

**Children with
Exceptional
Healthcare Needs**
National Managed Clinical Network

Children with Exceptional Healthcare Needs (CEN) ANNUAL REPORT 2019-20

Lead Clinician: Dr Susan Buck

Programme Manager: Shelley Heatlie

Programme Support Officer: Chris Williamson

Data Analyst: Louise Smith

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1. Executive Summary

During the 2019-20 reporting period the Children with Exceptional Healthcare Needs Network (CEN) has had another challenging year due to staff resource issues within the core Network Team, the network was without a Programme Support Officer (PSO) for a number of months and there were changes in the Programme Manager position. However, new members of the core team; Programme Manager and PSO were successfully appointed in February 2020 and priority network objectives have been progressed to mitigate risk to planned activity and work plan outputs.

The network has successfully delivered on a number of key achievements through effective communication and engagement with CEN stakeholders, clinicians and professionals from health, social care and third sector care settings. This has included the continued support and engagement with the network from families and carers. Other activities included; hosting an annual education day, Kindred Exceptional Families Project professionals' events and peer review meetings.

The network has facilitated two peer review meetings which had a focus on "Bowel & Bladder Dysfunction" and "Communication". The Peer reviews provided an excellent opportunity for health and care professionals to network, share best practice and also have the opportunity to discuss workplace scenarios through case discussions.

The CEN NMCN has continued to progress activities as set out in its education strategy; in particular, to raise awareness and promote excellence in care for CEN and the diverse range of professionals and care providers that look after this patient and family group.

The network held a successful national conference at the Tollcross International Swimming Centre, Glasgow in February 2020. The theme for this event was "Communication, Coordination and Compassion". This event was focussed on what matters to a CEN family and what affects their day to day life. Talks incorporated a parent and patient speaker which provided a first-hand insight into care received. Feedback from this event was extremely positive and is noted later in this report.

During 2019/20 the network continued to collaborate and work in partnership with Kindred to inform and engage with families through the work of the CEN network and the advocacy service provided through Kindred. This has been a valuable partnership for CEN NMCN, Kindred, CEN stakeholders and families; especially through the innovative work undertaken within the Exceptional Families Project. CEN NMCN would like to take this opportunity to congratulate Kindred on their achievements to date, which includes the continued drive to support and advocate for all families, children and young people within their care.

The Lead Clinician has continued to engage, consult and promote the CEN NMCN vision to lead stakeholders during this reporting period. This has included influential discussions and facilitation of presentations at senior stakeholder meetings; including wider CEN networking activities. These engagement activities have included key stakeholder organisations including the Royal College of GPs (RCGP), Child Health Commissioners (CHCs), Allied Health Professionals (AHPs) and third sector organisations.

The network continued to engage with Scottish government, responding to relevant consultations to ensure the voice of children with exceptional and complex healthcare needs are heard. The Network Lead Clinician also continued to attend the Disabled Children and Young People's Action Group (DCYPAG) on behalf of the network.

CEN NMCN continues to improve its communication channels and provision of resources for children, parents and professionals; in particular raise wider awareness about the needs of children and young people with exceptional and complex healthcare needs. The network actively pursues best practice and incorporates this governance within the development of evidence based clinical pathways which align to the national Getting It Right for Every Child (GIRFEC) principles and promote the need for a consistent approach in pathways of care for children with exceptional needs and their families.

2. Introduction

The CEN NMCN is a well-established national managed clinical network for Scotland, first commissioned in 2009. Children with Exceptional Healthcare Needs (CEN) are a sub group of children and young people (CYP) with multiple long-term health conditions; defined by the complexity of their care needs and requirements rather than diagnosis and requiring co-ordination of service provision to support their care. The number of children in this category has historically been low, however growing evidence through regional data gathering and local reporting highlights that these numbers are higher than initially expected.

The following CEN assessment criteria was developed in order to define a child or young person who has exceptional healthcare needs. There are six impairment categories used for assessing the children and young people which 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 four categories together with enteral/ parenteral feeding

OR

have severe impairment recorded in at least two categories and require ventilation/ Continuous positive airway pressure

AND

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

The nature of supportive resources required for this patient and family group is usually technical, resource intensive, high cost and highly sensitive. Providing the best standards of care requires expertise and seamless management of complex care programs including care pathways. This is frequently delivered by multiple professionals and practitioners from NHS, social care and third sectors. As a result of the complexity of care required for this patient group, there is a significant impact on parents and carers and professional teams in meeting the continuing care needs for these children and young people. A key priority for the CEN NMCN is to ensure a family centred approach is robustly embedded within the remit of the network activity.

The number of CEN patients in Scotland is currently unknown as there isn't a complete central registry of patients. The CEN Network have been working to populate a patient registry (Clinical Audit System (CAS)) and are currently working with NHS Board Child Health Commissioners to complete a quality improvement project which aims to have all Boards inputting on to the CAS by December 2020.

3. Report on Progress against Network Objectives in 2019-20

National networks have agreed core objectives that reflect the Scottish Government's expectations for managed clinical networks, as described in CEL (2012) 29¹. The network's core objectives are:

1. Design and ongoing development of an effective Network structure that is organised, resourced and governed to meet requirements in relation to SGHSCD Guidance on MCNs (currently CEL (2012) 29) and national commissioning performance management and reporting arrangements;
2. Support the design and delivery of services that are evidence based and aligned with current strategic and local and regional NHS planning and service priorities.
3. Effective Stakeholder Communication and Engagement through design and delivery of a written strategy that ensures stakeholders from Health, Social Care, Education, the Third Sector and Service Users are involved in the Network and explicitly in the design and delivery of service models and improvements.
4. Improved capability and capacity in the care of children with exceptional healthcare needs through the design and delivery of a written education strategy that reflects and meets stakeholder needs.
5. Effective systems and processes to facilitate and provide evidence of continuous improvement in the quality of care, including the development of a written quality improvement strategy.
6. Generate better value for money in how services are delivered.
7. To improve the equity of assessment, planning and delivery of interagency care planning for CEN within community settings, through the development of a National Children and Young Peoples Continuing Care Framework for Scotland, as identified within the recommendations of the Review of CEN NMCN in 2016.

This report gives an overview of progress against these objectives in the year 2019/20.

During the reporting period there were significant staffing changes within the Network Team, which resulted in some anticipated network activity being postponed or re-scheduled due to limited capacity to progress work. See [Section 3.1.1](#) for more details.

As noted in 2018-19 annual report, NSD commissioners recommended that the network prioritise and revise the timelines of the CEN strategic workplan and extend the review period by one year. The Network continued to work towards this revised strategic workplan in the 2019-20 period due to the continued staffing issues being faced.

The network is pleased to report that due to the resilience within the National Network Management Service (NNMS) and the commitment and dedication of CEN members and the support of commissioners the network has progressed the following programme of activity.

3.1. Effective Network Structure and Governance

The communication and engagement, education and quality improvement strategies required to be updated and ratified by the steering group, however, these strategies were not reviewed in the reporting period due to the re-scheduling of the Strategic Planning Day (due to staffing and then the COVID-19 pandemic). This work will be carried forward to the next reporting year.

The Network has a service level agreement with NHS NSS in place from March 2020 until March 2023.

¹ Please see: https://www.sehd.scot.nhs.uk/mels/CEL2012_29.pdf

3.1.1 Network Core Team

As noted in Section 3 above, the CEN network had another challenging year in terms of staffing in the Core Network Team. Dr Susan Buck remained Lead Clinician throughout the reporting period 2019-20. Dr Buck's tenure will cease on 31st May 2020. The recruitment process for the next Lead Clinician commenced during the reporting period.

Miss Shelley Heatlie was appointed as Programme Manager in February 2020 and Christopher Williamson was also appointed in February 2020 as Programme Support Officer. Miss Louise Smith remains Data Analyst for the network.

[Appendix 1](#) - Picture and biography of the CEN Core Team

3.1.2 Network Steering Group

The Steering Group met three times in the reporting period and the fourth meeting was cancelled due to the COVID-19 pandemic. The Steering group remains chaired by Ms Debbie McGirr, Clinical Nurse Manager Children's Hospice Association Scotland (CHAS). During this reporting period, CEN NMCN were delighted to welcome parent representatives to the Steering Group; going forward this will be beneficial to discussions and progress.

Steering Group membership includes representation from clinical, nursing and social care settings in addition to members represented from third sector organisations and patient and carer representatives. The network management structure including the terms of reference for the Steering Group and sub-group membership ensures CEN meets the core principles of the national managed clinical networks, as defined in CEL (2012) 29.

The full list of current CEN Steering Group members is included in: [Appendix 2](#)

3.1.3 Network Sub- Groups

To enable the network to progress activity the network has three well established working groups, the work progressed by each of these groups is outlined in sections 3.1.3 (i) – 3.1.3 (iii) below.

3.1.3 (i) Education Group

Throughout the reporting period the CEN Education sub-group progressed the following work;

- reviewed and refreshed the approach taken to collect post event CEN evaluations from all network educational events
- The group have agreed to progress the care pathways project through a short life working group (SLWG) to action priority areas of activity in the next financial year, agreed to be discharge planning.
- Agreed to circulate in advance all future meeting dates and venues for this group to improve attendance and support progress of work activity
- Made progress with work on a Speech and Language digital resource through collaboration with leads from NHS Lothian
- Encouraged effective stakeholder representation
- Made steps to gather feedback from Nursing Leads on CEN LearnPro modules, however no feedback was received

All future meetings of the CEN Education sub-group were put on hold following the COVID-19 pandemic and its effects on frontline staff's availability to attend.

3.1.3 (ii) Data Group

Throughout 2019-20 the CEN data group progressed the following work;

- Continued to engage with Boards and teams about the value of CAS and roll out CAS training to Boards
- Consent – A description of this can be found in [Section 3.5.2 \(ii\)](#)
- Child Health Commissioners CAS Project – A description of this work can be found in [Section 3.5.2 \(i\)](#)
- Worked on calculating an all-Scotland projection of CEN figures from Fife, Orkney and Shetland data as this is the only complete Board dataset currently on CAS.

3.1.3 (iii) Third sector project with Kindred (Exceptional Families Project)

A summary of the work carried out by the EFP this year can be found in [Section 3.3.5](#).

3.2. Service Development and Delivery

3.2.1 Consultation Responses

During the reporting period the CEN network responded to two government consultations for the reformation of CAMHS and the new Transitions Bill. The network received comments from steering group members in order to coordinate a network response to both of these.

3.2.1 (i) Transitions Bill

Transition is widely recognised to be a challenging time for many young people with exceptional healthcare needs and their families. A national consultation took place in response to a proposed Private Members Bill by Johann Lamont, MSP.

A response to the consultation was made by CEN NMCN, after discussion with the Steering and Education groups, and a request for information to the wider network. Individual organisations e.g. CHC's and local Health Boards e.g. Ayrshire and Arran shared their response CEN NMCN. The Lead Clinician contributed to the response from the Disabled Children and Young People Advisory Group.

