

Briefing

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Supportive and palliative care networks ...

The What, the When and the How

Supportive Care Strategy for Cancer Services

The NHS Cancer Plan sets out the aims of a supportive care strategy. A key element of that is the development by the National Institute for Clinical Excellence of guidance on supportive care. It is intended to provide evidence-based guidance on how best to ensure that patients receive high quality information, communication, symptom control, psychological support, social and spiritual support. The strategy does therefore embrace palliative care as well as other supportive care services. The NICE Guidance is expected to be available towards the end of 2001 together with the Department of Health's supportive care strategy.

Supportive Care Networks

The NHS Cancer Plan also envisages the establishment of supportive care networks alongside cancer networks to improve co-ordination of care. Since publication of the Plan, in recognition of the central role of palliative care in supportive care, there is now acceptance that these new networks should be called *Supportive and Palliative Care Networks (SPCNs)*. However, there is as yet no firm central guidance on what the functions, organisation and responsibilities of these networks should be. Nevertheless, the aim of this *Briefing* is to offer a view on what they will

probably look like by employing clues from a range of sources as well as describing how they may evolve from Cancer Network Palliative Care Strategy Groups (see below). That is necessary at this time in order to give palliative care providers sufficient guidance and encouragement to start building new networks in collaboration with their local cancer network.

Manual of Cancer Services Standards

The Manual was published by the Department of Health on its web site on 2 January 2001. Topic 10 sets out standards for Network Management Arrangements, Network Site Specific Groups as well as the co-ordination of cancer units and centres. Although there is no description or standards for a supportive and palliative care network there is a requirement for the establishment of a Network Palliative Care Strategy Group (NPCSG) that reports to the Cancer Network Managing Group. The NPCSG can probably be regarded as the forerunner of a comprehensive supportive and palliative care network. It is suggested that the latter can only be established in its definitive form after the publication of the NICE guidance and the Department's strategy on supportive care. It is likely then that the SPCNs will grow out of the NPCSGs and the palliative care networks that support them. Learning from each other's experience will be an important feature of this evolutionary process.

The Network Palliative Care Strategy Group

The Cancer Manual stipulates that the group should be multidisciplinary and include the lead clinician responsible for palliative care within the cancer centre, a palliative care nurse representative, representation from hospices and commissioner representatives. The Group is free to name additional members. Its core functions are to agree a network palliative care strategy, a drug formulary for palliative care and a network audit programme. These agreements are subject to the approval of the Cancer Network Management Group. In order that palliative care issues are fully taken into account by the Management Group, *representation of the NPCSG on the Cancer Network Management Group will be crucial.*

The Management Group will also need to recognise that palliative care services are provided for many disease and patient groups in addition to cancer and therefore the NPCSG may need to make links with commissioners and providers of services for such groups.

Objectives of Palliative Care Network Management Arrangements

The Cancer Manual sets out the objectives for the management arrangements for Cancer Networks. It is suggested that they are equally applicable to the initial NPCSGs and the eventual SPCNs.

Palliative care networks need to comprise a partnership of health service commissioners, providers in both the NHS and voluntary sectors and local authorities to deliver a comprehensive palliative care service across the patient pathway for the network population. Accordingly, the management objective may be assumed to be:

To ensure that all commissioners and providers of palliative care in the NHS and voluntary sectors and local authorities within the network work together effectively to deliver high quality care. This will be gained through:

- a. Establishment of an effective NPCSG which will develop and implement the strategy for the network in line with national policy
- b. Clear leadership of the NPCSG with adequate time and support being given to the palliative care lead clinician and palliative care nurse representative
- c. Agreement of network-wide policies and patient/carer pathways for the delivery of palliative care.

It will also be important to provide sufficient managerial time to project manage the establishment

of these initial NPCSGs. This managerial support will need to be ongoing as the NPCSG evolves eventually into a full supportive and palliative care network.

Who should be involved in the Network Palliative Care Strategy Groups?

The initial and developing palliative care networks will be serving cancer network populations of between half and two million. The number of different agencies that need to work as partners in the network is likely to be too numerous for them all to be members of the NPCSG. In order to secure involvement of all the partners *there is likely to be a need for a sub structure to the NPCSG.* It will be important to secure local agreement as to what that is. It will also be imperative to make sure that the partners who are members of the NPCSG are those who can make decisions on behalf of their organisations or particular constituencies. Reaching agreement about the terms of reference of the Group and any sub structure will be essential.

The principal partners in the NPCSG include:

- Commissioners of palliative care
- Specialist palliative care units and teams (hospice, community and hospital based) from NHS Trusts and the voluntary sector
- Primary Care Groups and Trusts
- Social care services
- Education centres providing training in palliative care
- Self help and users groups.

As the Strategy Group develops it may wish to expand its membership to include the following:

- Specialist psychological and psychiatric services
- Rehabilitation services
- Complementary therapy services.

All NHS services will be required as a matter of course to participate in the new networks. Independent providers in the voluntary sector will however have a choice and will need to be able to exercise that in the light of the arrangements agreed for each network. Due recognition in such arrangements will need to be given to the corporate status of voluntary hospices as independent charities and how that affects their role and responsibilities.

There are many providers of palliative care who will find themselves providing services to more than one Cancer Network. The question arises therefore as to whether such providers need to work as partners in all the networks they serve. Full participation in these new networks is going to take time and commitment and it is doubtful whether palliative care providers that tend to be small and with few resources can afford to participate in more than one network. It is therefore suggested that *providers participate fully only in the network in which they are geographically*

placed and/or the network they principally serve. They will however need to keep channels of communication open with other networks they serve.

