	333	38.2%	4	0.5%	8	0.9%	122	14.0%	405	46.4%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years, with submucous cleft palates, and those born with a diagnosed syndrome entered into the CRANE Database.

Table C. Distribution of CRANE-registered[a] consented children born in 2011-2013, with growth data (height and weight) recorded at the age of five by BMI categories, according to each cleft service.

Cleft Services	All eligible cases[1]	Eligible cases with 5 years growth data[2]		Underweight		Healthy BMI		Overweight		Obese	
	N	N	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Newcastle	186	148	79.6%	1	0.7%	126	85.1%	15	10.1%	6	4.1%
Leeds	195	148	75.9%	4	2.7%	125	84.5%	10	6.8%	9	6.1%
Liverpool	184	51	27.7%	1	2.0%	46	90.2%	3	5.9%	1	2.0%
Manchester	207	153	73.9%	2	1.3%	133	86.9%	10	6.5%	8	5.2%
Trent	264	129	48.9%	1	0.8%	113	87.6%	10	7.8%	5	3.9%
Cleft Net East	190	96	50.5%	1	1.0%	86	89.6%	4	4.2%	5	5.2%
North Thames	396	192	48.5%	4	2.1%	173	90.1%	12	6.3%	3	1.6%
Spires	263	138	52.5%	6	4.3%	119	86.2%	6	4.3%	7	5.1%
South Wales	116	91	78.4%	10	11.0%	77	84.6%	3	3.3%	1	1.1%
South West	204	22	10.8%	0	0.0%	20	90.9%	2	9.1%	0	0.0%
Evelina London	227	56	24.7%	0	0.0%	49	87.5%	4	7.1%	3	5.4%
Northern Ireland	111	29	26.1%	0	0.0%	22	75.9%	4	13.8%	3	10.3%
Total	2543	1253	49.3%	30	2.4%	1089	86.9%	83	6.6%	51	4.1%
Revised Total[3]	1905	1026	53.9%	19	1.9%	895	87.2%	69	6.7%	43	4.2%

[1]Registered in CRANE by 30 June 2021. Exclusions (not mutually exclusive): Children who died before the age of 5 years, with submucous cleft palates, and those born with a diagnosed syndrome entered into the CRANE Database. [2]Children without data for growth at five years are excluded. [3]Revised totals exclude Evelina London (due to being an outlier for consent verification), Liverpool, N. Ireland, South Wales and West Midlands (due to being an outlier for growth data at five years of age). The revised mean was used to produce funnel plot for percentage of children with healthy BMI.

Table D. Distribution of CRANE-registered[a] consented children born in 2014 with growth data (height and weight) recorded at the age of five by BMI categories, according to each cleft service.

Cleft Services	All eligible cases[1]	Eligible cases with 5 years growth data[2]		Underweight		Healthy BMI		Overweight		Obese	
	N	N	(%)	n	(%)	n	(%)	n	(%)	n	(%)
Newcastle	53	30	56.6%	0	0.0%	25	83.3%	3	10.0%	2	6.7%
Leeds	61	30	49.2%	5	16.7%	17	56.7%	7	23.3%	1	3.3%
Liverpool	77	20	26.0%	0	0.0%	18	90.0%	1	5.0%	1	5.0%
Manchester	70	55	78.6%	2	3.6%	48	87.3%	3	5.5%	2	3.6%
Trent	76	36	47.4%	4	11.1%	28	77.8%	3	8.3%	1	2.8%
Cleft Net East	54	20	37.0%	0	0.0%	18	90.0%	2	10.0%	0	0.0%
North Thames	130	66	50.8%	2	3.0%	52	78.8%	9	13.6%	3	4.5%
Spires	66	25	37.9%	0	0.0%	22	88.0%	2	8.0%	1	4.0%
South Wales	32	28	87.5%	1	3.6%	25	89.3%	0	0.0%	2	7.1%
South West	51	4	7.8%	0	0.0%	2	50.0%	1	25.0%	1	25.0%
Evelina London	71	17	23.9%	0	0.0%	16	94.1%	1	5.9%	0	0.0%
Northern Ireland	34	2	5.9%	0	0.0%	2	100%	0	0.0%	0	0.0%
Total[3]	775	333	43.0%	14	4.2%	273	82.0%	32	9.6%	14	4.2%

[1]Registered in CRANE by 30 June 2021. Exclusions (not mutually exclusive): Children who died before the age of 5 years, with submucous cleft palates, and those born with a diagnosed syndrome entered into the CRANE Database. [2]Children without data for growth at five years are excluded. [3]West Midlands cleft service is excluded as it did not submit growth data at five years in 2014.

Appendix 9: Dental health – raw data

Table A. Number (%) of CRANE-registered[a] consented children born in 2011-2013 with dmft scores or reasons this outcome was not collected at 5 years of age, according to cleft service.

