

**Cleft Lip and Palate Services**

**21 August 2025**

**1. Below are numbers of children born in NI with cleft lip and/or palate births from 1<sup>st</sup> Jan 2015 to date 30<sup>th</sup> June 2025.**

		CL	CP	UCLP	BCLP	CLEFT H TYPE	SMCP
	2015	9	15	8	5	<5	11
	2016	6	13	8	<5	<5	10
	2017	5	19	<5	<5	<5	8
	2018	<5	12	7	<5	<5	9
	2019	<5	16	9	<5	<5	<5
	2020	8	13	<5	5	<5	<5
	2021	5	12	<5	<5	<5	<5
	2022	3	16	<5	<5	<5	<5
	2023	13	15	<5	<5	<5	<5
	2024	<5	8	8	<5	<5	<5
	2025	<5	7	<5	<5	<5	<5

CL	Cleft Lip only
CP	Cleft Palate only
UCLP	Unilateral cleft lip and palate
BCLP	Bilateral cleft lip and palate
SMCP	Submucous cleft palate repaired/unrepaired
CLEFT H	Separate clefts of both lip and palate

**Standard procedures and recommended timelines for repairing cleft lips and palates.**

Cleft Type	IP/DC	DETAILS OF PROCEDURE		
		PROCEDURE 1	PROCEDURE 2	PROCEDURE 3
Isolated Cleft Lip (CL) – 1 procedure	DC	Procedure type: Repair of Cleft lip  Timing of surgery: 3-6 months <i>UK CUT OFF 6 MONTHS</i>	N/A	N/A
Isolated Cleft Palate (CP) – 1 procedure	DC or IP	Procedure type: Palate repair  Timing of surgery: 9-13 months <i>UK CUT OFF 13 MONTHS</i>	N/A	N/A

UCLP - 2 staged procedure	IP	Procedure type: Primary lip and hard palate repair  Timing of surgery: 3-6 months	Procedure type: Completion of palate  Timing of surgery: 9–13 months <i>UK CUT OFF 13 MONTHS</i>	N/A
BCLP – 3 staged procedure	IP	Procedure type: Lip adhesion & unilateral vomer  Timing of surgery: 2-3 months	Procedure type: Definitive lip and unilateral vomer  Timing of surgery: 6 months	Procedure type: Completion of palate  Timing of surgery: 9–13 months <i>UK CUT OFF 13 MONTHS</i>

**3. Key developmental milestones at which children are reviewed, and any additional surgeries or assessments are typically performed.**

PATIENT AGE AND TYPE OF CLINIC	CLEFT CLINICS	ATTENDED BY:
FIRST CLEFT CLINIC	Consultant Cleft Surgeon Cleft New Clinic – diagnosis dependent	All newborns
POST-OP REVIEW CLINIC	Consultant Cleft Surgeon/CNS Cleft Review Clinic – 6-8 weeks post-op following every operation	All children
AGE 6-9 MONTHS	Early Intervention Clinic	All children with cleft palate only
AGE 18 MONTHS	Speech and Language Therapy assessment	Children with palate involvement only
AGE 2.5 - 3 YRS	MDT Joint Cleft Palate Clinic	All children
AGE 5	MDT Joint Cleft Palate Clinic and National AUDIT	All children
AGE 7	MDT Joint Cleft Palate Clinic	Children with lip involvement only
ABG - AGE 7-9	Alveolar Bone Graft Clinic for pre/post-op reviews	Children with lip involvement only
AGE 10	MDT Joint Cleft Palate Clinic and National AUDIT	All children
AGE 15	MDT Joint Cleft Palate Clinic with Restorative Dentistry for pre/post operative osteotomy assessment	All young people

AGE 20	Joint Cleft Palate Multi-Disciplinary Clinic with Restorative Dentistry for pre/post operative osteotomy assessment	All adults
Additional Cleft Clinic if patient requires	Palatal Investigation Clinic with Consultant Cleft Surgeon and SLT	For Velopharyngeal Investigations & Pre Post Operative SLT Assessments (including VPD & Fistulae) * Including Non Cleft VPD Referrals at any age

**CLEFT PATHWAY**

**0-3 months**

All newborn infant with a cleft must be seen within 24 hours of receipt of referral by the Cleft Nurse Specialist in maternity hospital or at home. There are 4 types of cleft:

- Isolated cleft lip – child to have 1 operation@3months
- Isolated cleft palate – child to have 1 operation@9months
- Unilateral cleft lip and palate – child to have 2 operations@3 months and @9months
- Bilateral cleft lip and palate – child to have 3 operations@3 months, @6months, @9-12months

The family meet the consultant cleft surgeon as a New Outpatient patient, appointment timing is based on cleft type diagnosis and when 1<sup>st</sup> surgery is due. Parents are given information on upcoming treatment, operations. Patient is added to the waiting list. The family are given a baby pack which contains information leaflets, information on CRANE (cleft registry in the UK), bottles etc.

**3-6 months**

Any cleft with involvement of lip requires repair surgery usually when a child is at least 3 months old. Surgery typically takes 2 hours and can be a day case up to a 2 night stay.

**6 weeks post-op**

A 6 week Post-Op review with consultant surgeon or cleft nurse specialist is arranged. Depending on cleft diagnosis the following takes place at this clinic appointment:

**Cleft lip only** – no more surgeries and child will next seen at Joint Cleft Palate Multi-Disciplinary Clinic (Surgeon/Dental) when aged 2.5-3 yrs.

