CRANE Database

www.crane-database.org.uk

Annual Report 2011

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Abbreviations

BCLP	Bilateral cleft lip and palate
CAPS-A	Cleft Audit Protocol for Speech—Augmented
CARE	Craniofacial Anomalies Register
CDG	Cleft Development Group
CFSGBI	Craniofacial Society of Great Britain and Ireland
CI	Confidence interval
CLEFTSiS	The National Management Clinical Network for Cleft Service in Scotland
CSAG	Clinical Standards Advisory Group
DMFT	Decayed, missing and filled teeth
ENT	Ear, nose and throat
HES	Hospital Episode Statistics
ICD-10	International Classification of Disease 10th Revision
MCN	Managed Clinical Network
OPCS-4	Classification of Surgical Operations and Procedures 4th Revision
PEDW	Patient Episode Data Wales
SCG	Specialised Commissioning Group
SD	Standard deviation
SE	Standard error
SIG	Special Interest Group
UCLP	Unilateral cleft lip and plate
WHO	World Health Organization

Glossary

Alveolus / alveolar	The part of the jaw that supports the teeth and contains the tooth sockets.
Administrative Unit	A hospital that provides cleft surgery and submits data to the CRANE database, sometimes as part of a wider cleft centre or network.
Cleft	A failure of tissues to join during development.
Cleft Development Group (CDG)	NHS National group representing all stakeholders in cleft care that is responsible for the CRANE Database as well as oversight and guidance on all aspects of the delivery of reorganised cleft care.
Cleft surgeon	A surgeon undertaking cleft repair surgery in an Administrative Unit
Clinical Standards Advisory Group (CSAG)	A group established in 1991 to act as an independent source of expert advice on standards of clinical care for, and access to and availability of services to, NHS patients.
Craniofacial anomalies	A diverse group of deformities in the growth of the head and facial bones.
Craniofacial Society of Great Britain and Ireland (CFSGBI)	An inter-specialty group set up to study cleft lip and palate and other craniofacial anomalies. www.cfsgb.org.uk
Hospital Episode Statistics (HES)	A national database containing records on all admissions to NHS hospitals in England.
LAHSAL	A code used to classify clefts. Each letter (LAHSAL) relates to one of the six parts of the mouth that can be affected by a cleft.
Managed Clinical Network (MCN)	A formally organised network of clinicians.
National Information Governance Board (NIGB)	An independent statutory body established to promote, improve and monitor information governance in health and adult social care. http://www.nigb.nhs.uk
Patient Episode Data Wales (PEDW)	A national database containing records on all admissions to hospitals in Wales.
Submucous Cleft Palate	The term *submucous* refers to the fact that the cleft is covered over by the lining (mucous membrane) of the roof of the mouth. This covering of mucosa makes the cleft difficult to see when looking in the mouth.

Executive summary

The CRANE Database was established in 2000 and transferred to the Clinical Effectiveness Unit of the Royal College of Surgeons in 2005. The CRANE Database has two broad aims:

- to register birth and demographic data related to all children born in England, Wales and Northern Ireland with the congenital abnormality of cleft lip and/or palate;
- to record the treatment of children and adults with a cleft lip and/or palate and the outcome of such treatment.

Data are submitted to CRANE by 15 Administrative Units providing surgical treatment to cleft patients in England, Wales and Northern Ireland. This Annual Report describes the results of ongoing analyses of the CRANE database, examining trends in registrations and the timing of cleft diagnosis, patient referral to Administrative Units (hospitals providing cleft surgery) and first contact between Administrative Units and patients. It focuses primarily on children born in 2010. Furthermore, for the first time, we present information on cleft-related outcomes for children at five years of age.

This report also describes the analyses of data from Hospital Episode Statistics (HES), a database containing records on all NHS hospital admissions in England. These data are used to derive information on children diagnosed with, and receiving surgical treatment for, cleft lip and/or palate. Specifically, we focus on annual hospital and surgeon volumes of new patients undergoing primary repairs to either the lip, palate or both. In addition, for the first time, we present the burden of surgical care associated with cleft abnormalities, in terms of the number of hospital admissions and days spent in hospital in the first two years of life.

Children born with a cleft lip and/or palate in 2010

Overall, 9630 children born between 1 January 2000 and 31 December 2010 with a cleft lip and/or palate were registered on the CRANE database by 31 August 2011. Of these, 856 were born in 2010. It is estimated that a further 100 patients born in 2010 will be registered in due course. CRANE case ascertainment is very high, being around 95%, according to comparisons with HES and Patient Episode Data Wales (PEDW). The parental consent rate is 97%, according to reported figures from the Administrative Units.

Among children born in 2010, CRANE analyses revealed:

- 41% of children with clefts were diagnosed in the antenatal period through screening, which is the highest proportion since we started collecting the time of diagnosis.
- Only 1% of children with cleft palate only were diagnosed during antenatal screening; 66% were diagnosed at birth, leaving 33% who were diagnosed late according to the national standard.
- 58% of children were referred by a maternity unit to an Administrative Unit within 24 hours of birth. This compares to 51% in 2009.
- Referrals from maternity units within one day of birth varied from 22% to 83% according to the Administrative Unit receiving the referral.
- Administrative Units established contact with 90% of parents within 24 hours of their child's referral.

Cleft-related clinical outcomes at five years of age

CRANE collected clinical outcomes at five years of age, among children born in 2004 and 2005. These outcomes have been analysed for the first time, and include height and weight, number of decayed, missing and filled teeth (dmft), and Five Year Old Index scores. There was a high proportion of missing data for all outcomes (ranging from 73% to 86%). For those children with reported outcomes:

- 41% had at least one dmft, which reflects poor oral health. Although the proportion of children with at least one dmft varied according to cleft type, this variation was not statistically significant.
- Of the 35 children with a complete unilateral cleft lip and palate (UCLP) who had externally validated Five Year Old Index scores, 29% had scores of '4' or '5', reflecting poor dental arch relationships.

Hospital and surgeon volume of new cleft patients

The CSAG report, published in 1998, recommended that hospitals should treat at least 100 new cleft patients per year and surgeons should treat at least 40 new patients per year. We analysed HES data to examine the number of patients undergoing primary repairs. The analyses revealed that:

- The majority (54% in 2009 and 69% in 2010) of Administrative Units performed primary repairs on at least 70 new patients per year, while three Units in 2009 and four in 2010 performed primary repairs on the CSAG-recommended volume of at least 100 new patients.

- Almost half of all cleft surgeons performed primary repairs on at least 40 new patients per year as recommended in the CSAG report.

Hospital admissions for children with a cleft lip and/or palate

For the first time, we analysed HES data to examine all-cause hospital admissions and the total number of days spent in hospital by cleft patients. The main findings were:

- The majority (~75%) of admissions in the first six years of life occurred before the age of two.

- Cleft patients with syndromes and other complicating medical conditions (syndromic), who account for approximately 21% of all cleft patients, had approximately twice as many hospital admissions and spent almost four times as long in hospital as non-syndromic cleft patients.

- On average, non-syndromic children (children without a syndrome or associated medical condition) with a cleft had three admissions and spent a total of 10.6 days in hospital before the age of two.

- Among non-syndromic children, within the first two years of life:

    - The number of admissions and days in hospital varied significantly according to the type of cleft and appeared to be correlated with the severity of the cleft abnormality.

    - The number of admissions and days in hospital varied significantly according to the hospital performing the primary repair. The average number of admissions ranged from 2.9 to 3.6, while the average number of days in hospital ranged from 8.5 to 12.3 between hospitals.

Recommendations

- One third of the children born with a cleft palate are not diagnosed at birth. National and local guidelines for examining new born babies should be reviewed and recommendations should ensure proper visualisation of the palate to reduce the risk of a missed diagnosis and morbidity associated with late diagnosis.
- Administrative Units, together with maternity units, should ensure robust procedures are developed so that babies with a diagnosed cleft are referred promptly to the regional cleft team.
- All Administrative Units (Cleft Units) should have access to calibrated paediatric dentists who are able to examine children with clefts to determine their oral health status utilising decayed, missing and filled teeth (dmft) scoring.
- Cleft-related outcomes should be measured and recorded consistently at all Administrative Units and reported to CRANE to allow for national comparisons and to help improve standards of care across England and Wales.
- The impact of additional anomalies and different cleft types should be considered when commissioning cleft services across England and Wales, as these directly affect both the total number of hospital admissions and the length of stay in hospital during the first two years of life.
- Administrative Units should share areas of good practice to reduce the length of stay, where appropriate.

1. Introduction

Craniofacial abnormalities are among the most common of all birth defects.[1] Cleft lip and/or palate can affect a variety of functions, including speech and hearing. Appearance and psychosocial health may also be compromised in those with a cleft. Typically, children with these disorders need multidisciplinary care from birth to adulthood, and they have higher morbidity and mortality throughout life compared with unaffected individuals.[2]

The CRANE database is a national register that was established in 2000 to collect information on children born with a cleft lip and/or palate in England, Wales and Northern Ireland. The database collects birth, demographic and cleft diagnosis information. It also collects information about cleft-related treatment and outcomes. Hospital Episode Statistics (HES) is used to further examine treatment for cleft lip and/or palate in England. The HES database contains records on all NHS hospital admissions in England. It holds diagnostic and procedure information on each patient, allowing us to identify those with a cleft lip and/or palate and those undergoing cleft-related treatment.

This Annual Report includes trends in CRANE registrations since 2000, comparing the 15 Administrative Units and the four different types of cleft. Using CRANE data, we also report the proportion of babies born in 2010 who were diagnosed at birth, referred within 24 hours of birth, and contacted within 24 hours of referral. For the first time, cleft-related outcomes at five years of age are presented. These outcomes include height and weight, number of decayed, missing or filled teeth, and Five Year Old Index scores.

This report also describes the volume of patients undergoing primary repairs performed by each Administrative Unit and surgeon in England during 2009 and 2010. For the first time, we have analysed HES data to assess the burden of hospital care for children with a cleft lip and/or palate. We present the number of all-cause hospital admissions and days spent in hospital in the first two years of life, comparing cleft type and Administrative Unit.

1.1. Background to the CRANE database

The CRANE Database was established in 2000 in response to the report of the Clinical Standards Advisory Group (CSAG) on cleft care in the UK in 1998.[3] The report suggested that the outcome of cleft care in the UK was inferior to other countries in Western Europe. The

CRANE Database can be considered a continuation of the Craniofacial Anomalies Register (CARE) that since 1990 was maintained by the Craniofacial Society of Great Britain and Ireland (CFSGBI).

The CSAG report recommended that cleft care should be centralised into regional cleft teams that would treat larger numbers of patients. The rationale for this recommendation was that it would increase the experience of the cleft teams and facilitate genuine multi-disciplinary care. At the same time, it would also enable meaningful and statistically significant audit. The Health Services Circular 1998/238, which set out arrangements for commissioning cleft services according to the CSAG report, stated that 'a craniofacial anomalies register, with which all patients should be registered [should] form the basis of national audit'.[4] A high-quality national database could furthermore contribute to comparisons between countries.

Currently, the CRANE Database collects information about children born with a cleft lip and/or palate in England, Wales and Northern Ireland. Scotland maintains a separate database which is part of CLEFTSiS, the National Management Clinical Network for Cleft Service in Scotland.

The Cleft Development Group (CDG) is responsible for making arrangements for the running and commissioning of the CRANE Database. The funding for CRANE is provided by the Specialist Commissioners based on repeated two-year contracts. The CDG's membership is presented in Appendix 3.

1.2. Geographical representation of the cleft Administrative Units

The CRANE Database covers England, Wales and Northern Ireland. Cleft care is currently delivered by eight Regional Cleft Centres and two Managed Clinical Networks. Each of these ten geographical hubs, with the exception of Northern Ireland, treats at least 65 new children born with a cleft lip and /or palate each year. Several of the Regional Cleft Centres are split between two hospitals, where the primary surgery is usually undertaken. There are 15 Administrative Units (hospitals) who submit data to the CRANE Database (*Table 1*).

