CRANE Database

Tel: 020 7869 6610
E: crane@rcseng.ac.uk
W: www.crane-database.org.uk

DATA COLLECTION FORM 2:
OUTCOMES AT 5 and 10 YEARS – consented cleft patients only

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.
- Patients/parents are UK residents/nationals and were at the time of the patient's birth.
- NHS and Private Patients included.

1. Patient Registration   *As per Form 1*

1.2. Cleft team details   *(Numbering of section as per Form 1)*

[Δ]**Administrative Unit Name** _____   **Hospital Name** _____

[Δ]**Administrative Unit No.** _____   **Hospital No.** _____

1.3. Patient details   *(Numbering of section as per Form 1)*

[Δ]**CRANE ID** _____
Automatically generated by CRANE Database

[Δ]**Patient's NHS/CHI No.**

[Δ]**Reason patient's NHS/CHI Number not available**
☐ Patient from the Channel Islands ☐ Private UK patient
☐ Non-UK reside
☐ Other. [Δ]Please provide other reason:
_____

[Δ]**Date of birth**   /   /   (DD / MM / YYYY)

[Δ]**Date deceased**   /   /   (DD / MM / YYYY)
(Where applicable)

Present surname _____   **First names** _____

[Δ]**Sex** ☐ Male ☐ Female   **Postcode**

Surname at birth *(if different)*
_____

1.3. Patient details (continued)

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

See DATA COLLECTION FORM 1 for:
Cleft Details, Syndromes, and Outcomes at Birth and at 1 year (Sections 2, 3 & 4)

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5. Outcomes at 5 years
Note: This section is used to add outcome records.

5.1. Child Growth at 5 years – all cleft types

Weight at 5 years ☐☐ . ☐☐ (kg)

Date weight at 5 years record taken ___ / ___ / ___
(DD / MM / YYYY)

Height at 5 years ☐☐☐ . ☐ (cm)

Date height at 5 years 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:
  _____

5.2. Orthodontics at 5 years – <u>UCLP cases only</u>

Date study model taken ___ / ___ / ___
(DD / MM / YYYY)

Date photos taken ___ / ___ / ___
(DD / MM / YYYY)

Five Year Old Index *(Internally validated score)* _____ (1 to 5)
Externally validated score preferred, provide internal score only if external score not available

Five Year Old Index *(Externally validated score)* _____ (1 to 5)

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:
  _____

5.3. Paediatric Dentistry at 5 years – all cleft types

Date decayed, missing and filled teeth (dmft) record taken / /
(DD / MM / YYYY)

Total number of decayed teeth in primary dentition (dt)

☐☐ *(if none, specify 0)*

Total number of missing teeth in primary dentition (mt)

☐☐ *(if none, specify 0)*

Total number of filled teeth in primary dentition (ft)

☐☐ *(if none, specify 0)*

Total number of decayed, missing or filled teeth in primary dentition (dmft)*

☐☐ *(if none, specify 0)*

***Note: Total dmft score is automatically calculated in CRANE system from dt, mt, and ft scores. Please record above to confirm correct total.**

Developmental Defects of Enamel (DDE)
Select one option for each dental region:

	SN(R)	URB	URA	ULA	ULB	SN(L)
Normal	☐	☐	☐	☐	☐	☐
Hypomineralisation	☐	☐	☐	☐	☐	☐
Hypoplasia	☐	☐	☐	☐	☐	☐
Abnormal shape/size	☐	☐	☐	☐	☐	☐
Congenitally missing	☐	☐	☐	☐	☐	☐
Unable-restored	☐	☐	☐	☐	☐	☐
Unable-carious	☐	☐	☐	☐	☐	☐
Unable-extracted	☐	☐	☐	☐	☐	☐
Unable-exfoliated	☐	☐	☐	☐	☐	☐
Not present	☐					☐
DDE subtotal	☐	☐	☐	☐	☐	☐

Total DDE score** ☐

Date DDE record taken / / (DD / MM / YYYY)

****Note: Total DDE score is automatically calculated in CRANE system from sub-scores. Please record above to confirm correct total.**

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:
_____

DDE Guidance:
1. The presence of a 'Normal' supernumerary will result in a score of one, due to the treatment need, not zero as for other 'Normal' DDE scores.
2. When entering thi sinformation in the Database, a total score is not generated unless all 6 individual items audited / completed.

