



# **Children with Exceptional HealthCare Needs**

## **ANNUAL REPORT 2018/19**

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## 1. Executive Summary

During the 2018-19 reporting period the Children with Exceptional Network (CEN) had a challenging year due to prolonged and unplanned staff absence within the Network Team., In spite of this the network was able to deliver a number of achievements through ongoing work with CEN clinicians and stakeholders from primary, secondary and tertiary care, to enable equitable provision of high quality clinically services throughout Scotland.

The network held a facilitated peer review meeting (clinical case-based discussion) which focused on complexities of discharging children and young people who require long term ventilation (LTV) into the community.

The network held a very successful national conference at Murrayfield Stadium Conference Centre in February; with a theme of “Promoting Excellence in Care” the keynote speaker at the event was Minister for Children and Young People, Ms. Maria Todd. The conference focused on three key areas, policy and quality improvement, psychological aspects of care and technology enabled care.

The network continued to work in partnership with Kindred to engage families with the work of CEN NMCN alongside Kindred’s advocacy service.

The 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.

CEN supported the development of the Scottish Government resource ‘Supporting Disabled Children, Young People and their Families’ by facilitating one of eight national consultation events on behalf of Scottish Government. This event focused on 4 key areas chosen by parents, with round table discussions to inform Policy colleagues about of the lives of Children and Young People who have exceptional needs, their families and the services that are available to them. This work was for this was in addition to work undertaken by the CEN Network Team to gather information through consultation with CEN NMCN members. The resource was launched on April 24<sup>th</sup> by Ms Marie Todd, Minister for Children and Young people.

There has been an active programme of engagement and consultation with stakeholders including the Royal College of GPs (RCGP), Community Speech and Language Team (CSLT), and third sector organisations.

Work to establish a comprehensive national data set has proved challenging but has progressed significantly with training in and use of the CEN instance of the Clinical Audit System.

## 2. Introduction

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

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

## 3. Network Objectives

CEN aims to improve information for children, parents and professionals and raise awareness about the needs of children and young people with exceptional and complex healthcare needs.

The networks key 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) 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. Specifically, to improve the equity of assessment, planning and delivery of interagency care planning for CEN within a community setting, through 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.
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 health and other care provision for children with exceptional healthcare needs and their families through 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 (CQI).
6. Generate better value for money in how services are delivered.

## 4. Report against 2018 /19 Workplan

During the reporting period there was unforeseen and unplanned staff illness within the Network Team, which resulted in anticipated network activity being cancelled or postponed due to limited capacity to progress work.

In December 2019 the CEN Lead Clinician, Dr Susan Buck and the CEN Steering Group Chair, Ms Debbie McGirr met with the CEN commissioners as part of the network's Annual Performance Review (APR) and noted the concerns that they had. The commissioners recommended that the network prioritise and revise the timelines of the CEN strategic workplan that had been agreed through the National Specialist Services Committee (NSSC) and extend the review period by a year years. The revised and amended CEN strategic work plan was issued and endorsed electronically by the CEN Steering Group in January 2019 and supersedes the work plan and progress that was presented in the CEN 2018 Midyear Report.

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.

### 4.1 Communication and Engagement

To facilitate more efficient and effective communication with stakeholders the network collated existing national CEN distribution lists.

Dr Susan Buck (CEN Lead Clinician) engaged with a range of colleagues and groups to promote awareness of the challenges in caring for Children with Exceptional Needs. She also provided subject matter expertise to the Disabled Children and Young People's Advisory Group. This has included contributing to the development of the Scottish Government's "parent club" resource by providing information regarding children who have highly complex needs and resources developed by CEN NMCN.

#### 4.1.2 Peer Review Education Events

In April the network held a facilitated peer review meeting (clinical case-based discussion) titled "Care of Children and Young People Requiring Long Term Ventilation - Decision Support Tool". The review focused on the complexities of discharging children and young people who require long term ventilation (LTV) into the community. The event provided delegates with the opportunity to discuss what was currently working well and what could be improved as well as to consider opportunities to address variation and improve services going forward.

The CEN peer review outputs are available at: <https://www.cen.scot.nhs.uk>.

The information collated from the CEN peer review aligns with the recently published review of the use of Paediatric Intensive Care Unit (PICU) beds and how children requiring Long Term Ventilation (LTV) may have inappropriately extended hospital admissions. The network anticipates that the information gathered from the CEN peer review meeting will inform future network activity as it aligns with the Realistic Medicine agenda.

The planned Bladder and Bowel Incontinence peer review that had been scheduled to take place in October was rescheduled to May 2019. The network took the opportunity to extend the invitation to the Scottish Paediatric Renal and Urology Network (SPRUN) and promoted the event through its distribution lists, and Children and Young Peoples Twitter Account.

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### 4.1.3 Education Event

In February 2019, the network facilitated an education event titled “Promoting Excellence in Care”

The conference was focused around three key areas, policy and quality improvement, psychological aspects of care and technology enabled care. Dr Gregor Smith, deputy CMO highlighted the role of the network in enabling achievement of Realistic Medicine aims and Dr Eddie Doyle, Adviser to Scottish Government in Paediatrics chaired the afternoon session.

The event was free of charge to the 160 delegates that attended from across Scotland. The key messages report from the event is available at: <https://www.cen.scot.nhs.uk>.

### 4.1.4 Learn Pro

The network has developed seven Learnpro modules (appendix 2) that are accessible to all to staff working in NHS Scotland, Children’s Hospices Across Scotland (CHAS) and third sector colleagues and , with evidence that demand and completion for some is greater than others the network is considering ways of utilising this resource more effectively.

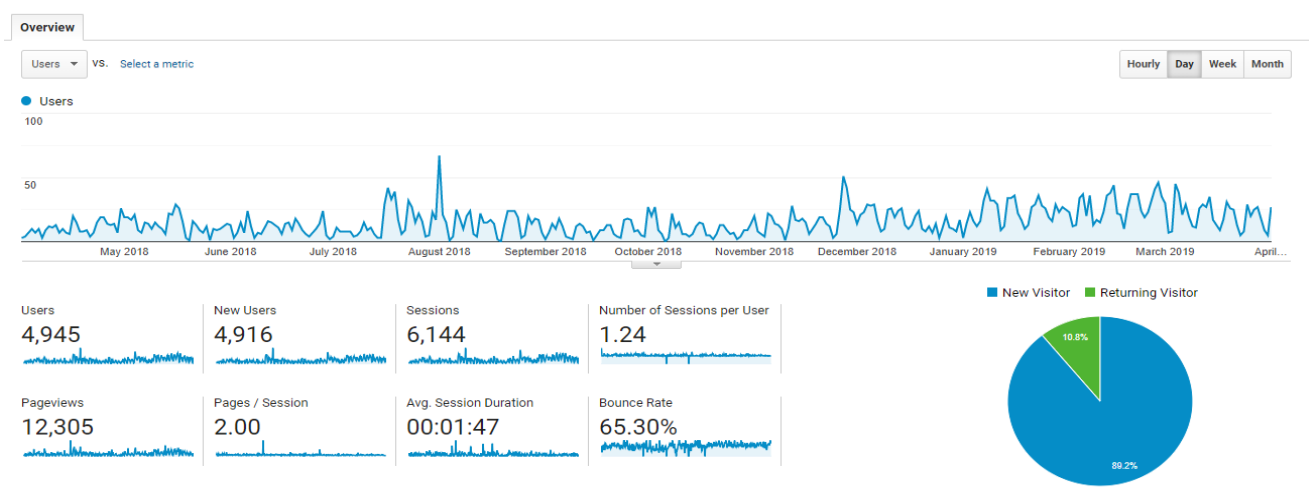
### 4.1.5 CEN Website

The CEN website is an important resource for the CEN community and its stakeholders to access up to date relevant educational information. During the reporting period the network focused its efforts on updating and maintaining the website, refreshing the education resources. Further to that work the network has seen a significant increase in the number of visits to the website (see figure 2) and a teacher contacted the network on behalf of a concerned parent, The network was able to bring together the clinical and professional expertise of the lead clinician, specialist nurse and Kindred who were able provide supportive clinical information for the teacher to share with the concerned parent.