Table 1. Regional Cleft Centres and Managed Clinical Network and their associated Administrative Units

Regional centre / MCN	**Administrative Unit**
Northern & Yorkshire	Royal Victoria Hospital, Newcastle Leeds General Infirmary, Leeds
North West & North Wales & Isle of Man	Alder Hey Children's Hospital, Liverpool Royal Manchester Children's Hospital, Manchester
Trent	Nottingham City Hospital, Nottingham
West Midlands	Birmingham Children's Hospital, Birmingham
East	Addenbrooke's Hospital, Cambridge
North Thames	Great Ormond Street Hospital, London Broomfield Hospital, Chelmsford
The Spires	John Radcliffe Hospital, Oxford Salisbury District Hospital, Salisbury
South Wales & South West	Morriston Hospital, Swansea Frenchay Hospital, Bristol
South Thames	Guy's Hospital, London
Northern Ireland	Royal Belfast Hospital for Sick Children, Belfast

1.3. Aims and objectives of the CRANE database

The aims of the CRANE Database are:

- to register birth, demographic and epidemiological data related to all children born in England, Wales and Northern Ireland with the congenital abnormality of cleft lip and/or palate;
- to record the treatment of children and adults with a cleft lip and/or palate and the outcome of such treatment.

These data will provide the basis for national audit of cleft care.

In line with these broad aims, the CRANE Database has the following specific objectives:

- to ensure there is an up-to-date register of all children with cleft lip and/or palate;
- to monitor the frequency and incidence of clefting in the population;

- to audit and report on the quality of care for patients with clefts, thus promoting high standards in clinical management;
- to work with and receive advice from the CFSGBI to improve the delivery of cleft care in the UK;
- to work in partnership with Specialised Commissioning Groups (SCGs) to inform commissioning of cleft services;
- to support research and focused studies.

1.4. Current priorities of the CRANE database

The agenda of the CRANE Database is constantly being updated. Currently, the main priorities are:

- to link CRANE with other data resources, including HES and PEDW;
- to report the burden of care associated with cleft lip and/or palate and to provide data that can support the commissioning of cleft services;
- to audit aspects of care over time following the implementation of the recommendations of the CSAG report;[3]
- to expand the range of clinical outcomes that is recorded in the CRANE Database.

2. Methods

This report contains information on patterns of care and outcomes derived from two sources of data: data from the CRANE database and Hospital Episode Statistics (HES).

2.1. CRANE

2.1.1. Data source

CRANE is an online custom-built secure database that holds information on children born with a cleft lip and/or palate in England, Wales and Northern Ireland. CRANE collects data pertaining to a patient's birth, demographics, type of cleft, time of diagnosis, time of referral to a cleft team, and time of first contact between a patient and cleft team. CRANE also collects information about cleft-related treatment and outcomes. These data are reported to CRANE by the 15 Administrative Units, listed in *Table 1*. Each child born with a cleft in England, Wales and Northern Ireland should be referred to one of these Units shortly after having their cleft diagnosed.

Currently, CRANE only collects information on children whose parents have consented to their child's data being submitted to the national database. Parental consent is obtained by the Administrative Unit, usually at some point between referral and the first primary repair. A coordinator within each Unit submits data to CRANE on the consenting children referred to them. Units are also requested to notify CRANE of the number of non-consenting children referred to them each year. Once a record has been created on CRANE for a particular child, it can later be updated with further information.

2.1.2. Patients

All data entered into the CRANE database by 31 August 2011 pertaining to children born between 1 January 2000 and 31 December 2010 have been included in the analyses described in this Annual report. Patients whose parents did not consent to their data being used by CRANE (2.6%) have been excluded from *Tables 2-8*. For comparison with previous CRANE reports, Appendix 7 presents *Tables 2* and *3* showing all CRANE-registered children, regardless of their consent status.

2.1.3. Data validation and cleaning

Logical and systematic data cleaning was undertaken to identify any potential data errors. Continuous data variables (birth weight, five-year weight and five-year height) were assessed in relation to valid ranges. Valid ranges for five-year body weight and five-year height were defined according to growth charts published by the World Health Organisation (WHO).[5]

2.1.4. Analyses

Data have been analysed according to year of birth, with Chapter 3 focusing on children born in 2010, unless otherwise stated. Five-year outcome data were restricted to children born in 2004 and 2005. Children dying before five years of age were excluded from these analyses.

Cleft type

Cleft type was defined according to reported *LAHSAL* codes. The *LAHSAL* code is used to classify clefts, with each letter relating to one of the six parts of the mouth that can be affected by a cleft:

L	**A**	**H**	**S**	**A**	**L**
Right Lip	Right Alveolus	Hard palate	Soft palate	Left Alveolus	Left Lip

The code also indicates whether there is a complete cleft (upper case letter, e.g. H), an incomplete cleft (lower case letter, e.g. h), or no cleft (left blank). Where *LAHSAL* has not been reported (4.1% of children registered in 2010), cleft type is based on the type reported by the Administrative Unit registering the child. Children with a unilateral cleft lip and palate (UCLP) were categorised according to whether the UCLP was complete or incomplete. A complete UCLP was defined as *LAHS* or *HSAL* codes, indicating a complete cleft affecting all three components of the mouth on either the right or left side.

Decayed, missing and filled teeth (dmft)

Dmft describe the amount of dental caries in an individual and is a measure of oral health. A dmft score reflects the total number of teeth that are decayed, missing or filled. Analyses on dmft data were restricted to children born in 2004 and 2005 without a submucous cleft palate.

Dmft data are not collected by Nottingham and Cambridge because they do not have paediatric dentists who would examine children to determine the dmft. Great Ormond Street and Chelmsford were unable to extract dmft in time for inclusion in this report, and Birmingham was unable to provide data for children whose consent status had not yet been verified.

Five Year Old Index

Dental models of five-year old children can be assessed using the Five Year Old Index to examine dental arch relationships. CRANE collected both internal and external Five Year Old Index scores for children born in 2004 and 2005 with a complete UCLP (*LAHSAL* codes *LAHS* or *HSAL*). Some cleft teams score the models of children treated in their Unit (internal scores) before they are sent off to be scored externally (external scores) by a blinded process undertaken by calibrated examiners. For the purpose of this report, external scores were prioritised; however, internal scores have been analysed where external scores are missing.

Data on Five Year Old Index were not collected by Nottingham or Belfast. Cambridge had not obtained scores for patients born in 2004 or 2005 by the time data were analysed for this report, and Oxford and Salisbury had not obtained scores for patients born in 2005. Great Ormond Street, Chelmsford and Swansea were unable to extract Five Year Old Index data in time for inclusion in this report, while Birmingham was unable to provide data for patients whose consent status had not yet been verified.

Missing data

Missing data have been excluded from the denominators presented in *Tables 4* to *8*. Appendix 8 presents the number and proportion of children with missing data according to Administrative Unit. All Units have some degree of missing data. The number of patients with missing data for five-year outcomes is high. A variety of reasons were reported by units. Reasons out of a Unit's control include children not attending an appointment or moving away from the area. There were four Units (Nottingham, Cambridge, Great Ormond Street, and Chelmsford) who were unable to provide any five-year data

2.2. Hospital Episode Statistics (HES)

2.2.1. Data source

HES is a national database containing records on all admissions to NHS hospitals in England. It includes data on private patients treated in NHS hospitals, patients who were resident outside of England and care delivered by treatment centres (including those in the independent sector) funded by the NHS. Data on admissions are available for every financial year from 1989/90 onwards. Since the 1997/98 financial year, a unique patient identifier has been available that enables records belonging to the same patient to be identified across years.

For this report, CRANE received an extract from HES on admissions for the 13 complete financial years between 1st April 1997 and 31st March 2010 and provisional data for the part-year between 1st April 2010 and 31st January 2011.

Diagnostic information is coded using the International *Classification of Disease* 10th revision (ICD-10), and procedure information is classified according to codes from the *Classification of Surgical Operations and Procedures* 4th Revision (OPCS-4).

We used HES data to identify hospitals and surgeons treating cleft patients and to examine hospital admissions and treatment for children with a cleft lip and/or palate. HES also allowed us to estimate the incidence of clefting among births in England.

2.2.2. Patients

Patients were extracted for our analyses if they had at least one HES record of a hospital admission with a diagnosis code for cleft lip and/or palate (ICD-10 codes Q35, Q36 or Q37) and a procedure code for a primary cleft repair (OPCS-4 codes F031 or F291). ICD-10 codes were used to identify cleft patients with additional associated congenital anomalies or syndromes (see Appendix 5 for a list of these codes). Non-UK patients were excluded from analyses as they do not reflect a 'typical cleft patient' in the UK. Non-UK patients were identified in HES as a 'Private patient' with an 'unavailable/not applicable postcode'. All included patients were followed up until 31 January 2011, unless otherwise stated.

2.2.3. Analyses

Hospital and surgeon volume

Patients undergoing their first primary cleft repair in 2009 or 2010 were identified. The hospitals and surgeons performing these primary cleft repairs were identified using the NHS provider code and consultant code assigned to the repair procedure episode in HES. Patients older than six years at the time of the primary repair were excluded, as further examination of these cases showed that the majority were unlikely to be 'true' first primary repairs but, instead, were procedures such as alveolar bone grafts or dental procedures. When assessing volume, we only counted the first primary repair procedure in each patient, in order to reflect patient volume rather than procedure volume.

Hospital admissions

Patients born between 1 January 1997 and 31 December 2008 were included in the analyses of hospital admissions. The total number of all-cause hospital admissions (including the birth episode) and the total number of days in hospital in the first two years of life were identified. Patients with additional congenital anomalies and syndromes and those whose total number of days in hospital exceeded the 95th percentile (>32 days) for non-syndromic patients were also excluded, as their admissions mostly reflected non-cleft-related care in the neonatal period (slow fetal growth and fetal malnutrition; disorders related to short gestation and low birth weight; birth asphyxia; respiratory distress of newborn). Analyses are presented according to cleft type and the Unit that performed the first primary repair. Analyses according to Unit include patients born between 1 January 2006 and 31 December 2008, as our analyses of HES data revealed that all cleft services had been centralised by the end of 2006.

2.3. Statistical analyses

Descriptive statistics include means and standard deviations (SD) for continuous variables and numbers and percentages for categorical data. The statistical significance of differences in percentages between groups was assessed using the chi-squared ($\chi2$) test, while ANOVA was used to test difference in means between groups. A p value <0.05 was considered statistically significant.

3. CRANE

In this chapter, we present data on children with a cleft lip and/or palate, born between 1 January 2000 and 31 December 2010 in England, Wales and Northern Ireland. Data entered into the CRANE database by 31 August 2011 have been analysed.

3.1. CRANE registrations, 2000-2010

A total of 9630 children born between 1 January 2000 and 31 December 2010 have been registered on the CRANE database. A further 35 children born over the past eleven years whose parents withheld consent have also been registered with limited information (See Appendix 7). *Table 2* shows that Birmingham registered the most births over the last ten years. The Northern and Yorkshire region, consisting of two Administrative Units is the region that has the most registrations overall.

For births in 2010, 856 consenting children were registered with CRANE. This figure is expected to increase, as there can be a time lag between birth or diagnosis and registration. There are several reasons for this lag. First, parental consent must be obtained before children are registered on CRANE. Second, consent is sometimes not sought until the time of primary repair, which may take place up to one year after birth. Third, some clefts are diagnosed late. The average number of annual registrations between 2005 and 2009 is approximately 944, so it is estimated that approximately 100 children born in 2010 will be added to CRANE in due course.

Registrations by Cambridge, Great Ormond Street and Guy's are substantially lower for 2010 births than preceding years, indicating that these centres may have the longest lag time between birth or diagnosis and CRANE registration.

The distribution of the four main cleft types is shown in *Table 3*. Cleft type was defined according to reported *LAHSAL* codes. Where *LAHSAL* has not been reported (4.1% of children registered in 2010), cleft type is based on the type reported by the Administrative Unit registering the child. Overall, 4.0% of the registered children born in 2010 did not have their type of cleft specified. Belfast and Great Ormond Street had the highest proportion of patients whose cleft type was not specified (19.1% and 13.6%, respectively).

