Guidance on Cancer Services

Improving Supportive and Palliative Care for Adults with Cancer

Manual

Consultation draft, October 2003

DRAFT FOR 2ND CONSULTATION

Contents

Supportive and Palliative Care Guidance
Executive Summary

Introduction

ES1   Over 230,000 people in England and Wales develop cancer each year, and cancer accounts for 25% of deaths. Diagnosis and treatment of cancer can have a devastating impact on the quality of patients' lives and on that of their families and carers. Cancer patients face uncertainty and may have to undergo unpleasant and debilitating treatments. Patients, families and carers need access to support from the time that cancer is first suspected, through stages of treatment to recovery or, in some cases, to death and into bereavement.

ES2   Studies of patients with cancer have consistently shown that, in addition to receiving the best treatments, patients want and expect to be treated as individuals, with dignity and respect, and to have their voice heard in relation to decisions about treatment and care. Most patients want to receive detailed information about their condition and about possible treatments and services. Good face-to-face communication is highly valued. Patients expect services to be of high quality and to be well co-ordinated. Should they need it, they expect to be offered optimal symptom control and psychological, social and spiritual support. They wish to be enabled to die in the place of their choice, which for many patients is their own home. They want to be assured that their families and carers will receive support during their illness and following bereavement.

ES3   Although many patients with cancer report positively on their experience of care, there are still too many who claim they did not receive the information and support they needed at different steps in the patient pathway. The first National Cancer Patient Survey[1] showed wide variations in the quality of care delivered by the best and worst hospitals across the country.

ES4   Patients' needs for supportive and palliative care may not be met for several reasons. First, the services from which they might benefit may not be universally available. Second, even when services are available, patients' needs may go unrecognised by professionals, who therefore do not offer referral. Third, poor inter-professional communication and co-ordination can lead to suboptimal care.

This Guidance: aims, development and implementation

ES5   The aim of this Guidance is to define service models which are likely to ensure that patients with cancer and their families and carers receive the support and care they need to help them cope with cancer and its treatment at all stages of the illness.

ES6   This Guidance is intended to complement the series of *Improving Outcomes* guidance manuals on specific cancer states. As with the *Improving Outcomes* manuals,

the Guidance makes recommendations on service models and is not intended to be a clinical guideline. The indications for specific clinical interventions (such as for pain control) have not, therefore, been evaluated. The focus of the Guidance is on services for adult patients with cancer and their families. It is anticipated, however, that the Guidance may inform the development of service models for other groups of patients.

ES7   The approach used to develop the Guidance is similar to that adopted for site-specific guidance manuals. The views of a wide range of professionals and service users (patients and carers) were canvassed at each step in the process. Proposals were critically appraised in the light of research evidence. An editorial panel then prepared draft guidance, which was made available for consultation through the National Institute for Clinical Excellence (NICE).

ES8   The Guidance sets out recommendations relating to each of the issues of importance to patients and carers listed in paragraph ES2 of the Executive Summary. Some of the recommendations relate to actions that can best be taken forward at national level by the Department of Health and the National Assembly for Wales. Most of the recommendations, however, will require concerted action from Cancer Networks, commissioners, Workforce Development Confederations (the Workforce Development Steering Group in Wales), provider organisations, multidisciplinary teams and individual practitioners.

ES9   *The NHS Plan*[2] for England set out the intention to make available authoritative guidance on all aspects of cancer care, and *The NHS Cancer Plan*[3] made it clear that the NHS will be expected to implement the recommendations in Guidance manuals. This was re-emphasised in the Planning and Priorities Guidance issued in December 2002. *Improving Health in Wales*[4] described how strategies for achieving health gain targets are underpinned by national standards of care set through National Service Frameworks and guidance produced by NICE. All services providing care to people with cancer are expected to be able to show that they meet these standards.

ES10   Some of the recommendations in the Guidance build on existing good practice and should be acted on as soon as possible. Other recommendations, particularly those that require training and appointment of additional staff, will inevitably take longer.

ES11   It is anticipated that the recommendations will promote clinical governance through incorporation into national cancer standards, so that the quality of supportive and palliative care services can be monitored through quality assurance programmes (such as the peer review appraisal programme in England). Peer review programmes currently involve secondary and tertiary service providers in the NHS. The Department of Health and the National Assembly for Wales will need to consider how best to assure the quality of services provided in primary care and the voluntary sector.

ES12   Audits of the outcome of supportive and palliative care delivery will need to be developed. The National Cancer Patient Survey[1] could form a basis for this.

ES13   The relative paucity of the research evidence related to many of the topic areas covered by this Guidance was recognised by the guidance developers, and is discussed in more detail in Topic Area 13, *Research in supportive and palliative care: current evidence and recommendations for direction and design of future research*. It is strongly recommended that further research should be targeted at gaps identified through this process.

Overview of the service model

ES14   The service model set out in this Guidance is based on Cancer Networks, which are the vehicle for delivery of the Cancer Plan. Cancer Networks are partnerships of organisations (both statutory and voluntary) needed for the effective planning, delivery and monitoring of supportive and palliative care services. They provide the framework for development of high quality services by bringing together relevant health and social care professionals, service users and managers.

ES15   The service model recognises:

- the patient's autonomy; individual patients have different needs at different phases of their illness, and services need to be responsive to patients' wishes and needs
- families' and carers' needs for support during the patient's life and in bereavement
- families' and carers' central role in providing support to patients
- the importance of primary and community services, as patients spend most of their time with cancer living in the community
- the needs of some patients for a range of specialist services at all stages of the patient pathway
- the importance of forging partnerships between patients and carers and health and social care professionals to achieve best outcomes
- the value of partnership in achieving effective multi-agency and multidisciplinary team working
- the value of patient and carer-led activities as an integral part of cancer care
- service users' value in planning services
- the importance of care for people dying from cancer
- the need for services to be ethnically and culturally sensitive, to take account of the needs of those whose preferred language is not English or Welsh, and to be tailored to the needs of those with disabilities and communication difficulties
- the value of high quality information for patients and carers at all stages of the patient pathway.

Co-ordination of care

ES16   Lack of co-ordination of care between sectors (hospital and community, for instance) and within individual organisations has repeatedly been reported in studies of patients' experience of care. Action is needed to tackle this at the level of Cancer

Networks, provider organisations and multidisciplinary teams. Individual practitioners will also need to ensure they have the skills to assess patients' needs for support and information, as this is a prerequisite for the delivery of co-ordinated care.

- **Key Recommendation 1: Within each Cancer Network, commissioners and providers (both statutory and voluntary) of cancer and palliative care services, working with service users, should oversee the development of services in line with the recommendations of this Guidance. Key personnel will need to be identified to take this forward.**

- **Key Recommendation 2: Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points in the patient pathway (such as at diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching). Cancer Networks should ensure that a unified approach to assessing and recording patients' needs is adopted, and that professionals carry out assessments in partnership with patients and carers.**

- **Key Recommendation 3: Each multidisciplinary team or service should implement processes to ensure effective inter-professional communication within teams and with other service providers with whom the patient has contact. Mechanisms should be developed to promote continuity of care, which might include the nomination of individuals to take on the role of 'key worker' for individual patients.**

User involvement

ES17   People whose lives are affected by cancer can make significant contributions to the planning, evaluation and delivery of services. Time, cost and training issues need to be addressed so that patients and carers can participate fully. People whose lives have been affected by cancer can also help other people affected by cancer through sharing experiences and ways of managing the impact of cancer on their lives.

- **Key Recommendation 4: Mechanisms should be in place to ensure the views of patients and carers are taken into account in developing and evaluating cancer and palliative care services. Cancer Partnership Groups[5] provide a mechanism for achieving this. Systems should be devised to support patients and carers to participate in their own care, including self-help activities and peer support schemes offering a wide variety of informal support opportunities within community settings.**

Face-to-face communication

ES18   Good face-to-face communication between health and social care professionals and patients and carers is fundamental to the provision of high quality care. It enables patients' concerns and preferences to be elicited and is the preferred mode of information-giving at critical points in the patient pathway. However, patients and carers frequently report the communication skills of practitioners to be poor.

❑ **Key Recommendation 5:** **Communicating significant news should normally be undertaken by a senior clinician who has received advanced level training and is assessed as being an effective communicator. It is recognised, however, that this is not always practical; all staff should therefore be able to respond appropriately to patients' and carers' questions in the first instance before referring to a senior colleague.**

❑ **Key Recommendation 6:** **The outcome of consultations in which key information is imparted and discussed should be recorded in patients' notes and communicated to other professionals involved in their care. Patients should be offered a permanent record of important points relating to the consultation.**

Information

ES19   Patients and carers cannot express preferences about care and make choices on involvement in decision making unless they have access to appropriate and timely information at each stage in the patient pathway. Many patients report, however, that they receive inadequate information from health and social care professionals. Action is needed to ensure that high quality information materials are available in places where patients can access them readily, and that patients are offered materials at key steps in the patient pathway.

❑ **Key Recommendation 7:** **Policies should be developed at local (network/provider organisation/team) level detailing what information materials should routinely be offered at different steps in the patient pathway for patients with particular concerns. These policies should be based on the findings of mapping exercises involving service users.**

❑ **Key Recommendation 8:** **Commissioners and provider organisations should ensure that patients and carers have easy access to a range of high quality information materials about cancer and about cancer services. These information materials should be free at the point of delivery and patients should be offered appropriate help to understand them within the context of their own circumstances.**

Psychological support services

ES20   Psychological distress is common among people affected by cancer and is an understandable and natural response to a traumatic and threatening experience. Patients use their own inner resources to respond to this distress and many derive emotional support from family and friends. For some patients, however, the level and nature of their distress is such that they are likely to benefit from additional professional assessment and intervention. In practice, patients' psychological symptoms are commonly not identified and they are not getting sufficient access to psychological support services.

❏ **Key Recommendation 9: Commissioners and providers of cancer services should work through Cancer Networks to ensure that all patients undergo systematic psychological assessment at key points in the patient pathway and have access to an appropriate level of psychological support. A four-level model of professional psychological assessment and intervention is the suggested model for achieving this.**

Social support services

ES21   The social impact of cancer is considerable and can reach beyond the patient and immediate family. Patients may need: support to preserve social networks; support with personal care, cleaning and shopping; provision of care for vulnerable family members; advice on employment issues; and assistance in securing financial benefits. This kind of support may be provided informally or formally, in both a planned and reactive manner. Commonly, however, patients and carers do not experience a coherent integrated system of social support.

❏ **Key Recommendation 10: Explicit partnership arrangements need to be agreed between local health and social care services and the voluntary sector to ensure that the needs of patients with cancer and their carers are met in a timely fashion and that different components of social support are accessible from all locations (including hospital, home, care home and hospice).**

Spiritual support services

ES22   The diagnosis of life-threatening disease can raise unsettling questions for patients. Some people will seek to re-examine their beliefs, whether philosophical, religious or broadly spiritual in nature, at various points in the patient pathway. The needs of patients for spiritual support are, however, frequently unrecognised by health and social care professionals, who may feel uncomfortable broaching spiritual issues. In addition, there may be insufficient choice of people to whom patients can turn for spiritual care when their needs are recognised. A wide range of staff in all settings should be sensitive to the spiritual needs of patients and carers, during life and after death.

❏ **Key Recommendation 11: Patients and carers should have access to staff who are sensitive to their spiritual needs. Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual care providers who act as a resource for patients, carers and staff. They should also be aware of local community resources for spiritual care.**

General palliative care services, incorporating care of dying patients

ES23   Patients with advanced cancer require a range of services to ensure their physical, psychological, social and spiritual needs are met effectively and to enable them to live and die in the place of their choice, if at all possible. Clinical circumstances can change rapidly. These services therefore need to be particularly well co-ordinated, and some need to be available on a 24-hour, seven days a week basis to prevent unnecessary suffering and unnecessary emergency admissions to hospital.

ES24   Much of the professional support given to patients with advanced cancer in their own homes, in hospitals, in care homes and in community hospitals is delivered by health and social care professionals who are not specialists in palliative care and who may have received little training in this area. It is important to empower, enable, train and support patients' usual health and social care professionals to achieve the delivery of effective care.

> ❑ **Key Recommendation 12: Mechanisms need to be implemented within each locality to ensure medical and nursing services are available on a 24-hours, seven days a week basis for patients with advanced cancer, and that equipment can be provided without delay. Those providing generalist medical and nursing services should have access to specialist advice at all times.**

> ❑ **Key Recommendation 13: Primary care teams should institute mechanisms to ensure that the needs of patients with advanced cancer are identified and their needs assessed, and that this is communicated within the team and with other professionals as appropriate. The *Gold Standards Framework*[6,7] provides one mechanism for achieving this.**

> ❑ **Key Recommendation 14: In all locations, the particular needs of patients who are dying from cancer should be identified and addressed. The *Liverpool Care Pathway for the Dying Patient*[8] provides one mechanism for achieving this.**

Specialist palliative care services

ES25   A significant proportion of people with advanced cancer suffer from a range of complex problems that cannot always be dealt with effectively by generalist services in hospitals or the community. In response to these needs, hospices and specialist palliative care services have been established across the country over the past three decades.

ES26   Access to and availability of specialist palliative care services is variable and inequitable throughout the country. Many hospitals do not have full multidisciplinary teams who can provide advice on a 24-hour, seven days a week basis. Community specialist palliative care services vary considerably in their ability to provide services at weekends and outside usual working hours. The number of specialist palliative care beds per million population varies widely between Cancer Networks.

> ❑ **Key Recommendation 15: Commissioners and providers, working through Cancer Networks, should ensure they have an appropriate range and volume of specialist palliative care services to meet the needs of the local population, based on local calculations. These services should, as a minimum, include specialist palliative care inpatient facilities and hospital and community teams. Specialist palliative care advice should be available 24 hours, seven days a week. Community teams should be able to provide support to patients in their own homes, community hospitals and care homes.**

Rehabilitation services

ES27   Cancer and its treatment can have a major impact on a patient's ability to lead a normal life. Activities which healthy people take for granted, such as mobilising, speaking, eating, drinking and swallowing and engaging in sexual activity could be severely impaired. Cancer rehabilitation aims to maximise physical function, promote independence and help people adapt to their condition. A range of allied health professionals and other professionals provide rehabilitation services.

ES28   Some patients are not getting access to rehabilitation services, either because their needs for rehabilitation are unrecognised by front-line staff or because of a lack of allied health professionals who are adequately trained in the care of patients with cancer.

- ❑ **Key Recommendation 16: Commissioners and providers, working through Cancer Networks, should institute mechanisms to ensure that patients' needs for rehabilitation are recognised and that comprehensive rehabilitation services and suitable equipment are available to patients in all care locations. A four-level model for rehabilitation services is the suggested model for achieving this.**

Complementary therapy services

ES29   Decision making regarding the provision of complementary therapy services for patients with cancer is complex. A considerable proportion of patients express interest in these therapies, but there is little conventional evidence regarding their effectiveness in relation to the relief of physical symptoms and psychological distress. This Guidance therefore focuses on the needs of patients to obtain reliable information to make decisions for themselves and on the measures providers should take to ensure that patients can access these therapies safely, should they wish to do so.

- ❑ **Key Recommendation 17: Commissioners and NHS and voluntary sector providers should work in partnership across a Cancer Network to decide how best to meet the wishes of patients for complementary therapy. As a minimum, high quality information should be made available to patients about complementary therapies and services. If services are to be commissioned by the NHS or provided in NHS facilities, guidelines should be developed and implemented relating to the training, qualification and competence of practitioners.**

Services for families and carers, incorporating bereavement care

ES30   Families and carers provide essential support for patients, but their own needs for emotional and practical support may go unrecognised - often because they put the needs of the patient first. Families' and carers' needs for support can be particularly profound around the time of diagnosis, at the end of treatment, at recurrence, and most particularly around the time of death and bereavement. Professional support is not always available for families and carers who need it.

> ❑ **<u>Key Recommendation 18</u>: Organisations providing cancer services should nominate a lead person to oversee the development and implementation of services that specifically focus on the needs of families and carers, reflecting cultural sensitivities, during the patient's life and in bereavement.**

Workforce development

ES31   Many of the recommendations in this Guidance are critically dependent on workforce development - the appointment of additional staff and the enhancement of knowledge and skills of existing staff. Front-line staff require enhanced training in the assessment of patients' problems, concerns and needs; in information giving; and in communication skills. Additional specialist staff will be needed in roles related to information delivery, psychological support, rehabilitation, palliative care and support for families and carers.

> ❑ **<u>Key Recommendation 19</u>: Cancer Networks should work closely with Workforce Development Confederations (the Workforce Development Steering Group in Wales) to determine and meet workforce requirements and to ensure education and training programmes are available.**

> ❑ **<u>Key Recommendation 20</u>: Provider organisations should identify staff who may benefit from training and should facilitate their participation in training and ongoing development. Individual practitioners should ensure they have the knowledge and skills required for the roles they undertake.**

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1. Department of Health. *National Surveys of NHS Patients: Cancer National Overview 1999-2000.* London: DoH. 2002.
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4. Welsh National Assembly Government. *Improving Health in Wales: a plan for the NHS with its partners.* Cardiff: Welsh Assembly Government. January 2001.
5. National Cancer Task Force. *User Involvement in Cancer Services.* Unpublished. April 2001.
6. Thomas, K. *Caring for the Dying at Home. Companions on a journey.* Oxford: Radcliffe Medical Press. 2003.
7. Thomas, K. The Gold Standards Framework in community palliative care. *European Journal of Palliative Care* 10:3, 113-115. 2003. (See also: The Macmillan Gold Standards Framework Programme: www.macmillan.org.uk or www.modern.nhs.uk/cancer or email gsf@macmillan.org.uk.)
8. Ellershaw, J., Wilkinson, S. *Care of the Dying. A pathway to excellence.* Oxford: Oxford University Press. 2003.

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Introduction

A. Aim of this Guidance

I1 The aim of this Guidance is to define service models needed to ensure that patients with cancer and their families and carers receive the support they need to help them cope with cancer and its treatment. Services may be needed at all stages of the patient's illness, from before diagnosis to the end of life and, for families and carers, into bereavement.

B. Rationale for developing the Guidance

Burden of cancer

I2 Cancer affects a large number of people each year in England and Wales. Around a quarter of a million people are diagnosed with cancer, many of whom have family, close friends and carers who are also affected by the diagnosis. An even larger number of people, probably well over a million, develop symptoms that could be due to cancer. These people and their families and carers may suffer significant levels of anxiety before they can be reassured that they do not have the disease.

What do patients and carers want and need?

I3 Research[1,2] has consistently shown that in addition to receiving the best possible treatment, patients want and expect to:

- be treated as <u>human beings</u> and as individuals, with dignity and with respect for culture, lifestyles and beliefs
- have their <u>voice heard</u>, to be valued for their knowledge and skills and to be able to exercise real choice about treatments and services
- receive detailed <u>high quality information</u> about the condition and possible treatment, given in an honest, timely and sensitive manner at all stages of the patient pathway
- know what <u>options</u> are available to them under the NHS, voluntary and private sectors, including access to self-help and support groups, complementary therapy services and information
- know that they will only undergo those interventions for which they have given <u>informed consent</u>
- have good <u>face-to-face communication</u> with health and social care professionals
- know that services will be <u>well co-ordinated</u>
- know that services will be of <u>high quality</u>
- know that their <u>physical symptoms</u> will be managed to a degree that is acceptable to them and is consistent with their clinical situation and clinicians' current knowledge and expertise
- receive <u>emotional support</u> from professionals who are prepared to listen to them and are capable of understanding their concerns
- receive support and advice on <u>financial and employment</u> issues
- receive support to enable them to explore <u>spiritual issues</u>

- die in the <u>place of their choice</u>
- be assured that their family and <u>carers will be supported</u> throughout the illness and in bereavement.

Current service provision

I4 Although there is evidence of much good practice in relation to the delivery of supportive care[2], there is also extensive evidence that patients do not always receive the information and support they need at all steps in the patient pathway. The first National Cancer Patient Survey[3], for instance, showed wide variations in the quality of care across the country.

Why are patients' needs not always met?

I5 There are many reasons, each of which needs to be addressed if outcomes are to be improved. They include:

- patients and carers being unaware of the existence of services that might help them
- professionals not eliciting patients' problems or concerns
- professionals being unaware of the potential benefits of existing services, and consequently not offering access or referral to those services
- services demonstrated to be of benefit not being universally available
- poor communication and co-ordination among professionals working within a team or between services leading to suboptimal care.

What needs to be done?

I6 The evidence from the surveys described above and others clearly suggests that services need to provide:

- better organisation, co-ordination and integration across Cancer Networks
- improved assessment of the individual needs of people with cancer, which includes all the domains of physical, psychological, social and spiritual care
- improved training for health and social care staff in providing supportive and palliative care
- enhanced provision of supportive and palliative care services to meet needs currently unmet and to reduce inequalities in service provision and access
- better signposting of information and support services, including voluntary sector services, by health and social care providers
- better access to high quality information
- active promotion of self-help and support groups, recognising the large management role people with cancer have in their own care and acknowledging the support they seek and receive from non-statutory sources such as local and national voluntary organisations.