With wide recognition of the importance of Transitions, this topic was included in the annual conference timetable with a talk by Professor Michael Brown, Senior Fellow, University of Belfast.

3.2.1 (ii) Reformation of Children Adolescent Mental Health Services (CAMHS)

In recognition that the CAMHS was not meeting the needs of the population, a task force review was commissioned and led by Dame Dr Denise Coia. In 2019 Programme Boards were established to implement the Task Force recommendations. Dr Buck highlighted the needs of CYP with disabilities being understood and met in the redesign of the service to the DCYPAG. She was asked to represent these needs on behalf of the DCYPAG and met with Jacqueline Campbell, Head of the Programme Boards. The Programme Boards are committed to the service meeting the needs of 'at risk' groups, which included young people with disabilities. The meeting remit was how the work of the programme board could ensure meeting the needs of children and young people with complex needs, and to update DCYPAG on the work that the Taskforce carried out and establish a link to the ongoing work of the programme board.

Dr Buck asked for consideration of:

- Referral criteria for accessing services
- Diagnosis: Interpreting 'distressed' behaviour
 - Difficulties with communication.
 - Different presentations, including 'withdrawn' behaviour.
- Access-CYP with disabilities often struggle to access services/interventions
- Interventions often require longer timescales
- Families, especially siblings, often need specialised mental health interventions for role as carers.
- Inconsistent provision across Scotland.

3.2.2 Disabled Children and Young Peoples Advisory Group

The CEN Lead Clinician continued to contribute to the Disabled Children and Young People Advisory Group (DCYPAG), a group that has an important national role in liaising and guiding Scottish Government policy and engagement with stakeholders.

3.2.3 Care Pathways

The network hoped to begin the process of reviewing care pathways, however due to staffing and resource issues this was not progressed in the reporting period. It is hoped that individuals can be identified to assist with this project and work can begin on this in 2020-21 however the impacts of COVID-19 are likely to affect clinician's availability to take part in this.

It was agreed that discharge planning will be the initial priority area for updating.

3.2.4 Care Quality Indicators

The network hoped to review the care quality indicators to ensure they were fit for purpose, however due to staffing and resource issues this was not progressed in the reporting period, this will be completed in 2020-21. [Appendix 5](#) – Current CEN Care Quality Indicators.

3.2.5 CEN NMCN Strategic Planning day

In this reporting period CEN began to plan a Strategic planning day, the purpose of this event was to review the network's current strategic work plan in order to create a new focused and clear work plan for CEN moving forward. The strategic work plan currently in place was reduced in the 2018-19 period due to staffing and availability of resources. Now that the network has a full Core Team in place the workplan can be developed again to reflect current and future work which CEN will progress.

This event was scheduled for January 2020 however was rescheduled to 28th May 2020 to allow a more valuable event to be delivered due to increased planning time for new staff members. Unfortunately, this date regrettably also had to be re-scheduled due to the current COVID-19 pandemic. It is hoped that this event can now take place in Autumn 2020.

3.3. Stakeholder Communication and Engagement

3.3.1 CEN Website

In the reporting period the network took steps to refresh and update the CEN website; to ensure all information and available resources hosted on the webpage were easily accessible, up to date and accessed as the "go to resource" for families, network members and wider stakeholders. As there was a period of time through the year that there was no network PSO this was not completed as fully as hoped. Reviewing the CEN website to will remain on the workplan for 2020-21.

Some of the key statistics for the CEN website during the reporting period compare to the previous year are as follows;

	2019-20	2018-19
Total Page Views	11,141 views	12,305 views
Total Sessions	4,999 Sessions	6,144 Sessions
Most Visited Pages (1st-3rd)	Home, Continuing Care Packages, CEN Criteria	Home, Parent Information Leaflets, E-learning Toolkit

3.3.2 CEN Newsletters

To maximise the reach of the CEN NMCN and improve communication channels to all stakeholders the network has issued regular CEN newsletters during this period. All of these newsletters are available on the CEN website (<https://www.cen.scot.nhs.uk/latest-news/>) and are distributed to network mailing lists.



3.3.3 Social Media

3.3.3 (i) Twitter

During the reporting period it was decided that all NNMS Clinical Networks who were involved in the care of paediatrics would tweet through the same [@CYPNMCN](https://twitter.com/CYPNMCN) account (including CEN), meaning that tweets were more regular and creating a central point for stakeholders to find information. To differentiate between networks on this twitter feed each network uses individual hashtags; #CEN and #CENEvent2020 were the main ones used this period. This activity has been useful to promote key messages, good news stories from the CEN community and highlight key network updates. Statistics for both #CEN and #CENEvent2020 are detailed below;

Date	Tweets	Impressions	Profile Visits	New Followers	Total Followers
Dec-19	16	7948	86	8	220
Jan-20	6	5116	102	14	234
Feb-20	25	11900	330	30	264
Mar-20	61	19800	399	32	296

28th February -28th March 2020: Network Impressions on Twitter

#CEN – 439 impressions (number of times a specific tweet is delivered to people's stream)

#CENEvent2020 - 5791 impressions from 7 tweets

General Tweets on @CYPNMCN - 5192 impressions (general guidance links, activity/resource links and retweets)



3.3.3 (ii) Parents' Facebook

During the reporting period discussion took place whether CEN should mediate a private parents' Facebook page. Lengthy discussions took place around this and the technicalities of mediating a page of this kind. An options appraisal was created and a vote was held. It was agreed that due to NHS information governance and social media policies it would be too difficult for CEN to mediate this page so CEN would not be carrying on with this project. It was agreed however that Kindred or parents themselves could run this page, however it was agreed that it would need to be mediated by Kindred alone and not branded as the Exceptional Families project as CEN is a partner.

3.3.4 Distribution Lists

During this reporting period the network has taken the opportunity to streamline the CEN distribution lists to ensure accurate update of all CEN stakeholders; to ensure effective communication is in place and circulated to all key stakeholders to enable effective progress of the work plan.

3.3.5 Kindred: Exceptional Families Project (EFP)

The CEN NMCN has continued to work in partnership with the third sector advocacy organisation Kindred, in the delivery of the joint “Exceptional Families Project” (EFP).

During this reporting period, Kindred have supported families to engage with relevant statutory services to enable meaningful outcomes and support health and care needs of this specialist population group. The project delivered three informative events for healthcare professionals within NHS Ayrshire and Arran, NHS Borders and NHS Tayside.

Practitioners who attended the events fed back that the facilitated sessions had been very informative and beneficial. The following qualitative feedback was received;

“Fantastic training event which related to my work with families and the most relevant training that I have had in quite some time”

“Having the time to talk to other professional colleagues”

“Hearing about the parent’s questions thoughts and experiences”

“Hearing about CEN, I will definitely be joining the Network!”

Participants recommended these events should be rolled out throughout NHS Scotland to raise awareness more widely and support ongoing professional learning needs. These events will continue in 2020-21.

Kindred were successful with their bid to the Henry Smith Foundation for funding to continue work on the aims of the EFP project. The three year grant (approximately £40,000 per annum) which has been awarded to the organisation will be specifically to work across all CEN families within their service.

EFP incorporates the following objectives:

- Parents will feel less isolated by receiving ongoing contact from Kindred staff.
- Parents will feel more empowered and better able to speak for their child and feel confident in liaising with medical staff and making decisions about their medical care.
- Parents will feel better informed

The network will continue to promote the work of Kindred and EFP through the network’s engagement and communication channels which includes promotion through the CEN website, Twitter account and within stakeholder newsletters and at the CEN annual conference. This will ensure that the EFP is promoted nationally and going forward this has the potential of engaging with more families and multi-agency practitioners across Scotland.

A full report on the Exceptional Families Project throughout 2019-20 can be seen in [Appendix 3](#).

3.4. Education

3.4.1 Education Event

On 27th February 2020 the CEN network facilitated an annual education event titled “Co-ordination, Compassion, Communication” in Tollcross, Glasgow. The day was a great success, presentations were delivered from a range of professionals, a CEN young person and a parent as well. The goal of the education event this year was to encapsulate subjects that were important to everyday life as a CEN family. The event was attended by a number of professions across a wide range of specialties which are illustrated in Figure 1 below;

Children with Exceptional Healthcare Needs (CEN): Annual Report 2019-20

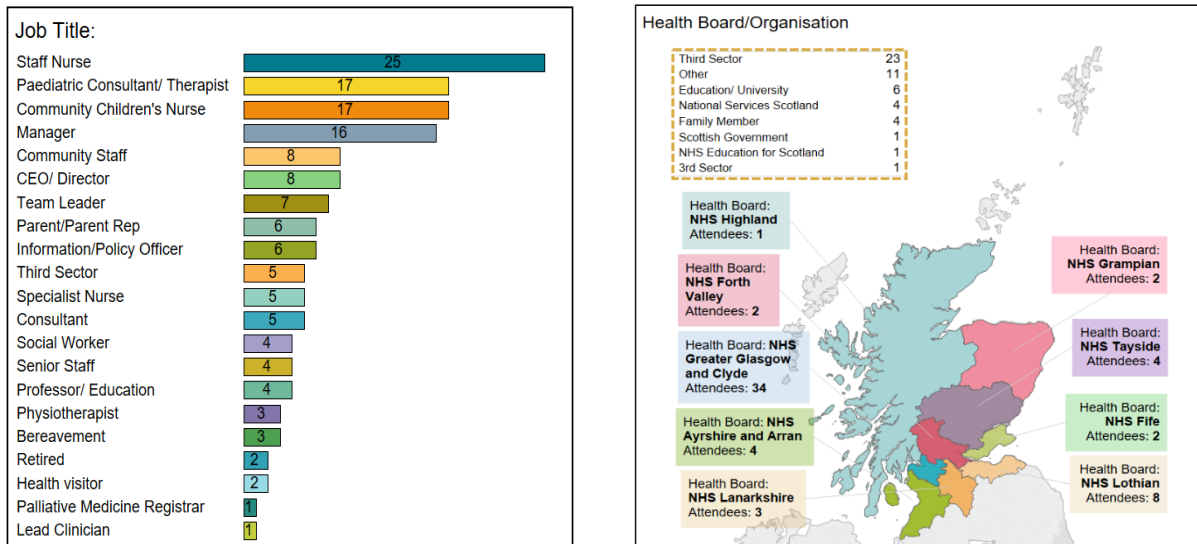


Figure 1 – Annual Event Attendees by Profession and Board

Feedback from the event highlighted that the main take away messages/ learning were around improved communication and engagement with patients and their families and increased information on what services are out there for use. This can be seen in Figure 2 below;

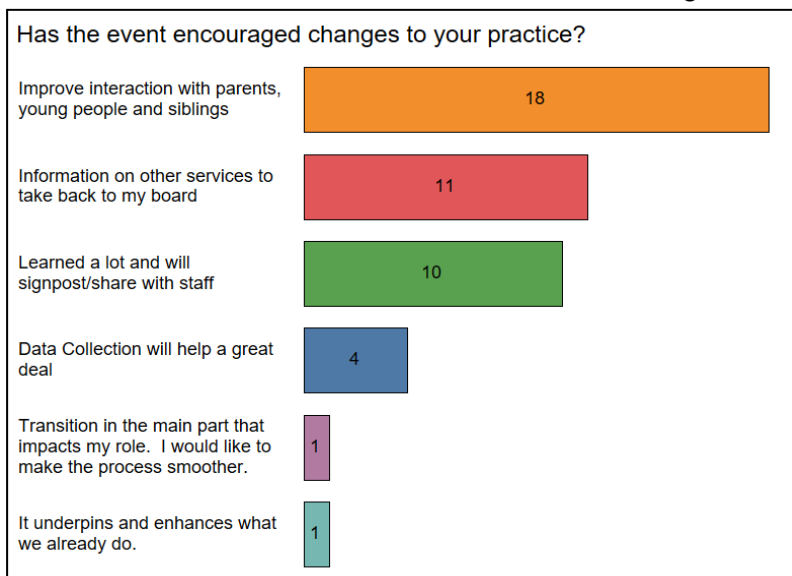


Figure 2 – What Change in Practice will be Made After Event?

