

CEN

National Managed Clinical Network

Peer Review Meeting

Care of children and
young people requiring
long term ventilation.

19th April 2018

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Section 1: Introduction

The CEN NMCN is committed to equality of care and resources across Scotland for CYP with exceptional healthcare needs. .

The biannual peer review meetings held by the CEN NMCN are an educational forum for the sharing of good practice and discussion of challenges faced in delivering excellence in care. Case review is used as a basis for discussion.

In this meeting we considered the complexities of discharge home for children who have long term ventilation [LTV]. This aligns with the recently published review of the use of PICU beds and how children requiring LTV may have inappropriately extended hospital admissions.

In sharing good practice four clinical cases were discussed and information on the Highland Technology Pathways shared. The use of the decision support tool as supporting effective discharge planning was represented in some of the case presentations.

The DoH National Framework (2016), recommends the Continuing Care Process to be a three staged process completed in partnership by the NHS, Local authority and third parties. It is recognised that discharge planning and provision of appropriate care packages is essential for excellence in care

There are three key stages to full assessment:

1. Assessment

The assessment is the first stage of the continuing care process and is led by a nominated healthcare professional this considers

- The preferences of the child and young person and their family
- Holistic assessment of the child and young person and their family, including a carer assessment
- Reports and risk assessments from the multidisciplinary team
- Use of a discharge planning tool, such as the Decision Support Tool for children and young people helps bring uniformity and equity.

2. Decision Making

The next phase, decision-making involves a multidisciplinary, multi-agency forum such as a joint funding panel, part of a Children's Service/Trust or an alternative local arrangement.

3. Development of a Care Package

The final phase is the development of a continuing care package using the information agreed within the Decision Support Tool. With this information NHS Board, Local authority and their partners undertake the planning and commissioning processes to agree a person centred care package as identified from the DST assessment process. The CEN NMCN is promoting the use of this domain based healthcare assessment to:

- Identify consistency, equity and ease of assessment of healthcare needs within NHS Boards following training in use of tool

- Develop an evaluation to identify further development of the DST for use within a national continuing care framework
- Using a recognised assessment process to promote the equity of care and service provision throughout Scotland for children and young people.

Section 2: Background

The Decision Support Tool asks the nominated healthcare professional to set out the individual child / young person's needs within 10 care domains. For every domain the level of description that most closely matches the individual child or young person's needs is chosen, with information supporting decision.

The Decision Support Tool is completed in partnership with the child or young person and family, the National Practice Model (GIRFEC) and risk assessments, providing an inclusive, comprehensive and holistic approach to the assessment phase.

The child or young person, parent or carers actively contribute to the assessment process.

Section 3: Communication and Collaboration

The peer review meeting used case based discussions around complex discharge planning at using these cases examples of good practice, the complex challenges and how practice could further be developed was discussed. Some cases illustrated the use of the DST.

The meeting was facilitated by Mrs Alison Gilhooly, Programme Manager for NMCN, who is wholly independent of the CEN NMCN.

The CEN NMCN was represented by:

- Dr Susan Buck, Lead Clinician
- Ms Robina Collins, Programme Support Officer, NHS NSS
- Mrs Catriona Johnson, Programme Associate Director, NHS NSS

We gratefully acknowledge the important contribution made by the professionals who presented cases and shared examples of good practice.

Stakeholders throughout the CEN MNCN were invited to the meeting.

Section 4: Case Review discussion

Group discussion took place following on from each case review and identified the following key points:

- **What went well**
 - Honorary contracts
 - Enabling systems
 - Capacity & skills – existing staff
 - Family finances supporting discharge options.
 - Existing system for funding
 - Experience within host health board

- Seamless journey
- Parental confidence to take child home
- Proactive involvement of HV/GP in discharge planning.
- Phased discharge
- CHAS resource
- Highland experience
 - Train the trainer – Band 5 RN's expensive model
 - Geographical challenges
- Model of HTP [Highland Technology Pathway]
- Standards / SOP's for organisations / roles
 - Band 3's trained by Band 6
 - 2 x 3rd party providers
 - Quarterly exchange