C. Definitions of supportive and palliative care

I7 The understandings of supportive and palliative care on which this Guidance is based lean heavily on work by the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS).

Supportive care

I8 The NCHSPCS has suggested the following working definition of supportive care. It is described as care that:

> '…helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.'[4]

I9 Supportive care is provided to people with cancer and their carers throughout the patient pathway, from pre-diagnosis[A] onwards (Figure I.1). It should be given equal priority with other aspects of care and be fully integrated with diagnosis and treatment. It encompasses:

- self help and support
- user involvement
- information giving
- psychological support
- symptom control
- social support
- rehabilitation
- complementary therapies
- spiritual support
- palliative care
- end-of-life and bereavement care.

I10 Supportive care is an 'umbrella' term for all services, generalist and specialist, that may be required to support people with cancer and their carers. It is not stage-of-disease dependent, and reflects the fact that people have supportive care needs from the time that the possibility of cancer is first raised.
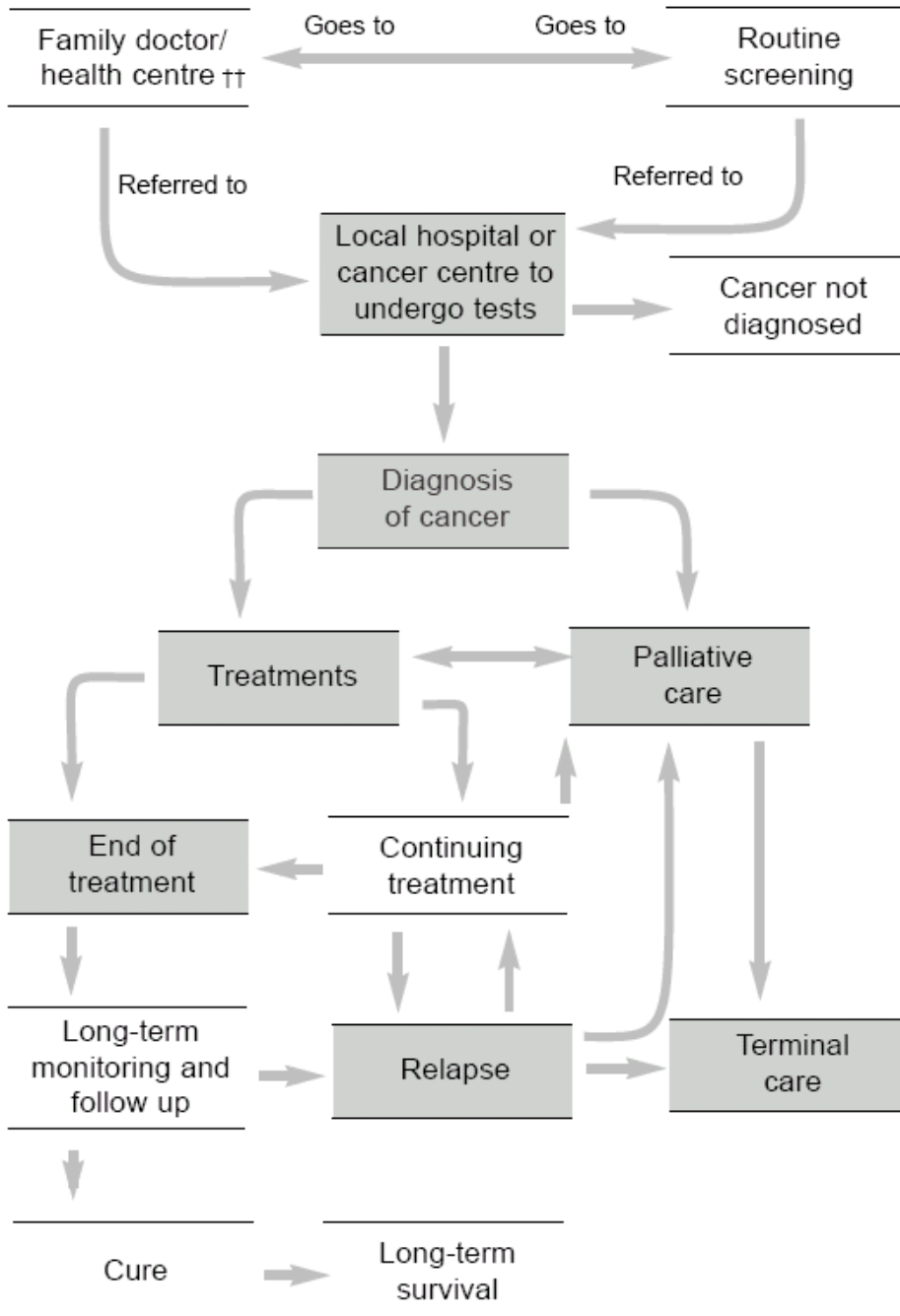
I11 Supportive care is not a distinct specialty but is the responsibility of all health and social care professionals delivering care that is informed and driven by theories, models and frameworks drawn from diverse sources. It is underpinned by open and sensitive communication and by organisations and teams who work in a co-ordinated way to ensure the smooth progression of patients from one service to another.

[A] Patients and carers can have a range of problems prior to diagnosis when cancer is suspected, including anxiety and physical symptoms. These need to be managed appropriately, and patients should be enabled to access information at this point in the patient pathway if they wish it.

Map of patient pathway † Fig I.1

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Family doctor/          Goes to        Goes to        Routine
health centre ††      ←─────────────────────→         screening

        │ Referred to                    Referred to │
        │                                            │
        ↓                                            ↓
                    Local hospital or
                    cancer centre to  ─────────→   Cancer not
                    undergo tests                   diagnosed
                           │
                           ↓
                    Diagnosis
                    of cancer
                     ╱        ╲
                    ↓          ↓
        Treatments  ←─────→  Palliative
                               care
         │                      ↑
         ↓                      │
    End of      ←   Continuing  │
    treatment       treatment   │
        │             │  ↑      │
        ↓             ↓  │      │
    Long-term                Terminal
    monitoring and →  Relapse →  care
    follow up
        │
        ↓
     Cure    →    Long-term
                  survival
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† Supportive care is provided at all stages
  of the pathway from pre diagnosis onwards

†† The family doctor features at every
   stage of the patient pathway

Key points in the cancer journey

Palliative care

I12. Palliative care is:

> '…the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.'[5]

I13 Palliative care is based on a number of principles, and aims to:

- provide relief from pain and other distressing symptoms
- affirm life and regard dying as a normal process
- neither hasten nor postpone death
- integrate the psychological and spiritual aspects of patient care
- offer a support system to help patients live as actively as possible until death
- offer a support system to help the family cope during the patient's illness and in their own bereavement
- use a team approach to address the needs of patients and their families, including bereavement support, if indicated
- enhance quality of life, and positively influence the course of illness
- be applied early in the course of illness in conjunction with other therapies that are intended to prolong life (such as chemotherapy or radiation therapy), including those investigations needed to better understand and manage distressing clinical complications[5].

I14 It is now widely recognised that palliative care has a crucial role in the total care received by the patient and carers at a variety of points throughout the course of the disease from diagnosis to end-of-life care, delivered in conjunction with anti-cancer and other treatments[6]. It tends to be associated in the minds of patients, carers and some health and social care professionals, however, with care provided to dying people[2]. This has significant implications for acceptability and access.

I15 Palliative care, like supportive care, is in many cases provided by the patient's usual informal carers, supported by health and social care professionals who fall into two distinct categories :

- the patient and carers' usual professional carers
- professionals who specialise in palliative care (consultants in palliative medicine and clinical nurse specialists in palliative care, for example), some of whom are accredited specialists[4].

I16 Palliative care encompasses many of the elements identified as 'supportive care', and the principles on which it is based are broadly similar. There are, however, well-defined areas of expertise within specialist palliative care to which the patient and carer may need access, such as interventions to deal with:

- unresolved symptoms and complex psychosocial issues in patients with advanced disease
- complex end-of-life issues
- complex bereavement issues.

Supportive and palliative care services

I17 Supportive and palliative care services should be delivered where patients and carers need them or want them, whenever possible – in the community (which includes not only the patient's home, but also care homes and community hospitals), in hospital, or in a hospice.

I18 Patients, families and carers play the central role in their own care and in making decisions about the care they receive. They need support from health and social care professionals to help them make decisions, to plan and evaluate their care, and to indicate whether their decisions remain the same, or have changed. User empowerment is therefore a key principle underpinning good supportive and palliative care. It must be recognised, however, that not all patients have close family and carers. Health and social care professionals should be sensitive to the needs of patients and be prepared to encourage their potential to plan, manage and contribute to their own care.

I19 A wide range of service providers and multidisciplinary teams is involved in delivering supportive and palliative care services, including those in primary care, secondary care and the voluntary and social sectors. Patients and carers also draw significant support from friends, family, support groups, volunteers and other community based non-statutory resources.

I20 Providing supportive and palliative care should be an integral part of every health and social care professional's role, but for most, the provision of support for people with cancer forms only a small part of their workload. It is relatively straightforward to categorise some groups of healthcare professionals as 'generalists' in the field (general practitioners (GPs) and district nurses, for example), while others are specialists who may have received additional training and qualifications in one or more aspects of supportive and palliative care and have acquired substantial practical experience. These specialists frequently dedicate all or most of their time to the care of people with cancer. Examples of specialists contributing to supportive and/or palliative care include:

- site-specific cancer nurse specialists
- cancer counsellors
- cancer information nurses/other professionals
- specialist allied health professionals
- physicians in palliative medicine and palliative care nurse specialists.

I21 For others, their 'generalist' or 'specialist' status will depend on the circumstances in which they work. A social worker with a local authority, for example, may be a generalist working with a wide range of clients, while a social worker employed by a hospice will be working as a specialist in palliative care.

I22 The patient pathway tends to fluctuate according to individual need, and services should remain flexible to address change during each patient's and carer's cancer experience. The relative contributions of those involved in supportive and palliative care, including patients and carers, are consequently liable to change also.

D. Context, scope and organisation of the Guidance

Context
I23 The Guidance has been commissioned by the Department of Health and National Assembly for Wales as part of the *Improving Outcomes* series of cancer manuals, and follows on from the Calman-Hine report, *A Policy Framework for Commissioning Cancer Services*[7], *The NHS Plan*[8], *The NHS Cancer Plan*[6], *Improving Health in Wales*[9], and the Cameron Report, *Cancer Services in Wales*[10].

I24 It also reflects the outcomes of the Kennedy Inquiry[11], which set out a number of recommendations in relation to communication skills for healthcare professionals, and draws on the Commission for Health Improvement/Audit Commission report on cancer services[2] and the National Cancer Patient Survey[3] in England, both of which clearly identify issues that require urgent review and action.

I25 *Shifting the Balance of Power: The Next Steps*[12] and *Improving Health in Wales: Structural change for the NHS in Wales*[13] highlight the drive to develop networks of care. The reports set out the role of the 34 Cancer Networks in England and the three Cancer Networks in Wales in developing integrated care, improving clinical outcomes, providing cost-effective services, improving the experience of patients and carers and securing equity of service provision.

I26 The Guidance forms a key element of the Supportive Care Strategy for England and is part of a series of initiatives designed to improve the experience of care of patients with cancer and their carers. These initiatives include:

- the development of a Supportive and Palliative Care Co-ordinating Group
- the development of the Cancer Information Strategy and establishment of the Coalition for Cancer Information[14]
- the User Involvement Strategy, which has led to a project run jointly by the Department of Health and Macmillan Cancer Relief to support user involvement in every Cancer Network
- the New Opportunities Fund *Living with Cancer* initiative

- Cancer Services Collaborative initiatives focused on improving patients' care experience and the community palliative care Gold Standards Framework Programme[15, 16]
- the development of draft National Standards for Specialist Palliative Care for Cancer Services
- a Department of Health-funded initiative on education and support for district and community nurses in every Cancer Network on the principles and practice of palliative care
- the development of an accredited training programme in advanced communication skills training
- the establishment of a National Partnership Group for specialist palliative care.

I27 Similar initiatives are under way in Wales, including:

- the establishment of the Wales Association of Palliative Care
- the development and publication of a strategy for palliative care services in Wales[17]
- the All-Wales Minimum Standards for specialist palliative care[18B]
- a Cancer Information Framework and the establishment of a Cancer Information Framework Project Board to oversee its implementation[19]
- the User and Carer Involvement Project, supported by Macmillan Cancer Relief and led by the South West Wales Cancer Network on behalf of the three Cancer Networks in Wales[20]
- measures to improve communication in health care and increase dissemination of healthcare information[21].

Scope

I28 This Guidance is intended to complement the site-specific guidance in the *Improving Outcomes* series. While the site-specific manuals focus on services required for patients with specific cancers, this Guidance reflects the common components of effective supportive and palliative care for *all* people with cancer and their carers. The Guidance does not attempt to review the effectiveness of individual technologies such as pharmacological and non-pharmacological interventions to control symptoms. Nor does it address issues that are general to the NHS rather than specific to cancer care, such as access to transport and social welfare for patients and carers. The scope of the Guidance is shown in Box I.1.

[B] To become the *All Wales Standards for Cancer* from March 2004

Box I.1 Scope of the Guidance
• The primary audience is those who will commission supportive and palliative care services from the statutory and voluntary sectors, and health and social care sectors, using NHS resources.
• The Guidance relates to services commissioned in England and Wales and covers all settings in which care may be delivered, including services provided by non-NHS providers that have been commissioned by the NHS under the terms of service level agreements.
• While it focuses on commissioning services for patients with cancer and their carers, it is anticipated that the Guidance may inform the development of effective service models for other groups of patients with similar needs.
• The primary focus is on commissioning services for adults, but the needs of children who may be affected by an adult carer or relative with cancer are also acknowledged.

I29 The following topic areas are covered:

- Co-ordination of care
- User involvement in planning, delivering and evaluating services
- Information
- Face-to-face communication
- Psychological support services
- Social support services
- Spiritual support services
- General palliative care services, incorporating care of dying patients
- Specialist palliative care services
- Rehabilitation services
- Complementary therapy services
- Services for families and carers, incorporating bereavement care.

I30 The order is intended to represent a logical sequence of issues, and does not reflect priorities.

I31 The topic areas reflected in the Guidance form part of a package of care which, if comprehensive, will meet patients' and carers' needs. From the perspective of patients and carers, many aspects of care are delivered simultaneously by one or more health and social care professionals aligned with a particular service, and may be provided at different times within patients' overall experience of care. For the practical purposes of producing the Guidance, however, we have had to present the components of services developed to meet the overall care needs of patients in separate sections, albeit with areas of significant overlap. While this satisfies the need to produce a coherent and logical document, we accept that it does not accurately reflect the actual day-to-day needs and experience of care of people with cancer. The key components of services are, however,

defined to a degree sufficient to describe a competent and effective supportive and palliative care service.

I32 In the original commissioning brief drawn up by NICE, the Guidance Development Team were asked whether, '*if possible, a distinction could be drawn between "core services"…and "non-core" services…*'(paragraph 8.5). This issue was considered at each step of Guidance development by the Editorial Board, alongside the issue of whether levels of service could be quantified through, for example, defining a number of beds per million population and the numbers of personnel necessary for services, particularly in relation to specialist palliative care services.

I33 Given the nature of evidence available across different aspects of supportive and palliative care, it was concluded that a range of services, including hospital and community palliative care teams and specialist inpatient facilities, is required in all parts of England and Wales, but because of different levels of need and demographic and geographical differences, the requisite numbers of beds and staff cannot be determined.

I34 For other services, such as palliative day care services, the evidence suggests a range of ways of providing services, but does not allow any single way to be determined as essential. In, for example, complementary therapies, there is clear evidence of patients and carers appreciating these services, but much less clear evidence on their impact on outcomes. The strength of recommendations in the Guidance reflects these characteristics of the evidence.

I35 The Guidance considers the needs for supportive and palliative care of all patients facing a diagnosis of cancer and their families and carers. It is recognised that specific groups of patients will have particular levels of need; for example, older people are more likely to have existing illnesses and disabilities and may be living alone. It is also recognised that patients for whom English or Welsh is not their preferred language may have specific communication needs. Recommendations are based on the premise that if people's needs are properly assessed, they will be identified and addressed, irrespective of age, gender and ethnicity.

I36 The particular needs of young people with cancer are being addressed through NICE guidance on children and young people with cancer (see: http://www.nice.org.uk/cat.asp?c=33917).

Organisation of the Guidance
I37 The Guidance is divided into three sources: a Guidance Manual, the Research Evidence, and the Economic Analysis. The topic areas are discussed in the same order for ease of cross-reference.

I38 The first source (The Guidance Manual) is based on all available sources of information. The manual consists of:

- an executive summary, including key recommendations from all topic areas

- the introductory section
- twelve topic areas with recommended actions
- a section focusing on the nature of evidence in supportive and palliative care with recommendations for the design and direction of future research
- summary of the main recommendations within the topic areas as they apply to: A - national governments; B - commissioners of cancer care; C – Cancer Networks; D – provider organisations; E – multidisciplinary teams/services; F – individual health and social care professionals; G – Workforce Development Confederations/the Workforce Development Steering Group in Wales
- appendices setting out how the guidance was developed and people involved in the process.

I39 Each topic area (with the exception of Topic 1, *Co-ordination of Care,* and Topic 11, *Complementary Therapy Services*) is organised in the same manner:

Introduction Highlights key issues related to patients' needs for services and care in the topic area. It also provides a brief review of the limitations of current service provision.

Objectives A short statement of what we are trying to achieve for patients and carers.

Recommendations Presented in three sections:

- *Overview* An overview of how services will need to be organised to achieve the objectives.
- *Service configuration and delivery* Specific recommendations about the service model and the processes required to achieve the objectives.
- *Workforce development* Covers the education, training and support requirements staff will need to deliver services.

Evidence Sets out the evidence supporting the recommendations. To ensure the Guidance is anchored in evidence, the research literature has been reviewed and critically appraised. The reliability and quality of evidence supporting the recommendations is graded from A-C[22] throughout the document, as shown in Table I.1 (see Appendix 1 for fuller description of the processes used to identify and grade evidence).

Table I.1 Grading of reliability and quality of evidence supporting recommendations[22].	
A	Evidence derived from randomised controlled trials (RCTs) or systematic reviews of randomised trials.
B	Evidence from non-randomised controlled trials or observational studies.
C	Professional consensus.

Research

Offers suggestions about the future direction of research and development. Knowledge gaps, evidence of what service users want and gaps between the recommendations in the Guidance and research evidence to support them drive these sections.

Resource implications Provides an overview of the implications for the NHS of implementing the recommendations. *[Note to consultees: The final version of the Guidance will have a short summary of the main points in relation to each topic area. This is not included in this draft – please refer to the Economic Analysis document.]*

I40 The second source (The Research Evidence) is a condensed version of systematic reviews of research used to inform the Guidance and is published in electronic format *[website address to come]* (see Appendix 1). It includes tables with information about individual studies and is fully referenced.

I41 The third source (The Economic Analysis), which also appears in electronic format only, presents an analysis of the potential cost implications of the recommendations. It outlines the scope of the work and details methods used to arrive at cost estimates.

I42 The final recommendations are also available in a version for the public.

E. Methods and approaches to Guidance development

I43 The Guidance is based, with some modifications, on an extensive, explicit and rigorous multi-stage process developed by the Chief Medical Officer's Cancer Guidance Group, chaired by Professor Haward of Leeds University. It also broadly adheres to the process set out by NICE in *The Guideline Development Process – Information for National Collaborating Centres and Guideline Development Groups*[23]. A summary of the methods and approaches to the development of the Guidance is given in Appendix 1.

I44 A wide range of individuals representing service users, professionals and policy-makers were involved in generating the Guidance, which has arisen from proposals for recommendations which were then critically appraised in the light of research evidence. The final Guidance document is drawn from material generated as a result of a number of complementary activities. These included a proposal-generating event, evidence review, guided discussion with commissioners and users and the deliberations of the Editorial Board (see Appendix 2.1 for membership).

I45 The process of developing the recommendations was underpinned by a framework depicting levels of service operation (Box I.2). While the recommendations are not presented in the Guidance under these headings, the framework gave the Guidance developers defined reference points and a coherent structure from which to formulate recommendations.

> **Box I.2 Framework of levels of service operation used to underpin formulation of recommendations**
>
> - National level
> - Cancer Network level
> - Provider organisation level
> - Team level*
> - Individual health and social care professional level
>
> *'Teams' refers to a wide range of people providing services to people with cancer in the statutory, voluntary and independent sectors. It includes, for example, primary care teams, site-specific cancer teams, therapy teams and specialist palliative care teams, and reflects the practice of multidisciplinary/multi-sectoral team working.

I46 The Summary of Recommendations sets out recommendations for action at each of these levels in relation to the main topic areas of the Guidance.

I47 The philosophy underpinning the development of the Guidance is based on an equal partnership model between patients/carers and health and social care professionals. Emphasis has been placed on the resources patients and carers have (with appropriate support) to enable them to meet their own needs, working with professionals on an equal footing, taking joint responsibility for treatment and care and using their own experience in a positive and constructive way. The involvement of patients in their own care, while not always made explicit in every topic area, is implicit in all aspects of service delivery.

