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CRANE Database – Complying with the National Data Opt-out

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The National Data Opt-out service allows patients to opt-out of their <u>confidential patient information</u> being used for purposes other than their immediate clinical care. All NHS organisations are required to be compliant with the national data opt-out policy.

Guidance on the <u>deadline for compliance</u> and how to comply is provided on the NHS website: <u>https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/compliance-with-the-national-data-opt-out</u>

For national clinical audits such as the CRANE, where families consent to the **audit function** of CRANE, and **registry information** is collected with Section 251 approval:

- 1. Cleft services are advised to continue to verify the consent status of patients, to be able to collect both registry and audit (outcomes) information as detailed in our information leaflets.
 - In addition, the withdrawal of patients' consent can be implemented at any time by changing the patient's consent status to 'No'.
- 2. An important consideration for cleft services is to remember that CRANE also has a **registry function**.
 - Therefore there is a minimum dataset that CRANE is allowed to collect, on all children born with a cleft, under our <u>Section 251 approval</u>. For a reminder of these data items please consult the <u>CRANE Data Dictionary</u> found in the <u>Resources</u> section of this website.
 - Nevertheless, if the parent chooses to opt-out of their child's confidential patient information being used for purposes other than their immediate clinical care, none of the child's data should be recorded in CRANE – this includes both registry and audit data.

Figure 1 on the following page provides a visual representation of the information above.



Thank you very much for your work with the CRANE Database.

If you have any questions about this User Guide, or wish to provide us with any feedback on this document, please contact us on 020 7869 6610 or <u>crane@rcseng.ac.uk</u>.