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

Annual Report 2013/14

NMCN CEN Lead Clinician: Dawn Moss
NMCN CEN Manager: Jayne Scotland
NMCN CEN Programme Support Officer: Lucy Johnston

www.cen.scot.nhs.uk
Executive Summary

The National Managed Clinical Network for Children with Exceptional Healthcare Needs (CEN) was established in March 2009 with the aim to strengthen and develop specialist services for children with complex and exceptional healthcare needs in Scotland. This group of children are defined by their complexity of care rather than their diagnosis and can have a wide variety of underlying diagnoses, meaning good links with other existing networks, professionals and agencies is essential. The total number of children with exceptional healthcare needs in Scotland is now identified as approximately 360 at February 2013.

Due to the complexity of care needs our client group are living with, the network continues to work closely with an extensive and diverse range of professionals, other networks, the voluntary sector and importantly, parents and carers. We reviewed and updated our extensive membership list earlier this year and our current CEN NMCN membership sits at 610 individuals (including parents, carers and professionals) who are actively involved. Our parents and carers are essential in determining the priorities and direction of the network and to help guide those changes which would bring the most benefit to families and their children.

CEN continues to provide a diverse range of resources for professionals and families available on our website, and provided as events across Scotland. The network continues to raise awareness of the complexity of care needs for this group of children and young people and facilitates discussions on issues and improvements to services provided to this client group. Our work is underpinned by evidence based, professionally developed and agreed clinical pathways and protocols and in line with the Scottish Government Getting It Right for Every Child (GIRFEC), which aims to establish a common language and shared way of identifying the needs and supporting children and young people. The idea is for children and young people with complex and exceptional healthcare needs to get the right help at the right time packaged for their particular needs.

The priority for CEN in 2013/14 was consolidation of the work of the network and a focus around Care Closer to Home for children with complex and exceptional healthcare needs and guardianship. We combined our Education and Service Users' Working Groups to look at our current educational resources and events and what we could plan for the coming year. The group identified the importance of continued development for professionals to develop their skills, knowledge and experience working with families with CEN as having a greater impact on their experience. We focused on development of a new CEN Toolkit of 5 e-learning modules in partnership with learnPro, peer reviews and parent/professional events. Our resources and links to them are available on the CEN website www.cen.scot.nhs.uk

Key achievements for 2013/14:

- Delivery of 5 Guardianship and Adults with Incapacity education workshops in partnership with PAMIS
- Development of scripts and evaluations for 5 CEN e-learning modules in partnership with Stirling University
- NHS Highland / CEN Parenting Project
- Delivery of 2 Peer Review Case workshops – Challenges in working with CEN / CEN & Transition
- CEN annual conference attended 120 delegates (40% were new attendees to a CEN conference)
- Analysis of CEN hospital admissions within NHS Lothian
- Co-ordinated - Parent Information Events in partnership with Glasgow Special School Head teachers
- Evaluation and updating of the CEN Care Pathway
• Continued promotion of our CEN educational resources
• Increase in use of SNS – membership of the National User Group
• CCHAT Tool promotion
• Review of membership and promotion of network
• 183 Communication and tube feeding DVD’s, 697 early support and expectation booklets and 730 tube feeding leaflets have been distributed throughout Scotland with increased interest from out with the UK
• 274 people have viewed communication and tube feeding videos within the CEN Website
• 800 approx view the website on an average month
• CEN Lead Clinician actively involved as a ‘Disability Champion’ by the Scottish Government

1. Aim/ Purpose/ Mission Statement

The purpose of the NMCN CEN is 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 and to ensure that each CEN is fully and appropriately assessed, and has access to a full range of specialist care, underpinned by evidence based, professionally developed and agreed clinical pathways and protocols. The work the NMCN undertakes champions and reflects the GIRFEC aims. Getting it right for every child is a programme that aims to improve outcomes for all children and young people.

We will do this through promotion of and local implementation of the CEN pathway of care and the development of a range of general and specialist educational resources developed in partnership with our stakeholders to ensure safe, effective and evidenced based child and family focussed care.