Table 2. Number of CRANE-registered babies born with a cleft lip and/or palate in England, Wales and Northern Ireland, according to Administrative Unit and year of birth, 2000-2010

		Year of birth											
Regional centre / MCN	**Administrative Unit**	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	All
Northern & Yorkshire	Newcastle	46	52	46	67	62	80	59	84	67	61	57	681
	Leeds	69	51	75	78	74	74	79	70	77	65	67	779
North West & North Wales	Liverpool	43	61	58	50	57	67	48	55	80	74	74	667
	Manchester	43	86	62	19	20	46	91	85	74	62	84	672
Trent	Nottingham	91	82	85	73	93	105	95	83	82	84	90	963
West Midlands	Birmingham	107	113	100	110	111	99	100	68	76	81	83	1048
East	Cambridge	76	48	75	65	74	82	74	67	68	69	38	736
North Thames	Gt Ormond St	56	67	12	13	30	68	61	59	103	95	66	630
	Chelmsford	45	39	21	21	29	35	22	29	28	35	37	341
The Spires	Oxford	49	38	31	42	37	38	43	31	26	44	31	410
	Salisbury	46	39	38	34	41	39	61	58	44	30	39	469
South Wales & South West	Swansea	32	30	30	36	34	42	47	45	43	47	43	429
	Bristol	61	74	63	61	52	47	56	61	68	49	68	660
South Thames	Guy's	58	60	56	44	72	83	98	102	105	82	58	818
Northern Ireland	Belfast	26	33	25	26	29	36	38	35	27	31	21	327
All	All	848	873	777	739	815	941	972	932	968	909	856	9630

Table 3. Number (%) of CRANE-registered babies born with a cleft lip and/or palate in England, Wales and Northern Ireland, according to cleft type and year of birth, 2000-2010

	Year of birth n (%)											
Cleft type	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	All
Cleft lip	151 (19.7)	176 (21.3)	183 (24.7)	144 (21.6)	174 (23.0)	162 (18.3)	215 (23.7)	220 (24.3)	230 (25.1)	187 (21.9)	215 (26.2)	2057 (22.8)
Cleft palate	362 (47.2)	398 (48.1)	333 (44.9)	312 (46.8)	334 (44.2)	432 (48.9)	405 (44.7)	380 (42.0)	404 (44.1)	386 (45.3)	343 (41.7)	4089 (45.2)
UCLP	182 (23.7)	165 (20.0)	158 (21.3)	158 (23.7)	170 (22.5)	211 (23.9)	197 (21.7)	208 (23.0)	210 (22.9)	185 (21.7)	172 (20.9)	2016 (22.3)
BCLP	72 (9.4)	88 (10.6)	67 (9.0)	52 (7.8)	77 (10.2)	79 (8.9)	90 (9.9)	96 (10.6)	73 (8.0)	95 (11.1)	92 (11.2)	881 (9.7)
Not specified	81 –	46 –	36 –	73 –	60 –	57 –	65 –	28 –	51 –	56 –	34 –	587 –
All	848 (100)	873 (100)	777 (100)	739 (100)	815 (100)	941 (100)	972 (100)	932 (100)	968 (100)	909 (100)	856 (100)	9630 (100)

UCLP, Unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate.

The distribution of cleft type is consistent over time. Cleft palate is the most common type of cleft, affecting just over 40% of the cleft population. This proportion is likely to increase to around 45% once late cleft palate diagnoses are reported to CRANE. Bilateral cleft lip and palate is the least common type, affecting around 10% of people with clefts. A total of 128 children registered in 2010 had complete unilateral cleft lip and palates (UCLP) (defined by either '*LAHS*..' or '..*HSAL*' *LAHSAL* codes), representing 74% of the 172 children with UCLP.

3.2. Case ascertainment

To determine case ascertainment, we identified in Hospital Episode Statistics (HES) and Patient Episode Database Wales (PEDW) all children with a diagnosis of a cleft lip and/or palate who had also undergone a primary lip or primary palate repair procedure. To allow for the time lapse between birth and repair, 2009 was the most recent birth year for which we can reliably present case ascertainment data. CRANE registered 831 consenting children born in 2009 with a cleft lip and/or palate who were treated in England, which represents 93.8% of the 886 identified in HES. For Wales, CRANE registered 47 consenting children treated in Swansea, which is higher (109.3%) than the 43 identified in PEDW. The Wales figures only represent children born and treated in South Wales at Swansea, as children born in North Wales are treated in England at Liverpool. Overall, CRANE registered 878 children in England and Wales, representing 94.5% of the 929 children identified through HES and PEDW. These figures demonstrate that case ascertainment by CRANE is high.

3.3. Characteristics of children born with a cleft lip and/or palate, 2010

Of the children born with a cleft in 2010, 45.1% were girls and 54.9% were boys. There are significant gender differences in the distribution of cleft type ($P<0.001$), as shown in the Annual Report published in 2009.[6] Isolated cleft palate is more prevalent among females (56.2% vs. 43.8% in males), while cleft lip and UCLP is more prevalent among males.

Gestational age was reported for only 87 (10.2%) babies born in 2010. The mean gestation was 38.8 weeks and ranged from 29 to 42 weeks. Fourteen per cent were premature (born before 37 weeks' gestation), which is higher than the six per cent background rate in England,[7] although it should be noted that the gestation recoded in CRANE may not be representative of all babies born with a cleft lip and palate as 90% of registered children were missing this information.

A valid birth weight was reported for 540 (63.1%) babies born in 2010. The median birth weight was 3.28kg (95% CI 3.2 to 3.3), which is consistent with the national average.[7]

Among the children born in 2010, there were six (0.7%) deaths reported to CRANE. Of these, one child died within one day of birth, two died within the first month and three died between one month and one year of age. It is not known from CRANE whether these children had additional anomalies or syndromes.

3.4. Timing of diagnosis, subsequent referral to and first contact with a cleft team, 2010

Of the 856 consenting children born in 2010 with a cleft diagnosis, 37 (4.3%) did not have the timing of their diagnosis reported to CRANE. This is considerably lower than the 13.4% of children born in 2009 who have not had the time of their diagnosis reported.

In total, 352 children born in 2010 had their cleft diagnosed during the antenatal period, representing 41.1% of all registered children – the highest proportion since we started collecting this information. The proportion of children diagnosed antenatally varied between cleft types, as shown in *Table 4*. Two thirds of children with cleft lip and approximately 80% of children with unilateral cleft lip and palate (UCLP) and bilateral cleft lip and palate (BCLP) were diagnosed in the antenatal period. Conversely, only 1% of children with a cleft palate were diagnosed antenatally, which demonstrates the difficulty of identifying this cleft type with current antenatal screening techniques.

Table 4. Number (%) of children born in 2010 according to timing of diagnosis and cleft type

	Time of diagnosis in relation to birth n (%)					
Cleft type	**Antenatal**	**At birth**	**≤1 week**	**≤1 month**	**≤6 months**	**All***
Cleft lip	135 (65.2)	67 (32.4)	2 (1.0)	1 (0.5)	2 (1.0)	207
Cleft palate	4 (1.2)	217 (66.2)	65 (19.8)	26 (7.9)	16 (4.9)	328
UCLP	136 (80.0)	33 (19.4)	1 (0.6)	0 (0.0)	0 (0.0)	170
BCLP	69 (77.5)	19 (21.3)	0 (0.0)	0 (0.0)	1 (1.1)	89
Not specified	8 (32.0)	10 (40.0)	3 (12.0)	3 (12.0)	1 (4.0)	25
All	352 (43.0)	346 (42.2)	71 (8.7)	30 (3.7)	20 (2.4)	819

CRANE, 2010

* 37/856 (4.3%) missing diagnosis time and excluded from table; UCLP, unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate

Of the 467 children not diagnosed during the antenatal period, 74.1% were diagnosed at birth, as shown in *Table 5*. This is consistent with data from 2009. Of those children who did not have their cleft identified antenatally, the majority (≥93%) with a cleft lip, UCLP and BCLP were diagnosed at the time of birth; however, one third of children with a cleft palate were not identified until later, with 5% of all children with a cleft palate being diagnosed between one and six months after birth.

It should be noted that some children born in 2010 with a cleft palate will not yet have had their cleft identified. In the preceding three years, the proportion of children born with a cleft palate who were diagnosed after six months of age ranged from 1.2% to 2.6%.

Table 5. Number (%) of CRANE-registered children born in 2010 with a cleft lip and/or palate, without an antenatal diagnosis, who were diagnosed and referred within 24 hours of birth and contacted within 24 hours of referral, according to cleft type

	Diagnosis		Referral		Contact	
	At birth	All*	Within 24h of birth	All§	Within 24h of referral	All¥
Cleft type	n (%)	N	n (%)	N	n (%)	N
Cleft lip	66 (93.0)	71	45 (61.6)	73	61 (84.7)	72
Cleft palate	217 (67.0)	324	118 (36.4)	324	282 (88.7)	318
UCLP	33 (97.1)	34	25 (73.5)	34	34 (100.0)	34
BCLP	19 (95.0)	20	14 (73.7)	19	16 (94.1)	17
Not specified	10 (58.8)	17	5 (33.3)	15	10 (71.4)	14
All	345 (74.0)	466	207 (44.5)	465	403 (88.6)	455

CRANE, 2010

352/856 (41.1%) children with an antenatal diagnosis excluded; 1/504 (0.3%) child died within one day of birth and is excluded; * 37/503 (7.4%) missing diagnosis time; §38/503 (7.6%) missing referral time; ¥ 48/503 (9.5%) missing contact time. Missing excluded in 'All' values; UCLP, unilateral cleft lip and plate; BCLP, bilateral cleft lip and palate.

Fifty-eight per cent of all CRANE-registered children born in 2010 were referred to an Administrative Unit within 24 hours of birth. Eighty per cent of children whose clefts were diagnosed antenatally were referred to an Administrative Unit within 24 hours of birth. This compares to 45% of the 465 children without an antenatal diagnosis. This proportion is not significantly different to the proportions in 2009 and 2008 (46%). *Table 5* shows that the proportion of referrals within 24 hours for children diagnosed at or after birth varied according to cleft type ($p<0.001$), with cleft palate patients having the lowest proportion (36%) out of those with a known cleft type, which corresponds with later diagnosis times for these children. Referrals within one day of birth varied significantly according to the Administrative Unit receiving the referral ($p<0.001$). Eighty-three per cent of children registered by Nottingham were referred from maternity units within 24 hours of birth, which is in contrast to only 22% of those referred to Bristol from maternity units.

Overall, Administrative Units established contact with almost 90% of all cleft patients within 24 hours of referral. This has increased significantly since 2007, when the figure was 81% (P=0.02). Manchester, Nottingham, Oxford and Belfast were in contact with 100% of their patients within 24 hours of referral. Great Ormond Street reported contacting 46% of their patients within 24 hours of referral, while all other Units contacted at least 77% of patients within one day of referral (not shown in Tables).

Table 6. Number (%) of CRANE-registered children with a cleft palate born in 2009-2010, without a prenatal diagnosis, who were diagnosed and referred within 24 hours of birth, according to Administrative Unit

		Diagnosis		**Referral**	
Regional centre / MCN	**Administrative Unit**	At birth n (%)	All* N	Within 24h of birth n (%)	All[§] N
Northern & Yorkshire	Newcastle	35 (74.5)	47	18 (37.5)	48
	Leeds	37 (67.3)	55	20 (36.4)	55
North West & North Wales	Liverpool	43 (65.2)	66	23 (34.8)	66
	Manchester	40 (65.6)	61	23 (38.3)	60
Trent	Nottingham	23 (74.2)	31	25 (80.6)	31
West Midlands	Birmingham	55 (87.3)	63	22 (34.9)	63
East	Cambridge	26 (70.3)	37	24 (64.9)	37
North Thames	Gt Ormond St	23 (37.7)	61	15 (25.9)	58
	Chelmsford	11 (52.4)	21	10 (47.6)	21
The Spires	Oxford	27 (96.4)	28	6 (23.1)	26
	Salisbury	16 (64.0)	25	12 (48.0)	25
South Wales & South West	Swansea	28 (80.0)	35	21 (60.0)	35
	Bristol	29 (65.9)	44	10 (21.7)	46
South Thames	Guy's	38 (63.3)	60	20 (33.3)	60
Northern Ireland	Belfast	17 (81.0)	21	5 (55.6)	9
All	All	448 (68.4)	655	254 (39.7)	640

CRANE, 2009-2010

7/734 (1.0%) children with a cleft palate antenatal diagnosis excluded; * 72/727 (9.9%) children missing diagnosis time, [§] 87/727 (12.0%) children missing referral time. Missing excluded in 'All' values; MCN, managed clinical network.