It was also clear from feedback that delegates were enthused to sign up to CEN groups, CEN will be making contact with these individuals to sign them up;

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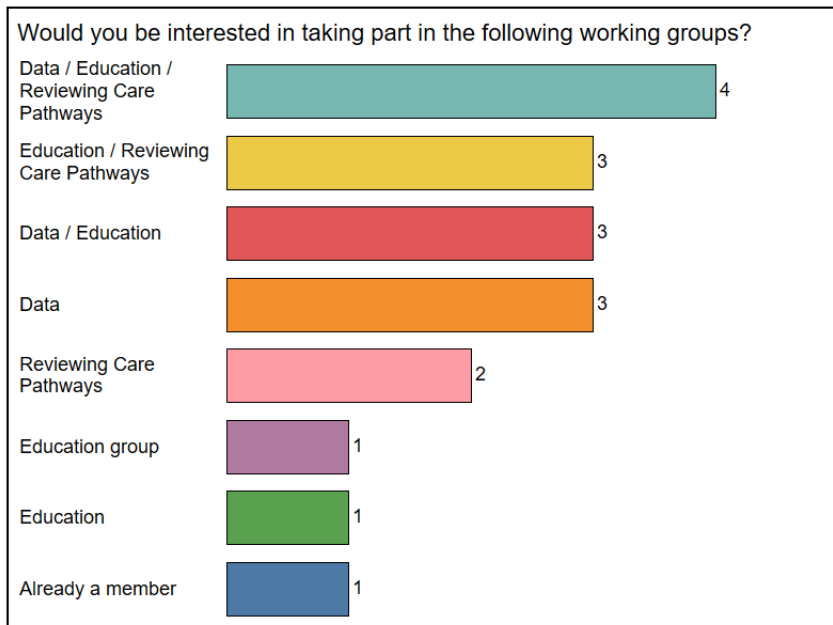


Figure 3 – CEN Group Sign up

From feedback it was clear that the presentations from both the CEN young person and CEN parent were exceptionally well received as can be seen from Figure 4 below

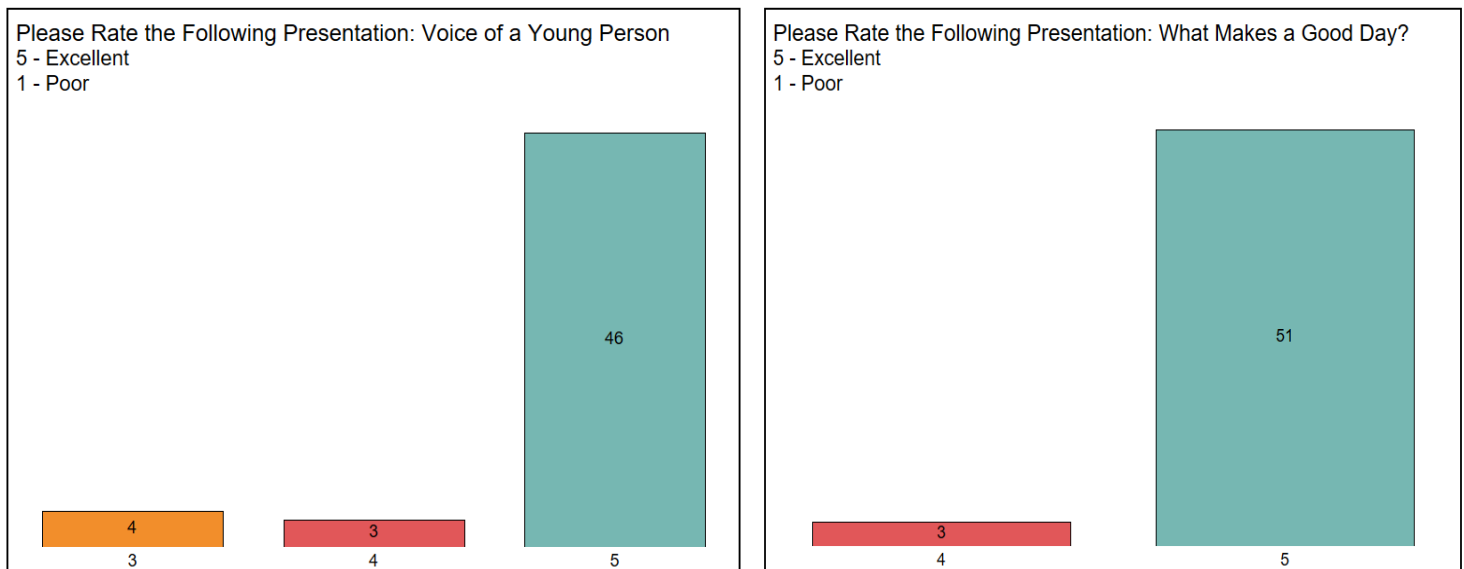


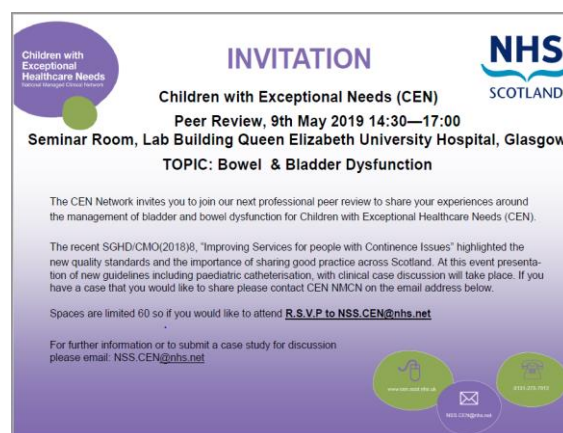
Figure 4 – Presentation Feedback

3.4.2 Peer Review Meetings

In this period CEN organised two peer review meetings which provide an educational forum for sharing good practice and enabling discussions to address the challenges faced in delivering excellence in care. As part of the Peer review sessions case reviews are used as a basis for discussion and learning.

3.4.2 (i) Bowel and Bladder Dysfunction Peer Review

This event took place in May 2019, it provided delegates with updates through presentations and discussions on new guidelines, paediatric catheterisation and clinical news. This session included professional clinical case discussions to benefit delegate learning and practice. This event included the importance of sharing good practice across Scotland to benefit patient care. There were some challenges in terms of Programme Support available when organising this event meaning that registration was negatively impacted and attendance was not as high as hoped.



3.4.2 (ii) Communication Peer Review

The second peer review took place in October 2019, this event enabled delegates to consider the fundamental importance of communication, and the need for every CEN child or young person to have the means and support to express themselves and their choices.

A key topic highlighted at this event was Article 12 of the UN convention on the rights of a child, which states “*all children have a right to be heard and to make choices in relation to their care*”. This is a key priority for CEN and Speech and Language Therapy (SaLT); to ensure all children including those who meet the CEN criteria are listened to and have a voice.

There was positive feedback following this event, delegate comments included:

“I need to learn the use of alternative communication that I can use as a doctor. Awareness that response does not necessarily mean understanding”

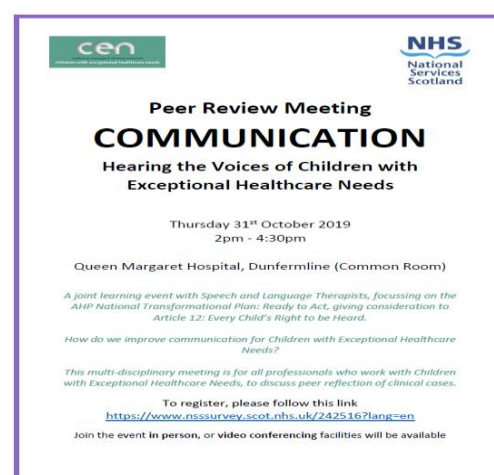
“Remembering to keep the child at the centre”

“It has reinforced the need for coordinated approaches with other team members. Reinforced need to revisit what is appropriate for them at the time”

“Confidence in communicating with children with additional needs”

“Top ten tips using non-verbal communication, excellent presentations”

The network values the feedback gathered from the peer review meetings; including proposals for future topics and discussions to benefit professional learning and improve patient care.



3.4.3 LearnPro Modules

The CEN network has seven LearnPro modules that are accessible to all to staff working in NHS Scotland, Children’s Hospices Across Scotland (CHAS) and third sector organisations. Figure 5 highlights CEN LearnPro activity between April 2019 and March 2020. These figures highlight that demand and completion for the CEN modules has been significantly greater for some than for others. To improve stakeholder engagement, the network will review the LearnPro modules during 2020-21 with the aim to creating one more streamlined module which covers all relevant areas.

