

# **Cleft Care Scotland**

## Annual Report

### 2022/23

**Lead Clinician:** David Drake  
**Programme Manager:** Gillian Kinstrie  
**Programme Support Officer:** Mary Glen

## **Introduction**

Around one in every 600 children are born with some form of cleft lip and/or palate in Scotland. Care for cleft patients is delivered by a multi-disciplinary team of professionals throughout childhood and into adulthood.

Cleft Care Scotland (CCS) provides a framework to facilitate delivery of standardised quality care for patients with cleft lip and/or palate throughout Scotland. The network's vision is that every patient with a cleft lip and/or palate is offered specialist cleft care from diagnosis to adulthood, and families are offered the right care in the right place at the right time to produce the best possible outcome for the patient.

## **Current Position**

The network achieved 13 of 14 (93%) objectives agreed for 2022/23. The objective to produce two newsletters this year was not achieved with only one newsletter issued (February 2023).

Two objectives were paused during the course of the year following agreement with the Senior Management Team:

- The objective to host a Patient Engagement Event was put on hold following the postponement of this event for a third time in September 2022. Feedback from the Patient Experience Survey and the Network Review will be used to inform how best to engage with patients/families.
- The objective to finalise and adopt the Network's Quality Strategy was carried forward into 2023/24 given the delays in joining CRANE and this is on track for completion by September 2023.

This year, as part of the National Services Division's commissioning process, a review of Cleft Care Scotland took place to appraise the performance of the Network and inform the future delivery. The review took place between November 2022 – January 2023 with the report's recommendations shared with the core team in May 2023.

The Network continued to make use of technology and remote communications to progress work this year. This has continued to be effective, saving time on travel and promoting economic and climate friendly practices.

## **Highlights**

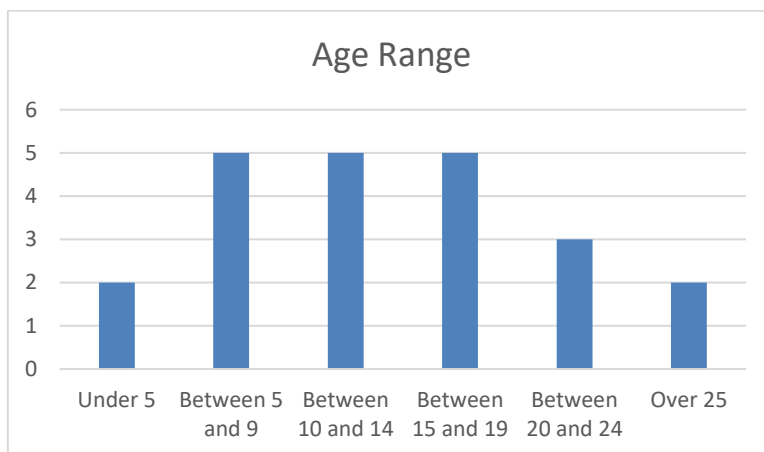
### Patient Experience and Engagement

The Network continues to ensure the experiences and priorities of people born with a cleft lip and/or palate and their carers inform our activities as outlined in our Patient Experience and Engagement Strategy.

Central to this is the direction and feedback provided by the Network's Patient Engagement Group which includes people born with a cleft, family representatives and voluntary sector organisations

with an interest in cleft care. Members of the Patient Engagement Group supported the development of a patient experience survey which was shared across cleft care services between January and March 23 in electronic and paper format.

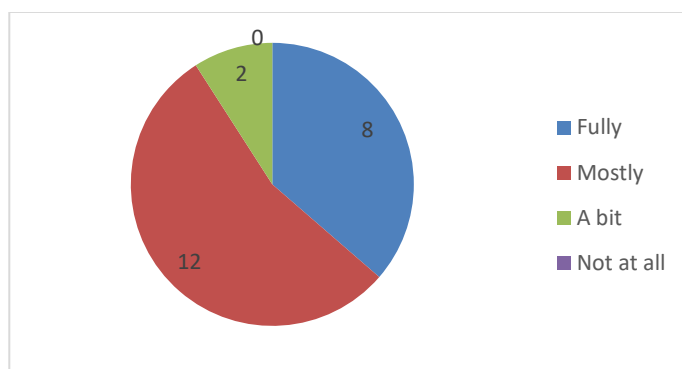
Of the 22 responses to the survey, 16 were from parent/carers of children born with a cleft and 6 were from adults who had been born with a cleft. The age of people born with a cleft who shared their experiences ranged from under 1 to 37.



