



# CRANE Database

Tel: 020 7869 6610

E: [crane@rcseng.ac.uk](mailto:crane@rcseng.ac.uk)

W: [www.crane-database.org.uk](http://www.crane-database.org.uk)

## DATA COLLECTION FORM 1: PATIENT REGISTRATION, CLEFT DETAILS, SYNDROMES, AND OUTCOMES AT BIRTH & 1 YEAR

This form is provided as a template to aid CRANE data collection. The data recorded on this form **MUST** be transferred to the CRANE electronic database. Paper forms cannot be accepted for entry.

The criteria for adding a new registration to the CRANE Database are:

- Cleft patient (or suspected cleft until confirmed).
- Documented consent for full registration – otherwise notification data<sup>Δ</sup> only.
- Patient/parents are UK residents/nationals.
- NHS and Private Patients included.

### 1. Patient Registration

Note: This section is used to collect basic patient information for cleft patients. It is required for each new patient.

#### 1.1. Patient consent

##### <sup>Δ</sup> Consent status

- Patient has given written confirmed consent  
 Patient has declined to consent  
 Consent status unknown - awaiting verification\*  
 Not possible to verify consent status\*

\*Please give further details \_\_\_\_\_

##### <sup>Δ</sup> Linkage of CRANE database to Health data

- Patient has given written confirmed consent  
 Patient has declined to consent  
 Consent status unknown - awaiting verification\*  
 Not possible to verify consent status\*

##### <sup>Δ</sup> Linkage of CRANE data to Education data

- Patient has given written confirmed consent  
 Patient has declined to consent  
 Consent status unknown - awaiting verification\*  
 Not possible to verify consent status\*

#### 1.2. Cleft team details

<sup>Δ</sup> Administrative Unit Name \_\_\_\_\_ Hospital Name \_\_\_\_\_

<sup>Δ</sup> Administrative Unit No. \_\_\_\_\_ Hospital No. \_\_\_\_\_

Current patient?  Attending centre  Not attending centre.

Reason not current: \_\_\_\_\_

*Patient Registration Section continues on next page.*

1.3. Patient details		
<p><b>△ CRANE ID</b> _____ Automatically generated by CRANE Database</p> <p><b>△ Patient's NHS No.</b> <input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/></p>	<p><b>△ Reason patient's NHS Number not available</b></p> <p><input type="checkbox"/> Patient from the Channel Islands</p> <p><input type="checkbox"/> Patient from Scotland</p> <p><input type="checkbox"/> Private UK patient</p> <p><input type="checkbox"/> Non-UK reside</p> <p><input type="checkbox"/> Other. <b>△</b> Please provide other reason: _____</p>	
<p><b>△ Date of birth</b>    /    /    (DD / MM / YYYY)</p>	<p><b>△ Date deceased</b>    /    /    (DD / MM / YYYY) (Where applicable)</p>	
<p><b>Present surname</b> _____ <b>First names</b> _____</p>		
<p><b>△ Sex</b>    <input type="checkbox"/> Male    <input type="checkbox"/> Female</p>	<p><b>Postcode</b> <input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/><input type="checkbox"/></p>	<p><b>Surname at birth (if different)</b> _____</p>

1.4. First contact information		
<p><b>△ Hospital of birth/referral</b> _____</p>	<p><b>△ Timing of diagnosis</b></p> <p><input type="checkbox"/> Antenatal</p> <p><input type="checkbox"/> At birth (within 24hrs of birth)</p> <p><input type="checkbox"/> Within 72 hours</p> <p><input type="checkbox"/> Within 1 week</p> <p><input type="checkbox"/> Within 1 month</p> <p><input type="checkbox"/> Within 6 months</p> <p><input type="checkbox"/> Later than 6 months</p>	