Cleft service	Consented eligible cases[b] N	dmft data n	(%)	Reason reported for not collecting outcome n	(%)	Total cases acc. for (%)	Missing data n	(%)
Newcastle	186	161	86.6%	24	12.9%	99.5%	1	0.5%
Leeds	195	135	69.2%	58	29.7%	99%	2	1%
Liverpool	184	86	46.7%	2	1.1%	47.8%	96	52.2%
Manchester	207	148	71.5%	32	15.5%	87%	27	13%
Trent	264	108	40.9%	29	11%	51.9%	127	48.1%
West Midlands	307	260	84.7%	29	9.4%	94.1%	18	5.9%
Cleft Net East	190	112	58.9%	14	7.4%	66.3%	64	33.7%
North Thames	396	40	10.1%	22	5.6%	15.7%	334	84.3%
Spires	263	179	68.1%	42	16%	84%	42	16%
South Wales	116	102	87.9%	8	6.9%	94.8%	6	5.2%
South West	204	69	33.8%	12	5.9%	39.7%	123	60.3%
Evelina London*	227	88	38.8%	2	0.9%	39.6%	137	60.4%
Northern Ireland	111	98	88.3%	10	9%	97.3%	3	2.7%
Total	2,850	1,586	55.6%	284	10%	65.6%	980	34.4%
Revised total[c]	2,623	1,498	57.1%	282	10.8%	67.9%	857	32.7%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years and with submucous cleft palates.
[c] Revised totals have excluded Evelina London due to being an outlier for consent verification (2011-2013 births). The revised mean was used to calculate funnel plots.

Table B. Number (%) of CRANE-registered[a] consented children born in 2014 with dmft scores or reasons this outcome was not collected at 5 years of age, according to cleft service.

Cleft service	Consented eligible cases[b] N	dmft data n	(%)	Reason reported for not collecting outcome n	(%)	Total cases acc. for (%)	Missing data n	(%)
Newcastle	53	35	66%	18	34%	100%	0	0%
Leeds	61	25	41%	36	59%	100%	0	0%
Liverpool	77	25	32.5%	0	0%	32.5%	52	67.5%
Manchester	70	1	1.4%	53	75.7%	77.1%	16	22.9%
Trent	76	30	39.5%	16	21.1%	60.5%	30	39.5%
West Midlands	97	57	58.8%	35	36.1%	94.8%	5	5.2%
Cleft Net East	54	36	66.7%	16	29.6%	96.3%	2	3.7%
North Thames	130	1	0.8%	20	15.4%	16.2%	109	83.8%
Spires	66	32	48.5%	11	16.7%	65.2%	23	34.8%
South Wales	32	28	87.5%	3	9.4%	96.9%	1	3.1%
South West	51	6	11.8%	7	13.7%	25.5%	38	74.5%
Evelina London*	71	22	31%	1	1.4%	32.4%	48	67.6%
Northern Ireland	34	11	32.4%	23	67.6%	100%	0	0%
Total	872	309	35.4%	239	27.4%	62.8%	324	37.2%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years and with submucous cleft palates.

Table C. Number (%) of CRANE-registered[a] consented children born in 2011-2013 with dmft >0 and dmft >5, according to cleft service.

Cleft service	Eligible cases with dmft reported N	At least one (>0) dmft N	(%)	dmft >5 N	(%)
Newcastle	161	52	32.3%	22	13.7%
Leeds	135	50	37.0%	21	15.6%
Liverpool	86	40	46.5%	10	11.6%
Manchester	148	68	45.9%	39	26.4%
Trent	108	41	38.0%	14	13.0%
West Midlands	260	80	30.8%	35	13.5%
Cleft Net East	112	56	50.0%	21	18.8%
North Thames	40	12	30.0%	1	2.5%
Spires	179	54	30.2%	12	6.7%
South Wales	102	38	37.3%	11	10.8%
South West	69	30	43.5%	5	7.2%
Evelina London*	88	35	39.8%	9	10.2%
Northern Ireland	98	46	46.9%	21	21.4%
Total	1,586	602	38.0%	221	13.9%
Revised total[c]	1,281	484	37.8%	192	15.0%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years and with submucous cleft palates.
[c] Revised totals have excluded Evelina London due to being an outlier for consent verification (2011-2013 births). The revised mean was used to calculate funnel plots.

Table D. Number (%) of CRANE-registered[a] consented children born in 2014 with dmft >0 and dmft >5, according to cleft service.

Cleft service	Eligible cases with dmft reported N	At least one (>0) dmft N	(%)	dmft >5 N	(%)
Newcastle	35	16	45.7%	4	11.4%
Leeds	25	11	44.0%	3	12.0%
Liverpool	25	12	48.0%	2	8.0%
Manchester	1	1	100.0%	0	0.0%
Trent	30	11	36.7%	3	10.0%
West Midlands	57	16	28.1%	5	8.8%
Cleft Net East	36	17	47.2%	8	22.2%
North Thames	1	0	0.0%	0	0.0%
Spires	32	10	31.3%	4	12.5%
South Wales	28	6	21.4%	0	0.0%
South West	6	4	66.7%	1	16.7%
Evelina London*	22	12	54.5%	4	18.2%
Northern Ireland	11	7	63.6%	2	18.2%
Total	309	123	39.8%	36	11.7%
Revised total[c]	35	16	45.7%	4	11.4%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years and with submucous cleft palates.

Table E. Number of CRANE-registered[a] consented children born 2014 with reported dental treatment and care, and average dental Treatment Index and average Care Index, according to cleft service. **The two halves of the table are sorted (separately) from lowest to highest mean index values.**

Cleft service	Eligible cases with dmft reported	Mean Treatment Index		Mean Care Index	
	N	N	(%)	N	(%)
Newcastle	35	35	63.0%	35	58.4%
Leeds	25	25	68.0%	25	58.0%
Liverpool	25	25	83.2%	25	60.8%
Manchester	1	1	0.0%	1	0.0%
Trent	30	30	87.0%	30	85.3%
West Midlands	57	57	77.9%	57	77.9%
Cleft Net East	36	36	87.9%	36	79.2%
North Thames	1	1	100.0%	1	100.0%
Spires	32	31	82.3%	31	75.8%
South Wales	28	28	86.6%	28	80.4%
South West	6	5	46.7%	5	46.7%
Evelina London	22	22	86.6%	22	76.2%
Northern Ireland	11	11	55.8%	11	52.1%
Total	1,586	1,572	76.4%	1,575	70.2%

[a] Registered in CRANE by 30 June 2021.