The NMCN CEN aims are to:

• Ensure a comprehensive and systematic identification and mapping of children within Scotland
• Be a focal point for children, young people and families for information and discussions to influence how services are provided
• Be a focal point for health professionals across agencies to provide information and resources to review and improve service provision
• Offer an opportunity for an evidence based approach to co-ordination of services to be provided in every health board area
• Develop a clear and uniform process for provision of service and appropriate service models
• Identify workforce needs - training and capacity
• Ensure the principles of the Scottish Government Getting It Right For Every Child approach is embedded in all aspects of CEN’s work
• Work closely with Transition Forum Scotland and champion their ‘Principles of Good Transition’ for CEN
The definition for Children with Exceptional Healthcare needs was agreed in September 2009 and remains as follows:

**CEN assessment criteria:**

The six impairment categories used for assessing the children and young people are:
- learning and mental functions
- communication
- motor skills
- self care
- hearing
- vision

A child or young person (up to the age of 19) is defined as having exceptional healthcare needs if they:

**Have severe impairment recorded in at least 4 categories together with enteral/ parenteral feeding**

**OR**

**Have severe impairment recorded in at least 2 categories and require ventilation/CPAP**

**AND**

**The impairments are sustained and ongoing or expected to be lasting for more than 6 months.**

2. **Prevalence**

CEN has adopted the existing national Support Needs System (SNS) for data collection and reporting and is an active member on its National User Group. In February 2013 at total of 360 children and young people with exceptional healthcare needs were recorded nationally captured within the SNS or a local database kept in collaboration with NMCN CEN.
<table>
<thead>
<tr>
<th>NHS board area</th>
<th>Number of children that meet CEN criteria in SNS. (Source: ISD, Feb 2013)</th>
<th>Number of children that meet CEN criteria reported separately (Source: NHS board provide CHI numbers of CEN recorded locally to ISD, Feb 2013)</th>
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</thead>
<tbody>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>27</td>
<td>0</td>
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<tr>
<td>Borders</td>
<td>13</td>
<td>0</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>13</td>
<td>0</td>
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<tr>
<td>Fife</td>
<td>5</td>
<td>34</td>
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<tr>
<td>Forth Valley</td>
<td>4</td>
<td>0</td>
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<tr>
<td>Grampian</td>
<td>38</td>
<td>0</td>
</tr>
<tr>
<td>Greater Glasgow and Clyde</td>
<td>70</td>
<td>0</td>
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<tr>
<td>Highland</td>
<td>4</td>
<td>38</td>
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<tr>
<td>Lanarkshire</td>
<td>37</td>
<td>0</td>
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<tr>
<td>Lothian</td>
<td>58</td>
<td>0</td>
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<tr>
<td>Orkney</td>
<td>0</td>
<td>2</td>
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<tr>
<td>Shetland</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Tayside</td>
<td>17</td>
<td>0</td>
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<tr>
<td>Western Isles</td>
<td>NA</td>
<td>0</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>286</strong></td>
<td><strong>74</strong></td>
</tr>
</tbody>
</table>

The prevalence of enteral/parenteral feeding; ventilation/CPAP and severe impairments in children with exceptional healthcare needs is as follows:

- 97.6% Severe self care impairments
- 97% Enteral/parenteral feeding
- 93.4% Severe motor skill impairments
- 91% Severe learning and mental function impairments
- 90% Severe communication impairments
- 46% Severe vision impairments
- 10.4% Severe hearing impairments
- 8% Ventilation
- 5% CPAP

The definition ‘severe’ was used as detailed in the SNS system.
### 3. NMCN CEN Year report detailed progress May 2014

<table>
<thead>
<tr>
<th>RAG status</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>RED (R)</td>
<td>Little/no progress been made to date to achieving network objective/standard</td>
</tr>
<tr>
<td>AMBER (A)</td>
<td>Significant progress been made to date to achieving network objective/standard, however further work is required to fully achieve the network objective</td>
</tr>
<tr>
<td>GREEN (G)</td>
<td>The network has been successful in achieving the network objective/standard</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Objective</th>
<th>Planned start/ end dates</th>
<th>Description of progress towards meeting objective</th>
<th>Outcome / evidence</th>
<th>RAG status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PERSON CENTRED: Providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions</td>
<td></td>
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<td>Green</td>
</tr>
</tbody>
</table>

**CEN Key Objective 1: Encourage and facilitate the involvement of families, children and patient support groups in the network and engage them in service improvement**

**CEN Work Plan task 1:** Organise 2-3 Service Users Working Group meetings a year and have ongoing e-mail and phone contact with parents.

- • Service users working group merged with the Education working group to ensure education and users linked in a productive way.
- • Regular meetings delivered and well attended
- • Parent events delivered to increase user involvement within the network

**CEN Work Plan task 2** Involve parents in the planning of the annual conference Care Closer to Home, a topic prioritised by parents and professionals. Parents will be involved in presentations and discussions at the conference.

