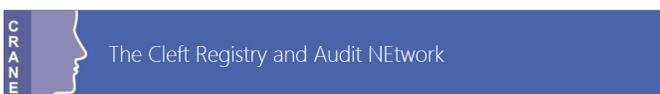


CRANE Database eNewsletter

Two NEW live Tables added to the CRANE Website & Database

In addition to the 10 live Tables (Reports) summarising CRANE data found behind the database log-in, the public pages of the CRANE Website now host [two additional live Tables summarising births by region and by cleft type](#) (outside of the log-in). These live tables update automatically as records are created and amended.



Number of children born between 2007 and 2016 with a cleft lip and/or palate in England, Wales and Northern Ireland registered on the CRANE Database, according to region / unit grouped within Regional Cleft Centre / Managed Clinical Network (MCN) and year of birth.

| Regional centre / Administrative Unit | Year of birth (n) | | | | | | | | | | All |
|---------------------------------------|-------------------|-------|-------|-------|-------|-------|-------|-------|-------|-------|--------|
| | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 | |
| ▶ Northern & Yorkshire | 162 | 141 | 129 | 134 | 138 | 131 | 145 | 126 | 128 | 115 | 1,349 |
| ▶ North West & North Wales | 153 | 172 | 147 | 175 | 146 | 135 | 146 | 164 | 145 | 167 | 1,550 |
| ▶ Trent | 85 | 107 | 96 | 103 | 107 | 95 | 101 | 86 | 91 | 106 | 977 |
| ▶ West Midlands | 100 | 123 | 118 | 108 | 112 | 129 | 120 | 121 | 121 | 118 | 1,170 |
| ▶ East | 83 | 83 | 84 | 81 | 66 | 89 | 94 | 59 | 86 | 66 | 791 |
| ▶ North Thames | 174 | 192 | 152 | 127 | 166 | 181 | 153 | 155 | 134 | 147 | 1,581 |
| ▶ The Spire | 125 | 99 | 89 | 96 | 113 | 99 | 98 | 79 | 97 | 90 | 985 |
| ▶ South Wales & South West | 109 | 116 | 106 | 123 | 109 | 121 | 128 | 98 | 118 | 79 | 1,107 |
| ▶ South Thames | 112 | 107 | 85 | 69 | 83 | 149 | 120 | 130 | 146 | 130 | 1,131 |
| ▶ Northern Ireland | 42 | 37 | 36 | 38 | 44 | 33 | 47 | 37 | 33 | 30 | 377 |
| | 1,145 | 1,177 | 1,042 | 1,054 | 1,084 | 1,162 | 1,152 | 1,055 | 1,099 | 1,048 | 11,018 |

This is in response to requests for increased feedback on CRANE data to both cleft teams and the public.

The CRANE project team aims to continue to seek opportunities to report summarised, live (anonymised) data such as that now made available in the two new tables. If you wish to share any additional suggestions on presenting CRANE data on our website, **please contact us** via crane@rcseng.ac.uk

Patient Reported Experience Measure (PREM) feasibility study: Next steps



Thank you for your participation in this 14-month feasibility study, conducted upon request by the Craniofacial Society of Great Britain and Ireland (CFSGBI) Council and the Cleft Development Group (CDG).

The Feasibility Study Team presented a summary report of quantitative findings at the 18 May 2017 CDG meeting. Overall parents and patients expressed high levels of satisfaction with the care they receive from cleft teams.

Next steps:

- ◆ Once the CDG has signed off on an updated version of the report, including qualitative / comments findings, we will make this available to you on the CRANE Website and notify you via an email Newsletter.
- ◆ We will send a summary of the qualitative / comments data for individual teams to PREM nominee(s) within each team.
- ◆ The findings presented to CDG will be forwarded to the CFSGBI along with recommendations for implementation.

Issue 2017 (2)
1 June 2017

Data collection cut off dates for 2017 analyses

- ◆ **2017 Annual Report:**
Friday 1 September 2017.

CFSGBI Annual Scientific Meeting, Newcastle upon Tyne, April 2017



Thank you for visiting our stand at the CFSGBI Annual Scientific Meeting in Newcastle on the 6 April 2017.

In addition to answering questions about our re-developed CRANE Database, we were happy to share lessons learned in developing CRANE with visitors from Malaysia and Portugal.

Updated Parental Consent Form

The Parental Consent Form, prepared to help you gain documented consent from parents or carers, who are speakers of English (alongside the Information Leaflets), has been updated to record the child's name on the front page of the form.

This amendment was made in response to feedback that this would be especially helpful for children and carers who do not share the same surname.

Now found in the [Information for Cleft Teams](#) section of our [Website](#).