F. Implementation of recommendations

I48 Commissioners and providers will need to work together through Cancer Networks to implement the recommendations in this Guidance. Partnership (service-user) groups and Cancer Services Collaboratives Improvement Partnerships should be involved.

I49 The Guidance relates to services commissioned and funded by the NHS. It is recognised that the voluntary sector has made, and will continue to make, a very considerable contribution across the range of supportive and palliative care service provision for people with cancer, and may be commissioned to provide any of the services outlined.   In partnership with the NHS, voluntary sector organisations will play an important role in the planning and delivery of services at local and national level.

I50 As many of the recommendations relate to workforce development, close involvement of Workforce Development Confederations in England and the Workforce Development Steering Group in Wales will be needed to ensure that high quality training programmes are available to deliver (over time) the necessary increases in human resources and skills. It is not, however, part of the remit of the Guidance to make specific recommendations on workforce issues.

I51 With respect to user involvement, the need to ensure routine and systematic user involvement in cancer services has been recognised with the implementation of the Cancer Partnership Project in England – a joint Department of Health and Macmillan

Cancer Relief initiative[24]. The Cancer Services Collaborative Improvement Partnership Patient Experience project[25] is actively promoting patient and carer involvement in the change process. These, combined with the current Public and Patient Involvement Policy[26], which established the Patient Advice and Liaison Services (PALS) and the Expert Patient Programme[27], are creating a significant infrastructure to support the process.

I52 In Wales, where Community Health Councils remain, an All Wales User Involvement initiative is funded by Macmillan Cancer Relief. Network structures have been established to incorporate user views. The Health Plan for Wales, *Improving Health in Wales*[9], commits the NHS to enabling each citizen and community to play a role, directly or through representative bodies, in the development of health policy. It sets out a raft of measures to encourage patient and public involvement, including the development of Local Health Alliances, the *Communities First* programme aimed at encouraging participation among people from socio-economically deprived communities, and the establishment of a National Advisory Group to further develop public and patient involvement in Wales.

I53 The National Assembly for Wales, in partnership with the Office for Public Management, has also produced *Signposts*[28], a guide to Patient and Public Involvement (PPI) for those responsible for taking PPI forward within their organisations, and *Signposts Two*[29], which focuses on tackling the challenges of developing PPI practice.

I54 We envisage that the recommendations will be incorporated into the *Manual of Cancer Services Standards*[30] in England and the *All-Wales Minimum Standards for Specialist Palliative Care*[18C], and the quality of supportive and palliative care services will be monitored through the peer review process. This currently applies only to secondary and tertiary services in the NHS. The Department of Health and National Assembly for Wales will need to consider how best to extend this to cover primary care and services provided by the independent sector for the NHS[D]. While the Standards largely relate to structures and process elements, Cancer Networks need to develop mechanisms to monitor the outcomes of supportive and palliative care services.

Priorities
I55 The recommendations represent a set of priorities in areas most likely to make a difference to patients in relation to supportive and palliative care. Many may have been implemented already in some areas, and some incorporate recommendations generated by other sources, such as the Cancer Information Advisory Group in England.

[C] To become the *All Wales Standards for Cancer* from March 2004

[D] Independent hospices in England have been inspected since April 2002 as part of the work of the National Care Standards Commission. These inspections include assessments of standards that were specifically developed for hospices and which draw on earlier drafts of this Guidance. From April 2004, this responsibility will transfer to the Commission for Healthcare Audit and Inspection (CHAI). The Care Standards Inspectorate for Wales, set up under the Welsh Assembly Government, carries out assessments of standards in hospices in Wales, based on national standards and other guidance on specific areas of care delivery.

I56 It is not anticipated that all the recommendations will be achieved in all areas immediately, or in the short term. Some may be relatively straightforward to implement, while others will be goals at which to aim. Strategic Health Authorities (SHAs), Welsh Assembly Regional Offices, Health Commission Wales, Primary Care Organisations, Local Health Boards, NHS Trusts, Cancer Networks and voluntary organisations will need to assess current service provision against the recommendations. From this, they will be able to recognise areas where the greatest deficiencies in current services exist and identify what will be needed to remedy the situation.

I57 It might seem reasonable to prioritise on the basis of the likely impact of change – as far as this may be judged from the evidence – but this, too, depends on the degree to which the current service model differs from that recommended.

I58 The topic areas vary widely, and the evidence suggests that change in some areas will have more impact than change in others. The amount and strength of supporting evidence available also varies, partly reflecting the fact that research into supportive and palliative care has tended to focus on specific issues.

I59 Suggestions have been made at various points in the Guidance on some of the ways in which commissioners and providers might consider addressing a particular recommendation. No directly applicable research evidence exists for a number of these, but they draw on the clinical experience and service-user experience of the Editorial Board established to support the Guidance development and other experts who have contributed to the consultation process.

I60 Local circumstances will dictate modifications in the way the Guidance is implemented, and Cancer Networks (in collaboration with users and providers of services) should be leading discussions about the configuration of local services and the nature of care to be provided. Commissioners need to be fully engaged in this process, with primary care lead clinicians for cancer likely to play a key role.

Ongoing research
I61 Unanswered questions and areas of uncertainty on the best models for supportive and palliative care services remain. In particular, research is needed on comparisons of different models or ways of providing interventions and measuring outcomes important to patients and carers. The final topic of the Guidance is devoted to summarising the nature of the current evidence in this area and outlining suggestions for future direction of research with respect to interventions, populations, outcome measures and systematic review methods.

I62 It is anticipated that the Guidance will be useful in determining the priorities for the research agenda for supportive and palliative care. The National Cancer Research Institute (NCRI) in England, with the formation of a number of clinical studies development groups which have direct relevance to this area of knowledge development (palliative care and primary care oncology, for example), and the Wales Cancer Trials Network (WCTN), might act as vehicles through which to develop relevant portfolios of

studies. Evidence of the current state of research in this area and suggestions for the direction and design of future research have been submitted by the authors of the Guidance and Evidence Review to the Supportive and Palliative Care Strategic Planning Group of the NCRI.

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1. Co-ordination of Care

A. Introduction

1.1 People with cancer may require supportive and palliative care at different stages of the patient pathway and from a range of service providers in the community, in hospitals, hospices, care homes and community hospitals. This means that services need to work together effectively to ensure that patients' and carers' needs are assessed and addressed at all times.

1.2 Patients' and carers' usual professional carers must be at the core of these services, and should be able to:

* assess the care and support needs, including palliative care, of each patient and carer across the patient pathway and in all domains of care
* meet those needs within the limits of their knowledge, skills and competence
* know when to seek advice from or refer to specialist services
* know how to support and enable patients and carers to utilise their own knowledge and skills effectively.

1.3 *A Policy Framework for Commissioning Cancer Services* (the Calman-Hine Report)[1] emphasised the need for care to be seamless from the patient's perspective. Continuity, or the experience of a co-ordinated and smooth progression of care from the patient's point of view, is a challenge. A number of elements need to operate effectively to create continuity, including:

* excellent information transfer following the patient
* effective communication between professionals and services, and with patients and carers
* flexible responses to individuals' changing needs over time
* care being delivered by as few professionals as possible, consistent with need.

1.4 The Commission for Health Improvement/Audit Commission report[2], however, identified numerous deficiencies in the co-ordination of care for people with cancer. Unnecessary duplication of services has been found, leading to confusion between service providers and the waste of scarce resources. Communication between sectors (such as secondary and primary care) on patients' conditions, treatments and needs for supportive and palliative care is commonly poor. Patients may consequently suffer through delays in the provision of services.

1.5 Inadequate assessment of patients' physical symptoms and psychosocial needs leads to failure to recognise their needs for supportive and palliative care, resulting in necessary services being denied to them. Effective assessment hinges on the provision of appropriate education and training for health and social care professionals, feasible and sensitive assessment tools and the availability of skilled personnel.

1.6 Improved quality of life and higher patient and carer satisfaction with services will result if provision is better planned and organised at strategic and operational levels. Essentially, well co-ordinated services aim to address four key problems, each of which can lead to failure in service provision:

- patients' needs being unrecognised, and consequently not being met
- patients' needs being recognised, but relevant services not being available because of lack of planning, funding or workforce capacity
- patients' needs being recognised, but health and social care professionals not accessing other relevant services because they are unaware of them
- patients' needs being recognised, the service being available and the patient being referred, but as a consequence of poor communication and lack of co-ordination between providers, services fail to bring maximum benefit to patients and carers.

1.7 At national level, many of these issues are being addressed through the establishment of a Supportive and Palliative Care Co-ordinating Group in England and the Cancer Services Co-ordinating Group in Wales.

1.8 *The NHS Cancer Plan*[3] for England stated that supportive care networks would be established alongside Cancer Networks. Since then, many local areas have developed a variety of groups tailored to meet local needs and work closely with Cancer Networks. Regardless of the organisational structure at local level, Cancer Networks, provider organisations, multidisciplinary teams and individual practitioners have an important role to play in ensuring that care is of the highest possible quality and is well co-ordinated from the perspective of patients and carers.

1.9 The Cancer Network is the vehicle for taking forward the implementation of the *NHS Cancer Plan*[3] in England and *Improving Health in Wales*[4]. Cancer Networks are partnerships involving:

- Primary Care Organisations/Local Health Boards
- NHS Trusts
- Hospices and other voluntary sector organisations
- Councils with social services responsibilities
- Health and social care professionals
- Patients and carers.

Cancer Networks also work in close partnership with Strategic Health Authorities (SHAs) and Health Commission Wales and their associated Workforce Development Confederations (the Workforce Development Steering Group in Wales).

1.10 At the current time, caring for patients with cancer comprises a very large part of the workload of supportive and palliative care providers, although it is recognised that this may change with time. Taking account of these factors, the Guidance has been developed on the basis that supportive and palliative care will be organised within the Cancer Network model.

B. Objectives

1.11 The objectives are to ensure that:

- services required by patients are available to all who need them, when they need them
- patients who may benefit from services are identified and afforded access
- care delivered by multiple providers in different locations is well-co-ordinated and non-overlapping from the perspective of patients and carers
- services are of the highest possible quality and are sensitive to people's needs and preferences.

C. Recommendations

C.1 Service provision and planning: specific recommendations
1.12 SHAs and Local Health Boards, working through Cancer Networks, should ensure structures and processes are in place to plan and review local supportive and palliative care services. All relevant stakeholders in the provision and commissioning of such services (both health and social care) should be included. This will involve:

- assessing local need
- assessing current service provision
- making recommendations on service configuration and priorities for development to the Cancer Network Board and contributing to the service delivery plan
- overseeing the development of network-wide policies, guidelines and directories
- co-ordinating with Workforce Development Confederations in England and the Workforce Development Steering Group in Wales on training and manpower needs
- developing joint operational policies and care pathways in partnership with local authorities and the voluntary and statutory sectors
- putting in place Cancer Network-wide arrangements to ensure access by health and social care professionals to up-to-date clinical information about patients and carers
- ensuring the views of patients and carers are taken into account from an early stage
- developing strategies that seek to engage with and identify service planning needs of people within local communities who are socially excluded and who have difficulty accessing services .

1.13 Many elements of supportive and palliative care are provided by the voluntary sector and mechanisms should be established to support effective partnership working on service planning and provision. The principles of the Government's Compact with the voluntary sector, and the associated codes of good practice, should guide these partnerships at local level.

1.14 The development agenda for supportive and palliative care is large and diverse. The nomination of an individual (or individuals) at Cancer Network level to lead on supportive and palliative care, reporting to the Cancer Network management board, would be an effective way to manage it.

1.15 Provider organisations should also nominate an individual (or individuals) to lead the development of supportive and palliative care services within the organisation and to contribute to the development of the Cancer Network-wide strategy.

C.2 Assessment: specific recommendations

1.16 Assessment of patients' individual needs is a critical first step in ensuring they receive the supportive and palliative care services they require. The process should fully reflect the shared nature of assessment between patients and professionals and should support patients in assessing their own needs.

1.17 Patients should not be subjected to repeated assessments from different professionals aiming to elicit similar information. To facilitate this, providers and teams, working through Cancer Networks, should develop common approaches to assessment, including the use of specific assessment tools which link with assessment approaches used in other domains, such as continuing, social and intermediate care. Mechanisms should be developed to enable the sharing of assessment data at key points (as listed in 1.20) among different members of the multidisciplinary team involved in planning and delivering care to an individual patient.

1.18 Assessments should encompass all the domains of supportive and palliative care (see I9). These include patients' and carers' needs and preferences in relation to:

- written and other forms of information
- face-to-face communication and involvement in decision making
- control of physical symptoms
- psychological support
- social support
- spiritual support
- rehabilitation
- complementary therapies
- family and carer support, self-management and peer support
- bereavement support
- involvement in the design and delivery of services.

Central to the process should be asking patients how they are feeling, and helping them to assess their own needs – patients are often the most effective assessors of their needs.

1.19 Teams should ensure that structured assessments are undertaken at key points in the patient pathway and are recorded. The format for recording the findings from the assessment should be agreed locally, with findings discussed at multidisciplinary team meetings.

1.20 While assessment should be an ongoing, continuous process throughout the course of a patient's illness experience, structured assessments should, as a minimum, be undertaken at each of the following key points:

- around the time of diagnosis
- commencement of treatment
- completion of the primary treatment plan
- disease recurrence
- the point of recognition of incurability
- the point at which dying is diagnosed
- at any other time the patient requests it.

1.21 Following each assessment, potential interventions to manage problems and concerns should be discussed with patients and carers and a mutually agreed action plan formulated.

1.22 Provider organisations should ensure that health and social care professionals have received training in how to competently perform assessments of patients' and carers' needs. Health and social care professionals have a responsibility to ensure they have received such training before performing assessments of patients' and carers' needs.

C.3 Referral and access: specific recommendations
1.23 Prompt referral to services that may be of benefit to patients should be discussed and agreed with patients following assessment. Teams should develop referral guidelines, in accordance with any relevant Cancer Network guidelines, for services they offer.

1.24 Cancer Networks should ensure that a service directory is available to health and social care professionals, patients and carers. It should include information about national and local supportive and palliative care services provided by NHS, statutory and voluntary organisations, professionally led support groups and self-help groups and local and national telephone helplines. The directory should include information on accessing information services (see Topic 4), psychological support services (Topic 5), specialist palliative care services (Topic 9), complementary therapy services (Topic 11) and support for families and carers (Topic 12). The directory should be kept up-to-date and a full review conducted annually.

1.25 Teams should ensure that patients and carers are given information on who they can contact at any time of day or night for advice, support and provision of services. Written information given to patients should include details of who to contact locally if they have particular questions about their treatment and care. These resources should be available in languages appropriate to meeting local community needs, bearing in mind specific issues relating to black and ethnic minority communities and the needs of those with sensory impairment. Service providers may wish to consider the provision of a single, common, 24-hour, seven day a week telephone access-point for patients and carers.

C.4 Co-ordination within teams: specific recommendations
1.26 To enhance co-ordination within teams (whether hospital, hospice or primary care based) in relation to supportive and palliative care, teams should:

- discuss individual patients' needs at multidisciplinary meetings
- record the outcomes of these discussions and communicate them to the patient and carer (with the patient's permission)
- review the dynamic process within the team and with other teams/services to maintain their continuing effectiveness in the light of the nature of the work; external support may be required to enable this.

1.27 While taking full account of national guidelines, teams should also develop their own policies/protocols in relation to communication, information and other key aspects of supportive and palliative care. This might be facilitated by mapping supportive care pathways for different groups of patients to identify which members of the team provide specific aspects of supportive care.

1.28 Teams (including primary care teams) should be able to identify patients currently under their care. An example of how this might be achieved is provided in the Macmillan Cancer Relief/NHS Modernisation Agency Gold Standards Framework Programme[5,6], in which general practices are asked to maintain a cancer register to record, plan and monitor patient care[E]. The 2003 GP contract[7] includes disease-specific registers (including cancer) as a quality indicator.

1.29 Teams, whether hospital, hospice or primary care based, should develop mechanisms to promote clinical continuity for patients. There is good evidence that patients want someone they can contact and who can co-ordinate their care at any one time. There is less evidence to indicate exactly how this may be achieved. Teams may wish to consider whether, for each patient, an individual (such as a community nurse, allied health professional, nurse specialist or social worker) should be nominated (in consultation with the patient) to act as a 'key worker'. This role might involve:

- orchestrating assessments to ensure patients' needs are elicited
- ensuring that plans of care to address these needs have been agreed with patients
- ensuring that findings from assessment and agreed plans of care are communicated to others involved in patients' care
- ensuring patients know who to contact when help or advice is needed; if in doubt, patients or carers should be able to contact their 'key worker' who will then put them in touch with appropriate personnel
- managing transitions of care.

A number of practitioners are likely to perform this function on behalf of individual patients over time. Changes in who fulfils the 'key worker' role are likely to be warranted at transition points in the patient pathway. Where it becomes necessary to change 'key worker', this should be negotiated with the patient and carer and a clear hand-over organised. Evaluation of different models of the 'key worker' concept is highly desirable.

[E] The NHS Information Authority is carrying out work to support the development of practice-based registers in primary care for a range of patient groups, including those with cancer. See http://www.nhsia.nhs.uk/phsmi/datasets/pages/pbrs.asp

1.30 Each team should identify an individual to act in the capacity of administrative contact for patients and professionals. The role might involve organising multidisciplinary meetings, maintaining the mechanisms necessary to ensure teams are able to identify patients under their care and acting as a common access point 09.00-17.00, Monday-Friday. Patients and teams/individuals involved in care provision should be informed about these individuals and made aware of how to contact them, including written telephone contact details.

1.31 Provider organisations should ensure that multidisciplinary teams have access to office space and administrative support to enable all team members to effectively fulfil their function and ensure that skills are used to best effect.

C.5 Co-ordination between teams: specific recommendations
1.32 Patients move frequently between sectors (home, hospital and hospice, for instance), between teams (such as primary care, cancer and palliative care teams) and between NHS, local authority and voluntary agencies. Co-ordination among these teams and services should be proactive to enhance continuity of care.

1.33 Co-ordination can be achieved in a variety of ways and will depend on local circumstances. Each team, however, should identify the other teams/services with which it most frequently interacts within and across different sectors, and should develop plans to promote co-ordinated care. These plans might include:

- undertaking joint clinics
- undertaking joint ward rounds
- participating in multidisciplinary meetings that include people from different sectors
- tele-conferencing.

1.34 Mechanisms to achieve comprehensive and timely information transfer between teams/services about patient care and treatment plans should be in place. This can be achieved in a number of different ways, and might involve electronic transfer of information, hand-over forms, or patient-held records and correspondence. These should be consistent with the *Information for Health* strategy of the NHS Information Authority[8] in England, and in Wales with *Informing Healthcare: transforming healthcare using information and IT*[9]. In line with the English Electronic Patient Record (EPR) national programme and the Welsh Single Integrated Electronic Record, the largely paper-based system currently in operation will be transformed by the implementation of national programmes for IT and associated integrated care records services[F].

C.6 Quality: specific recommendations
1.35 Wherever possible, care should be evidence-based and delivered in accordance with guidelines, policies and care pathways agreed at Cancer Network level.

[F] For more information on the Integrated Care Records Sytem (ICRS), visit:
http://www.doh.gov.uk/ipu/whatnew/specs_12d.htm

1.36 Relevant experts from different provider organisations should contribute to the development of policies related to the individual domains of supportive care. These policies should be reviewed regularly.

1.37 Cancer Network-wide audits, based on agreed policies, should be undertaken and results used to inform service development.

1.38 Cancer Networks should encourage and facilitate research into supportive and palliative care. The establishment of the National Cancer Research Institute (NCRI) and the Cancer Research Networks in England and the Wales Cancer Trials Network (WCTN) should facilitate the development and conduct of high quality clinical studies.

1.39 Progress should be reviewed with patient and carer representatives, and their views should be taken into account in the planning and operation of services. Cancer Network-wide arrangements for regularly and systematically obtaining patient and carer views about the experience of using supportive and palliative care services should be developed.

C.7 Research and development: specific recommendations
1.40 Empirical research is needed to map the patient pathway, to identify different services and patterns of care received, and to identify ways to improve co-ordination.

1.41 Evaluative research is needed to test and compare different interventions or strategies to facilitate co-ordination between hospital and home, and health and social care.

D. Evidence

1.42 There is no evidence to support the establishment of a particular structure and process to plan and review services in this area. The managed clinical network is currently being developed as a way of organising and developing cancer services, but as yet there is little independent evaluation of the strengths and weaknesses of this approach. An evaluation is ongoing, centred on the London Cancer Networks[10]. Needs assessment has become an established method of determining and more closely meeting needs, and data on needs assessment are available in palliative care[11]. There is significant risk of gaps and duplication in service provision if no systems are in place to link and co-ordinate the activities of providers of supportive and palliative care[2] [C].

