

Cleft Care Scotland

Annual Report

2023/24

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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 aim is to achieve the best possible clinical and other outcomes for children and adults living in Scotland who were born with a cleft lip and/or palate, and reduce the burden of care for cleft patients and their families. This is achieved through better access to high quality specialist care by enabling Scottish Government and Health and Social Care Department (SGHSCD) policy aims of safe, effective, person-centred care delivered as close to home as possible.

Current Position

A review of CCS was undertaken during 2022/2023. In May 2023 the network was advised that continued designation was conditional on the completion and effective implementation of an action plan to address the review recommendations. The completed action plan was presented to the Review Team in February 2024 with the final outcome on network designation anticipated in June 2024.

The network achieved 23 of 26 (88%) of its objectives within its business plan in 2023/24. Three objectives were delayed due to the volume of activity required to implement the action plan and will be completed in 2024/25:

- **Establish a mechanism to monitor and assess the impact of the patient pathways.**
Monitoring of pathways takes place via the Cleft Registry and Audit Network (CRANE) and local audits. The impact will be demonstrated via Patient Pathway research project started in 2023, via benchmarking and patient feedback.
- **Develop information materials to support communication with patients/families/carers across all stages of the patient pathway.**
Work will continue with speciality groups and the national cleft surgical service to identify what is needed and how the network can support the development of patient information.
- **Update the Networks website to include links to UK cleft care guidelines and provide additional information about the national service/cleft care pathways to support parents/families/carers.**
While the website has been redeveloped, further work is still required to give context to the Cleft Guidelines. A new website for the National Cleft Surgical Service is in development and collaboration is planned to ensure information is available on the relevant website with links in place to avoid duplication.

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

Implementation of Action Plan

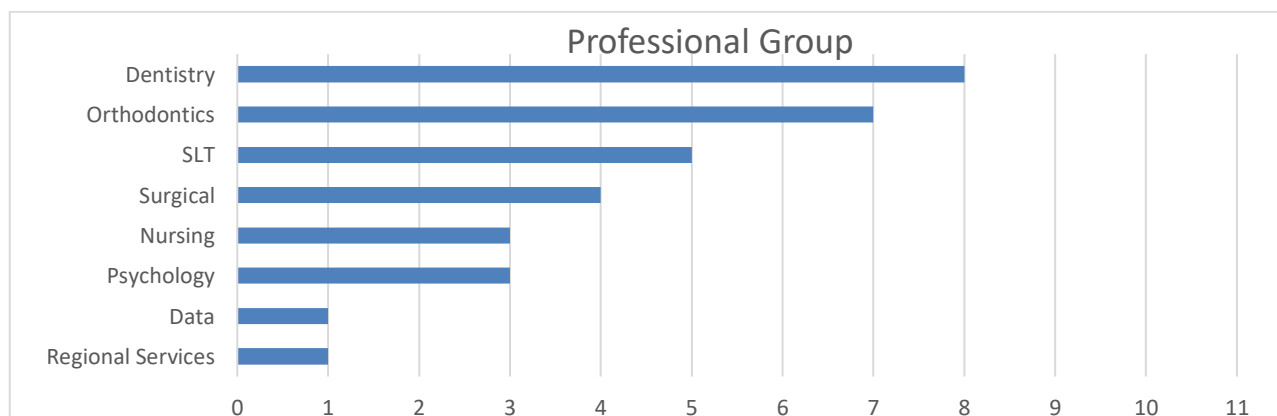
In May 2023 following the review of CCS, the network was tasked to develop an action plan to address the recommendations from the review. The Action Plan was presented to the Review Team for approval in August 2023 following which the network members had a further six months to implement this.

The key achievements during this period include:

- Refreshed structure of the network, and terms of reference for all groups, to ensure there is a multidisciplinary and collaborative approach to supporting improvements in cleft care.
- Strengthening of relationships between CCS and the National Cleft Surgical Service and shared understanding of respective roles and responsibilities through the development of a RACI ('responsible, accountable, consulted and informed') matrix, glossary of network terms and regular Cleft Network/Service Liaison Group meetings.
- A refreshed Education Strategy informed by a learning needs analysis.
- Refreshed Network Strategies for Communications, Patient Engagement and Patient Experience Strategy and Quality Improvement.
- The 2024-2027 Strategic Workplan developed with network members which outline key short-term and long-term priorities for CCS ensuring a shared vision for how the network will support improvements in cleft care.
- Increasing the opportunities for accessing education and sharing research in cleft care.