- Jan 2013-Sept 2013
- • Parents were involved in identifying topics and speakers for presentations at the Sept 2013 conference.
- • Parent video diary and verbal story key parts of the conference

- • Two presentations at 2013 conference – Video Diary and verbal story ‘Welcome to my home, I think’ presented at the conference (Sept 2013). Parents shared personal experiences which supported the discussion and set scene for parents views of life at home.

Green
<table>
<thead>
<tr>
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</tr>
</thead>
</table>
| CEN Work Plan task 3: Deliver Family Information events in partnership with voluntary organisations | April 2013 – April 2014 | • Two small working groups from voluntary sector members met to plan events  
• Met with Head Teachers from Special Schools within Greater Glasgow and Clyde  
• Programme planned together for delivery | • The majority of conference speakers (Sept 2013) were suggested by the Service Users and Education Working Group  
• Feb 2014 Information event delivered at Kelbourne Primary School in Glasgow with 36 parents/carers/grandparents attending. Excellent feedback,  
• 18 new parent members to CEN  
• Kindred, Family Fund Trust and CEN presenting and meeting families  
• Next event planned June 2014 | Green |

2. SAFE: Avoiding injuries to patients from care that is intended to help them. Promote best clinical practice.

CEN Key Objective 2: Develop the Pathway of Care for children with exceptional healthcare needs and audit the Pathway.

| CEN Work Plan task 4: Continue to develop and update the information in the Pathway of Care and extend the Pathway to include information about ‘early support’ and ‘ongoing support in the community’. The Pathway of Care Working Group will support implementation of the Pathway of Care and will promote best clinical practice incorporating the GIRFEC principles. | Complete by Sept 2013 | • The Lead Clinician and Network Manager reviewed all content and resources within the Pathway of Care.  
• Steering Group and Education sub groups reviewed work undertaken to agree changes to content. | • Work completed and re launched at conference in September 2013.  
• Outcomes and measures identified for each step of the pathway  
• To be added as an ongoing CEN work | Green |

3. EFFECTIVE: Providing services based on scientific knowledge

CEN Key Objective 3: Agree data collection, audit, and research to provide a basis for further service improvement and in monitoring clinical outcomes.

<p>| CEN Work Plan task 5: continue to work with professional links within the Pathway of Care | April 2013- | • Work with professional links within | • NHS Fife have appointed | Green |</p>
<table>
<thead>
<tr>
<th>Objective</th>
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<th>Description of progress towards meeting objective</th>
<th>Outcome / evidence</th>
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</tr>
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<tbody>
<tr>
<td>increase use of the Support Needs System targeting specific health board areas: Forth Valley, Tayside and GGC</td>
<td>March 2014</td>
<td>identified health boards to encourage use and input into SNS where used. • Join SNS national user group to influence data collection</td>
<td>Scotland’s 1st Advanced Nurse Practitioner for CEN who will lead in data collection for NHS Fife • NHS Tayside and GGC both increased use of SNS in 2013/14 • Attended SNS NUG and shared importance of CEN data and how used nationally. CEN on NUG agenda.</td>
<td>Green</td>
</tr>
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</table>

CEN Work Plan task 6: Collect and analyse data on hospital admissions for children with exceptional healthcare needs in 2011 and report on the admission patterns and reasons for admission to hospital. | April 2013 - August 2013 | Part of the data on hospital admissions for children meeting the CEN criteria in 2011 has been provided by ISD. This data has provided important insights into local patterns of hospital admissions for children meeting the CEN criteria. | Differences in hospital admissions patterns (for example the number of long term stays and number of children meeting the CEN criteria with no hospital admissions in 2011) between the different health boards were presented and discussed at the CEN conference 2013 | Green |

CEN Work Plan task 7: Work with NHS Lothian Business Intelligence Unit to analyse hospital admission patterns in relation to home care support packages in NHS Lothian | Feb 2013 – April 2014 | NHS Lothian local data report on 9 CEN receiving care packages within NHS Lothian and their admission rates against general paediatric population | Data report completed and shared at conference 2013. Template for undertaking similar study in other health boards available for local study. | Green |

CEN Work Plan task 8: Develop audit tool for case file/practice review using improvement methodology | April 2013 – April 2014 | Data and Education sub group drafted audit tool to capture key area within the CEN care pathway with focus on discharge planning from Tertiary to primary care setting. Tool signed off by steering group. | Tool developed and trial commenced between Yorkhill and NHS AAA Initial challenge in identifying clients for audit pathway timescale extended into next work plan 2014. | Amber |