D.1 Assessment
1.43 While the perceptions of patients, carers and health and social care professionals differ frequently, the process of assessment can produce a common understanding of needs and preferences. Studies have reported that the assessment of physical symptoms and psychosocial needs is often inadequate [B]. Patients' needs and preferences will change as they progress through different phases of the patient pathway; re-assessment at regular intervals is therefore essential. Systematic assessment is associated with reduced symptom distress over time [B].

D.2 Communication, co-ordination and continuity

1.44 The need for effective communication, co-ordination and continuity of care grows with the involvement of increasing numbers and categories of practitioners and interventions. Observational work has described patients' and carers' perspectives of continuity and barriers, and how this negatively influences the experience of care[12] [B].

1.45 Few studies examine the impact of continuity of care, or lack of it, on the process and outcomes of care[13]. Most have originated from specialist centres aiming to improve and extend their care. By far the most comprehensive was a Norwegian randomised controlled trial of integrated care, which fielded a dedicated team to provide quick home care nurse referral, shared records, good GP links and a dedicated hospital-based co-ordinating group. This generated large increases in contacts and patient satisfaction [A].

1.46 There is evidence that introducing a greater degree of co-ordination to existing services through the introduction of organisational interventions such as hospital-based nurse specialists and community-based nurse co-ordinators leads to positive outcomes [A]. Professionals and patients often feel there is inherent value in initiatives designed to improve the experience of care, such as the notion of the 'key worker', a professional to whom patients and their carers can turn in the first instance for information and advice[6,14,15] [C].

1.47 Guidelines to maintain interactions between services and the establishment of multidisciplinary care plans have been shown to be worthwhile [A]. Many of these innovations have been evaluated only within the context of palliative care, but it is likely that enhanced co-ordination and co-operation would result if similar interventions were also applied at other phases of the patient pathway. These need to be evaluated. In addition, many specialist palliative care teams include co-ordination as part of their role, and there is good evidence that this is effective [A] (see evidence review in Topic 9, *Specialist Palliative Care*).

1.48 Professional communication across organisational boundaries is a problem; the Cancer Services Collaborative has developed a 'Fax Pack'[16] setting out six triggers for communication by fax between primary and secondary care services, ranging from an initial referral, through the diagnosis and start of treatment, to communication of a death. It includes a 'safe haven' policy, referring to a process by which confidential information can be received and despatched securely in line with the Caldicott Guardian recommendations [C].

1.49 Evidence of the impact of patient records designed to transfer information as patients move between home, hospital and primary care is equivocal. A number of small-scale studies have suggested that the development of an acceptable patient-held record is often welcomed by patients, but is not without difficulty [B].

1.50 More than 20 teams within the Cancer Services Collaborative have been developing patient-held record systems of various kinds. To give one example, a chemotherapy

'handbook' developed by the Northern Cancer Network which involved both information and records was almost universally appreciated by those responding to an evaluation questionnaire [B]. The Collaborative has also developed a template for patient-held records, providing suggestions of the core components with an accompanying toolkit containing information on some practical issues; patients and carers were consulted on the items to be covered[17] [C].

1.51 A recent large-scale, UK-based study that set out to evaluate prospectively the introduction of a patient-held record in the management of patients with advanced cancer provided no evidence on which to base their widespread promotion, although the study team acknowledged that local projects with committed clinicians and patients may prove popular and effective[18] [A]. While patients and carers largely appreciated the record, the main problem was disappointing levels of communication among professionals.

1.52 Further examples of tools to improve communication and co-ordination within and between teams include multidisciplinary meetings, case conferences, unified assessment tools and hand-over forms. The value of these tools remains unsubstantiated. While there is consensus about the value of the concept of the 'key worker' role, the effectiveness of new key worker models needs to be evaluated as evidence emerges.

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DRAFT FOR 2ND CONSULTATION

2. User Involvement in Planning, Delivering and Evaluating Services

A. Introduction

2.1 People whose lives are affected by cancer can and do make significant contributions to the planning, evaluation and delivery of services. They participate in:

- service planning at national and local levels to ensure services meet the needs of patients and carers
- the evaluation of services; this can be achieved using a variety of methods, including telephone, postal and face-to-face interview surveys of patient experience and focus groups and discussions with existing user groups
- their own care through self-help and in the care of others affected by cancer (through, for instance, patient support groups and individual peer-to-peer support schemes).

2.2 For the purposes of this Guidance, we have drawn a distinction between the aspects of user involvement set out above and participation in their own decision making by individual patients, which is a theme that runs through each of the topic areas.

2.3 User involvement means enabling people who use or may use services to voice their experiences and influence broader care. Effective user involvement should reflect the diversity of those whose lives are affected by cancer and demands that views be elicited from a variety of groups[1].

2.4 Service users need to be heard in a range of care settings, including community, acute and hospice, and in local, regional and national settings. User involvement may be direct (where users are personally involved in decision making through, for example, user groups and user representation on committees and panels) or indirect (where health professionals gather information about user views using methods such as those listed above). Direct involvement ensures that users are actively engaged in working with health and social care professionals, but the choice of method will depend on the purpose of the exercise, the resources available and the preference of the users involved.

2.5 Not all patients and carers will wish to be involved in their care, however; nor are all patients in a position to be involved. In addition, some patients, including those who are very ill, people who are socially excluded and those whose preferred language is not English or Welsh, can face significant barriers in having their views heard[2]. Users may feel ill-equipped to engage effectively with health and social care professionals with regard to service planning and evaluation. Professionals can feel uncomfortable and may lack the confidence and skills necessary to work effectively in this area.

2.6 Involving service users in evaluating services they have received is fundamental to ensuring patient-centred provision. This can occur in different ways and during any or all of the processes involved, including setting the evaluation agenda, undertaking evaluation, and interpreting and disseminating results. Service providers commonly lack

knowledge and expertise in techniques and methods that can be used to undertake evaluations of patients' experiences of care. Service users often complain that they do not hear the results of such exercises and any action that has been taken as a result.

2.7 Patients frequently express a need to receive support from others who are in similar circumstances[3]. Patient and carer self-help and support groups are an invaluable resource and an excellent mechanism for achieving this within local communities. They range from the independent, lay-led group, to Trust-run, professionally led meetings.

2.8 People who have had cancer in the past are in a particularly good position to communicate effectively with, and offer emotional support to, those recently diagnosed, but can feel inadequately prepared to undertake this role. Support groups can encounter difficulties finding suitable accommodation, advertising their services to those who might benefit most from joining, knowing how to link with professional staff and maintaining capacity[4]. Patients and carers often fail to receive details of local support groups early enough to make best use of this resource as staff are not always aware enough, or willing enough, to pass on details of relevant groups, with few established systems in place to put people in touch with them[5].

B. Objectives

2.9 The objectives are to ensure that:

- user involvement is valued as an integral aspect of service planning and delivery
- the views of patients and carers are obtained, taken into account and acted upon (where appropriate) while developing and evaluating cancer services
- patient and carer-led activity is recognised and supported as an integral part of cancer care.

C. Recommendations

C.1 Overview
2.10 Mechanisms should be established to ensure that the views of people with cancer and their carers influence the development, delivery and evaluation of cancer services.

2.11 Regular opportunities should be provided for service users to offer information on the adequacy of cancer service provision, with feedback about how findings have subsequently been addressed.

2.12 Patients and professionals involved in user involvement activities should have an opportunity to develop skills and knowledge to foster confidence and underpin effective working relationships.

2.13 Patients with cancer and their carers should be given information about relevant local and national self-help and support groups.

2.14 Systems to enable individual patients and groups to become involved in the provision of support and information to fellow patients should be supported.

C.2 Service configuration and delivery: specific recommendations
2.15 Cancer Networks should establish and support Partnership Groups involving patients, carers and practitioners and should take into account the views of these groups when planning services.

2.16 Partnership Groups should develop mechanisms to ensure they are able to draw on views that are representative of the local community in any planning and evaluation activity, including direct representation or advocacy for black and ethnic minority groups and those who have difficulty accessing services.

2.17 Partnership Groups should engage with other bodies established across the NHS to support public and patient involvement, such as Patient Advice and Liaison Services and Patient Forums, ensuring their activities are synergistic and complementary.

2.18 Partnership Groups should establish effective relationships with local self-help and support groups to establish what services are currently provided or planned. They might wish to develop locally agreed guidelines to inform the working practices of these groups, consistent with the *Declaration of Good Practice for Cancer Self-help and Support Groups*[6].

2.19 Cancer Networks should ensure that information about local self-help and support groups, user groups and advocacy services is incorporated into service directories.

2.20 Provider organisations should nominate an individual to take the lead on developing and sustaining user involvement. This individual should liaise with all clinical teams and services related to cancer to ensure the views of patients are being elicited, collated and addressed.

2.21 Provider organisations should develop mechanisms to ensure the views of patients with cancer and their carers are elicited and taken into account. The choice of method(s) will depend on the purpose of the exercise, resources and expertise available and preferences of users involved. Results should be fed back to patients and carers, staff, management and the public (where appropriate). This should include information about changes that result from the process, and explanations on why some issues cannot be addressed.

2.22 All multidisciplinary teams and services should have mechanisms in place to gather the views of patients and carers on a regular basis.

2.23 Provider organisations should work with local self-help and support groups to establish the most effective ways of supporting their activities. This might, for example, involve the provision of accommodation for their meetings and/or offering training and support for support group leaders, co-ordinators and managers.

2.24 Teams should establish a process through which all newly diagnosed patients with cancer and their carers are offered promptly details of local patients' self-help and support groups using, for example, local service directories.

2.25 Teams should develop mechanisms to enhance patient access to different forms of peer-to-peer support.

C.3 Workforce development: specific recommendations

2.26 Cancer Networks should ensure that members of Partnership Groups (users and professionals) have access to training and support. In particular, patients and carers may need training in confidence building, representational and committee skills and information about how the NHS is organised and managed. Users and professionals might be trained together, where they are working as part of a group.

2.27 Providers of care should ensure that health and social care professionals have access to education in the principles and importance of user involvement and training in user involvement methods and in how to act on user views.

C.4 Research and development: specific recommendations

2.28 Exploratory research is needed to determine the effects and consequences on practice of policies and specific strategies for user involvement and the experience of users.

2.29 Research is needed to determine the best mechanisms for achieving patient/user participation in the delivery of supportive and palliative care (for example, self-help groups, peer-to-peer support and user self-management programmes).

D. Evidence

2.30 A number of studies which aimed to elicit the views of cancer patients and carers using different kinds of methods have been published, both nationally and locally[7-9] [B]. Some of these have been used directly to influence service decisions[10] [B]. Successful methods of involving service users in planning, developing and evaluating services have been developed by a range of different healthcare organisations[11,12] [C].

2.31 There is, however, a paucity of research which documents the impact of user involvement in health care. This may be partly due to the difficulty of tracing impact: policy issues can change rapidly, and it is not easy to attribute decisions to a particular source.

2.32 Two systematic reviews suggest that patient involvement in planning can result in some changes in service provision across a range of settings [A]. Such changes tend to concern patient information or access to services, but can also include the provision of new services. In addition, patient involvement can lead to a change in organisational culture. These findings are confirmed by a study of user consultation within Primary

DRAFT FOR 2ND CONSULTATION

Care Organisations and Trusts, which notes that arrangements for such involvement are becoming increasingly common and they have some impact, albeit fairly limited[13] [B].

2.33 Some research attention has been given to the training needs of patients likely to become involved in health policy or planning. Lay people would welcome joint training with professionals, with the aim of increasing collaboration [B]. Training should consist of communication skills training, representation skills and information on the NHS and voluntary sector. An evaluation of an advocacy training programme for patients with breast cancer found that participants became increasingly involved in boards and committees, clinical trial recruitment issues, patient resources and breast cancer advocacy groups, but not in every form of advocacy activity [B].

2.34 A number of studies have looked at patient support groups. An exploratory study evaluated the role of cancer support groups in the UK and identified strategies to improve communication with hospital staff [B]. Local support groups were found to be a considerable resource for patients with cancer, offering mutual support with a range of services not provided elsewhere. Hospital staff were not well informed about such groups, however, and were reluctant to refer patients to them. Another small study explored the activities of an advocacy project for patients with cancer, finding high attendance at meetings and positive feedback from participants [B].

2.35 From the limited research available, it is clear that patient involvement in decisions about health care can bring about changes in the provision of services, and partnerships between patients and healthcare professionals offer significant opportunities to improve health care. In addition, patient involvement can change the culture of organisations, making them more responsive to patients' perspectives. There is a need to enhance capacity through training and development for patients and practitioners and developing the contribution of patients' organisations[14] [C].

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3. Face-to-Face Communication

A. Introduction

3.1 Interpersonal communication is the process of information exchange among patients, carers and health and social care professionals. It is underpinned and enhanced by mutual understanding, respect and awareness of individuals' roles and functions, and is the process through which patients and carers are helped to explore issues and arrive at decisions.

3.2 Face-to-face communication with skilled health and social care professionals who are able to 'engage with patients on an emotional level, to listen, to assess how much information a patient wants to know, and to convey information with clarity and sympathy'[1] is highly valued by patients and carers. It is the usual mode of information-giving at critical points in the patient pathway, supplemented by written or multi-media materials and telephone communications, and in tandem with opportunities for reflection and questioning. There is a close relationship between giving and receiving information and the provision of emotional support.

3.3 Good communication is a prerequisite for enabling patients and carers to make informed decisions about care. Good communication among health and social care professionals, patients and carers, in which patients are encouraged to participate and to direct the flow of the communication, is likely to result in improved patient outcomes in terms of greater understanding, heightened ability to participate in the decision-making process, enhanced health-related quality of life and a better experience of care. Professionals should ask patients what they want to know, and not make assumptions about the level of information they require.

3.4 Good communication skills are therefore key to the delivery of effective supportive and palliative care services, but patients and carers frequently report health and social care professionals' communication skills to be poor.

3.5 Professionals may feel inadequately trained in aspects of communication such as listening, communicating significant news, explaining complex treatment options, exploring uncertainty (particularly in relation to prognosis) and discussing end-of-life issues. They may lack the necessary skills to be able to communicate effectively with the children and grandchildren of people with cancer, people with hearing, sight, speech or combined sensory disabilities, those with learning disabilities, people whose preferred language is not English or Welsh and those from minority ethnic backgrounds and traditions. They may also lack skills in eliciting patients' needs for information and their desire for involvement in decision making.

B. Objectives

3.6 The objectives are to ensure that:

- all patients and carers have the opportunity throughout the patient pathway to raise and discuss problems or concerns related to the disease, its treatment and its impact with professionals who, in addition to being knowledgeable about the relevant aspect of care, are also skilled communicators
- all health and social care professionals listen and respond to patients and carers in a manner that enables decisions to be made in an atmosphere of genuine partnership
- all patients are given the opportunity to participate in decision making about their treatment and care.

C. Recommendations

C.1 Overview

3.7 Patients' and carers' preferences in relation to face-to-face communication and involvement in decision making should be assessed on an ongoing basis throughout the patient pathway. Emphasis should be placed on patients' own knowledge of their condition, treatment and care, and professionals should seek to elicit this during consultations.

3.8 All health and social care professionals must be able to judge whether they have addressed an individual patient or carer's communication needs; having recognised the need to access a more experienced professional, this should be arranged without delay. Professionals should also act appropriately when patients make requests to see a more experienced professional, and express strong opinions about whether or not individual professionals can address their communication needs.

3.9 Communicating significant news should normally be undertaken by a senior, experienced and competent clinician who has received training and has been assessed as being an effective communicator. It is recognised that this is not always practical – patients and carers can and do ask less experienced staff searching questions about their condition and care – so all staff should be able to respond appropriately in the first instance before referring to a senior colleague.

3.10 The outcome of consultations with all health and social care professionals in which key information is imparted and discussed should be recorded in the patient's notes, and the patient should be offered a permanent record of important points relating to the consultation. The outcome of the consultation should be communicated to other health and social care professionals involved in the patient's care.

3.11 Patients should be offered the opportunity to discuss matters further with a professional of their choice.

3.12 For those individuals whose preferred language is not English or Welsh, or where patients have made a specific request, professional healthcare interpreters or advocates should always be present at consultations where key information is communicated and discussed and important choices have to be made.

C.2 Service configuration and delivery: specific recommendations

3.13 Provider organisations should ensure that all health and social care professionals have the skills to communicate effectively with patients and carers and are alert to their possible needs and preferences in relation to face-to-face communication. Those who communicate particularly complex or distressing information should have enhanced skills or be supported by someone who has those skills.

3.14 Teams should ensure that patients and carers have access to health and social care professionals who are able to judge whether they have sufficient knowledge and skills to communicate effectively with individual patients and carers, or whether a more experienced member of staff should be consulted.

3.15 Patients and carers should have access to professionals who have a level of communication skills appropriate to their current needs, and should have the opportunity to discuss problems, concerns and treatment options with a member of staff who has expertise in the relevant area and is an effective communicator.

3.16 Multidisciplinary teams should ensure that face-to-face communication with patients and carers at key points of the patient pathway involves, wherever possible, a senior clinician who has expertise in the disease and in options for treatment and care, and who has received advanced communication skills training. If the initial communication of significant news has to be made by someone other than a senior team member, the patient and carers should be offered an opportunity to discuss issues as soon as possible with a senior clinician with the requisite level of training.

3.17 A diagnosis should be communicated honestly to the patient with the minimum of delay. This information should be communicated in a comfortable, quiet area with privacy and without interruption, ideally in the company of a close relative or friend (if the patient so wishes) and in the presence of a specialist nurse where possible. Multidisciplinary teams might choose to follow the guidelines outlined in the report *Breaking Bad News*[2].

3.18 Teams should ensure that patients' and carers' involvement in decision making is facilitated where desired. People are likely to vary in the extent to which they want to participate in decision making and in the decisions in which they wish to be involved. Preferences are likely to change over time, and should be ascertained at key points in the patient pathway. Choices on involvement should be recorded and shared with all those involved in the care of the patient and carers.

3.19 Teams need to develop mechanisms to enable patients to review what has been discussed during key consultations at a later date, should they so wish. At the close of a

key consultation, the patient should be offered an opportunity to explore issues and ask further questions. This can be done in a number of ways: for instance, a nurse specialist might remain behind to provide support and further information, and/or a second appointment might be offered and the contact details of the patient's 'key worker' reinforced (see Topic 1, *Co-ordination of Care)*.

3.20 Provider organisations should ensure that suitably trained and skilled interpreters (such as a professional healthcare interpretation service) and advocates, supported by cancer practitioners, are available for patients whose preferred language is not English or Welsh and who want or need them[G].

3.21 The potential role of family members as interpreters is acknowledged and, where the patient wishes and authorises it and the family member is willing, should be utilised. Services should not over-rely on family members as interpreters, however, and should only seek their participation in extraordinary circumstances.

3.22 It is not recommended that children be asked to provide interpreting services for parents or other members of their family.

3.23 Health and social care professionals should ensure they have an understanding and appreciation of the cultural dimensions of face-to-face communication with patients and carers and of the cultural sensitivities relating to cancer and its treatment. They should ensure that as far as is possible they respect individuals' cultural values and traditions when engaging in face-to-face communication.

3.24 Provider organisations should ensure suitable services are available for people with hearing, sight, speech or combined sensory disabilities and for people with learning disabilities, to ensure they can participate fully in the process of information exchange. Provider organisations should ensure health and social care professionals are aware of these services and have direct access to them.

C.3 Workforce development: specific recommendations
3.25 It is essential that staff have the necessary communication skills to underpin and develop quality services. Effective communication is, to a large extent, dependent upon staff being trained in communication skills. Commissioners and Workforce Development Confederations in England (the Workforce Development Steering Group in Wales) should ensure that accredited training courses in communication skills are available for all health and social care professionals who come into contact with patients and carers. A pilot scheme is currently under way in England under the auspices of the Department of Health and the NHSU, examining the feasibility of a cascade model of communication skills training. This involves training communication skills facilitators at Cancer Network-level who will deliver courses to an agreed curriculum to senior practitioners.

[G] *The NHS Plan* committed to having a national translation and interpretation (T&I) service under the auspices of NHS Direct. NHS Direct has been charged with procuring a national T&I service provider that will enable them and the wider NHS to access a quality assured service at a negotiated rate. More information will be made available during 2004/2005.

3.26 Commissioners and Workforce Development Confederations in England (the Workforce Development Steering Group in Wales) should also ensure that health and social care professionals undergo diversity/cultural awareness training to promote effective communication with people from ethnic minorities.

3.27 Cancer Networks, in association with Workforce Development Confederations in England and the Workforce Development Steering Group in Wales, should decide which staff groups should be given highest priority for advanced training. For example, they may want to ensure that, as a first priority, advanced skills training courses are available for senior personnel (such as consultants, specialist registrars, nurse specialists and GPs) who frequently have to break significant news, explain complex treatment options or discuss end-of-life issues.

3.28 Provider organisations should develop mechanisms to identify individual staff who may benefit from communication skills training, and a system should be established to evaluate how effectively they communicate (for instance, through a performance appraisal process, which should involve a means of gathering the views of patients and carers). A process should be in place to effectively manage those members of staff who repeatedly demonstrate poor communication skills.