As highlighted above, very few children with a cleft palate are diagnosed in the antenatal period, and a significant proportion remains undiagnosed at birth. For this reason, we examined in greater detail the diagnosis and referral of children born with a cleft palate in 2009 and 2010, who were not diagnosed antenatally (*Table 6*). The proportion of children who had their cleft palate diagnosed at birth varied from 38% to 96% according to the cleft Administrative Unit registering the child ($P<0.001$). The wide variation in the proportion of cleft palates diagnosed at birth suggests that some maternity units are better than others at identifying clefts during newborn examinations.

Referrals to a cleft team within 24 hours of birth ranged from 22% to 81% ($P<0.001$). Referral within 24 hours of birth was not necessarily dependent on quick diagnosis. For example, although Oxford had the highest rate of cleft palate diagnoses at birth, it had one of the lowest 24-hour referral rates, suggesting a delay between diagnosis and referral to the Administrative Unit.

3.5. Five-year outcomes among children born with a cleft lip and/or palate, 2004 and 2005

For the first time, CRANE is reporting outcomes for children aged five years, who were born in 2004 and 2005. These outcomes include height and weight, decayed, missing and filled teeth (dmft), and Five Year Old Index.

3.5.1. Height and weight

Five-year height and weight were reported for 14% of the 1721 children born in 2004-2005 who were alive at five years of age. The mean (SD) height was 110.5cm (5.8) while the mean weight was 19.56kg (3.01). There is a very high proportion of missing data for five-year height and weight. Only Newcastle, Leeds, Bristol and Guy's were able to provide data on these outcomes. Birmingham reported collecting these data but they were unable to provide the information as consent status had not been verified for their registered children. The remaining ten Units reported not collecting height and weight at five years of age.

3.5.2. Decayed missing and filled teeth (dmft)

Dmft describe the amount of dental caries in an individual and is a measure of oral health. A dmft score reflects the total number of teeth that are decayed, missing or filled. The risk of dental caries is thought to be higher among children with a cleft lip and/or palate compared to children without an oral cleft.[8;9] We collect dmft data on CRANE-registered children at five years of age. Out of 1645 children born in 2004 and 2005 (excluding 35 children dying before five years of age and 76 with submucous cleft palates), dmft scores were provided for 447 (27.2%).

Table 7 shows that 41.4% of children with a cleft had at least one decayed, missing or filled tooth. The mean number of dmft at five years among children registered in CRANE was 1.8 (3.2), with scores ranging from 0 to 20. Forty-seven children (10.5%) had a dmft score greater than 5. Dmft data, obtained in 2005, are available for five-year old children in the general population in England and Wales. These data showed that 38.8% of five-year olds had at least one dmft, with a mean number of 1.5.[10] These figures are lower than those found in children with a cleft lip and palate; however, the overall difference is small and not statistically significant.

Table 7. Number (%) of children born in 2004-2005 according to number of decayed, missing or filled teeth (dmft) at age five years and cleft type

	Number of decayed, missing or filled teeth (dmft)			
	0	>0		
Cleft type	n (%)	n (%)	95% CI	All*
Cleft lip	46 (67.6)	22 (32.4)	21.1 – 43.6	68
Cleft palate	98 (59.8)	66 (40.2)	32.7 – 47.8	164
UCLP	84 (57.1)	63 (42.9)	34.8 – 50.9	147
BCLP	27 (49.1)	28 (50.9)	37.5 – 64.3	55
Not specified	7 (53.8)	6 (46.2)	17.9 – 74.4	13
All	262 (58.6)	185 (41.4)	36.8 – 46.0	447

CRANE, 2004-2005

77 children with submucous clefts excluded; 35 children who died before the age of five (of whom one had a submucous cleft) excluded; *1198/1645 (73%) children with missing dmft data excluded; UCLP, unilateral cleft lip and plate; BCLP, bilateral cleft lip and palate.

Table 7 shows the prevalence of dental caries according to cleft type. Although the proportion of children with at least one dmft varied according to cleft type, this variation was not statistically significant (p=0.296). Interestingly, the proportion of children with a cleft lip only who had at least one dmft was smaller than the proportion in the general population. This could be due to raised parental awareness of dental caries and increased access to dental services through cleft teams, thereby increasing the level of caries prevention in a group not particularly at increased risk as compared to more severe cleft types. Children with a cleft palate, UCLP and BCLP all had higher mean dmft scores than the general population. Children with a BCLP had the highest mean dmft score, at 2.7 (95% CI 1.6 to 3.8).

The fact that dmft were submitted for only 27% of children means that these data should be interpreted with caution. Five Administrative Units did not provide dmft data for any of their patients. Thus, it is possible that the overall findings from the limited data made available to CRANE may not be representative of the cleft population. Analyses of data from a greater number of children are necessary to examine true differences that may exist between the cleft population and general population.

Table 8. Number (%) of children born in 2004-2005 according to number of decayed, missing or filled teeth (dmft) at age five years and Administrative Unit

		Number of decayed, missing or filled teeth (dmft)			
		0	>0		
Regional centre / MCN	**Administrative Unit**	n (%)	n (%)	95% CI	All*
Northern & Yorkshire	Newcastle	50 (52.6)	45 (47.4)	32.3 – 57.5	95
	Leeds	–	–	–	–
North West & North Wales	Liverpool	27 (67.5)	13 (32.5)	17.8 – 47.2	40
	Manchester	31 (63.3)	18 (36.7)	23.1 – 50.4	49
Trent	Nottingham	–	–	–	–
West Midlands	Birmingham	9 (69.2)	4 (30.8)	4.6 – 57.0	13
East	Cambridge	–	–	–	–
North Thames	Gt Ormond St	–	–	–	–
	Chelmsford	–	–	–	–
The Spires	Oxford	33 (60.0)	22 (40.0)	26.9 – 53.1	55
	Salisbury	23 (69.7)	10 (30.3)	14.3 – 46.3	33
South Wales & South West	Swansea	6 (75.0)	2 (25.0)	7.2 – 57.2	8
	Bristol	35 (66.0)	18 (34.0)	21.1 – 46.9	53
South Thames	Guy's	31 (46.3)	36 (53.7)	41.7 – 65.8	67
Northern Ireland	Belfast	17 (50.0)	17 (50.0)	32.9 – 67.1	34
All	All	262 (58.6)	185 (41.4)	36.8 – 46.0	447

CRANE, 2004-2005

77 children with submucous clefts excluded; 35 children who died before the age of five (of whom one had a submucous cleft) excluded; *1198/1645 (73%) children with missing dmft data excluded; 95% CI, 95% Confidence intervals.

Table 8 shows the number and proportion of five-year old children with at least one dmft according to Administrative Unit. Of the 10 Units who submitted dmft data, Guy's had the highest proportion of children with one or more dmft, which was significantly different compared to the overall proportion among cleft lip and palate patients and the national average among five-year old children.[10] Swansea had the lowest proportion, reflecting better oral health; however, it should be noted that dmft data were only provided for eight children at Swansea (11% of their eligible children), and so these figures should be interpreted cautiously. In fact, with the exception of Newcastle, Manchester and Oxford, who submitted dmft data for at least 75% of their eligible children, all other Units submitted data for fewer than 65% of their registered children.

Regional differences in the levels of dental disease will not only be affected by the dental care received by children. Oral health will also be affected by water fluoridation levels. A systematic review found that water fluoridation is associated with an increased proportion of children without caries and a reduction in the number of teeth affected by caries.[11] Fluoridation levels vary between regions throughout the UK. For example, the West Midlands and the North East receive fluoridated water, whereas other areas do not.

3.5.3. Five Year Old Index

Dental models of five-year old children with a complete unilateral cleft lip and palate (UCLP) were assessed using the Five Year Old Index to examine dental arch relationships. The index evaluates the effects of primary surgery on the facial growth of children with UCLP before any other interventions, such as orthodontics or alveolar bone grafting, which may influence this growth further.[12] Dental arch relationships at five years are thought to predict treatment outcome in terms of facial growth on a population basis rather at the individual child level.[13] The Five Year Old Index may, therefore, also be used to compare treatment outcomes between centres and surgeons. Patients categorised as '1' and '2' on the index are considered to have the best possible outcome, while those categorised as '4' and '5' are thought to have very poor outcomes in terms of facial growth, and they may benefit from further surgery to correct their facial disproportion once facial growth is complete.

CRANE collected Five Year Old Index scores for children born in 2004 and 2005 with a complete UCLP. Five children who died before their fifth birthday were excluded. Scores were provided for 63 (24.9%) eligible children by eight of the 15 Administrative Units (*Table 9*). Of these 63 scores, 40 (63.5%) were externally validated; the remaining 23 were internal scores, which were analysed in the absence of external scores. For the 119 children with a complete UCLP born in 2004, 41 (34.5%) scores were reported, of which 40 (97.6%) were externally validated. Twenty-two (16.4%) out of the 134 eligible children born in 2005 had Five Year Old Index scores reported to CRANE; all of these scores were internal.

Only Newcastle, Salisbury and Guy's provided data for more than 75% of their eligible patients, and, thus, scores for other Units should be interpreted with caution. The small number of patients within each Unit means that statistical comparison between Units is not currently appropriate. CRANE will continue to collect these outcomes over the next few years, and as numbers increase meaningful comparison between Units will become possible.

Table 9. Number (%) of children born in 2004-2005 with a complete unilateral cleft lip and palate, according to Five Year Old Index scores and Administrative Unit

		Five Year Old Index n (%)					
Regional centre / MCN	**Administrative Unit**	1	2	3	4	5	All*
Northern & Yorkshire	Newcastle	3 (23.1)	1 (7.7)	7 (53.8)	1 (7.7)	1 (7.7)	13
	Leeds	0 (0.0)	0 (0.0)	2 (100.0)	0 (0.0)	0 (0.0)	2
North West & North Wales	Liverpool	1 (10.0)	3 (30.0)	4 (40.0)	2 (20.0)	0 (0.0)	10
	Manchester	0 (0.0)	1 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	1
Trent	Nottingham	_	_	_	_	_	_
West Midlands	Birmingham	_	_	_	_	_	_
East	Cambridge	_	_	_	_	_	_
North Thames	Gt Ormond St	_	_	_	_	_	_
	Chelmsford	_	_	_	_	_	_
The Spires	Oxford	0 (0.0)	1 (50.0)	0 (0.0)	1 (50.0)	0 (0.0)	2
	Salisbury	1 (14.3)	4 (57.1)	1 (14.3)	1 (14.3)	0 (0.0)	7
South Wales & South West	Swansea	_	_	_	_	_	_
	Bristol	0 (0.0)	0 (0.0)	0 (0.0)	2 (66.7)	1 (33.3)	3
South Thames	Guy's	1 (4.0)	12 (48.0)	6 (24.0)	4 (16.0)	2 (8.0)	25
Northern Ireland	Belfast	_	_	_	_	_	_
All	All	6 (9.5)	22 (34.9)	20 (31.7)	11 (17.5)	4 (6.3)	63