4. EFFICIENT: Avoiding waste, including waste of equipment, supplies, ideas, and energy
<table>
<thead>
<tr>
<th>Objective</th>
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<tbody>
<tr>
<td><strong>CEN Key Objective 4</strong>: Identify training needs and facilitate the design, development and delivery of education and make this training available across Scotland.</td>
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<td><strong>CEN Work Plan task 9</strong>: Develop CEN Education Modules consisting of CEN educational resources (eg: tube feeding, communication, early support and girfec).</td>
<td>April 2013- April 2014</td>
<td>Jo Smith Stirling University led on development of module scripts for 5 e-learning modules in partnership with CEN and Education and service users sub group. CEN and LearnPro develop skin and assessment /reflection tools for modules Include range of interactive resources within modules and reflective journal. Pre-post assessments to evidence learning</td>
<td>• 5 Scripts completed and translated into Learnpro modules.  • Include existing CEN resources, updated for e-learning resource  • Pre-post assessments completed to ensure evidence of learning  • Reflective journal created to aid learning</td>
<td>Amber</td>
</tr>
<tr>
<td><strong>CEN Work Plan task 10</strong>: Deliver two peer review case workshops for professionals.</td>
<td>April 2013- March 2014</td>
<td>Chair venues and dates for diaries identified. Topics for peer reviews taken from CEN education questionnaire 2011. VC available to ensure access to remote clinicians. Peer reviews delivered around Challenges of working with CEN / CEN and Transition. Evaluation of events carried out with positive outcome and suggested topics for future events in 2014/15.</td>
<td></td>
<td>Green</td>
</tr>
<tr>
<td><strong>CEN Work Plan task 11</strong>: Deliver 4 education workshops around transition services and guardianship</td>
<td>April 2013- June 2013</td>
<td>CEN and PAMIs developed educational resource around Guardianship and Adults with Incapacity Education sessions offered nationally within paediatric setting</td>
<td>5 events held in end. NHS Lanarkshire funded additional event for local staff. Well attended and evaluated. Identified lack of knowledge gap within paediatric settings around the Adults with Incapacity Act 2000 and guardianship. Evaluation report shared with Child Health Commissioners in Scotland</td>
<td>Green</td>
</tr>
<tr>
<td>Objective</td>
<td>Planned start/ end dates</td>
<td>Description of progress towards meeting objective</td>
<td>Outcome / evidence</td>
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<tr>
<td>CEN Work Plan task 12: Work with NHS Highland re Parenting Chidden and young people with complex Needs project, within includes the development of a parenting educational resource for professionals.</td>
<td>Dec 2012 – Sept 2013</td>
<td>Jointly funded 2 phase project plan developed. External consultant developed project and led on work with NHS Highland. Met with identified CEN families to provide evidence to support educational resource around capacity and parenting. Phase one report complete.</td>
<td>Claire Edwards independent consultant completed this work / and interviews with families. Educational resource produced. Phase 1 report produced and available on website. Due to consultant illness project slipped on timescale but report delivered in April 2014. Train the trainers sessions to be delivered within 2014/15 work plan timescale.</td>
<td>Green</td>
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5. EQUITABLE: Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status

CEN Key Objective 5: Ensure effective systems and processes are in place to identify stakeholders and engage stakeholders from across Scotland in the ongoing development of the network.

CEN Work Plan 13: Improve stakeholder involvement of new and existing stakeholders through presentation, newsletter regular updates on the CEN website. Work together with other NMCN’s networks.

Ongoing | Quarterly CEN Newsletter circulated widely across membership and other organisations and child health commissioners to circulate. Increased membership to network following Conference and parent events. Chare work of CEN at conferences | Newsletter only delivered three editions in this reporting period. Conference places oversubscribed and well attended on day – 40% new attendees to event. Parent information events delivered and 18 new parent members joined network from one event. Presented at: British society of Paediatric Dentistry National Conference (Edinburgh) 2013 | Green |
<table>
<thead>
<tr>
<th>Objective</th>
<th>Planned start/ end dates</th>
<th>Description of progress towards meeting objective</th>
<th>Outcome / evidence</th>
<th>RAG status</th>
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</table>
| **CEN Work plan 14:** Work together with Complex care group of the Scottish government to take forward recommendation of scoping on home care packages for children with complex needs across Scotland the use of the CCHAT assessment tool. | April 2013 March 2014 | Clinical lead presented overarching CCHAT report to:  
- Scottish Government  
- Director’s of Nursing group  
- Child Health Commissioners group  
- Presentation to the Children & Young people’s Health Support Group (Scottish Government) | Outcome achieved – to champion and hand over this piece of work to Child Health Commissioners group with regard to further national development of a strategy for Continuing Care – which CEN would be an active participant.  
Will follow up over 2014/15 | Green |
4. Network Governance

