

CEN Network

Annual Report

2024/25

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This document has been prepared by NHS National Services Scotland (NSS) on behalf of CEN. 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. The CEN Network is a collaboration of stakeholders involved in care of paediatric patients with exceptional healthcare needs and their families, who are supported by an NSS Programme Team to drive improvement across the care pathway. All content is available under the [Open Government Licence v3.0](#) except for graphic assets and where otherwise stated.

Introduction

The National Managed Clinical Network (NMCN) for Children with Exceptional Healthcare Needs (CEN) was launched in 2009 with the aim of strengthening specialist services for children with exceptional healthcare needs in Scotland.

CEN was commissioned to achieve this through improved networking across the multi professional and multi-agency teams across health, social care, education, third sector and service users and through the development of education and support initiatives to support this specialist group of children and their families.

CEN assessment criteria

The six impairment categories used for assessing the children and young people are:

- learning and mental functions
- communication
- motor skills
- self care
- hearing
- vision

A child or young person (up to the age of 19) is defined as having exceptional healthcare needs if they:

have severe impairment recorded in at least 4 categories together with enteral/ parenteral feeding

OR

have severe impairment recorded in at least 2 categories and require ventilation/CPAP

AND

the impairments are sustained and ongoing or expected to last for more than 6 months.

Current Position

Interim leadership arrangements have been in place during 2024/25, ensuring continuity of activity while formal recruitment is aligned with national review outcomes. 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, prioritising three actions for completion by the end of March 2025 while continuing their business as usual activity in the 2024/25 workplan.

The actions prioritised for CEN were:

Priority Action	Progress
Develop a strategic work plan for 2025-2028.	• A scoping survey was sent out which had 16 responses from professionals and 7 from families. The results informed the strategic planning day. • A strategic planning day took place on 12 December 2024, 20 delegates attended on the day from a range of Boards and

	organisations. This was a face-to-face event at a free venue which worked well for discussion and participation. • 2 presentations on current 'hot topics' in the field were arranged: 1) Implementation of UNCRC for children with exceptional healthcare needs and 2) The Compass Transition App. • Feedback from planning sessions was collated and should be used to create patient pathways and priorities for children with exceptional healthcare needs and their families. • Further discussion and refinement will be undertaken with the steering group.
Deliver an updated data plan outlining data to be collected and purpose.	• The strategic planning day took place on 12 December 2024, see the update above. In addition to the above update on the planning day, there was discussion around what data would be required to support the suggested improvements. • It was agreed that at the next data group meeting the members would further discuss what data will be needed and how that can be collected. • Data reports have been pulled by IMS on all the children on the CAS for each Board. This has been split by Board of residence and Board of treatment. This was sent to Boards to confirm it is an accurate depiction of their case load and note any numerical changes.
Produce and deliver communication plan for the updated 'What to Expect' and 'Emotional Impact of Tube Feeding' Patient Information leaflets.	• Draft leaflets were presented to the steering group in 2024, small changes were suggested, and stakeholders took actions to provide the necessary text. This has now been agreed. • The distribution of the leaflets was discussed, and it was agreed there should be a launch event for these leaflets in the new year and then make them available on the CEN website. • Link to leaflets will be distributed once the launch event has taken place.

All business as usual objectives on the 2024/25 workplan were completed.

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

Stakeholder Survey- Strategic Planning

Prior to the strategic planning day, a scoping survey was sent out to all stakeholders, there was 16 responses gathered. Respondents represented, NHS Greater Glasgow and Clyde, NHS Lothian, NHS Lanarkshire, NHS Forth Valley, NHS Highland, NHS Tayside, NHS Dumfries and Galloway, NHS Borders and NHS Western Isles. Professions respondents represented can be seen in table 1 below.

Team Leader/ Service co-ordinators/ Lead Nurse	6
Nursing	6
Speech and Language Therapy	2
Paediatrics Team	1
Chief Midwife	1

Table 1- Professions of survey respondents.

