

Minutes

Children with Exceptional Healthcare Needs (CEN) Network

Annual Performance Review (APR) Meeting

27th Aug 2020, Microsoft Teams

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Present:

Dr Una MacFadyen	CEN Lead Clinician	NHS National Services Scotland
Mrs. Debbie McGirr	Clinical Nurse Manager (CEN Steering Group Chairperson)	CHAS
Mrs. Catriona Johnson	Programme Associate Director	NHS National Services Scotland
Mrs. Alexandra Speirs	Senior Programme Manager	NHS National Services Scotland
Mrs. Claire Lawrie	Senior Programme Manager	NHS National Services Scotland, Information Management Services
Miss Shelley Heatlie	Programme Manager	NHS National Services Scotland
Mx Christopher Williamson	Programme Support Officer	NHS National Services Scotland

1. Welcome and Introductions

Mrs. Catriona Johnson, Programme Associate Director, NHS National Services Scotland, welcomed everyone to the meeting; formally noting this as the first Annual Performance Review (APR) Meeting with Dr Una MacFadyen as Lead Clinician for the CEN Network. Mrs. Johnson noted her thanks to previous Lead Clinician, Dr Susan Buck, for her contribution to the Network and wished Dr Buck well for the future.



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2. Outstanding Actions from last APR

It was noted that the minutes from the previous Annual Performance Review, held on 22 October 2019, had been approved internally within NHS National Services Scotland, however had not yet been ratified by the Steering Group (SG). It was noted that the approval process would take place at the SG after this APR.

Action: CEN Steering Group to ratify the minutes of the APR held on 22 October 2019.

Mrs. Johnson stated that the Service Level Agreement for the Network had been updated as per previous APR action and will be in place from March 2020- March 2023.

It was noted that a group met internally to discuss CEN's partnership with Kindred and the Exceptional Families' Project. Miss Heatlie confirmed she had visited the Kindred offices in February 2020 and agreement was made on how the partnership would progress as well as exploring the Kindred family database. Unfortunately, in light of the Covid-19 pandemic it was noted that many of the opportunities highlighted during this meeting would now be on hold. Miss Heatlie stated that a professionals' education event had been organised to take place on 9 September 2020 by Kindred. This event would look at results of the Covid-19 data project Kindred and CEN had completed together regarding the effects on CEN families who were shielding during the Covid-19 pandemic. Miss Heatlie confirmed that representatives from Kindred would continue to attend the CEN Steering Group Meetings and vice versa as well as promoting each other on websites and social media.

Mrs. Johnson emphasised the need for transparency and robust governance where CEN is identified as a partner in any funding bids. The steering group should have sight of final proposals before they are submitted. She commended recent efforts to improve collaborative working, including a Kindred site visit and the Covid-19 research project.

Mrs. Johnson took the opportunity to reflect, as Commissioner, on the progress of the Network and acknowledged that disruption within the NNMS support model had hampered progress. She thanked Mrs. McGirr for working with Dr Buck to prioritise delivery of key objectives. Mrs. Johnson confirmed that there was now a full support team in place for the Network and this was the right time to review the direction and focus of the CEN Network. She suggested that the Network should consider whether to reinstate the Continuing Care Framework as an objective as this had been a major strategic focus that had recently stalled. Mrs. Johnson highlighted the need for strategic priorities to be agreed at the Strategic Planning Session that was planned for October.

Action: CEN should agree strategic priorities going forwards

Dr MacFadyen suggested that a key piece of work would be to clarify the CEN criteria and Network scope for stakeholders, recognising that there would be families who do not meet the CEN criteria but do have significant healthcare needs. The Network should consider what it can offer to these families e.g. website signposting to resources. It was suggested that Kindred or other third sector agencies may also be able to help this cohort of vulnerable families. Mrs. Johnson suggested that the Network create a visual to clearly identify the cohort that the Network was established to support as a priority.

Action: Creation of a visual aid to highlight the focus of the network.

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3. Current service agreement position and review timetable

Miss Heatlie confirmed that the Service Level Agreement had been updated and that this covered the period 1st April 2020 to 31st March 2023.

Mrs. Johnson stated that the Network was last reviewed in 2017 and that, given the changes in the support team, she proposed to delay the next review (currently scheduled to report in March 2021) in order to give the network the opportunity to flourish again with the full support of a network team and a refreshed work plan. She highlighted the synergy between the CEN Network and the Paediatric End of Life Care Network (PELiCaN) and noted there was a need to understand the implications for the Network and its stakeholders of this emerging strategic landscape.

