



Setting up a Managed Clinical Network in Children's Palliative Care

December 2017

Introduction

This guidance is written for local services and networks who are considering establishing Managed Clinical Networks to deliver children's palliative care. It focuses on the development of Managed Clinical Networks (MCN) in England. The fundamental activities remain relevant in other countries, but they would need to recognise local equivalent policy and organisations.

There is a plethora of evidence relating to the value of networks in a wide range of settings. Together for Short Lives recognises and values the work of the UK-wide Children's Palliative Care networks and their essential role in achieving the sustainable, high quality service provision required by children, young people and families. We believe that MCNs can help to further transform children's palliative care by working to plan and deliver care to a shared agenda and purpose, with clarity of purpose and mobilising resources to best effect to facilitate consistency of care, focusing on continually improving the patient experience, improving outcomes and providing best value for money.

In 2016 NICE produced a guideline¹ for the planning and management of end of life and palliative care in for infants, children and young people (aged 0–17 years) with life-limiting conditions. It aims to involve children, young people and their families in decisions about their care, and improve the support that is available to them throughout their lives. In this guideline, NICE recommend the establishment of Children's Palliative Care Managed Clinical Networks, stated "Services should have agreed strategies and processes to support children and young people who are approaching the end of life and are being cared for at home. These services should be based on managed clinical networks, and should collaborate on care planning and service delivery".

In Scotland, National Networks were introduced in 1998 as a model for linking hospital services within NHS Boards and are recognised as vehicles for change and improvement. They work across professional, organisational and geographical boundaries to support Scottish Government policy aims of safe, effective healthcare which is designed around patients, carers and families. National Networks are required where the full range of specialist care for patients with rare conditions and/or complex needs are not available within an NHS board, or even within a region.

The All Wales Managed Clinical Network for children's palliative care provides an all Wales tertiary service, as well as local secondary support in the care of children with any life-shortening condition, malignant or otherwise. It is administratively based at the Children's Hospital in Cardiff, but individual members of the Network have their base in each of the Health Boards of the Principality, as well as the children's hospices that serve Wales. Its core members are the doctors, nurses and therapists delivering clinical care and other professionals are co-opted as is appropriate.

In Northern Ireland clinical networks are recognised as having the potential to bring together an appropriate range of primary, secondary and tertiary medical services to ensure equitable provision of high quality, clinically effective services

¹ NICE End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61)

What is an MCN?

1. A Managed Clinical Network² is “A linked group of health professionals and organisations from primary, secondary, and tertiary care, working in a coordinated way that is not constrained by existing organisational or professional boundaries to ensure equitable provision of high quality, clinically effective care . . . The emphasis . . . shifts from buildings and organisations towards services and patients.”

Why a MCN?

2. Managed Clinical Networks help to build a strategic and joined up approach to children’s palliative care across health and social care services and bring together statutory and charitable providers.
3. Typically, MCNs will establish a programme of meetings to deal with the work, dependent on the priorities for service development and consider the locality – e.g. hold less frequent but longer meetings if travel is an issue. The governance processes should be established early in the setting up of the MCN and consider structural issues which might act as barriers to effective MCN working, such as decision-making processes, clinical and information governance, I.T, key roles, performance management cycles, communication and reporting links.
4. Existing MCNs (for diabetes and neonatal) are recognised as bringing about:
 - cost-effective services
 - improved patient experience
 - improved clinical outcomes
 - integrated care
 - equity of service provision

The strategic importance of MCN’s

5. MCNs for children’s palliative care can play a key role in supporting the Government’s ‘Our Commitment to You for End of Life Care: The Government Response to the Review of Choice’³. The government states to support high quality personalised care for children and young people, commissioners and providers of services must prioritise children’s palliative care in their strategic planning; this is so that services can work together seamlessly, and advance care planning can be shared and acted upon.
6. With so few Local Authorities and CCGs delivering this commitment, MCN can play a key role in helping to make this commitment a reality. And with funding being directed towards STPs, MCNs can play a key role in partnering and informing areas wide activity across health, education and social care for children’s palliative care.