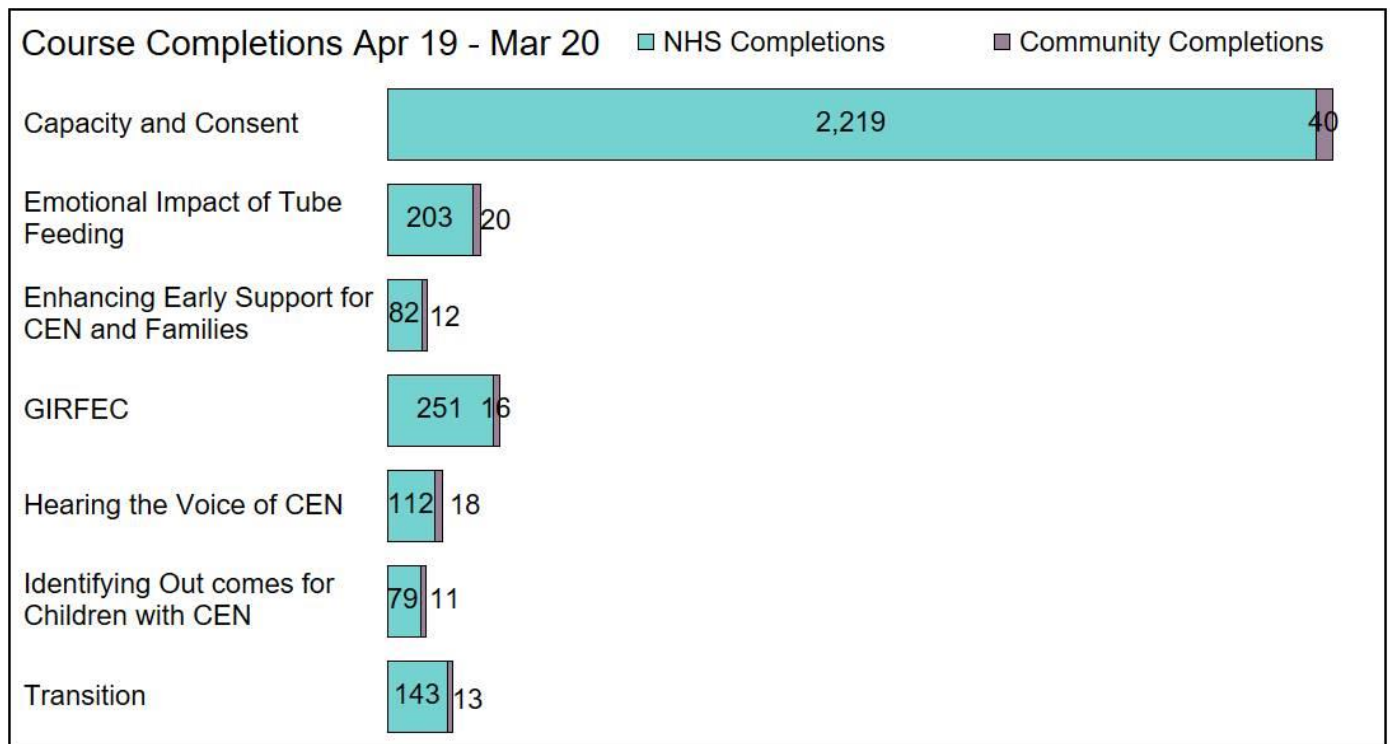


Figure 5 LearnPro Activity April 2019 –March 2020

3.5. Audit and Continuous Quality Improvement

3.5.2 Clinical Audit System

The network continued its plans to roll out the Clinical Audit System (CAS) throughout this year. To date, the CAS has 131 patients on the system with Fife, Orkney and Shetland being the only boards to have completed their data entry. This is an 82% increase on the previous annual report which report 67 patients on the system. Tayside and Lothian are in the process of collecting data with other boards being more stagnant. It is hoped that endorsement from the Child Health Commissioners will generate movement to collect data in the remaining locations as they have supported the work we are doing for the year ahead.

It is estimated that there are around 648 CEN children and young people in Scotland, this figure was extrapolated for each Board based on population figures and the full data set CEN received from NHS Fife. This allowed CEN to gain an estimated figure for all remaining boards. It is thought from conversations with Boards that this is likely to be an accurate figure to work towards in comparison to the previous estimate which came from the previous support needs system (SNS) in 2015. Figure 6 identifies the presumed number of children in each Board and the number currently on CAS. A CAS highlight report for the 2019-20 period can be seen in Figure 7.

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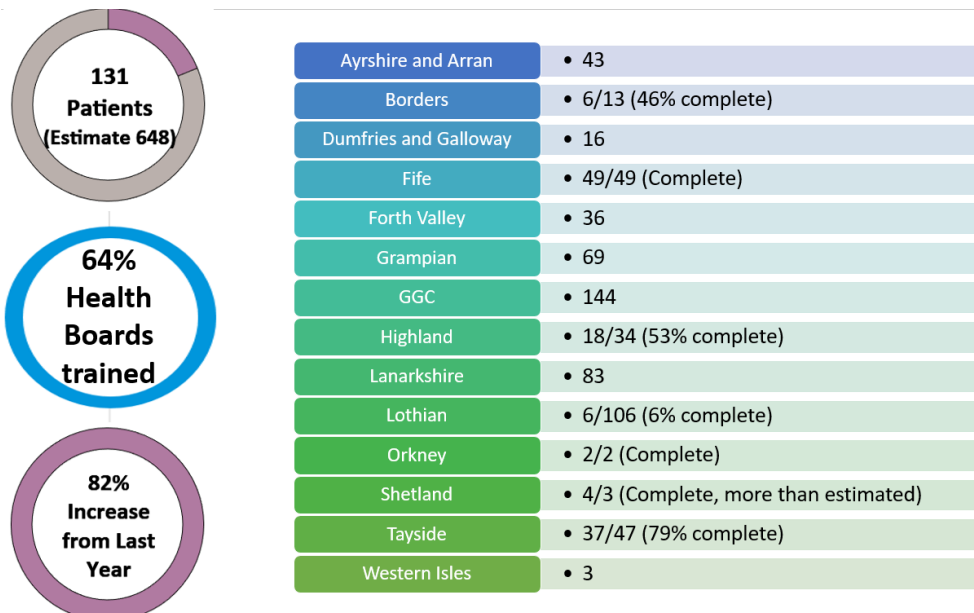


Figure 6 – Preumed CEN Children figures and number on CAS

Some work took place throughout the year between CEN and NHS Information Services Division to try and establish a set of procedure codes that could be used by Boards to aid identification of CEN patients by identifying specific procedures they may have received in order to add them to CAS. It is thought that this may help identify those patients who are harder to identify e.g. those not being looked after by paediatric services or who don't have regular contact with CCN. This piece of work is still being progressed by the CEN Data group and should be piloted in 2020/21.

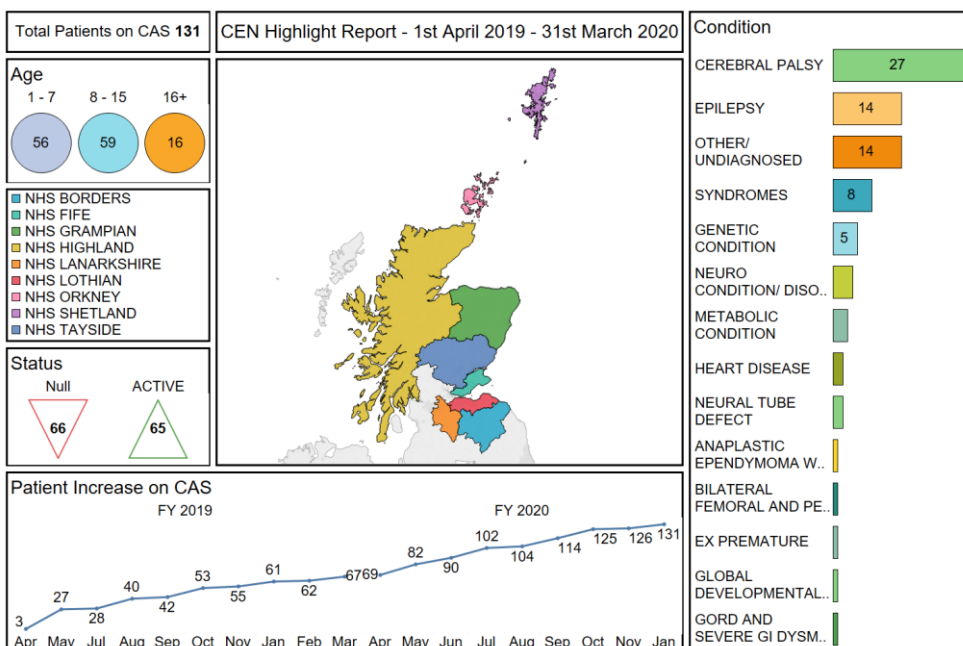


Figure 7- CAS Highlight Report 2019-20

3.5.2 (i) CAS Child Health Commissioners Quality Improvement Project

During the reporting period CEN were invited to present at a Child Health Commissioner's (CHC) meeting. This was an opportunity to highlight the importance of the CEN data collection on CAS and the benefits that could come from having accurate Scotland wide CEN data. The CHCs were very much in support of the need for data collection across Scotland and have agreed to complete this as a quality improvement project within this year. The reasons for supporting this project were noted as being; lack of current national data, growing number of CYP with exceptional needs who are living longer, high resources required to care for this group, increased vulnerabilities of this group of patients and their families due to complexities of conditions and the need to have accurate data for the number of CYP transitioning into adult services to ensure accurate planning for services. The aim of this project is to have all NHS Boards trained and capturing essential CEN data by the end of 2020 with the support and engagement of Child Health Commissioner's.

3.5.2 (ii) Consent

The network's CAS roll out required to be reviewed to take into account the revised consent process which was introduced as part of General Data Protection Regulation (GDPR). This has meant that some NHS Boards have stopped adding patients until they have a clear position on whether patients should be consented or not. NNMS have been working to have this reviewed and are waiting on the decision from the NSS Information Governance Committee regarding this.

3.6. Value

Throughout the reporting period the CEN network strived to create best value for its stakeholders, with some examples noted below;

- CEN made use of video conferencing in meetings and events to reduce travel and ensure equitable access regardless of location. An example of this was running an online link during the October Peer Review meeting via WebEx to allow remote linkages in for stakeholders to this event.
- CEN maintained links with key third sector organisations such as Kindred, CHAS and worked towards others such as with the Alliance and Royal Blind School
- CEN made links with other relevant agencies and networks such as the Paediatric End of Life Care Network to avoid duplication of work and effort and to ensure open communication.

3.6.1 Network Finance

Figure 8 contains a breakdown of how the CEN annual budget of £5K was spent. The network held an annual education event which was a significant spend at £2772.50, 48% of the overall budget. A venue was booked for this which was suitable for CEN families (with a changing place toilet and was fully accessible) unfortunately, venue options are significantly reduced when looking for this specific requirement and are often more expensive. Promotional materials including bags and pens as well as network postcards were also purchased as a cost of £1139.45. Other network spending included; meeting room bookings, catering and travel. The network was over budget by £739.02, this overspend was ratified by NSD.

