

CEN Network

Annual Report

2025/26

The Network is supported by a dedicated programme team within Public Services Delivery Scotland consisting of:

- Shelley Heatlie, Programme Manager

This document has been prepared by the National Services Directorate (NSD) of Public Services Delivery Scotland (PSD Scotland) on behalf of the Children with Exceptional Healthcare Needs Network (CEN). Accountable to Scottish Government, PSD Scotland 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. CEN is a collaboration of stakeholders involved in the care of children with exceptional healthcare needs who are supported by a PSD Scotland Programme Team to drive improvement across the care pathway.

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

A child or young person (up to the age of 19 years) is considered to have exceptional healthcare needs where they have severe impairment recorded in at least four of the following categories, together with enteral or parenteral feeding:

- Learning and mental functions
- Communication
- Motor skills
- Self-care
- Hearing
- Vision

OR

have severe impairment recorded in at least two of the categories above and require ventilation or CPAP;

AND

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

Current Position

Activity during 2025/26 reflected national prioritisation set during a period of review. Alongside evolving national planning arrangements, Managed Clinical Networks were asked to focus activity on a number of core priorities.

Looking ahead, and consistent with the direction set by the Health and Social Care Service Renewal Framework and Scotland's Population Health Framework (June 2025), and recognising that CEL 29 (2012) *Managed Clinical Networks: Supporting and Delivering the Healthcare Quality Strategy* remains the extant mandate for Managed Clinical Networks, [Network Name] will build on its established approach by undertaking a Strategic Needs Assessment to inform the 2026/27 workplan and ensure priorities remain aligned to population need, current pathways, available data and stakeholder perspectives.

The priorities for CEN in 2025/26 were:

Priority Action	Progress
Produce a priority action paper following the strategic planning work in 2024/25	• A paper has been produced and considered by the network steering group and actions identified which will inform the 2026/27 workplan.
Host a launch event for the CEN family information leaflets	• This action is complete; recording is on the CEN website.
Progress with updating the CEN Turas Modules	• This project began but was impacted by the merge with NES, carried forwards to 2025/26 business plan. See more detail below.

All business-as-usual objectives on the 2025/26 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

1. Strategic Planning

Throughout the reporting period CEN continued to work with stakeholders to summarise the findings from the recent strategic planning work. The aim was to produce a list of priority improvements for this group of patients. Most of the improvement areas identified related to education and communications or data. Both the Education and Communications group and the Data groups worked together to develop this based on the feedback from the strategic planning day. The draft list was then discussed at the most recent Network steering group. This work will inform be further developed via the Strategic Needs Assessment project being carried out in 2026/27.

2. CEN Patient Information Leaflet Launch

A launch event was held in December 2025 for two CEN leaflets that had been revised and published in May 2025. The launch event highlighted the importance of the new family information leaflets, [The Emotional Impact of Tube Feeding](#) and [What to Expect When Your Child Has Exceptional Healthcare Needs](#). Developed with input from parents and carers, the resources combine practical information with lived experience, helping families better understand and navigate the challenges associated with caring for a child with exceptional healthcare needs.

Speaking at the launch event, family representative Allan Peattie reflected on his own experiences as a parent and highlighted the importance of resources developed **"with families, for families"**. He described how families can often feel overwhelmed when first navigating complex healthcare needs and how the leaflets help bridge the gap between clinical information and lived experience. He also emphasised the importance of supporting parents and carers to feel informed, connected and confident in their role as partners in care.

The leaflets provide practical guidance, emotional support and reassurance for families, while also signposting to sources of information, support and professional advice. Together, they aim to ensure that families feel better supported, understood and less isolated throughout their care journey.

The launch event also provided an opportunity for families, clinicians and stakeholders to discuss the resources and their role in supporting children with exceptional healthcare needs and their families across Scotland.

3. CAS Data

In 2025/26, a significant piece of work was undertaken to review the completeness of the information in the National Clinical Audit System (NCAS) to inform strategic planning work. This work has now been completed, and Health Boards have now returned to updating their systems and receiving quarterly reports on their data. A full all Scotland CAS report can be seen in Appendix 2.

A piece of work is underway to review the quarterly reports to ensure they are useful and effective for Boards this will continue into 2026/27.

4. Turas Modules Review

Turas provides a platform for providing online training resources for health and care professionals. Work commenced during 2025/26 to review the three current CEN Turas modules, including Communication, Co-ordination and Compassion. During the review period, discussions were undertaken with relevant PSD Scotland colleagues regarding future arrangements for module governance, quality assurance and alignment with wider e-learning standards. To allow these arrangements to be fully considered, it was agreed that the review would continue into 2026/27.

The Network was satisfied that the existing modules remained current and suitable for use during this period, and work will continue during 2026/27 to support their ongoing development and alignment with future requirements.

Uptake figures as of April 2026 for the CEN Turas modules can be seen in Appendix 3.

5. Consent and Capacity Leaflet

The CEN Consent and Capacity Leaflet was reviewed and updated during the reporting period to ensure that the information remains current and accessible for children, young people, families and professionals. The updated leaflet was approved by the Network Steering Group in February 2026 and forms part of the wider suite of CEN information resources available to support those navigating exceptional healthcare needs. The leaflet will be available via the CEN website during 2026/27.

Looking forward – 2025/26

Throughout 2026/27 the CEN Network will:

- CEN will undertake a Strategic Needs Assessment to inform the workplan for the next 3-5 years and agree clear, evidence-based, and measurable outcomes.
- CEN will deliver three online e-learning sessions.
- CEN to continue Turas module review, linking in with NES.
- CEN will work with IMS to update quarterly CAS report template.