² Baker CD, Lorimer AR. Cardiology: the development of a managed clinical network. MJ 2000;321:1152–3.

³ Department of Health. 2016. ‘Our Commitment to you for end of life care: The Government Response to the Review of Choice’. Available to download from: <http://bit.ly/2oOU5fi>

What is the difference between a Children's Palliative Care Network and a Managed Clinical Network?

7. UK children's palliative care networks are usually informal, interdisciplinary structured groups representing providers and sometimes users and commissioners of services over a defined geographical area, drawn together with the common aim of sharing best practice, co-ordinating, strengthening and developing services for children and young people life-limiting conditions.
8. When a network becomes a funded Managed Clinical Network, its function changes to take on a more formal management structure to support the delivery of care, to have defined objectives and to have a clear governance framework, thereby acquiring authority and influence (RCPCH, 2012).
9. The purpose of an MCN is to improve the care and support of babies, children and families in terms of quality, access, convenience and co-ordination and cut across traditional organisational and professional boundaries

What makes networks effective?

10. The Health Foundation (2011)⁴ identified a series of features that are commonly found in effective networks:
 - shared purpose and identity
 - address big issues or have a compelling purpose
 - meets member needs
 - adapted leadership
 - strong relationships and ties
 - generate helpful outputs

What population should an MCN cover?

11. Existing Managed Clinical Networks provide care to a wide range of population sizes, with a key consideration appearing to be the need for the network to be flexible, to respond to local conditions and to consider natural population flows.
12. RCPCH⁵ note that the population base for a network primarily takes into consideration the critical mass for clinical effectiveness and rarity of the condition, but should consider accessibility including travelling time for those requiring frequent care at the specialist centre.

Who should be involved in an MCN?

13. Together for Short Lives recommend that a MCN should involve:
 - Network chair /clinical leads.

⁴ Malby B, Anderson-Wallace M, Archibald D, Collison C, Edwards S, Constable A, Dove C. *Supporting networks that improve the quality of healthcare. A developmental diagnostic process to support network development*. London: Health Foundation; 2011.

⁵ Bringing Networks to Life – an RCPCH guide to implementing clinical networks

- Network manager.
- Provider representation (e.g. tertiary children's hospital, district general hospitals, community nursing services, children's hospices).
- CCG or equivalent representation.
- User representative.
- Administrative support.
- Local authority/Health and Wellbeing Board or equivalent representative.
- Sustainability and Transformation Partnership or equivalent representative.

How much does it cost to set up a MCN?

14. The main costs are:

- Network manager to provide administrative leadership and function within the MCN to establish processes and governance and maintain relationships between key personnel providing a facilitative and co-ordinating role, which deals with the day-to-day MCN work and organising MCN activities.
- Travel expenses for user representative and key staff.
- Clinical Leads - sessional reimbursement to ensure the availability of protected time for network Lead Clinicians who have clinical credibility across professional groups who can encourage buy-in to the MCN activity.

What does a MCN have to do?

15. The essential requirement of an MCN is to provide Governance and Authority, and to lead the planning and delivery of safe, efficient, cost effective services to meet identified needs through a formal networked arrangement between local and specialist professionals and services.

What benefits can an MCN bring?

16. The RCPCH (2012) state that funded Managed Clinical Networks would:

- Ensure collective capacity and expertise
- Have clear pathways for accessing specialist advice.
- Facilitate high quality training.
- Improve governance and quality improvement mechanisms and facilitate strategy development.

