



CLEFT REGISTRY & AUDIT NETWORK

CRANE core set of indicators

Key: A – Audit (function); BCLP – Bilateral Cleft Lip and Palate; CAPS-A - ; Cleft Audit Protocol for Speech; CP – Cleft Lip; CP – Cleft Palate; dmft – decayed, missed or filled teeth; HES – Hospital Episode Statistics; O – outcome indicator (type); P – process indicator (type); R – Registry (function); UCLP – Unilateral Cleft Lip and Palate.

Core set of indicators (n=14)

Pathway	Function : Type	#	Indicator	Denominator	Numerator	Consideration
Diagnosis	Registry (R) : Process indicator	1	Timely detection of Cleft Palate (CP), within 24/72 hours from birth	Children diagnosed with a CP	Children diagnosed with a CP within 24/72 hours from birth	
Diagnosis	R : P	2	Antenatal diagnosis for CL, UCLP and BCLP	Children diagnosed with a CL, UCLP and BCLP antenatally	Children diagnosed with a CL, UCLP and BCLP within 24 hours from birth	
Referral and contact	R : P	3	Referral to a cleft care team within 24 hours of birth	Patients diagnosed with cleft lip and/or palate who have records on the CRANE Database system	Families were referred to a cleft care team within 24 hours of birth	Related to CLP01: % parents contacted by a cleft team Clinical Nurse Specialist (CNS) within 24 hrs of referral with an antenatal diagnosis of CLP
Referral and contact	R : P	4	Contact with a cleft care team within 24 hours of referral	Patients diagnosed with cleft lip and/or palate who have records on the CRANE Database system	Families were contacted by a cleft care team within 24 hours of referral	Related to CLP02: % parents, of infants diagnosed with CLP, who receive a visit from a cleft team CNS within 24 hrs of first referral (following birth)

Pathway	Function : Type	#	Indicator	Denominator	Numerator	Consideration
Referral and contact	R : P	5	Consent verification undergone with all families of children with an orofacial cleft recorded in the CRANE Database (Participation in audit is a mandatory requirement of service provision contract > cannot audit without consent)	Patients diagnosed with cleft lip and/or palate who have records on the CRANE Database system	Families approached for consent verification – who have reached the decision to accept or decline consent to records being shared with CRANE for follow-up / audit purposes.	
Outcomes / Treatment:: Nursing	A : Outcome indicator (O)	6	Healthy Body Mass Index (BMI) at 5 years of age	All consented children, without submucous cleft palates, alive at the age of 5 years – with child growth data	Patients with a healthy BMI at 5 years of age	
Outcomes / Treatment: Dental	A : O	7	Dental decay at 5 years of age	All consented children, without submucous cleft palates, alive at the age of 5 years – with dental health data	Patients with at least one dmft (dmft >0) at 5 years of age	
Outcomes / Treatment: Dental	A : O	8	Dental treatment index at 5 years of age	All consented children, without submucous cleft palates, alive at the age of 5 years – with dental health data	Patients with treatment indices of 1 (no untreated disease) at 5 years of age	Mirrors CLP06: % of 5 year old children with CLP, who have had a treatment index recorded by a calibrated paediatric dentist (dmft scores)
Outcomes / Treatment: Orthodontic	A : O	9	Facial growth at 5 years of age	All consented children with complete UCLP, without submucous cleft palates, alive at the age of 5 years – with Five Year Old Index scores	Patients with Five Year Old Index scores reflecting 'good' dental arch relationships	Mirrors CLP09: % of five year old children, with complete UCLP who have good maxillary growth as determined by the 5 Year Growth Index
Outcomes / Treatment: Speech and language therapy	A : O	10	Speech within the normal range at 5 years of age	All consented children with CP, UCLP and BCLP, without submucous cleft palates, without diagnosed syndromes, alive at the age of 5 years – with speech data (all 16 Cleft audit protocol for speech (CAPS-A) data items)	Patients achieving speech within the normal range at 5 years of age	

Pathway	Function : Type	#	Indicator	Denominator	Numerator	Consideration
Outcomes / Treatment: Speech and language therapy	A : O	11	Speech without difficulties resulting from existing or previous structural anomalies at 5 years of age	All consented children with CP, UCLP and BCLP, without submucous cleft palates, without diagnosed syndromes, alive at the age of 5 years – with speech data (CAPS-A data items)	Patients achieving speech without difficulties resulting from existing or previous structural anomalies at 5 years of age	
Outcomes / Treatment: Speech and language therapy	A : O	12	Speech without significant cleft-related articulation difficulties at 5 years of age	All consented children with CP, UCLP and BCLP, without submucous cleft palates, without diagnosed syndromes, alive at the age of 5 years – with speech data (CAPS-A data items)	Patients achieving speech without significant cleft-related articulation difficulties at 5 years of age	
Treatment / Process: Psychology	A : P	13	Psychology screening (at least one) before the age of 6 years	All consented children, without submucous cleft palates, without diagnosed syndromes, alive at the age of 5 years – with date of psychological screen data	Families screened at least once before the age of 6 years	
Outcomes / Treatment: Psychology	A : O	14	Psychological concerns identified at the age of 5	All consented children, without submucous cleft palates, alive at the age of 5 years	Patients with 'high' or 'very high' TIM scores	

Notes: (1) Case ascertainment and surgical indicators require HES linkage so not added here.

(2) We piloted data quality indicators in 2021.

Because adding data to CRANE is a requirement – Data Quality indicators piloted in 2021

Pathway	Function : Type	#	Indicator	Denominator	Numerator	Consideration
Data Quality / Process: Diagnosis	A : P	A	Gestational age and birth weight recorded for all eligible children	All live births registered in CRANE	Patients with a gestational age and birth weight data recorded in CRANE	
Data Quality / Process: Nursing	A : P	B	Child growth at 5 years recorded for all eligible children	All consented children, without submucous cleft palates, alive at the age of 5 years	Patients with child growth (height & weight) data at 5 years of age recorded in CRANE	
Data Quality / Process: Dental	A : P	C	dmft at 5 years recorded for all eligible children	All consented children, without submucous cleft palates, alive at the age of 5 years	Patients with recorded dmft scores at 5 years of age recorded in CRANE	

Data Quality / Process: Orthodontic	A : P	D	Facial growth at 5 years recorded for all eligible children	All consented children with UCLP, without submucous cleft palates, alive at the age of 5 years	Patients with recorded Five Year Old Index scores at 5 years of age recorded in CRANE	
Data Quality / Process: Speech and language therapy	A : P	E	Speech scores at 5 years recorded for all eligible children	All consented children with CP, UCLP and BCLP, without submucous cleft palates, without diagnosed syndromes, alive at the age of 5 years	Patients with CAPS-A scores (all 16) at 5 years of age recorded in CRANE	
Data Quality / Process: Psychology	A : P	F	Psychology data at 5 years recorded for all eligible children	All consented children, without submucous cleft palates, alive at the age of 5 years	Patients with psychology screening information and TIM scores at 5 years of age recorded in CRANE	

References

Standards / guidelines – described in the individual summary tables / sections of the report.