[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years and with submucous cleft palates.

Appendix 10: Facial Growth – raw data

Table A. Number (%) of CRANE-registered[a] consented children born in 2011-2013 with facial growth outcome data or reasons this outcome was not collected at 5 years of age, according to cleft service.

Cleft service	Consented eligible cases[b] N	Five-year-index data n	(%)	Reason reported for not collecting outcome n	(%)	Total cases acc. for (%)	Missing data n	(%)
Newcastle	23	17	73.9%	5	21.7%	95.7%	1	4.3%
Leeds	33	17	51.5%	13	39.4%	90.9%	3	9.1%
Liverpool	27	18	66.7%	1	3.7%	70.4%	8	29.6%
Manchester	37	32	86.5%	3	8.1%	94.6%	2	5.4%
Trent	40	33	82.5%	4	10%	92.5%	3	7.5%
West Midlands	65	49	75.4%	13	20%	95.4%	3	4.6%
Cleft Net East	37	21	56.8%	10	27%	83.8%	6	16.2%
North Thames	58	38	65.5%	2	3.4%	69%	18	31%
Spires	42	23	54.8%	3	7.1%	61.9%	16	38.1%
South Wales	22	9	40.9%	3	13.6%	54.5%	10	45.5%
South West	45	20	44.4%	3	6.7%	51.1%	22	48.9%
Evelina London*	55	46	83.6%	9	16.4%	100%	0	0%
Northern Ireland	23	11	47.8%	3	13%	60.9%	9	39.1%
Total	507	334	65.9%	72	14.2%	80.1%	101	19.9%
Revised total[c]	452	288	63.7%	63	13.9%	77.7%	101	22.3%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years, with submucous cleft palates, and those born with a diagnosed syndrome entered into the CRANE Database.
[c] Revised totals have excluded Evelina London due to being an outlier for consent verification (2011-2013 births). The revised mean was used to calculate funnel plots.

Table B. Number (%) of CRANE-registered[a] consented children born in 2014 with facial growth outcome data or reasons this outcome was not collected at 5 years of age, according to cleft service.

Cleft service	Consented eligible cases[b] N	Five-year-index data n	(%)	Reason reported for not collecting outcome n	(%)	Total cases acc. for (%)	Missing data n	(%)
Newcastle	8	5	62.5%	3	37.5%	100%	0	0%
Leeds	7	0	0%	5	71.4%	71.4%	2	28.6%
Liverpool	13	0	0%	0	0%	0%	13	100%
Manchester	14	0	0%	1	7.1%	7.1%	13	92.9%
Trent	16	16	100%	0	0%	100%	0	0%
West Midlands	16	0	0%	0	0%	0%	16	100%
Cleft Net East	10	0	0%	5	50%	50%	5	50%
North Thames	22	0	0%	1	4.5%	4.5%	21	95.5%
Spires	9	5	55.6%	1	11.1%	66.7%	3	33.3%
South Wales	3	0	0%	0	0%	0%	3	100%
South West	6	0	0%	0	0%	0%	6	100%
Evelina London*	12	1	8.3%	0	0%	8.3%	11	91.7%
Northern Ireland	5	0	0%	0	0%	0%	5	100%
Total	141	27	19.1%	16	11.3%	30.5%	98	69.5%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years, with submucous cleft palates, and those born with a diagnosed syndrome entered into the CRANE Database.

