Children with Exceptional Healthcare Needs National Managed Clinical Network (CEN)

Annual Report
2020/21

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1. Summary of Year / Current Position

This year the Children with Exceptional Healthcare Needs (CEN) Network delivered on 63% of workplan objectives. The Covid -19 pandemic was a significant factor in the network not being able to complete all of the planned workplan activities. Information on exceptions to the workplan and the mitigating actions that were taken can be found in Section 4 of this report.

Throughout 2020-21 CEN had a transformational year with a new compliment of staff. The network hosted a virtual strategic planning day and took the opportunity to refresh its strategic objectives to ensure that its future focus is reflective of the views of the network members and stakeholders.

Whilst the pandemic brought challenges, the network was still able to progress a revised programme of work; one of its main achievements was the quality improvement project that was endorsed by the Child Health Commissioners to complete the National dataset of CEN patients recorded Clinical Audit System (CAS), by March 2021. Another was the updating and upgrading of its catalogue of stand-alone LearnPro on line learning modules to create two Turas e-learning modules. The network was also involved in a joint project with Kindred Advocacy, gathering qualitative information from parents of children with exceptional healthcare needs regarding the effects of shielding throughout the Covid-19 pandemic.

The network took the decision to use the IT structure that was available to it to facilitate a number of its meetings virtually, this enabled network members and stakeholders to progress work throughout the Covid-19 pandemic. Where meetings were postponed relevant updates were provided electronically.

2. Key Highlights

Network Core Principle Links: Effective Structure, Service Development and Delivery & Stakeholder Communication and Engagement

2.1 Network Refresh
Throughout the reporting period, CEN worked to refresh its strategic priorities and overall objectives for the future. A number of activities were carried out in relation to this as detailed below.

2.1.1 Strategic Planning Day

The Network hosted a virtual Strategic Planning event in October; the purpose of this event was to; re-focus, re-align and re-engage with CEN members and stakeholders, old and new. The event was successful with 44 registrants and 38 attendees on the day.

There was opportunity for delegates to reflect on what the network had accomplished, whether the current programme of work was still relevant and to assess if historic pieces of work, that had not been not completed (e.g. updating care pathways and developing a Scottish continuing care framework) were still relevant.

Delegates also considered developments in the strategic landscape in order to enable the network and its stakeholders to develop a 3-year (2012-2023) strategic workplan and associated documents.

2.1.2 Membership of Groups

Throughout 2020-21 the CEN Core Team reviewed group membership, adopting a strategic approach to ensure that new members bring reflect the range of professional groups/disciplines and geographical areas. Other developments include the creation of a Communication and Engagement sub-group, responsible for delivery and oversight of the communication and engagement strategy and objectives and an Experts by Experience' (EBE) family engagement group.

Expert by Experience membership draws on families, carers, siblings and grandparents have the option to be involved in the network at a number of different levels;

- Informed –where members are kept up to date via email correspondence.
- Participate –where members share their experiences by attending and speaking at network conferences.

Families and careers who want to be part of the EBE group are able to join the group through the link on the Children and Young Peoples twitter feed or via the network website. Network family engagement continues to be complimented by Kindred's Exceptional Families Project (EFP) and the Kindred Facebook group. Figure 1 below illustrates the total twitter engagements with tweets regarding EBE group recruitment, these are excellent figures with only 16 tweets over four months, reaching over 11,400 people and over 200 interactions (e.g. clicks on tweet or opening links in tweet) showing the effectiveness of using this platform to reach stakeholders;

Network:	CEN		
Date of Tweet	No. of Tweets	Tweet seen by	Number interacted
Jan-21	3	1594	41
Feb-21	4	5159	88
Mar-21	4	3693	73
Apr-21	5	1000	5
TOTAL	16	11446	207

Figure 1 – EBE Group Twitter Engagements

Network Core Principle Link: Audit and Quality Improvement

2.2 Clinical Audit System (CAS) Project

During the reporting period, the network in collaboration with the Child Health Commissioners (CHCs) collected CEN Clinical Audit System (CAS) data from 11 Health Boards and achieved 92% completion of data from across Scotland (632 of estimated 689 children who meet the CEN network criteria). This was a significant improvement from the previous reporting period when the network only had data from three Health Boards and was limited to extrapolation of that data to estimate the

number of children in Scotland within the cohort. Specific success factors were the CHC's agreeing to support this work locally as part of a quality improvement project and addition of regular communication to staff in Boards to update them on local progress and gaps in data.

The project delivery date was extended from December 2020 until March 2021 due to the impact of the COVID-19 pandemic on staff capacity. The extension provided additional time for clinicians in the Boards to input data.

A summary of the data gathered can be seen in the figures below. The network will now share these data with stakeholders to consider how the information can be used to support service planning;

Health Board	CEN Patients on CAS	Estimated number of CEN Patients in Board	% CEN patients on CAS	Change since 03/20
Ayrshire & Arran	57	57	100%	+100%
Borders	18	18	100%	+67%
Dumfries & Galloway	7	16	44%	+44%
Fife	40	40	100%	-
Forth Valley	39	39	100%	+100%
Highland	39	39	100%	+53%
Grampian	20	69	28%	+28%
GGC	133	133	100%	+100%
Lothian	105	105	100%	+100%
Lanarkshire	93	93	100%	+100%
Tayside	74	74	100%	+49%
Islands* (Shetland, Orkney and Western Isles)	6	6	100%	-

*Combined due to low figures. 2 boards have completed data entry.

