British Isles Network of Congenital Anomaly Registers

BINOCAR Standard Operating Procedure for Data matching CRANE

Instructions for the Registration and Surveillance of Congenital Anomalies in England and Wales

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Introduction and background

Congenital anomaly registers achieve high levels of ascertainment and completeness by collecting information from multiple sources.

This document describes the process of data matching between any regional congenital anomaly register (CAR) and a national disease specific register for a defined geography (CRANE).

High quality CRANE data are available from 2000; however earlier data are available. Further information on CRANE can be found here https://www.crane-database.org.uk/.

The purpose of matching is:

- To estimate ascertainment levels of both registers.
  Both registers will estimate ascertainment based on the proportion of matched and missed cases.
- To increase ascertainment levels for both registers (within IG approval).
  CARs will identify cases that they have missed i.e. that have been notified to CRANE only, and add these to their register
- To increase completeness for both registers (within IG approval).
  In cases that are ascertained by both registers, each register to complete missing data items (where consent practices allow).

Information Governance

BINOCAR registers collect data under section 251 of the NHS Act 2006. BINOCAR registers have approval to match data from regional registers with data from for surveillance purposes.

CRANE collects data using explicit patient consent. BINOCAR can therefore receive CRANE data for the purposes of surveillance; however it cannot transfer data to CRANE without consent.

A data-sharing agreement (CRANE proforma) needs to be completed by both register Leads. Person-identifiable data is then transferred from CRANE to the CAR. CRANE is hosted by The Royal College of Surgeons of England (Clinical Effectiveness Unit) which does not have access to NHS net mail. Data are therefore transferred by CRANE using the PHE drop box.

CARs undertake the matching process, as they have approval to receive CRANE data, and so can access both data sets.

Timescale and frequency

In the first instance, matching should be undertaken for the period from the start of the CAR inception or the start of CRANE data collection (whichever is later) to the latest complete CAR year. Matching should then take place annually.

CRANE contact details

Lynn Copley Data Manager
LCopley@rcseng.ac.uk 020 7869 6609

Data extraction

Cohort of cases for matching are extracted from CRANE, for the agreed time period and geography. CRANE supply data as a *.CSV file with 1 record per baby/case

Case definition

Cases: **Affected cases (cleft cases)** - cleft lip and/or cleft palate i.e. all anomalies reported to CRANE
Live births only

Geography: Cases resident with register area at birth selected by maternal postcode
Where postcodes are incomplete, cases are selected by Hospital of treatment
Within CRANE, postcodes are not routinely mapped to NHS geography and therefore CARs must provide CRANE with a list of postcode prefixes to select

Time period: Cases are selected by date of birth (baby)

Table 1 –Data items to be extracted from CRANE and CAR

Field	Format	Purpose	CRANE field	CAR field
Register case ID	Text	Admin	**crane_id**	
Child NHS#	Text	Matching	**nhs**	
Sex	Text	Matching	**sex** 1 = F, 2 = M (non-standard format)	
Date of birth	Date	Matching/ selecting	**dob**	
Date of death	Date	Matching	**dod**	
Number of fetuses	Number	Identifying multiple pregnancies		
Referral hospital	Text		**hosp_refer**	
Postcode current	Text	Matching/ selecting	**pcode** variable length single space, PC at birth not recorded	
Cleft diagnosis	Text	Validation/ completion	**cleft_type (**UCLP etc)	**ICD10 codes or description**
LAHSAL code	Text	Validation/ completion	**l_code**	
Cleft centre (treatment)	Text	Validation/ completion	**hosp_refer**	

CRANE also collects data on timing of diagnosis and other syndromes present.

Data matching process

The number of records/matches in any files generated should be documented to estimate ascertainment.

It is recommended that initial matching is between CRANE cases and all live born CAR cases i.e. is not restricted to CAR cases with clefts.