Table C. Number (%) of CRANE-registered[a] consented children born in 2011-2013 with reported five-year-index scores at 5 years of age, with good/fair/poor scores, according to cleft service.
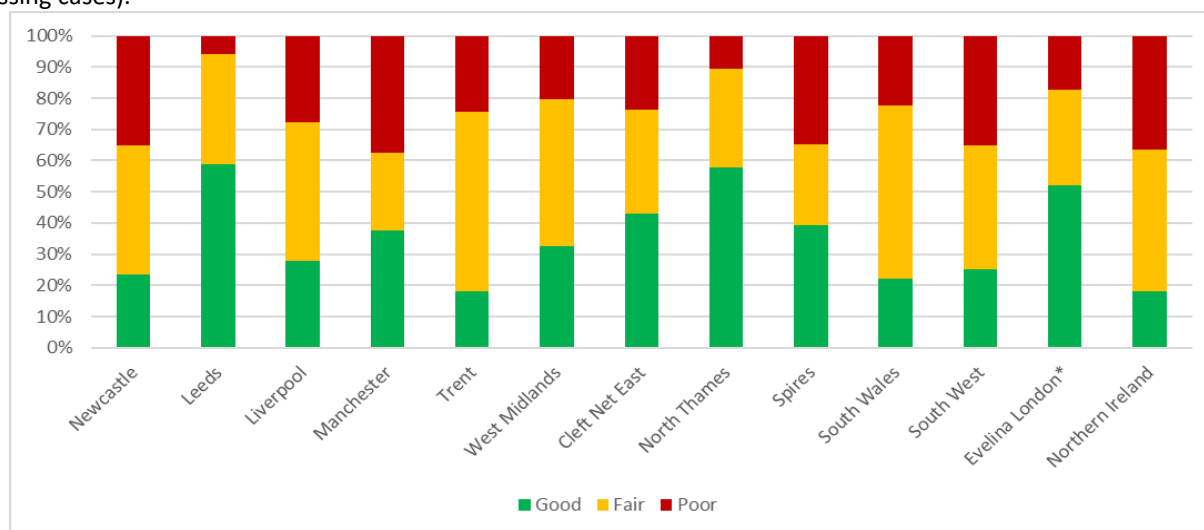
Cleft service	Reported Five Year Index [b] N	Good facial growth (scores 1 or 2) n	(%)	Fair facial growth (score 3) n	(%)	Poor facial growth (score 4 or 5) n	(%)
Newcastle	17	4	23.5%	7	41.2%	6	35.3%
Leeds	17	10	58.8%	6	35.3%	1	5.9%
Liverpool	18	5	27.8%	8	44.4%	5	27.8%
Manchester	32	12	37.5%	8	25.0%	12	37.5%
Trent	33	6	18.2%	19	57.6%	8	24.2%
West Midlands	49	16	32.7%	23	46.9%	10	20.4%
Cleft Net East	21	9	42.9%	7	33.3%	5	23.8%
North Thames	38	22	57.9%	12	31.6%	4	10.5%
Spires	23	9	39.1%	6	26.1%	8	34.8%
South Wales	9	2	22.2%	5	55.6%	2	22.2%
South West	20	5	25.0%	8	40.0%	7	35.0%
Evelina London*	46	24	52.2%	14	30.4%	8	17.4%
Northern Ireland	11	2	18.2%	5	45.5%	4	36.4%
Total	334	126	37.7%	128	38.3%	80	24.0%
Revised total[c]	288	102	35.4%	114	39.6%	72	25.0%

[a] Registered in CRANE by 30 June 2021.

[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years, children with submucous cleft palates, and children born with an incomplete UCLP.

[c] Revised totals have excluded: Evelina London due to being an outlier for consent verification (2011-2013 births). The revised mean was used to calculate funnel plots.

Figure A. Breakdown of good, fair and poor facial growth outcomes for each cleft service, for 2011-2013 births (minus missing cases).

Table D. Number (%) of CRANE-registered[a] consented children born in 2014 with reported five-year-index scores at 5 years of age, with good/fair/poor scores, according to cleft service.

Cleft service	Reported Five Year Index [b]	Good facial growth (scores 1 or 2		Fair facial growth (score 3)		Poor facial growth (score 4 or 5)	
	N	n	(%)	n	(%)	n	(%)
Newcastle	5	2	40.0%	2	40.0%	1	20.0%
Leeds	0	0	0.0%	0	0.0%	0	0.0%
Liverpool	0	0	0.0%	0	0.0%	0	0.0%
Manchester	0	0	0.0%	0	0.0%	0	0.0%
Trent	16	8	0.0%	5	31.3%	3	18.8%
West Midlands	0	0	0.0%	0	0.0%	0	0.0%
Cleft Net East	0	0	0.0%	0	0.0%	0	0.0%
North Thames	0	0	0.0%	0	0.0%	0	0.0%
Spires	5	2	40.0%	0	0.0%	3	60.0%
South Wales	0	0	0.0%	0	0.0%	0	0.0%
South West	0	0	0.0%	0	0.0%	0	0.0%
Evelina London	1	1	100.0%	0	0.0%	0	0.0%
Northern Ireland	0	0	0.0%	0	0.0%	0	0.0%
Total	27	13	48.1%	7	25.9%	7	25.9%

[a] Registered in CRANE by 30 June 2021.

[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years, children with submucous cleft palates, and children born with an incomplete UCLP.

Appendix 11: Speech – raw data

Table A. Number (%) of CRANE-registered[a] consented children born in 2011-2013 with speech outcome data or reasons this outcome was not collected at 5 years of age, according to cleft service.

Cleft Service	Consented eligible cases*	All 16 CAPS-A scores reported		<16 CAPS-A scores reported		Reason reported for not collecting outcome		Total cases acc. for	Missing data	
	N	n	(%)	n	(%)	n	(%)	(%)	n	(%)
Newcastle	112	94	83.9%	1	0.9%	16	14.3%	99.1%	1	0.9%
Leeds	112	93	83.0%	2	1.8%	16	14.3%	99.1%	1	0.9%
Liverpool	134	79	59.0%	5	3.7%	28	20.9%	83.6%	22	16.4%
Manchester	135	103	76.3%	3	2.2%	28	20.7%	99.3%	1	0.7%
Trent	159	130	81.8%	6	3.8%	23	14.5%	100.0%	0	0.0%
West Midlands	215	139	64.7%	2	0.9%	61	28.4%	94.0%	13	6.0%
Cleft Net East	134	75	56.0%	4	3.0%	40	29.9%	88.8%	15	11.2%
North Thames	263	148	56.3%	5	1.9%	60	22.8%	81.0%	50	19.0%
Spires	179	125	69.8%	5	2.8%	47	26.3%	98.9%	2	1.1%
South Wales	75	59	78.7%	1	1.3%	15	20.0%	100.0%	0	0.0%
South West	139	102	73.4%	3	2.2%	34	24.5%	100.0%	0	0.0%
Evelina London**	159	121	76.1%	1	0.6%	31	19.5%	96.2%	6	3.8%
Northern Ireland	80	49	61.3%	1	1.3%	29	36.3%	98.8%	1	1.3%
All	1,896	1,317	69.5%	39	2.1%	428	22.6%	94.1%	112	5.9%
Revised totals**	1,737	1,196	68.9%	38	2.2%	397	22.9%	93.9%	106	6.1%

*Exclusions: children who died before the age of 5 years, those with submucous cleft palates, and those with a diagnosed syndrome entered onto the CRANE Database.