- **What could be improved / Issues**

- Criteria standardised e.g. use of the DST to prevent inequity of assessment.
- Variation in:
 - service models – some child specific
 - Equipment with different specifications required by different HBs.
- Lack of proactive response from host Board
- Need to involve all stakeholders in planning meetings
- Remembering the place of the family in planning discharge.
- Lack of family commitment to discharge
- Format of negotiations with 3rd party providers
- Limited capacity to train
 - Exacerbated by ward layout or cross border
- Inadequate housing for discharge
- Variation in policy – employee safety
- Range of solutions – e.g. paying for second carer. This varies in different regions
- Respite access and model
 - Parents feel tied with some packages
 - Some good examples of more flexible arrangements.
- Challenges common across Scotland

- **Opportunities**

- Key points of contact



- Lothian process:
- Robust systems shared across Scotland.
 - Funding
 - Employees
 - Training

- National framework for equipment to assist training and equipment provision
- Keep family informed
 - Cross border health board/HSCP
- Phased discharge via D.G.H
- Role for CHAS
- National agreement / standards
 - Performance level
- Consistent tool / criteria
 - Sharing Existing pathway
- Publicise economic call for meeting accessible housing needs versus long term care
- Holistic assessment (DST) – quantifiable?
- Adopt SHANARI model to identify proportion attainable to each area
- Development of a National group
 - Paediatric / adult standard
 - LTV

Section 5: Conclusions and next steps

In this peer review meeting there was a positive discussion with wide engagement from the case presenters and the audience. Areas of Scotland represented included Orkney, Highland, Lothian, Greater Glasgow and Lanarkshire Health Board's along with representatives from CHAS. This helped to build up a national picture.

Shared themes were the availability and training of staff, adequate funding, parental commitment, a proactive approach to planning, with 'wide buy in' involving health board with the local health board and PHCT in discharge planning. The same issues were reflected in the challenges faced. Additional difficulties were a negative response from the host Board, getting wide involvement of all the stakeholders in the planning process including the family and variations across health boards such as policies of staff and equipment. Further geographical variations are in support provided for the carers. Lack of appropriate accessible housing is a barrier to discharge and has been highlighted in other CEN NMCN consultations.

In considering the opportunities for ongoing development there was significant agreement within the group. Given the complexity, and the high cost of care there are clear benefits of building on the opportunities. This would bring it improvement to the well-being of children, young people and their families whilst maximising the use of resources. The opportunities agreed are identifying a key point of contact, sharing of pathways across health boards, and health and social care partnerships boundaries. Furthermore this would support congruence for national standards of performance across Scotland. A national framework agreeing equipment would greatly assist training and equipment provision. Intermediate discharge to a district general hospital whilst finalising the home care package would help families and also use resources more appropriately. Using a holistic model for assessment such as the decision support tool and adopting the SHANARI model would further facilitate discharge.

There is a widely recognised need for accessible family housing with an evidence base that this saves health and social care budgets, as well as improving family well-being.

This development will require political drivers to influence local policy. The framework for supporting disabled children, young people and their families is a significant consultation by the Scottish government with the planned publication of the framework 2018 the year of the young person. Consensus was reached on the benefits of a national group to look at the standards for care for children and young people who require long-term ventilation.

The outcomes of this discussion will be given to the Scottish Government as part of the consultation for the Framework for Supporting Disabled Children, Young People and Their Families.

The CEN NMCM gratefully acknowledges the contribution of informed professionals to this peer review event leading to a shared consensus for a complex area of care across Scotland.

The CEN NMCM uses the National Managed Clinical Networks to influence policy and service development to promote excellence in care for this vulnerable group of children and young people.

Appendix A: Meeting Programme – Case Reviews

CEN Peer Review Meeting – Decision Support Tool
Queen Elizabeth University Hospital
Thursday 19th April 2018
2.30 -4.30pm

<u>2.15 – 2.30pm</u>	Registration and refreshments	
<u>2.30pm-2.40pm</u>	Welcome	Mrs Alison Gilhooly / Dr Susan Buck
<u>2.40pm – 3pm</u>	What went well / Discussion	Ms Elspeth Jardine
<u>3 – 3.20pm</u>	A less positive experience / Discussion	Ms Elspeth Jardine
<u>3.20 – 3.40pm</u>	DST & RHSC Discharge Process / Discussion	Mr Gordon Linton
<u>3.40 – 4pm</u>	DST of a LENS Child / Discussion	Ms Xanthe Baker
<u>4 – 4.20pm</u>	Highland TP Experiences / Discussion	Mrs April Emmott
<u>4.20 - 4.30pm</u>	Next steps and close	Dr Susan Buck