Figure 2 – Full data picture for CEN as at 1st April 2021

Figure 3 – CEN Patients on CAS by Condition

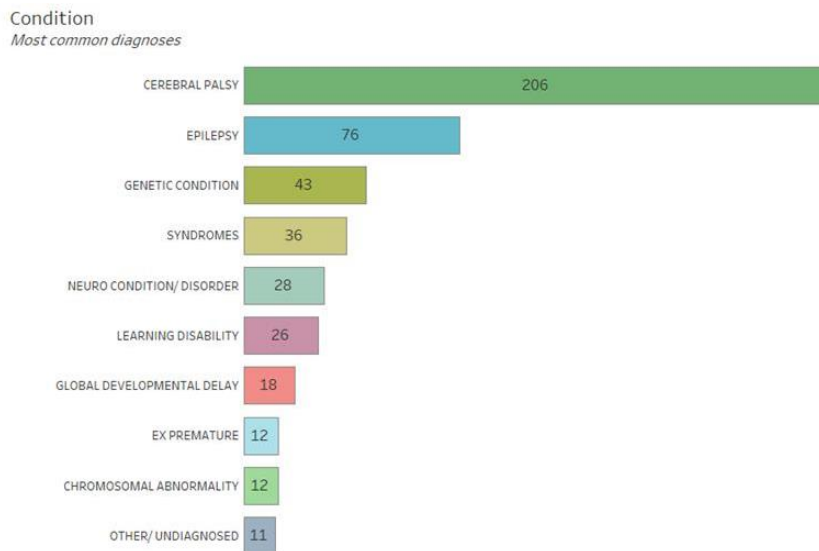Figure 4- Number of Patients Added to CEN CAS per Month

Patient Increase on CAS

There has been a steady push in getting patients onto the system over the past two years with the last five months having the biggest impact.
* 261 patients were added onto the system in the first week of April 2021 and therefore excluded from this graphic but are included in the overall figures.

Figure 5 – CEN Patients on CAS by Age

Age

| 1 - 7 | 8 - 15 | 16+ |
| 36% | 51% | 13% |
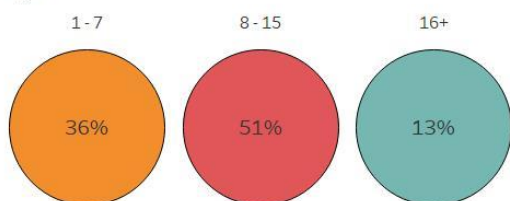
*85 Children are expected to transition into adult services in the coming years.

Total CEN patients split by Health Board

Total Patients on CAS **632**

Islands: 6
*combined due to
small figures
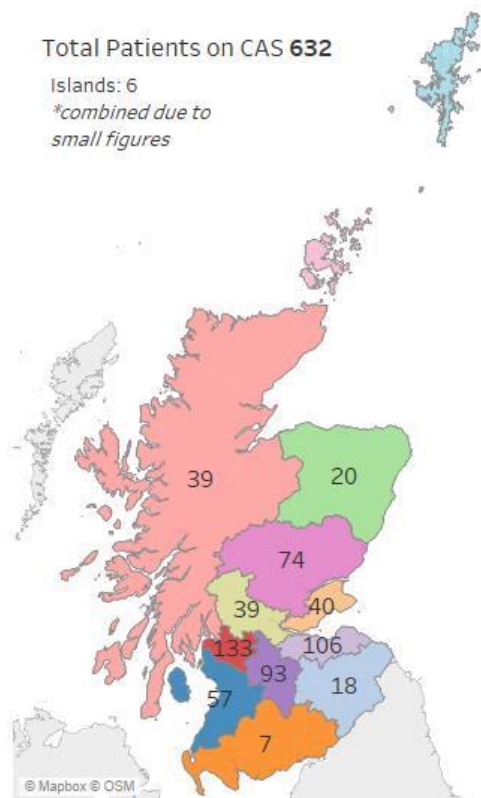
Figure 6 – Map of Patients on CEN CAS by Health Board

Network Core Principle Link: Education

2.3 Turas Module Development

In October the network undertook work to develop two of a suite of three new Turas e-learning Modules, replacing seven historic LearnPro modules. The new modules combine key content from previous modules and new content to create concise and succinct modules suitable for all professionals working with children with exceptional healthcare needs and their families. The titles of the new modules correlate to the theme of the 2020 CEN conference, 'Communication, Co-ordination and Compassion'. This theme had been identified from a Kindred case study, in which a parent suggested that good care for their CEN child could be categorised into one of those three headings; illustrating the importance role the network has in continuing to engage and collaborate with both families and third sector organisations.

