CRANE Database

Tel: 020 7869 6610
E: crane@rcseng.ac.uk
W: 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^Δ 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

ΔConsent 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** ________________________

ΔLinkage 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*

ΔLinkage 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

ΔAdministrative Unit Name	______________________________	**Hospital Name**	______________________________
ΔAdministrative Unit No.	______________________________	**Hospital No.**	______________________________

1.3. Patient details

ΔCRANE ID _____________________

Automatically generated by CRANE Database

ΔPatient's NHS/CHI No.

☐☐☐☐☐☐☐☐☐☐

ΔReason patient's NHS/CHI Number not available

☐ Patient from the Channel Islands
☐ Private UK patient
☐ Non-UK reside
☐ Other. ΔPlease provide other reason:____________________

ΔDate of birth / / (DD / MM / YYYY)

ΔDate deceased / / (DD / MM / YYYY)
(Where applicable)

ΔNotification only fields i.e. Patient consent = No/DK

Present surname ___________________________ **First names** ________________________________

^Δ^**Sex** ☐ Male ☐ Female

Postcode ☐☐☐☐ ☐☐☐

Surname at birth *(if different)* ____________________

Δ**Ethnic group**

White
- ☐ White British
- ☐ White Irish
- ☐ Any other White background

Mixed/ Multiple ethnic groups
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed/ Multiple ethnic background

Asian/ Asian British
- ☐ Indian
- ☐ Pakistani

Asian/ Asian British (continued)
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background

Black/ African/ Caribbean/ Black British
- ☐ African
- ☐ Caribbean
- ☐ Any other Black/ African/ Caribbean background

Other ethnic group
- ☐ Arab
- ☐ Any other ethnic group

1.4. First contact information

Δ**Hospital of birth/referral**

____

Δ**Timing of diagnosis**
- ☐ Antenatal
- ☐ At birth (within 24hrs of birth)
- ☐ Within 72 hours
- ☐ Within 1 week
- ☐ Within 1 month
- ☐ Within 6 months
- ☐ Later than 6 months

1.5. For Antenatal Diagnosis

Δ**Date and time cleft team informed of antenatal diagnosis**

/ / ___:___
(DD / MM / YYYY) (HH:MM)

Δ**Date and time of first contact with cleft team following antenatal diagnosis**

/ / ___:___
(DD / MM / YYYY) (HH:MM)

Δ**Was contact made within 24 hours of receiving the antenatal referral by a clinical nurse specialist?**

☐ Yes ☐ No

Δ**Reason contact NOT made within 24 hours of receiving the antenatal referral?**
- ☐ No answer to phone calls
- ☐ Incorrect contact details
- ☐ Interpreter required (and not possible to arr. within 24hrs)
- ☐ Other reason.

Δ**Other reason contact NOT made with 24hrs of receiving antenatal referral details:**

____

1.6. For ALL Births

Δ**Date and time cleft team informed following birth**

/ / ___:___
(DD / MM / YYYY) (HH:MM)

Δ**Date and time of first contact with cleft team following birth**

/ / ___:___
(DD / MM / YYYY) (HH:MM)

Δ**Date and time of 1st visit by a member of the cleft team following birth** / / ___:___
(DD / MM / YYYY) (HH:MM)

Δ**Was a visit made within 24 hours of receiving the postnatal referral by a Clinical Nurse Specialist?** ☐ Yes ☐ No

Δ**Reason visit NOT made within 24 hours of receiving the postnatal referral?**
- ☐ No CNS available
- ☐ Travel distance from unit (not poss. within 24hrs)
- ☐ Clinical decision – feeding well and no concerns
- ☐ Clinical dec. – other comorbidities, advised not attend by NICU.
- ☐ Other reason.