***“Thank you everyone for your advice and support. I’ll contact mum today and discuss.  
All of your advice is extremely helpful.”***

Figure 1 professional feedback

The CEN website is available at: <https://www.cen.scot.nhs.uk>.



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Figure 2 illustrates the 55% increase in website use from data gathered in December 2017-July 2018 and August 2018-March 2019

Page	Pageviews	Unique Pageviews	Avg. Time on Page	Entrances	Bounce Rate	% Exit	Page Value
	12,305 % of Total: 100.00% (12,305)	9,518 % of Total: 100.00% (9,518)	00:01:46 Avg for View: 00:01:46 (0.00%)	6,131 % of Total: 100.00% (6,131)	65.30% Avg for View: 65.30% (0.00%)	49.83% Avg for View: 49.83% (0.00%)	\$0.00 % of Total: 0.00% (\$0.00)
1. /	2,625 (21.33%)	1,991 (20.92%)	00:01:45	1,847 (30.13%)	58.15%	51.12%	\$0.00 (0.00%)
2. /parent-information-leaflets/	492 (4.00%)	359 (3.77%)	00:02:34	319 (5.20%)	35.83%	55.69%	\$0.00 (0.00%)
3. /elearning-toolkit/	491 (3.99%)	372 (3.91%)	00:02:58	234 (3.82%)	54.27%	61.30%	\$0.00 (0.00%)
4. /home/pathways-of-care/discharge-planning/	379 (3.08%)	182 (1.91%)	00:01:03	159 (2.59%)	37.74%	33.51%	\$0.00 (0.00%)
5. /continuing-care-packages/	374 (3.04%)	219 (2.30%)	00:03:32	177 (2.89%)	69.44%	51.87%	\$0.00 (0.00%)
6. /cen-criteria/	328 (2.67%)	280 (2.94%)	00:02:32	123 (2.01%)	68.80%	53.96%	\$0.00 (0.00%)
7. /home/useful-links/	316 (2.57%)	201 (2.11%)	00:02:23	169 (2.76%)	67.26%	50.32%	\$0.00 (0.00%)
8. /palliative-care/	284 (2.31%)	192 (2.02%)	00:03:14	162 (2.64%)	59.39%	62.68%	\$0.00 (0.00%)
9. /learning/	281 (2.28%)	213 (2.24%)	00:00:41	48 (0.78%)	40.43%	26.33%	\$0.00 (0.00%)
10. /contact-us/	250 (2.03%)	181 (1.90%)	00:01:34	23 (0.38%)	69.57%	40.40%	\$0.00 (0.00%)

Figure 3 illustrates the number of visits to the CEN website pages

### 4.1.5 Twitter

The network began using the National Network Management Service (NNMS) Children and Young Peoples Twitter Account at its annual event with Conference Chair, Dr Pat Carragher, Medical Director Children's Hospices across Scotland (CHAS) inviting delegates to share their learning through the Twitter Account using the hashtag #CEN2019.

### 4.1.6 Working in Partnership

The network has continued to maintain its close working relationship with the parent led 3<sup>rd</sup> sector organisation Kindred. In August the CEN steering group agreed to submit a joint application to the Big Lottery Fund to support continuation of the Exceptional Families Project (EFP). Unfortunately this was not supported due to the high number of applications. However, the project will continue until August 2019 with existing commitment of £56K from the Big Lottery Fund limited the award to and the £64K match funding from Scottish Government.

The network was successful in engaging a family member to represent families and careers on the CEN steering group for future meetings. Through the EFP distribution list, CEN NMCN has contacted parents to invite them to become involved in the network as members for information and consultation.

The EFP project report is available on the CEN website at: <https://www.cen.scot.nhs.uk>





Figure 4: Collage of images from the Kindred Exceptional Families Project

## 4.2 Collection of Standardised Data: Clinical Audit System

Collecting accurate data about the incidence and complexity of children and young people with exceptional healthcare needs has always been a challenge. This group are very diverse, are seen in many different clinic settings and are a small group numerically dispersed throughout Scotland.

At inception the network adopted the National Support Needs System (SNS) as a means of data collection and reporting. This was despite its limitations as not all Boards that used the system collected the same data. In 2017 following a strategic SGHSCD decision to decommission the SNS and delays in developing a replacement, the network opted to develop an instance of the Clinical Audit System (CAS) to meet the needs and requirements of the network and only collects information regarding patients that met the CEN NMCN criteria.

The CAS will provide CEN NMCN with a more accurate figure for Scotland which will enable the network to effectively contribute to service development and planning for Children Young People and their families, as well as evidencing the resource need in Scotland.

### 4.2.1 Clinical Audit System Training (CAS)

During the reporting period the network focused on delivering training to support the ongoing development and use of the CAS to enable more accurate and consistent data collection. Figure 5 illustrates the current position in relation to completion of training requirements in each NHS Board.