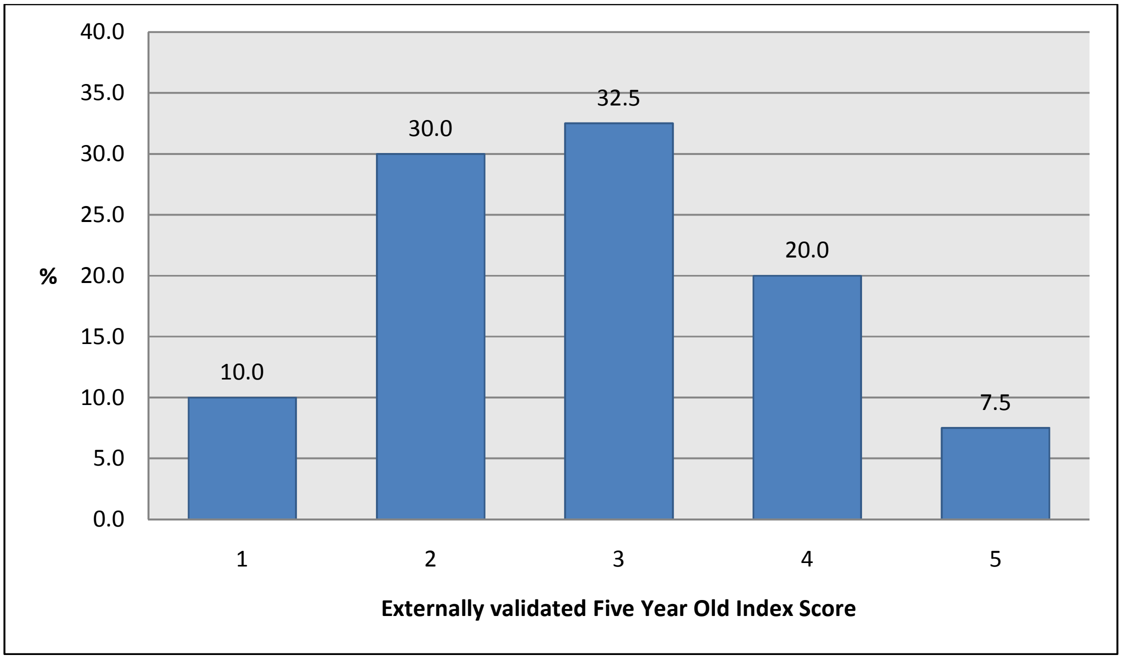
CRANE, 2004-2005

* 190/253 (75.1%) children with missing Five Year Old Index scores excluded; MCN, managed clinical network.

Overall, 44.4% of complete UCLP patients born in 2004 and 2005 had Five Year Old Index scores in the two groups considered to have the best possible dental arch relationships (scores '1' or '2') while 23.8% of children had scores '4' or '5', reflecting poor dental arch relationships. This compares to 36% (of 239 children) with poor dental arch relationships at five years old in 1996.[3]

Figure 1 shows the distribution of externally validated Five Year Old Index scores only. The proportion of children in the two groups considered to have the best dental arch relationships was slightly smaller than the proportion based on both external and internal scores (40.0% vs. 44.4%). Children with the two poorest scores represented 27.5%. These discrepancies highlight the importance of obtaining externally validated scores, where possible.

Figure 1. Percentage of children born in 2004 with a complete unilateral cleft lip and palate, according to externally validated Five Year Old Index scores



4. Hospital Episode Statistics

In this section, we present data on children who have at least one HES record of an English NHS hospital admission with a diagnosis code for cleft lip and/or palate as well as a procedure code for a primary cleft repair (that is, a first repair of the lip and/or palatal cleft).

4.1. Hospital and surgeon volume, 2009 and 2010

Tables 10.1 and *10.2* show the annual volume of new patients in 2009 and 2010 according to each Administrative Unit and each surgeon performing primary repairs. Three Units (Birmingham, Great Ormond Street and Guy's) treated at least 100 patients in both years. Although Chelmsford treated the fewest patients in 2009 and 2010, its cleft surgeons also work at Great Ormond Street hospital, and, collectively, they treated in excess of 145 new patients annually. In 2009, two non-cleft hospitals performed primary repairs on cleft patients. One of these repairs was performed on a syndromic patient by a recognised cleft surgeon. The other repair was undertaken in a non-syndromic patient aged five years by a plastic surgeon who had previously treated cleft patients and was continuing treatment for those previously under his/her care. No primary repairs were performed outside of the 13 Administrative Units in England during 2010.

In 2009, there were 24 cleft surgeons performing primary repairs on new cleft patients. Volumes ranged from four to 80 patients per cleft surgeon, with 11 (46%) surgeons performing repairs on 40 or more new patients, as recommended by CSAG.[3] There were two surgeons with low volumes (<10 new patients). One of these surgeons was newly appointed that year and the other had higher volumes in previous years. HES records indicated that three other (non-cleft) surgeons were responsible for primary cleft repairs in 2009. Further examination of these cases showed that the patients receiving these repairs were undergoing additional procedures during the same hospital episode. The consultants reported to HES as being responsible for the patients' episodes were of specialties related to the other procedures. HES can identify only one consultant per hospital episode, which is problematic if more than one speciality is involved in one episode and if multiple procedures in different surgical disciplines and anatomical areas are carried out at the same time.

Table 10.1 Number of patients undergoing a primary repair in 2009 according to Administrative Unit and Surgeon

Regional centre / MCN	Administrative Unit	Units' total patients	Cleft Surgeons				Other surgeons*
			1	2	3	4	
Northern & Yorkshire	Newcastle	49	49				
	Leeds	61	60				1
North West & North Wales	Liverpool	85	44	41			
	Manchester	72	34	38			
Trent	Nottingham	89	38	51			
West Midlands	Birmingham	114	36	37	41		
East	Cambridge	73	35	38			
North Thames[§]	Gt Ormond St	107	80	67			
	Chelmsford	40					
The Spires	Oxford	48	48				
	Salisbury	48	44	4			
South West	Bristol	53	28[∞]	26			
South Thames	Guy's	114	42	32	33	6	1
Other	Other[¥]	2					1
All	All	955					

HES, 2008-2009

MCN, managed clinical network; * three distinct non-cleft surgeons performed primary repairs; [§] Cleft surgeons in the North Thames worked across the two Administrative Units; [∞] one cleft surgeon at Bristol performed a primary repair on a patient at a non-cleft centre; [¥] two other centres performed primary cleft repairs on a total of two patients, one of whom was operated on by a cleft surgeon from Bristol.

In 2010, there were 27 cleft surgeons performing primary repairs on new cleft patients (*Table 10.2*). Volumes ranged from five to 74 new patients for recognised cleft surgeons, with eight (30%) performing at least 40 primary repairs on new patients. There were three surgeons performing fewer than 15 primary repairs, all of whom were newly appointed in 2010.

Three patients were identified in HES as having received repairs from non-cleft surgeons. Of these, two were undergoing other procedures during the same episode and the surgeons reported to HES were related to the appropriate specialties for the other procedures. The third patient's record in HES indicated no other procedure or diagnosis for the hospital episode. No further information was available for this case.

Table 10.2. Number of patients undergoing a primary repair in 2010 according to Administrative Unit and Surgeon

Regional centre / MCN	Administrative Unit	Units' total patients	Cleft Surgeons				Other surgeons*
			1	2	3	4	
Northern & Yorkshire	Newcastle	65	65	-	-	-	-
	Leeds	72	72	-	-	-	-
North West & North Wales	Liverpool	76	37	39	-	-	-
	Manchester	72	34	38	-	-	-
Trent	Nottingham	113	49	50	14	-	-
West Midlands	Birmingham	112	36	36	38	-	2
East	Cambridge	82	38	44	-	-	-
North Thames[§]	Gt Ormond St	105	54	74	12	5	-
	Chelmsford	40					
The Spires	Oxford	45	45	-	-	-	-
	Salisbury	49	27	22	-	-	-
South West	Bristol	67	39	28	-	-	-
South Thames	Guy's	110	38	35	18	18	1
Other	Other	-	-	-	-	-	-
All	All	1008					

HES, 2009-2010[∞]

MCN, managed clinical network; * three distinct non-cleft surgeons performed primary repairs; [§] Cleft surgeons in the North Thames worked across the two Administrative Units; [∞] HES data for 2010 are provisional and may be subject to change.

Overall, these data show that annual patient volume for Administrative Units and surgeons is substantially higher than volumes prior to the centralisation of cleft services. To put these data into context, in 1998 there were 44 hospitals providing cleft surgery. Of these, two thirds treated fewer than 20 patients per year. In the same year, there were 102 surgeons operating on cleft patients, of whom 75% performed primary repairs on fewer than 10 patients. Only one surgeon treated at least 40 patients, as recommended by CSAG (see CRANE report 2010[6]).

4.2. Hospital admissions among non-syndromic children born with a cleft lip and/or palate in England

This section presents data reflecting the number of all-cause hospital admissions and days spent in hospital up to two years of age for a typical non-syndromic cleft patient in the UK. We have focused on admissions within the first two years, as the majority (~75%) of admissions in the first six years occur by the age of two years. Syndromic cleft patients have approximately twice as many hospital admissions and spend almost four times as long in hospital as non-syndromic patients, often for reasons not related to their oral cleft. We therefore restricted our analyses for this Annual Report to non-syndromic patients in order to best reflect admissions related to cleft care.

Table 11 shows that children born between 1997 and 2008 with a cleft had, on average, around three hospital admissions and spent a total of 10.6 days in hospital by the age of two years. Admissions and days in hospital varied significantly according to the type of cleft ($p<0.001$) and appeared to be correlated with the severity of the abnormality. Cleft lip was associated with the fewest admissions and the lowest number of days in hospital, while children with a bilateral cleft lip and palate had the highest number of admissions and days in hospital.

Table 11. Total number of all-cause hospital admissions and days in hospital for non-syndromic cleft patients in the first two years of life, according to cleft type; year of birth 1997-2008

		Total number of admissions		**Total number of days in hospital**	
Cleft type	N*	Mean	(SE)	Mean	(SE)
Cleft lip	1825	2.45	(0.03)	7.42	(0.10)
Cleft palate	2782	2.51	(0.03)	9.46	(0.11)
UCLP	2563	3.50	(0.03)	12.37	(0.12)
BCLP	920	4.12	(0.06)	15.05	(0.21)
All	8090	3.00	(0.02)	10.56	(0.07)

Hospital Episode Statistics, England 1997-2010

* Non-UK patients and patients with total number of days in hospital in the first two years of life >95th percentile are excluded; SE, standard error; UCLP, unilateral cleft lip and plate; BCLP, bilateral cleft lip and palate.

Table 12 shows the number of all-cause admissions and days in hospital up to the age of two years according to the Administrative Unit performing the first primary repair. To reflect care provided by centralised services, only children born between 2006 and 2008 have been included in these analyses.

The mean number of admissions up to two years of age ranged from 2.9 (Guy's, Liverpool) to 3.6 (Oxford). An even greater range was observed for the total number of days spent in hospital. Children receiving their primary repair at Great Ormond Street spent, on average, the shortest time in hospital (8.5 days), while children undergoing their repairs at Manchester spent the most time in hospital (12.3 days).

Table 12. Total number of all-cause hospital admissions and days in hospital for non-syndromic cleft patients in the first two years of life, according to Administrative Unit performing the primary repair; year of birth 2006-2008

Regional centre / MCN	Administrative Unit	N*	Total number of admissions Mean	(SE)	Total number of days in hospital Mean	(SE)
Northern & Yorkshire	Newcastle	129	3.53	(0.15)	11.51	(0.50)
	Leeds	151	3.46	(0.12)	11.04	(0.47)
North West & North Wales	Liverpool	135	2.92	(0.17)	9.42	(0.40)
	Manchester	176	3.23	(0.13)	12.28	(0.51)
Trent	Nottingham	192	3.21	(0.09)	11.33	(0.42)
West Midlands	Birmingham	224	3.80	(0.13)	9.28	(0.37)
East	Cambridge	141	3.31	(0.12)	12.06	(0.44)
North Thames	Gt Ormond St	187	3.04	(0.12)	8.52	(0.37)
	Chelmsford	92	3.37	(0.13)	9.79	(0.56)
The Spires	Oxford	112	3.60	(0.16)	9.63	(0.47)
	Salisbury	126	3.23	(0.16)	10.93	(0.57)
South West	Bristol	144	3.35	(0.14)	9.6	(0.44)
South Thames	Guy's	275	2.91	(0.08)	8.11	(0.30)
All	All	2084	3.28	(0.04)	10.13	(0.13)

Hospital Episode Statistics, England 2006-2010

* Non-UK patients and patients with total number of days in hospital in the first two years of life >95th percentile are excluded; SE, standard error; MCN, managed clinical network; SE, standard error.