Audit Event

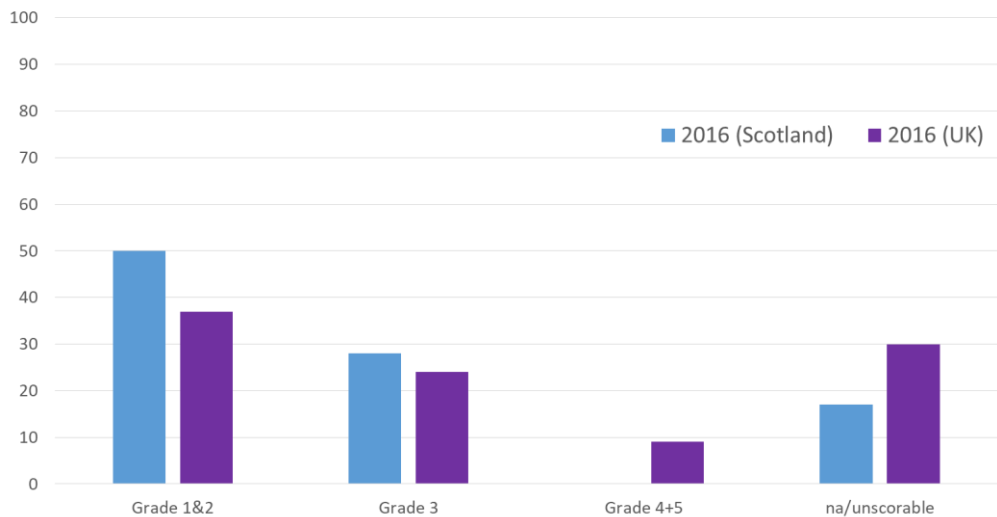
CCS hosted an Audit Event on 24 April 2023 in Stirling. In total, 32 people attended the event with the professional group mix noted below:



The purpose of the event was to enable specialty leads from across Scotland to present and discuss the audit of five year olds born in 2016. This event was designed as a “first run” to look at the network’s ability to collect and collate the required outcome data. Data collected was compared to CRANE data informally for guidance and in advance of future bench marking.

Presentations followed the same format for each audit: Key Findings, Successes and Challenges, and Future Actions. The audits demonstrated very good data collection and collation. In terms of actual outcomes, standards in all domains are very good and all above UK standards. Some of the key findings were:

Nursing Audit	<ul style="list-style-type: none">94% cleft lip diagnosed antenatally (UK is 76%)Postnatal diagnosis all cleft types 91% within 24 hours of birth (UK figure not available)Post-natal cleft palate 82% (UK is 73%)Referral within 24 hours 94% (UK is 84%)Cleft nurse specialist contact direct 72% but voicemail left (antenatal)97% seen within 24 hours post-natal (UK is 93%)								
Speech and Language Therapy Audit	<p>Speech outcomes were all achieved and were above prescribed standards.</p> <ul style="list-style-type: none">Standard 1: - 73% (50% is standard) (The achievement of speech with no evidence of a structurally related problem and no cleft speech characteristics requiring intervention)Standard 2a - 85% (70% is standard) (The absence of structurally related speech difficulties and no history of velopharyngeal surgery or fistula repair for speech purposes)Standard 3 - 73% (The absence of significant cleft-related speech characteristics (CSCs) on sentence repetition, which may require therapy and/or surgery)								
Psychology Audit	<p>Percentage of people screened before 6th birthday</p> <ul style="list-style-type: none">78/88 invited to be screened (89%)10/88 missed/not invited to audit <p>Of the 78 invited to be screened before 6th birthday</p> <ul style="list-style-type: none">4 DNA/ left without seeing Clinical Psychology8 Clinically contraindicated or Syndromic Diagnosis15 missing SDQ* data51 patients with SDQ results <table><tr><td>SDQ Scores</td><td>Normal</td><td>Borderline</td><td>Abnormal</td></tr><tr><td>Total</td><td>36 (70%)</td><td>9 (18%)</td><td>6 (12%)</td></tr></table> <p>*SDQ is the most-used instrument for assessing mental health status for people in the age range 2 to 18.</p>	SDQ Scores	Normal	Borderline	Abnormal	Total	36 (70%)	9 (18%)	6 (12%)
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Dental Audit	<ul style="list-style-type: none">67% of Scottish patients had dmft scores* or reasons that this outcome was not collected at 5 years of age								