4.1 Staffing
- NMCN CEN Lead Clinician: Dawn Moss, Nurse Consultant Vulnerable Children & Young People, NHS Borders; her post is backfilled for 2 sessions a week to allow her to work for the NMCN CEN.
- NMCN Manager: Jayne Scotland new manager commenced on the 8th May. This post is part-time, 2.5 days a week.
- The CEN manager is line managed by Mike Massaro-Mallinson who sits within Directorate of Strategic Planning, Performance Reporting and is the strategic Programme Manager for child and maternal health for NHS Lothian.
- NMCN Project Support officer: Lucy Johnston replaced Anna Gardiner in this post in Feb 2014.
- Weekly meetings between the NMCN CEN Manager and NMCN CEN Lead Clinician and regular email updates ensure effective management of the network work plan and objectives.

4.2 Steering Group and Working Groups
The NMCN has 3 working groups (see below and appendix 1 for group membership) that meet up 2-4 times a year and the chair of each of the working groups is a member of the Steering group. From June 2012 CEN piloted joint service users and education group meetings as the agenda and discussion for each group are very similar. The Chair provides feedback on the work of the working groups to the Steering Group.
A yearly CEN work plan is agreed by the Steering Group. In November and May CEN provides a report with an update on the progress against the work plan for the Steering Group and NSD.

Remit of the Steering Group

The remit of the steering group is to support and steer the development of the National Managed Clinical Network for Children with Exceptional healthcare Needs and the related services in Scotland by:

a. Developing the strategic direction of the CEN NMCN
b. Agreeing objectives of the CEN NMCN
c. Agreeing priorities for the annual work plan
d. Monitoring and evaluating progress
e. Actively promoting the concept of the network
f. Actively involve other networks
g. Promoting and facilitating information collection, audit and stimulate research
h. Look into opportunities to influence policies and strategies

NMCN CEN Working Groups:

- **Joint service users and education group**: Combining group ensures the impact of parents of CEN can directly influence CEN’s education programmes, our current services and possible improvements. Influences planned education training for year ahead and how to ensure continued user involvement.

- **Data and audit group**: Oversee CEN data collection and reporting and all audit programmes undertaken for children with exceptional healthcare needs, as well as looking at research in this area.

- **Pathway Implementation group**: Virtual group, come together to review and update the CEN care pathway. This will now be required annually. Group also identify ways CEN can promote the implementation of the steps of the pathway and increase awareness of the resources that are available as part of this online resource.

The NMCN CEN actively engages with a number of networks and groups including the Scottish Paediatric Children and Young People’s Palliative Care Executive, Scottish Paediatric Children and Young People’s Palliative Care Network, Community Children’s Nursing Network, Speech and Language Therapist Network, Physiotherapist Network, Ventilation network and West of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Managed Clinical Network.

The NMCN CEN Lead Clinician and Manager present the work of the network at meetings and provide e-mail updates to keep the Child Health Commissioners Group, the Child Health Support Group and Scotland’s Commissioner for Children and Young People informed about the progress of the network; there is regular communication with these groups which ensures effective engagement. The network has also established links with the GIRFEC team and Children & Young People with Disability Teams at the Scottish Government. The network aims to keep the Regional Planning
Groups informed about its work and is looking with NSD and other NMCNs at possible ways to improve the communication with the Regional Planning Groups.