Step	Action	Document	Responsible
1	Data extracted from CRANE	# records	CRANE Lead
2	Data extracted from CAR – all live births		CAR Lead
3	Variables converted to a consistent format in both files	# records	
4	Identify and exclude any case with incorrect DOBs *Any out of CAR area cases are not excluded at this stage as CRANE postcodes are those at notification/treatment and not at birth.*	# records	CAR Lead
5	Automatic matching of [Baby NHS#]+[DOB]	# matches (of CRANE records)	CAR Lead
6	*For residual unmatched CRANE cases:* Automatic matching of [DOB]+ [SEX] +[PC] singletons only (selected as singleton from CAR) Repeat for CAR delivery and postnatal PCs	# matches (of CRANE records)	CAR Lead
7	*For residual unmatched CRANE cases:* Manual matching using [Baby NHS#] with validation of DOB and/or PC	# matches (of CRANE records)	CAR Lead
8	*For residual unmatched CRANE cases:* Manual matching any other field combinations where confident	# matches (of CRANE records)	CAR Lead
9	*For residual unmatched CRANE cases (usually small number of cases where NHS number is missing within CRANE):* Additional data (names) required and requested from CRANE to match		CAR Lead
10	Additional names supplied from CRANE for residual unmatched cases		CRANE Lead
11	Manual match cases using names and any other field combinations where confident.	# matches (of CRANE records)	CAR Lead
12	General draft list of residual unmatched CRANE cases	# draft unmatched CRANE records	CAR Lead
13	Validate postcodes with CRANE unmatched cases Confirm PC at birth using Spine Summary Care Record (SCR) or Child Health Depts. Exclude out of CAR area cases.	# final unmatched CRANE records	
14	Review and validate matched records, to identify possible duplicates within CRANE (single CAR case matched to 2+ CRANE records) Advise CRANE Lead of any duplicate CRANE records		CAR Lead
15	Review and validate matched records, to identify incorrectly matched twins/triplets		CAR Lead
16	Generate final list of CAR CRANE matches and retain linked ID numbers	# final matched records	CAR Lead

Notes on CRANE data quality

NHS# this data item is 15-20% complete for the period 1995-1999, and 98% complete from 2000 onwards. It is noted that occasionally the NHS number in the CRANE record relates to the mother and not the baby.

Duplicate records do exist within the CRANE dataset, however CRANE resolve any duplicate NHS numbers. Any possible duplicates within CRANE will therefore have different NHS numbers or will not be complete in both duplicate records.

Postcodes – within CRANE these relate to postcode at referral and may be updated throughout treatment. They should be treated with caution, and matched where possible to any CAR postnatal/current postcodes as well as CAR postcode at delivery/booking.

Data cleaning process – CRANE data

There is no IG approval for CARs to share PID data on unmatched cases, or data items on matched cases with CRANE. However the following information should be shared:

Duplicate CRANE records - Step 14 may generate a list of duplicate records within the CRANE dataset. CARs should share this information with the CRANE Lead, by sending combinations of the pairs of relevant CRANE unique identifiers.

Missed CRANE records – cleft cases recorded by CAR that are not matched to CRANE records. If the cleft treatment/surgical centre is recorded within the CAR dataset, then CAR notifiers at the centre can be advised that relevant cases have not yet been notified to CRANE.

Data cleaning process – CAR data

Missed CRANE cases – any missed cases should be validated locally and added to the CAR, and then completed where possible.

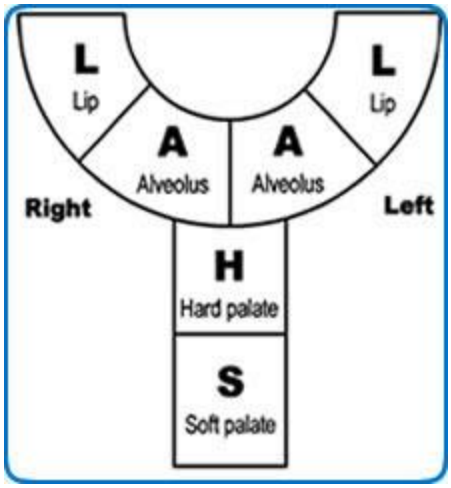
Matched cases: cleft diagnoses – CRANE cases may be matched to CAR cases with no recorded diagnoses of clefts – these records should be validated, and cleft codes can be added to the relevant CAR case. CAR leads may also confirm if the correct cleft code has been used as CRANE records generally include a precise description of the anomaly. LAHSAL codes can be translated to ICD 10 codes using the table in Appendix 1.