**Revised totals have excluded Evelina London due to being an outlier for consent verification (2011-2013 births). The revised mean was used to calculate funnel plots. The grey column indicates data presented in the funnel plot.

Table B. Number (%) of CRANE-registered consented children born with a cleft affecting the palate in 2014, according to speech data and cleft service.

Cleft Service	Consented eligible cases*	All 16 CAPS-A scores reported		<16 CAPS-A scores reported		Reason reported for not collecting outcome		Total cases acc. for	Missing data	
	N	n	(%)	n	(%)	n	(%)	(%)	n	(%)
Newcastle	30	15	50.0%	2	6.7%	13	43.3%	100.0%	0	0.0%
Leeds	35	10	28.6%	2	5.7%	23	65.7%	100.0%	0	0.0%
Liverpool	46	13	28.3%	0	0.0%	29	63.0%	91.3%	4	8.7%
Manchester	50	28	56.0%	0	0.0%	22	44.0%	100.0%	0	0.0%
Trent	52	41	78.8%	0	0.0%	11	21.2%	100.0%	0	0.0%
West Midlands	61	14	23.0%	0	0.0%	2	3.3%	26.2%	45	73.8%
Cleft Net East	42	0	0.0%	0	0.0%	41	97.6%	97.6%	1	2.4%
North Thames	92	0	0.0%	0	0.0%	0	0.0%	0.0%	92	100.0%
Spires	47	31	66.0%	2	4.3%	13	27.7%	97.9%	1	2.1%
South Wales	22	16	72.7%	0	0.0%	6	27.3%	100.0%	0	0.0%
South West	31	17	54.8%	0	0.0%	14	45.2%	100.0%	0	0.0%
Evelina London	54	7	13.0%	0	0.0%	46	85.2%	98.1%	1	1.9%
Northern Ireland	25	6	24.0%	0	0.0%	19	76.0%	100.0%	0	0.0%
All	587	198	33.7%	6	1.0%	239	40.7%	75.5%	144	24.5%

Note: Registered in CRANE by 29 June 2021. Exclusions (not mutually exclusive): children who died before the age of 5 years, those with submucous cleft palate, and those with a diagnosed syndrome entered into the CRANE Database

Distribution of scores across the individual 16 CAPS-A speech parameters for those born 2011-2013

Table C. Number (%) of CRANE-registered[a] and consented children born with a cleft palate in 2011-2013, according to the four parameters for resonance and nasal airflow

Description	Score	N	(%)
RESONANCE – HYPERNASALITY			
Absent	0	1,006	76.4%
Borderline – minimal	1	156	11.9%
Mild – evident on close vowels	2	78	5.9%
Moderate – evident on open and close vowels	3	36	2.7%
Severe – evident on vowels and voiced consonants	4	40	3.0%
RESONANCE – HYPONASALITY			
Absent	0	1,076	81.7%
Mild – partial dentalization of nasal consonants and adjacent vowels	1	222	16.9%
Marked – dentalization of nasal consonants and adjacent vowels	2	19	1.4%
NASAL AIRFLOW – AUDIBLE NASAL EMISSION			
Absent on pressure consonants	0	1,188	90.2%
Occasional: pressure consonants affected <10% of the sample	1	94	7.1%
Frequent: pressure consonants affected >10% of the sample	2	35	2.7%
NASAL AIRFLOW – NASAL TURBULENCE			
Absent on pressure consonants	0	1,047	79.5%
Occasional: pressure consonants affected <10% of the sample	1	229	17.4%
Frequent: pressure consonants affected >10% of the sample	2	41	3.1%
Total		1,317	100%

Table D. Number (%) of CRANE-registered[a] consented children born with a cleft palate in 2011-2013, according to the twelve Cleft Speech Characteristics (CSCs) parameters.

Cleft Speech Characteristics (CSCs)		Score	N	(%)
ANTERIOR ORAL CSCs	1. Dentalisation / Interdentalisation	A	1,065	80.9%
		B	252	19.1%
	2. Lateralisation / Lateral	A	1,205	91.5%
		B	72	5.5%
		C	40	3.0%
	3 Palatalisation / Palatal	A	1,002	76.1%
		B	146	11.1%
		C	169	12.8%
POSTERIOR ORAL CSCs	4. Double Articulation	A	1,266	96.1%
		B	43	3.3%
		C	8	0.6%
	5. Backed to Velar / Uvular	A	1,160	88.1%
		C	68	5.2%
		D	89	6.8%
NON ORAL CSCs	6. Pharyngeal Articulation	A	1,291	98.0%
		C	9	0.7%
		D	17	1.3%
	7. Glottal Articulation	A	1,243	94.4%
		C	32	2.4%
		D	42	3.2%
	8. Active Nasal Fricatives	A	1,179	89.5%
		C	79	6.0%
		D	59	4.5%
	9. Double Articulation	A	1,284	97.5%
		C	21	1.6%
		D	12	0.9%
PASSIVE CSCs	10. Weak and or nasalised consonants	A	1,237	93.9%
		C	38	2.9%
		D	42	3.2%
	11. Nasal realisation of plosives	A	1,268	96.3%
		C	25	1.9%
		D	24	1.8%
	12. Gliding of fricatives	A	1,295	98.3%
		C	15	1.1%
		D	7	0.5%
		Total	1,317	100.0%

Raw speech standard data for funnel plots

Table E. Number (%) of CRANE-registered consented children born with a cleft affecting the palate in 2011 - 2013 with reported speech outcomes at 5 years of age, meeting each speech outcome standard, according to Cleft Service.