	<ul style="list-style-type: none"> • 33% of Scottish patients had a dmft>0 (some decay experience) • 13% of Scottish patients had a dmft>5 (experience of severe dental decay) <p>Scotland 2016 births when compared to UK (2015) data</p> <ul style="list-style-type: none"> • Scotland was a positive outlier for cleft dmft reporting • almost positive outlier for patients having some dental decay (dmft >0) • close to the UK mean for patients having severe dental decay (dmft>5) <p>*dmft score: used to assess dental caries prevalence and treatment needs.</p>
Orthodontic Audit	<ul style="list-style-type: none"> • 17 people with a unilateral cleft lip and palate (UCLP) born 2016. Records available for 14. 2 refused images and one had multiple DNA's  <p>Scotland performed well vs UK scores for Children born with UCLP in 2016. 50% were grade 1&2 (good facial growth)</p> <p>Records for 14/17 patients was 82% a good result and as high as any cleft centre from the 2012-2014 cohort.</p>

Evaluation forms were completed by 30 participants (94%).

- All respondents highlighted that the event was 'highly relevant' (87%) or 'mostly relevant'(13%) to their job role.
- All respondents rated the presentations as 'excellent' (77%) or 'good' (23%).
- 97% felt that the event should be repeated annually.

Following the success of this event and as outlined in the networks quality improvement strategy, CCS plan to repeat this event annually to support continuous quality improvement within cleft care in Scotland.

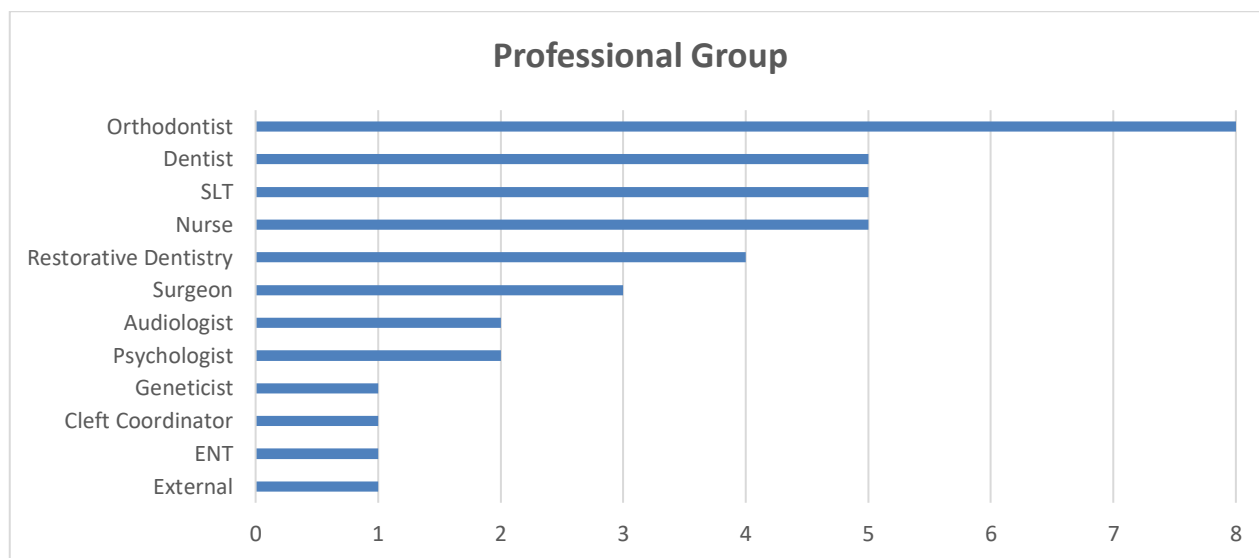
Annual Education Event

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

This 2023 event took place on 23rd November in Perth with the theme 'Care of Newborn Babies and Their Families with a Cleft'. In addition to presentations on this theme from the

multidisciplinary team involved in cleft care, the event also offered clinicians the opportunity to share their latest research in cleft care and professional group networking. In the dedicated time for professional networking, each specialty group were invited to feedback on their priorities for cleft care to inform development of the networks strategic workplan.

In total, 38 people attended the event with the professional group mix noted below:



Evaluation forms were completed by 22 participants (58%):

- Attendees were asked to score each presentation. The results reflected that the majority of attendees agreed that the 'delivery' and 'content' of each was well received and to a high standard.
- 21 respondents 'strongly agreed' (73%) or 'agreed' (23%) that the event had 'increased their knowledge of the care provided to newborn babies with a cleft and their families.'
- 21 respondents 'strongly agreed' (68%) or 'agreed' (27%) that the event offered attendees 'the opportunity to network and learn from each other'.
- 20 respondents said the event would be 'very effective' (23%) or 'effective' (68%) in changing their practice.

