

Cleft Care Scotland

Annual Report

2024/25

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This document has been prepared by NHS National Services Scotland (NSS) on behalf of the Cleft Care Scotland (CCS). Accountable to Scottish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. CCS is a collaboration of stakeholders involved in care of people born with a cleft lip and/or palate who are supported by an NSS Programme Team to drive improvement across the care pathway.

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

Following a review of the network, 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 recommendations from the review. During 2023/24 the action plan was agreed and an overview of the work undertaken by the network was presented to the review team in February 2024.

In June 2024, the National Specialist Service Committee (NSSC) approved the recommendation from NSD to continue the network until 30 September 2024, following which the network model would be 'stepped down'. The significant work undertaken by the network through the implementation of the action plan and the progress made addressing the review recommendations was acknowledged, however it concluded that the '2024-2027 CCS Strategic Plan did not include enough development and limited supporting evidence for a full network model to continue'.

The recommendation for the network to establish a 'stepped down' approach was in line with a range of network and leadership models that were being considered at that time as part of the Scottish Government's review of national networks. The network undertook some exploratory work with NSD and stakeholders to consider the activities that could continue within the 'stepped down' model however this was paused pending further information on the recommended models from Scottish Government. From 1 October 2024 given the 'stepped down' model, there was no longer dedicated time for a Lead Clinician or Project Support Officer Support and Programme Manager support was reduced.

In light of the ongoing Scottish Government review of national networks, planning has been adapted to focus on core priorities and ensure continuity of essential services. We await further guidance to inform future strategic development. With the concept of what the 'stepped down' model would look like, CCS agreed two priority areas:

- An in-person annual education event would take place
- Explore with network members/NSD what a 'stepped down model' will encompass and how this will be resourced.

The 2024/25 business plan agreed in May 2024 was therefore reviewed to reflect the changing landscape for both CCS and networks generally with all objectives that remained on the workplan being achieved.

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.

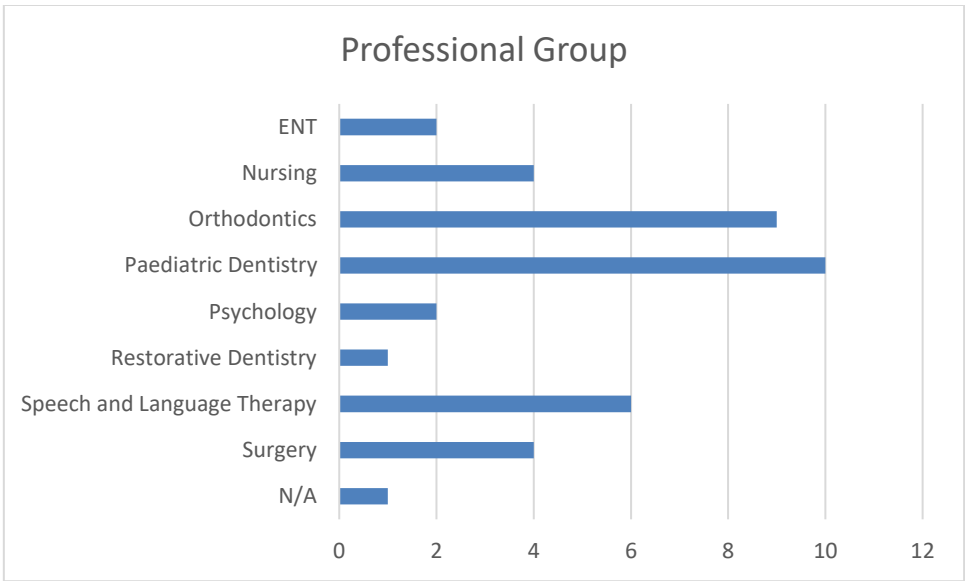
Highlights

Annual Education Event

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

This 2024 event took place on 21 November in Perth with the theme ‘Reducing the Burden of Care’. In addition to presentations on this theme from the multidisciplinary team involved in providing cleft care, the event 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 was invited to feedback on what activities they thought would be important to continue in the ‘stepped down’ network model.

In total, 39 people attended the event with the professional group mix noted below:



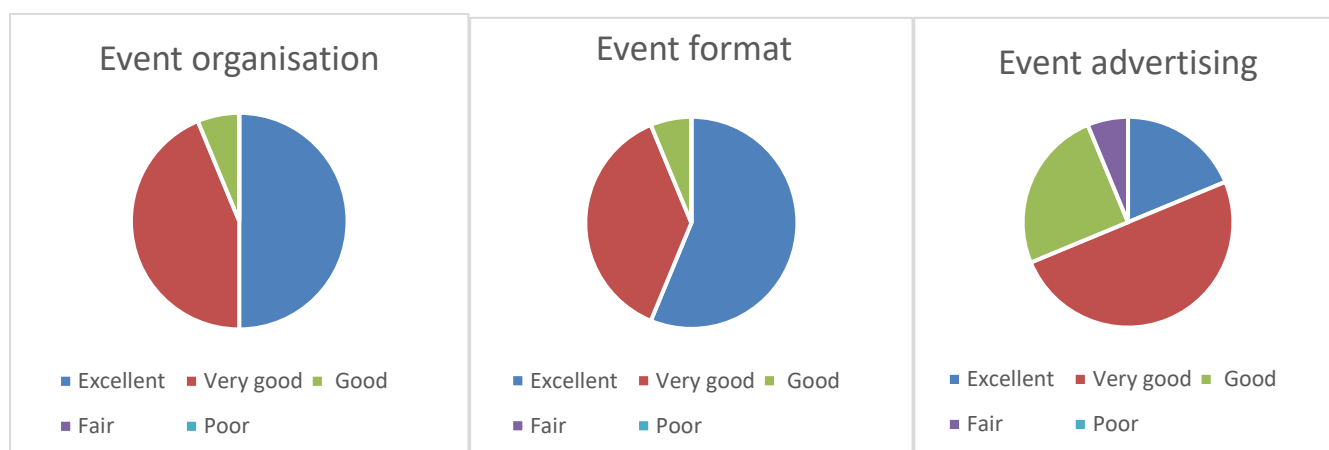
Evaluation forms were completed by 16 participants (41%):

- All respondents 'strongly agreed' (88%) or 'agreed' (12%) that the event had met its objective by giving them 'a broader understanding of reducing the burden of cleft care'.
- Attendees were asked to score each presentation. The results reflected that the majority of attendees agreed that the 'delivery' and 'content' of each was 'excellent' or 'very good'.
- When asked what people valued most about this event, respondents highlighted the benefit of networking face to face with colleagues across the multidisciplinary team supporting cleft care across Scotland.
- All respondents said the event would be 'very effective' (19%) or 'effective' (81%) in changing their practice.

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

- Continue to adapt practice in the context of reducing overall burden of care and also considering the reduction in resources across the NHS and education.
- Less people in clinics, maybe trainees need to swap into clinic rather than all stay for duration.
- Provide more dental health education at Nurse Run Clinic.
- Much more conscious of impact of time off school for appointments, much more aware of patients wishes to be informed prior to their appointments
- Review patient experience

When asked to rate the event for event organisation, event format and event advertising the responses were:



All respondents said the learning from this session would contribute to their CPD requirement for revalidation and they would recommend the event to their colleagues. The event provided 234 hours of CPD to health care professionals.

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

Informing the 'Stepped Down' Network Model

In July 2024 the network was informed of the final outcome of the review and they were asked to influence how the network would continue as a 'stepped down' model. Two extraordinary meetings of the Steering Group were held in August 2024 to discuss possible activities that could continue moving forward. As the outcome from the Scottish Government review was anticipated imminently there was agreement to await further information of what they expected from a 'stepped down' network rather than implementing a model which may need redefining again in the short term.

While the outcome of the Scottish Government review was still awaited discussions took place with professional groups via email, meetings and at the annual education event to inform what activity stakeholders would like to see continue. Stakeholders agreed that the priorities should be the delivery of the annual programme of education/networking through delivery of the audit event (May) and education event (November), and to continue the Cleft Care Scotland website to communicate with patients/families/health care professionals.

In October 2024, the Patient Engagement Group met to discuss what the 'stepped down' model would mean for the network's patient engagement activity. The group agreed that instead of maintaining an ongoing patient engagement group, a more flexible approach would be beneficial. This could involve forming specific groups as needed, allowing for targeted engagement based on specific issues or developments. It was felt this approach could lead to more meaningful contributions from patients who are relevant to the discussions at hand, ultimately enhancing the engagement process. The Steering Group were supportive of this plan and the patient engagement group was subsequently disbanded.

The Cleft Care Scotland/Cleft Surgical Service Liaison Group was established in 2023 to support efficient and effective working across Cleft Care Scotland and the National Cleft Surgical Service for Scotland and provide a forum to inform and support delivery of cleft care within Scotland. With the network moving to a 'stepped down' model the Steering Group agreed that this group should also be disbanded.

Looking forward – 2025/26

Due to ongoing review of national networks, networks have only been asked to plan business as usual activity for Quarter 1, 2025/26.

The network will hold an Audit Event in Perth on 29 May 2025 where specialty leads from across Scotland will present the audits of five-year-olds born in 2018 focussing on key findings, successes and challenges, and future actions. The event will also provide the opportunity for stakeholders to share their latest research in cleft care and include dedicated time for professional networking.

The CCS Steering Group is continuing to support communication across the network and meet governance requirements pending the outcome of the review of networks providing clarity on the 'stepped down' model.

Finance

The itemised costs and total spend for 2024/25 is given below:

Detail Code	Spend
Exhibition/Conferences	
• CCS Annual Education Event (21 November 2024) refreshments	£114
TOTAL SPEND	£114

Risks & Issues

Cleft Care Scotland has continued with some activity following the recommendation to 'step down' and awaiting further guidance to inform future strategic development. Network members were disappointed following the outcome of the network review despite the activity undertaken by the network to successfully implement the action plan and address the recommendations of the review. The transformational clinical lead role ended on 30 September 2024 and the network continues with interim leadership arrangements to support continuing activity pending the outcome of the Scottish Government review of networks.