The Communication and Co-ordination modules were developed in the reporting period, delays due to changes in the script development extended the delivery date from March 2021. to April 2021.

Final usage figures for the original Learn Pro modules from throughout the reporting period can be seen below (accessed- how many times started, passes- how many times passed on completion);

CEN modules	NHS		COMMUNITY		COUNCIL	
	PASSES	ACCESSES	PASSES	ACCESSES	PASSES	ACCESSES
CEN: Capacity and Consent	2005	2597	123	145	30	33
CEN: Communication - Hearing the Voice of CEN	126	219	34	53	7	14
CEN: Co-ordinating Care for CEN - GIRFEC	235	317	35	37	16	22
CEN: Enhancing Early Support for CEN and Families	89	114	30	30	20	23
CEN: Identifying Outcomes for Children with CEN	94	127	28	28	7	7
CEN: The Emotional Impact of Tube Feeding	293	341	36	36	11	18
CEN: Transition	186	212	33	33	41	41
	3028	**3927**	**319**	**362**	**132**	**158**
Total passes - 3479						
Total accesses - 4447						

Figure 7- Learn Pro Usage Figures 1st April 2020-31st March 2021

2.4 Learning Needs Analysis

A learning needs analysis online survey was created based on the Paediatric End of Life Care Network (PELiCaN) template, developed with colleagues from Edinburgh Napier University. The purpose of this was to scope training and educational needs of professionals who work with Children with Exceptional Healthcare Needs in Scotland and identify any gaps and inform future education provision from the network.

The survey was available for professionals who work with children with exceptional healthcare needs to complete for 5 weeks (15th December 2020 15th January 2021). A total of 79 participants took part, 11 of them responded on behalf of a team, which accumulated to 70 people from across Scotland.

3. Looking Forward & Remobilisation

Throughout 2021-22 the CEN Network will work on a number of key projects as well as business as usual tasks. Projects planned include;
- Finalise the refresh governance structure and group membership
- Develop a suite of network KPI's
- Conduct a quality improvement project around the use of NearMe remote consultations for CEN families to reduce journeys
- Create a suite of updated CEN Care Pathways
- Develop the 'Compassion' Turas module and promote use of new modules in Boards
- Analyse results from the learning needs analysis to update the Education Strategy and create education and training materials
- Produce a report on the CAS QI project to share findings with stakeholders and inform next steps

4. Exceptions/ Risks/Issues
4.1 Annual Event and Case Review

The due to the COVID-19 pandemic the CEN annual event did not take place
The network will use the information that it collated from its strategic planning day, and the Learning Needs Analysis (LNA) to facilitate its next annual education event.

4.2 Care Pathway Refresh

This program of work was halted due to staffing resources being impacted by the COVID-19 and will be carried forward to 2021-22 work plan.

4.3 Membership Refresh

There was a slight delay to this piece of work due to COVID-19 as it was identified that staff were increasingly busy and meetings were on hold, therefore it was agreed that invites would not go out until such times that sub-groups were going to meet again. This was carried forward to a priority task on the 2021-22 workplan.

4.4 Care Quality Indicators (CQI) Creation / Refresh

In the absence of a full Clinical Audit System (CAS) dataset until this year, this objective could not be progressed. Work will start in early 2021 and will be reported in CEN business plan.

4.5 Capacity Planning Jan 2021-March 2021

Due to the second wave of the Covid-19 pandemic, National Services Division (NSD) directed all networks to only progress programmes of work that, if paused, would have a detrimental impact on clinical service delivery. In light of this directive the network paused non–essential meetings and where these were cancelled the network provided, written updates to its members and stakeholders, to keep them up to date with work that it was still progressing behind the scenes.

4.6 Covid-19 Pandemic

There is a risk that if the pandemic continues for an extended period of time, it will negatively impact the progress of the network. CEN will mitigate against this by monitoring progress of objectives closely and regularly at Core Team Meetings and the Steering Group and putting any required supports as soon as possible.

5. Finance

An overspend of £6,457.60 for a suite of e-learning modules was underwritten from the National Networks budget.
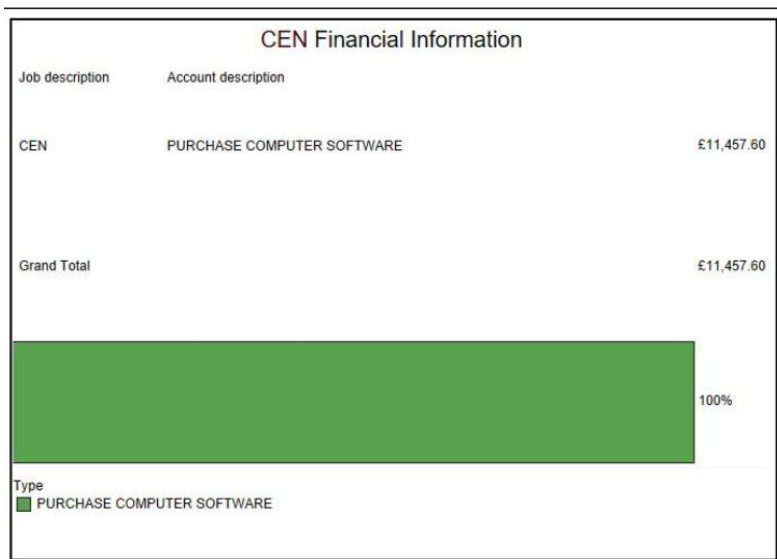