Cleft Service	Reported* (n)	Standard 1: Normal speech		Standard 2a: No structurally-related speech difficulties		Standard 3: No cleft-related articulation difficulties	
		n	(%)	n	(%)	n	(%)
Newcastle	94	61	64.9%	68	72.3%	65	69.1%
Leeds	93	46	49.5%	63	67.7%	55	59.1%
Liverpool	79	49	62.0%	54	68.4%	52	65.8%
Manchester	103	57	55.3%	64	62.1%	70	68.0%
Trent	130	85	65.4%	110	84.6%	96	73.8%
West Midlands	139	92	66.2%	112	80.6%	97	69.8%
Cleft Net East	75	40	53.3%	46	61.3%	48	64.0%
North Thames	148	88	59.5%	95	64.2%	104	70.3%
Spires	125	71	56.8%	89	71.2%	84	67.2%
South Wales	59	37	62.7%	46	78.0%	38	64.4%
South West	102	60	58.8%	73	71.6%	67	65.7%
Evelina London**	121	69	57.0%	74	61.2%	75	62.0%
Northern Ireland	49	37	75.5%	41	83.7%	38	77.6%
All	1,317	792	60.1%	935	71.0%	889	67.5%
Revised totals**	1,048	635	60.6%	766	73.1%	710	67.7%

*Exclusions: children who died before the age of 5 years, those with submucous cleft palates, and those with a diagnosed syndrome entered onto the CRANE Database. Grey column indicates data presented in funnel plot

Table F. Number (%) of CRANE-registered consented children born with a cleft affecting the palate in 2014 with reported speech outcomes at 5 years of age, meeting each speech outcome standard, according to Cleft Service.

Cleft Service	Reported* (n)	Standard 1: Normal speech		Standard 2a: No structurally-related speech difficulties		Standard 3: No cleft-related articulation difficulties	
		n	(%)	n	(%)	n	(%)
Newcastle	15	14	93.3%	14	93.3%	15	100.0%
Leeds	10	8	80.0%	9	90.0%	8	80.0%
Liverpool	13	10	76.9%	10	76.9%	10	76.9%
Manchester	28	17	60.7%	18	64.3%	20	71.4%
Trent	41	27	65.9%	31	75.6%	29	70.7%
West Midlands	14	10	71.4%	12	85.7%	11	78.6%
Cleft Net East	0	0	0%	0	0%	0	0%
North Thames	0	0	0%	0	0%	0	0%
Spires	31	16	51.6%	20	64.5%	20	64.5%
South Wales	16	12	75.0%	13	81.3%	12	75.0%
South West	17	14	82.4%	12	70.6%	15	88.2%
Evelina London	7	4	57.1%	4	57.1%	5	71.4%
Northern Ireland	6	4	66.7%	4	66.7%	5	83.3%
All	198	136	68.7%	147	74.2%	150	75.8%

*Exclusions: children who died before the age of 5 years, those with submucous cleft palates, and those with a diagnosed syndrome entered onto the CRANE Database.

Appendix 12: Psychology – raw data

Table A. Number (%) of CRANE-registered[a] consented children born in 2011-2013 with psychology outcome data or reasons this outcome was not collected at 5 years of age, according to cleft service.

Cleft service	Consented eligible cases[b] N	All 8 psychology 5-year-audit items reported n	(%)	1 to 7 psychology 5-year-audit items reported n	(%)	Reason reported for not collecting outcome n	(%)	Total cases acc. for (%)	Missing data n	(%)
Newcastle	159	128	80.5%	3	1.9%	28	17.6%	100%	0	0%
Leeds	168	124	73.8%	2	1.2%	40	23.8%	98.8%	2	1.2%
Liverpool	170	115	67.6%	29	17.1%	26	15.3%	100%	0	0%
Manchester	186	103	55.4%	7	3.8%	57	30.6%	89.8%	19	10.2%
Trent	233	2	0.9%	0	0%	128	54.9%	55.8%	103	44.2%
West Midlands	279	138	49.5%	93	33.3%	41	14.7%	97.5%	7	2.5%
Cleft Net East	183	97	53%	12	6.6%	29	15.8%	75.4%	45	24.6%
North Thames	385	220	57.1%	56	14.5%	38	9.9%	81.6%	71	18.4%
Spires	249	155	62.2%	33	13.3%	47	18.9%	94.4%	14	5.6%
South Wales	104	92	88.5%	11	10.6%	0	0%	99%	1	1%
South West	190	118	62.1%	9	4.7%	26	13.7%	80.5%	37	19.5%
Evelina London*	214	117	54.7%	11	5.1%	48	22.4%	82.2%	38	17.8%
Northern Ireland	102	14	13.7%	3	2.9%	46	45.1%	61.8%	39	38.2%
Total	2,622	1,423	54.3%	269	10.3%	554	21.1%	85.7%	376	14.3%
Revised total[c]	2,408	1,306	54.2%	258	10.7%	506	21%	86%	338	14%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years, with submucous cleft palates, and those born with a diagnosed syndrome entered into the CRANE Database.
[c] Revised totals have excluded Evelina London due to being an outlier for consent verification (2011-2013 births). The revised mean was used to calculate funnel plots.

