

**A framework for the operation
of
MANAGED CLINICAL NETWORKS
IN PALLIATIVE CARE**

**Report of a Working Party of
the Scottish Partnership Agency
for Palliative and Cancer Care**

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Summary

This report of a Working Party set up by the Scottish Partnership Agency for Palliative and Cancer Care suggests a Framework for the operation of Managed Clinical Networks in Palliative Care in Scotland. The report sets out the benefits which the Working Party believe it should be possible to achieve for patients, carers and health professionals through the establishment of Managed Clinical Networks in Palliative Care. It describes the aims and characteristics of MCNs in Palliative Care and makes recommendations about membership and structure, allowing some flexibility so that Networks can be targeted to suit local needs and circumstances.

Recommendation

The Working Party recommends that the Framework set out in this report should be piloted in a number of contrasting areas in Scotland and that evaluation of the pilot Networks should determine the future development of Managed Clinical Networks in Palliative Care.

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1. Introduction

In December 1998 the Scottish Partnership Agency for Palliative and Cancer Care (SPA) accepted a request from the NHS Management Executive that it should consider the application of the concept of Managed Clinical Networks (MCNs) to the field of palliative care. A steering group was established and a Workshop was organised by the SPA. The Workshop was held in August 1999 and was attended by 120 delegates from all parts of the NHS, voluntary sector and patient representative bodies. As a result of the Workshop it was agreed to set up a Working Party (Annex A) whose remit would be to develop a framework for the operation of Managed Clinical Networks in Palliative Care. It was proposed that this framework be submitted to the Management Executive, with the intention of a number of pilot networks being set up early in 2000.

The Working Party started from agreement that:

Networking across different settings of care (i.e. primary, secondary and tertiary) and across professions and agencies is particularly important in palliative care and the potential of MCNs to improve care should be explored and tested.

The Management Executive has stressed the flexibility of the MCN concept so there is an opportunity to develop networks which are specifically designed for palliative care and targeted to suit local needs and circumstances.

MCNs provide an opportunity to promote best practice both through local interpretation and implementation of Guidelines, and by providing a forum in which innovation (through sharing of experience and ideas) can be supported and encouraged, and its implications discussed and understood.

In drafting these proposals the Working Party took account of the guidance in NHS MEL (1999) 10 and drew on the discussions at the Multi-professional Workshop on MCNs in Palliative Care held in Stirling in August 1999.

2. The aim of a Managed Clinical Network in Palliative Care should be:

To create effective, efficient communication links among health professionals and with patients and carers, and to co-ordinate palliative care provision across hospitals, hospices and primary care, including nursing homes

To ensure that palliative care of an equally high standard is available to everyone who needs it throughout the catchment area of the Network

To improve standards of palliative care by promoting evidence based practice, with the management of pain as the first priority, and by a programme of continuous professional development for members of the Network

To ensure that a system to audit the outcome of evidence based practice is in place and that results are disseminated timeously to those in the Network

To ensure that patients and carers have the information and understanding they need to make choices about their palliative care.

The management of pain is identified as the first priority for Palliative Care Networks because there is evidence that pain relief is not uniformly as good as it could be, and because the imminent publication of a SIGN Guideline on the Control of Pain in Patients with Cancer provides an opportunity to implement and audit evidence-based practice. An initial focus on pain should enable a natural progression to include other aspects of palliative care.

3. Links with Cancer Managed Clinical Networks

MCNs are being established at regional level for each of the common cancers. Formalised and ongoing links between the cancer MCNs and palliative care MCNs will be essential if improvements in patient care are to be made at the critical interfaces between primary and secondary care and between cancer treatment and palliative care. In order that palliative care is provided as an integral part of cancer treatment each Managed Clinical Network for different cancers will need to include representation from palliative care and primary care. The main focus of the cancer MCNs will however be on cancer treatment. Palliative care MCNs, operating at a more local level, will have the advantage of being able to focus entirely on palliative care, involving professionals from primary care, hospitals, hospices and other local organisations. The links between the cancer and palliative care networks will need to be reciprocal and to be recognised by local health boards and trusts. In the West and East of Scotland there are also wider regional networks or groups encompassing all the cancer MCNs. Palliative care MCNs will need to become part of these regional cancer structures.

4. Characteristics

Palliative care is provided by a complex combination of hospital based services, primary care teams, specialist community nursing services, hospices and voluntary organisations. The exact combination varies in different parts of Scotland. The shape of Managed Clinical Networks in Palliative Care in each area should be determined by local policy and practice and by the local pattern of services. Palliative Care Networks need to be flexible enough to suit each local situation and will also need to take account of some common core principles, including those set out in MEL (1999) 10. They are grouped here under the following headings:

- a) Clarity and unity of purpose
- b) Coverage, structure and management
- c) Membership
- d) Involvement of patients
- e) Clinical governance
- f) Education and training
- g) Value for money

a) Clarity and Unity of Purpose

Patients and health professionals must be clear about the overall aims of the network as in para 1 above and about the specific clinical, service and personal improvements expected to result from the establishment of the network such as:

- Improved communication
- More collaborative working
- Increased satisfaction of patient choice
- Better symptom management
- Greater continuity of care across hospital, hospice and community
- Improved access to specialist advice and support for health professionals
- Feedback for health professionals on their performance

Networks may find it helpful in the early stages to undertake a needs assessment which will identify any particular problems or gaps in services in their area and then to focus on how these can be resolved. The work of the MCN must be integrated with the local Health Improvement Programme and Trust Implementation Plan in accordance with local palliative care strategy. Multi-professional case conferences or meetings to discuss the management of more complex individual patient care should be a regular part of the Network's activity for educational purposes.

b) Coverage, Structure and Management

Palliative Care Networks should have primary care at their centre because most palliative care is provided to patients in their own homes. The network boundaries might therefore equate either to the total catchment area of a Primary Care Trust or to a group of LHCCs. In larger Primary Care Trusts where there is more than one hospice/specialist palliative care unit a Network might cover the catchment area of a hospice and the LHCCs within it.