CEN Financial Information

Job description	Account description	
CEN	PURCHASE COMPUTER SOFTWARE	£11,457.60
Grand Total		£11,457.60

Type
■ PURCHASE COMPUTER SOFTWARE

Figure 8- CEN Finance 2020-21

Appendix 1 – Annual Workplan

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/20	Anticipated Outcome	RAGB status
1. Effective Network Structure and Governance [linked to Quality Dimensions 3,4,5,6]						
2020-01	By Summer 2020 CEN will appoint a new Lead Clinician	3,4,5,6	NSD	Complete- Dr Susan Buck's tenure ended in May 2020, Dr Una MacFadyen, was appointed as the CEN Lead Clinician in July 2020 for a three-year tenure	CEN will successfully appoint a Lead Clinician at the end of current tenure	B
2020-02	By December 2020 CEN will re-invigorate the Steering Group by ensuring pan-Scotland, cross-speciality membership	3,4,5,6	CEN Core Team & LC	Progress has been slow on this objective due to staff capacity (C-19). Will continue into 2021-22. A list of all members including suggested new members has been drawn up ready for use. Some new members have got in touch with the network e.g. when contacted to take part in the CAS data entry and asked if they can join a network group. A full review of all members will take place in 2021-22.	CEN will have a representative steering group of the whole of Scotland	A
2020-03	By December 2020 CEN will update relevant strategies (data, education and QI) following the strategic planning day	3,4,5,6	CEN Core Team & LC	Work on refreshing the strategic work plan began in early 2021 but is not ratified yet, the strategies are yet to be written following the Strategic planning session on 29th October 2020.	CEN will have refreshed strategies that have clear projects within	A
2020-04	CEN will host regular Steering Group meetings throughout 2020-21	3,4,5,6	CEN Core Team & LC	Complete, final SG meeting in 2021 was replaced by a written update due to Covid-19 capacity saving	CEN will host regular steering group meetings to inform the work of the network	B
2020-05	CEN will host regular Sub-group meetings for Data and Education groups throughout 2020-21	3,4,5,6	CEN Core Team & LC	All meetings took place or cancelled due to COVID-19 capacity plans, members were notified of any changes. New third sub-group created in 2020-21 for communication and engagement. They will be 'owners' of an 'experts by experience' family-group for families to come together and share views. This group will also be responsible for the delivery of the network communications and engagement strategy.	CEN will have effective sub-groups that progress work contained in the workplan	B

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/20	Anticipated Outcome	RAGB status
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	Strategic Planning Session took place in October 2020, draft strategic workplan has been created but not yet ratified by commissioners or steering group, will happen in early 2021.	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 [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-07	Throughout 2020-21 CEN will continue to respond to appropriate consultations as and when required.	1,2,3,4,5,6	CEN Core Team. Steering Group & LC	There have been no further consultations to date requiring CEN's input.	CEN will have a voice for their patients and their families in government consultations	B
2020-08	CEN will continue to have a voice at the Disabled Children and Young People Advisory Group (DCYPAG) throughout 2020-21	1,2,3,4,5,6	CEN Core Team & LC	Dr MacFadyen has taken over from Dr Buck as the representative from CEN at the Disabled Children and Young People's Action Group (DCYPAG).	CEN will contribute to decisions made and provide expert guidance and advice	B
2020-09	By April 2021 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 to hold this piece of work until 2021-22 where a full review will take place. It was agreed at strategic planning session that all topics were still relevant, amendments were suggested and reviewers were identified for each pathway. All new pathways will be ratified by the steering group and placed on network website for use. It is noted that there are other networks who may need to be involved in this process e.g. PELiCaN or Neonatal Network.	CEN will begin to refresh care pathways that are up to date and fit for purpose	R
2020-10	Before December 2020 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	Complete- 29th October 2020.	CEN will have a clear understanding of its strategic landscape in order to create a relevant workplan and strategies	B
3. Stakeholder Communication and Engagement [linked to Quality Dimensions 1,3,4,5,6]						
2020-11	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	Amendments to the CEN website were made to try and give it a more user-friendly look and feel. The	CEN will have a concise website that is easy to navigate and all	B