5.4. Psychology at 5 years: SDQ & TIM – all cleft types

Date of psychosocial screen using Strengths and Difficulties Questionnaire (SDQ) at age 5 / /
(DD / MM / YYYY)

Parent SDQ Total (0-40) ☐☐

Parent SDQ Emotional (0-10) ☐☐

Parent SDQ Conduct (0-10) ☐☐

Parent SDQ Hyperactivity (0-10) ☐☐

Parent SDQ Peer Problems (0-10) ☐☐

Parent SDQ Prosocial (0-10) ☐☐

Note: CRANE will collect SDQ scores for children born up to 31 December 2017 only.
SDQ will no longer be collected for births from 1 January 2018.

SDQ 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
☐ Screen only partially completed *(for Psychology only)*
☐ Not completed due to language barriers *(for Psychology only)*
☐ Parents declined to complete *(for Psychology only)*
☐ Other reason. Details: _____

Psychology scoring at 5 years of age continues on the next page…

…Psychology scoring at 5 years of age continues from previous page.

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Date of psychosocial screen using Tiers of Involvement Measure (TIM) at age 5   /   /
(DD / MM / YYYY)

TIM score ☐☐
Tiers of Involvement Measure (TIM) scores take the form of 0a, 0b, 0c, 0d, 0e, 1a, 1b, 2a, 2b, 2c, 3, 4, 5 or 6.

</td><td>

TIM 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
☐ Screen only partially completed *(for Psychology only)*
☐ Not completed due to language barriers *(for Psychology only)*
☐ Parents declined to complete *(for Psychology only)*
☐ Other reason. Details: _____

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5.5. Speech and Language Therapy at 5 years: CAPS-A – <u>CP, UCLP & BCLP cases only</u>

Date of Speech Audit Recording / / (DD / MM / YYYY)   **VP surgery / Fistula repair before Audit?** ☐ Yes ☐ No

Context of Evaluation
☐ Consensus Listened (includes an external CAPS-A trained listener)
☐ Consensus Listened (internal listeners with a minimum of 2 CAPS-A trained listeners)
☐ Other

		0	1	2	3	4	8
Hypernasality		☐	☐	☐	☐	☐	☐
Hyponasality		☐	☐	☐			☐
Audible Nasal Emission		☐	☐	☐			☐
Nasal Turbulence		☐	☐	☐			☐

Scoring for each of the Summary Categories of Cleft Speech Characteristics (CSCs) – definitions:
A Dark Green on CAPS-A   B Light Green on CAPS-A
C Amber on CAPS-A   D Red on CAPS-A

Anterior Cleft Speech Characteristics (CSCs)	1.	Dentalisation / Interdentalisation	☐ A	☐ B	
	2.	Lateralisation / Lateral	☐ A	☐ B	☐ C
	3.	Palatalisation / Palatal	☐ A	☐ B	☐ C
Posterior CSCs	4.	Double articulation (posterior)	☐ A	☐ B	☐ C
	5.	Backed to velar / Uvular	☐ A	☐ C	☐ D
Non Oral CSCs	6.	Pharyngeal articulation	☐ A	☐ C	☐ D
	7.	Glottal Articulation	☐ A	☐ C	☐ D
	8.	Active Nasal Fricatives	☐ A	☐ C	☐ D
	9.	Double articulation (non-oral)	☐ A	☐ C	☐ D
Passive CSCs	10.	Weak and or nasalised consonants	☐ A	☐ C	☐ D
	11.	Nasal realisation of plosives	☐ A	☐ C	☐ D
	12.	Gliding of fricatives	☐ A	☐ C	☐ D

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
☐ Not appointed before 6 years *(for Speech only)*
☐ Other reason. Details:
_____

6. Outcomes at 10 years   Note: This section is used to add outcome records.

6.1. Paediatric Dentistry at 10 years – all cleft types

Date decayed, missing and filled teeth (DMFT) record taken   /   /
(DD / MM / YYYY)

