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CLEFT REGISTRY & AUDIT NETWORK

CRANE Database – Psychology outcomes data entry

Prepared by the CRANE Database Project Team

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The CRANE Database system allows the collection of Psychology outcome information for patients registered in the CRANE Database; who have given explicit consent¹ for collection of their outcome data.

1. Psychology outcome data collection up until September 2020

Up until the end of September 2020, Psychology outcome information was captured as one set of nine data items:

- As in **Figure 1** (right) – as per the CRANE Data Collection Form on outcomes (Form 2).²
- The nine data items included two screening dates, one Tiers of Involvement Measure (TIM) score and six Strengths & Difficulties Questionnaire (SDQ) scores.

Psychology data items became available to complete, in the ‘Outcomes at 5 years’ section of the CRANE Database, once the child turned 5 years old.

- If these nine data items were not recorded in the ‘Outcomes at 5 years’ section, a ‘Reason outcome not collected’ could be completed (as shown, right).

Figure 1. Psychology outcome data collection up until September 2020

5.4. Psychology – all cleft types	
Date of 1 st face to face psychosocial screen	/ / (DD / MM / YYYY)
Date of psychosocial screen at age 5	/ / (DD / MM / YYYY)
TIM score	<input type="checkbox"/> <input type="checkbox"/>
<i>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.</i>	
Parent SDQ Total (0-40)	<input type="checkbox"/> <input type="checkbox"/>
Parent SDQ Emotional (0-10)	<input type="checkbox"/> <input type="checkbox"/>
Parent SDQ Conduct (0-10)	<input type="checkbox"/> <input type="checkbox"/>
Parent SDQ Hyperactivity (0-10)	<input type="checkbox"/> <input type="checkbox"/>
Parent SDQ Peer Problems (0-10)	<input type="checkbox"/> <input type="checkbox"/>
Parent SDQ Prosocial (0-10)	<input type="checkbox"/> <input type="checkbox"/>
Reason outcome not collected	
<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:	

2. Psychology outcome data collection from October 2020

The CRANE Database system continues to collect the data items (detailed above). This information is now collected in three sections:

¹ <https://www.crane-database.org.uk/resources/information-leaflets-and-parental-consent-forms/>

² An updated version is available to download online <https://www.crane-database.org.uk/resources/crane-data-dictionary/>

The first section is available for completion from birth to record the ‘date of 1st psychology consultation’.

- This therefore now appears in the ‘Outcome at birth’ section, rather than ‘Outcome at 5 years’ section of the CRANE Database.

Figure 2. Psychology data collection from October 2020 – from birth

4.1. Outcomes at birth	
Child Growth – all cleft types	Psychology – all cleft types
Gestational age <input type="text"/> <input type="text"/> (weeks) Weight at birth <input type="text"/> <input type="text"/> <input type="text"/> (kg) (Do NOT adjust for gestational age) Date weight at birth record taken / / (DD / MM / YYYY) Reason outcome not collected <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: _____	Date of 1st psychology consultation / / (DD / MM / YYYY) Reason outcome not collected 1st Section <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: _____ <input type="checkbox"/> No consultation before 5 year appointment (for Psychology section only)

- If this data item is not available, a ‘Reason outcome not collected’ can be completed. Including the new response option ‘No consultation before 5 year appointment’. As in Figure 2 (above) – as per the CRANE Data Collection Form on registration (Form 1).³
- Figure 3 and Figure 4 show how this appears in the CRANE Database.

Figure 3. Psychology data item collected from birth, in the CRANE Database – from October 2020⁴

174 - Johnson Evan
 Date of birth: 2011 (Age: 9 years)
 Consent status: Patient has given written confirmed consent
 Submucous: Not entered
 Cleft type: Unilateral cleft lip and palate (UCLP) [...hsal]
 Patient's NHS number: 943-476-7091
 Administrative unit name: Belfast
 Administrative unit number: 100077
 Confirmed syndromic diagnosis: Yes, named

Information and other warnings

CONSENT PATIENT DETAILS CLEFT DETAILS SURGICAL PROCEDURES SYNDROMES **OUTCOMES** NOTES HISTORY

Outcomes

Outcome information is collected according to age of patients and cleft type: All Outcomes

Outcome at Birth Outcome at 1 year Outcome at 5 years Outcome at 10 years

Outcome at Birth (consented patients only)

Child Growth **Psychology**

Psychology

Date of 1st psychology consultation dd/mm/yyyy

³ An updated version is available to download online <https://www.crane-database.org.uk/resources/crane-data-dictionary/>

⁴ All images in this document are taken from the Demo System, using test data. No confidential patient information appears in this document.