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/20	Anticipated Outcome	RAGB status
	information that is out of date will be removed or updated.			communications and engagement sub group will share the load in terms of content design and maintenance. Work on the families' section will have input from the 'experts by experience group' to ensure a family friendly feel and useful content.	information is up to date and relevant	
2020-12	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 throughout 2020-21.	1,3,4,5,6	CEN Core Team & LC	All sent, minus final edition for the year which was cancelled to save capacity (Covid-19).	CEN will have well informed stakeholders who are kept up to date with network news	B
2020-13	CEN will continue to contribute and regularly tweet from the @CYPNMCN twitter account and monitor the impacts that tweets are having throughout 2020-21	1,3,4,5,6	CEN PSO	Ongoing quality improvement project by Mx Williamson, Programme Support Officer, in 2020-21, really improved followers and engagements. In January 2020 the account had 239 followers with 5116 impressions from tweets regarding the Networks. By March 2021, the number of followers had grown to 728, with 31000 impressions.	CEN will have well informed stakeholders who are kept up to date with network news	B
2020-14	CEN will invest time to increase membership of subgroups and attendance at meetings of these groups throughout 2020-21	1,3,4,5,6	CEN Core Team & LC	See comments in objective '2020-02'	CEN will understand why members may not attend meetings and what can be done to improve this in turn increasing attendance	A
2020-15	CEN will continue to engage with the Kindred EFP partnership and maintain cross-communication channels as such throughout 2020-21.	1,3,4,5,6	CEN Core Team, Kindred & LC	Discussion took place in early 2021 to discuss the future of the Exceptional Families Project (EFP) work, it was agreed that this would now be known as a joint 'project' instead of 'partnership' and that our partnership with Kindred was in fact separate to the EFP. It was agreed that both parties would be more transparent and communicate openly and honestly with each other. A joint data project was carried out which looked at the effects of shielding on families of children with exceptional healthcare needs. A professionals' education event was held on 9th September to	CEN will have an effective relationship with Kindred EFP with regular communications and updates	B

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/20	Anticipated Outcome	RAGB status
				share the finding of this project. Unfortunately, CEN's name could not be included in the final report as the Network cannot be linked to lobbying. There were no EFP steering groups due to covid-19 and Kindred have attended the CEN Steering Group as normal. A number of events planned which Kindred were attending (which the EFP/CEN would have been promoted/in attendance) were also cancelled due to Covid-19.		
4. Education [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-16	By March 2021 CEN will host an annual education meeting on relevant and hot topics.	1,2,3,4,5,6	CEN Core Team & LC Education Group	Agreed not to take place due to COVID-19, instead of an online event the network decided to undertake a learning needs analysis to ensure future education provision is appropriate and required by the stakeholder population. A GAP analysis will be produced from results in early 2021-22.	CEN will ensure stakeholders are kept abreast with current developments in the field	R
2020-17	By April 2021 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 Education Group	See comments in objective '2020-17'	CEN will be clear on the way forwards for peer review meetings and the format of these.	R
2020-18	By 31st March 2021 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	Two of three new Turas ELearning modules are in development and will be delivered on 30th April 2021, this is one month later than expected (31st March 2021). This was due to some slippage in the script development phase.	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 [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-19	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	10 of 14 Boards data entry complete compared to 2 of 14 in 2019-20.	CEN will have a full set of Scotland wide data for all CEN children	G

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/20	Anticipated Outcome	RAGB status
2020-20	CEN will provide regular update reports to Child Health Commissioners (CHC) and NSD SMT on the progress of the CHC CAS Project throughout 2020-21	1,2,3,4,5,6	CEN Core Team & LC Data Group Louise Smith	Complete	CEN will keep CHC's well informed of project progress	B
2020-21	CEN will review Care Quality Indicators (CQI) to ensure fit for purpose by 31st March 2021	1,2,3,4,5,6	CEN Core Team & LC Data Group Louise Smith	Agreed that these could not be updated until CAS data was more representative of the whole of Scotland. Project on hold until 2021-22.	CEN will have clear understanding of the purpose and use of QCI's	R
2020-22	By Summer 2020 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 Louise Smith	Complete- as of June 1st 2020 Networks were granted implied consent for data collection on CAS, meaning formal consent was no longer required. This was communicated to Boards and a new data privacy notice was uploaded to the CEN website. This can be printed and displayed in clinics or given to parents as a leaflet by clinicians. A formal leaflet was not required at this time.	CEN will ensure Boards are well informed on changes in consent	B
2020-23	By summer 2020 CEN will update CEN Consent leaflets to reflect new consent legislation	1,2,3,4,5,6	CEN Core Team & LC Data Group	As objective 2020-22. Complete	CEN will have relevant and up to date information leaflets for use	B
2020-24	By October 2020 CEN will plan a qualitative data gathering project with CEN families	1,2,3,4,5,6	CEN Core Team & LC Data Group	CEN and Kindred worked together on a qualitative data project which investigated the effects of shielding throughout COVID-19 – see comments in Objective '2020-15'	CEN well be clear on the purpose and practicalities of a possible qualitative data project.	B
6. Value [linked to Quality Dimensions 1,2,3,4,5,6]						
2020-25	Throughout 2020-21CEN will continue to ensure meetings can be attended via remote means	1,2,3,4,5,6	CEN Core Team & LC	CEN used MS Teams for all meetings, it is expected that this will be ongoing and is helping encourage attendance at meetings.	CEN will allow for members to connect remotely to meetings	B
2020-26	Throughout 2020-21 CEN will ensure that work is not duplicated with other networks for example PELiCaN or Long Term Ventilation pieces of work	1,2,3,4,5,6	CEN Core Team & LC	Ongoing- the network continues to make links with a number of organisations and agencies as well as making links with other networks to ensure no duplication of effort.	CEN will work in conjunction with other networks without repetition	B