Action: Miss Heatlie to map network strategic landscape

4. Summary of delivery against core objectives (2019-20)

Mrs. Johnson invited Mrs. Debbie McGirr, Chair of CEN SG, to give an overview of success and challenges for the CEN Network over the past year.

Mrs. McGirr stated that the website was more user-friendly and commended Miss Heatlie and Mx Williamson, Programme Support Officer, NHS National Services Scotland, on their work in this area. Mrs. McGirr acknowledged that the CEN Core Team now needed to address areas that require bringing up to date.

Action: Mx Williamson to review the CEN Website and highlight areas of development to Miss Heatlie and Dr MacFadyen.

Mrs. McGirr highlighted the work of Mrs. Claire Lawrie, Senior Programme Manager, NHS National Services Scotland, Information Management Services, on the CAS roll-out. She confirmed that two years ago the Network had just one Health Board inputting data for children with exceptional healthcare needs and as this work has been picked up by the Child Health Commissioners the network should continue to see more Health Boards entering data onto this system.

The work of the Exceptional Families Project and Kindred was also highlighted as a success of the Network. It was noted that this is ongoing and the challenge for the network will be around building robust communication and collaboration with Kindred with the tightening of the Terms of Reference for this project around communication and joint leadership/working.

Action: Update the Terms of Reference for the Exceptional Families Project with representatives from Kindred.



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Looking ahead, Mrs. McGirr suggested that the CEN Network should review the workplan at the Strategic Planning Day with a view to devising measureable outcomes. She also acknowledged previous challenges within the support team but also stated that the support from Commissioners had been extremely gratefully received and appreciated.

Action: Arrange CEN Network Strategic Planning Day with a view to reviewing the work plan for the network.

Communication and Engagement

Dr Macfadyen noted she would continue to represent the CEN Network on the Disabled Children and Young People's Group (DCYPAG), taking over from the previous Lead Clinician.

Action: Dr MacFadyen to represent the CEN Network on the Scottish Government DCYPAG.

Mrs. Johnson noted that the CEN Network were producing regular Newsletters for members and invited Mx Williamson to highlight how the Children and Young People's National Managed Clinical Network's (CYPNMCN) Twitter account is being used to provide information on the work of the CEN Network. Mx Williamson stated that at the end of January 2020 the Twitter account had 239 followers and by 24th August 2020 this had been increased to 478, with tweets engaging over 13,000 people in the month of August 2020. This showed that the Twitter account has an invaluable and growing role in the dissemination of information to children, families and clinicians.

Action: Mx Williamson to continue to promote the work of the CEN Network on the CYPNMCN Twitter account.

Mrs. Lawrie identified that within NNMS it had been agreed that each network would now need to develop a website strategy which would sit alongside the network's communications strategy. The purpose of the website strategy was noted as assisting networks to plan and identify any changes to websites over the year, allowing for a more strategic and measurable approach.

Action: Mrs. Lawrie to work with Miss Heatlie to devise the Website Strategy for the CEN Network.

It was noted that there was a need for the CEN network to re-engage with families as this had decreased over time. It was noted that an 'experts by experience (EBE)' survey would shortly be sent out which would aim to increase family involvement. Dr MacFadyen had suggested other existing groups which might be useful to contact to increase family involvement.

Action: Dr MacFadyen to make contact with groups in Scotland with a view to engaging them with the work of the CEN Network and CEN to send out EBE survey.

Discussion took place around the possibility of parents being able to 'share their story' or 'ask an expert' on topics relating to CEN. It was noted there may be agencies such as PAMIS (Promoting A More Inclusive Society) or the Scotland Yard Project who could help with this. It was noted that the Kindred Facebook page was also somewhere parents could ask questions or seek advice, where Kindred pass on relevant questions to CEN. It was suggested that CEN could consider identifying designated advisors for use in these scenarios (for example Long Term Ventilation).

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Mrs. McGirr highlighted that the Scottish Government DCYPAG as a contact for increasing involvement and communication and it was also suggested the Child Health Commissioners have become an increasingly important stakeholder group who may be able to assist.

Action: Stakeholder engagement to be discussed within the Strategic Planning Day.

Education and Training.

It was noted that the network education strategy was in need of updating and would be done following the strategic planning day. It was identified that Ms Anne Wilson, Head of Development, Children's Health Scotland, would take over as Lead of the Education Group. Mrs. Johnson noted thanks to Mrs. Beth Frank, the previous lead, for her huge commitment and contribution to the CEN Network.