Although there are some differences in cleft type distribution between Administrative Units, these do not appear to explain the observed differences between Units in terms of the number of days in hospital. For example, although children undergoing primary repairs at

Great Ormond Street spent the shortest time in hospital, Great Ormond Street had one of the highest proportions of children with BCLP, which is associated with the most time in hospital.

It is important to recognise that differences between hospitals do not necessarily reflect differences in the quality of care, but may instead reflect differences in treatment protocols, particularly with regards to repairing the cleft lip and palate during the same operation or on separate occasions. For instance, according to HES coding, Cambridge never performs combined lip and palate repairs, whereas 32% of all primary repairs in Liverpool are combined lip and palate repairs. Geographical differences may also account for some variation. Children who live further away from Administrative Units may be discharged later than those who live closer as they would have to travel further to return to the Unit in the event of problems or complications.

Finally, it should be acknowledged that, since these data reflect all admissions and are not restricted to the hospital performing the primary repair, some admissions will have occurred because of non-cleft-related treatments at non-cleft hospitals. Although this may have a small influence on the presented figures, it is unlikely that systematic differences between regions exist.

5. Development of the CRANE database and future directions

5.1. Data linkage

The exercise to link the CRANE Database to HES was described previously in the Progress Report.[14] In September 2011 we were able to perform a corresponding linkage exercise to the Patient Episode Data for Wales (PEDW), the administrative database of admissions to the NHS hospitals in Wales, for patients registered by Swansea. It should be noted that cleft patients from North Wales have their surgery in Liverpool under the North West and North Wales Regional Centre.

The success of the linkage process relies on the completeness of patient identifiers and this has improved since our last report (see Appendix 9).

It is envisaged that these linkage exercises will be repeated annually.

The analysis of the linked data will:

- support data validation by assessing the correspondence of the recorded cleft type between the two data sources (CRANE Database and HES/PEDW);
- enable the examination of risk factors for delayed diagnosis of clefts in England and Wales;
- enable more extensive reporting of outcomes and treatment for children with clefting

5.2. Consent for registrations on the database

5.2.1. Consent for children born in 2010

Each Administrative Unit was requested to notify CRANE of the consent status for children born in 2010. The consent status of 861 children born in England and Wales (data not received from Belfast) was confirmed by mid September 2011. Of these, there were only 22 (2.6%) children whose parents did not provide consent. There were a further 192 children born in 2010 with a cleft lip and/or palate whose consent status had not been verified by the time figures were reported to CRANE (see Appendix 6, Table 2).

These figures are based on what has been reported by units, according to their local records. There are some minor discrepancies between these figures and the number of consenting registrations added to CRANE in time for inclusion in this report. These discrepancies are most likely due to differences in the time at which data were submitted.

5.2.2. Consent for existing CRANE registrations

As part of the consent taking process, centres have been retrospectively verifying consent for existing CRANE-registered patients born between 2000 and 2006, whose consent status was unclear (as detailed in the Annual Report 2009[15]). However, there was uncertainty about whether it was permitted to carry on processing an existing record while a patient's consent status remained un-verified. In August 2011, we submitted an application to the National Information Governance Board (NIGB) seeking section 251 approval to continue to process patient-identifiable information from existing records for the purpose of collecting outcomes data until such time as consent can be verified. Section 251 of the NHS Act 2006 (originally enacted under Section 60 of the Health and Social Care Act 2001) allows the common law duty of confidentiality to be set aside in specific circumstances where anonymised information is not sufficient and where patient consent is not practicable.[16] Section 251 approval has been granted to CRANE for a one-year period in the first instance and is subject to confirmation of satisfactory security arrangements.

The CRANE Project Team is currently discussing how these changes can best be incorporated in the on-line data entry screens. Centres will be informed of changes to the data collection arrangements in due course.

5.2.3. Consent for new CRANE registrations

In response to a previous decision by the Patient Information Advisory Group (PIAG) (now NIGB), the database has, since November 2008, not permitted new registrations unless patient consent has been obtained. The consent taking process led to delays in registering new births, for example, some centres do not seek consent until the time of the primary surgery. Furthermore CRANE could not completely fulfil its registry function as we were unable to hold any information about the small proportion of non-consenting births. In August 2011, we re-submitted an application to NIGB seeking section 251 approval to process a limited amount of patient-identifiable information without consent for the purpose of maintaining a register of cleft births. This application was approved subject to confirmation of satisfactory security arrangements.

The CRANE Project Team is currently discussing how these changes can best be incorporated and Units will be informed of changes to the consent and data collection arrangements in due course.

5.3. Outcome selection consultation process

Currently the outcome section of the database is hampered by the lack of agreed measures which have been shown to be valid and reliable in assessing the outcome of cleft care.
As part of the continuing development of recording outcomes on the database, a number of groups of the CFSGBI have been approached to identify and recommend outcome measures which are appropriate for evaluating cleft care on a national basis.

5.3.1. Speech

The Cleft Audit Protocol for Speech—Augmented (CAPS-A) tool, a valid and reliable measure of speech outcome,[17] has been piloted against agreed national speech standards derived by the Lead Speech and Language Therapy group in the last 24 months. Previous recommendations about training and increasing the robustness of the measuring tool have been described.[18] This development within the UK is in contrast to the varied measures and reporting used in the US cleft teams.[19] We are in final discussions with this group about the appropriate use of CAPS-A for recording speech outcomes on a national basis on the database.

5.3.2. Hearing

A number of interested clinicians with an active role in assessing hearing and providing Ear Nose and Throat (ENT) services have been contacted to agree valid and reliable outcome measures for assessing hearing in children with cleft lip and palate. These measures require further development before they can be adopted by CRANE.

5.3.3. Psychology

A meeting has been held with researchers with an interest in developing an outcome measure tool to be used by psychologists when assessing children with clefts. Any developed tools will need to be assessed for validity and reliability before being adopted by the CRANE database.

In summary, the current lack of well defined valid and reliable measures is preventing the project from reporting on a range of cleft-related outcomes. Further research to develop these measures is required urgently. This research should consider measures reflecting a 20-year treatment pathway, as well measures to assess quality of life. One of the priorities of the new Clinical Studies Group, which is being established for cleft-related research, should be to facilitate research into the development of validated measures.

5.4. CRANE database meeting with users

CRANE organises meetings with representatives of the Administrative Units approximately once a year. The last meeting took place on 2 November 2010. Key points from the meeting are listed below.

Consent and case ascertainment

- The estimated rate of non-consent for CRANE is low. Consequently, CRANE results are robust and representative of the cleft population in England, Wales and Northern Ireland.

- Case ascertainment is determined by comparing CRANE registrations with Hospital Episode Statistics (HES). This comparison showed that CRANE is achieving excellent levels of case ascertainment. We congratulated the teams and thanked them for their continued efforts.

- The new consent form and information leaflets were circulated after the meeting. Teams were asked to start using the forms and to feed back any issues to the CRANE project team. To date, no feedback has been received.

Data collection

- The importance of reporting the patient NHS number was emphasised as a fundamental requirement to enable linkage of patient-level CRANE data to HES data. Teams were receptive to the benefits of improving the capture of patient identifiers, acknowledging that the data entry burden relating to the recording of surgical procedures in CRANE will be greatly reduced if we can successfully link the two data sources.

- Teams were advised that website changes to streamline the collection of outcomes for Nursing, Orthodontics and Paediatric dentistry would shortly go live.
- Teams were advised that improvements to data downloads in response to user feedback would shortly go live.

The next CRANE database Users' meeting is scheduled for 31 January 2012.

5.5. Publications and presentations related to the CRANE database

Publications

We have submitted the following paper for peer review publication:
Fitzsimons KJ, Mukarram S, Copley LP, Deacon SA, van der Meulen J. "Centralisation of services for children with cleft lip or palate in England: a study of Hospital Episode Statistics."

Currently, we are working on a paper related to hospital admissions for children with cleft lip and palate and plan to submit this for peer review publication in 2012.

Oral presentations

Deacon S. "Does the primary surgical care for cleft births with syndromic/additional anomalies differ from non-syndromic births?" **Craniofacial Society of Great Britain and Ireland Conference** (14 April 2011)

6. Conclusions

This Annual Report presents national-level data on children born with a cleft lip and/or palate in England, Wales and Northern Ireland. Case ascertainment levels are very high, being around 95%, and the parental consent rate is 97%.

CRANE data showed that 41% of all babies born with a cleft were diagnosed in the antenatal period, which is the highest proportion since we started collecting this information. Cleft palates are notoriously difficult to identify during antenatal screening (1% are diagnosed antenatally). One third of cleft palates remain undiagnosed at birth. This reinforces our recommendation in the 2010 Annual Report,[20] which called for maternity guidelines to include guidance on proper visualisation of the palate during examinations of the newborn child at delivery.

Referral times from maternity units varied according to Administrative Unit. Overall, 58% of all CRANE-registered children born in 2010 were referred to an Administrative Unit within 24 hours of birth. This represents improved performance, as 51% of all children born in 2009 were referred within 24 hours of birth. Once children were referred, 90% were contacted by the Administrative Unit within 24 hours, with several Units contacting 100% of their patients within 24 hours of referral.

For the first time, CRANE has reported outcomes at five years of age among children with a cleft. There was a high proportion of missing data. Height and weight were provided for 14% of children, data on the number of decayed missing and filled teeth (dmft) were provided for 27% of eligible children, and Five Year Old Index scores were submitted for 23% of eligible children. Administrative Units reported a variety of reasons for the missing data. Two Units did not have a calibrated paediatric dentist who is required to determine dmft, and two Units reported not collecting Five Year Old Index. The inconsistent collection of cleft-related outcomes between Administrative Units limits our ability to comment on the quality of care delivered and is a concern.

Of those children with reported outcomes, 41.4% of five year olds had at least 1 dmft, which is not significantly higher than the 38.8% of five year olds in the general population.[10] However, compared to the general population, children with a cleft receive additional dental care, with particular focus on the prevention of caries. Thus, it may be argued that children with clefts should have better oral health than the general population. This was apparent among children with a cleft lip only. It should be noted that these findings are limited by the small number of children for whom data were submitted. The analysis of data from a greater number of children is necessary to examine true differences that may exist between different cleft types and between the cleft population and general population.

Twenty-eight per cent of children with a complete UCLP had externally validated Five Year Old Index Scores of ‘4’ or ‘5’, reflecting poor dental arch relationships. CRANE will continue to collect these outcomes and meaningful comparison between Units will become possible once the number of children for whom we have outcome data increases.

Analyses of data from Hospital Episode Statistics (HES) revealed that Administrative Units and cleft surgeons performed high volumes of primary repairs in both 2009 and 2010. The majority of Administrative Units performed primary repairs on at least 70 new patients per year. Almost half of all cleft surgeons performed primary repairs on at least 40 patients per year.

For the first time, using HES data, we have examined all-cause hospital admissions and the total number of days spent in hospital by non-syndromic cleft patients in the first two years of life. On average, children with a cleft have three admissions and spend a total of 10.6 days in hospital before the age of two. Admissions and days in hospital varied significantly according to the type of cleft and appeared to be correlated with the severity of the abnormality, as might be expected. We intend to analyse these data further to examine differences in patterns of care between syndromic and non-syndromic children.

We recommend that health professionals involved in the care of patients with a cleft lip and/or palate review the key findings within this report and identify areas in which local improvements, particularly in terms of data completeness, may be required.