Matched cases: data items – where additional data items (e.g. NHS number) exist within the CRANE record but are missing from the CAR record, data items should be validated and updated within the CAR record.

Estimates of ascertainment

When matching is complete and duplicate and unmatched records are validated, the CAR lead should estimate ascertainment for both registers using capture-recapture technique. Estimates of CRANE ascertainment should be provided to the CRANE Lead.

Appendix 1 Cleft LAHSAL to ICD 10 code (WMCAR)



The LAHSAL code splits the relevant parts of the mouth into six parts:

- Right lip
- Right alveolus
- Hard palate
- Soft palate
- Left alveolus
- Left lip

Note the order in which it is written - is from the perspective of someone looking at the patient (i.e. the first character is for the patient's right lip, and the last character for the patient's left lip).

LAHSAL	cleft_type	ICD10 code EUROCAT	ICD10 description
..H...	CP	Q35.1	Cleft hard palate
...S..	CP	Q35.3	Cleft soft palate
..hS..	CP	Q35.5	Cleft hard palate with cleft soft palate
l....l	CL	Q36.0	Cleft lip, bilateral
l...AL	CL	Q36.0	Cleft lip, bilateral
lA...l	CL	Q36.0	Cleft lip, bilateral
la..aL	CL	Q36.0	Cleft lip, bilateral
.....l	CL	Q36.90	Cleft lip, specified as unilateral
....AL	CL	Q36.90	Cleft lip, specified as unilateral
la....	CL	Q36.90	Cleft lip, specified as unilateral
.a....	CL	K08.8	Other disorders of teeth and supporting structures
l.....	CL	Q36.90	Cleft lip, specified as unilateral
LaH..L	BCLP	Q37.0	Cleft hard palate with cleft lip, bilateral
LAH.AL	BCLP	Q37.0	Cleft hard palate with cleft lip, bilateral
..H.AL	UCLP	Q37.1	Cleft hard palate with cleft lip, specified as unilateral
la.s.l	BCLP	Q37.2	Cleft soft palate with cleft lip, bilateral
la.sal	BCLP	Q37.2	Cleft soft palate with cleft lip, bilateral
...s.l	UCLP	Q37.3	Cleft soft palate with cleft lip, specified as unilateral
...Sal	UCLP	Q37.3	Cleft soft palate with cleft lip, specified as unilateral
l..s..	UCLP	Q37.3	Cleft soft palate with cleft lip, specified as unilateral
la.s..	UCLP	Q37.3	Cleft soft palate with cleft lip, specified as unilateral
l.HS.l	BCLP	Q37.4	Cleft hard and soft palate with cleft lip, bilateral
l.HSAL	BCLP	Q37.4	Cleft hard and soft palate with cleft lip, bilateral
LAHS.l	BCLP	Q37.4	Cleft hard and soft palate with cleft lip, bilateral
LAHSAL	BCLP	Q37.4	Cleft hard and soft palate with cleft lip, bilateral
..HS.L	UCLP	Q37.5	Cleft hard and soft palate with cleft lip, specified as unilateral
..HSAL	UCLP	Q37.5	Cleft hard and soft palate with cleft lip, specified as unilateral
L.HS..	UCLP	Q37.5	Cleft hard and soft palate with cleft lip, specified as unilateral
lAHS..	UCLP	Q37.5	Cleft hard and soft palate with cleft lip, specified as unilateral