5. Plans for 2014/15

**NMCN CEN Work plan April 2014-April 2015** (Approved by CEN Steering Group April 2013)

<table>
<thead>
<tr>
<th>Outcome / measure for improvement</th>
<th>Action plan for CEN</th>
<th>Planned start/end dates</th>
<th>Lead</th>
<th>Costs</th>
</tr>
</thead>
</table>
| 1. Children with exceptional health needs are identified to enable a comprehensive and systematic identification and mapping of children across Scotland All children with exceptional health care needs are recorded within the SNS system for Scotland (or a local equivalent) within 4 weeks of identification. | 1.1 6 monthly reporting from SNS around CEN within Scotland  
1.2 Share SNS and hospital admission data with Health Boards to support local planning  
1.3 Identify low uptake areas where SNS in use  
1.4 Create way of identifying CEN in health boards not currently using SNS  
1.5 Collect and analyse data on hospital admissions for children with exceptional healthcare needs in 2013 and report on the admission patterns and reasons for admission to hospital (raise awareness of 2013 report to enable discussion and local planning) | Data & Audit Subgroup   |      |                              |
| 2. Children with exceptional health care needs will have an individualised Child's Plan with actions, outcomes, timescales and responsibilities recorded with identified Named Person and Lead Professional (as appropriate) | 2.1 Update CEN Pathway of Care to ensure that this is a 'live' resource (monitor access through hits to website)  
2.2 Test self assessment tool within identified health boards using PDSA, with aim for implementation to all health boards  
2.3 Implement CEN service / self assessment tool to identify if all CEN have an individualised child’s plan. | Data & Audit Subgroup   |      |                              |
| 3. Young people will have an improved experience for their transition to adult health services | 3.1 Endorsement of Scottish Transitions Forum: Principles of Good Transitions 2  
3.2 Joint project with Talking Mats to get the views of young people with exceptional healthcare needs and | Service User and Education Subgroup |      |                              |
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|   | their parents to find out what matters to them  
3.3 Development of E-Learning Module for Adults with Incapacity (Scotland) Act (2000) and Guardianship  
3.4 Raise awareness about Transition from Children to Adult Health Services with the Scottish Person Centred Health and Care Collaborative |
|   |   |
| 4. | Improve engagement with children/young people and their families  
4.1 Deliver 2 Family Information events in partnership with CEN multiagency stakeholders from health, social work, education and voluntary sector |
|   | Service User and Education Subgroup |
| 5. | Identify workforce knowledge and skills needs and develop education and training resources to support staff development  
5.1 Deliver strategy to promote the 5 CEN e-learning modules accessed via Learn Pro  
5.2 Evaluate access and impact of new e-learning modules  
5.3 Deliver 4 local education days across Scotland  
5.4 Promote joint NHS Highland/CEN Parenting Workshop as part of the local education days  
5.5 Deliver 2 Peer Case Review workshops  
5.6 Update CEN Education Strategy |
|   | Service User and Education Subgroup |
| 6. | Continue core CEN activities  
6.1 Updating, monitoring and evaluation of CEN website  
6.2 Communication with stakeholders including quarterly newsletter  
6.3 Promotion of CEN information and resources (pathway of care, communication and tube feeding DVDs, early support booklet, e-learning modules) |
|   | CEN Manager and Project Support |
Appendix 1: Network membership

The network now has over 600 contacts.
Below are the members of the Steering Group and Working Groups.

Steering Group

Dawn Moss  Clinical Lead CEN NMCN
Jayne Scotland  Network Manager CEN
Elaine Berry  Council and SW Aberdeen
Mary Cloughley  Head Teacher Hampden Primary School, Glasgow
Jackie Crum  Consultant Paediatrician, SNS lead NHS Grampian
Phil Davies  Consultant Paediatrician
Claire Edwards  Independent consultant and Parent
Sally Egan  NHS Lothian Child Health Commissioner
Sarah Hay  CCN Sister GGC
Arlene Honeyman  Clinical Psychologist - CHAS
Catriona Johnson  NSD lead
Margaret Johnston  Community Service Manager, NHS Lanarkshire
Nancy Little  SALT, NHS Fife
Ciara McColgan  Consultant Paediatrician (Chair of Data and Audit group)
Margaret McFadden  Head Teacher, Kelbourne Special school, Glasgow
Sophie Pilgrim  Director of Kindred and Chair of Service Users working group
Scott Read  Development Officer Transitions Forum Scotland
Karen Sinclair  Clinical Nurse Educator WoS gastric and heptology network
David Smyth  ANP Children with Exceptional Healthcare Needs, NHS Fife
Laura Somerville  Consultant Paediatrician and Chair virtual Pathway Group
Chloe Swift  Lead Policy Officer, SCCYP
Laura Wiggins  Physiotherapist
Anne Wilson  Policy Development officer AfSCS
Jackie Young (McMahon)  Clinical Manager NHS Fife
Jane Reid  AHP Lead for Children & Young People
**Data and Audit Working Group**

Ciara McGolgan  
Consultant Paediatrician, NHS Greater Glasgow & Clyde (Chair)

Dawn Moss  
NMCN CEN Lead Clinician

Jayne Scotland  
NMCN CEN Manager

Lila Agrawal  
Consultant Paediatrician, NHS Lanarkshire

Caroline Clark  
Paediatric Consultant, NHS Highland

Nuno Cordeiro  
Paediatrician, Rainbow House, NHS Ayrshire and Arran

Lyn Cresswell  
Consultant Paediatrician, NHS Lothian

Jacqueline Crum  
Consultant Paediatrician, NHS Grampian

Gill Currie  
Community Children’s Nurse, NHS Highland

Babs Henderson  
Director, CHAS at Home

Annemarie King  
Paediatric Complex Care Sister, NHS Forth Valley

Gordon Linton  
Discharge Liaison Nurse, NHS Lothian

Beth Frank  
Complex Needs Nurse Coordinator, NHS Ayrshire & Arran

Jacqueline Reilly  
Discharge Nurse Coordinator, Children & Young People, NHS Greater Glasgow & Clyde