**Bilateral cleft lip and palate** – child will be added to waiting list for 2<sup>nd</sup> operation named definitive lip and unilateral vomer to be done when 6 months of age, ie 3 months post-1<sup>st</sup> lip repair.

**Unilateral cleft lip and palate** – child will be added to waiting list for 2<sup>nd</sup> operation named completion of palate when 9 to 12 months of age, ie 6 months post-lip repair.

#### 6-9 months

The Early Years Pathway involves parents attending the *Early Intervention Clinic* which is a joint SLT/ Cleft Nurse Specialist/ Dental clinic when their baby is aged 6-9 months with cleft palate involvement. Parents are offered a webinar by SLT to inform them on supporting their baby's speech, language and communication skills (SLCN).

Bilateral cleft lip and palate diagnosis – child will be admitted to hospital for 2<sup>nd</sup> operation named definitive lip and unilateral vomer. This is typically a 2-2.5 hour surgery with a 1-2 night hospital stay.

#### A further 6 weeks post-op review for BCLP patients

A 2<sup>nd</sup> 6 week Post-Op review with consultant surgeon or Cleft Nurse Specialist is arranged. Child will be added to waiting list for 3<sup>rd</sup> operation named completion of palate when 9-12 months of age.

#### 9 months-12 months

Bilateral cleft lip and palate diagnosis – child will be admitted to hospital for 3<sup>rd</sup> operation named completion of plate.

**Cleft palate only** – child will be admitted for repair surgery named Furlow palatoplasty or IVVP for soft palate only.

#### A further 6 weeks post-op review for BCLP, UCLP and cleft palate only patients

A 6 week Post-Op review with consultant surgeon or Cleft Nurse Specialist is arranged. Child will next be seen by surgeon at Joint Cleft Palate Multi-Disciplinary Clinic when age 2.5-3 yrs.

#### 18 months – 5 years

*SLT Clinic assessment* occurs at 18 months to ensure SLCN are progressing typically. Any concerns at this stage are considered for further management and/or intervention.

*Joint Cleft Palate Multi-Disciplinary Clinics:* child to be seen at age 2.5-3 yrs (all patients), 5 yrs (all), 7 yrs (if lip involvement), 10 yrs (all), 15 yrs (all), 20 yrs (if lip involvement).

All children are invited to MDT review at 30-36 months and 5 years. Many see some disciplines in between these standard MDT review clinics. Secondary surgery will take place at this stage, typically lip revision, minor nose adjustments or speech surgery.

A child with a cleft should receive a full assessment by all specialists in the cleft team at age 5 which is an Audit point, to ensure that any ongoing or emerging issues are being dealt with appropriately and child can be referred to *Palatal Investigation Clinic* with consultant surgeon and SLTs.

#### 6 years – 16 years

Joint Cleft Palate Multi-Disciplinary Clinic Reviews continue at 7 years, 10 years which is also an Audit point for dental scoring, and 15 years. A consultant restorative dentist from School of Dentistry now starts to see age 15 patients and not paediatric dental surgeons.

At age 7 yrs JCPC, children are referred to the *Alveolar Bone Graft Clinic* for assessment +/-alveolar bone graft surgery with consultant surgeon and consultant orthodontist. The orthodontist will monitor the position of the child's teeth, including their adult teeth when they start to come through. Treatment may be needed to correct their position, which often includes fitting braces.

An Alveolar Bone Graft (ABG) procedure is performed when there is insufficient bone in the area of the gum-line defect. Surgical repair involves taking bone from the patient's hip/ shin and grafting it into the cleft in the bony ridge. Alveolar Bone Grafting takes place when child is aged between 9-12 years (dependent on dentition).

At age 15 JCPC, a consultant restorative dentist from School of Dentistry now starts to see age 15 patients and not the paediatric dental surgeon.

#### 16+

Transition to adults usually occurs at 16. A further review takes place at 20 years for lip involvement patients. Many individuals with a cleft also have Orthognathic surgery which involves re-aligning the jaws to change the appearance of a person's profile. This is usually offered to patients who have an *underbite*, and is usually completed after their face has finished growing at 16-18 years old.

Adults may re-enter the Regional Cleft Service at any time for a consultation about any aspect of their care, which includes speech therapy, surgical assessment, genetic counselling and specialist dental treatment with Restorative Dentistry.

#### **Additional Secondary surgeries typically performed are:**

Furlow re-repair

Pharyngoplasty

Revision repair of cleft palate - IVVP

Palatoplasty for lengthening of palate with bilateral buccinator flaps

Closure of palatal fistula

Open tip rhinoplasty

V-Y lip revision

Fat grafting to cheek

**4. The percentage of children who receive surgeries and assessment within the recommended timeframes over the services for each of the past five years.**

This information is not recorded on the database held with Cleft Team.

**5. The percentage of the Trust's annual budget allocated to the department responsible for cleft lip and palate services for each of the past five years.**

**This information is not centrally collated therefore it is not possible for the service to make this calculation as there are a significant number of variables involved.**

It is not possible for the service to make this calculation as there are a significant number of variables involved as the information is not centrally collated.

**6. Any changes in funding levels for this department over the specified period.**

This information is not centrally collated as this service is provided jointly by both Belfast Health and Social Care Trust and South Eastern Health and Social Care Trust. It is not possible for Belfast Health and Social Care Trust to provide a comprehensive response on this matter.