The network broke down the patient pathway and asked what the enablers, blockers and change ideas for improvement at each stage of the pathway are. A breakdown of the stages of the pathway discussed can be seen in the figure below.

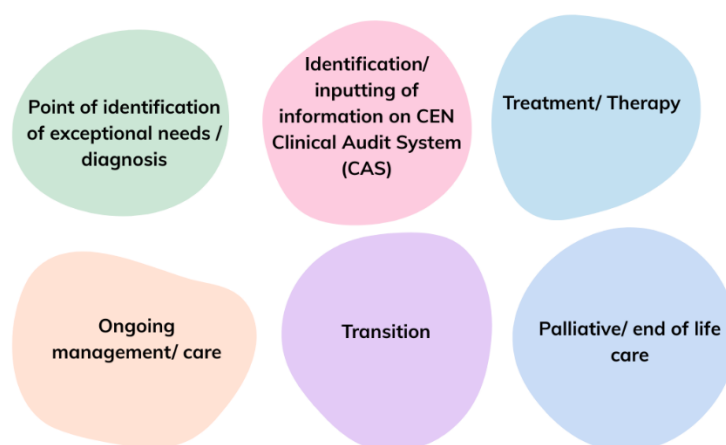


Figure 2 – Pathway stages from the stakeholder survey.

The findings from the survey were presented back to attendees on the strategic planning day to inform discussion on the day, to develop finalised priorities and change ideas for the Network going forwards.

Strategic Planning Day

The strategic planning day was held face to face on 12 December 2024 at the Craighalbert Centre in Cumbernauld. There were 20 delegates in attendance representing 6 Boards and 3 organisations. The previous lead clinician was also in attendance on the day. The purpose of the day was to establish the current priorities and concerns for the patient group. We broke down the patient pathway into three sections; point of identification/diagnosis (recognising that some children never receive a diagnosis), ongoing management and transition. Suggested change ideas from each of the sessions are summarised in Figure 1 below.