Objective Number	Smart Objective	Planned start/ end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 30/09/20	Anticipated Outcome	RAGB status
2020-27	Throughout 2020-21 CEN will maintain links with third sector organisations and other relevant agencies	1,2,3,4,5,6	CEN Core Team & LC	CEN is working towards creating 'partnerships' with a range of third sector organisations to ensure that all taking part in the network are receiving the benefits. Work will continue in 2021-22 to create a terms of reference for this.	CEN will be well connected and known in third sector.	G

Appendix 2 – Work Plan for 2021-22

CEN Network (NNMS) BAU Action Plan		
Core Principle	Program of Work	Owner
Effective Network Structure and Governance	PELiCaN will host regular steering and sub-group meetings throughout 2021, ensuring timely notification of dates or any changes	PSO
Effective Network Structure and Governance	CEN will strive to ensure that group membership is representative of the whole of Scotland and varied professional groups	PM/PSO
Effective Network Structure and Governance	CEN will continue to provide NSS Senior Management with regular Covid-19 impact assessments to evidence the potential impacts the pandemic is having on achieving objectives.	PM
Service Development and Delivery	CEN will continue to respond to appropriate consultations as and when required.	All
Service Development and Delivery	CEN will continue to have a voice at the Disabled Children and Young People Advisory Group (DCYPAG)	LC

Service Development and Delivery	CEN with PELiCaN will contribute to the update of the children's ACP document by end of 2021	LC/PM
Stakeholder Communication and Engagement	CEN will work to promote a consistent message regarding the networks purpose and existence, work will be carried out throughout the year to promote the network in Boards.	All
Stakeholder Communication and Engagement	Throughout 2021 CEN will continue to develop the Network website	PSO/ Comms & Engagement Group
Stakeholder Communication and Engagement	Throughout 2021 CEN will continue to distribute regular newsletters to stakeholders on the new Sway platform, with spotlight topics.	PSO
Stakeholder Communication and Engagement	Throughout 2021 CEN will continue to contribute and regularly tweet from the @CYPNMCN twitter account and monitor the impacts that tweets are having	PSO
Stakeholder Communication and Engagement	Throughout 2021 CEN will continue to engage with the Kindred EFP project and maintain cross-communication channels as such	All
Stakeholder Communication and Engagement	CEN will work to ensure that all written communications are written in plain English throughout 2021.	All

Stakeholder Communication and Engagement	CEN will utilise its 'Experts by Experience' Group to bring the family voice to all work.	All
Stakeholder Communication and Engagement	CEN's Communications and Engagement Sub-Group will be responsible for delivery of the updated Communication and Engagement strategy throughout 2021	Comms & Engagement Group
Education	CEN will host an online Education Event in 2021 based on topics highlighted in the Learning Needs Analysis	Education and Training Group
Education	CEN will host one Peer Review session based on topics highlighted in the learning needs analysis by March 2022	Education and Training Group
Education	CEN will strive to promote inter-professional learning opportunities e.g. sharing web based learning resources from other areas e.g. AHP's Learning Community	Education and Training Group
Education	CEN will promote the new suite of Turas Modules with stakeholders throughout 2021	Education and Training Group
Audit and Continuous Quality Improvement	CEN Data group will be responsible for meeting the objectives set out in the network Quality Improvement strategy throughout 2021	Data Group