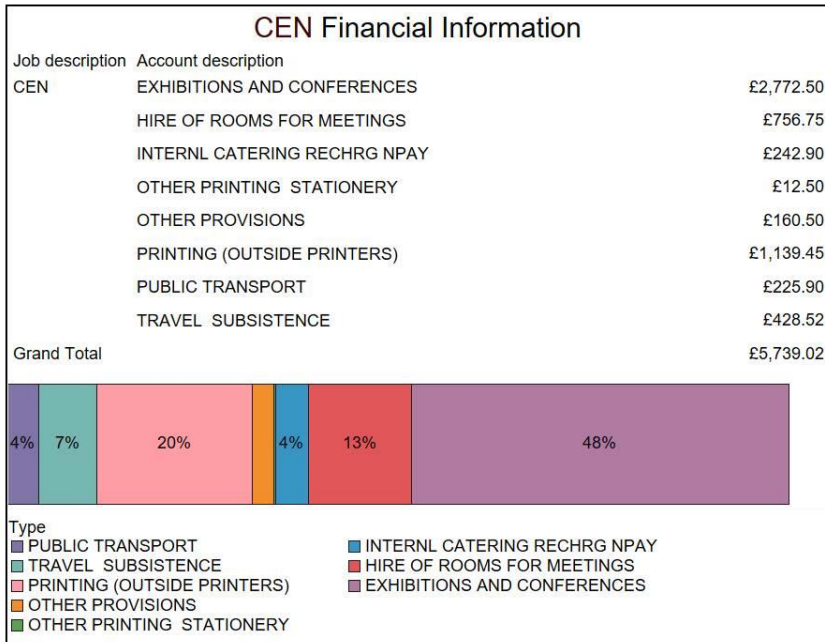


Figure 8 – Network Spend 2019-20

3.7 Continuing Care Framework

3.7.1 Value Improvement Fund Bid

CEN NMCN were delighted to submit a project proposal in July 2019 for the Value Improvement fund; aligned to the Scottish Government’s vision for Realistic Medicine. The CEN NMCN proposal “*The case for excellence in Children and Young Peoples Continuing Care Package*” aimed to embed a consistent approach to care pathways; reduce variation and improve delivery of care packages for this vulnerable population group. While the proposal was endorsed by NHS National Services Scotland’s Realistic Medicine (RM) leads, unfortunately on this occasion the proposal was not successful in the final selection. The Network received positive feedback from the Scottish Government RM lead, who praised the overall project aims and intentions to improve care delivery in Scotland. However, this highlighted the need for current data and patient experience to strengthen future bids. A qualitative study looking at families’ experience of care provision was designed but not progressed due to staffing issues and will be progressed in 2020-21.

4. Plans for the Year Ahead

4.1 Sub-Groups

4.1.1 Data Group

The CEN data group will progress the following actions in 2020-21;

- CAS Data Project – continue to progress the CAS CHC data project in order to have all Boards inputting data by the end of 2020
- Qualitative Data Project – CEN hope to complete a qualitative data project with parents to gather some more rich information on care packages.
- Continue work on identifying procedure codes for identifying CEN children with NHS ISD

4.1.2 Education Sub-group

The CEN education group will progress the following actions in 2020-21;

- Review learn pro modules – evaluate if all are still relevant, if any could be merged/deleted/updated
- Annual Education Event – assist the network Core Team with planning the annual education event
- Peer Review meetings – The CEN network must decide if these meetings will continue
- Encourage collaboration with NES at future educational meetings
- Continued review of CEN website

4.1.3 Kindred: Exceptional Families Project

CEN will continue with partnership engagement with Kindred through the Exceptional Families Project, including ongoing engagement with families and dedicated Parent Forum. Further professionals' events will be held across Boards in Scotland who have not participated already. CEN will collaborate with Kindred on their 30th anniversary plans where appropriate.

4.2 Care Pathways

The CEN network core team must establish a Care Pathways sub-group who will work on updating the CEN care pathways in order of priority. It was agreed that this group will need to be formed of medical staff and therefor the impacts of COVID-19 may affect the ability for front line staff to take part in this.

4.3 Strategic Planning Day

The CEN network will re-schedule and host a strategic planning day, the purpose of this event is outlined in Section 3.2.5.

4.4 Continuing Care Framework

CEN NMCN will decide if a refreshed proposal should be submitted to the Value Improvement Fund during 2020/21. It was felt that updated data would help with this application.

4.5 Website

The network PSO will work with the Lead Clinician to review the CEN website; there is a lot of information on the website so this will be checked for relevance and appropriateness. This will in turn make a more user friendly website for both professionals and families.

4.6 Membership

The CEN core team will spend time to ensure that membership of groups is representative of pan-Scotland and cross specialties. This will include measuring why people don't attend meetings in order to put in place measures to encourage attendance.

4.7 Risks and issues

- CEN will have a new Lead Clinician this year, this may mean that the priorities of the network change slightly or are given a different emphasis. The new Lead will also take time to adjust and fit in to the role. The full effects of this will not be known until the new Lead Clinician is in place
- The length of impacts of COVID-19 are currently unknown, in order to project potential risks an impact assessment has been carried out for the network. It is thought that the main effects will be on the availability of front line staff to attend meetings and progress network work and the 'catch-up' from meetings and events missed during social distancing period. A copy of the network impact assessment can be seen in [Appendix 4](#)

5. Detailed Description of Progress in 2019-20

Insert updated Annual Workplan here, detailing their status as of 31 March of the reporting year. All network initiatives/projects mentioned in section 4 of the report must be listed in the Annual Workplan.

WORKPLAN – 2019-20

RAG status	Description
RED (R)	The network is unlikely to achieve the objective/standard within the agreed timescale
AMBER (A)	There is a risk that the network will not achieve the objective/standard within the agreed timescale, however progress has been made
GREEN (G)	The network is on track to achieve the objective/standard within the agreed timescale
BLUE (B)	The network has been successful in achieving the network objective/standard to plan

The Institute of Medicine's six dimensions of quality are central to NHS Scotland's approach to systems-based healthcare quality improvement, therefore objectives should be linked to these dimensions:

1. **Person-centred:** providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions;
2. **Safe:** avoiding injuries to patients from healthcare that is intended to help them;
3. **Effective:** providing services based on scientific knowledge;
4. **Efficient:** avoiding waste, including waste of equipment, supplies, ideas, and energy;
5. **Equitable:** providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status; and
6. **Timely:** reducing waits and sometimes harmful delays for both those who receive care and those who give care.

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31.05. 2020	Anticipated Outcome	RAGB status
1.Effective Network Structure and Governance						
(linked to Quality Dimensions 3:4:5:6)						
2019-01	Develop the future role and remit of Network alongside the National Network Management Service and review Network structure and membership to ensure it remains fit for purpose during March 2019-March 2020	31/03/19 31/03/2020	Lead Clinician CEN NMCN Core Team	A new CEN NMCN team is in place and will continue to progress this work within this financial year as planned. Due to COVID-19 the strategic planning day which would look at refreshing the CEN workplan was re-scheduled this will hopefully take place in Autumn 2020	Effective support structures for CEN in Scotland, with effective coordination between national service, network and local services	G
2.Service Development and Delivery						
(linked to Quality Dimensions 1:2:3:4:5:6)						
2019-02	Care Quality Indicators During 2019/2020 the Network will review the 5 Care Quality Indicators that it established in 2017	31/03/19 31/03/2020	Lead Clinician CEN NMCN Core Team	This piece of work was not completed in the reporting period	Effective quality measures that underpin performance monitoring of the commissioned service and facilitate ongoing quality improvement activity	R

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2019-03	<p>Care pathways</p> <p>The CEN care pathway 'steps' and embedded resources on the website are out of date. CEN will update this online resource for professionals by developing a SMART project plan</p>	31/03/19 31/03/2020	Lead Clinician CEN NMCN Core Team	This work has been slow to progress due to dedicated staff resource in place to support this work. CEN NMCN will support progress of this project activity through a short life working group (SLWG) in the 2020-21 period	The CEN care pathway "steps" will be reviewed, re-written and updated so that they remain current and relevant	A
<p>3.Stakeholder Communication and Engagement</p> <p>(linked to Quality Dimensions 1,3,4,5,)</p>						
2019 -04	The Network will review the CEN communication and engagement strategy to ensure that it reflects the needs of CEN and its stakeholders	31/03/19 31/09/2020	Lead Clinician CEN NMCN Core Team	This piece of work was due to be updated following the strategic planning day, unfortunately as this was postponed this document has not been updated	CEN communicate and engages with the Network and its stakeholders in a variety of different communication channels Newsletter Website Social Media (Twitter)	R

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2019 -05	By April 2020 the Network will issue 3 newsletters	01/06/2019-30/03/2020	Lead Clinician CEN NMCN Core Team	CEN have created and distributed regular newsletters for stakeholders, these have been tweeted and shared on the website.	CEN will keep stakeholders up to date with ongoing work and future plans through newsletters available online	B
2019 -06	During 2019/2020 the Network will continue to develop and maintain the CEN website	31/04/2019-31/03/2020	Lead Clinician CEN NMCN Core Team	The CEN NMCN team regularly refreshed and updated the CEN website to include updated and current resources with the aim to improve information sharing to all stakeholders and the CEN community.	CEN will have a useful and informative website that is user-friendly	B
2019-07	CEN will continue to work in partnership with the Kindred Exceptional Families Project (EFP); included but not exhausted to attending the EFP Steering Group and attending the EFP professional engagement events	01/01/2019-31/03/2019	Lead Clinician CEN NMCN Core Team Kindred	The progress of this work is being supported by the CEN NMCN team. Kindred have secured a 3-year funding grant from the Henry Smith Foundation to continue project activity. The outcomes of the project are to improve the outcomes of children and their families within the specialist population with robust support from identified Kindred staff. The CEN NMCN team continued to support this work within this financial year as planned.	Increased engagement of patients and families to identify priorities for service development.	B

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4.Education						
(linked to Quality Dimensions 1,2,3,4,5,6)						
2019-08	CEN will review its Education strategy	31/03/19-31/03/2020	Lead Clinician CEN NMCN Core Team	This piece of work was due to be updated following the strategic planning day, unfortunately as this was postponed this document has not been updated	CEN will have clear plans for education and its delivery	R
2019-09	CEN will facilitate 2 peer review meetings	01/01/2019-31/03/2020	Lead Clinician CEN NMCN Core Team	The first bi - annual CEN Peer review meeting took place on the 9 th May 2019 at the Queen Elizabeth University Hospital in Glasgow The topic for this meeting was " <i>Bowel & Bladder Dysfunction</i> ". The second CEN Peer review took place on 31 st October at the Queen Margaret Hospital in Dunfermline. The topic for discussion: <i>COMMUNICATION "Hearing the Voices of Children with Exceptional Healthcare Needs"</i> .	CEN clinicians and other networks have the opportunity to learn about current developments	B
2019-10	CEN NMCN will facilitate a CEN Annual conference by March 2020	01/03/2019-30/03/2020	Lead Clinician CEN NMCN Core Team	The CEN NMCN Annual event took place in February 2020 at the Tollcross Swimming Centre in Glasgow.	CEN and its stakeholders have the opportunity to learn about strategic policy initiatives.	B

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5.Audit and Continuous Quality Improvement						
(linked to Quality Dimensions 1,2,3,4,5,6)						
2019-11	CEN will review its Quality Improvement Strategy	31/03/19-31/03/2020	Clinical Lead CEN NMCN Core Team	This piece of work was due to be updated following the strategic planning day, unfortunately as this was postponed this document has not been updated.	Quality Improvement methodology underpins all of the network's activity	R
2019-12	CEN will continue to support clinicians and boards to use the Clinical Audit System during 31 st March 2019- 31 st March 2020	31/03/19-31/03/2020	Clinical Lead CEN NMCN Core Team CEN Data Analyst	The Network continues to facilitate the dissemination of the Clinical Audit System (CAS) throughout the regional boards in Scotland. There has been a positive increase in both the volume and quality of data being captured. Early data has been gathered for base line purposes and this data has been used as evidence to measure ongoing improvement and progress in this area. CEN is exploring the possibility of using ICD10 procedure codes to identify harder to reach CEN children within Boards- this will continue in 2020-21.	Data will facilitate service improvements	B