Finance

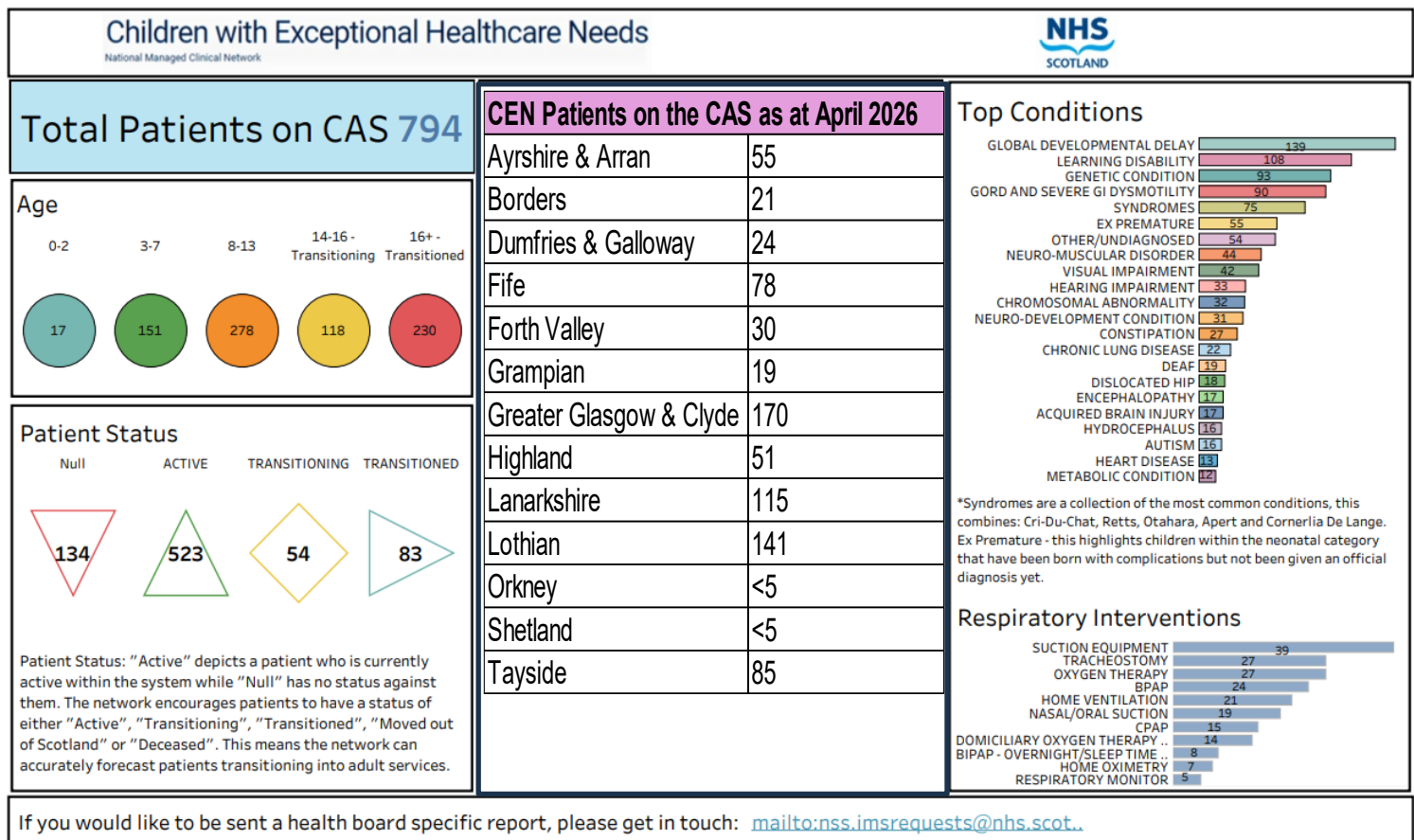
The Network is funded through Public Services Delivery Scotland and operated within its approved budget during 2025/26.

Appendix 1 – Website Statistics

CEN Website Statistics - April 2026	Visitors	Views
Home	8,241	25,248
Talking Mats	2,860	3,909
A Place for the Family	1,423	2,011
About CEN	1,418	1,542
Contact Us	993	1,147
Useful links	963	1,059
Professionals zone	921	1,040
CEN Clinical Audit System - For Professionals	909	988
CEN Steering Group	903	936
CEN Criteria	868	1,040
Communicating with Children	837	970
Past Events & Conferences	836	989
News & Events	801	888
Education	794	869
Parent information leaflets	792	940
National Managed Clinical Networks	619	683
CEN Clinical Audit System - For Patients & Families	586	657
Meet the Team	568	609
Planning for Care in the Future	537	567
Transition	495	516
Social Security Scotland - Special Rules for Terminal Illness	478	528
News	476	514
Mental Health and Wellbeing	405	423
Experts by Experience Family Engagement Group	403	422
Young Family Members	395	411
Educational Videos	389	410
Events & Conferences	375	402
Grandparents	373	390

A visitor is each unique person visiting the page, views is the total number of times the visitors have accessed each page.

Appendix 2– All Scotland CAS Report



Appendix 3– Turas Feedback Statistics

CEN Turas Modules	Communication	Co-ordination	Compassion
Total module completions	502	304	352
Number of learners who provided feedback	109	65	54
% of learners who rate the modules 4 or 5 stars (out of 5)	97%	92%	92%
Comments from learners	Excellent, learned a lot, great to reflect on practice and make improvements.	Very comprehensive course, raised awareness of the issues being faced by families.	Really thought provoking, great insight into how practice can affect parents/carers experiences