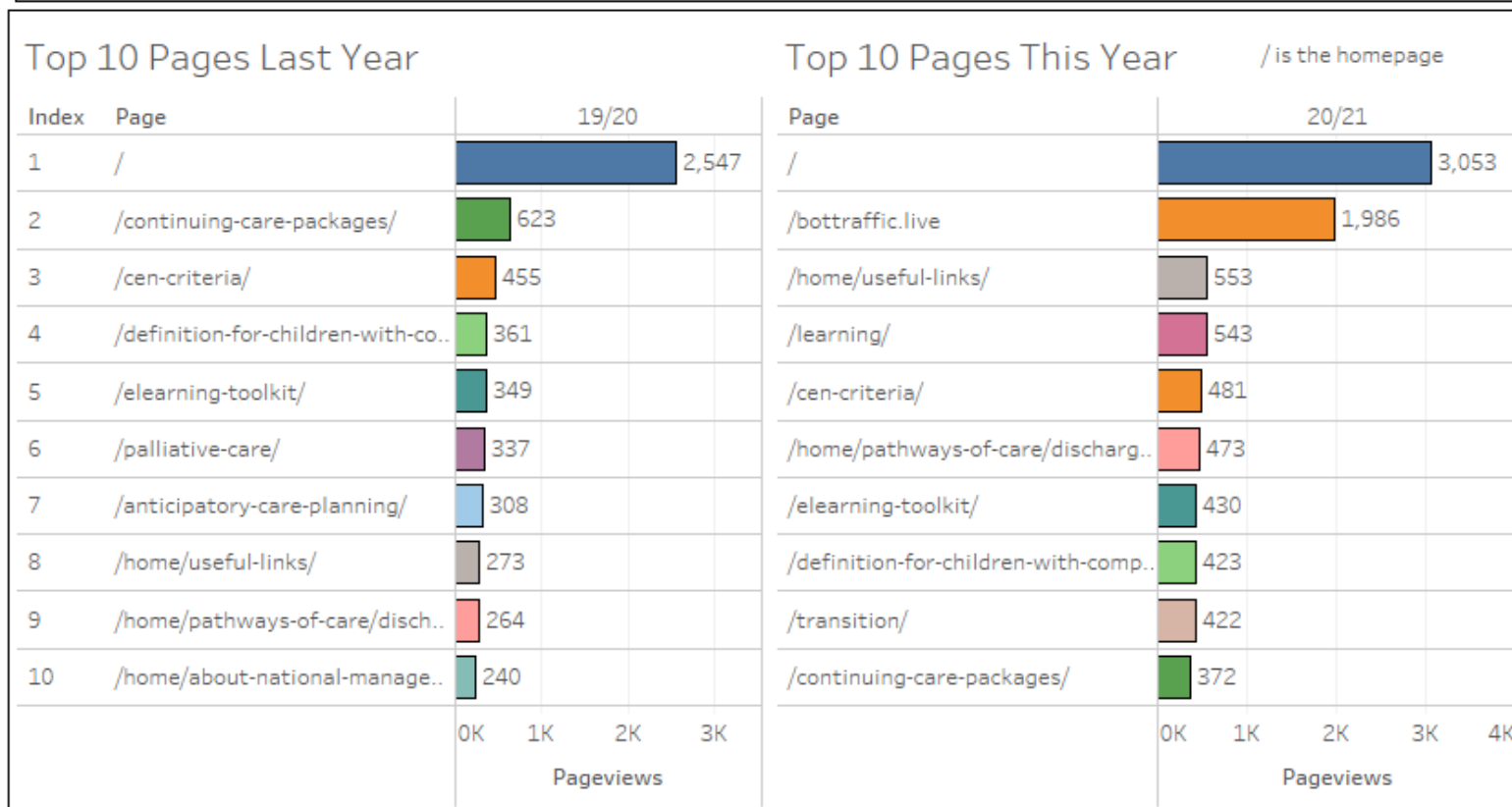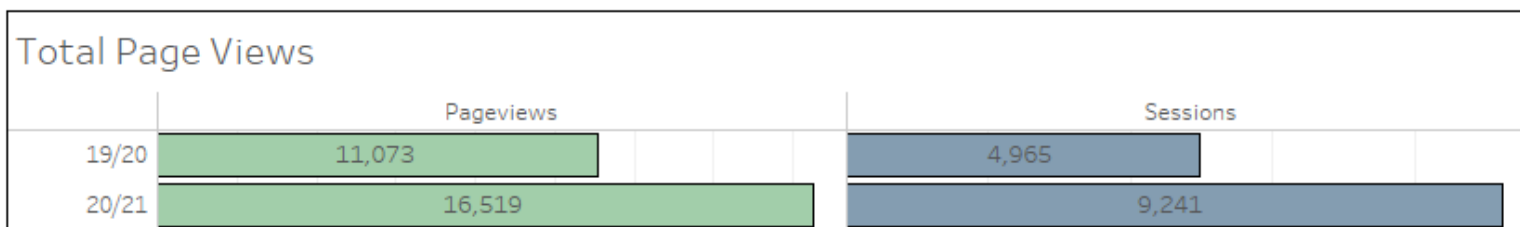|		
Audit and Continuous Quality Improvement	CEN and the information management service will maintain data completeness on CEN CAS system throughout 2021	Data Group/CEN CAS Champions
Audit and Continuous Quality Improvement	CEN will continue to provide required training on CAS its use in Boards	IMS
Value	CEN will continue to make use of tools such as MS Teams through 2021 to allow members to access meetings remotely	All
Value	CEN will continue to increase collaboration with other networks to ensure there is no avoidable duplication of work	All
Value	CEN will explore the remit and work of regional networks who may be involved in CEN children and young people's care	All
Value	CEN will increase its presence and input with a range of third sector organisations throughout 2021	All
Value	CEN will ensure that work is carried out in a Lean way and all non-essential steps are minimised, to ensure best use of stakeholders time.	All