Table B. Number (%) of CRANE-registered[a] consented children born in 2014 with psychology outcome data or reasons this outcome was not collected at 5 years of age, according to cleft service.

Cleft service	Consented eligible cases[b] N	All 8 psychology 5-year-audit items reported n	(%)	1 to 7 psychology 5-year-audit items reported n	(%)	Reason reported for not collecting outcome n	(%)	Total cases acc. for (%)	Missing data n	(%)
Newcastle	39	23	59%	0	0%	16	41%	100%	0	0%
Leeds	54	37	68.5%	0	0%	17	31.5%	100%	0	0%
Liverpool	72	34	47.2%	13	18.1%	24	33.3%	98.6%	1	1.4%
Manchester	66	48	72.7%	0	0%	6	9.1%	81.8%	12	18.2%
Trent	72	0	0%	0	0%	34	47.2%	47.2%	38	52.8%
West Midlands	97	0	0%	65	67%	2	2.1%	69.1%	30	30.9%
Cleft Net East	51	38	74.5%	4	7.8%	7	13.7%	96.1%	2	3.9%
North Thames	130	79	60.8%	11	8.5%	40	30.8%	100%	0	0%
Spires	60	45	75%	4	6.7%	11	18.3%	100%	0	0%
South Wales	31	26	83.9%	5	16.1%	0	0%	100%	0	0%
South West	44	19	43.2%	2	4.5%	1	2.3%	50%	22	50%
Evelina London	71	40	56.3%	16	22.5%	8	11.3%	90.1%	7	9.9%
Northern Ireland	31	4	12.9%	0	0%	27	87.1%	100%	0	0%
Total	818	393	48%	120	14.7%	193	23.6%	86.3%	112	13.7%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years, with submucous cleft palates, and those born with a diagnosed syndrome entered into the CRANE Database.

Table C. Number (%) of CRANE-registered[a] consented children born in 2011-2013 with reported psychology outcomes at 5 years of age, meeting each psychology process or outcome standard, according to cleft service.

Cleft service	Reported Psychosocial screen	Psychosocial screen before age 6		Reported TIM scores	TIM scores 1a+		Reported SDQ scores	High/very high SDQ scores	
	N	n	(%)	N	n	(%)	N	n	(%)
Newcastle	131	130	99.2%	130	127	97.7%	129	21	16.3%
Leeds	126	126	100.0%	126	126	100.0%	126	15	11.9%
Liverpool	166	166	100.0%	144	133	92.4%	115	16	13.9%
Manchester	105	105	100.0%	110	105	95.5%	103	14	13.6%
Trent*	2	2	100.0%	2	2	100.0%	2	0	0.0%
West Midlands	230	208	90.4%	227	199	87.7%	142	46	32.4%
Cleft Net East	109	108	99.1%	100	99	99.0%	104	14	13.5%
North Thames	341	339	99.4%	263	225	85.6%	232	29	12.5%
Spires	204	185	90.7%	172	166	96.5%	168	27	16.1%
South Wales	103	98	95.1%	103	101	98.1%	92	13	14.1%
South West	128	126	98.4%	121	115	95.0%	124	28	22.6%
Evelina London*	163	158	96.9%	126	111	88.1%	119	39	32.8%
Northern Ireland*	17	14	82.4%	15	15	100.0%	16	0	0.0%
Total	1,825	1,765	96.7%	1,639	1,524	93.0%	1,472	262	17.8%
Revised total[c]	1,643	1,591	96.8%	1,496	1,396	93.3%	1,335	223	16.7%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years, with submucous cleft palates, and those born with a diagnosed syndrome entered into the CRANE Database.
[c] Revised totals have excluded: Evelina London due to being an outlier for consent verification (2011-2013 births), and Trent and Northern Ireland due to being an outlier for psychology data completeness at 5 years. The revised mean was used to calculate funnel plots.

Table D. Number (%) of CRANE-registered[a] consented children born in 2014 with reported psychology outcomes at 5 years of age, meeting each psychology process or outcome standard, according to cleft service.

Cleft service	Reported Psychosocial screen	Psychosocial screen before age 6		Reported TIM scores	TIM scores 1a+		Reported SDQ scores	High/very high SDQ scores	
	N	n	(%)	N	n	(%)	N	n	(%)
Newcastle	25	24	96.0%	23	22	95.7%	23	2	8.7%
Leeds	37	37	100.0%	37	37	100.0%	37	1	2.7%
Liverpool	70	70	100.0%	43	40	93.0%	38	6	15.8%
Manchester	48	48	100.0%	48	48	100.0%	48	9	18.8%
Trent	0	0	0.0%	0	0	0.0%	0	0	0.0%
West Midlands	66	55	83.3%	63	49	77.8%	0	0	0.0%
Cleft Net East	42	40	95.2%	38	38	100.0%	42	7	16.7%
North Thames	123	123	100.0%	90	73	81.1%	79	10	12.7%
Spires	57	55	96.5%	49	49	100.0%	45	6	13.3%
South Wales	31	25	80.6%	31	30	96.8%	28	4	14.3%
South West	21	21	100.0%	20	20	100.0%	20	2	10.0%
Evelina London	58	58	100.0%	55	54	98.2%	41	4	9.8%
Northern Ireland	4	4	100.0%	4	4	100.0%	4	1	25.0%
Total	582	560	96.2%	501	464	92.6%	405	52	12.8%

[a] Registered in CRANE by 30 June 2021.
[b] Exclusions (not mutually exclusive): Children who died before the age of 5 years, with submucous cleft palates, and those born with a diagnosed syndrome entered into the CRANE Database.