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6.Value						
(linked to Quality Dimensions 1,2,3,4,5,60)						
2019-13	CEN will demonstrate the value that that it has for CEN families, contained within other actions on the work plan	31/03/19 31/03/2020	Clinical Lead CEN NMCN Core Team	The CEN NMCN team will explore future project work which aligns to CEN value improvement activity within this financial year as planned.		B
7.Continuing Care Framework						
(linked to Quality Dimensions 1,2,3,4,5,60)						
2019-14	CEN will continue to work towards developing a continuing care framework to ensure consistency of complex care planning and delivery for families in Scotland	ongoing	CEN Lead Clinician CEN Programme Manager	The CEN NMCN submitted a project proposal to the Value Improvement fund which is aligned to the Scottish Government's vision for Realistic Medicine. The project proposal was <i>"The case for excellence in Children and Young Peoples Continuing Care Package"</i> . The proposal was successfully accepted by NHS National Services Scotland's criteria for submission. The proposal was not successful in the final selection process for funding.	CEN will create a tool that allows for consistency of complex care planning and delivery for families in Scotland	B

6. Proposed Work Plan for 2020-21

Full draft Annual Workplan for the following year;

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 02/04/20	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance <small>[linked to Quality Dimensions 3,4,5,6]</small>						
2020-01	CEN will appoint a new Lead Clinician	3,4,5,6	NSD		CEN will successfully appoint a Lead Clinician at the end of Current tenure	G
2020-02	CEN will review Steering group membership; ensuring pan-Scotland, cross-speciality membership	3,4,5,6	CEN Core Team & LC		CEN will have a representative steering group of the whole of Scotland	G
2020-03	CEN will update relevant strategies (data, education and QI) following the strategic planning day	3,4,5,6	CEN Core Team & LC		CEN will have refreshed strategies that have clear projects within them	G
2020-04	CEN will host regular steering group meetings with adequate notification to members	3,4,5,6	CEN Core Team & LC		CEN will host regular steering group meetings to inform the work of the network	G

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 02/04/20	Anticipated Outcome	RAGB status
2020-05	CEN will host regular Sub-group meetings for Data and Education groups	3,4,5,6	CEN Core Team & LC		CEN will have effective sub-groups that progress work contained in the workplan	G
2020-06	CEN will create a refreshed 5-year strategic work plan following the strategic planning day.	3,4,5,6	CEN Core Team & LC		CEN will have a clear workplan to follow that is accurate and reflects the strategic landscape of the network	G
2. Service Development and Delivery <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-07	CEN will respond to appropriate consultations as and when required.	1,2,3,4,5,6	CEN Core Team. Steering Group & LC		CEN will have a voice for their patients and their families in government consultations	G
2020-08	CEN will contribute to the Disabled Children and Young People Advisory Group (DCYPAG)	1,2,3,4,5,6	CEN Core Team & LC		CEN will contribute to decisions made and provide expert guidance and advice	G

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 02/04/20	Anticipated Outcome	RAGB status
2020-09	CEN will progress the Care pathways sub-group which will initially look at updating the discharge planning pathway as a priority.	1,2,3,4,5,6	CEN Core Team & LC Care Pathways Group	Agreed at October SG meeting – Discharge planning would be priority	CEN will begin to refresh care pathways that are up to date and fit for purpose	G
2020-10	CEN will organise and host a strategic planning day which will look at updating the CEN strategic workplan and in turn allow the network strategies to be updated.	1,2,3,4,5,6	CEN Core Team & LC		CEN will have a clear understanding of its strategic landscape in order to create a relevant workplan and strategies	G
2020-11	CEN will continue to work towards developing a continuing care framework to ensure consistency of complex care planning and delivery for families in Scotland	1,2,3,4,5,6	CEN Core Team & LC		CEN will create a tool that allows for consistency of complex care planning and delivery for families in Scotland	G
3. Stakeholder Communication and Engagement <small>[linked to Quality Dimensions 1,3,4,5,6]</small>						
2020-12	CEN Website – CEN will work on ensuring content on the website is appropriate and in date, any	1,3,4,5,6	CEN Core Team, CEN PSO & LC		CEN will have a concise website that is easy to navigate and all	G

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 02/04/20	Anticipated Outcome	RAGB status
	information that is out of date will be removed or updated.				information is up to date and relevant	
2020-13	CEN Newsletters – CEN will continue to distribute regular newsletters to stakeholder to ensure they are well informed of work that is ongoing and coming up as well as any news stories.	1,3,4,5,6	CEN Core Team & LC		CEN will have well informed stakeholders who are kept up to date with network news	G
2020-14	CEN will continue to contribute and regularly tweet from the @CYPNMCN twitter account and monitor the impacts that tweets are having	1,3,4,5,6	CEN PSO		CEN will have well informed stakeholders who are kept up to date with network news	G
2020-15	CEN will invest time to increase membership of subgroups and attendance at meetings of these groups	1,3,4,5,6	CEN Core Team & LC		CEN will understand why members may not attend meetings and what can be done to improve this in turn increasing attendance	G
2020-16	CEN will continue to engage with the Kindred EFP partnership and maintain cross-communication channels as such. Partnership working includes; <ul style="list-style-type: none"> • Attending steering groups 	1,3,4,5,6	CEN Core Team, Kindred & LC	Professional events may be held virtually this year due to COVID	CEN will have an effective relationship with Kindred EFP with regular	G

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 02/04/20	Anticipated Outcome	RAGB status
	<ul style="list-style-type: none"> Attending 2 professional events organised by Kindred (D&G and FV) Participate in Kindred's 30th anniversary celebrations Kindred will attend CEN SG's Kindred will attend CEN Annual Education events and strategic planning day Kindred will provide CEN with regular data updates on the EFP Kindred can provide an update for the CEN newsletter Links on each other's website 				communications and updates	
G4. Education <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-17	CEN will host an annual education meeting on relevant and hot topics.	1,2,3,4,5,6	CEN Core Team & LC Education Group		CEN will ensure stakeholders are kept abreast with current developments in the field	G
2020-18	CEN will review use of Peer review meetings and decide on the best format for these in the future	1,2,3,4,5,6	CEN Core Team & LC		CEN will be clear on the way forwards for peer review meetings	G

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 02/04/20	Anticipated Outcome	RAGB status
			Education Group		and the format of these.	
2020-19	CEN Education Group will review the current LearnPro modules to ensure fit for purpose.	1,2,3,4,5,6	CEN Core Team & LC Education Group		CEN will have a clear idea of what is required in terms of learn pro modules and make appropriate changes to streamline these as such.	G
5. Audit and Continuous Quality Improvement <small>[linked to Quality Dimensions 1,2,3,4,5,6]</small>						
2020-20	CEN will have all Boards trained and inputting patients on the clinical audit system (CAS) by December 2020	1,2,3,4,5,6	CEN Core Team & LC Data Group Louise Smith		CEN will have a full set of Scotland wide data for all CEN children	G
2020-21	CEN will provide regular update reports to Child Health Commissioners (CHC) and NSD SMT on the progress of the CHC CAS Project	1,2,3,4,5,6	CEN Core Team & LC Data Group Louise Smith		CEN will keep CHCs well informed of project progress	G

Children with Exceptional Healthcare Needs (CEN): Annual Report 2019-20

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 02/04/20	Anticipated Outcome	RAGB status
2020-22	CEN will review Care Quality Indicators (CQI) to ensure fit for purpose	1,2,3,4,5,6	CEN Core Team & LC Data Group Louise Smith		CEN will have clear understanding of the purpose and use of QCI's	G
2020-23	CEN will update Boards on Consent for registering patients on CAS following guidance from government	1,2,3,4,5,6	CEN Core Team & LC Data Group		CEN will ensure Boards are well informed on changes in consent	G
2020-24	CEN will update CEN Consent leaflets to reflect new consent legislation to create new information leaflets	1,2,3,4,5,6	CEN Core Team & LC Data Group		CEN will have relevant and up to date information leaflets for use	G
2020-25	CEN will plan a qualitative data gathering project with CEN families	1,2,3,4,5,6	CEN Core Team & LC Data Group		CEN will be clear on the purpose and practicalities of a possible qualitative data project.	G
6. Value [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-26	CEN will continue to ensure meetings can be attended via remote means	1,2,3,4,5,6	CEN Core Team & LC		CEN will allow for members to connect remotely to meetings	G

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Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 02/04/20	Anticipated Outcome	RAGB status
2020-27	CEN will ensure that work is not duplicated with other networks for example PELiCaN or Long Term Ventilation pieces of work or VINCYP for joint education	1,2,3,4,5,6	CEN Core Team & LC		CEN will work in conjunction with other networks without repetition	G
2020-28	CEN will maintain and further develop links with third sector organisations and other relevant agencies	1,2,3,4,5,6	CEN Core Team & LC		CEN will be well connected and known in third sector.	G

Appendix 1: Core Team Profiles

Lead Clinician & Chair of Data Group – Dr Susan Buck, NHS NSS

Dr Susan Buck has wide experience working as a GP in rural and city practices. She has a portfolio career, combining her interests of Children's Health and Wellbeing, with medical postgraduate education. In Susan's role as Lead Clinical she has been privileged to work with dedicated teams and parents committed to their families' care. She is committed to understanding the challenges families may face and how children and young people are cared for to influence service development for improved quality of life. Supporting professionals, especially their education, is an important part of her role.



Susan is an Associate Adviser in GP Postgraduate Education, GP Appraiser, Assessor for PLAB and a member of the RCGP International.

Network Programme Manager – Miss Shelley Heatlie, NHS NSS

Shelley is the Programme Manager for PELiCaN and CEN, she started with the network in August 2019 as an Assistant Programme Manager and has previously been a Programme Support Officer (PSO) within the National Managed Diagnostic Networks. In her role she will support the Lead Clinician with driving key national commissioned areas of work aligned to the networks work plan and manage the core principles, which underpin the network.



She has an honours degree in Management and has many years' experience working in the public sector having previously worked in education services for children with additional support needs. She is passionate about quality improvement and managing change and hopes that she can use these skills to drive the PELiCaN and CEN network forwards.

Network Programme Support Officer – Christopher Williamson, NHS NSS

Chris joined NNMS in February 2020 from the Royal Hospital of Children in Edinburgh where he worked as a Project Support Manager planning, managing and coordinating a diverse array of programmes of work for the service management and clinical teams. A former NHS Lothian nominee for Employee of the Year and Edinburgh Evening News Health Hero, Chris used CQI tools whilst in the role of Medical Secretary team lead to develop and implement a system to share best practice achievements across the whole of the Edinburgh Cancer Centre at the Western General Hospital and comes to us with over 10 years of NHS experience gained within roles in three NHS Trusts.