3.29 Staff should undergo regular evaluation and updating of communication skills and should be able to access clinical supervision or other effective means of ongoing support.

C.4 Research and development: specific recommendation
3.30 Evaluative research is needed to determine the best ways of ensuring that health and social care professionals trained in communication skills maintain these skills in practice over time, particularly in emotionally charged situations.

D. Evidence

D.1 Communication skills training
3.31 There is growing evidence to support the development of effective models through which to deliver training for specific groups [A]. As this is a relatively new study area, only one systematic review has been published on communication, and a further systematic review has been published through the Cochrane Collaboration Effective Practice and Organisation of Care (EPOC) Group[3].

3.32 Training in communication skills can change healthcare professionals' attitudes, improve methods of eliciting concerns and offering information, and increase their confidence in dealing with communication challenges such as informing patients about their diagnosis and prognosis.

3.33 Intensive communications skills training programmes have been demonstrated to improve senior doctors' communication behaviours [A]. Other studies support the

positive effects of education courses in improving healthcare professionals' communication skills, with ongoing training being necessary to maintain skills [A].

3.34 Evaluated training programmes have varied in both content and design, but those that lead to positive outcomes tend to:

- include cognitive, behavioural and emotional aspects of communication and focus on the acquisition of specific skills and/or strategies for dealing with specific situations
- use a combination of didactic and experiential methods, including role play, group work and discussion
- be learner-centred
- provide a safe environment for the development of skills, reflection and self-awareness
- have defined and measurable core competencies
- be led by professionals who are trained and understand issues relevant to the clinical context
- provide constructive feedback.

3.35 Improvements are most likely to be maintained where courses involve a large component of experiential learning over an extended period of time [B]. Most experience has been gained using a single profession approach to introducing training, but the benefits of training healthcare professionals together are increasingly acknowledged [A].

D.2 Communication process
3.36 There is considerable evidence of problems with communication between healthcare professionals and patients and carers. Diverse methods aimed at improving the face-to-face communication process and supporting patient involvement in decision making (where they have expressed a preference for this) have been evaluated. Attempts to improve communication through different media can have positive effects on a variety of patient outcomes, such as satisfaction, recall of information, self care, symptom management and psychological distress. The following approaches have been found to be beneficial.

- A written or taped record of the consultation [A]. These can help patients by improving their recall and giving them the opportunity to consider information after the consultation. They can also facilitate discussion with friends and relatives. Although most patients find them helpful, they can increase distress in those who want minimal information and in those for whom the prognosis is poor. A number of teams within the Cancer Services Collaborative have initiated taped consultations and written summaries of consultations. In Leicester, two-thirds of patients with lung cancer and lymphoma took up an offer of tapes of their consultation and, of those who responded to a survey (about 51%), all found them useful. They commonly listened to their tape on several occasions and felt that it provided much useful information and clarification [B]. In Wirral, four-fifths of the patients in one consultant surgeon's outpatient clinic took up an offer to receive copies of correspondence to their GP. This required some additional time in explanations to patients and paperwork, but was considered to work well [C].

- Individualised patient and carer education sessions, usually provided by nurses [A].
- Supporting patient involvement in treatment decision-making through the use of decision aids [A]. While a systematic review[4] acknowledges that evidence about likely effects in people with cancer is limited, decision aids might offer a useful way of displaying and providing information about treatment and care options. Individual preferences for different levels of involvement in decisions must be respected.
- Pre-consultation training in the waiting room [B], which has been found to be beneficial for patient participation in decision making and as preparation for significant consultations.

3.37 To date, no published research evidence on professional interpretation services has been found. Current consensus is drawn from patient and clinical experience [C].

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4. Information

A. Introduction

4.1 Patients and carers want and need up-to-date, high quality information, in a variety of formats, at all stages in the patient pathway. Many factors, including cultural and ethnic influences, play a significant part in determining how much information individuals will want, and the levels of information sought may be variable. The level and type of information individuals require is, however, entirely their prerogative, and health and social care professionals should be prepared to respond appropriately to the lead patients and carers give. Professionals should ask patients what they want to know, and not make assumptions about the level of information they require. They also have a responsibility to ensure that needs and preferences for information are assessed on an ongoing basis.

4.2 In order to inform, support and reassure patients and carers, information needs to be of high quality. 'High quality' is defined here as: nationally accredited, independent, evidence-based, peer reviewed, regularly updated, culturally sensitive, and available in a variety of formats. The provision of information material for patients and carers is likely to best take place in the course of face-to-face communication (see Topic 3, *Face-to-Face Communication).*

4.3 Patients and carers cannot express preferences about their care and make choices on whether to be involved in decision making unless they are given sufficient and appropriate information. Many report, however, that they receive insufficient information from health and social care professionals, and that much of the information they receive is inadequate and of variable quality.

4.4 Many different organisations at local and national level are involved in the production of information, which can lead to unnecessary duplication of effort, inconsistency in quality and failure to use evidence-based methods. Information products may not be available where they are needed most - whether in a primary health care centre, a cancer unit/centre or the community – or may be out-of-date. Culturally sensitive materials in languages other than English are lacking, as are those suitable for children of patients, people with sensory deficits and people with learning disabilities. There is an enormous amount of information on the Internet, which can be of variable quality. Many patients and carers currently lack the skills and resources to access and use this particular resource.

4.5 Health and social care professionals may under-estimate patients' desire for information, with the result that patients do not always receive as much information as they wish. Patients should be encouraged to express their preferences and health and social care professionals should be wary of making exclusive assessments of what information patients are ready to receive.

4.6 Providing information to people with cancer and carers is an ongoing process, not a one-off activity. While it is important that the right products should be available at the time they are required, people also need to know that their information needs will continue to be met at each stage of the patient pathway.

B. Objectives

4.7   The objectives are to ensure that:

- all patients and carers have access to high quality information materials where they need them and when they need them, in a format and at a level of complexity appropriate to their needs
- patients and carers are provided with assistance to help them understand information materials, should they so request, to put them in a strong position to decide what care options are most appropriate for them
- patients and carers have access to sources of emotional support to help them cope with the impact of the information they have received.

C. Recommendations

C.1 Overview
4.8 Commissioners, working through Cancer Networks, should ensure that a comprehensive range of high quality information materials is available to patients, free at the point of delivery.

4.9 Health and social care professionals, in addition to responding to requests for information, should assess on an ongoing basis the information needs and preferences of individual patients and their carers, asking what they would like to know and responding with appropriate information and materials. They should direct patients and carers to other reliable and confidential local and national sources of information.

4.10 Patients and carers should be offered a locally agreed selection of high quality information products relating to the disease, treatment options and available services, with access to further information should they require it. This should support patients in exploring their own care options and determining which is best suited to meet their needs.

4.11 Patients and carers should be offered assistance to help them understand the content of information products and should be given written details of a contact should they wish further information.

4.12 People with cancer and carers should be offered support to help them cope with the emotional impact of the information they receive.

4.13 The adequacy of local provision of information for patients and carers should be reviewed regularly, in collaboration with groups of service users.

4.14 Decisions on local policy should be driven by the experiences of patients and carers identified from, for example, patient surveys.

C.2 Service configuration and delivery: specific recommendations
4.15 A number of steps need to be taken to ensure that high quality information is available and accessible to people with cancer and their carers as and when they need it. For this to happen, information in all formats has to be:

- developed
- disseminated to a location where patients and carers can access it
- delivered, free at the point of delivery for the patient and carer

In addition, information should be updated on a regular basis and out-of-date material destroyed.

Development
4.16 The Department of Health and National Assembly for Wales should oversee the commissioning, design, quality assurance[H] and compilation of a comprehensive range of high quality information products for people affected by cancer, covering three different levels of information (Box 4.1). In England, the Coalition for Cancer Information, which brings together people from the statutory and voluntary sectors, will undertake this role. The Coalition should accredit organisations that develop information at national and local level, according to specified criteria, and should ensure that commissioners of cancer services and other provider organisations are made aware of such nationally accredited information products.

Box 4.1 Three levels of information
• Brief introductory information
• General information on issues such as diet and cancer, radiotherapy and chemotherapy and information on specific types of cancer, types of treatment and aspects of living with cancer
• Detailed and focused information, such as that presented in The Cancer Library available via The Cochrane Library.

Dissemination
4.17 High quality, nationally developed and accredited information materials should be disseminated to all locations where people with cancer and carers can access them. Commissioners should ensure that a comprehensive range of information materials is available to patients, free at the point of delivery. Materials should be produced, where possible, in a variety of formats to ensure they are accessible to as many people as possible. Electronic formats have the advantage that they can be updated more readily than hard-copy versions. Where this is not possible, the material should be delivered in

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[H] The Coalition for Cancer Information for England is taking forward work on quality assurance guidelines which, following piloting, will be reviewed.

hard-copy format to key locations such as GP surgeries, primary health care centres, cancer centres, cancer units and hospices.

4.18 Service users, representing the community, should be integral to the decision-making process not only about what information products are made available, but also in relation to the kind of information required and how that information can best be presented. Policies should be developed at local (Cancer Network/provider organisation) level detailing which information materials should routinely be offered as a minimum at various stages in the patient pathway for patients with particular cancers. Additional information materials will be needed to meet individuals' requests and needs. For example, new patients might be provided with a cancer information pack that contains timely, clear information in a convenient format. This information could be tailored to their personal needs and could be supplemented with generic information that helps them put their own experiences in context. A representative of each multidisciplinary team should be involved in developing these policies.

Delivery
4.19 Provider organisations (cancer centres, cancer units, hospices and Primary Care Organisations) should ensure that patients and carers have easy access to a comprehensive range of high quality information materials (books, leaflets, audio and videocassettes, Internet, CD-ROM and DVD) that are culturally sensitive for the local community and are appropriate to patients' and carers' age ranges, background and stage of disease. These materials should be available in sufficient quantities to ensure that all patients at all stages of the patient pathway have the same opportunities to receive information. Materials should be archived so that patients and staff can find the relevant materials efficiently. Within acute hospitals, this might be achieved by providing a dedicated cancer information centre, or through a facility that encompasses information for a broader range of diseases.

4.20 People with cancer request different styles of information, in different formats, and at different levels. While many will actively seek information, others may be less inclined. Health and social care professionals must be prepared not only to help patients navigate the different sources of information available and respond positively to requests for information, but also to assess the information needs and preferences of individual patients and carers on an ongoing basis. The assessment process should identify how people with cancer and carers might wish information to be personalised or tailored. Patients should be encouraged to express their preferences for information, and health professionals should be wary of making decisions about what information patients are ready to receive.

4.21 Teams should ensure that patients and carers have the opportunity to talk through the information they have been given with a health or social care professional in a supportive and private environment. Patients should have their attention drawn to other sources of assistance to help them understand and interpret information, such as voluntary sector helplines and information services.

4.22 Provider organisations should ensure that patients and carers are offered advice and support on how to access and use information materials, including those located on the Internet. Service directories produced by Cancer Networks should contain a list of high quality websites, including NHS Direct Online, which plays a key role as a gateway to sources of accredited information.

4.23 Provider organisations should ensure that arrangements are in place to translate culturally sensitive information materials (where translations are not currently available) into the patient's preferred language. Organisations should purchase materials from a nationally accredited information provider, unless materials in the appropriate language are not available[I].

4.24 Provider organisations should make arrangements to ensure the provision of suitable information resources for people with hearing, sight, speech or combined sensory disabilities and people with learning disabilities. There should also be information sources suitable for sharing with children and younger people.

C.3 Workforce development: specific recommendations
4.25 Teams should be familiar with their local patient information resources and should be able to provide the relevant materials to patients if required. Cancer Networks and Trusts providing cancer services should nominate a lead for cancer information. The network lead should oversee the development and implementation of effective strategies across all tumour types and locations. The Trust-level lead will ensure coherence across tumour types. He or she will be responsible for ensuring that up-to-date materials are available and that patients actually receive them. This may be a full-time post in larger acute Trusts.

4.26 Each specialist site-specific cancer team and each service (such as radiotherapy, chemotherapy, palliative care and primary care) should nominate an individual to take a lead on information to implement policy at local level. The person may come from one of several professional backgrounds - a nurse specialist or community nurse, radiographer or pharmacist, for example – and will contribute to the development of Cancer Network-wide policies for his or her area.

C.4 Research and development: specific recommendations
4.27 Research is needed to determine cost-effective ways of exchanging information (such as decision aids and innovative technology) at different stages of care.

4.28 Research is needed to determine cost-effective ways to support patients in using information resources.

[I] A 'content bank' of core information on cancer is currently being produced. This will be available to be 'cut and pasted' from the NHS Direct Online website for anyone to use. Materials will be available in translation, and some work is currently being undertaken within NHS Direct to identify appropriate languages for specific materials. More information will be made available during 2004/2005.

D. Evidence

4.29 There is a substantial body of evidence on the information needs of people with cancer, the effectiveness of different ways of presenting information in a clinical setting, patient satisfaction with information-giving by health professionals, and the direct and indirect benefits of receiving information.

4.30 A systematic review has evaluated methods of giving information to patients with cancer and their carers [A], with strong evidence from studies that patients and carers value and benefit from receiving accurate and relevant information. Outcomes of giving full and clear information include improvements in knowledge and understanding, reductions in anxiety, increased preparedness for events, enhanced sense of control, enhanced compliance and increased satisfaction with treatment.

4.31 Support for information being provided in a variety of formats and at all stages of the patient pathway is available, mainly through studies conducted to establish the effectiveness of different methods of providing information. Such formats include:

- cancer information booklets, both general and specific [B]
- individualised, structured nursing interventions to provide information and teach self-care and problem-solving skills [A]
- group information, discussion and support sessions [A]
- audiotapes, video tapes and slide tape programmes [A]
- interactive media, such as computer assisted learning [B].

4.32 The timing of information provision appears to be important. Patients appreciate receiving information prior to first appointments [B]. They prefer to receive general cancer information at the treatment decision stage [B], and look for specific information before treatment [B].

4.33 The evidence further emphasises the importance of tailoring information to match patients' and carers' educational background, cultural needs, and general level of comprehension[1]. Patients also prefer information based on their own medical records, rather than general information [A].

4.34 Many Cancer Services Collaborative projects aimed at improving the experience of care are piloting different ways in which to tailor written information, although formal evaluation has been patchy [C]. Much of this activity involves local tumour-specific information, with attention to the expected treatment in a local hospital; the Royal Devon and Exeter NHS Trust, for instance, has developed a leaflet on its joint gynaecology/oncology clinic. Some teams have also developed tumour-specific information materials to be used across the Cancer Network; for example, a standardised information pack has been developed for patients with breast cancer in mid-Trent. Personal Information Files have been implemented in some clinical areas[2] [B], and recordings or summaries of consultations have also been provided (see Topic 3, *Face-to-Face Communication*).

4.35 The Cancer Services Collaborative has also offered patients 'key contact' cards, setting out who they should contact when they have concerns or in an emergency, with telephone numbers (see, for instance, the system in operation in Avon, Somerset and Wiltshire Cancer Network) [B].

4.36 If the information needs of patients and carers are to be met, it is acknowledged that health and social care professionals are likely to need support[1]. The significant organisational challenges in producing, implementing and reviewing guidelines devoted to patient information, such as ensuring adequate funding, space and time, have been recognised, and the recommendations reflect those already in existence[3] [C]. Instruments are available to assess the quality of written information and guidance has been developed to assist in both the production of and search for good quality information materials[4-9].

4.37 Promoting access to information is a prime concern, and there are many locations where cancer information could be made available to patients and carers and by a variety of different agencies in the statutory and voluntary sectors. Hospital, community and mobile Cancer Information Centres, cancer telephone helplines and the National Electronic Library for Health have been developed. Evaluations indicate that patients and carers are highly satisfied with the quality and amount of information they receive from these types of information resources[10,11] [B], but the number of people contacting and using them suggests a need for provider organisations to promote increased access to existing sources of high quality information materials.

4.38 The most effective ways of extending access to cancer information for people from black and ethnic minority communities are currently being explored through the National Opportunities Fund *Living With Cancer* projects[J], and an evaluation is in process at City University, London.

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DRAFT FOR 2ND CONSULTATION

5. Psychological Support Services

A. Introduction

5.1 Psychological distress is common among people affected by cancer and is an understandable and natural response to a traumatic and threatening experience. Patients at every stage of the patient pathway will have to deal with issues that have the capacity to cause distress, which extends along a spectrum ranging from feelings of sadness and worry to psychological symptoms so intense they interfere with quality of life and ability to function on a day-to-day basis.

5.2 People respond to and manage distress they experience as a consequence of having cancer using a range of resources. Importantly, these include inner personal resources, as well as confiding in and deriving emotional support from family and friends. For some patients, however, the level and nature of their distress is such that they are likely to benefit from professional support and intervention.

5.3 Broadly, around the time of diagnosis, around half of people with cancer experience levels of anxiety and depression severe enough to adversely affect their quality of life. Over the next six months, the percentage of people so affected falls to about 25%. Around one in ten patients will experience symptoms that are severe enough to warrant intervention by specialist psychological/psychiatric services in the year following diagnosis. At the point of disease recurrence, levels of anxiety and depression severe enough to adversely affect quality of life increase once again to 50% and stay at this elevated level throughout the course of advanced illness. Between 10-15% of patients at this stage in the patient pathway will experience levels of distress severe enough to be managed with a specific psychological/psychiatric therapy.

5.4 Patients and carers are likely to benefit from some form of professional psychological support whether they are experiencing mild, transient emotional turmoil or severe depression accompanied by suicidal feelings (for particular aspects of service provision for families and carers, see Topic 12, *Services for Families and Carers, incorporating Bereavement Care)*. The selection of an appropriate psychological intervention will depend on the nature and severity of the person's psychological problem, his or her previous psychological problems, the quality of social support and the likely prognosis of the cancer.

5.5 Psychological support services aim to provide assessment and intervention for patients with all types and levels of severity of psychological problems. These problems include:

- anxiety, including adjustment disorders, generalised anxiety states, phobias and panic attacks
- depression, ranging from adjustment disorders to severe clinical depression
- interpersonal relationship problems
- psychosexual difficulties (such as erectile dysfunction and loss of libido)

- problems communicating with health professionals
- alcohol and drug-related problems
- personality disorder
- deliberate self-harm
- psychotic illness
- organic brain syndromes.

5.6   Health and social care services offer a range of psychological interventions for people with cancer, provided by both the statutory and voluntary sector. Front-line clinical staff provide much general psychological support and play a key role in psychological assessment and prevention and amelioration of distress. More specific and specialised services include counselling, clinical and health psychology, liaison psychiatry and social work. These may be available as an integral part of local cancer services, part of generic mental health services, part of primary care services or part of hospice care. They can therefore be located in GP practices, cancer units, cancer centres or hospices. The voluntary sector provides a range of services including telephone helplines and self-help support groups.

5.7 Patients' psychological symptoms are commonly not being identified, and patients and carers are not getting sufficient access to psychological support services[1]. Health and social care professionals often lack assessment skills in this domain of care and may underestimate the effectiveness of psychological support. Some don't know to whom they can turn for advice and support for patients and carers in distress.

5.8   There are insufficient numbers of professionals equipped to offer support to patients and carers in psychological distress, and no uniform agreement exists on the services professional disciplines can and should provide. Professionals offering different levels and types of psychological intervention lack co-ordination; consequently, psychological support services are neither available to, nor accessed by, many people living with cancer who have unmet psychological care needs.

B. Objectives

5.9 The objectives are to ensure that:

- the psychological needs of all patients and carers are assessed on a regular basis throughout the patient pathway, with attention being given to points that are recognised as being particularly challenging for patients, such as around the time of diagnosis, as treatment ends and at recurrence
- patients and carers are offered a level of psychological support appropriate to their needs and preferences, and those found to be experiencing psychological distress are referred to professionals with the relevant level of specialist expertise
- the psychological needs of staff who are caring for patients and carers facing difficult circumstances are adequately met.

C. Recommendations

C.1 Overview
5.10 The psychological well-being of patients and carers should be explicitly assessed at key points in the patient pathway.

5.11 All staff directly responsible for patient care should offer patients general emotional support based on skilled communication, effective provision of information, courtesy and respect.

5.12 Patients and carers found to have significant levels of psychological distress should be offered prompt referral to services in which staff are trained to provide specialist psychological care.

5.13 Emergency psychiatric services should be made available when necessary. Patients with severe mental health problems may require emergency responses both in and out of working hours.

5.14 Psychological assessments and interventions should be undertaken in facilities that are quiet, comfortable and which confer privacy.

5.15 Staff providing psychological care should be adequately trained and supervised, and mechanisms to ensure support should be available.

C.2 Service configuration and delivery: specific recommendations
5.16 Commissioners, working through Cancer Networks, should ensure that all patients undergo regular systematic psychological assessment at key points in the patient pathway and have access to an appropriate level of psychological intervention. A Cancer Network-wide approach to psychological support service delivery, consisting of professional and non-professional workers based in cancer centres, cancer units and primary care settings who are competent in a variety of psychosocial interventions, would facilitate this aim. Voluntary sector services should be integral to the network of service provision.