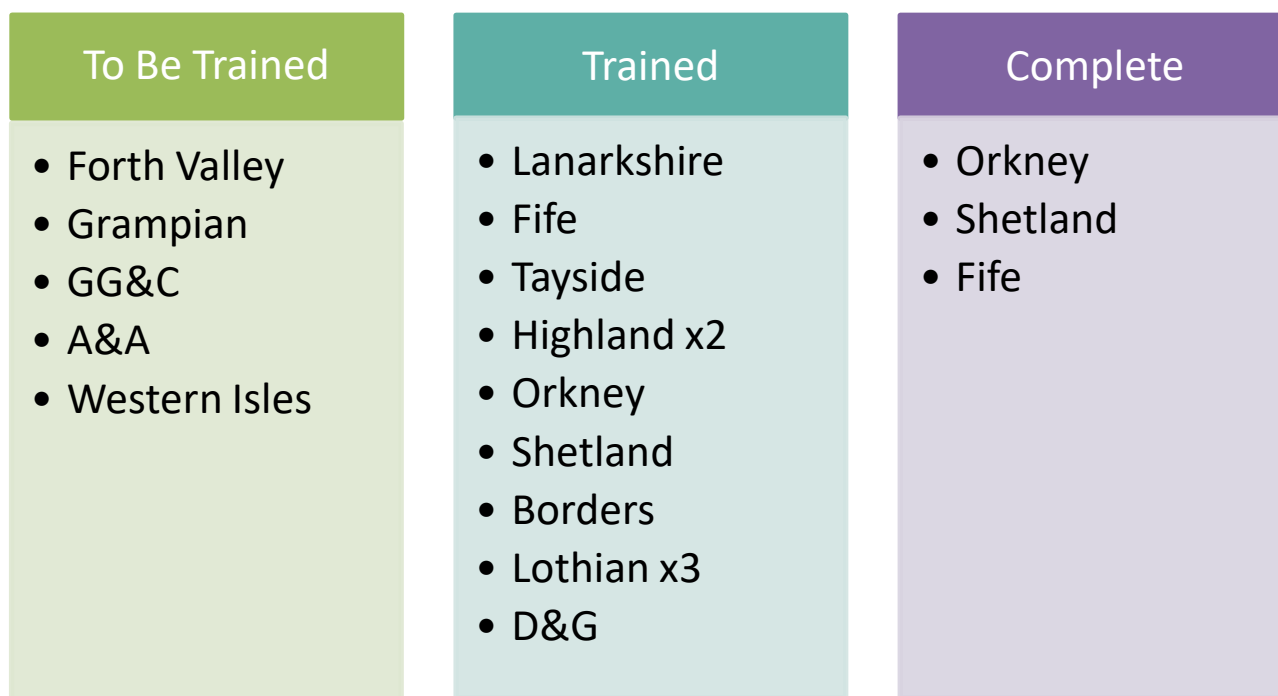


Figure 5-Illustrates the CAS training plan in the boards

#### 4.2.2 Kindred Data

The Exceptional Families Project is a collaboration between CEN NMCN and Kindred which aims to improve awareness of the network and access to support for families of CEN. An important measure is the number of CEN families who have engaged through the EFP. In January 2019 the CEN Data Analyst and the Director of Kindred met to ascertain the number of CEN patients that were on the Kindred database. It was noted that whilst it may appear that Kindred do not have many CEN patients on their database, this could be because Kindred staff may not be trained to identify whether a patient meets the CEN criteria.

To facilitate a greater understanding of the number of CEN children on the Kindred data base, the CEN Lead Clinician met with the Director of Kindred to inform them of the CEN criteria that was used for CEN assessment. Kindred are working with the CEN network to highlight the benefits of accurate data collection using CAS and the process of giving consent.

The CEN Data Analyst will continue to work with Kindred and NHS Boards board to improve consistency and accuracy in data collection to assist ongoing and future service planning.

### 4.3 Training and Education

There has been an ongoing programme of developing website resources to support education and contributing to other education events e.g. the Lothian Community Paediatrics Team's study day.

#### 4.3.1 Learnpro Modules

To date the network has developed seven Learnpro modules (appendix 2) that are accessible to all to staff working in NHS Scotland, Children's Hospices Across Scotland (CHAS) and third sector colleagues.

## 4.4 Service Planning and Development

### 4.4.1 Realistic Medicine Value Improvement Fund

In August 2018 the network submitted an application to the Realistic Medicines Value Improvement Fund to progress work on the Children & Young Peoples Continuing Care Framework - Development of a National Decision Support Tool (DST),

Due to the large number of applications from across Scotland, the network application was not successful. In advance of the 2019 application process the network has sought feedback from Dr Alex Stirling, National Services Scotland (NSS) Realistic Medicine Champion on how it can improve and strengthen its application for funding.

to evaluate the use of the “Decision Support Tool”, which supports planning for continuing care packages delivered by NHS Boards within the community setting.

### 4.4.2 NHS Lothian –Providing Clinical Expertise

In February 2019 CEN NMCN was invited to contribute to the NHS Lothian Paediatric Palliative Medicine Service strategic planning event by Ms Marina Copping, Clinical Information Manager NHS Lothian Maternal and Child Health Planning, Policy and Performance Directorate.

Dr Buck, CEN Lead Clinician attended the event and presented to the Clinical Director and Senior Nurse from Great Ormond Street Hospital (GOSH) palliative care services who had been invited to review the current services in NHS Lothian and make recommendations on how the service should be developed to enable it to be benchmarked across national standards for excellence in care.

Dr Buck provided an oversight of how the CENNMCN works to promote engagement and quality of care at a national level, and gave an oversight of the changes within the Primary Health Care Team (PHCT) in Scotland and how this would affect service delivery.

### 4.4.3 Paediatric End of Life Care Network (PELiCAN) Providing Clinical Expertise

CEN contributed to and supported the development of the Paediatric End of Life Care Network (PELiCAN) application to become a commissioned network by providing clinical expertise during the consultation and engagement process. The PeLiCAN network was commissioned in April 2019. SCYPPEX, to which CEN NMCN contributed, will no longer meet as it has been subsumed by the new network.

## 4.5 Quality improvement

### 4.5.1 Quality Improvement Strategy for CEN Managed Clinical Network

The network has developed a Quality Improvement (QI) strategy that was endorsed by the CEN steering group in March 2019. During the reporting period the network progressed the following QI priorities

- Creating parent/professional areas within the CEN Website

Refer to section 4.1.4

- Delivery of annual conference

Refer to section 4.1.4

Whilst the network did not have capacity to create a Parent Forum from the Exceptional Families Project (EFP), through Kindred the network sent a letter to families in April inviting them to become involved in the CEN NMCN, as well as informing them about the CAS.

#### 4.5.2 Care Quality Indicators (CQIs)

Care Quality Indicators CQI's were reviewed by CEN and agreed in March 2017 for the ongoing work of the network (appendix 5). The network had identified that it would evaluate the CQIs each year. However, limited capacity within the Network Team meant that this was not undertaken this year.

#### 4.5.3 CEN Care Pathways

The network steering group highlighted that the CEN care pathway 'steps' and associated resources on the website are out of date. Agreement has been reached to hide this resource in the meantime and label this section "under development". A clear project plan will be developed to manage the updating of this online resource for professionals, initially by the development of a short life working group (SLWG) to review the pathways.

### 5. Effective Network Structure and Governance

The CEN NMCN Lead Clinician is Dr Susan Buck. Dr Buck is a GP and Associate Adviser in GP Postgraduate Education and was appointed as Lead Clinician 1.5 P/A in 2018, her tenure ends in 2020.

The CEN Service Level Agreement runs concurrently from 2017 until 2020.

### 6. Plans for the Year Ahead

The National Network Management Service (NNMS) will continue to provide CEN with effective Programme Management and Programme Support Officer resources to enable the network to progress the following programme of activity during the 2018-19 reporting period.

The network will review the network structure and membership to ensure it remains fit for purpose and ensures that there are effective support structures for CEN in Scotland that has effective coordination between national services, the network and local services.

The network will ensure that the terms of Reference for the Steering Group. Data group and Education group are up-to-date

The network will engage with families, including through the EFP to provide information and signposting to resources and consult about their needs. Parents will be represented on the CEN steering group.

#### 6.1 Service Development and Delivery

The network will continue to contribute to national policy development through being active members of the DCYPAG.

The CEN NMCN will promote the work that it undertakes through the Realistic Medicine Agenda and use approved QI methodology in the work that it progresses

##### 6.1.1 Care Quality Indicators

The network will review the 5 Care Quality Indicators to ensure that they are fit for purpose and align with the CAS

### **6.1.2 Care pathways**

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, actioned through the establishment of a SLWG.

## **6.2 Stakeholder Communication and Engagement**

The network will review the CEN communication and engagement strategy to ensure that it reflects the needs of CEN and its stakeholders.

It will keep the CEN NMCN membership group informed of recent developments and current consultations.

### **6.2.1 Newsletter**

The network will issue three newsletters as a mechanism of engaging with the CEN community and its stakeholders on the work that the network undertakes and plans to do.

### **6.2.2 Website**

The network will continue to maintain and further develop the CEN website to ensure that it provides up to date information and resources for both families and professionals. This will include developing sections on the Highland Technology Pathway, housing issues, carers including young carers and resources following on from the peer review events for continence and communication.