Chris is degree educated and worked within hospitality and financial services prior to joining the NHS. He is an excellent communicator and is passionate about the importance of building and developing relationships and networks that can serve to develop and improve the services we provide to our population

Network Data Analyst – Miss Louise Smith, NHS NSS IMS

Louise has been working with NSS for 5 years now, 2 years as a Data Analyst within the Information Management Service and CEN Network. Her main focus has been on the Clinical Audit System rollout with 60% of boards trained and inputting data on the system.



Appendix 2: Steering Group Membership

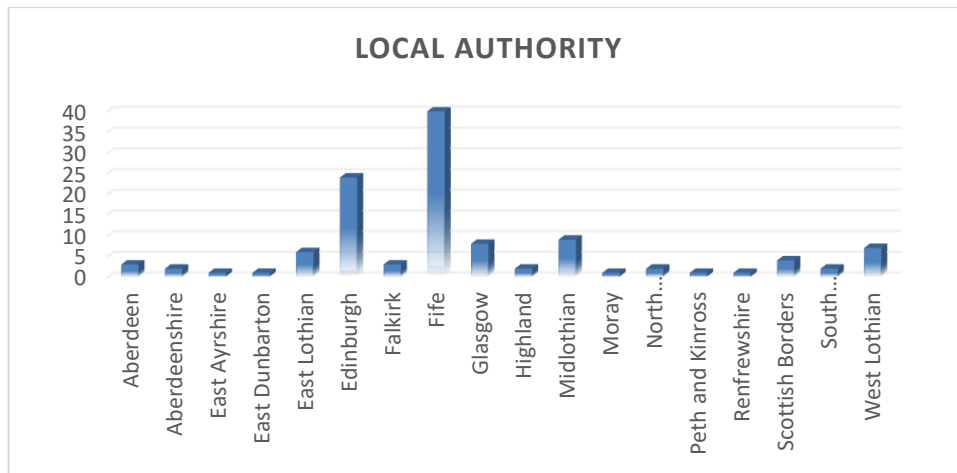
Health Board / Organisation	Name	Designation
CEN Lead Clinician	Susan Buck	Lead Clinician CEN NMCN
CHAS (Steering Group Chair)	Debbie McGirr	Lecturer in Child Health
Children and Young People's Commissioner Scotland	Megan Farr	Policy Officer, Children & Young People
Children's Hospice Association Scotland	Jennifer Carson	Social Worker
Children's Health Scotland	Anne Wilson	Development Officer
KINDRED	Sophie Pilgrim	Director Kindred
National Services Scotland	Shelley Heatlie	Programme Manager, National Managed Clinical Network
National Services Scotland	Chris Williamson	Programme Support Officer
National Services Scotland	Louise Smith	Data Analyst
NHS Ayrshire & Arran	Elsbeth Mair	Speech & Language Therapist
NHS Ayrshire and Arran	Beth Frank	CEN Ed Group Chair NHS A&A
NHS Fife	David Smyth	Advanced Nurse Practitioner CEN
NHS Fife	Karen Allan	Speech & Language Therapist
NHS GG&C	Dr Ciara McColgan	Clinical lead for Specialist Children's Services
NHS Highland	April Emmott	Senior Nurse
NHS Highland	Patricia Rankine	CCN Team Leader
NHS Highland	Cheryl DeSouza	Paediatric Physiotherapist
NHS Lanarkshire	Margaret Johnston	Team Leader for Integrated Community Children's Nursing Services
NHS Lothain	Jill Yates	Consultant Paediatrician
NHS Lothian	Dr Anna Chillingworth	Consultant Community Paediatrician
NHS Lothian	Sally Egan	Child Health Commissioner
NHS Tayside	Audrey Toshney	Children's Complex Needs/Palliative Care Specialist Nurse
PAMIS	Barbara Garrard	Self-directed Support Lead
Parent	Claire Palmer	
Parent	Laura McCartney	
Scottish Government	Pauline Beirne	AHP CYP National Lead

Appendix 3: Kindred CEN Exceptional Families Report 2019-20

1. Introduction

Over the last 12 months Kindred staff have provided support to 127 parents of children with exceptional healthcare needs (CEN). The distribution of support is broadly reflective of funding. We now have most funding for Fife, where we are supporting 40 CEN families.

We have supported families from 18 local authority areas across Scotland. Most families are situated along the East side of Scotland (reflecting our base at the Royal Hospital for Sick Children).



In response to Covid-19 many families have been self-isolating due to the high risk to their child's health. Kindred has set up a closed Facebook group to help families to communicate with each other and share ideas and mutual support. We have also been in touch with all families who are still 'open' on our database (i.e. families for whom we are still providing a service).

In terms of support provided to families, staff have delivered a very wide range of support including statutory services and financial matters. Over the 12 months we have raised a total of £1,300,153.14 in additional income for families.

In terms of major pieces of advocacy work for families, Kindred staff completed 35 Disability Living Allowance forms, 99 grant applications, 4 successful placing requests for special schools and assisted 10 families to move house to suitably adapted homes.

2. Covid-19

Kindred staff have contacted all current CEN families. Some appear to be coping better than others, but all are feeling isolated and are concerned about their child's needs being fully met through this uncertain period. Recurrent themes include:

- All review appointments have been cancelled and parents are worried about how their child's condition will be monitored effectively, and that significant issues could arise. Parents understand why reviews have been cancelled but are concerned about when reviews might take place.
- All therapeutic (physiotherapy, occupational therapy, speech and language therapy) support has now stopped. Again, parents understand why, but are concerned that their child will regress and complications may arise.
- Some families are continuing with support from carers and others are completely self-isolating. Parents reporting that they cannot source Personal Protective Equipment (PPE) for carers coming into the home.
- All respite away from home has stopped due to staff being off and needed elsewhere, including respite at children's hospices.
- Parents are concerned that they cannot source repeat prescriptions and describe standing in a queue for over an hour and then being told medication is not in stock.

- Significant time delay in parents being able to obtain medical supplies, tubing, gloves etc. Lots of discussion about "shielding". Parents feel little or no advice has been given from professionals as yet, although some had received letters identifying their child as meeting the criteria for shielding.
- Concerns about siblings and impact on mental health and parents struggling with a divided role. Some siblings are taking on a significant role helping with care.
- There is a big disparity between local authorities over whether families are able to adapt their Self Directed Support packages and employ carers (for those who are not in total isolation).
- Some children are remaining in residential care and parents are not able to visit their child.
- Parents worry about what will happen if they become ill and cannot care for their child. Or if their child becomes ill, whether they will be able to visit them.

In response, Kindred has set up a closed Facebook group for parents and we continue to support parents individually by phone, email and text. We are also developing counselling support for parents which will be made available to parents on an individual basis (to manage demand). Kindred staff have been looking into the availability of grant funding for families in need of financial support.

3. More detail on our outcomes

Parents were supported in 18 local authority areas. We have made efforts to follow up on an event for professionals in Scottish Borders. We have also managed to sustain contact with some families in Glasgow.

1 family supported in: East Ayrshire, East Dunbartonshire, Moray, Perth & Kinross, Renfrewshire

2 families supported in: Aberdeenshire, Highland, North Lanarkshire, South Lanarkshire

3 families supported in: Aberdeen, Falkirk

4 families supported in: Scottish Borders

6 families supported in: East Lothian

7 families supported in: West Lothian

8 families supported in: Glasgow

9 families supported in: Midlothian

24 families supported in: Edinburgh

40 families supported in: Fife

Outcome for families are as follows:

Education:	Financial
17 supported with assessment	20 Carers Allowance
1 child excluded from school	35 Disability Living Allowance (care)
4 successful placing requests	26 Disability Living Allowance (mobility)
10 supported with transition	1 Personal Independence Payment (care)
	24 Family Fund
	47 Golden Ticket (Dynamic Earth)

<p>Health support</p> <p>Discussions with following professionals:</p> <p>10 CAMHS</p> <p>28 a consultant</p> <p>40 specialist nurse consultant</p> <p>22 Occupational Therapy</p> <p>20 Physiotherapy</p> <p>17 Speech and Language Therapy</p>	<p>1 Neonatal grant</p> <p>26 other grant</p> <p>14 other holiday grant</p> <p>9 Samaritans grant</p> <p>25 Take a Break</p> <p>23 Tax Credits</p>
<p>Housing</p> <p>15 achieved housing adaptation</p> <p>12 achieved housing benefit</p> <p>10 achieved rehousing</p>	<p>Total increase in annual income: £1,300,153.14</p> <p>The average per family is: £10,237</p>

4. Feedback from our professional's event (Dundee 10 October)

Our event for professionals was facilitated by Claire Edwards. Seven healthcare professionals attended including a paediatrician, OT and specialist nurses. Shelley Heatlie gave an input specifically on CEN towards the end of the workshop and invited participants to link in with the network. There was lively and positive discussion throughout. Those attending were provided with a handout with links to CEN and other resources.

Feedback includes -

'Great opportunity to talk with other professionals about working collaboratively with families'

'Helpful and informative session'

'Thought provoking session, well facilitated'

'Very interesting session, welcome chance to talk through issues'

'Although facilitator's child not CEN the parent perspective was so useful'

'It was good to reflect on the ways we can improve things for families'

5. Engagement of parents in the CEN Network

Parents have been invited to join the CEN steering group meeting and attend the CEN annual conference in February 2020. The Exceptional Family Project steering group have been involved in setting up the Facebook group and have already exchanged useful information and support. CEN NMCN is part of the EFP steering group.

6. Update on Kindred

Kindred has National Lottery Community Fund and Fife Health & Social Care funding; hence the highest level of support is delivered in Fife. We also have funding from NHS Lothian. Nationally, we have funding from the Henry Smith Foundation and Scottish Government. As our experience grows, we are able to reach out and support parents across Scotland. Our Facebook group will hopefully help us to contact families further afield. Our new database (Lamplight) is already enabling us to generate more information on the work of our staff and this will result in more detailed reporting in future.

Appendix 4: COVID 19 Impact Assessment

CEN National MCN

Report authors: Shelley Heatlie, Programme Manager & Susan Buck, Lead Clinician

Reporting Period: March – June 2020

Network Status		
Current network status and high level statement e.g. lack of clinical/scientific capacity to contribute. R – Activity Suspended A – Partial Activity G – Full Activity		
A	Partial Activity	All network activity which is face to face has been suspended. All Steering and sub-group meetings and education events have been postponed. A number of projects have been identified which will be able to continue.