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Appendices

Appendix 1: CRANE Project Team

Members of CRANE project team

Scott Deacon	Clinical Project Lead, Lead Consultant Orthodontist	Clinical Effectiveness Unit; South West Cleft Unit; University of Bristol
Kate Fitzsimons	Research Fellow	Clinical Effectiveness Unit
Lynn Copley	Data Manager	Clinical Effectiveness Unit
Jan van der Meulen	Clinical Epidemiologist	Clinical Effectiveness Unit; London School of Hygiene and Tropical Medicine
Jackie Horrocks	CRANE Administrator	Clinical Effectiveness Unit

Appendix 2: Governance and funding

Ownership

It has been agreed that the “ownership” of the CRANE Database lies with the Craniofacial Society of Great Britain and Ireland (CFSGBI) as it represents the multidisciplinary group of professionals involved in the care of patients with a cleft lip and/or palate.

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 and Wales. It includes representatives from all the stakeholders in cleft care in England and Wales, 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.

Funding

Funding of the CRANE Database is currently coordinated and agreed by representatives of the national Specialised Commissioning Group for England and the Wales Specialised Health Services Committee. Funds are raised through a levy calculated on a weighted per capita basis from the commissioning bodies in England and Wales. The levy is currently collected by Derbyshire County PCT.

Appendix 3: Members of the Cleft Development Group

Members of Cleft Development Group

Adrian Sugar	Chair / Wales Clinicians
Jon Currington	Vice Chair / East Midlands Specialised Commissioning Group
Liz Albery	President, Craniofacial Society of Great Britain and Ireland (CFSGBI)
Geoffrey Carroll	Medical Director, Wales Health Specialised Services Committee
Sue Carroll	Cleft Lip and Palate Association (CLAPA) Acting Chief Executive
Michelle Collard	Paediatric Dentistry (Special Interest Group (SIG) CFSGBI)
Scott Deacon	CRANE Clinical Project Lead
Mark Devlin	Scotland Clinicians
Adrian Drake-Lee	Cleft Surgery Interface Committee
Mandy Elder	East of England Specialised Commissioning Group
Sue Gregory	Department of Health (Dept. CDO England)
Per Hall	Cleft Surgeon (British Association Of Oral and Maxillofacial Surgeons)
Chris Hill	Northern Ireland Clinicians
Nichola Hudson	Specialist Cleft Nurses (SIG CFSGBI)
David Landes	North of England Dental Public Health Consultant
Fiona Mackison	South East Coast SCG
Fiona Marley	National Specialised Commissioning Group
Kate Le Marechal	Clinical Psychologists (SIG CFSGBI)
Jan van der Meulen	Clinical Epidemiologist
David Orr	Ireland Clinicians
Stephen Robinson	Orthodontics (SIG CFSGBI)
Debbie Sell	Lead Speech and Language Therapists Group
Alison Sims	Cleft Co-ordinators and Managers (SIG)
Rona Slator	Chair, Cleft Centres Clinical Directors/Managers Group
Alistair Smyth	Cleft Surgeon (British Association of Oral and Maxillofacial Surgeons)
Mike Winter	Medical Director, National Services Division, Scotland
Ken Wragg	East Midlands Dental Public Health Consultant
Christopher Allen	Deputy for Ken Wragg and David Landes
Jackie Horrocks	Minutes Secretary, CRANE/Clinical Effectiveness Unit

Appendix 4: Terms of Reference for the Cleft Development Group

The Origins of the Cleft Development Group (CDG)

The NHS Cleft Development Group was formed in November 2004 out of the previous CRANE/Cleft Levy Board, the CRANE Management Group and their Advisory bodies. These groups and bodies had been responsible for the national cleft database, CARE and then CRANE. The implementation of the DoH's guidance regarding the re-organisation of cleft services in the UK which stemmed from the DoH Clinical Standards Advisory Group report into the care of patients with Clefts of the Lip and/or Palate (1998) was the responsibility of the Cleft Implementation Group (CIG). When this group was terminated by the DoH, a new body took over its role, the Cleft Monitoring Group. When that body was terminated, the Cleft Development Group (CDG) was asked to take over its role too.

The Roles of the CDG

The CDG has two distinct roles which arise from its origins.

1. The CDG is responsible for guidance on all aspects of the delivery of re-organised cleft care in England and Wales and, when asked, by Scotland and Northern Ireland. It gives advice to the cleft centres, to health organisations, trusts, boards, commissioning groups and consortia and to the Departments of Health in England and the devolved administrations. It represents all stakeholders in cleft care and works with all to ensure the highest quality of cleft care in the UK to all patients who need it. It inherits the responsibilities of the Cleft Implementation Group and the Cleft Monitoring Group which were largely advisory.
2. The CDG is responsible for the commissioning of, the strategic governance of and is ultimately responsible for the national cleft database which used to be called CARE and is now called CRANE. It must negotiate and agree a contract for the running of CRANE and have operational oversight of the implementation of that contract. It is responsible for funding of the CRANE Register and is responsible for ensuring that the agreed levy is collected annually through the NHS Specialist Commissioners. It will approve an annual budget and business plan for CRANE drawn up with the contract holders and will review income and expenditure and ensure that the terms of reference are implemented. It will determine the location of the register and will appoint the Clinical Director/Project Leader who will be accountable to the Group.
3. The CDG's responsibility stems from Health Services Circular 1998/238 which states that "A CARE Register, with which all patients should be registered, will be maintained by the Craniofacial Society of Great Britain – this will form the basis for national audit".
4. The database was UK wide when run by the Craniofacial Society of Great Britain and Ireland and before it became the responsibility of the CRANE Levy Board. Devolution of government in the UK resulted in four distinct health services and as a result CDG came to be responsible for a national database for the recording of all children with clefts of the lip and/or palate born and treated in England and Wales, as the health service in Wales indicated its support for this development at an early stage. It has since then successfully sought to include in its work strong relationships also with the cleft services in Scotland, Northern Ireland and the Irish Republic.
5. The CDG is responsible for providing data for cleft births and cleft treatment for England and Wales and it also endeavours, with the cooperation of the health services in Scotland and Northern Ireland, to do so for the whole of the UK.
6. The national CRANE database has two primary functions:-

    a. the recording of all birth, demographic and epidemiological data related to children born in England and Wales with the congenital abnormality of clefting of the lip and/or palate, and where possible extending this to the whole of the UK and Ireland;

b. the recording of all treatment of children and adults in England and Wales with clefts of the lip and/or palate and the outcome of such treatment, and where possible extending this to the whole of the UK and Ireland.

7. The data from (a) will provide the same kind of information as other congenital anomaly registers and will be the basis for reports, audit and research in that area. The data from (b) will provide the basis for national cleft audit which is intended to be a major and integral role of CRANE.
8. The relationships between the bodies involved in the national cleft database, CRANE, are defined by a Tripartite Agreement (2007) between the Cleft Development Group, the NHS Specialist Commissioners and the Craniofacial Society of Great Britain and Ireland.

Composition of the Cleft Development Group

The composition of the Cleft Development Group should reflect all stakeholders involved in cleft care. Consequently its composition (and consequently these Terms of Reference) will need to be changed from time to time. The Members of the Cleft Development Group will normally and primarily be active clinical members of a designated Cleft Team, public health consultants, commissioners of cleft care, and representatives of parent/patient organisations. Membership of the **Group** will be for a term of three years which can be extended at the behest of the nominating organisation, except for members ex-officio who will be members during their terms of that office whether it be less or more than three years. The **Group** will elect its own Chair, who will remain in office for three years. The Group will also elect a Vice Chair. Either the Chair or the Vice Chair should be a Specialist Commissioner. The Group may decide to re-elect the holders of these offices.

The composition will be:

1. Commissioners of Cleft Care. These should include at least two specialised commissioners from Specialised Commissioning Groups in England (nominated nationally), one from Wales, one from Scotland and one from Northern Ireland (each nominated by their equivalent national specialist commissioning body). It is intended that there should be no more than six specialist commissioners in total to be agreed and appointed by the bodies which contribute data to the database (in the case of Scotland by sharing its data with CDG). Only those commissioning groups which pay the levy may vote on issues relating to CRANE.
2. Public Health Consultants. These should include representatives of commissioning areas who are actively involved in cleft commissioning, and will normally be Consultants in Dental Public Health. There should be at least two (to be nominated by the BASCD Consultants in Dental Public Health Group).
3. A Lay representative from a Parent Support Group (1) (to be nominated by CLAPA)
4. Cleft surgeons (2) (one to be nominated by BAOMS and one by BAPRAS)
5. The President of the Craniofacial Society of Great Britain and Ireland
6. The Chair of the Cleft Interface Group on cleft surgery training
7. A Speech & language therapist (1) (to be nominated by the Lead Cleft Speech and Language Therapy Group)
8. An Orthodontist (1) (to be nominated by the Cleft Orthodontists Special Interest Group).
9. A Specialist Cleft nurse (1) (to be nominated by the Cleft Nurses Special Interest Group)
10. A Psychologist (1) (to be nominated by the Cleft Psychologists Special Interest Group)

11. A Paediatric Dentist (1) (to be nominated by the Cleft Paediatric Dentists Special Interest Group)
12. The Co-ordinator/Chair of the UK Cleft Centres Clinical Directors' Group (1)
13. A Cleft Co-ordinator/Manager (1) (to be nominated by the Cleft Coordinators and Managers Special Interest Group).
14. A Representative from the group of 'other' specialities involved in cleft care (1) (to be nominated by CFS Council).
15. A Clinical representative from England (1) / Northern Ireland (1) / Scotland (1) / Wales (1) (as appropriate, if not already represented) (to be nominated by those countries). There may also be a representative of the cleft service in Ireland.
16. There may be representation as determined by CDG as considered appropriate of any national bodies representative of Audit (1) and Research (1)
17. The Clinical Director/Project Leader of the CRANE service will be in attendance at Group meetings to which he/she will report, except when required to be absent because their own position is being discussed/decided. This individual will not be a voting member of the Group unless in another capacity and will not be eligible to become Chair.
18. The Director of the body which holds the contract for CRANE will be in attendance at Group meetings to which he/she will report, except when required to be absent because their own position is being discussed/decided. The Director will not be a voting member of the Board and will not be eligible to become the Chair.
19. A representative of the DoH will always be invited to meetings and will receive minutes but will not be a voting member of the Board and will not be eligible to become the Chair.
20. Such other people who from time to time would serve the interests of the Cleft Development Group may be co-opted for a period of one year at a time.

Deputies for members may be appointed from time to time provided they are done so formally in writing by the nominating body to the CDG Chair. Where an individual comes to represent two positions on CDG, that person will continue to fulfil those roles and no additional person will be elected.

Additional representation will be considered (e.g. cleft paediatricians, cleft anaesthetists, cleft ENT and Audiology, cleft genetics) as and when those disciplines have formally established national specialist interest groups which genuinely represent those disciplines.

Meetings

Meetings will normally be held three times per year but must be held at least twice yearly with administrative support provided by the body which holds the CRANE contract, or the DoH or NHS bodies.

CDG amended and approved 21 Oct 2011

Appendix 5: Diagnosis and procedure codes, Hospital Episode Statistics

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) procedure 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 anomalies used to identify 'syndromic' cleft patients. Patients were 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 that patient's 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

Code	Description
	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: Case ascertainment and consent status

Table 1. Case ascertainment for children born in 2009

Data Source	England	Wales	England & Wales
HES	886	-	929
PEDW	-	43	878
CRANE	831	47	
CRANE ascertainment (%)	93.8	109.3	94.5

CRANE, HES, PEDW

Case ascertainment cannot be determined for Northern Ireland.

Table 2. Consent status for children born in England and Wales in 2010, data reported to CRANE in September 2011

Consent status	Number	% of all cleft births	% of births with confirmed consent
Yes	839	79.7	97.4
No	22	2.1	2.6
Awaiting verification	171	16.2	-
Not possible to verify	21	2.0	-
Total number of cleft births	1053	100.0	-

Administrative Units

Consent status not reported for Northern Ireland; note that these figures do not necessarily reflect CRANE registrations (See section 5.2).