### **6.2.3 CEN-Kindred Exceptional Families Project**

CEN will continue working in partnership with the Kindred for the Exceptional Families Project (EFP), by attending the EFP Steering Group, and attending the EFP professional engagement events. CEN will continue to engage with other non statutory organisations to ensure that engagement and advocacy is available nationally

## **6.3 Education**

### **6.3.1 CEN Education Strategy**

The network will refresh its education strategy to ensure that it accurately reflects the needs to CEN and its stakeholders.

### **6.3.2 CEN Education Group**

The CEN NMCN education group will review and refresh all educational resources to ensure currency. The group will liaise closely with Third Sector and Government partners to promote and publicise relevant policy and resources

### **6.3.3 CEN Conference**

The CEN NMCN Education Group will provide strategic direction and oversight of the CEN 2020 annual conference.

### **6.3.4 Peer Review meetings**

The CEN NMCN will facilitate 2 peer education events on the topics of Continence and as a joint event with the SLT teams on Communication.

## 6.4 Audit and Continuous Quality Improvement

### 6.4.1 Quality Improvement Strategy

CEN will review and update its Quality Improvement Strategy.

The network is planning to develop a quality improvement pilot with the RCGP Interface Lead looking at identifying children with exceptional healthcare needs in primary care, ensuring that they have ACP and eKIs with identification of their carers, as well as linking PHCT members to the CEN NMCN website.

### 6.4.2 Clinical Audit System (CAS)

The CEN Information analyst will continue to work with clinicians and boards to promote all boards in Scotland using the CEN CAS

Through the CEN NMCN Data Group, CEN will work to establish accurate data about CEN, their geographical location, health needs including type of feeding and support for breathing. Initial data collection indicates that the numbers of CYP nationally will be higher than previous estimates, providing powerful evidence for resource need.

## 6.5 Value

The CEN NMCN brings together professionals from statutory and non statutory services in NHS Scotland to make recommendations and improve care for CEN and their careers.

The CEN NMCN provides up-to date educational and training resources for professionals on the CEN NMCN website.

## 6.6 Risk and issues

The network is moving into the next reporting period without dedicated human resources.

## Appendix 1: CEN Criteria

A child or young person (up to the age of 19) is defined as having exceptional healthcare needs if they have severe impairment recorded in at least 4 categories together with enteral/parenteral feeding or have severe impairment recorded in at least 2 categories and require ventilation/ Continuous Positive Airway Pressure (C-PAP) and the impairments are sustained and ongoing or expected to last for more than 6 months.

- Learning and Mental Functions
- Communication
- Motor skills
- Self care
- Hearing
- Vision

## Appendix 2: Learnpro modules

The network developed the following seven Learnpro modules.

- Consent and Capacity
- Communications
- Early Support
- Emotional Impact
- GIRFEC (Getting It Right for Every Child)
- Identifying Outcomes
- Transition

The modules are accessible to all to staff working in NHS Scotland, Children's Hospices Across Scotland (CHAS) and third sector colleagues.

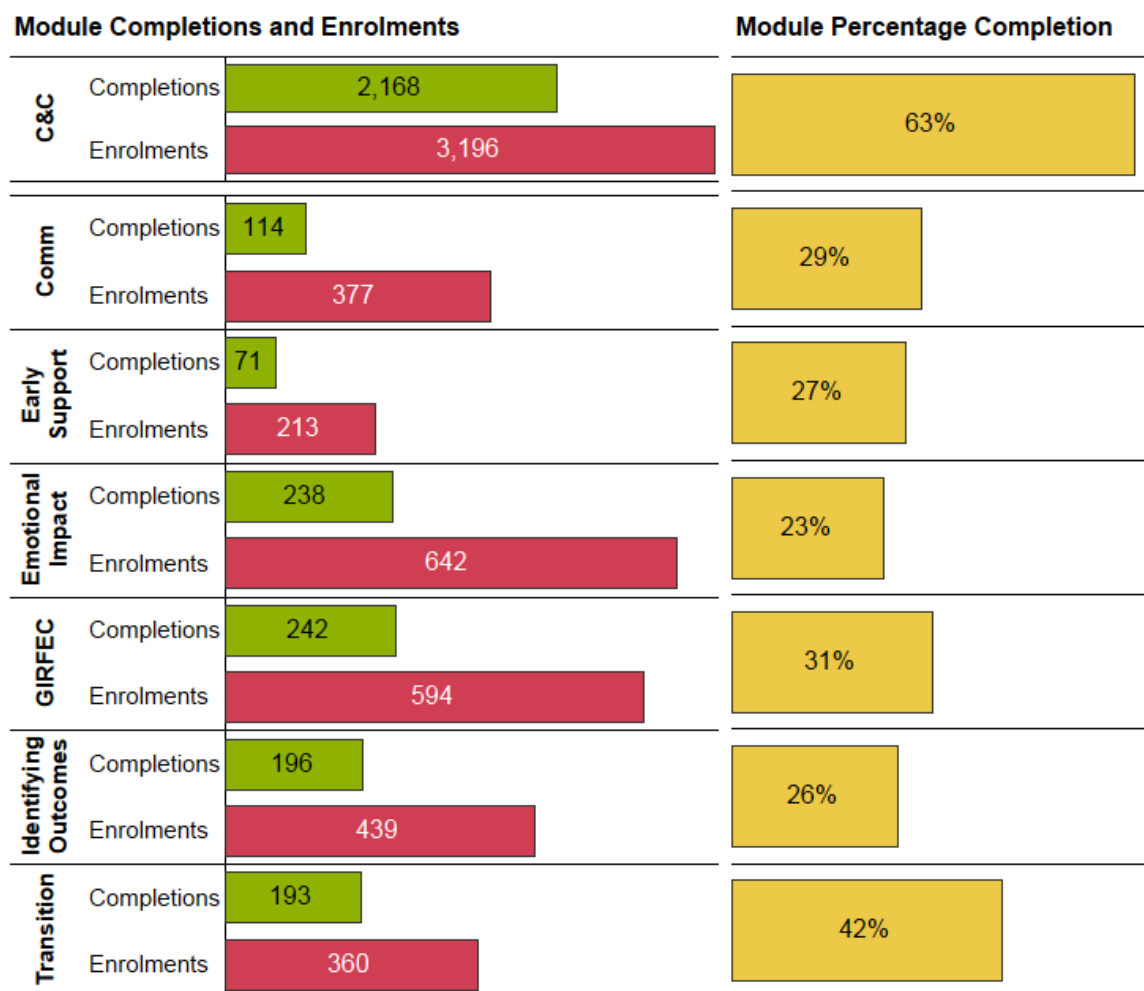


Figure 1: Shows the number of completions against number of enrolments with a percentage of completion.



