

1 Welcome, Apologies & Introductions

Mrs. Catriona Johnson, Associate Director, NHS National Services Scotland, welcomed attendees to the annual performance review (APR) for the Children with Exceptional Healthcare Needs (CEN) Network. Introductions took place and apologies noted.

2 Purpose

Mrs Johnson explained that the APR was part of the annual performance management and review cycle of CEN as a commissioned network. She noted the purpose of the meeting was to review what the network had achieved over the past year and identify priorities and actions for the network going forward.

Mrs Johnson advised that she was representing National Service Division (NSD) as commissioner of the network, noting that NSD were accountable to Scottish Government for the effective commissioning and performance management of all networks designated through national commissioning.

3 Minutes and Outstanding Actions from previous APR

Mrs Johnson confirmed the position of the network in terms of the previous APR; minutes were ratified by the Steering Group on 19th November 2020, and noted that there were outstanding actions which would be discussed during the meeting.

4 Current service agreement position

Miss Heatlie, Programme Manager, NHS National Service Scotland stated that the current Service Agreement was in place from 1st April 2020 until 31st March 2023. Mrs Johnson confirmed that a review of the Network was due and confirmed that because of the COVID-19 pandemic Board Chief Executives had agreed with NSD to suspend routine reviews of Networks. Furthermore, NSD were in the process of completing a transformation project. A recommendation arising from that work was for NSD to establish a dedicated team that would be responsible for all reviews as a means to enhance objectivity. That team was being recruited and Mrs Johnson confirmed that CEN members would be informed in due course, about when the network would next be reviewed.

5 Annual Report - Summary of delivery against core objectives (2020/21)

Mrs Johnson thanked the Network for its Annual Report and invited Dr MacFadyen to provide an update on the achievements of the network over the reporting period.

Dr MacFadyen acknowledged the dedication of CEN members, its subgroup leads and the NSD team for its work in progressing the workplan over the past year.

Dr MacFadyen provided the following updates:

Strategic Planning Event

This had taken place on 5th November 2020 and a Learning Needs Analysis completed which informed plans for the network's Education Strategy. Moreover, this work forged links and opportunities for collaborative working with the Paediatric End of Life Care Network (PELiCaN) and a joint education event was being planned on Loss and Bereavement for the Spring of 2022.

E-Learning Modules

Dr MacFadyen spoke to the ongoing work to create a suite of three TURAS modules for the Network under the headings of Communication, Compassion and Coordination. Dr MacFadyen thanked the Leads of the development groups for their input to this project. Mrs Johnson noted that other

networks planning to embark on a similar exercise would benefit from the CEN experience and asked what lessons could be shared.

Dr MacFadyen made specific reference to the dedication of all involved and highlighted the importance of there being a wide variety of professionals and organisations involved in the development of education materials. She confirmed that new links had been established with third sector organisations as a direct result, and the focus for CEN had been on finding common ground in terms of communication across services.

Care Pathways

Dr MacFadyen confirmed that work had begun on the revision of the CEN Care Pathways; transition and early years being the first two to be progressed. She stated that the revised pathways would move away from healthcare defined pathways to ones that focussed on the child and family.

Dental Care

Dr MacFadyen suggested that she would like for CEN to incorporate dental care into the workplan and had been working to engage with colleagues in dentistry for future projects. Mrs Johnson noted that there is a National Dental Advisor within NHS National Services Scotland who might be able to provide advice or signpost to a suitable resource.

Action: Mrs Johnson to provide contact details to Dr MacFadyen.

NHS Inform

Mrs Johnson confirmed she was aware that this work had not progressed and asked Miss Heatlie to refer to Dr Anna Lamont, Interim Medical Director, NHS National Services Scotland, for an update via email.

Action: Miss Heatlie to contact Dr Anna Lamont.

Post meeting note: Mrs Johnson raised this with Dr Lamont opportunistically. Dr Lamont advised that the project had stalled due to lack of capacity within NHS 24 and she would engage them again with a view to seeking endorsement at a more senior policy level.

CAS Data

Miss Heatlie confirmed that Boards had completed the inputting of data to the Clinical Audit System (CAS) and that a final update for the Child Health Commissioners was booked for December 2021.

Mrs Johnson congratulated the network for achieving a complete data set and asked how this data will be used. She noted that Scottish Government had sought data about children on long term ventilation during the pandemic and at that time only NHS Fife had a complete data set so this was a significant step forward.

Discussion took place around the difficulties faced by families and clinicians when children move between localities and/or services whilst retaining medical equipment and the potential for CEN data to support improvement in this area. Ms Susan Walls, Service Manager, Contact, commented on family feedback that described transition to adult services as 'fragmented', noting that CEN data would hopefully prove beneficial to both families and the NHS.

Mrs Johnson commented that NSD had begun a scoping exercise on Long Term Ventilation however this had stalled due to COVID-19 impact on capacity. She suggested CEN could collate data from across Scotland on what happens with medical equipment during movement between Health Boards, and when transitioning to adult services.

Action: Consider equipment for 2022-23 CEN workplan

Dr MacFadyen confirmed that as the network's family stakeholder group had recently expanded this could be progressed and stated that the inclusion of the experience of Community Children's Nurses would be pivotal to the project.

Mrs Johnson commented that Dr MacFadyen had identified a large amount of work for the network and noted that the current network model focusses on a small number of patients with rare conditions or complex needs. She acknowledged that the current mandate may constrain network potential. Mrs Johnson asked for comment from Mr Peter Campbell, CEN Steering Group Chair and Associate Nurse Director of Children's Services, NHS Lothian, who confirmed the importance of continuous review of the landscape the CEN network operates within to ensure it can have the greatest impact. Dr MacFadyen outlined the intention to include Medical Physics representation, and collaborate effectively with a range of Networks where there were obvious synergies e.g. National Neonatal Network. She also introduced Ms April Emmott, Senior Nurse for Paediatrics, NHS Highland, who provided details of work undertaken to address problems NHS Highland had experienced in relation to equipment for children being repatriated

Mrs Johnson confirmed her appreciation of the work completed by the network.

6 Finance

Mrs Johnson noted that there had been an over-spend in the network budget due to the costs incurred from the development of the TURAS e-learning modules. She confirmed this had been underwritten from the wider NN budget.

Miss Heatlie stated that all events and meetings had taken place on-line and therefore no expenses, in relation to this activity, had been incurred.

7 Risks/Issues

Mrs Johnson noted that there continued to be a risk to achieving network objectives caused by continuing restrictions and responses to the Covid-19 pandemic.

8 Looking ahead – endorsement of annual workplan

Miss Heatlie confirmed the plan to implement the role of CEN CAS Champion in all Health Boards. She also stated that work on a quality improvement project on the use of Near Me was ongoing, as was the development of the CEN Education Strategy.

Mrs. Johnson thanked and commended the network on its achievements despite the challenges of the year. She noted that clear plans were in place for the progression of work, and confirmed that she was able to endorse the workplan for 2022/23.

9 Any other business

None.