Appendix 13. Diagnostic codes used to identify congenital malformations in the HES records of children with a cleft.

ICD-10 code	Description
	Congenital malformations of the nervous system
Q00	Anencephaly and similar malformations
Q01	Encephalocele
Q02	Microcephaly
Q03	Congenital hydrocephalus
Q04	Other congenital malformations of brain
Q05	Spina bifida
Q06	Other congenital malformations of spinal cord
Q07	Other congenital malformations of nervous system
	Congenital malformations of eye, ear, face and neck
Q10	Congenital ptosis
Q11	Anophthalmos, microphthalmos and macrophthalmos
Q12	Congenital lens malformations
Q13	Congenital malformations of anterior segment of eye
Q14	Congenital malformations of posterior segment of eye
Q15	Other congenital malformations of eye
Q16	Congenital malformations of ear causing impairment of hearing
Q17	Other congenital malformations of ear
Q18	Other congenital malformations of face and neck
	Congenital malformations of the circulatory system
Q20	Congenital malformations of cardiac chambers and connections
Q21	Congenital malformations of cardiac septa
Q22	Congenital malformations of pulmonary and tricuspid valves
Q23	Congenital malformations of aortic and mitral valves
Q24	Other congenital malformations of heart
Q25	Congenital malformations of great arteries
Q26	Congenital malformations of great veins
Q27	Other congenital malformations of peripheral vascular system
Q28	Other congenital malformations of circulatory system
	Congenital malformations of the respiratory system
Q30	Congenital malformations of nose
Q31	Congenital malformations of larynx
Q32	Congenital malformations of trachea and bronchus
Q33	Congenital malformations of lung
Q34	Other congenital malformations of respiratory system
	Other congenital malformations of the digestive system
Q38	Other congenital malformations of tongue, mouth and pharynx
Q39	Congenital malformations of oesophagus
Q40	Other congenital malformations of upper alimentary tract
Q41	Congenital absence, atresia and stenosis of small intestine
Q42	Congenital absence, atresia and stenosis of large intestine
Q43	Other congenital malformations of intestine
Q44	Congenital malformations of gallbladder, bile ducts and liver
Q45	Other congenital malformations of digestive system
	Congenital malformations of the genital organs
Q50	Congenital malformations of ovaries, fallopian tubes and broad ligaments
Q51	Congenital malformations of uterus and cervix
Q52	Other congenital malformations of female genitalia
Q53	Undescended testicle
Q54	Hypospadias
Q55	Other congenital malformations of male genital organs
Q56	Indeterminate sex and pseudohermaphroditism

	Congenital malformations of the urinary system
Q60	Renal agenesis and other reduction defects of kidney
Q61	Cystic kidney disease
Q62	Congenital obstructive defects of renal pelvis and congenital malformations of ureter
Q63	Other congenital malformations of kidney
Q64	Other congenital malformations of urinary system
	Congenital malformations and deformations of the musculoskeletal system
Q65	Congenital deformities of hip
Q66	Congenital deformities of feet
Q67	Congenital musculoskeletal deformities of head, face, spine and chest
Q68	Other congenital musculoskeletal deformities
Q69	Polydactyly
Q70	Syndactyly
Q71	Reduction defects of upper limb
Q72	Reduction defects of lower limb
Q73	Reduction defects of unspecified limb
Q74	Other congenital malformations of limb(s)
Q75	Other congenital malformations of skull and face bones
Q76	Congenital malformations of spine and bony thorax
Q77	Osteochondrodysplasia with defects of growth of tubular bones and spine
Q78	Other osteochondrodysplasias
Q79	Congenital malformations of the musculoskeletal system, not elsewhere classified
	Other congenital malformations
Q80	Congenital ichthyosis
Q81	Epidermolysis bullosa
Q82	Other congenital malformations of skin
Q83	Congenital malformations of breast
Q84	Other congenital malformations of integument
Q85	Phakomatoses, not elsewhere classified
Q86	Congenital malformation syndromes due to known exogenous causes, not elsewhere classified
Q87	Other specified congenital malformation syndromes affecting multiple systems
Q89	Other congenital malformations, not elsewhere classified
	Chromosomal abnormalities, not elsewhere classified
Q90	Down syndrome
Q91	Edwards syndrome and Patau syndrome
Q92	Other trisomies and partial trisomies of the autosomes, not elsewhere classified
Q93	Monosomies and deletions from the autosomes, not elsewhere classified
Q95	Balanced rearrangements and structural markers, not elsewhere classified
Q96	Turner syndrome
Q97	Other sex chromosome abnormalities, female phenotype, not elsewhere classified
Q98	Other sex chromosome abnormalities, male phenotype, not elsewhere classified
Q99	Other chromosome abnormalities, not elsewhere classified