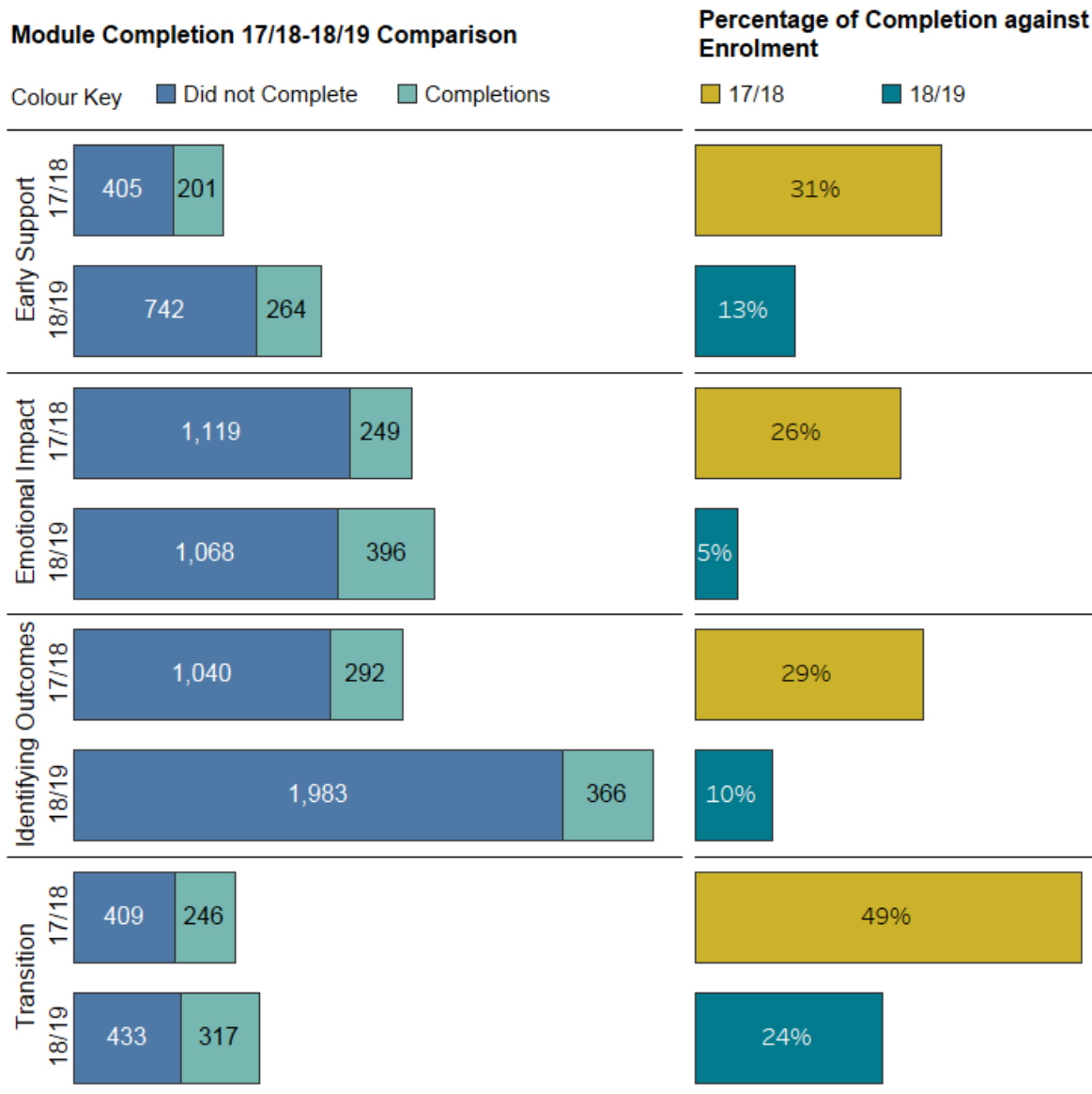
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### Modules Completed by Division/Trust

NHS Greater Glasgow and Clyde	1,082
NHS Lothian	634
NHS Lanarkshire	394
NHS Dumfries and Galloway	226
NHS Highland	222
NHS Fife	164
NHS Ayrshire and Arran	147
NHS Tayside	50
NHS Forth Valley	42
NHS Borders	16
NHS Shetland	6
NHS Orkney	4
NHS National Services Scotland	2
NHS Western Isles	1
NHS Grampian	0
Education	228
Care Homes	0
Charities	0
Healthcare Professionals	0
Voluntary Sector	0

**Figure 2: Indicates location in which modules were complete with Greater Glasgow and Clyde having the highest uptake.**

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**Figure 3: Compares modules completed between financial years 17/18 and 18/19.**

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Appendix 3: CEN 2018-2019 Workplan

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 01/06/2018	Anticipated Outcome / evidence	RAGB status
1	The network will complete the objectives identified in the CEN NMCN / Kindred Exceptional Families Project by November 2018	1:5	April 2018 – November 2018	Education group	Final report of EFP project completed and published.  EFP Steering group become dedicated CEN NMCN Parent Forum.	EFP report circulated nationally to all NHS Boards.  Project and report shared at network conference Feb 2019  Families caring for CEN feel active partners within the network  Families caring for CEN actively contribute to national policy and guidance.	A
2	The network will develop a project and working group to co-ordinate the update the CEN Care pathway resource by March 2019	1:2:3:4:5:6	April 2018 – March 2019	Programme Manager /Steering group /Education sub group	Care pathways on website to be hidden as under construction.  Education sub group to identify working group for care pathway review and development  Development of project	Block access to pathways  Develop project plan for care pathway development and first areas for development.  Identify members for	R

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 01/06/2018	Anticipated Outcome / evidence	RAGB status
					<p>plan to update sections of pathway and associated resources.</p> <p>Review the outcomes and measures indented within each step are clinically effective and set standard of care</p> <p>Capture baseline for website activity of access to care pathways</p>	working group.	
3	The Network will deliver an Annual Conference by end February 2019.	1:3:4	01/05/2018 – 28/02/2019	Education working group/Steering group	<p>Venue Confirmed with suitable disabled access.</p> <p>Save the Date sent.</p> <p>Market place advertised</p> <p>Programme and speakers identified –professionals and parents</p> <p>Evaluation form created</p> <p>CPD identified for professional attendees</p>	<p>Conference delivered successfully.</p> <p>Evaluation from attendees identifies learning has occurred and topics for future events.</p>	<b>G</b>
4	The Network will deliver two, topic specific,	1:2:3:4:5:6	01/05/2018 – 31/11/2018	Education sub group	Co-ordination, delivery and evaluation of two	2 Peer reviews have been completed	

### Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 01/06/2018	Anticipated Outcome / evidence	RAGB status
	Professional Peer Review events for NHS professionals by end November 2018.				<p>Professional Peer Review Education events.</p> <p>Booking and planning of suitable venues with Chair and VC for events.</p> <p>Advertising nationally and within professional membership the events.</p> <p>Peer Review 1: Decision Support Tool, Learning Centre, QEUH, Glasgow</p> <p>Peer Review 2: Bladder and Bowe Dysfunction – Learning Centre, QEUH, Glasgow</p>	<p>Evaluation from Peer Reviews highlights learning taken place.</p> <p>Topics for future events identified.</p>	A
5	The network will write an Education Strategy for 2018 – 2020 by end March 2019	1:3:4:5	01-04-2018 – 31-03-2019	Programme Manager/ Education group	Development of education strategy within NSS templates.	<p>Strategy document completed.</p> <p>Clear evidence of education plan for network till 2020.</p> <p>Document captures educational outcomes for network.</p>	R

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 01/06/2018	Anticipated Outcome / evidence	RAGB status
6	<p>The network will roll out training of CEN NMCN Clinical Audit System across all NHS boards by end October 2018</p> <p>The network will identify a CEN NMCN CAS Data Champion within each NHS Board by End October 2018</p> <p>PHI will provide an annual data report on CEN hospital admissions from the SNS and additional CHI provided by end March 2019</p> <p>The network will ensure that CAS Data provides measurement for CEN NMCN CQI's by March 2019.</p>	1:3:4:5	01/04/2018 – 31/03/2019	PM/Data & Audit working group	<p>Training of CAS delivered within all NHS Boards in Scotland.</p> <p>CHI data shared with PHI to identify hospital admission data.</p> <p>Data champions list to be updated</p> <p>CAS data to be reviewed to identify if capturing CEN NMCN CQI's.</p> <p>GDPR is reflected within all CAS documentation and data collection.</p>	<p>CEN NMCN Annual data report from CAS sent to all Data champions within NHS Boards.</p> <p>CAS data captured as identified within CEN NMCN CQI's</p> <p>Network cannot identify numbers of CEN who have not consented to join CAS.</p>	A

### Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

7	The network will identify 2 champion NHS boards to Undertake pilot study of use of DST ad evaluate outcome by end March 2019.	3:4:5	01/04/18 – 31/03/2019	Steering group	<p>Application to QI Hub to support project.</p> <p>Identify with Medical Director possible trainee to take on project</p> <p>Pilot of DST health assessment care tool to be completed for ventilated CYP coming into community setting.</p> <p>Development of DST evaluation tool</p>	<p>Funding/project lead identified.</p> <p>Evaluation of DST as a health assessment care tool to completed</p>	R
	The network will review all group memberships within CEN NMCN in line with GDPR requirements by end December 2018	3:4:5	01-05-2018 – 31-12-2018	PSO	All members of network/ steering and working groups will be reviewed and consent for membership accepted		R
9	The Network Website resources are evidence based and up to date by end March 2019.	1:2:3:4:5:6	01-04-2018 – 31-03-2019	Education working group/steering group			A
10	The network will identify a project plan to develop a Primary Care Resource for all practitioners around CEN	1:2:3:4:5:6	01/04/2018 – 31/03/2019	Education working group/Steering group	<p>Capture feedback from Cradle to Grave events re learning preferences</p> <p>Utilise the NES CPD Connect survey results</p>		R

### Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 01/06/2018	Anticipated Outcome / evidence	RAGB status
	by end March 2019.				and changes in PHCT new GP contract to influence resource development.		
11	<p>The network will review annually its CQI's through steering group by end March 2019. CQI's to.</p> <p>The network will develop a Quality Strategy by end December 2018</p> <p>The network will engage with C&amp;YP Improvement Collaborative for Scotland to identify joint work by end March 2019</p>	1:2:3:4:5:6	01-04-2018 – 31-03-2019	Steering group/PM/LC	<p>Evidence CQI's can be captured by the new CEN CAS</p> <p>Quality strategy to reflect CQI's and outcomes of the work plan</p>		R
12	The network will co-ordinate meeting with national neonatal networks identify transition pathway for CEN neonates by end March 2019 need for the development of an inter-professional Care pathway step for CEN transition from Neonatal	1:2:3:4:5:6	<p>Ongoing from 2017/18 workplan</p> <p>01/01/2018 – 31/03/2019</p>	<p>Education group</p> <p>Lead Clinician</p> <p>Programme Manager</p>	<p>Review 5 year Plan document for CEN</p> <p>Arrange meeting with neonatal regional network leads to identify if role for CEN within maternity pathway</p>		R



**Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19**

Objective Number	SMART Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 01/06/2018	Anticipated Outcome / evidence	RAGB status
	to paediatric services.						

## Children with Exceptional Need (CEN)

### WORKPLAN – 2019-20

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](#));
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 User are involved in the Network and explicitly in the design and delivery of service models and improvements.
4. Improved capability and capacity in CEN care through 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 (CQI).
6. Generate better value for money in how services are delivered.

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at April 2019	Anticipated Outcome	RAGB status
<b>1.Effective Network Structure and Governance</b>						
(linked to Quality Dimensions 3:4:5:6)						
2019-01	Develop the future role and remit of network alongside the national 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	Programme Manager and Dr Susan Buck		Effective support structures for CEN in Scotland, with effective coordination between	<b>G</b>

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at April 2019	Anticipated Outcome	RAGB status
					national service, network and local services	
<b>2.Service Development and Delivery</b> (linked to Quality Dimensions 1:2:3:4:5:6)						
2019-02	<b>Care Quality Indicators</b> During March 2019 and March 2020 the network will review the 5 Care Quality Indicators that it established in 2017	31/03/19 31/03/2020	CEN		Effective quality measures that underpin performance monitoring of the commissioned service and facilitate ongoing quality improvement activity	<b>G</b>
2019-03	<b>Care pathways</b> 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.	31/03/19 31/03/2020	CEN Programme Manager Lead Clinician		The CEN care pathway "steps" will be reviewed and re-written/updated so that they are current and relevant	<b>G</b>

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at April 2019	Anticipated Outcome	RAGB status
<b>3.Stakeholder Communication and Engagement</b> (linked to Quality Dimensions 1,3,4,5,)						
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			CEN communicate and engages with the network and its stakeholders in a variety of different communication channels  Newsletter  Website  Social Media (Twitter)	<b>G</b>
2019 -05	By April 2019 the network will issue 3 newsletters	01/06/2019- 30/04/2020	CEN  Programme			

### Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at April 2019	Anticipated Outcome	RAGB status
			Manager  Programme Support Office			
2019 -06	During 2018/2019 the network will continue to develop and maintain the CEN website			<p>CEN will continue to update the website with up to date information and resource.</p> <p>CEN will update the information that it has in the following area's on its website</p> <ul style="list-style-type: none"> <li>• Highland technology Pathway</li> <li>• Digital Communication</li> <li>• Young Carers, Communication.</li> </ul>		<b>G</b>
2019-07	CEN will continue to work in partnership with the attend the Kindred Exceptional Families Project (EFP); included but not exhausted too attending the EFP Steering	01/01/2019-31/12/2019			Increased engagement of patients and families to	<b>G</b>

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at April 2019	Anticipated Outcome	RAGB status
	Group attending the EFP family engagement events				identify priorities for service development.	
<b>4.Education</b> (linked to Quality Dimensions 1,2,3,4,5,6)						
2019-08	CEN will review its Education strategy	31/03/19-30/09/2019				
2019-09	CEN will facilitate 2 peer review meetings	01/01/2019-31/12/2019			CEN clinicians and other networks have the opportunity to learn about current developments	<b>G</b>
2019-10	CEN will facilitate a CEN conference in April 2020.	01/03/2019-30/04/2020			CEN and its stakeholders have the opportunity to learn about strategic policy initiatives.	<b>G</b>

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at April 2019	Anticipated Outcome	RAGB status
<b>5.Audit and Continuous Quality Improvement</b>						
(linked to Quality Dimensions 1,2,3,4,5,6)						
2019-11	CEN will review its Quality Improvement Strategy	31/03/19-30/09/2019			Quality Improvement methodology underpins all of the networks activity	<b>G</b>
2019-12	CEN will continue to support clinicians and boards to use the Clinical Audit System during 31 <sup>st</sup> March 2019- 31 <sup>st</sup> March 2020	31/03/19 31/03/2020			Data will facilitate service improvements	<b>G</b>
<b>6.Value</b>						
(linked to Quality Dimensions 1,2,3,4,5,60)						
2019-13	CEN will demonstrate the value that that it has for CEN and families, contained within other actions on the workplan.	31/03/19 31/03/2020				<b>G</b>

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

RAGB status	Description
<b>RED (R)</b>	The network is unlikely to achieve the objective by the agreed end date.
<b>AMBER (A)</b>	There is a risk that the network will not achieve the objective by the agreed end date but progress has been made.
<b>GREEN (G)</b>	The network is on track to achieve the objective by the agreed end date.
<b>BLUE (B)</b>	The network has been successful in achieving the network objective 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