Aileen Crighton  
Well Child Children & Young People’s Liaison Nurse

Audrey Toshney  
Senior Staff Nurse, Paediatric Outreach, NHS Tayside

**Joint Education and Service Users Working Group**

Dawn Moss  
NMCN CEN Lead Clinician (Chair)

Jayne Scotland  
NMCN CEN Manager

Anne Wilson  
Development Officer, Action for Sick Children Scotland

Claire Edwards  
Training Consultant

Debbie McGirr  
School of Nursing Midwifery & Social Health, Napier University

Ellen Baird  
Speech and language therapist, NHS Borders

Fiona Fenton  
Occupational Therapist NHS Grampian

Hilary Cartwright  
Lead Service Manager - Allied Health, Capability Scotland

Irene McTaggart  
School of Nursing & Midwifery, University of Dundee

Joanna Smith  
Lecturer/Practitioner, University of Stirling

Karen Sinclair  
Clinical Nurse Educator West of Scotland Gastro Network

Katherine McKay  
National Clinical Lead, Children and Young People’s Health, Scottish Government

Sophie Pilgrim  
Director, Kindred and parent (Co-Chair)

Allison Morrison  
NHS GGC

Laura Somerville  
Consultant Paediatrician NHS Greater Glasgow and Clyde

Lesley McLaren  
Family Support Coordinator, PAMIS

Margaret Johnston  
Team Leader Community Children's Nursing, NHS Lanarkshire

Nadine McArthur  
Advocacy Worker, Kindred/Parent

Gemma Passmore  
Paediatric Physiotherapist, NHS Shetland

Winnie Taylor  
Head of Speech & Language Therapy, NHS Grampian
A group of 13 parents of children with complex and exceptional healthcare needs attend and contribute to the work of this group.

**Pathway of Care Implementation Working Group**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position/Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alison Rennie</td>
<td>Consultant Paediatrician</td>
</tr>
<tr>
<td>Andrew Cooper</td>
<td>Paediatric Trainee</td>
</tr>
<tr>
<td>Angela Hall</td>
<td>Specialist School Nurses (Team Leader)</td>
</tr>
<tr>
<td>Ann Kendall</td>
<td>Paediatric Physiotherapist</td>
</tr>
<tr>
<td>Anna Emslie</td>
<td>Paediatric Community (Physio)</td>
</tr>
<tr>
<td>Annmarie King</td>
<td>Paediatric Complex Care Sister</td>
</tr>
<tr>
<td>Arlene Honeyman</td>
<td>Social Worker</td>
</tr>
<tr>
<td>Audrey Toshney</td>
<td>Senior Staff Nurse</td>
</tr>
<tr>
<td>Barbara Simpson</td>
<td>Community Children's Nurse</td>
</tr>
<tr>
<td>Carol Graham</td>
<td>Community Children's Nurse</td>
</tr>
<tr>
<td>Carolyn Arbothnott</td>
<td>Care Coordination Manager</td>
</tr>
<tr>
<td>Dawn Moss</td>
<td>Nurse Consultant Child Health</td>
</tr>
<tr>
<td>Deirdre Simpson</td>
<td>Paediatric Physiotherapist</td>
</tr>
<tr>
<td>Elizabeth Gillespie</td>
<td>Sister (CCN team)</td>
</tr>
<tr>
<td>Elspeth Mair</td>
<td>Speech &amp; Language Therapist</td>
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<tr>
<td>Fiona Houlihan</td>
<td>Community Children's Nurse</td>
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<tr>
<td>Fiona Ogungbaro</td>
<td>Social Worker</td>
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<tr>
<td>Fiona Shevill</td>
<td>GIRFEC team-Scottish Govt</td>
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<tr>
<td>Gill Sutherland</td>
<td>Complex Needs Coordinator</td>
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<tr>
<td>Heather Carrick</td>
<td>Can Care coordinator</td>
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<tr>
<td>Helen Gibson</td>
<td>Consultant Paediatrician</td>
</tr>
<tr>
<td>Irene McArthur</td>
<td>Clinical Nurse Specialist neurologist</td>
</tr>
<tr>
<td>Isla Davies</td>
<td>Speech &amp; Language Therapist</td>
</tr>
<tr>
<td>Jackie Young</td>
<td>Team Nurse Manager</td>
</tr>
<tr>
<td>Jacqueline Elliott</td>
<td>Staff Nurse/Care Supervisor</td>
</tr>
<tr>
<td>Jacqueline Reilly</td>
<td>Discharge Nurse Coordinator</td>
</tr>
<tr>
<td>Jane Thompson</td>
<td>Additional Needs Liaison Nurse in Schools</td>
</tr>
<tr>
<td>Karen Ross</td>
<td>Consultant Paediatrician Trainee</td>
</tr>
<tr>
<td>Lesley McDonald</td>
<td>Community Paediatrician</td>
</tr>
<tr>
<td>Liling Payne</td>
<td>Principal Officer Children with Disabilities Team</td>
</tr>
<tr>
<td>Linda Sanders</td>
<td>Team Leader-West Lothian Council</td>
</tr>
<tr>
<td>Linda Howard</td>
<td>Care Coordinator</td>
</tr>
<tr>
<td>Louise Adam</td>
<td>Parent/CCNUK Trainer</td>
</tr>
<tr>
<td>Lynne Allan</td>
<td>Paediatric Epilepsy nurse</td>
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<tr>
<td>Matt Hayes</td>
<td>Acute Hospitals Learning Disabilities</td>
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<tr>
<td>Nicola Tennent</td>
<td>Paediatric Physiotherapist</td>
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<tr>
<td>Rosina Latta</td>
<td>Deputy Head Teacher</td>
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<tr>
<td>Ruth Macleod</td>
<td>Staff Nurse/Care Supervisor</td>
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<tr>
<td>Sally Mair</td>
<td>Depute Head Teacher</td>
</tr>
<tr>
<td>Shiuili Russell</td>
<td>SpR in Paediatrics</td>
</tr>
<tr>
<td>Valerie Orr</td>
<td>Paeditarics</td>
</tr>
</tbody>
</table>
Appendix 2: Finance