Total number of <u>decayed</u> teeth in permanent dentition (DT)

☐☐ *(if none, specify 0)*

Total number of <u>missing</u> teeth in permanent dentition (MT)

☐☐ *(if none, specify 0)*

Total number of <u>filled</u> teeth in permanent dentition (FT)

☐☐ *(if none, specify 0)*

Total number of <u>decayed, missing or filled</u> teeth in primary dentition (dmft)*

☐☐ *(if none, specify 0)*

*Note: Total DMFT score is automatically calculated in CRANE system from DT, MT, and FT scores. Please record above to confirm correct total.

Developmental Defects of Enamel (DDE)
Select one option for each dental region:

	SN(R)	UR2	UR1	UL1	UL2	SN(L)
Normal	☐	☐	☐	☐	☐	☐
Hypomineralisation	☐	☐	☐	☐	☐	☐
Hypoplasia	☐	☐	☐	☐	☐	☐
Abnormal shape/size	☐	☐	☐	☐	☐	☐
Congenitally missing		☐	☐	☐	☐	
Unable-restored	☐	☐	☐	☐	☐	☐
Unable-carious	☐	☐	☐	☐	☐	☐
Unable-extracted	☐	☐	☐	☐	☐	☐
Not present	☐					☐
DDE subtotal	☐	☐	☐	☐	☐	☐

Total DDE score**   ☐

Date DDE record taken   /   /   (DD / MM / YYYY)
**Note: Total DDE score is automatically calculated in CRANE system from sub-scores. Please record above to confirm correct total.

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:
_____

DDE Guidance:
1. The presence of a 'Normal' supernumerary will result in a score of one, due to the treatment need, not zero as for other 'Normal' DDE scores.
2. When entering thi sinformation in the Database, a total score is not generated unless all 6 individual items audited / completed.

6.2. Speech and Language Therapy at 10 years: CAPS-A – <u>CP, UCLP & BCLP cases only</u>

Date of Speech Audit Recording	/ / (DD / MM / YYYY)	VP surgery / Fistula repair before Audit? ☐ Yes ☐ No

Context of Evaluation	☐ Consensus Listened (includes an external CAPS-A trained listener) ☐ Consensus Listened (internal listeners with a minimum of 2 CAPS-A trained listeners) ☐ Other

	Hypernasality	☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 8
	Hyponasality	☐ 0 ☐ 1 ☐ 2 ☐ 8
	Audible Nasal Emission	☐ 0 ☐ 1 ☐ 2 ☐ 8
	Nasal Turbulence	☐ 0 ☐ 1 ☐ 2 ☐ 8

Scoring for each of the Summary Categories of Cleft Speech Characteristics (CSCs) – definitions:
A Dark Green on CAPS-A   B Light Green on CAPS-A
C Amber on CAPS-A   D Red on CAPS-A

Anterior Cleft Speech Characteristics (CSCs)	1.	Dentalisation / Interdentalisation	☐ A ☐ B
	2.	Lateralisation / Lateral	☐ A ☐ B ☐ C
	3.	Palatalisation / Palatal	☐ A ☐ B ☐ C
Posterior CSCs	4.	Double articulation (posterior)	☐ A ☐ B ☐ C
	5.	Backed to velar / Uvular	☐ A ☐ C ☐ D
Non Oral CSCs	6.	Pharyngeal articulation	☐ A ☐ C ☐ D
	7.	Glottal Articulation	☐ A ☐ C ☐ D
	8.	Active Nasal Fricatives	☐ A ☐ C ☐ D
	9.	Double articulation (non-oral)	☐ A ☐ C ☐ D
Passive CSCs	10.	Weak and or nasalised consonants	☐ A ☐ C ☐ D
	11.	Nasal realisation of plosives	☐ A ☐ C ☐ D
	12.	Gliding of fricatives	☐ A ☐ C ☐ D

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
☐ Not appointed before 11 years *(for Speech only)*
☐ Other reason. Details:
   _____

END OF DATA COLLECTION FORM 2