Appendix 7: All CRANE-registered children, regardless of consent status

Table 2. Number of all CRANE-registered children* born with a cleft lip and/or palate in England, Wales and Northern Ireland, according to Administrative Unit and year of birth, 2000-2010

		Year of birth											
Regional centre / MCN	**Administrative Unit**	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	All
Northern & Yorkshire	Newcastle	46	52	46	67	62	80	59	84	67	61	57	681
	Leeds	69	51	75	78	74	74	79	70	77	65	68	780
North West & North Wales	Liverpool	43	61	59	50	57	67	48	55	80	74	74	668
	Manchester	43	86	62	20	20	46	91	85	74	62	84	673
Trent	Nottingham	91	82	86	75	93	105	95	83	96	84	90	980
West Midlands	Birmingham	108	116	101	115	112	100	112	87	96	81	83	1,111
East	Cambridge	76	48	75	65	74	82	74	67	68	69	38	736
North Thames	Gt Ormond St	56	67	12	13	30	68	61	68	105	95	66	641
	Chelmsford	45	39	21	21	29	35	22	29	28	35	37	341
The Spires	Oxford	49	41	31	42	37	38	43	58	33	46	31	449
	Salisbury	46	39	38	34	41	39	61	58	44	30	39	469
South Wales & South West	Swansea	32	30	30	36	34	43	47	45	43	48	43	431
	Bristol	61	75	64	61	53	53	57	64	68	49	68	673
South Thames	Guy's	60	60	60	58	88	100	101	112	105	82	58	884
Northern Ireland	Belfast	30	39	25	27	29	37	41	40	28	31	21	348
All	All	855	886	785	762	833	967	991	1005	1012	912	857	9865

CRANE, 2000-2010

*All children included, regardless of consent status; MCN, managed clinical network.

Table 3. Number (%) of CRANE-registered children* born with a cleft lip and/or palate in England, Wales and Northern Ireland, according to cleft type and year of birth, 2000-2010

	Year of birth n (%)§											
Cleft type	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	All
Cleft lip	151 (19.6)	176 (21.1)	184 (24.6)	152 (22.1)	183 (23.1)	176 (19.3)	221 (23.9)	241 (24.7)	243 (25.4)	189 (22.0)	215 (26.1)	2131 (22.9)
Cleft palate	364 (47.3)	403 (48.2)	338 (45.1)	320 (46.4)	352 (44.4)	442 (48.5)	414 (44.9)	406 (41.6)	423 (44.2)	389 (45.2)	345 (41.8)	4196 (45.2)
UCLP	182 (23.7)	168 (20.1)	160 (21.4)	165 (23.9)	179 (22.6)	213 (23.4)	198 (21.5)	223 (22.8)	218 (22.8)	187 (21.7)	173 (21.0)	2066 (22.2)
BCLP	72 (9.4)	89 (10.6)	67 (8.9)	52 (7.5)	79 (10.0)	81 (8.9)	90 (9.8)	107 (11.0)	73 (7.6)	95 (11.0)	92 (11.2)	897 (9.7)
Not specified	86 _	50 _	36 _	73 _	40 _	55 _	68 _	28 _	55 _	52 _	32 _	575 _
All	855 (100.0)	886 (100.0)	785 (100.0)	762 (100.0)	833 (100.0)	967 (100.0)	991 (100.0)	1005 (100.0)	1012 (100.0)	912 (100.0)	857 (100.0)	9865 (100.0)

CRANE, 2000-2010

* All children included, regardless of consent status. § Percentages represent the distribution of the four main cleft types and are calculated excluding patients without a reported cleft type. UCLP, unilateral cleft lip and plate; BCLP, bilateral cleft lip and palate.

Appendix 8: Missing data by Administrative Unit

Table 1. Number of children born in 2010 who are missing the time of diagnosis, referral and first contact, according to Administrative Unit

		Diagnosis		Referral		Contact	
Regional centre / MCN	**Administrative Unit**	Missing n (%)	All n	Missing n (%)	All n	Missing n (%)	All n
Northern & Yorkshire	Newcastle	–	57	–	57	–	57
	Leeds	2 (3.0)	67	3 (4.5)	67	3 (4.5)	67
North West & North Wales	Liverpool	2 (2.7)	74	1 (1.4)	74	1 (1.4)	74
	Manchester	–	84	–	84	–	84
Trent	Nottingham	10 (11.1)	90	11 (12.2)	90	11 (12.2)	90
West Midlands	Birmingham	2 (2.4)	83	2 (2.4)	83	6 (7.2)	83
East	Cambridge	–	38	–	38	2 (5.3)	38
North Thames	Gt Ormond St	4 (6.1)	66	6 (9.1)	66	12 (1701)	66
	Chelmsford	2 (5.4)	37	2 (5.4)	37	2 (5.4)	37
The Spires	Oxford	2 (6.5)	31	–	31	–	31
	Salisbury	–	39	–	39	1 (2.6)	39
South Wales & South West	Swansea	2 (4.7)	43	3 (7.0)	43	3 (7.0)	43
	Bristol	3 (4.4)	68	3 (4.4)	68	5 (7.4)	68
South Thames	Guy's	–	58	–	58	–	58
Northern Ireland	Belfast	8 (38.1)	21	13 (61.9)	21	16 (76.2)	21
All		37 (4.3)	856	44 (5.1)	856	62 (7.2)	856

CRANE, 2010

Relates to Tables 4 and 5 in the main Report. Note that Table 5 in the main report presents data for the 504 children without an antenatal diagnosis only.

Table 2. Number of children born with a cleft palate in 2009 and 2010 who are missing the time of diagnosis and referral, according to Administrative Unit

		Diagnosis		Referral	
Regional centre / MCN	**Administrative Unit**	Missing n (%)	All n	Missing n (%)	All n
Northern & Yorkshire	Newcastle	1 (2.1)	48	_	48
	Leeds	_	55	_	55
North West & North Wales	Liverpool	2 (2.9)	68	2 (2.9)	68
	Manchester	3 (4.7)	64	4 (6.3)	64
Trent	Nottingham	49 (61.3)	80	49 (61.3)	80
West Midlands	Birmingham	1 (1.6)	64	1 (1.6)	64
East	Cambridge	1 (2.6)	38	1 (2.6)	38
North Thames	Gt Ormond St	1 (1.6)	62	4 (6.5)	62
	Chelmsford	2 (8.7)	23	2 (8.7)	23
The Spires	Oxford	1 (3.4)	29	3 (10.3)	29
	Salisbury	3 (10.7)	28	3 (10.7)	28
South Wales & South West	Swansea	_	35	_	35
	Bristol	4 (8.3)	48	2 (4.2)	48
South Thames	Guy's	_	60	_	60
Northern Ireland	Belfast	4 (16.0)	25	16 (64.0)	25
All		72 (9.9)	727	87 (12.0)	727

CRANE, 2009-2010

*7/734 (1.0%) children with a cleft palate antenatal diagnosis excluded.
Relates to Table 6 in main report.

Table 3. Number of children born in 2004 and 2005 who are missing data on the number of decayed, missing or filled teeth (dmft) at age five years, according to Administrative Unit

		Decayed, missing or filled teeth (dmft)	
Regional centre / MCN	**Administrative Unit**	Missing n (%)	All n
Northern & Yorkshire	Newcastle	19 (16.7)	114
	Leeds	132 (100.0)	132
North West & North Wales	Liverpool	75 (65.2)	115
	Manchester	15 (23.4)	64
Trent	Nottingham	179 (100.0)	179
West Midlands	Birmingham	191 (93.6)	204
East	Cambridge	152 (100.0)	152
North Thames	Gt Ormond St	87 (100.0)	87
	Chelmsford	63 (100.0)	63
The Spires	Oxford	17 (23.6)	72
	Salisbury	44 (57.1)	77
South Wales & South West	Swansea	67 (89.3)	75
	Bristol	43 (44.8)	96
South Thames	Guy's	87 (56.5)	154
Northern Ireland	Belfast	27 (44.3)	61
All	All	1,198 (72.8)	1,645

CRANE, 2004-2005

Relates to Tables 7 and 8 in main report

Table 4. Number of children born in 2004 and 2005 with a complete unilateral cleft lip and palate who are missing data on Five Year Old Index, according to Administrative Unit

		Five Year Old Index	
Regional centre / MCN	**Administrative Unit**	Missing n (%)	All n
Northern & Yorkshire	Newcastle	3 (18.8)	16
	Leeds	21 (91.3)	23
North West & North Wales	Liverpool	14 (58.3)	24
	Manchester	5 (83.3)	6
Trent	Nottingham	27 (100.0)	27
West Midlands	Birmingham	32 (100.0)	32
East	Cambridge	21 (100.0)	21
North Thames	Gt Ormond St	11 (100.0)	11
	Chelmsford	7 (100.0)	7
The Spires	Oxford	2 (50.0)	4
	Salisbury	–	7
South Wales & South West	Swansea	17 (100.0)	17
	Bristol	10 (76.9)	13
South Thames	Guy's	8 (24.2)	33
Northern Ireland	Belfast	12 (100.0)	12
All	All	190 (76.6)	253

CRANE, 2004-2005

Relates to Table 9 in the main report

Appendix 9: Number (%) of CRANE-registered patients with missing identifiers, which are required for linkage with Hospital Episode Statistics (HES) and Patient Episode Database Wales (PEDW), according to year of birth and Administrative Unit

		Missing identifiers n (%)							
Regional centre / MCN	**Administrative Unit**	**NHS Number**		**Sex**		**Postcode**		**≥1 identifier**	
		2000-2009	2010	2000-2009	2010	2000-2009	2010	2000-2009	2010
Northern & Yorkshire	Newcastle	2 (0.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.3)	0 (0.0)
	Leeds	77 (10.8)	0 (0.0)	5 (0.7)	0 (0.0)	0 (0.0)	0 (0.0)	81 (11.4)	0 (0.0)
North West & North Wales	Liverpool	4 (0.7)	1 (1.4)	9 (1.5)	0 (0.0)	2 (0.3)	0 (0.0)	13 (2.2)	1 (1.4)
	Manchester	4 (0.7)	0 (0.0)	2 (0.3)	0 (0.0)	3 (0.5)	0 (0.0)	7 (1.2)	0 (0.0)
Trent	Nottingham	537 (61.5)	2 (2.2)	29 (3.3)	2 (2.2)	23 (2.6)	4 (4.4)	548 (62.8)	6 (6.7)
West Midlands	Birmingham	10 (1.0)	1 (1.2)	9 (0.9)	1 (1.2)	3 (0.3)	1 (1.2)	21 (2.2)	1 (1.2)
East	Cambridge	193 (27.7)	0 (0.0)	9 (1.3)	0 (0.0)	5 (0.7)	0 (0.0)	195 (27.9)	0 (0.0)
North Thames	Gt Ormond St	50 (8.9)	0 (0.0)	16 (2.8)	1 (1.5)	13 (2.3)	1 (1.5)	65 (11.5)	2 (3.0)
	Chelmsford	55 (18.1)	2 (5.4)	2 (0.7)	2 (5.4)	3 (1.0)	3 (8.1)	55 (18.1)	3 (8.1)
The Spires	Oxford	23 (6.1)	0 (0.0)	14 (3.7)	0 (0.0)	7 (1.9)	0 (0.0)	33 (8.7)	0 (0.0)
	Salisbury	10 (2.3)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.2)	0 (0.0)	11 (2.6)	0 (0.0)
South Wales & South West	Swansea	23 (6.0)	17 (39.5)	13 (3.4)	2 (4.7)	9 (2.3)	2 (4.7)	32 (8.3)	17 (39.5)
	Bristol	21 (3.6)	0 (0.0)	4 (0.7)	0 (0.0)	1 (0.2)	0 (0.0)	26 (4.4)	0 (0.0)
South Thames	Guy's	20 (2.6)	0 (0.0)	6 (0.8)	0 (0.0)	10 (1.3)	1 (1.7)	32 (4.2)	1 (1.7)
Northern Ireland	Belfast	248 (81.1)	15 (71.4)	1 (0.3)	1 (4.7)	12 (3.9)	6 (28.6)	248 (81.1)	15 (71.4)
All	All	1277 (14.6)	38 (4.4)	119 (1.4)	9 (1.1)	92 (1.1)	18 (2.1)	1369 (15.6)	46 (5.4)