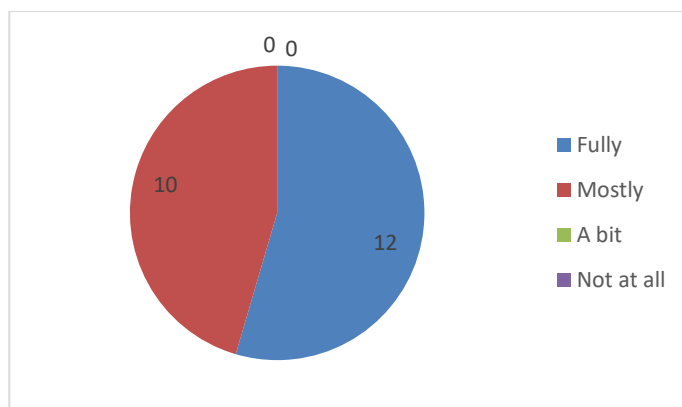
The survey people to outline what would be the most helpful to them when thinking about cleft care services. One key theme highlighted was the need for good and regular communication including knowing who the cleft care team are and having a key contact throughout the patient pathway. Information on treatment pathways and support available was also noted with several people highlighting that meeting other parents and learning from their experiences would be helpful. Respondents was also encouraged to share a range of areas where things had worked well and some areas where things could have been improved.

The survey also sought to find out how well their care had met their needs and how involved they felt in their care. The results for this were very positive as noted in the pie charts below and people were asked to share why they felt this way:

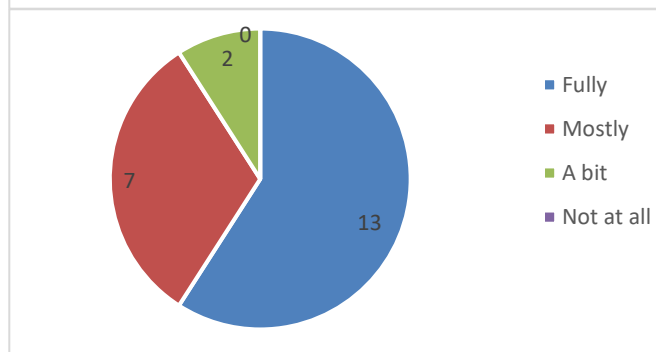
**Overall how well do you feel that your cleft care met your needs?**



**Overall do you feel that people involved in your/ your child's cleft care listened to you when asking questions or raising concerns?**



**Do you feel included in decision making about your/ your child's cleft care?**



The feedback from the survey will be further collated and considered by the Patient Engagement Group and Steering Group to inform network activities in the coming year and the refresh of the Network Strategies.

### Review of Cleft Care Patient Pathways

In 2020, the Network launched new pathways for cleft lip, cleft palate, and cleft lip and palate. The pathways were developed in conjunction with people working across all of the specialities involved in providing cleft care and with third sector/patient representatives. The full roll out of these pathways were impacted by the COVID pandemic and therefore it was agreed to delay the review of these pathways until this year.

The format for the review was to meet with the professional groups involved in cleft care to explore their experience of the pathway and explore worked well, any challenges and the impact of COVID. Meetings were held with Specialist Nurses, Speech and Language Therapists, Psychology between August and October 2022. Formal meetings were unable to take place with the other professional groups although all were given the opportunity to provide feedback on the pathways through their professional group lead.

The feedback received highlighted that the pathways worked well but some minor changes/additions were required to reflect what happens now. Following discussion with the specialist nurse group about capturing patient experience it was agreed that they would look to adapt their existing feedback form and use this to routinely request feedback from families when children reach a year old.

An interim paper summarising the discussion from the meetings with professional groups and any changes required to the pathway was presented to the Steering Group in February 2023.

The pathways and interim paper were discussed with the Patient Engagement Group in February 2023 and verbal feedback was shared at the Steering Group. The patient group noted that the pathways are aimed at health care professionals rather than patients/parents. The group suggested that while the existing pathways outline what should take place less prescriptive written information would be helpful at key stages throughout the patient journey.

Feedback from the patient experience survey in relation to the patient pathway was also reviewed. It was highlighted that having a key contact within cleft care throughout the patient pathway would be helpful. Patient Engagement Group members agreed this would be helpful and should be available to both children and adults to help them navigate the pathways.

The Steering Group endorsed the proposed changes to the existing pathways and agreed to develop information materials for patients/families linked to key stages in the pathway and assign a key contact for patients.

#### Equitable and Timely Access to Cleft Care Services

Cleft lip and palate services in Scotland operate as a 'Hub and Spoke' model. The nationally commissioned surgical element of the service is provided by surgeons, specialist nurses and psychologists. All other aspects of care for people born with a cleft lip and/or palate is provided by the local NHS Boards and includes the areas of speech and language therapy, orthodontics, paediatric dentistry, restorative dentistry, ENT and audiology. Nationally agreed care pathways are in place to ensure optimal outcomes are achieved.