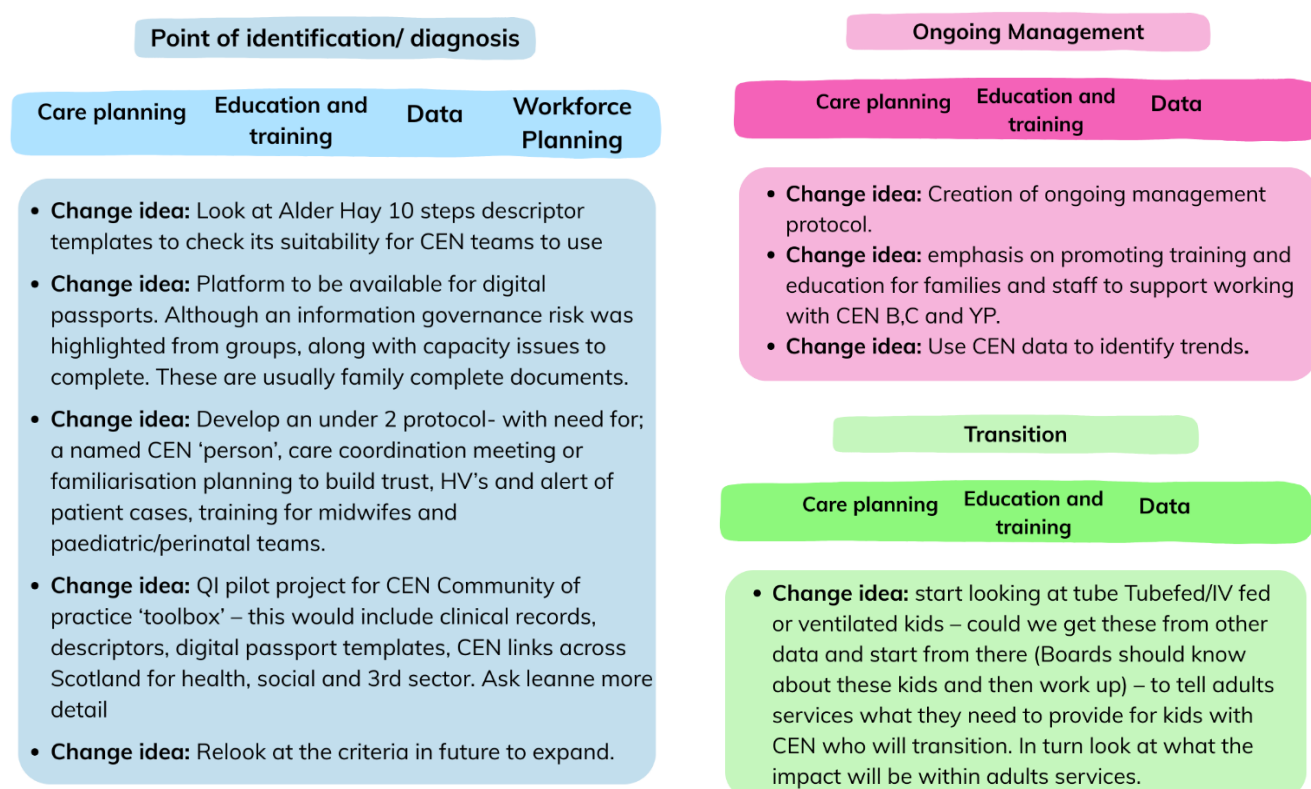


Figure 1 – Change ideas from the strategic planning day

A plan for actioning these change ideas and priorities has not yet been progressed with stakeholders due to the ongoing Network review by Scottish government. It was envisioned that the findings would inform production of a new Network business and data plan, but this has not been produced yet.

Additionally on the day there was two presentations on 'hot topics', one on the implementation of the United Nations Convention of the Rights of the Child (UNCRC) and the impacts of this on children with exceptional healthcare needs. The other was from ARC Scotland on the COMPASS transition app and how to use this tool within Boards.

CAS Data Review

The Network identified through early strategic planning activity that there were some unexplained variations in prevalence of children entered from each health board on the National Clinical Audit System (NCAS). A piece of work took place to calculate the percentage of the population in each Board area who were on the NCAS.

Initial analysis of CAS data has highlighted potential variation in recording practices across Boards. Work is underway to validate and refine these datasets to ensure they accurately reflect service demand and inform equitable planning. A full table of population figures from this project can be seen in Appendix 1.

A current all of Scotland CAS report can be seen in Appendix 2.

Patient Information Leaflets

CEN worked throughout the year to finalise two new patient information leaflets, titled 'What to expect when your child has exceptional needs' and 'The emotional impact of tube feeding'. These were updated from previous leaflets which were written in 2017 with the help of the Network Experts by Experience family group. The leaflets went to the Network Steering Group on 7th November 2024 where comments were received. There was a slight delay to getting the amended text in for this however the documents were amended in early 2025 and finalised. The network will launch the leaflets in quarter one of 2025-26 and they will be available on the CEN website.



Figure 3 – New CEN leaflet front covers.

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.

- Distribute the new patient information leaflets to Boards and the website.
- Establish method of gathering feedback on the leaflets. To establish the need and use of them within Boards

Finance

The network operated within its allocated budget in 2024/25, focusing on low-cost, high-impact activities such as virtual education and digital resource development.”