1.5. For <u>Antenatal</u> Diagnosis	1.6. For <u>ALL</u> Births
<p><b>△ Date and time cleft team informed of <u>antenatal</u> diagnosis</b> _____/_____/_____:_____ (DD / MM / YYYY) (HH:MM)</p> <p><b>△ Date and time of first contact with cleft team following <u>antenatal</u> diagnosis</b> _____/_____/_____:_____ (DD / MM / YYYY) (HH:MM)</p> <p><b>△ Was contact made within 24 hours of receiving the <u>antenatal</u> referral by a clinical nurse specialist?</b> <input type="checkbox"/> Yes    <input type="checkbox"/> No</p> <p><b>△ Reason contact NOT made within 24 hours of receiving the <u>antenatal</u> referral?</b></p> <p><input type="checkbox"/> No answer to phone calls</p> <p><input type="checkbox"/> Incorrect contact details</p> <p><input type="checkbox"/> Interpreter required (and not possible to arr. within 24hrs)</p> <p><input type="checkbox"/> Other reason.</p> <p><b>△ Other reason contact NOT made with 24hrs of receiving <u>antenatal</u> referral details:</b> _____</p>	<p><b>△ Date and time cleft team informed following birth</b> _____/_____/_____:_____ (DD / MM / YYYY) (HH:MM)</p> <p><b>△ Date and time of first contact with cleft team following birth</b> _____/_____/_____:_____ (DD / MM / YYYY) (HH:MM)</p> <p><b>△ Date and time of 1st visit by a member of the cleft team following birth</b> _____/_____/_____:_____ (DD / MM / YYYY) (HH:MM)</p> <p><b>△ Was a visit made within 24 hours of receiving the postnatal referral by a Clinical Nurse Specialist?</b> <input type="checkbox"/> Yes    <input type="checkbox"/> No</p> <p><b>△ Reason visit NOT made within 24 hours of receiving the postnatal referral?</b></p> <p><input type="checkbox"/> No CNS available</p> <p><input type="checkbox"/> Travel distance from unit (not poss. within 24hrs)</p> <p><input type="checkbox"/> Clinical decision – feeding well and no concerns</p> <p><input type="checkbox"/> Clinical dec. – other comorbidities, advised not attend by NICU.</p> <p><input type="checkbox"/> Other reason.</p> <p><b>△ Other reason visit NOT made within 24 hours of receiving the postnatal referral details:</b> _____</p>

## 2. Cleft Details

Note: This section is used to describe the cleft. It is required for each new patient.

<b>▲ Is this a submucous cleft?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No		<b>Pierre Robin Sequence present?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No		<b>Forme Fruste present?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No					
<b>▲ Cleft description (Please circle in the rows below):</b> . = Not present    I = Incomplete    C = Complete									
	<b>Patient's Right</b>			<b>Patient's Left</b>					
<b>Simonart's Bands</b>	.	Y			.	Y			
<b>Lip</b>		.	I	C		.	I	C	
<b>Alveolus</b>			.	I	C		.	I	C
<b>Hard palate</b>				.	I	C			
<b>Soft palate</b>				.	I	C			
<b>▲ Cleft type category</b>	<input type="checkbox"/> Isolated cleft lip (CL)		<input type="checkbox"/> Isolated cleft palate (CP)		<input type="checkbox"/> Unilateral cleft lip and palate (UCLP)		<input type="checkbox"/> Bilateral cleft and palate (BCLP)		

## 3. Syndromes

Note: For consented cleft patients only

<b>Confirmed syndromic diagnosis present</b> <input type="checkbox"/> No <input type="checkbox"/> Yes, named <input type="checkbox"/> Yes, unknown	<b>Syndrome name(s) 1.</b> _____ (Where applicable) <b>2.</b> _____
<b>Description of affected systems</b> _____	

## 4. Outcomes at birth and at 1 year

Note: For consented cleft patients only. This section is used to add outcome records.

4.1. Outcome at birth	4.1. Outcome at 1 year
<b>Child Growth</b>	
<b>Gestational age</b> <input type="checkbox"/> <input type="checkbox"/> (weeks) <b>Weight at birth</b> <input type="checkbox"/> . <input type="checkbox"/> <input type="checkbox"/> (kg) <i>(Do NOT adjust for gestational age)</i> <b>Date weight at birth record taken</b> /    / (DD / MM / YYYY)	<b>Weight at 1 year</b> <input type="checkbox"/> <input type="checkbox"/> . <input type="checkbox"/> <input type="checkbox"/> (kg) <b>Date weight at 1 year record taken</b> /    / (DD / MM / YYYY) <b>Height at 1 year</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> . <input type="checkbox"/> (cm) <b>Date height at 1 year record taken</b> /    / (DD / MM / YYYY)
<b>Reason outcome not collected</b> <input type="checkbox"/> Patient deceased or emigrated <input type="checkbox"/> Patient transferred in or out of area <input type="checkbox"/> Syndromic Diagnosis <input type="checkbox"/> Clinically contraindicated (other than syndromic) – this record type for this patient. Reason details: _____ <input type="checkbox"/> Lack of staff/ facilities/ equipment <input type="checkbox"/> Patient DNA/ cancelled/ did not consent/ cooperate <input type="checkbox"/> Other reason. Details: _____	<b>Reason outcome not collected</b> <input type="checkbox"/> Patient deceased or emigrated <input type="checkbox"/> Patient transferred in or out of area <input type="checkbox"/> Syndromic Diagnosis <input type="checkbox"/> Clinically contraindicated (other than syndromic) – this record type for this patient. Reason details: _____ <input type="checkbox"/> Lack of staff/ facilities/ equipment <input type="checkbox"/> Patient DNA/ cancelled/ did not consent/ cooperate <input type="checkbox"/> Other reason. Details: _____

**END OF DATA COLLECTION FORM 1**

See DATA COLLECTION FORM 2 for: Outcomes at 5 years and 10 years