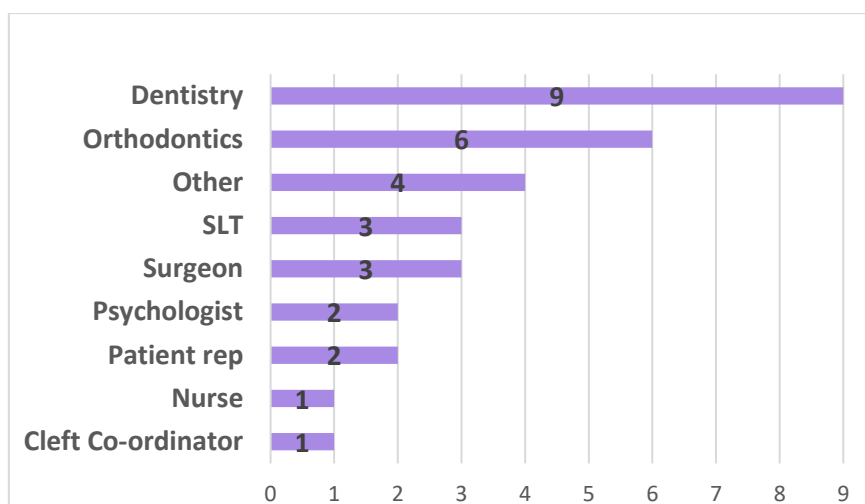
To ensure clinical outcomes are not adversely affected, everyone born with a cleft lip and/or palate should have equitable and timely access to all of the specialist services they require. For both nationally commissioned and NHS Board commissioned elements of the service there is a duty to ensure all services are available, are adequately staffed and contingencies are in place to ensure any periods of staff absence are covered appropriately.

Linking to the NSS Strategic Objective of Workforce sustainability, a paper highlighting the need for equitable and timely access to cleft specialist services and the services local boards were responsible for providing was developed. A meeting took place with service managers responsible for Speech and Language Therapy (SLT) Cleft Care services across Scotland to highlight that staff working within cleft care services are supportive of providing cross cover for short term temporary periods of absence. Where there is a gap in service, all routine care should continue to be provided locally but where assessment/specialist management is required this should be provided by one of the specialist SLTs from another area. This proposal was supported by the service managers for SLT services. Discussions will now take place with staff and service managers involved in providing other elements of cleft care to ensure cross cover arrangements are in place when required.

### Annual Education Event

Education is a core objective for all Managed Clinical Networks and a key action within Cleft Care Scotland's Education Strategy is to host an annual education event for staff supporting cleft care in Scotland.

This year's event took place on 24<sup>th</sup> November 2022 and had the theme '*Multidisciplinary Cleft Care – The Dental Specialties*'. The event was the first face to face event held by the Network since the COVID-19 pandemic and was attended by 31 people across a range of specialties:



Evaluation forms were completed by 25 participants (81%). Feedback on the event was very positive with 23 respondents rating the event as very relevant (48%) or mostly relevant (44%) to their educational needs. All respondents rated the effectiveness of the meeting as very effective (72%) or mostly effective (28%).

In response to a question on what attendees gained from the event, people highlighted that the event included 'interesting presentations' which provided a '*greater understanding of services and the patient journey*'. Respondents also welcomed the networking opportunities provided by the event with 21 people (84%) responding that future event should also take place in person. When asked what they would do differently as a result of attending the meeting, responses included '*more awareness of the care pathways available*', '*asking about dental care more routinely in interactions with children and families*' and '*collating data on my work and outcomes*'. The feedback received, including suggested topics for future events, will be considered by the Steering Group to inform planning for future education events.

### **Looking forward – 2023/24**

The review of the Network published in May 2023 recommended its continued designation conditional on the completion and effective implementation of an action plan. To support the development and delivery of the action plan some Network activity will be paused, however, many of the actions required were planned to be undertaken in 2023/24.

The areas for the Network to focus on to support its continued designation include:

- Revising the network structure to focus on delivering network objectives ensuring all subgroups have clear terms of reference.
- Undertaking a gap analysis with the network and service to understand the roles and responsibilities of data and audit leading to the development of a Data Plan
- Attending a facilitated workshop for the network and service to understand roles and responsibilities of each and agree how best to interact.
- Developing a Quality Improvement Plan.
- Ensuring measures are in place to monitor and assess the impact of the patient pathways.
- Reviewing the education, communication and engagement strategies and identifying measures to assess their impact.
- Reviewing UK cleft care guidelines and standards, identifying any areas in the pathway which are not covered and developing a plan for how the network will address this.
- Ensure the network delivers effective communication for patients/ families/ carers across all aspects of the patient pathway which are not covered by the surgical service.

## Finance

The Network spent £1,320 in 2022/23. All costs relate to the costs for hosting the Annual Education Event in November 2022.

<b>Detail Code</b>	<b>Spend</b>
Exhibition/Conferences	£1,033
Travel Subsistence	£112
Public Transport	£175
<b>TOTAL SPEND</b>	<b>£1,320</b>

## Risks & Issues

The tenure for the Lead Clinician ended on 31<sup>st</sup> March 2023. In light of the recommendations from the review of the network, a one-year transformational clinical lead role will be offered for 2023/24 on the basis of 1PA. Should this post remain unfilled following discussion with the existing Lead Clinician and Network members the Network will be de-designated. There is also a risk that some Network members do not support the changes required to continue designation and disengage with the network impacting on progress with the action plan.