Needs assessment

The NPCSG is responsible for agreeing a network palliative care strategy. Such a strategy will need to be based on health needs assessment of the network population. Much of the data required to undertake such assessments is available only on a health authority or local authority basis. The boundaries of the network populations will therefore need to be coterminous with such boundaries. From information currently available it is clear that the many of the 34 cancer networks straddle Regional and health authority boundaries. It is not yet clear whether the resulting boundaries are in all cases coterminous with local authorities. Whatever the answer to that question, *for the purposes of palliative care needs assessment it will be important to base such assessment on a population that is defined by health authority and/or local authority boundaries.*

Functions of the Network Palliative Care Strategy Groups

The network group functions described in Topic 10 of the Cancer Manual are very limited and will need to be considerably extended as the Strategy Group develops and network priorities are assessed. While the full extent of the agenda for supportive and palliative care networks can only be defined after NICE has produced its evidence based guidance, it is nevertheless important to offer a view on what that agenda will probably cover. The Strategy Group will need to know what is the likely direction of its development.

Work in progress at national level on the development of national standards and performance indicators can be used to help assess what the eventual range of responsibilities might be since standards are likely to apply to the activities of supportive and palliative care networks as well as to providers. What is being proposed is that there should be two complementary sets of standards differentiated by the responsibilities of networks as opposed to those of providers. The draft standards for networks can therefore be used to derive a comprehensive agenda of matters that networks will probably need to address. That agenda would include the following:

Strategic issues

- Developing a palliative care strategy based on health needs assessment for the population served and ensuring that its recommendations for implementing the strategy are incorporated into local Health Improvement Programmes
- Ensuring that there is a range of core palliative care

services that provide equitable access to patients and their carers across the network

- Ensuring that those core services are adequately resourced

Patient and carer services

- Developing network wide patient and carer pathways that incorporate common criteria for core services for referral, assessment, admission and discharge
- Putting in place network wide arrangements for the palliative care contribution to out of hours support
- Making network wide arrangements with Social Services for continuing care (including funding) and for social support
- Deciding what clinical guidelines should be adopted across the network
- Developing a core drug formulary and ensuring the ready availability of medicines prescribed

Workforce

- Identifying the workforce needs in terms of numbers of specialist and other staff required
- Developing and co-ordinating a network education programme

Research, audit and evaluation

- Co-ordinating a network audit programme
- Encouraging collaborative, multi-site research
- Monitoring and evaluating the performance of network core services against national standards and performance indicators

Information strategy

- Making arrangements to ensure that health and social care professionals have continuous access to up to date records about patients and their carers
- Appraising and ensuring that the appropriate IT structure and support is in place
- Arranging for the collection of patient activity and other data.

It will be recognised that this is a formidable agenda and that the developing networks will need time and resources to address fully. The resource question is crucial to the success of the initial Network Palliative Care Strategy Groups as they evolve towards the full Supportive and Palliative Care Networks. It is suggested that at this stage in network development the minimum resources required are those that will allow the lead palliative care clinician and palliative care nurse representative to drive the network forward. Managerial support will also be required. The Department of Health together with Health Authorities and the Cancer Networks will need to consider as a matter of some urgency how the necessary funding can be made available.

Partnership working

The developing networks are essentially partnerships of the key stakeholders. They will bring together many different kinds of organisation – the NHS, voluntary hospices and other charities, local government, the private sector as well as informally established bodies in the voluntary sector. They will have different perspectives and different problems in agreeing and delivering a common network agenda. The network will require an individual and collective discipline on the part of all the partners to accept and implement network decisions. That will entail the voluntary surrender of some organisational independence by each partner in the network. The result should be less competition between organisations and more focus on employment of the collective resources of the network for the benefit of patients and their carers. However none of that will happen unless all partners regard and treat one another as equal partners.

It is suggested that each network will need to set out the 'rules of engagement' which govern the relationship of the partners. The following principles may be helpful as a foundation for that:

- Each provider, commissioner or other body works as an equal partner in the network
- Each provider agrees to deliver core palliative care services in accordance with the decisions of the network
- Each commissioner agrees to commission core palliative care services in accordance with the decisions of the network
- Each provider agrees to share data about their core service activities and costs with the network.

Getting started

There will be a variety of productive ways of getting the Strategy Groups up and running. Much will depend on what arrangements are already in existence for bringing palliative care interests together, the geography of the Cancer Network and how far palliative care strategy has already been developed in the various health authority areas that make up the Network area. However, there are perhaps some general observations that may be helpful.

1. Start building a palliative care network with the initial membership as suggested above but recognise that in time it will need to grow into a full supportive and palliative care network.
2. Ensure that an early meeting of that potential membership is called to discuss how to proceed e.g. setting up a steering group to consider matters of organisation, priorities, resourcing of the network, leadership.
3. Arrange for one of the local health authorities to provide a neutral chair for the first meeting.
4. Begin work on developing a network palliative care strategy – make use of what work has already been completed in the various parts of the network.
5. Limit the initial agenda to what can be achieved.
6. Begin to discuss the rules of engagement i.e. the responsibilities and accountabilities of the partners in the network.
7. Develop proposals for service developments in 2001/02 and beyond that can be considered for funding from the additional allocation for palliative care in the NHS Cancer Plan.

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