CEN Network (NNMS) Special Programmes Action Plan						
Core Principles	Description of Work	BOSCARD (Yes / No)	Owner	Current status	Start Date	End date
Effective Network Structure and Governance	CEN will work in the CEN Communication and Engagement Group to define and implement the role of CEN Champion and CEN CAS Champion in all Boards by Winter 2021. They will be responsible for promoting work of CEN and helping with any queries regarding the network or CAS data entry.		Comms and Engagement Group	Role of CEN data champion- to help with data entry issues, to input data, may be the contact for Neonatologists to add in patients for them once they begin to put 0-2yrs patients on CAS as so few numbers. Role of CEN champion - to share information on the network with colleagues and ensure events etc. are promoted within Boards. * need to ensure that both roles are required, definitely role for CEN CAS/data champion	01/09/2021	31/03/2022
Service Development and Delivery	CEN Comms and engagement group will create project groups to refresh its Care Pathways by the end of March 2021, fully incorporating feedback from the strategic planning day in 2020.		Comms and Engagement Group	Names added to contact list of those who may need to be involved Una bringing example of format of Care pathway she likes, Shelley also asked in team if any care pathway templates that could be used as standard.	01/09/2021	31/03/2022
Education	The CEN Education and Training Group will analyse results of the recent Learning Needs Analysis to create an action plan for future education and training provision for the network. Including development of any learning during the reporting period		Education Group		26/08/2021	31/03/2022

Education	CEN will develop and publish a final Turas module to complete the series of three (two of which developed in 2020) by end December 2021	Yes	PM/APM Education Group	Luke Rush, Assistant Programme Manager will run the project for this piece of work on behalf of the network.	01/06/2021	31/12/2021
Education	CEN will take part in a feasibility study and pilot with NHS Inform (NHS 24) to establish whether National Networks are in a position to act as subject matter experts to update and maintain NHS Inform whilst promoting the existence of networks. Anna Lamont, Medical Director is leading on this piece of work from a management point of view.		Medical Director / Core Team	SBAR drafted by Anna Lamont following intro meeting with PM/LC/AD Scoping meeting between NSD and NHS Inform took place- LC took notes, in file. Unsure on timescales for this project as in hands of MD and NHS Inform.		
Audit and Continuous Quality Improvement	By March 2022 CEN will develop KPI's around; - Education provision and measuring the impact that education has had on practice -Data on CAS to replace the 2017 Care Quality Indictors -Standard Network Quality KPI's	No	Education Group/Data Group/ Core Team			
Audit and Continuous Quality Improvement	CEN will write up a report on the project with child health commissioners in 2020/21 to ensure lessons learned are shared and achievements celebrated by Winter 2021. This will include the creation of a communication plan for distributing this report and data summary to Boards	Yes	PM/ Data Group		24/06/2021	31/10/2021

Audit and Continuous Quality Improvement	CEN will conduct a QI project looking at the benefits of NearMe consultations on CEN families	Yes	Core Team		01/06/2021	31/03/2022
Service Development and Delivery	By end April 2022 CEN will have conducted a mapping exercise of all services and workforce across Scotland with the aim of using data to reduce variation and ensure equity of care for patients			don't know if this will be happening - waiting on update from Catriona, this would be linked to the scoping exercise that PELiCaN may do - waiting on status update.		

Appendix 3 – Website statistics

Full year report

Total Page Views

	Pageviews		Sessions
19/20	11,073		4,965
20/21	16,519		9,241

Top 10 Pages Last Year

/ is the homepage

Index	Page	19/20
1	/	2,547
2	/continuing-care-packages/	623
3	/cen-criteria/	455
4	/definition-for-children-with-co..	361
5	/elearning-toolkit/	349
6	/palliative-care/	337
7	/anticipatory-care-planning/	308
8	/home/useful-links/	273
9	/home/pathways-of-care/disch..	264
10	/home/about-national-manage..	240

Pageviews

Top 10 Pages This Year

Page	20/21
/	3,053
/bottraffic.live	1,986
/home/useful-links/	553
/learning/	543
/cen-criteria/	481
/home/pathways-of-care/discharg..	473
/elearning-toolkit/	430
/definition-for-children-with-comp..	423
/transition/	422
/continuing-care-packages/	372

Pageviews

Appendix 4 – Twitter Statistics 2020-21 @CYPNMCN

Month	Tweets	Impressions	Average Impressions Per Tweet	Profile Visits	Mentions	New Followers	Average New Followers Per Tweet	Total Followers
Jan-20	6	5116	852.67	102	9	14	2.33	239
Feb-20	25	11900	476.00	330	36	30	1.20	269
Mar-20	62	19900	320.97	414	27	31	0.50	300
Apr-20	96	30800	320.83	486	43	74	0.77	374
May-20	65	22800	350.77	285	22	34	0.52	408
Jun-20	91	24100	264.84	396	9	41	0.45	449
Jul-20	44	9790	222.50	132	11	15	0.34	464
Aug-20	79	22800	288.61	285	13	25	0.32	489
Sep-20	59	22300	377.97	286	25	32	0.54	521
Oct-20	71	21900	308.45	373	14	43	0.61	564
Nov-20	113	40700	360.18	616	20	66	0.58	630
Dec-20	106	35100	331.13	745	8	16	0.15	646
Jan-21	100	30900	309.00	872	12	30	0.30	676
Feb-21	76	29400	386.84	864	6	29	0.38	705
Mar-21	77	31000	402.60	1294	10	23	0.30	728
Apr-21	61	32000	524.59	798	6	28	0.46	756
May-21								
Running Total	1131	358567	317.04	7541	271	531	0.47	