Some of the ways attendees stated this event would change their practice included:

- Be more aware of impact of cleft on patients and carers and the patient experience.
- Increased awareness of referral pathways to Adult Psychology and reinforces management of referrals and pathways.
- Being more aware of what other members of MDT are doing.
- Education of students.
- More aware of genetic implications of cleft, increased knowledge of speech and babble advice, both will improve quality of care I provide for patients.

The feedback received, including suggested topics for future events, has been considered by the Steering Group to inform planning for future education events.

Stakeholder Survey

A stakeholder survey was shared in March 2024 to gather feedback from people who currently work within, are involved in, or are impacted by the Network. The survey was shared with 57 stakeholders and 11 responses were received (19% response rate).

While the number of responses was disappointing, a lot of positive feedback was received and highlights the value added by the network:

- 82% responses 'strongly agreed' or 'agreed' that the network provided a structure to make service improvements in cleft care.
- 73% responses 'strongly agreed' or 'agreed' that the networks service development activity adds value to cleft care.
- 83% responses from staff 'strongly agreed' or 'agreed' that the networks education offering adds value to cleft care.
- 36% responses 'strongly agreed' or 'agreed' that the networks audit and continuous quality improvement activity adds value to cleft care.

The survey was also an opportunity for stakeholders to share feedback on network strengths, network challenges, areas for improvement and the priorities for the next few years. The responses are summarised below:

Strengths	Areas for Improvement
<ul style="list-style-type: none"> • Forum for interdisciplinary communication and collaboration for cleft clinicians across Scotland. • Adds value through service development by gathering data and developing/reviewing pathways. • Adds value through the Annual Education Event. • Adds value through audit and continuous quality improvement activities through support to gather/report data and provides data to inform practice/improvements. 	<ul style="list-style-type: none"> • Greater clarity on distinction between CCS and National Surgical Service, and respective roles and responsibilities. • Delivers quality improvement for patients.
Suggested Future Priorities (3-5 years)	Network Challenges/Threats
<ul style="list-style-type: none"> • Development of patient related outcomes. • Support patient/family understanding of patient pathways and ensure patients are well informed. • Continue to facilitate multi-disciplinary collaboration. • Evolve digital technology and continue to evaluate outcomes. • Continue education days. • Improving clinical network related provision in the boards. 	<ul style="list-style-type: none"> • Ensuing network can provide a clear role and purpose given developments in recent year such as National Surgical Service and data entry into CRANE. • Demonstrating and recognising the added value to patients. • Finance. • Ensuring face to face opportunities for interdisciplinary communication and collaboration for cleft clinicians.

The feedback received will be considered by the Steering Group and an action plan to support areas for improvement will be developed.

Looking forward – 2024/25

Some of the key activities planned by the Network for the year ahead include:

- Undertake a scoping exercise to identify any areas where care may not be equitable, understand the reasons for this and try to address any gaps.
- Undertake a scoping exercise to identify where the burden of care is highest and if there is anything further that can be done to reduce this.
- Develop detailed patient pathways which outline minimum expectation of care for each specialty.
- Host education session(s) for Health Visitors to increase their knowledge on supporting children with a cleft.
- In conjunction with speciality groups, the surgical service and patients, identify what additional patient information would be helpful and support the development of this.
- Monitor compliance against the pathways for audiology, dentistry and orthodontics.
- Review and benchmarking of quality assurance data collected across cleft care (via CRANE and local audits) and continue associated research for quality improvements and innovations in cleft care.

Finance

The itemised costs and total spend for 2023/24 is given below:

Detail Code	Spend
Exhibition/Conferences	
• CCS Audit Event	£779.20
• CCS Annual Education Event	£1,410.01
TOTAL SPEND	£2,189.21

Risks & Issues

Despite the activity undertaken by the network to successfully implement the action plan and address the recommendations of the review, it is still not known whether designation of the network will be continued. Should de-designation be recommended, further work will need to take place to understand the impact of this and to identify what areas of activity would need to continue and how these could possibly be delivered.

The Lead Clinician continues in the transformational clinical lead role until 30th September 2024 pending the outcome of network designation. Should designation of the network continue agreement on clinical leadership from October 2024 is required to ensure the delivery of the network's business plan.

Due to the current financial constraints within NHS Scotland, Networks have been asked to hold events virtually to reduce costs to local NHS Boards for staff travel. CCS members value the

opportunity network events offer to meet with staff from a range of specialties supporting cleft care working across Scotland. They have requested that both the annual audit event and annual education planned for 2024-25 take place in person. Should the events take place virtually network members feel they would be of limited value, offer little return from a networking perspective and therefore attendance will be greatly impacted.