**TOTAL NMCN CEN 2013/14 (funded by NSD):**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>NMCN CEN Lead Clinician Backfill (2 sessions)</td>
<td>£18,387</td>
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<tr>
<td>NMCN CEN Manager</td>
<td>£21,000</td>
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<tr>
<td>NMCN CEN Administrator</td>
<td>£13,000</td>
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<tr>
<td>NSD annual allocation</td>
<td>£10000</td>
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</table>

**Other funding sources:**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
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</thead>
<tbody>
<tr>
<td>NHS Highland to fund joint NHS Highland and CEN parenting project</td>
<td>£7500</td>
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<tr>
<td>Extra funding from MB salary (under spend confirmed)</td>
<td>£2500</td>
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</tbody>
</table>

**Total Income CEN 2013/14:** £72,387

**Actual non pay spend breakdown:**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPD</td>
<td>£548.00</td>
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<tr>
<td>Pamis (Guardianship and workshops)</td>
<td>£1975.90</td>
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<tr>
<td>Annual Website (Globalweb)</td>
<td>£1512.00</td>
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<tr>
<td>LearnPro modules</td>
<td>£12,500.00</td>
</tr>
<tr>
<td>CEN Conference</td>
<td>£3,600.00</td>
</tr>
<tr>
<td>Conference / Learnpro films</td>
<td>£570.00</td>
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<tr>
<td>CEN resources DVD’s</td>
<td>£522.00</td>
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<tr>
<td>Leaflets / booklets</td>
<td>£524.00</td>
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<tr>
<td>Posters</td>
<td>£84.00</td>
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<tr>
<td>Travel &amp; Accommodation</td>
<td>£791.75</td>
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<tr>
<td>Misc Stationary</td>
<td>£6.95</td>
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<tr>
<td>Meeting Room booking</td>
<td>£106.00</td>
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</tbody>
</table>

**Total non pay:** £22740.60

(CEN 2013/14: overspend £2740.60. NB: Allocated salary costs included in this report have not been fully utilised over 2013/14 with NHS Lothian finance statement Period 12 identifying under spend of £6449. This overspend was to be balanced across NHS Lothian based NMCN’s.)
Appendix 3:

Supporting documentation for CEN Work plan 2014/15
(some papers available on request)

Outcome 1:
- CEN SNS and hospital admission data report (March 2014)

Outcome 2:
- CEN pathway
- Project outline re: testing self evaluation tool with Yorkhill and Ayrshire & Arran (available on request)

Outcome 3:
- CEN Transition Work Plan (March 2014)

Outcome 4:
- Family Event report (February 2014)

Outcome 5:
- E-learning draft promotional flier (available on request)
- Parenting Report (Clare Edwards)
- CEN Draft Education Strategy 2014 (available on request)

Outcome 6: no links