5.17 It is recommended that a four-level model of professional psychological assessment and intervention be developed and implemented in each Cancer Network (Figure 5.1). Professional psychological support at Levels 1 and 2 will, in the first instance, be provided by health and social care professionals who are directly responsible for the care of people with cancer. More severe psychological distress (Levels 3 and 4) will be managed by a variety of psychological specialists, including counsellors, mental health nurses, clinical and health psychologists, psychotherapists and liaison psychiatrists. It may be necessary for psychological specialists to work across different components of the Cancer Network - primary care, cancer units, cancer centres, hospices and the community - to achieve this model of care. Fundamental to assessment and intervention at all of these levels is the concept of health and social care professionals empowering and equipping patients to recognise and manage their own psychological needs.

5.18 GPs, oncologists and palliative care physicians also have an important role in the psychological care of patients and carers affected by cancer, including the prescription of antidepressant and other psychotropic medication.

Figure 5.1

Recommended model of professional psychological assessment and support

Level	Group	Assessments	Interventions
1	All health and social care professionals	Recognition of psychological needs	Effective information-giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological interventions (such as anxiety management and problem solving)
3	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological therapies, such as cognitive behavioural therapy (CBT) and solution-focused therapy, delivered according to an explicit theoretical framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions

Self help and informal support

5.19 The model is underpinned by patients' and carers' assessments of their own emotional status and an ability to recognise and meet their own needs for support. Patients might choose to seek personal support from family, friends, peers, self-help and support groups and can, if they choose, develop a significant repertoire of self-management strategies.

5.20 The model recognises the range of psychological skills and expertise that patients may draw on and represents the diversity of psychological skills possessed by various professional disciplines. The function of each different level of professional care provision is as follows:

Level 1
5.21 Involves all staff directly responsible for patient care and is focused on general emotional care.

Assessment
5.22 Staff should be able to recognise psychological needs. All health and social care professionals should be able to recognise psychological distress and should be competent in avoiding causing psychological harm to patients and carers. They should be able to identify when they have reached the boundary of their competence and should refer the patient to a more specialist service.

5.23 Cancer Networks should develop referral criteria for specialist psychological support services. Teams should be familiar with criteria and the mechanisms through which to expedite referral.

Intervention
5.24 Staff should be able to:

- communicate honestly and compassionately with those affected by cancer (see also Topic 3, *Face-to-Face Communication)*
- treat patients and carers with kindness, dignity and respect
- establish and maintain supportive relationships.

5.25 Professionals' ability to function effectively at Level 1 is likely to have a significant impact on demand for services at Level 2 and beyond. Appropriate interventions at this level may prevent the development of more severe psychological problems among patients and carers.

Level 2
Assessment
5.26 Professionals operating at this level should also be able to screen for psychological distress at key points in the patient pathway, including:

- around the time of diagnosis
- during treatment episodes
- as treatment ends
- at the time of recurrence.

5.27 Designated professionals (such as nurse specialists, social workers and GPs) who have been appropriately trained in screening for psychological distress should undertake these assessments. They should include an assessment of the impact of cancer on

people's daily lives, family relationships (including intimate and sexual relationships), their mood and work, eliciting concerns, worries and feelings by establishing trust and listening in a permissive and non-judgemental manner. The assessment process itself may lead to the resolution of concerns and should result in appropriate psychological support being made available. Patients experiencing significant psychological distress should be offered referral for specialist psychological support/intervention.

Intervention

5.28 Level 2 involves psychological interventions delivered by trained and supervised health and social care professionals to manage acute situational crises encountered at key points in the patient pathway. Appropriate interventions include anxiety management training and problem solving. Among others, clinical nurse specialists could potentially be trained and supported to undertake these assessments and deliver interventions as an integral part of their practice.

Level 3

Assessment

5.29 Trained and accredited professionals should be able to differentiate between moderate and severe levels of psychological need and onward refer those with severe needs to mental health specialists.

Intervention

5.30 Level 3 involves specific psychological therapy, such as counselling delivered according to an explicit theoretical framework by a trained, accredited and supervised counsellor. It aims to manage mild to moderate levels of psychological distress, including anxiety, depression and anger. Specific psychological therapies at this level are also appropriate for dealing with mild to moderate cancer-related concerns such as worries about treatment, relationships with hospital staff and personal relationships (including sexual relationships), as well as the spiritual issues a life-threatening condition raises.

Level 4

Assessment

5.31 Mental health specialists should be able to assess complex psychological problems, including severe affective disorders, personality disorders, substance misuse and psychotic illness.

Intervention

5.32 Level 4 involves specialist psychological and psychiatric interventions delivered by mental health specialists to manage moderate to severe mental health problems experienced by those affected by cancer. These include severe depression and anxiety, organic brain syndromes, severe inter-personal difficulties (including severe psychosexual problems), alcohol and drug-related problems, personality disorder and psychotic illness.

5.33 It may not always be possible to make a clear distinction between the boundaries of expertise of various professionals (particularly in the case of Level 2 and Level 3), and there is likely to be some overlap between the levels.

5.34 Professionals involved in offering different levels and types of psychological interventions should develop and implement mechanisms to co-ordinate their service provision to ensure that patients and carers are offered interventions most appropriate to their needs. This may involve the use of referral guidelines for each level/type of psychological intervention, including counselling, clinical and health psychology and psychiatry. If different psychological specialists within the psychological support service work in an integrated way, referrals for psychological intervention could initially be made to the overall service. A system of assessment and triage could then be used to decide which patients might be offered which particular level/type(s) of intervention. This approach would be based on an acceptance that choice of treatment should also be guided by the patient's preference, and that there is considerable overlap between the mental health problems in which different therapeutic approaches can be effective.

5.35 Commissioners should ensure that emergency psychiatric services are available for patients who have developed acute mental health problems and are potentially a danger to themselves and/or others, and that healthcare professionals have 24-hour, seven days a week access to advice on caring for patients who have acute mental health problems. This will typically be provided by the local mental health team.

5.36 Appropriate facilities should be made available for undertaking psychological assessments and interventions. Facilities should reflect the needs of patients and carers for privacy and comfort. In circumstances where patients are unfit to travel but are likely to benefit from specialist psychological/psychiatric interventions, this may be provided through domiciliary visits and/or additional support for local healthcare teams.

5.37 Psychological care services should have agreed processes for transfer of information within their service and with referring services/practitioners and other teams involved in the care of individual patients and carers. Information should include the findings from individual patient assessments, proposed treatment plans and outcomes of treatment. There will need to be an agreed formal process within teams for managing sensitive and private issues.

5.38 Many patients talk of the transition out of active treatment and into 'survivorship' as being one of the most psychologically demanding phases of the patient pathway. When a patient completes active treatment, he or she should be informed about the range of support services available and the means to access them directly. They may need to access these services some considerable time after the cessation of treatment. In the first instance, this is likely to be through the GP or 'key worker'.

5.39 Service directories related to supportive and palliative care should include information on psychological support services and the range of support groups available locally, in hospital and the community.

C.3 Workforce development: specific recommendations

5.40 Practitioners responsible for the delivery of psychological care at each of the different levels should be identified.

5.41 An individual (or individuals) should be identified within each cancer site-specific team to take responsibility for providing Level 2 care (that is, screening for psychological distress and providing simple psychological interventions).

5.42 Psychiatrists, psychologists, psychotherapists and counsellors should be identified at Cancer Network-level to provide care at Levels 3 and 4. If these staff have not previously worked with people with cancer and their carers, they will require additional training. Psychological care experts with extensive experience in cancer and who have worked with oncologists and palliative care specialists are the most appropriate providers of training.

5.43 All staff providing psychological support within the recommended model require training and ongoing supervision. Those working at the higher levels of the model should normally provide continuing professional development opportunities, training and supervision for those operating at the lower levels.

5.44 Psychological specialists should also play a significant role in the development and maintenance of communication skills through teaching and training (see Topic 3, *Face-to-Face Communication*).

C.4 Research and development: specific recommendation

5.45 Evaluative research is needed to determine which psychotherapeutic interventions are most effective and cost-effective for different patient groups at different stages of disease.

D. Evidence

D.1 Overall benefit

5.46 While there is no formal evidence on the potential benefits of implementing this particular model of psychological assessment and intervention, a considerable body of evidence supports the effectiveness of different elements of the model. Five systematic reviews have been done in this area; while one was equivocal, the other four found evidence of benefit among those affected by cancer in relation to:

* reductions in psychological distress
* improvements in overall quality of life and other functional outcomes
* making the experience of having cancer more acceptable
* improvements in adherence to cancer treatments.

5.47 All people with cancer are likely to benefit from effective information-giving and sensitive communication throughout the patient pathway. About 15% of patients

experience mild to moderate levels of distress at any one time in the first year after diagnosis of early disease and are likely to benefit from psychological interventions from a trained cancer health professional or a specific psychological therapy. Ten per cent experience more severe levels of psychological distress at any one time and are likely to benefit from specialist psychological or psychiatric intervention. The prevalence of all severities of psychological distress is somewhat higher for patients with advanced disease, so a greater proportion of these patients are likely to benefit from some form of psychological intervention.

5.48 Establishing a comprehensive and co-ordinated psychological support service will provide major benefit to all those affected by cancer.

D.2 Assessment
5.49 There is fairly strong evidence that healthcare professionals' current abilities to detect the psychological needs of people with cancer are limited. Abilities can be developed through training designed to improve assessment skills by focusing on the structure and coverage of individual assessments [B].

D.3 Benefit of different approaches
5.50 An eclectic mix of psychotherapeutic and psychiatric interventions has been employed to meet the various needs of people with cancer. There is evidence that individual [A] and group-directed [A] approaches realise benefits.

5.51 Interventions have been delivered in a variety of contexts, including home and hospital environments. A range of health, social and psychological care workers have been involved in the development and delivery of interventions, both as individuals [A] and working in teams [A]. Interventions delivered by psychiatrists, counsellors, psychologists, social workers, specialist nurses and psychotherapists have been subject to evaluation.

5.52 While the magnitude of benefit to be derived from effective communication and psychological interventions by trained cancer health and social care professionals is difficult to quantify, counselling and specialist psychological and psychiatric interventions are likely to confer moderate to major benefit on those who receive them. They produce significant improvements in psychosocial functioning and overall quality of life for particular individuals [A].

5.53 There is strong evidence from meta-analyses to suggest that specialist psychological and psychiatric interventions (Level 4) confer benefit in terms of reducing anxiety and depression and bringing about emotional and functional adjustment. It is beyond the scope of this Guidance to consider psychopharmacological interventions, but services should ensure they follow the most effective practice.

5.54 Specific psychological therapies, such as counselling and cognitive behavioural therapy (Level 3), have been evaluated in the context of cancer care with positive

outcomes on a range of variables, including coping, anxiety, depression, and self-esteem [A].

5.55 Psychological interventions at Level 2 consist of a diverse range of activities. The most effective include those designed to enhance self-care skills, provide information and enhance control, promote anxiety management, improve ability to adjust to life situations and problem solve [A]. Psychoeducational approaches, often drawing on a variety of techniques, have also been shown to bring benefit to patients who are suffering distress as a result of certain symptoms, such as pain, nausea and breathlessness [A].

D.4 Training and support

5.56 Psychological support serves to enhance the ability of health and social care staff and volunteers to provide good quality care. It has a role in managing occupational stress, and in the recognition and prevention of 'burn-out'. There is general recognition that those providing psychological care need to be properly supervised, either in one-to-one situations, or in groups, peer groups and work teams [C].

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6. Social Support Services

A. Introduction

6.1 The social impact of cancer is considerable[1]. People affected by cancer may have a range of needs for social care and support at different stages of the patient pathway. These include:

- emotional support derived from engaging in social activities, companionship and befriending and contact with care professionals
- help with personal care – bathing and dressing, for instance
- assistance to secure financial support through, for example, advice and help on making claims for benefit
- advice on work and employment issues
- help inside and outside the home, such as cleaning and shopping
- practical aids, including wheelchairs and other equipment
- help to care for children and other dependants (such as older relatives).

6.2 The social implications of cancer can be far reaching, extending beyond the patient's immediate family and carers to relatives, friends, employers and work colleagues.

6.3 Social care for patients and carers encompasses:

- access to safe living environments which comply (at least) with minimum standards
- practical help
- income maintenance
- preservation and/or enhancement of social networks
- provision of information on local and national resources
- emotional support.

6.4 This kind of support may be provided by family and friends or other social networks, or by providers of statutory and voluntary health and social care services. Councils with social service responsibilities assess individual need to provide or commission personal and domestic care at home or in residential settings. They offer social work, occupational therapy and other elements of social care services in the home. Respite and day care, assisted transport, support groups, volunteer visitors and bereavement care may be provided by local authority, NHS or voluntary organisations.

6.5 It is recognised that some needs may only be fully addressed by individuals and agencies outside of the health service. This topic area of the Guidance, developed under the auspices of NICE, is primarily concerned with the actions that commissioners and providers of health services should take to ensure that the needs of patients and carers for social support are met. It is based on the tenet that an appreciation of social needs on the part of healthcare providers can assist patients in adjusting to cancer and its practical demands, whether or not providers are able to directly meet these needs. The need for

strong collaboration between health and social services is paramount, but recommendations relating to the responsibilities of social service departments are outwith the scope of the Guidance. The text for this topic area has been written in consultation with the Social Care Institute for Excellence (SCIE).

6.6 Historically, health and social care services have been poorly integrated, but there is now a duty of partnership on health authorities and councils (social services, housing and other council services). Commonly, however, patients and carers do not experience a coherent, integrated system of social support. The number of agencies involved in planning and delivering services makes collaboration difficult – services are neither well understood nor well known by healthcare professionals. Often there is uncertainty about how to access social workers, or there may be staff shortages that make access difficult. This can lead to delays in getting an assessment of social care needs and access to the services social workers can supply.

6.7 New targets for assessment and receipt of services have been announced and new performance indicators for these targets will be published in October 2004. As a result of the Community Care (Delayed Discharges) Act 2003[2], social services will be required to provide services within a specified time limit or reimburse the NHS Trust for the patient's consequential extended stay in hospital. The Fair Access to Care Services initiative is addressing inequities in how eligibility criteria are defined and applied[3].

6.8 Assessment of need can be difficult because some patients and carers might be reluctant to ask for help, either because of a desire to maintain independence and dignity, or because they perceive resources to be limited. Also, while interventions from professionals may be seen as supportive by some patients and carers, others may see them as intrusive or inappropriate.

6.9 Patients and carers often lack the skills and information to access and secure benefits. The resources of the community in all its different guises, including peer support, friends and family, self-help and support groups, are often not maximised in providing social support for patients and families, and healthcare professionals tend to undervalue this form of support.

B. Objectives

6.10 The objectives are to ensure that:

- the social care needs of individual patients and carers are identified and they are helped and supported in finding ways to address them
- patients and carers experience a coherent and integrated system of social support matched to their personal and social circumstances and aiming to make it easier for them to cope with the knowledge and social consequences of living with cancer
- practical and financial support is made available to patients and carers where and when needed.

C. Recommendations

C.1 Overview

6.11 Commissioners and councils with social services responsibilities should establish a joint approach to the planning and delivery of care to ensure services are organised to meet patient and carer needs for social care.

6.12 Needs and preferences for social support should be elicited as an integral component of routine assessment, ideally undertaken with or by social care professionals.

6.13 The level of support offered to patients should be appropriate to their needs and should be acceptable to them, with signposts provided to other services outside the immediate healthcare environment.

6.14 Patients and carers should be offered assistance to understand and secure benefits potentially available to them; professionals who are informed and knowledgeable about the benefits system should provide this service.

C.2 Service configuration and delivery: specific recommendations

6.15 Patients with cancer need health and social services and the voluntary sector to work together to deliver the care they need, when they need it. To further this end, commissioners, working through Cancer Networks and councils with social services responsibilities, should establish collaborative working relationships. A range of different collaborative options exists that can strengthen the links between the NHS and social services at local level, and Cancer Networks should adopt the option most appropriate to meeting local needs. The options for partnership working in England provided by section 31 of the Health Act 1999[4] are pooled budgets, lead commissioning and integration of services. Cancer Networks should seek to build on existing arrangements for planning and commissioning services. In Wales, there is a joint duty upon Local Health Boards and local authorities to develop Heath, Social Care and Well-being strategies with statutory and voluntary organisations and local people[5].

6.16 Commissioners, working through Cancer Networks and councils with social services responsibilities, should ensure the different components of social support are available within a Cancer Network and are accessible from all settings, domestic or institutional (patients' homes, hospital, hospice, care homes and community hospitals). The balance of services necessary may differ within each setting, but the main components are:

- practical support, including provision of personal and domestic care in the patient's place of residence
- support to maintain employment status
- support to maintain independent living, including adaptation of living environments and the provision of equipment
- access to individuals, such as welfare rights and benefits advisors, who can provide information and offer assistance in completing applications

- services to assess and protect the rights and needs of vulnerable adults or children where a family member has cancer and which can support people with cancer in caring for vulnerable adults and/or children
- respite and day care in social and healthcare settings as appropriate
- care home placements
- carer support (such as help with the washing and cooking)
- emotional support.

6.17 Cancer Networks, in conjunction with Primary Care Organisations and councils with social services responsibilities (Local Partnerships in Wales), should review the community equipment service with respect to the needs of patients with cancer to ensure necessary equipment can be delivered speedily and flexibly. *The NHS Plan*[6] for England set out the intention to achieve a single integrated community equipment service by 2004[K].

6.18 Teams should ensure that each patient with cancer has his or her social care needs initially identified as a part of routine assessment, to allow an overview of the person's needs and circumstances to be developed. Assessment should cover the domains of personal care, aspects of relationships (including social contacts and involvement in leisure, hobbies, work and learning), and immediate environment and resources (such as care of the home, housing, finances and access to local facilities and services). Local collaborative arrangements should ensure that assessment is undertaken by or with the help of social care professionals.

6.19 Based on this overview assessment, the patient's usual healthcare professional should arrange for access to sources of more specialist assessment, if necessary. Providers should ensure that healthcare professionals can readily access the most appropriately qualified professional to carry out specific specialist assessments.

6.20 Providers, working with councils with social services responsibilities, should ensure that patients with cancer and their families and healthcare professionals working in cancer centres, cancer units, hospices and primary care settings can readily access social workers. Site-specific and palliative care teams should be linked with named social workers or teams of social workers.

6.21 Healthcare teams in hospitals and hospice and primary care settings should establish mechanisms to promote effective working relationships with social services departments. Agreement should be reached about professional responsibility for different aspects of assessment, referral arrangements between professions or agencies, and information sharing.

6.22 As a result of the assessment process, teams should be in a position to offer support and advice, and to help patients and carers locate additional sources of assistance.

[K] As a result of the Community Care (Delayed Discharges) Act 2003[2,] the discretion for social services to charge for community equipment services has been removed since June 2003. This should make integration of NHS and social services community equipment services more straightforward.

Patients should be given clear advice on how to secure access to different types of services.

6.23 Provider organisations should ensure patients and carers have easy access to a range of information resources on social care appropriate to age, culture and background. Providers might consider integrating sources of information and support with general cancer information services or Patient Advice and Liaison Services (where these exist or are planned) and with primary care and local community information points (such as libraries and citizens' advice services). Systems that serve to direct patients to sources of advice on which particular benefits they might be eligible to apply for, and which provide support in completing applications forms, should be in place.

6.24 Provider organisations should have mechanisms in place to raise patients' awareness of different types and sources of support available, including professional and volunteer-led support groups, helplines, peer support systems and other types of support offered by the voluntary sector (see Topic 2, *User Involvement in Planning, Delivering and Evaluating Services*).

6.25 Cancer Networks should ensure that directories include information about local social services and statutory and voluntary sources of support. Networks in England should refer to *Fair Access to Care Services*[3] when reviewing and developing information about services that are available. In Wales, networks and multidisciplinary teams are responsible for delivering the national healthcare information strategy[7]. They are required to provide patients with information about services, including access to social services and sources of support.

C.3 Workforce development: specific recommendations
6.26 The full range of professionals likely to be involved in carrying out a front-line assessment will need to be skilled in assessment practice in this domain of care. Workforce Development Confederations in England (the Workforce Development Steering Group in Wales), working in collaboration with Cancer Networks, should assess the level of need for education and training on social care needs of individual patients and carers among these groups of healthcare workers.

6.27 Providers should ensure that staff are familiar with current working arrangements on securing specialist assessment and access to the range of social support services available (including safe and accessible living environments, practical help, income maintenance and emotional support).

C.4 Research and development: specific recommendations
6.28 Research is needed to determine the best ways to ensure effective co-ordination between social and healthcare services.

6.29 Research is needed to determine the particular role and contribution of social workers and of volunteers in supportive and palliative care.

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D. Evidence

6.30 Patients report unmet needs with respect to managing daily life, managing emotions and managing changes in social identity[1,8,9]. Although descriptive studies are useful, the lack of outcome evaluations is regrettable. The body of evidence concerning the role and impact of various forms of social support for patients with cancer is small. With respect to assessment, there is evidence to suggest that setting up systems for the early identification of support needs can make a substantial difference to getting help to patients when they are first diagnosed [A]. Attention to identifying needs for terminally ill people in a sensitive manner can also help to increase the support offered to them [B].