It was highlighted that the network's seven learn pro modules were due to be updated this year. It was hoped a more streamlined version of each could be created on TURAS. It was noted there was a requirement to find out who would be able to access these modules on TURAS as the current modules are used by third sector and students. It was noted that Together for Short Lives have e-learning modules that can be accessed by everyone so may be a good to find out more on the practicalities.

Action: Education Group to review and update the LearnPro Learning Modules currently available via the CEN Website.

It was identified that CEN previously had an objective to create an e-learning module for GP training on caring for children with long term conditions. It was noted that this piece of work had not been progressed but did fit under the remit a number of national networks. Mrs. Johnson noted that there may be an option for this piece of work to be facilitated by NSD and would progress this through the correct channels.

The network was congratulated for the quality of the education event which was held on 27th February 2020 in Tollcross, Glasgow, it was noted that the team had pushed boundaries by covering topics such as ethics within the day, Mrs. Johnson commended all speakers.

Data and QI.

Mrs. Johnson noted the QI strategy for the network required updating and invited Mrs. Lawrie to provide an update.



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Mrs. Lawrie noted there had been some key developments for CEN CAS in the period, noting that the need to collect written consent had been removed and implied consent had been granted for all networks. It was also noted that Child Health Commissioners had taken on the roll out of CAS as a quality improvement project so should lend weight to the network's aim to get all Boards populating the system. It was noted that IMS can provide Boards with reports and data back from the CAS system once data has been uploaded, they can also enter a "dump" of information on the system to get them started using CHI numbers.

Mrs. Johnson acknowledged the variation between Health Boards in terms of how they operate but also confirmed the importance and the value of CAS data for Health Boards when planning services and understanding their future needs in terms of human and other resources.

5. Finance

Mrs. Johnson noted that the CEN Network had overspent on their budget, with prior agreement, during the year 2019 – 2020 due to the Network Education Event. This had been underwritten by the NNMS.

6. Risks/Issues

- COVID 19 impact on services.

The impact of Covid-19 on network activity is a continually changing landscape, initially in March 2020 a decision was made to postpone all network meetings however, this has now been reinstated. In light of a second wave there may be a negative impact on network activity and the availability of network members to participate in work. Regular Covid-19 impact assessments are written by the network Programme Manager and reported to senior management in NSD.

7. Looking Ahead

Mrs. Johnson suggested giving the network an opportunity to develop their work-plan over the next three months and then to revisit this after the mid-year report around November 2020, with a view to endorsing the new updated work-plan on behalf of Commissioners at that time. Miss Heatlie stated that the Strategic Planning Day would be held on 29th October 2020 and all workplans and strategies would be updated following this ready to report back to commissioners towards the end of the year.

8. Any Other Business

N/A

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Date of Meeting	Agenda Item	Owner	Description
27-Aug-20	2	CEN Steering Group	CEN Steering Group to ratify the minutes of the APR held on 22 October 2019.
27-Aug-20	2	CEN Steering Group	CEN should agree strategic priorities going forwards
27-Aug-20	2	CEN Steering Group	Creation of a visual aid to highlight the focus of the network.
27-Aug-20	3	Miss Heatlie	Map network strategic landscape
27-Aug-20	4	Mx Williamson	Review the CEN Website and highlight areas of development to Miss Heatlie and Dr MacFadyen.
27-Aug-20	4	Miss Heatlie	Update the Terms of Reference for the Exceptional Families Project with representatives from Kindred.
27-Aug-20	4	Miss Heatlie / Dr MacFadyen	Arrange CEN Network Strategic Planning Day with a view to reviewing the work plan for the network.
27-Aug-20	4	Dr MacFadyen	Represent the CEN Network on the Scottish Government DCYPAG.
27-Aug-20	4	Mx Williamson	Continue to promote the work of the CEN Network on the CYPNMCN Twitter account.
27-Aug-20	4	Miss Heatlie / Mrs Lawrie	Devise the Website Strategy for the CEN Network.
27-Aug-20	4	Dr MacFadyen	Make contact with groups in Scotland with a view to engaging them with the work of the CEN Network and CEN to send out EBE survey.
27-Aug-20	4	CEN Steering Group	Stakeholder engagement to be discussed within the Strategic Planning Day.
27-Aug-20	4	CEN Education Group	Review and update the LearnPro Learning Modules currently available via the CEN Website.



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