17. Together for Short Lives believe that MCNs in children's palliative care offer an effective solution to establishing equity of care and improving network planning and delivery and partnership working. MCNs also facilitate broader engagement and ownership of the delivery of care to children and young people with life-limiting conditions and their families. MCNs are able to:

- Help defining the scope for children's palliative care in the local area.
- Help to identify the population in need of palliative care.
- Identify local services to act as partners in the process.
- Identify relevant policies.
- Identify existing datasets and baseline (or links to national activity in relation to this work).
- Identify commissioning needs and population needs (current & future).
- Identify best practice.
- Identify gaps in existing service provision and key priorities for service improvement.
- Establish and share outcome measure/key performance indicators.
- Contribute to the discussions about potential service redesign to improve outcomes and reduce cost (e.g. saved bed nights; reduced admission/readmission).

How can MCNs support CCG, Local Authority and STP activity?

18. Based on existing materials⁶ relating to diabetes, MCNs which are well established in England, could support activity in relation to children's palliative care by:

- Translating national policy e.g. NICE Guidelines or ReSPECT processes into local action – provide a forum and support mechanism for CCGs to deliver on national and local care standards and provide channels to disseminate this information to the local health economy.
- Supporting the Health and Wellbeing Board to establish the population need.
- Commissioning services that reflect the population need.
- Gathering and interpreting data to inform commissioning decisions.
- Incorporating best practice – from expertise of network stakeholders, this encourages shared learning and the ability to resolve issues that may arise.
- Defining priorities which are reflected into a detailed work plan that is reflective of national guidelines and local and service user priorities and provide the forum to achieve those objectives.
- Providing a forum for service redesign and improvement.
- Improving stakeholder relations – bridging the gap between providers and commissioners.
- Providing a forum of support for healthcare professionals and commissioners.
- Improving services to reduce variability in health care provision – by understanding the local population need and gathering local intelligence from stakeholders tailoring commissioning intentions can improve patient outcomes.
- Improving the cost effectiveness of the service.
- Improving data quality.

How could a MCN support service development?

19. When considering the local benefits to service development, professionals and service leads should consider:

- Are the care and support needs of babies, children and young people with life-limiting conditions being met?
- Do babies, children and young people have access to the range of services they need?
- Are NICE quality standards being achieved? If not, why not?

⁶ Implementing Local Diabetes Network Diabetes UK 2012

- Are there quality improvement programmes?
- Are there examples of clinical guidelines and care pathways?
 - Do these local clinical guidelines align with endorsed national guidelines?
- Are there any examples of good multi-disciplinary teams?
- Are there examples of good audit practice which should be shared?
- Are there agreed service specifications across the locality with planners and commissioning bodies? If so, are they being implemented and evaluated?
- Are outcomes measured and driving service improvement?

What are the next steps?

- Secure the support and understanding of those who have the control of resources to make the development process either possible or impossible.
- Identify and appoint a project team and project leader – you need champions to take the work forward.
- Set a time frame.
- Create a development plan:
 - Agree lead roles. MCNs must be managed rather than drifting, they need clear structures, there should be a lead role and there should be clear responsibilities for all concerned.
 - Identify role and membership of working groups.
 - Create terms of reference.
 - Agree aims and priorities of the network.
- Build on existing networks and knowledge: reach out to those previously not engaged with the partnership working:
 - Know your stakeholders.
 - Know your population and their needs.
 - Know your services/entry points to care/referral processes. The process of service mapping is invaluable in finding out just how much reality differs from what appears on paper.
 - Identify existing care pathways and guidelines in use.
 - Consider patient flow.
 - Consider geographical boundaries.
- Identify gaps in knowledge.
- Decide on the population to be covered.
- Agree structure of the MCN.
- Agree clinical governance arrangements.
- Think about how the MCN will reach out to all those who have a role in delivering care e.g. community paediatricians; general paediatricians. Some networks have established clinical forums to attract such colleagues.

Useful resources

Managed Clinical Networks – a guide to implementation

<http://www.smn.scot.nhs.uk/documents/nhs%20scotland%20-%20mcns%20-%20a%20guide%20to%20implementation%5B1%5D.pdf>

Bringing Networks to Life – an RCPCH guide to implementing clinical networks

http://www.rcpch.ac.uk/system/files/protected/page/Bringing%20Networks%20to%20Life%20for%20web_0.pdf

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