



CRANE

CLEFT REGISTRY & AUDIT NETWORK

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CRANE Database Newsletter

Updated CRANE consent documentation

Issue 2018 (3)

8 October 2018

CRANE is committed to protecting and safeguarding the personal data of cleft care patients.

We have updated our consent documentation as part our commitment to meeting the new European data protection law, known as the General Data Protection Regulation (GDPR) .

Some key clarifications include:

- The amount of time that CRANE retains data;
- how we keep children's information safe; and
- More information on linkage between the CRANE database and other records.

The updated documents can be found on the [Information for Cleft Teams](#) and [Information for Patients and Parents/Carers](#) pages; as well as referenced by the CRANE [Privacy Policy](#).

Consent Q&A:

Q: Is there a time limit on seeking consent?

A: No, there is no cut-off for seeking parental informed consent to add information on children with a cleft to CRANE.

CRANE Database & Website supplier – contract renewal

We have recently extended the contract of delivery with CROWN Informatics Limited for another year. We look forward to building on recent work to publish [data on detection and diagnosis timings for clefts including delayed CP diagnosis, which is still an issue in the UK](#)

CRANE Database 2018 Annual Report publication

- Thank you for your data submissions this summer, for the 2018 Annual Report.
- A draft of the 2018 Annual Report will be reviewed at the Cleft Development meeting on the 22 November 2018.
- We aim to publish the final version of the report in December 2018.
- For more information about CRANE reports contact us at crane@rcseng.ac.uk

Consultation on Outcomes for Children over 5 years of age

After conducting Round 1 in the Spring of 2018, the online questionnaire for Round 2 can be completed via the link below <https://www.surveymonkey.co.uk/r/CRANE-cons-children-over-5yrs-R2>

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