6.31 Most research has focused on the effectiveness of interventions to provide support of various kinds. A large systematic review of research on the effectiveness of the palliative care team model found a small positive benefit on outcomes for both patients and carers [A]. Providing a variety of forms of care for terminally ill patients in their home makes it more likely that they will be able to die at home [B]. Care is also welcomed by carers, giving them a period of respite [B].

6.32 The impact of providing emotional support by various means to patients with cancer has been evaluated, and evidence for their effectiveness is presented in Topic 5, *Psychological Support Services*. Research shows that patients can be helped to cope with emotional reactions to terminal illness through group support sessions, gaining access to other patients with cancer who can serve as role models, and through the provision of a dedicated social worker [A]. In some cases, significant improvements have been found in the level of depression and other psychiatric symptoms.

6.33 There is a growing number of descriptions of services, which are valuable in terms of providing information about the design and format of interventions and suggest models of good practice [C]**.** Volunteers are often central to these initiatives, which include:

- schemes designed to offer specialist benefits advice and assistance to access benefits[10]
- information and support, such as that provided by the Liverpool Cancer Support Centre through the Advocacy Project[11].

6.34 These should now be subject to evaluation. Acceptability needs to be considered at an early stage as, despite recognition of unmet need, self-reliance and independence are important values, and barriers to accepting use of services need to be more fully understood[12].

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7. Spiritual Support Services

A. Introduction

7.1 The diagnosis of life-threatening disease has a profound effect on people who are ill and on significant people in their life. Unsettling questions quickly begin to arise. They ask: 'Why should this be happening to me? What is the cause of this – is it my fault? Who am I now? How can I make sense of it, and how am I going to cope?' Many questions are of a specific existential nature and are related to identity and self-worth as patients seek to find the ultimate meaning of their life.

7.2 These questions emerge and re-emerge at various points in the patient pathway but tend to be more focused when:

- new symptoms appear
- side-effects of treatment become distressing
- the patient has to adapt to changes in lifestyle, with emotional and social consequences
- changes occur in relationships with significant others.

7.3 The net result for the patient can be a deep sense of disconnectedness from self and other people and from whatever he or she might have believed in, which may result in some distress. Some people will seek to re-examine their beliefs (whether religious or not) and either re-affirm, abandon or initiate an exploration into them according to how well they answer their questions and offer support.

7.4 Spiritual care enables individuals and groups to respond to spiritual, emotional and psychological need, and to the experience of life and death, illness and injury, in the context of a personal belief system. Beliefs can be philosophical, religious and/or broadly spiritual in nature[1,2].

7.5 Religion is a means of expressing an underlying spirituality, but spiritual belief is a broader concept and may not always be expressed in a religious way. 'Spiritual' relates to the search for existential or ultimate meaning within a life experience. This belief usually includes reference to a power other than self. People may (or may not) describe the power as 'God' or higher power, or as forces of nature. The power is seen as helping the person to transcend the 'here and now' experience and re-establish hope[3].

7.6 It follows that spiritual care is not just the facilitation of appropriate ritual. This has implications for the way in which health and social care professionals assess spiritual need. The key issues in delivering effective spiritual and existential support to people experiencing the effects of illness, treatment and/or approaching death are:

- listening to the patient's experience and the existential questions that may arise when assessing spiritual needs in a broad way
- affirming the person's humanity or personhood

- protecting the person's dignity, self worth and identity
- ensuring that spiritual care is offered as an integral part of an holistic approach to health that encompasses psychological, spiritual, social and emotional care, and within the framework of the patient's set of beliefs or philosophy of life.

7.7 Spiritual needs of patients and carers may change over time, place and stage of the disease and in response to clinical care and inter and intra-personal factors (family relationships, social support, emotional state, cognition, experience of loss and grief and relationships with faith leaders or others providing spiritual support, for instance). For many, the need may be expressed only once. This means that an ongoing, accurate and timely evaluation of the nature of the difficulty presented is necessary. Despite interventions, some people have enduring spiritual difficulties that may require continuous facilitation.

7.8 The level of support people need may range from an informal sharing of ideas about life, death and the ultimate purpose of our existence, to the provision of a formalised religious ritual. The means of providing for a particular need will vary in relation to location, resources and skills available, as well as the actual needs assessed.

7.9 Most aspects of spiritual care can be offered in any setting where patients with cancer and their families are cared for - at home, in hospitals, hospices, care homes or community hospitals. Care may be provided by:

- the patient's own family, friends or faith group
- staff groups (of any discipline) within in-patient care settings or by the patient's GP/community nursing service, with additional support from a specialist palliative care service (see Topic 9, *Specialist Palliative Care Services*)
- officially appointed and authorised faith leaders from within a local community selected and trained to work within a cancer and palliative care setting, or a healthcare chaplain.

7.10 Spiritual care provision is seen as a responsibility of the whole team, but it is recognised that an individual may hold specific responsibility for ensuring that it is provided to an acceptable standard (a hospice or healthcare chaplain[4-6], for instance). There are indications, however, that spiritual needs are not being met within cancer services. For instance:

- in the hospice sector, there is disparate provision of spiritual care[7]
- within the hospital sector, there are insufficient numbers of chaplains to meet needs; a hospital-based chaplain has responsibility for supporting patients and carers throughout the entire service, and not just those receiving cancer treatment or palliative care[8]
- patients have insufficient choice in people to whom they can turn for spiritual care, and may be unaware of choices available to them
- health and social care staff have insufficient awareness of how to access individuals who can provide spiritual care

- health and social care staff may be reluctant to call for chaplains' services or may not detect the need for spiritual support at key stages of the patient pathway
- some health and social care professionals feel awkward and vulnerable when broaching spiritual issues with patients and may also feel awkward about discussing, or even considering, their own spiritual needs as professional carers[9,10].

7.11 These deficiencies suggest that patients and carers may not have their spiritual needs appropriately assessed, and consequently will not have their spiritual needs met.

B. Objectives

7.12 The objectives are to ensure that:

- all patients and carers receive the support they desire to make sense of difficult life events through an exploration of existential issues, fostering hope and promoting well-being within an integrated care approach
- all health and social care professionals recognise the need to acknowledge issues of spiritual significance and are able to respond in a flexible, non-judgemental and non-imposing way when working with patients and their carers
- spiritual needs of staff are recognised, providing a source of strength and support and a means to discharge some of the effects of working in this area of care.

C. Recommendations

C.1 Overview
7.13 Patients with cancer and their carers should have access to different forms of spiritual support, according to their needs and wishes.

7.14 Patients with cancer and their carers should have opportunities for their spiritual needs to be assessed at various points in the patient pathway, ensuring that the spiritual elements of illness are taken into account.

7.15 Spiritual care for patients with cancer and their carers should be an integral part of the health and social care provided in all care environments and should be open to similar levels of scrutiny and supervision as other aspects of non-physical care.

7.16 Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual care providers who act as a resource for patients, carers and staff. They should also have up-to-date awareness of local community resources for spiritual care.

C.2 Service configuration and delivery: specific recommendations
7.17 Cancer Networks, providers and teams should ensure that patients and carers are offered information about the resources available for spiritual care within a particular organisation or community and also information on how to access spiritual help and support.

7.18 Teams should ensure that accurate and timely evaluation of spiritual issues is facilitated through a form of assessment based on a recognition that spiritual needs are likely to change with time and circumstances. Assessment of spiritual needs do not have to be structured, but should include core elements such as exploring how people make sense of what happens to them, what sources of strength they can and wish to draw upon, and whether these are helpful to them at this point in their life.

7.19 Informal carers may offer important components of spiritual care and, if the patient wishes, should be supported by providers and teams in doing so, especially if the care is within the framework of the patient's own beliefs or philosophy of life.

7.20 A proportion of patients and carers may require the support of authorised healthcare chaplains, appointed in accordance with NHS national criteria[11]. For those patients cared for at home, and in particular those who are close to death, primary care teams should develop links with authorised faith leaders who can be accessed for advice and support.

7.21 Commissioners should ensure that multidisciplinary teams have access to suitably qualified, authorised and appointed spiritual care providers who are capable of delivering spiritual care in a broad and flexible way and who can act as a resource for patients, carers and staff[4-6]. This does not necessarily mean representation within every team; rather, a spectrum of skill to an agreed level of competence should be accessible to support and evaluate spiritual care.

7.22 Each provider organisation should nominate a staff member to be responsible for liaison with local faith leaders. A healthcare chaplain/spiritual care giver would usually undertake this role.

7.23 Spiritual care should be seen as a responsibility of the whole team, while recognising that an individual may hold specific responsibility for ensuring its provision. Individual team members responsible for spiritual care provision should contribute to the regular review of care plans by the team, especially for those patients with an already identified belief/spiritual need. Patient consent to information being shared on a 'need to know' basis among team members, which includes spiritual care providers, so that care can be planned in collaboration with patients, is in the patient's best interests.

7.24 Providers (within in-patient or day care facilities) should ensure a dedicated and accessible 'quiet space' or room is made available, suitably furnished in a flexible way to allow for use by various faith groups or as a quiet space for those of no faith. The room should be equipped with religious equipment appropriate to the needs of faith groups likely to use the space – for example, a portable cross, table suitable for Christian use, communion vessels, worship books for different faith groups, prayer mats, washing facilities and a compass for identifying the direction of Mecca for use by people who are Muslims. Careful local consultation and assessment is advisable before deciding on the form of accommodation.

7.25 Spiritual care does not stop at death. Providers should ensure a suitable room (which may be off-site) is available for the deceased patient to remain while religious rituals are performed. This can be for 2-3 days in the case of a Jewish person dying on the eve of the Sabbath. The room and staff concerned with its management should be respectful of the dead person. Providers should have a process in place to observe the religious ritual of speedy burial of, for example, Muslim and Jewish people.

C.3 Workforce development: specific recommendations
7.26 Skilled, sensitive and appropriate spiritual care can be provided by a variety of people, including volunteers, family members, health and social care staff and faith groups. It is essential that professional health and social care staff have the necessary skills, knowledge and support to deliver sensitive care. Commissioners and Workforce Development Confederations in England and the Workforce Development Steering Group in Wales should ensure that staff working within supportive and palliative care services have access to:

- basic training in understanding the spiritual needs of patients and of ways of assessing spiritual need
- training in the specific religious needs and rites of patients from different faith groups; a developed sensitivity to the inter-relationship between culture, ethnicity and belief is necessary to avoid the attendant risks of labelling and stereotyping
- appropriate spiritual care for their own needs as they arise in the course of their work
- local faith leaders from the community to ensure better continuity of care when patients are discharged. Training opportunities should be available for local clergy as all are not necessarily skilled, or confident, in this aspect of pastoral care[12].

7.27 Workforce Development Confederations in England and the Workforce Development Steering Group in Wales should ensure that all core staff within specialist palliative care teams (see Topic 9, *Specialist Palliative Care Services)* are sufficiently competent to assess and address existential difficulties in relation to dying. Senior healthcare professional training programmes in supportive and palliative care should include study of the theory and practice of spiritual care.

C.4 Research and development: specific recommendations
7.28 Research is needed to promote understanding of how the spiritual needs and sources of support of different patient groups evolve over time and how spiritual concerns are best assessed and measured.

7.29 Research is needed to determine the best ways of providing spiritual support for different patient groups, in different settings, and at different stages of disease.

D. Evidence

7.30 There appears to be growing interest in the relationship between spiritual support and health, but relatively little research has been carried out in this area. Some has centred on the nature of provision of spiritual support for patients.

Hospitals and hospices appear to be changing the nature of their arrangements for spiritual support in line with changes in the religious beliefs of the wider population. There is an increasing use of multi-faith/quiet rooms as spiritual focal points, compared to traditional chapels, and expansion of the role of chaplains/spiritual care providers from one that is purely religious [B]. There is also interest in developing provision for spiritual support within the care home sector [B].

7.31 Patients have been found to have needs for spiritual support, some of which are rooted in formal religion and some from a broader interpretation of spirituality. The differentiation but inter-relatedness of religion and spirituality is becoming more widely accepted [B]. Many patients view spirituality as a mechanism for coping with their health [B]. The question of which professionals should provide such care to patients has also received some attention. Nurses are seen to be in a key position to respond to patients' needs for spiritual care, but often view it in terms of formal religion and therefore refer to clergy.

7.32 It has been argued that multidisciplinary teams for palliative care should include chaplains/spiritual care providers [B], and standards that relate to chaplaincy services within the context of palliative care have been published[5]. Measurement tools that have the capacity to inform the development of assessment approaches with regard to this domain of need in clinical practice have been developed and tested (see, for example, [13]) [B].

7.33 Research is beginning to address the relationship between spiritual belief and health outcomes for patients. A number of studies have found a positive relationship in terms of risk of disease, survival times and coping with bereavement, but there is also evidence in the opposite direction where belief strength is ill formed [B]. Some research including patients with cancer suggests that spirituality is an important contributor to both physical well-being and quality of life [B]. A UK cohort study concluded that people who profess stronger spiritual beliefs resolve their grief more rapidly and completely after the death of a close person than do people with no spiritual belief [14] [B]. Evidence on the impact of prayer on healthcare outcomes is inconclusive [A].

7.34 There are some examples of good practice with respect to defining competencies and standards in this area which could be drawn upon to help develop education and training initiatives for members of multidisciplinary teams. They are to be tested and implemented within Marie Curie Cancer Care during 2003[4].

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8. General Palliative Care Services, incorporating Care of Dying Patients

A. Introduction

8.1 The patient's usual health and social care professionals provide the mainstay of support to patients with advanced cancer, their families and carers. Support is offered in community and hospital settings and the personnel involved include:

- GPs and other members of primary care teams
- community nurses
- care home staff
- doctors and nurses in hospitals and hospices
- allied health professionals in the community and in hospitals
- social workers
- general and community dental practitioners
- self-help and support groups.

8.2 These personnel, bodies and organisations are involved in assessing the care and support needs of patients and families, meeting their needs within the limits of their knowledge and competence and seeking advice from, or referring to, specialist services when necessary.

8.3 General palliative care is a core aspect of care and at its best includes the provision of:

- information for patients and carers with 'signposting' to relevant services
- accurate holistic assessment of patient needs
- co-ordination of care teams, in and out of hours and across boundaries of care
- basic levels of symptom control
- psychological, social, spiritual and practical support
- open and sensitive communication with patients, carers and professional staff.

8.4 Training, supporting, and enabling patients' usual health and social care professionals is important in providing the most effective support for patients in all settings, including those where little or no specialist service is available. Palliative care may form only a small part of the normal workload of these professionals, and some may not have had access to education and training in palliative care. Generalists deliver the majority of care, and measures to empower and enable them to provide a quality service are to be encouraged.

8.5 Although many patients and carers report high levels of satisfaction with the care they receive in the community and in hospitals, inadequacies in care are also frequently reported. These deficiencies commonly relate to the issues identified in previous topic areas, and include:

- inadequate assessment of patients' needs
- poor co-ordination of care
- poor face-to-face communication
- lack of information
- inadequate psychological, social or spiritual support.

8.6 In the community and in hospitals, health and social care professionals responsible for the care of patients with advanced cancer may not be aware of the expertise available from specialist palliative care services.

8.7 Specific problems related to the delivery of care in the community in some parts of the country include:

- a lack of 24-hour, seven days a week district nursing services
- a lack of systems to organise and optimise general palliative care
- inadequate anticipatory care and discharge planning
- inadequate communication between daytime and out-of-hours medical services
- inadequate access to pharmacy services outside usual working hours
- inadequate access to equipment needed by patients at home
- lack of availability of and access to specialist services, and lack of clarity about their benefits.

Care of dying patients
8.8 Hospices have developed a 'model of excellence' for care of dying patients. The care given to patients who are dying in hospitals and care homes can be suboptimal. This may be due to staff failing to recognise or acknowledge impending death. It may also be due to lack of education and training in best practice in initial assessment and care, ongoing assessment and care, and care after death.

8.9 Improvements in the provision of community care, including the organisation of services, symptom control, and psychological, social and spiritual support, may lead to fewer crises, fewer admissions to hospitals, more rapid discharges, and more patients being enabled to die in the place of their choice.

B. Objectives

8.10 The objectives are to ensure that:

- all patients with advanced cancer receive high quality care at all times and in all settings (this includes optimal symptom control and the provision of psychological, social and spiritual care)
- people's preferences on location of care are followed, whenever possible.

Care of dying patients
- all patients have a dignified death and family and carers are adequately supported during the process.

C. Recommendations

C.1 Overview
8.11 All patients with advanced cancer should have their physical, psychological, social and spiritual needs, and their preferences for the nature and location of care, assessed on a regular basis.

8.12 Patients' usual health and social care professionals should know when to seek advice from, or refer to, specialist palliative care services.

8.13 Ongoing care of patients with advanced cancer provided by their usual professional carers in hospital and the community should be based on locally agreed protocols and guidelines delivered within the context of a managed system or pathway.

8.14 Staff providing general palliative care should be trained in the identification of needs of patients and carers and in the general principles and practice of palliative care.

Care of dying patients
8.15 When death is imminent, particular attention should be given to assessing and accommodating the needs and wishes of patients, families and carers. Staff should be trained in best practice on the care of dying patients and measures should be in place to ensure that integrated care is delivered.

C.2 Service configuration and delivery: specific recommendations
8.16 Each patient with advanced cancer should have his or her needs systematically assessed on a regular basis across the domains of physical, psychological, social and spiritual needs, using agreed assessment tools. As needs at this stage of the patient pathway can change rapidly, the need for re-assessment should be revisited at frequent intervals.

8.17 Assessments should be made by appropriately trained healthcare professionals who have received further education and training in palliative care (Figure 8.1). Where this is not available, the assessments should be done either in conjunction with members of the local specialist palliative care team or solely by the local specialist palliative care team.

Figure 8.1

Proposed pathway for management within general setting
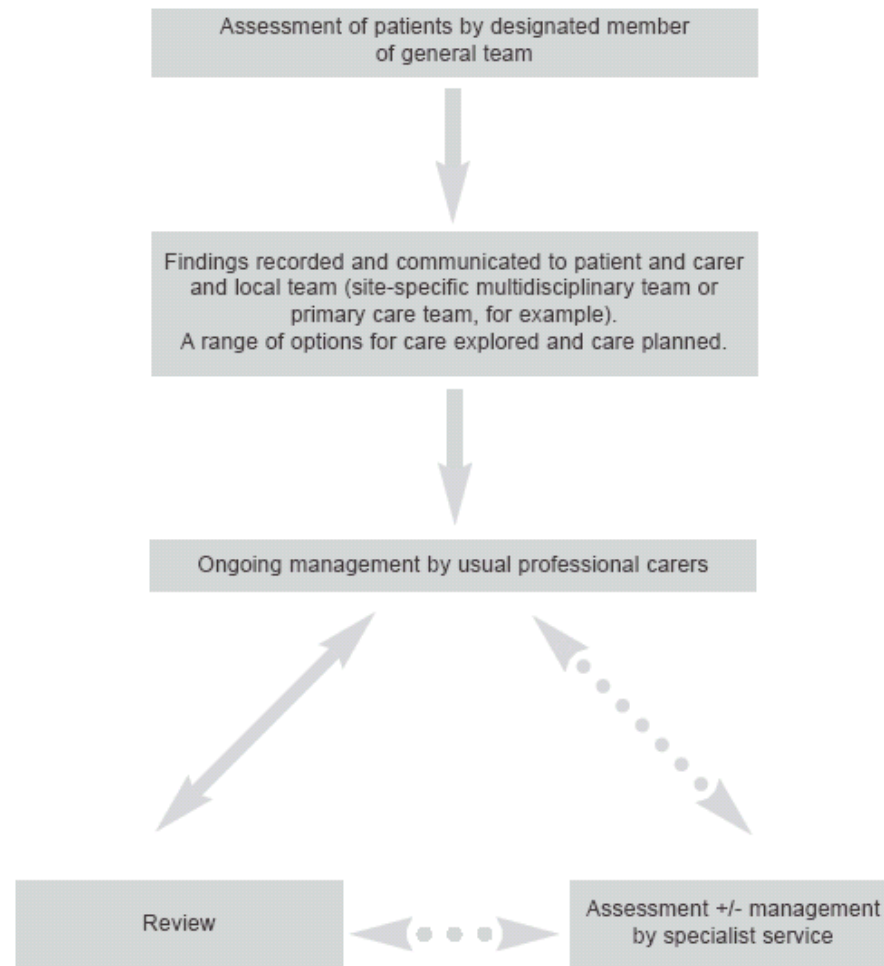
8.18 The findings of assessment and the identified main needs of patient and carers should be recorded in the patient's records and formally discussed within the team providing care. There should be a recognised means to enable communication within and between teams.

8.19 Discussion with the local specialist palliative care service (community, hospice or hospital based, as appropriate) should allow joint decisions to be made on whether further involvement by the specialist palliative care team is required at this point in the patient pathway.

