

## CRANE Consent form (England and Wales)

### Recording information about your child in the CRANE Database

A member of the cleft team should have given you the CRANE Database information leaflet: ‘**Has your child been born with a cleft lip and/or palate?**’ You should read this leaflet and ask any questions you have before signing this form. There is more information on our website at [www.crane-database.org.uk](http://www.crane-database.org.uk)

CRANE collects some identifiable registry information on children born with a cleft in England and Wales without consent, under a legal provision called Section 251 support. This provision is granted by the Secretary of State for Health and Social Care following advice from the Confidentiality Advisory Group (CAG). CAG is an independent group that checks patient data is used lawfully and ethically.

To complete this pdf form electronically, open the document using an Acrobat Reader PDF software and click on the fountain pen icon, which should appear at the top of the document, as part of the toolbar. Hover over the boxes for ticking and then sign your name at the end.

#### 1. The CRANE Database

Please give your child’s name (here): \_\_\_\_\_

Do you agree to the CRANE Database collecting information related to your child’s cleft lip and/or cleft palate treatments and measures of progress? **Tick one box** Yes  No

#### 2. Data linkage to access other information in official records

I understand that my child’s details, including their name, date of birth, postcode and NHS number, may be used to link to their official records (listed below) to collect more information for use by the CRANE Database.

**Tick one box** Yes  No

2.1. **Health records:** Do you agree to CRANE linking to your child’s information held by the National Health Service (NHS) databases and records, the Office for National Statistics (ONS), and NHS England (or its successor body)?

**Tick one box** Yes  No

2.2. **Education records:** Do you agree to CRANE linking to your child’s information held by the Department for Education (DfE)?

**Tick one box** Yes  No

A list of the databases and records we link to is available on the [Privacy Policy](#) page of our website.

#### 4. I confirm that:

- I have read the information leaflet about the CRANE Database and understand it.
- I have been given the chance to ask a member of the cleft team questions about the CRANE Database.
- I understand that I can choose for information about my child’s care not to be recorded in the CRANE Database and that I am free to withdraw my child’s information from the database at any time, without giving any reason and without this affecting the treatment that they receive.
- I know who to contact if I change my mind and want my child’s information withdrawn from the CRANE Database.
- I understand that any information about my child will be kept confidential and used for the CRANE Database only.

\_\_\_\_\_  
Name of parent or legal guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