Because of the complex nature of palliative care provision across hospital, hospice and primary care services and including NHS, local authority and voluntary services, it may be advisable for Palliative Care Networks to start simply at a local level and for there to be consideration at a later stage of the benefits of regional networks. Regional networks could provide the structure needed to facilitate benchmarking and a coordinated approach to data collection.

Each network should have a defined structure setting out the points at which palliative care is delivered, and the connections between them. The main service points will be the primary care team, specialist palliative care team in the cancer centre and district general hospital, hospice/specialist palliative care unit, community hospitals, nursing homes and social work department. Linkages with ambulance services; with other local authority departments e.g. housing, and with relevant voluntary organisations will need to be defined.

MEL (1999) 10 requires all networks to have clear management arrangements and to appoint a person who is recognised as having overall responsibility for the operation of the Network. This lead clinician or clinical manager might be from any of the relevant professions. Alternatively a lead doctor and lead nurse might be appointed. Dedicated time will need to be provided for the lead clinician(s) who must be supported by a network manager/coordinator. Dedicated administrative, IT, governance (including clinical audit, quality assurance and financial governance) and clerical support will be necessary. This minimum staffing level will be essential to create and run effective, viable networks without creating an additional bureaucracy.

Management arrangements will be determined by the size and structure of the MCN which should reflect the population size and geography of the area covered. The aim should be to encourage maximum involvement with minimum hierarchy.

c) Membership

Membership of the MCN should be open to any health professional in the area who is involved in palliative care. This could be a very large number of individuals who could not all be active members in the sense of attending meetings on a regular basis. All members must however be willing to practice in accordance with the SIGN Guideline on the Control of Pain in Patients with Cancer, and with any other evidence based guidelines adopted by the Network or local good practice guidelines developed by it. All members must also be willing to participate in a continuous programme of audit (see para 8 below)

Membership of each Network will vary according to local circumstances but the core membership should include representatives of:

- Patients and Carers
- Primary Care Teams
- Specialist Palliative Care Services
- Cancer Services
- Social Work Department
- Relevant voluntary organisations.

Other professions and organisations should be represented according to local circumstances. Ways need to be found to ensure the appropriate representation and active participation of primary care in the Network through LHCCs and to ensure good communication with all members about network activities and decisions. Employers and managers must recognise the need to free up staff time to enable them to participate in the Network.

d) Involvement of Patients and Carers

Patients and carers must be part of the core membership of the Network and should be given appropriate information and support to enable them to contribute to all aspects of its work. The involvement of patients and carers in the Network and collection of their views and opinion

ns will help health professionals to look at services from the patient's point of view. The involvement of patients and carers with experience of palliative care requires particular sensitivity and care. It may be necessary to consider various ways of hearing the patient's viewpoint. There must be a clear policy on the dissemination of information to patients and on the nature of that information, and patients and carers should be involved in developing both the information itself and the policy for its dissemination. Local cancer support organisations and organisations for carers may be able to help the Network by disseminating information.

e) Clinical Governance

Assuring a high quality service is one of the main purposes of Managed Clinical Networks. All Networks will be required to work to standards which are acceptable to the Clinical Standards Board for Scotland. Standards for palliative care are currently being developed by the Board in co-operation with the Scottish Cancer Group.

The SIGN Guideline on the Control of Pain in Patients with Cancer is due to be issued early in 2000. It is suggested that Palliative Care Networks should initially focus on pain management and implement the SIGN Guideline by using it as the basis of local guidelines, and by using its related Minimum Core Data

Set to audit the results. The SIGN Referral Letter and Immediate Discharge Document should also be considered and adapted as necessary for palliative care and for the local situation. Networks are also expected to be committed to the development and use of local good practice guidelines (which are evidence based when possible) where national Guidelines do not yet exist. All health professionals in the Network must participate in a continuous programme of audit and in the open review of results.

f) Education and Training

The Network should identify the education and training needs of its members and ensure that an appropriate programme of continuous professional development is in place. The potential for sharing best practice and expertise, and for exchanging staff across hospital, hospice and primary care should be used to the full. The particular needs should be recognised of those working in rural or more isolated areas for access to specialist advice and support. The needs of patients and carers for education and training, e.g. in the principles of pain management, should be considered in order to encourage maximum involvement in decisions about care and treatment.

g) Value for Money

Networks are required to show that they have explored the potential to generate better value for money. In palliative care there may be potential for making better use of resources through more effective prescribing, which may lead to reductions in acute hospital admissions due to better symptom management in the community; and through better communication and easier multi-professional working across the NHS, local authority and voluntary sector. The emphasis should be on provision of quality care by making better use of the resources available in accordance with local palliative care strategy and local HIPs and TIPs. There should be a recognition by health boards and NHS trusts that Networks will only be able to provide quality palliative care if services are adequately resourced.

5. SPA Working Party on Managed Clinical Networks in Palliative Care

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