Details
<i>What has been happening to lead to the RAG status above and what does it mean going forward?</i>
<p>There has been agreement from the Lead Clinician that all CEN meetings would be postponed until at least September 2020 to allow members to focus on front line COVID work.</p> <p>There is also a possibility that staff in paediatrics may be subject to redeployment to adult care due to the significant impact COVID is having on adult services.</p> <p>A number of activities have been identified which can be taken forward in the short term. The network has tried to adopt a proactive and responsive approach to the Covid-19 pandemic, as many of the CEN patients are at significantly higher risk, have disruption of normal therapies, loss of care packages and increased concern about family carers becoming unwell etc. Other tasks include updating website, writing network workplans, creating guidance and advice for parents and carers and 'behind the scenes' type work.</p> <p>Once staff have returned to 'normal' there may be a period of catch up due to routine admissions to hospital/operations etc. being reinstated so it is thought that network work will be slower at that point as well. It may be some time before Teams will be able to release time/people to contribute actively to development to CEN resources and Workstreams.</p> <p>The sign-off of the removal of consent required for entering CAS data has been delayed by other priorities related to Covid-19.</p>

NNMS Management Team is asked to:	
1	<i>e.g. note progress or endorse proposed action to mitigate cause of amber/red status</i>

Exception to Workplan (March to June 2020) – incomplete objectives		
<i>Key impact on major planned activities in next reporting period</i>		
Activity	Current Position	Revised plan

Steering Group Meeting – 30 April 2020	Meeting Cancelled	Next SG planned for 27 th August hopefully will go ahead.
All Sub-group meetings which were scheduled are postponed (Data/Education)	All meetings of sub-groups postponed	All meetings will be re-scheduled ASAP once permitted to do so.
CEN CAS Child Health Commissioners (CHC's) Project	This may potentially slow down as staff time taken up in COVID work and unable to devote time to CAS entry and delay in sign off of removing the need for consent.	May need to look at the project Schedule and move dates back.

1. Workplan Objectives 2020-21					
Objective Number	Smart Objective	Planned end dates	Projected End Date	RAGB status	Position
2020-01	CEN will appoint a new Lead Clinician	May 2020	Ongoing	A	LC tenure is due to finish and that outcome of recruitment exercise is awaited as COVID-19 has impacted on usual process timescales
2020-02	CEN will re-invigorate the Steering group ensuring pan-Scotland, cross-speciality membership	December 2020	March 2021	A	This may take longer as people will be getting back to 'normal' after COVID
2020-03	CEN will update relevant strategies (data, education and QI) following the strategic planning day	May 2020	At least December 2020	A	Strategic Planning Day on hold until after COVID- Maybe October time
2020-04	CEN will host regular steering group meetings	Ongoing	Ongoing	A	April cancelled, next meeting August
2020-05	CEN will host regular Sub-group meetings for Data and Education	Ongoing	Ongoing / on hold	A	All CEN meetings on hold
2020-06	CEN will create a refreshed 5-year strategic work plan following the strategic planning day.	May 2020	At least December 2020	A	Strategic Planning Day on hold until after COVID- Maybe October time
2020-07	CEN will continue to respond to appropriate consultations as and when required.	As and when	As and when	G	No requests at current

1. Workplan Objectives 2020-21					
Objective Number	Smart Objective	Planned end dates	Projected End Date	RAGB status	Position
2020-08	CEN will continue to have a voice at the Disabled Children and Young People Advisory Group (DCYPAG)	Ongoing	Ongoing	G	LC is contacted by email for updates/information/consultation. This will pass directly to the new LC
2020-09	CEN will progress the Care pathways sub-group which will initially look at updating the discharge planning pathway as a priority.	Sept 2020	On Hold	A	All sub-group on hold at current
2020-10	CEN will organise and host a strategic planning day which will look at updating the CEN strategic workplan and in turn allow the network strategies to be updated.	May 2020	At least September/Oct 2020	A	Strategic Planning Day on hold until after COVID- Maybe October time
2020-11	CEN Website – CEN will work on ensuring content on the website is appropriate and in date, any information that is out of date will be removed or updated.	Ongoing	Ongoing	G	Time to do this during COVID period. However, some resources e.g. that are based on the outcome of the conference, are delayed due to the difficulties teams outside of NSS are facing Project with GP Trainee as pilot for using new criteria for WPBA in GP Training cancelled due to primary care commitments. Ai for pilot study was to develop links with EYC and Primary care as a model for wider engagement. Aim for poster at RCGP conference.
2020-12	CEN Newsletters – CEN will continue to distribute regular newsletters to stakeholder to ensure they are well informed	Ongoing	Ongoing	G	Sent most recent N/L in April 2020 to share our position as a network on COVID and what we were doing to help

1. Workplan Objectives 2020-21					
Objective Number	Smart Objective	Planned end dates	Projected End Date	RAGB status	Position
	of work that is ongoing and coming up as well as any news stories.				
2020-13	CEN will continue to contribute and regularly tweet from the @CYPNMCN twitter account and monitor the impacts that tweets are having	Ongoing	Ongoing	G	Excellent way of communicating with stakeholders at current
2020-14	CEN will invest time to increase membership of subgroups and attendance at meetings of these groups	Dec 2020	March 2021	A	Network was doing to send out a questionnaire to stakeholders scoping why not attending and if anything can be done to help. Time can be spent now making the survey but not sending that will be on hold until after back to 'normal'
2020-15	CEN will continue to engage with the Kindred EFP partnership and maintain cross-communication channels as such.	Ongoing	ongoing	G	Unaffected. Facebook established and ongoing liaison. Engagement events in bid to Henry Smith Foundation are postponed/cancelled and usual Steering group meetings are also postponed
2020-16	CEN will host an annual education meeting on relevant and hot topics.	Feb 2021	Feb 2021	G	Should be ok by then
2020-17	CEN will review use of Peer review meetings and decide on the best format for these in the future	Once new LC starts	Once new LC starts	G	Likely that will only be able to do one instead of two this year due to COVID. Planned meeting for sensory impairment postponed
2020-18	CEN Education Group will review the current LearnPro modules to ensure fit for purpose.	Autumn 2020	Winter 2020	A	Education group to progress, meetings postponed at current so work can't progress
2020-19	CEN will have all Boards trained and inputting patients on	December 2020	December 2020	G	On track to meet this deadline, plan in place, unsure of effects of COVID on this. COVID has

1. Workplan Objectives 2020-21					
Objective Number	Smart Objective	Planned end dates	Projected End Date	RAGB status	Position
	the clinical audit system (CAS) by December 2020				highlighted the need for accurate data.
2020-20	CEN will provide regular update reports to Child Health Commissioners (CHC) and NSD SMT on the progress of the CHC CAS Project	Ongoing	Ongoing	G	IMS to send regular highlight reports to CHC's
2020-21	CEN will review Care Quality Indicators (CQI) to ensure fit for purpose				This should be part of each annual review.
2020-22	CEN will update Boards on Consent for registering patients on CAS following guidance from government	Ongoing	Ongoing	G	Claire Lawrie updating boards as and when appropriate
2020-23	CEN will update CEN Consent leaflets to reflect new consent legislation	Can't progress until consent process approved	Can't progress until consent process approved	A	Will be progressed by Education Group. Will become information , not consent leaflets.
2020-24	CEN will plan a qualitative data gathering project with CEN families	Spring 2021	Spring 2021	G	CEN will have a better idea of what's required and who is going to do this piece of work once a APM is appointed for Clinical networks.
2020-25	CEN will continue to ensure meetings can be attended via remote means	Ongoing	Ongoing	G	Unaffected
2020-26	CEN will ensure that work is not duplicated with other networks for example PELiCaN or Long Term Ventilation pieces of work	Ongoing	Ongoing	G	Unaffected
2020-27	CEN will maintain links with third sector organisations and	Ongoing	Ongoing	G	Unaffected.

1. Workplan Objectives 2020-21					
Objective Number	Smart Objective	Planned end dates	Projected End Date	RAGB status	Position
	other relevant agencies				<p>Email and skype meetings but no face to face meetings nor visits e.g. to Craighalbert School.</p> <p>Planned teaching about CEN to CLW with alliance not going ahead as all teaching/meetings cancelled.</p>

Planned for the Next Reporting Period April-June 2020				
Task Name/Detail	Baseline Date	Current Forecast Date	RAG Status	Dependency Milestone ID
CEN will host quarterly Steering Group Meetings	30 April 2020 cancelled	27 August - planned	G	
CEN will host regular sub-group meetings and ensure work is being progressed	Meetings postponed until September	At least September 2020	A	
CEN will develop/update key network documents including; annual and 5-year work plan, annual reports	End May 2020	End May 2020 for annual report and 1-year work plan. End December at least for 5 year work plan update	A	
Website Development	Ongoing	Ongoing	G	
Appoint New Lead Clinician	End May 2020	Ongoing	A	LC tenure is due to finish and that outcome of recruitment exercise is awaited as COVID-19 has impacted on usual process timescales

Risk Management					
Risk / Issue (R / I)	ID	This	Last	Issue/Risk Name (as listed in Register)	Action/Progress
				There is a risk that...	
R				Items on the network workplan may not be completed in reporting period	
R				Could possibly be further disengagement with the network from stakeholders as meetings were cancelled/postponed	
R				LC tenure is due to finish and that outcome of recruitment exercise is awaited as COVID-19 has impacted on usual process timescales	

There are currently no risks logged in the Risk Log for CEN, potential risk noted above.

Appendix 5: Current CEN Care Quality Indicators

CQI	Definition/ clarification	Measurement
1. % of CEN within Scotland with: <ul style="list-style-type: none"> • Person Centred Childs Plan • Identified Named person • Identified Lead professional. • Continuing Complex Care package 	<ul style="list-style-type: none"> • The interventions required should be identified and form part of the Child's Plan (Children and Young Peoples Act Scotland 2014) Girfec. 	<ul style="list-style-type: none"> • Clinical Audit System
2. Identify the number of CEN at age 14 who have commenced transition in line with national guidelines from Scottish Transitions Forum 2017	<ul style="list-style-type: none"> • Identify date of initial planned Transition meeting within Childs Plan • Reflection of the Principles of Good Transition 3 (2017) evidenced within transition planning. Interventions required should be identified and form part of the Child's Plan (Children and Young Peoples Act Scotland 2014) • Nice Quality Guidance QS140 	<ul style="list-style-type: none"> • Clinical Audit System
3. Identify the number of CEN from birth to age 2 years being referred to Community paediatric service	<ul style="list-style-type: none"> • Time of referral to Community paediatrician / paediatric service from neonates. • Time of identification is 1st clinic date • CEN children require early intervention to provide practical strategies and emotional support. Early identification and support is particularly important to the development of young children • The Best Start – A 5 year Forward Plan for Maternity and Neonatal Care in Scotland: http://www.gov.scot/Resource/0051/00513175.pdf 	<ul style="list-style-type: none"> • Clinical Audit System • Data from developmental Physiotherapists working in tertiary neonatal units
4. 10% Increase in active parent members within the CEN NMCN network	<ul style="list-style-type: none"> • Kindred project - Develop robust family engagement strategy enabling parents to actively participate in network activity • DCYPAG national working group • Education group 	<ul style="list-style-type: none"> • Membership numbers and Feedback from parents involved in various projects relating to CEN and parent and family engagement
5. Engage with undergraduate training providers across Scotland within health, education, social work and third sector to identify educational resources / input for staff caring for CEN and their families	<ul style="list-style-type: none"> • Contact with all HEI's • Share CEN learnPro resources with lead trainers/educators across Scotland with a view to embed them in their local training and education programmes 	<ul style="list-style-type: none"> • Data from HEI's and training providers • Annual statistical uptake of learnPro activity