Δ**Other reason visit NOT made within 24 hours of receiving the postnatal referral details:**_________________________________

2. Cleft Details

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

[Δ]Is this a submucous cleft? ☐ Yes ☐ No	Pierre Robin Sequence present? ☐ Yes ☐ No	Forme Fruste present? ☐ Yes ☐ No

[Δ]**Cleft description** *(Please circle in the rows below)*: **. = Not present I = Incomplete C = Complete**

	Patient's Right			Patient's Left		
Simonart's Bands	.	Y		.	Y	
Lip	.	I	C	.	I	C
Alveolus	.	I	C	.	I	C
Hard palate	.	I	C			
Soft palate	.	I	C			

[Δ]**Cleft type category**	☐ **Isolated cleft lip (CL)**	☐ **Isolated cleft palate (CP)**
	☐ **Unilateral cleft lip and palate (UCLP)**	☐ **Bilateral cleft and palate (BCLP)**

3. Syndromes

Note: For consented cleft patients only. Please **do not record Pierre Robin Sequence (PRS)** (or any PRS features) as a syndrome. PRS information is entered under 'Cleft Details' information.

Confirmed syndromic diagnosis present

☐ No ☐ Yes, named ☐ Yes, unknown name

Complete this section only if you have selected "Yes, named" for previous question.
Does the child have a main or secondary confirmed named syndromic diagnosis?
Do not include developmental delay or autism here, as these are not syndromes.

Please select no more than one option per column

	Main syndrome or additional diagnoses:	Secondary syndrome or additional diagnoses:
CHARGE syndrome	☐	☐
Chromosome or gene abnormalities not elsewhere specified (e.g. trisomy, deletion, duplication)	☐	☐
Congenital malformations of the circulatory system (arteries, veins or heart)	☐	☐
Congenital malformations of the nervous system (e.g. Microcephaly, spina bifida)	☐	☐
Di George syndrome / 22q11.2 Deletion syndrome / Velocardiofacial syndrome	☐	☐
Fetal alcohol syndrome	☐	☐
Goldenhar syndrome / Hemi-facial macrosomia	☐	☐
Stickler syndrome	☐	☐
Van der Woude syndrome	☐	☐
Other, please specify:	____________________	____________________

If syndrome is 'Yes, unknown name' please specify affected system(s):

☐ Circulatory/cardiovascular system
☐ Digestive/excretory system
☐ Endocrine system
☐ Nervous system
☐ Renal system
☐ Respiratory system
☐ Skeletal system
☐ Other, please specify: ________________________________

[Δ]Notification only fields i.e. Patient consent = No/DK

4. Outcomes at birth and at 1 year

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

4.1. Outcomes at birth

Child Growth – all cleft types

Gestational age ☐☐ (weeks)

Weight at birth ☐.☐☐ (kg) *(Do NOT adjust for gestational age)*

Date weight at birth record taken / / (DD / MM / YYYY)

Reason outcome not collected

- ☐ Patient deceased or emigrated
- ☐ Patient transferred in or out of area
- ☐ Syndromic Diagnosis
- ☐ Clinically contraindicated (other than syndromic) – this record type for this patient. Reason details: ____
- ☐ Lack of staff/ facilities/ equipment
- ☐ Patient DNA/ cancelled/ did not consent/ cooperate
- ☐ Other reason. Details: ____

Psychology – all cleft types

Date of 1st psychology consultation / / (DD / MM / YYYY)

Reason outcome not collected

- ☐ Patient deceased or emigrated
- ☐ Patient transferred in or out of area
- ☐ Syndromic Diagnosis
- ☐ Clinically contraindicated (other than syndromic) – this record type for this patient. Reason details: ______________
- ☐ Lack of staff/ facilities/ equipment
- ☐ Patient DNA/ cancelled/ did not consent/ cooperate
- ☐ No consultation before 5 year appointment *(for Psychology only)*
- ☐ Other reason. Details: ________________________________

4.2. Outcomes at 1 year

Child Growth – all cleft types

Weight at 1 year ☐☐.☐☐ (kg)

Date weight at 1 year record taken / / (DD / MM / YYYY)

Height at 1 year ☐☐☐.☐ (cm)

Date height at 1 year record taken / / (DD / MM / YYYY)

Reason outcome not collected

- ☐ Patient deceased or emigrated
- ☐ Patient transferred in or out of area
- ☐ Syndromic Diagnosis
- ☐ Clinically contraindicated (other than syndromic) – this record type for this patient. Reason details: ____
- ☐ Lack of staff/ facilities/ equipment
- ☐ Patient DNA/ cancelled/ did not consent/ cooperate
- ☐ Other reason. Details: ____

END OF DATA COLLECTION FORM 1

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

[Δ] Notification only fields i.e. Patient consent = No/DK