Figure 4. Reasons outcome not collected – for Psychology data item at birth, in the CRANE Database – from October 2020

The screenshot shows a web form for data entry. At the top, there are tabs for 'Outcome at Birth', 'Outcome at 1 year', 'Outcome at 5 years', and 'Outcome at 10 years'. The 'Outcome at Birth' tab is active, and a sub-header reads 'Outcome at Birth (consented patients only)'. A dropdown menu is open, listing several reasons for why an outcome was not collected. The options are: 'Patient deceased or emigrated', 'Patient transferred in or out of area', 'Syndromic Diagnosis', 'Clinically contraindicated (other than syndromic) - this record type for this patient', 'Lack of staff / facilities / equipment', 'Patient DNA / cancelled / did not consent / cooperate', 'No consultation before 5 year appointment', and 'Other reason'. Below the dropdown is a text input field for 'Reason outcome not collected'. There are also fields for 'Clinically contraindicated (other than syndromic) reason - details' and 'Other reason - details'. A 'Save' button is at the bottom left.

The second section collects the ‘date of psychosocial screen using SDQ at age 5’ and 6 SDQ scores.

- If these data items are not collected, a ‘Reason outcome not collected’ can be completed. Including 3 new response options – as listed in Figure 5 (right). As per the CRANE Data Collection Form on outcomes (Form 2).⁵.

The third section collects the ‘date of psychosocial screen using TIM at age 5’ (which in most cases will be the same as the ‘date of psychosocial screen using SDQ at age 5’) and the TIM score. As in Figure 5 (right).

- ‘Reason outcome not collected’ can be collected as TIM scores 0a to 0e.
- Figure 6, Figure 7 and Figure 8 show how this appears in the CRANE Database.

Figure 5. Psychology data collection from October 2020 – at 5 years

The screenshot shows a form titled '5.4. Psychology: SDQ & TIM – all cleft types'. It contains several sections. The first section is 'Date of psychosocial screen using SDQ at age 5 / / (DD / MM / YYYY)'. Below this are six rows for SDQ scores: '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)', and 'Parent SDQ Prosocial (0-10)', each with two empty boxes for input. The next section is 'Reason outcome not collected', which includes a list of checkboxes: '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', and 'Other reason. Details: _____'. Below these are three more checkboxes: 'Screen only partially completed (for Psychology section only)', 'Not completed due to language barriers', and 'Parents declined to complete'. The final section is '5.5. Psychology: TIM – all cleft types', which includes 'Date of psychosocial screen using TIM at age 5 / / (DD / MM / YYYY)' and 'TIM score' with two empty boxes. A note below states: '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.' A red box highlights the SDQ and TIM sections, and a red '2nd Section' label is placed next to the 'Reason outcome not collected' section.

⁵ An updated version is available to download online <https://www.crane-database.org.uk/resources/crane-data-dictionary/>

Figure 6. SDQ Psychology data items collected at 5 years, in the CRANE Database – from October 2020

CONSENT PATIENT DETAILS CLEFT DETAILS SURGICAL PROCEDURES SYNDROMES **OUTCOMES** NOTES HIS

Outcomes

Outcome information is collected according to age of patients and cleft type: All Outcomes

Outcome at Birth Outcome at 1 year **Outcome at 5 years** Outcome at 10 years

Outcome at 5 years (consented patients only)

1. Child Growth 2. Orthodontics 3. Paediatric Dentistry **4a. Psychology SDQ** 4b. Psychology TIM 5. Speech

Strengths & Difficulties Questionnaire (SDQ)

Date of psychosocial screen using SDQ at age 5

Parent SDQ Total [0-40]

Parent SDQ Emotional [0-10]

Parent SDQ Conduct [0-10]

Figure 7. Reasons outcome not collected – for Psychology data item at 5 years, in the CRANE Database – from October 2020

Strengths & Difficulties Questionnaire (SDQ)

Date of psychosocial screen using SDQ at age 5

Parent SDQ Total [0-40]

Parent SDQ Emotional [0-10]

Parent SDQ Conduct [0-10]

Syndromic Diagnosis

Clinically contraindicated (other than syndromic) - this record type for this patient

Lack of staff / facilities / equipment

Patient DNA / cancelled / did not consent / cooperate

Other reason

Screen only partially completed

Not completed due to language barriers

Parents declined to complete

Reason no SDQ score collected

Figure 8. TIM Psychology data items collected at 5 years, in the CRANE Database – from October 2020

The screenshot shows the 'OUTCOMES' tab in the CRANE Database. The 'Outcome at 5 years' tab is highlighted with a red box. Below it, the '4b. Psychology TIM' sub-tab is selected. The form includes a date field for 'Date of psychosocial screen using TIM at age 5' and a 'TIM score' dropdown menu.

Updated versions of the **CRANE Data Dictionary**, as well as the CRANE Data Collection Forms on registration (Form 1) and outcomes (Form 2), are available to download online <https://www.crane-database.org.uk/resources/crane-data-dictionary/>

3. Importing Psychology Data

If you use “Import Templates” to upload your data – as per the CRANE Import Guide found online <https://www.crane-database.org.uk/resources/quick-reference-for-importing/>:

- The current template is still available for use,
- but it will not capture the new reasons outcome not collected (at birth and for the SDQ at 5 years section), or the date of the TIM assessment.

An updated version of the Import Template will follow soon. If you need this urgently, contact us at crane@rcseng.ac.uk

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

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 6639 or crane@rcseng.ac.uk.