Risks & Issues

The network recognises the importance of maintaining national coordination in areas such as education, clinical guidance, and quality improvement. Continued support will be essential to sustain these benefits for patients and professionals

Appendix 1 – CAS population figures

Board	Total 0-19 Population	Number of patients on CAS	Number of patients on CAS (by residence postcode) per 1000 of population
NHS Ayrshire and Arran	73512	57	0.78
NHS Borders	22704	21	0.92
NHS Dumfries and Galloway	27639	25	0.90
NHS Fife	78391	58	0.74
NHS Forth Valley	64240	31	0.48
NHS Grampian	124969	20	0.16
NHS Greater Glasgow and Clyde	245507	150	0.61
NHS Highland	62286	51	0.82
NHS Lanarkshire	144517	112	0.77
NHS Lothian	188794	149	0.79
NHS Orkney	4291	5	0.53
NHS Shetland	5158		
NHS Tayside	84424	81	0.96
NHS Western Isles	No Logged CYP on CAS		

Appendix 2 – All Scotland CAS Report

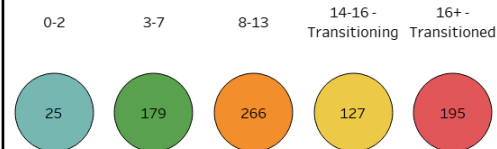
Children with Exceptional Healthcare Needs

National Managed Clinical Network

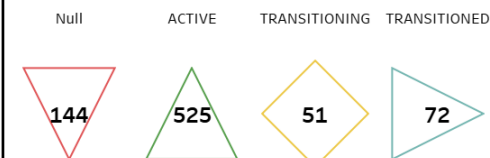


Total Patients on CAS **792**

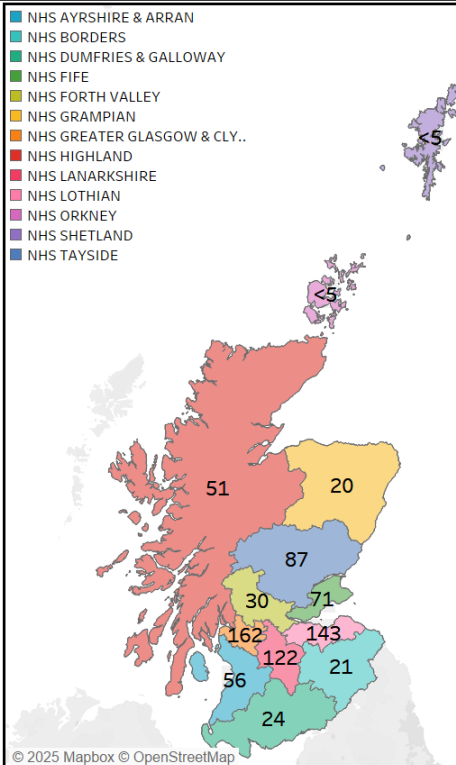
Age



Patient Status

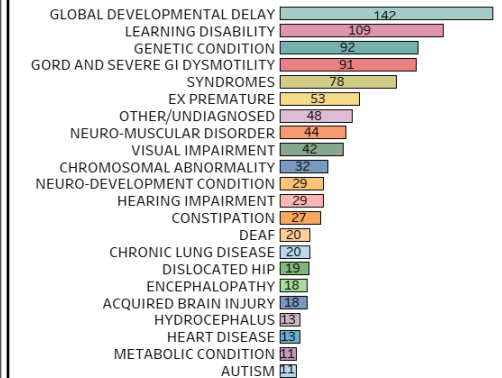


Patient Status: "Active" depicts a patient who is currently active within the system while "Null" has no status against them. The network encourages patients to have a status of either "Active", "Transitioning", "Transitioned", "Moved out of Scotland" or "Deceased". This means the network can accurately forecast patients transitioning into adult services.



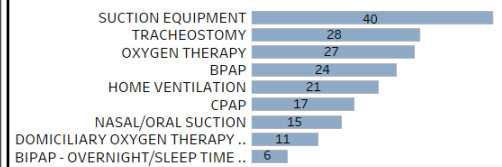
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Top Conditions



*Syndromes are a collection of the most common conditions, this combines: Cri-Du-Chat, Retts, Otahara, Apert and Cornerlia De Lange. Ex Premature - this highlights children within the neonatal category that have been born with complications but not been given an official diagnosis yet.

Respiratory Interventions



If you would like to be sent a health board specific report, please get in touch: <mailto:nss.imsrequests@nhs.scot..>