### Appendix 4: CEN 5 Year Strategic Workplan

SMART Objective/ Strategic Aim	Year 1 (2017)	Year 2 (2018)	Year 3 (2019)	Year 4 (2020) Outcomes	Year 5 (2021)	Governance: who should chair who should be involved
<b>1. Communication and engagement</b>  By 2020 CEN NMCN will have an established national parent forum actively contributing to the work of the network	CEN will revise and deliver a refreshed communication strategy  CEN will be proactive in engaging and shaping disseminating	CEN/Kindred Exceptional Families project will deliver 5 engagement events.  EFP final report will be completed and published	Findings from EFP will be delivered at CEN conference  CEN will facilitate an Annual Event  CEN parent membership will be increased by 10%	Formal CEN parent forum is established within the network  CEN will facilitate an Annual Event  Disabled Children & Young People's Advisory Group	CEN family stakeholders are actively involved in network membership, steering and working groups.  CEN will facilitate an Annual Event CEN NMCN will provide stakeholder feedback to:	<ul style="list-style-type: none"> <li>NNMS</li> <li>Lead Clinician</li> <li>Education working group</li> </ul>



## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

SMART Objective/ Strategic Aim	Year 1 (2017)	Year 2 (2018)	Year 3 (2019)	Year 4 (2020) Outcomes	Year 5 (2021)	Governance: who should chair who should be involved
	<p>national policy</p> <p>CEN will issue Quarterly newsletters</p> <p>CEN/Kindred Exceptional Families Project (EFP) launched at the Scottish Parliament and will deliver 5 engagement events with CEN/families</p> <p>CEN website develops family resource area</p> <p>Disabled Children &amp; Young People's Advisory Group (DCYPAG)</p>	<p>nationally</p> <p>Disabled Children &amp; Young People's Advisory Group (DCYPAG)</p>	<p>CEN/Kindred will undertake phase 2 of the family engagement project</p> <p>Disabled Children &amp; Young People's Advisory Group (DCYPAG)</p>	<p>(DCYPAG)</p>	<p>Disabled Children &amp; Young People's Advisory Group (DCYPAG)</p> <p>Scottish Children &amp; Young People's Palliative Executive group (SCYPPEX)</p> <p>CEN will have contributed to shaping and proactively contributed to shaping national policy by engaging with families <i>and CEN stakeholders</i></p>	
<p><b>2. Collection of standardised data</b></p> <p>By 2021 CEN will ensure that health boards capture CEN data using the same data definition which will be held within</p>	<p>Establish a SLWG that will scope the required definitions for the CAS</p> <p>The SLWG will</p>	<p>Pilot of CEN CAS data collection will commence within 1 health boards by October 2018.</p>	<p>Evaluation of CEN CAS data collection in NHS Fife will be undertaken to identify any gaps in</p>	<p>Review of data collection from further health boards undertaken by April 2020</p>	<p>NMCN CEN CAS data collection will be introduced to the remaining health boards to ensure all health boards in Scotland are</p>	<ul style="list-style-type: none"> <li>• CEN NMCN</li> <li>• CEN Data &amp;</li> </ul>

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

SMART Objective/ Strategic Aim	Year 1 (2017)	Year 2 (2018)	Year 3 (2019)	Year 4 (2020) Outcomes	Year 5 (2021)	Governance: who should chair who should be involved
<p>the Clinical Audit System (CAS).</p> <p>CEN will produce annual data reports re: numbers of CEN across Scotland</p>	<p>agree the national minimum data set for CAS for CEN NMCN data collection</p>	<p>Ongoing evaluation of CAS data will occur the year</p>	<p>data requirement.</p> <p>Review of data set to identify further data collection requirements</p> <p>NMCN CEN revised CAS data collection will be introduced to a further 3 health boards</p>	<p>NMCN CEN CAS data collection will be introduced to a further 6 health boards</p> <p>Annual data reports will be provided to HB's from CEN.</p>	<p>involved in completing CAS for CEN NMCN.</p> <p>Knowledge of the number of CEN children in Scotland location and technology enabled care</p> <p>Improved, consistent data collection which will ensure that NHS boards have accurate data to support local delivery planning and development</p>	<p>Audit Group</p> <ul style="list-style-type: none"> <li>• NSS CAS team</li> </ul>
<p><b>3. Develop an education strategy to inform the workforce and families</b></p>	<p>NMCN CEN education group will begin process of creating 'parent information' pages on CEN website</p>	<p>NMCN CEN education group will review and refresh all educational resources to ensure currency. The group will liaise closely with Third Sector and Government partners to promote and publicise relevant policy and resources</p>	<p>NMCN CEN will create educational 'development for professionals' pages on the website</p> <p>NMCN CEN education group will review and refresh all educational resources to ensure currency. The group will liaise closely with Third Sector and Government partners to promote and publicise</p>	<p>NMCN CEN education strategy will be reviewed and updated</p> <p>CEN will raise its profile across primary and secondary healthcare interface and become involved in primary healthcare team education opportunities</p>	<p>NMCN CEN will be actively involved in engaging with primary health care community staff learning events to promote awareness of the specialist needs of this client group</p> <p>Review the CEN learnpro modules regarding relevant and current</p>	<ul style="list-style-type: none"> <li>• CEN Steering group</li> <li>• Royal college of GPs in Scotland</li> <li>• CEN Education working group</li> </ul>

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

SMART Objective/ Strategic Aim	Year 1 (2017)	Year 2 (2018)	Year 3 (2019)	Year 4 (2020) Outcomes	Year 5 (2021)	Governance: who should chair who should be involved
			<p>relevant policy and resources</p> <p>Using national survey of education choices for Primary care this data will be used to shape the CEN education strategy relating to Primary care</p>			
<b>4. Development of a Children &amp; Young Peoples Continuing Care Framework (CCF) for Scotland to ensure consistency of complex care planning and delivery for families in Scotland</b>	Gain ethics approval for national pilot of the Decision Support Tool (DST) for continuing care assessment with identified health boards in Scotland.	Explore and engage with funding bodies to gain finance for pilot project	<p>Explore and engage with funding bodies to gain finance for pilot project</p> <p>SLWG to create draft project plan for DST pending funding</p>	<p>Develop CCF working group for project with identified co-ordinator</p> <p>Undertake pilot of the DST with identified health boards</p>	Combine literature with findings from pilot projects to develop a continuing care framework document	<ul style="list-style-type: none"> <li>• Scottish Government Child Health Support Group</li> <li>• CEN Steering group</li> <li>• CCF working group</li> </ul>
<b>5. Development of Governance Quality improvement Strategy for CEN NMCN</b>	<p>Development of agreed Care Quality Indicators (CQI's) for CEN NMCN between 2017 - 2021</p> <p>Annual evaluation of CQI outcomes</p>	<p>Annual evaluation of CQI outcomes within reporting structure of NNMS</p> <p>Contribution to national government policy</p>	<p>Annual evaluation and review of CQI outcomes within reporting structure of NNMS</p> <p>Development of a quality improvement</p>	<p>Annual evaluation and review of CQI outcomes within reporting structure of NNMS</p> <p>Contribution to national government policy development</p>	<p>Renewal of CEN Governance strategy</p> <p>Development of new CQI's as part of National Network /designation review process</p> <p>Contribution to national</p>	<p>CEN Steering group</p> <p>Lead clinician</p> <p>Programme manager</p>

### Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

SMART Objective/ Strategic Aim	Year 1 (2017)	Year 2 (2018)	Year 3 (2019)	Year 4 (2020) Outcomes	Year 5 (2021)	Governance: who should chair who should be involved
	<p>within reporting structure of NNMS</p> <p>Engagement with the C&amp;YP Improvement Collaborative for Scotland – identify CEN NMCN engagement plan</p> <p>Contribution to national government policy development agenda through active membership of DCYPAG and other policy and strategy initiatives</p>	<p>development agenda through active membership of DCYPAG and other policy and strategy initiatives</p>	<p>strategy document for CEN NMCN</p> <p>Contribution to national government policy development agenda through active membership of DCYPAG and other policy and strategy initiatives</p>	<p>agenda through active membership of DCYPAG</p> <p>Contribution to national government policy development agenda through active membership of DCYPAG and other policy and strategy initiatives</p>	<p>government policy development agenda through active membership of DCYPAG and other policy and strategy initiatives</p>	

**Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19**

**Appendix 5: CEN Care Quality Indicators (CQI) 2017/2020**

Continuous Quality Indicator	Definition/ clarification	Measurement
<p>1. % of CEN within Scotland with:</p> <ul style="list-style-type: none"> <li>• Person Centred Childs Plan</li> <li>• Identified Named person</li> <li>• Identified Lead professional.</li> <li>• Continuing Complex Care package</li> </ul>	<p>The interventions required should be identified and form part of the Child's Plan (Children and Young Peoples Act Scotland 2014) GIRFEC</p>	<p>Clinical Audit System</p>
<p>2. Identify the number of CEN at age 14 who have commenced transition in line with national guidelines from Scottish Transitions Forum 2017</p>	<p>Identify date of initial planned Transition meeting within individual Person Centred Childs Plan</p> <p>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 )</p> <p>Nice Quality Guidance QS140</p>	<p>Clinical Audit System</p>
<p>3. Identify the number of CEN from birth to age 2 years being referred to Community paediatric service</p>	<p>Time of referral to Community paediatrician / paediatric service from neonates.</p> <p>Time of identification is 1<sup>st</sup> clinic date</p> <p>Children with exceptional healthcare needs require early intervention to provide practical strategies and emotional support. Early identification and support is particularly important to the development of young children</p> <p>The Best Start – A 5 year Forward Plan for Maternity and Neonatal Care in Scotland: <a href="http://www.gov.scot/Resource/0051/00513175.pdf">http://www.gov.scot/Resource/0051/00513175.pdf</a></p>	<p>Clinical Audit System</p> <p>Data from developmental Physiotherapists working in tertiary neonatal units</p>
<p>4. 10% Increase in active parent members within the CEN NMCN network</p>	<p>Kindred project - <b>Develop robust family engagement strategy enabling parents to actively participate in network activity</b></p> <p>DCYPAG national working group</p> <p>Education group</p>	<p>Membership numbers and Feedback from parents involved in various projects relating to CEN and parent and family engagement</p>

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

<b>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</b>	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	Data from HEI's and training providers  Annual statistical uptake of learnPro activity
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## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

### Appendix 6: Steering Group Membership

*Alphabetical list of Steering Group members as of 31 March of reporting year, stating their designation and where applicable, the Health Board/organisation they represent.*

#### CEN Steering Group Membership 2017-18

Name	Surname	Role
Debbie	McGirr	Chair
-	-	CEN NMCN; Programme Manager; NSS
Dr Susan	Buck	CEN NMCN; Lead Clinician
Karen	Allen	Service Lead Speech & Language Therapy; NHS Lothian
Pauline	Beirne	AHP CYP National Lead; NHS NES
Elaine	Berry	Representing Councils and Social work (Independent consultant)
Sally	Egan	Child Health Commissioner; NHS Lothian
Hannah	Cairns	Child and Young Peoples Allied Health and Nursing Professional Lead; Capability Scotland
Dr Anna	Chillingworth	Consultant Community Paediatrician; NHS Lothian
Dr Phil	Davies	Respiratory Consultant Paediatrician; NHS Greater Glasgow & Clyde
Jean	Davies	Clinical Nurse Manager, Children's Services; NHS Ayrshire & Arran
Cheryl	DeSouza	Advanced Paediatric Practitioner Physiotherapist; NHS Greater Glasgow & Clyde
Beth	Frank	Complex Needs Nurse Co-ordinator; NHS Ayrshire & Arran
Sarah	Hay	Community Children's Nursing Sister; NHS Greater Glasgow & Clyde
Babs	Henderson	Associate Nurse Director, Children's Hospice Association Scotland (CHAS)
Margaret	Johnston	Team Leader; Integrated Community Nursing Service, NHS Lanarkshire
Dr Ciara	McColgan	Consultant Community Paediatrician, NHS Greater Glasgow & Clyde
Margaret	McFadden	Head Teacher, Croftcroign; Primary School, Glasgow
Seana	Moore	Head Teacher, Hampden Primary School, Glasgow
Lesley	McLaren	Family Support Co-ordinator; PAMIS
Dr Katherine	McKay	Consultant Paediatrician, Scottish Government
Susan	Orr	Social Work Scotland
Sophie	Pilgrim	Director; Kindred
Scott	Richardson-Read	Policy & Development Officer; ARC Scottish Transitions Forum
Corinna	Robertson	Family support team manager
Karen	Sinclair	Girfec Education Lead; NHS NES
David	Smyth	Paediatric Advanced Nurse Practitioner, Children with Complex Healthcare Needs; NHS Fife
Dr Laura	Somerville	Consultant Community Paediatrician; NHS Greater Glasgow & Clyde
Winnie	Taylor	Lead Speech and Language Therapist Community Child Health, NHS Grampian

## Children with Exceptional Health Care Needs (CEN): Annual Report 2018/19

Anne	Wilson	Development Officer; Action for Sick Children Scotland
Jackie	Young	Service Manager Child health Services/Lead Nurse; NHS Fife
Megan	Farr	Policy Officer SCCYP
Alexandra	Speirs	Senior Programme Manager ; National Networks, NSS

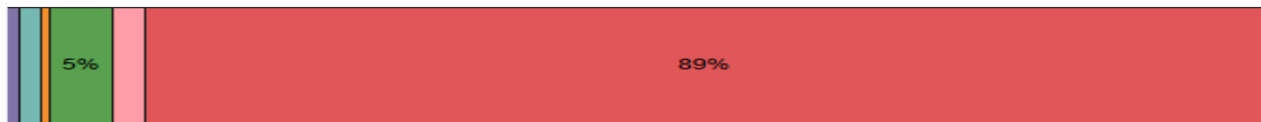
### Appendix 7: Finance

During the reporting period the network facilitated an annual event to over 160 multi professional statutory and non statutory health care staff and families.

The CEN commissioners agreed that the network could exceed it allocated budget to facilitate this event.

#### CHILD EXCEP HEALTH NEEDS (CEN) Financial Information

Job description	Account description	18/19
CHILD EXCEP HEALTH NEEDS (CEN)	HIRE OF ROOMS FOR MEETINGS	£7,252.84
	INTERNL CATERING RECHRG NPAY	£211.20
	OTHER PRINTING STATIONERY	£417.60
	OTHER PROVISIONS	£47.70
	PUBLIC TRANSPORT	£81.20
	TRAVEL SUBSISTENCE	£147.00
<b>Grand Total</b>		<b>£8,157.54</b>



Type	
<span style="color: purple;">■</span> PUBLIC TRANSPORT	<span style="color: green;">■</span> OTHER PRINTING STATIONERY
<span style="color: teal;">■</span> TRAVEL SUBSISTENCE	<span style="color: pink;">■</span> INTERNL CATERING RECHRG NPAY
<span style="color: orange;">■</span> OTHER PROVISIONS	<span style="color: red;">■</span> HIRE OF ROOMS FOR MEETINGS