8.20 Cancer Network-wide eligibility criteria for specialist palliative care should be developed to inform this decision-making process. Cancer Networks might consider implementing assessment tools designed to indicate when referral to specialist palliative care could be of benefit.

8.21 Cancer Network-wide protocols and guidelines should be developed and implemented in relation to symptom control and palliative interventions for common emergencies (such as spinal cord compression, superior vena cava obstruction and hypercalcaemia). These should be subject to regular audit.

Care of dying patients
8.22 Cancer Network-wide protocols and guidelines should be developed to include referral criteria to specialist palliative care services and management of complex symptoms in relation to care of dying patients and their carers. These should be subject to regular audit (see Topic 9, *Specialist Palliative Care Services*).

Community-specific issues
8.23 In partnership with relevant stakeholders, NHS Commissioners should identify the full range of palliative care service provision, both generalist and specialist, in their locality. In the commissioning of palliative care provision within care homes, Commissioners should ensure that the quality of care ^L reflects the level of care defined in the care home's Statement of Purpose.

8.24 Commissioners and providers should work together to develop policies for the provision of out-of-hours palliative care to patients with cancer. This should be underpinned by an assessment of local needs and deficiencies.

8.25 Commissioners should ensure that medical and nursing services are available 24-hours, seven days a week for patients with advanced cancer living at home.   District nursing services should have the capacity to provide intermittent visiting, day or night, which can be increased in frequency as required.

8.26 Where 24-hour, seven days a week district nursing services are not available, alternative means of providing patients with advanced cancer with access to qualified nurses around the clock should be agreed between commissioners and the Cancer Network. Account should be taken of the likely needs of patients at night, so that an appropriate balance of qualified nurses (who can undertake specialist interventions in a patient's home) and care assistants (who can stay for prolonged periods in the home) can be reached.

8.27 Teams should develop mechanisms to ensure the transfer of relevant clinical information about patients between those providing care 09.00-17.00, Monday-Friday,

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^L Commissioners will need to make reference to bodies responsible for setting national standards in this area to ensure guidance on quality is relevant and converges with national standards.

and those providing services and care out of hours using, for instance, handover forms (paper or electronic).

8.28 In line with other measures[M], teams should agree means of identifying patients with advanced cancer who have needs through, for example, establishing a register or database. An agreed framework or managed plan of care provided by the primary care team, such as the Gold Standards Framework[1,2], is also recommended. Box 8.1 outlines key components of best practice in community palliative care.

Box 8.1 Key components of best practice in community palliative care[1,2]
• Patients with needs for palliative care are identified according to agreed criteria and a management plan discussed within the multidisciplinary team
• These patients and their carers are regularly assessed using agreed assessment tools
• Anticipated needs are noted, planned for and addressed
• Patient and carer needs are communicated within the team and to specialist colleagues, as appropriate
• Preferred place of care and place of death are discussed and noted, and measures taken to comply, where possible
• Co-ordination of care is orchestrated by a named person in a practice team
• Relevant information is passed to the those providing care out-of-hours, and anticipated drugs left in the home
• A protocol for care in the dying phase is followed, such as the Liverpool Care Pathway for the Dying Patient[3]
• Carers are educated, enabled and supported, which includes the provision of specific information, financial advice and bereavement care
• Audit, reflective practice, development of practice protocols and targeted learning are encouraged as part of personal, practice and primary care organisation/NHS Trust development plans.

8.29 Commissioners should ensure that equipment needed to enable patients to continue living in the community is available within an agreed timescale, and should be removed promptly and sensitively when no longer required (see Topic 6, *Social Support Services)*.

Hospital-specific issues
8.30 If the patient is to be cared for in a location in which there are no health professionals with post-registration experience/training in palliative care, the hospital specialist palliative care team should be informed about the patient. Assessment of the patient's needs will determine the level of involvement required by the specialist palliative care team.

[M] As part of its work on minimum data sets, the National Health Service Information Authority (NHSIA) is developing practice-based registers for cancer: see www.nhsia.nhs.uk/phsmi/datasets. This applies to England only.

8.31 Lines of responsibility for out-of-hours medical care should be agreed and recorded in the patient's notes. Ways of accessing advice from cancer and/or specialist palliative care staff should also be documented in the patient's records.

8.32 The discharge of a patient from secondary care should ideally occur when all the necessary support services are in place. Providers may consider the benefits of identifying a designated discharge co-ordinator to liaise with relevant services.

8.33 The patient and carers should be aware of the person or service to contact if problems arise following discharge.

Care of dying patients
8.34 Provider organisations should ensure that managed systems to ensure best practice in care of dying patients are implemented by all multidisciplinary teams. This might, for example, be achieved through implementation of the Liverpool Care Pathway for the Dying Patient[3] and would include addressing issues outlined in Box 8.2.

Box 8.2 Best practice in the last hours and days of life[4]

- Current medications are assessed and non-essentials discontinued
- 'As required' subcutaneous medication is prescribed according to an agreed protocol to manage pain, agitation, nausea and vomiting and respiratory tract secretions
- Decisions are taken to discontinue inappropriate interventions, including blood tests, intravenous fluids and observation of vital signs
- The patient's, family's and carers' ability to communicate in English or Welsh is assessed
- The patient's, family's and carers'insights into the patient's condition are identified
- Religious and spiritual needs of the patient, family and carers are assessed
- Means of informing family and carers of the patient's impending death are identified
- The family and carers are given appropriate written information
- GP practice is made aware of the patient's condition
- A plan of care is explained and discussed with the patient, family and carers.

8.35 Providers should ensure the environment in which patients who are dying are cared for is conducive to the needs of patients and carers. Issues that merit attention include consideration of the means to achieve:

- privacy around the bed area
- washing, bathing and toilet facilities suitable for the needs of extremely frail people
- a quiet and restful environment, without intrusive background noise
- sufficient space to allow relatives and friends to sit comfortably with the patient
- facilities for relatives to stay overnight in a location close to the patient, to receive comfort when distressed and to have time away from the bedside

- facilities for children who are relatives to be with the dying patient.

8.36 The patient's wishes concerning location of care and place of death should be sought and respected.   Providers should ensure flexible systems to obtain rapid discharge are in place to enable the safe transfer of patients who wish to die at home.

8.37 Commissioners should ensure that continuous support can be provided for patients in their homes as end of life approaches, in compliance with the wishes of patients and carers. This may involve either qualified nurses and/or trained carers, according to the patient's needs.

8.38 Arrangements should be made to ensure 24-hours, seven days a week access to medications that may be required in the dying patient's home. Commissioners should work towards existing recommendations that relate to making medications available to patients at the time and in the place of consultation[5] (in this case, the patient's home). This could be effected through:

- pre-emptive planning
- leaving a supply of appropriate medications in the home
- making medications available to out-of-hours providers through the provision of 'palliative care bags'[6].

C.3 Workforce development: specific recommendations
8.39   Cancer Networks, working with Workforce Development Confederations and Primary Care Organisations in England, and the Workforce Development Steering Group and NHS Trusts in Wales, should identify priorities for training staff in palliative care (in England, this would require building on the Department of Health-funded district nurse training programme). The aim should be to ensure that all patients with advanced cancer can be cared for by teams with at least one member who has undergone post-registration education and training.

8.40 Education and training should be designed to enable health and social care professionals to conduct assessments of needs, deliver general palliative care services, incorporating care of dying patients, and recognise when to seek advice or refer to specialist services. Staff require designated time to fulfil their education and training requirements.

8.41 Education and training programmes should include staff working in all care settings, including the community, care homes, community hospitals and acute hospitals.

Care of dying patients
8.42   Provider organisations should work with Workforce Development Confederations (the Workforce Development Steering Group in Wales) to ensure that all relevant staff are educated and trained in best practice regarding the care of dying patients (such as. implementation of the Liverpool Integrated Care Pathway for the Dying Patient[3]).

C.4 Research and development: specific recommendations

8.43 Evaluative research is needed to determine the most cost-effective ways to train, sustain the skills of, and provide guidance and protocols for general practitioners, district nurses and hospital and care home staff in palliative care.

8.44 Research is needed to determine cost-effective ways of providing general palliative care to patients and families out of hours

8.45 Evaluative research is needed to determine the best models of multidisciplinary working between generalist and specialist palliative care to ensure high quality care for all patients who need it; this includes access to services and support for different patient groups, particularly older people with cancer.

D. Evidence

D.1 Assessment

8.46 Survey evidence suggests that symptoms and concerns in patients with advanced cancer, whether in a hospital or the community, are often poorly assessed and controlled in the general setting[7,8]. Better methods of assessment and the use of guidelines and protocols may improve this situation [B].

8.47 Performing structured assessments and seeking the views of patients receiving care have been shown to increase patient satisfaction with communication and decision making [A]. Combining detailed assessment with individualised interventions has been demonstrated to improve both physical and psychological status [A]. Assessment tools can also be of value in improving diagnostic skills (such as distinguishing neuropathic pain)[9], communicating to relatives and within teams, monitoring patient progress, and stimulating referral to specialist palliative care services[10] [B].

Care of dying patients
8.48 To care for dying patients, it is essential to diagnose dying[11]. Recognising the key signs and symptoms of dying is acknowledged as an important clinical skill in diagnosing dying, but this can be a complex process. Clinicians are sometimes reluctant to make the diagnosis if any hope of improvement exists, and are even more reluctant if no definitive primary diagnosis has been made[4]. Reluctance on the part of healthcare professionals may stem from that fact that many may not have received education and training in how to care for dying patients, and therefore feel unprepared and helpless. Once dying has been diagnosed, the team can refocus care appropriately for patients and their relatives.

D.2 Advice from, and referral to, specialist palliative care
8.49 The involvement of specialist staff in the support and education of healthcare professionals, particularly nurses, has been shown to facilitate communication between patients and their usual professional carers and to enhance symptom management [A]. Topic 9, *Specialist Palliative Care Services,* gives further evidence on outcomes associated with involvement of specialist palliative care teams.

8.50 Generally, audit and observational data point to the fact that those managing patients with advanced cancer may not always follow guidelines and protocols (for example, in relation to pain control) [B]. There is, however, very strong general evidence that the use of clinical guidelines and protocols can improve the processes and outcomes of care[12] [A]. Specifically, the introduction of clinician-developed guidelines on pain has been shown to improve pain management when introduced as part of a broader education programme [A].

8.51 The use of 'eligibility criteria' for referral to specialist palliative care services is felt to help clarify interlinking and co-working between generalist and specialist teams[13] [C].

Care of dying patients
8.52 Integrated care pathways, such as the Liverpool Care Pathway for the Dying Patient[3], are multidisciplinary tools designed to develop, co-ordinate, monitor and improve care. The Liverpool Care Pathway for the Dying Patient is a framework of the hospice model of 'excellence for care of the dying'. It enables the hospice model of best practice to be transferred into other healthcare settings, including hospitals, the community and care homes. Implementation and support of the pathway is facilitated by specialist palliative care services [C].

D.3 Access to services
8.53 Studies confirm that many people would prefer to die at home, yet only about 25% of people with cancer do so, with approximately 50% dying in hospital and the remainder dying in a hospice or care home[14]. It is also recognised that patients change their minds about preferences over location of care and place of death.

8.54 It is postulated that a variety of factors leads to this situation, but a prime issue is believed to be the dramatic reduction in patient and carer support out of hours. This includes lack of out-of-hours nursing care within the home, medications and equipment being unavailable in the location and at the time required, and difficulties that result from GP services provided by co-operatives/deputising services[6, 15, 16].

8.55 Provision of 24-hour, seven days a week nursing care at home, compared to usual care, appears to decrease the need for out-of-hours GP visits. It is not possible to conclude that intensified nursing care increases the likelihood of dying at home [A], but studies demonstrate support for the contention that standard home care alone may be insufficient to deliver the additional interventions required by patients dying at home [A].

D.4 Education and training
8.56 Survey data demonstrate that although many healthcare professionals are extremely competent and inspire high satisfaction levels among carers[17], some have inadequate knowledge and feel ill-prepared to care for patients in the advanced phase of their illness[18, 19] [B].

8.57 The benefits of providing education and training to enhance the knowledge, skills and competence of healthcare professionals are universally acknowledged. In the domain of palliative care, improvements are likely to be seen in a number of areas, including:

- increased confidence and competence when dealing with physical and psychological concerns
- increased patient and carer satisfaction
- timely and appropriate referral to specialist services[20].

8.58 The Macmillan GP Facilitator Programme in cancer and palliative care is a peer educational programme that funds GPs with experience and interest in palliative care to work with practices in their own localities to support and enhance primary palliative care. There are around 80 GP facilitators in the UK and their role includes making practice visits, undertaking local needs assessment, liaison with local specialist services and participation in strategy development.   An evaluation in England found that a strength of the programme was the enhancement of GPs' positive attitudes towards specialist services, improving communication between primary and specialist palliative care[21] [B].

8.59 Programmes of education and training, particularly in pain management, have been shown to lead to improvements in knowledge, attitudes and clinical behaviours of doctors and nurses [A].

8.60 The Gold Standards Framework Programme[1,2] [C] aims to improve palliative care provided by the whole primary care team and is designed to develop the practice-based system or organisation of care of dying patients. The main processes are to first, identify, then assess, then plan care for these patients, with better communication featuring throughout. The famework focuses on optimising continuity of care, teamwork, advanced planning (including out-of-hours), symptom control and patient, carer and staff support. A planned, step-wise approach to change is utilised, with centrally supported facilitated groups, a toolkit and practice-based external education sessions.

8.61 The Gold Standards Framework Programme is currently being implemented across the UK, and early evaluation data are becoming available[22]. The Cancer Services Collaborative, University of Huddersfield and other independent researchers have been commissioned to evaluate the programme.

8.62 The impact of education and training of community staff on achieving preferred place of care is currently being evaluated by the Lancashire and South Cumbria Cancer Network[23N] through completion of a Preferred Place of Care Plan (PPCP). This will provide data on what happens to patients who express a wish to die at home at the outset and then die in hospital or a hospice. The PPCP provides a vehicle to initiate discussions about death and dying with patients and carers and a mechanism to identify and meet their expressed preferences.

[N] For further information on this project, contact Chris Pemberton, Project Facilitator:
Chris.Pemberton@clha.nhs.uk

Care of dying patients

8.63 The Liverpool Care Pathway for the Dying Patient[3] has the capacity to promote the educational and empowerment roles of specialist palliative care services. It provides demonstrable outcomes of care[24] to support clinical governance, and should reduce complaints associated with this area of care. The initiative gained NHS Beacon status in 2000[25] and has recently been incorporated in phase three of the Cancer Services Collaborative to facilitate its dissemination and evaluation across the NHS.

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9. Specialist Palliative Care Services

A. Introduction

9.1 A significant proportion of people with advanced cancer suffer from a range of complex problems[P] – physical, psychological, social and spiritual – which cannot always be dealt with effectively by generalist services in hospitals or the community. Their families and informal carers may also need expert support during their lives and in bereavement (see Topic 12, *Services for Families and Carers*).

9.2 In response to these needs, hospices and specialist palliative care services have been established across the country over the past three decades. These services are provided by the voluntary and statutory sectors and cover the spectrum of community, hospice, day therapy and hospital settings. The voluntary sector plays a significant role in providing specialist palliative care in people's homes, in inpatient, outpatient and day care specialist units, and in providing support to generalist teams in hospitals and care homes.

9.3 Access to and availability of specialist palliative care services is variable and inequitable throughout the country. A survey undertaken by the National Council for Hospice and Specialist Palliative Care Services on behalf of the Department of Health[1] revealed major variations between Regions in the provision of specialist (hospice) palliative care beds and palliative care nurse specialists, and the availability of hospital palliative care teams.

9.4 Around 50% of patients with cancer die in acute hospitals[2]. However, the appraisal of hospital services in England against the National Cancer Standards, which was undertaken in 2001, showed that only 55% had a full multidisciplinary palliative care team including consultants and nurse specialists. Less than half of the 176 hospital specialist palliative care teams appraised were able to provide 24-hour access to advice[3].

9.5 Concerns have been expressed that the needs of people with cancer in care homes are not being adequately met. While this situation may be related to factors such as insufficient numbers of staff to meet the needs of dying patients in this care location and a lack of training for staff, there is also the issue that community specialist palliative care services vary considerably in staffing levels and consequently in their ability to provide advice and/or direct patient support to care home staff at weekends and outside the hours of 09.00-17.00, Monday-Friday.

9.6 Concerns have also been expressed that patients' needs are not always adequately assessed and that the potential benefits of referral to specialist palliative care services are sometimes not recognised soon enough. This can cause unnecessary suffering to patients.

[P] Complex problems are defined as those that affect multiple domains of need and are severe and intractable, involving a combination of difficulties in controlling physical and/or psychological symptoms and the presence of family distress and social and/or spiritual problems. They also exceed the capacity and competence of providers to meet the needs and expectations of the patient and carers.

9.7 In addition to their role in the delivery of care, specialist palliative care services have an important function in providing education and training on the principles and practice of palliative care to the wide range of generalists who offer care to people with advanced, progressive, life-threatening disease and their carers (see Topic 8, *General Palliative Care Services, incorporating Care of Dying Patients*). They also have a role in research and audit.

B. Objectives

9.8 The objectives are to ensure that:

- those patients who may benefit from specialist palliative care services are identified and referred without delay
- all patients who need specialist palliative care services can access services as and when they need them, from hospitals, hospices and from the community.

C. Recommendations

C.1 Overview

9.9 All patients with advanced cancer should have their physical, psychological, social and spiritual needs assessed by a competent healthcare professional (see Topic 8, *General Palliative Care Services, incorporating Care of Dying Patients*).

9.10 Specialist palliative care teams should work closely with general providers to ensure that patients access specialist services at the right point in the patient pathway.

9.11 All specialist palliative care service providers should have agreed mechanisms for co-ordinating care with their referring services and have agreed eligibility criteria for referral.

9.12 A range of specialist palliative care services should be available across the Cancer Network with levels of service provision sufficient to meet the needs of the local population (taking account of cancer death rates, deprivation levels and other key factors).

9.13 These services are likely to include, as a minimum:

- multidisciplinary specialist palliative care teams providing assessment, advice and care for patients in all locations
- specialist inpatient facilities (such as hospice beds) for patients with complex problems which cannot be adequately managed in other settings
- bereavement support services (see Topic 12, *Services for Families and Carers, incorporating Bereavement Care)*.

9.14 Each specialist palliative care service should have a range of staff to provide the expertise needed by patients.

9.15 Across a Cancer Network, there should be sufficient staff to enable the delivery of care 24 hours, seven days a week, and to contribute as needed to the education and training of general staff.

9.16 Within a Cancer Network, all specialist palliative care service providers should develop and implement guidelines against which practice in relation to the assessment, treatment and care of patients can be audited and monitored.

C.2 Service configuration and delivery: specific recommendations

Organisation and planning of services
9.17 Commissioners, working through Cancer Networks, should ensure they provide an appropriate range and volume of specialist palliative care services to meet the needs of the local population. There is a lack of evidence to support specified levels of service provision, such as the number of specialist inpatient beds required per million population. Commissioners should plan services flexibly around the needs of patients, recognising there will be more than one way of achieving this. The levels and nature of provision will depend on a number of factors, including:

- local demography (such as age, levels of social deprivation and ethnicity)
- number of cancer deaths
- local service-user views
- nature, extent and distribution of existing services.

Volumes of service are interdependent; for example, an increase in the resources of a community specialist palliative care team may lessen the need for inpatient care. In addition to comparing local services with national averages and services elsewhere, Cancer Networks should carry out needs assessments, including audits of patients who meet eligibility criteria for referral to specialist palliative care services but are unable to access services, as these may provide the strongest case for service expansion.

9.18 The range of services provided by specialist multidisciplinary palliative care teams should include:

- assessment, advice and care for patients being cared for in any setting (including acute hospitals, community hospitals, care homes and at home)
- specialist inpatient facilities (hospices or hospitals) for patients with complex problems who would benefit from the continuous support of a multi-professional specialist palliative care team.

9.19 Where specialist day facilities are already established, their objectives and the types of interventions offered should be agreed between commissioners and providers. Commissioners may wish to extend this form of provision, but only after careful consideration of the interface of any specialist palliative day care facility with other supportive and palliative care services.

9.20 Services should have the capacity to provide intensive co-ordinated home support to patients with complex needs who wish to stay at home and avoid admission to institutionalised care. Support may be provided in response to a crisis in the care of the patient at home, for the last few days of terminal care, or for longer periods. A range of co-ordinated inputs will be required but will generally involve:

- the specialist palliative care team
- practical nursing care and support for extensive periods throughout the day and night
- the patient's GP
- support from other services such as those provided by allied health professionals and social services departments.

9.21 To achieve the capacity set out in paragraph 9.20, commissioners might need to review the balance between inpatient bed provision and services provided in the home. Some 'hospice at home' services attempt to provide this type of support and may combine the roles of a specialist palliative care team with practical nursing. The Marie Curie Nursing Service, for example, provides practical nursing care and support for extended periods for patients with advanced cancer. 'Hospice at home' services vary in terms of services provided and employ different models of care in different parts of the country.

9.22 Mechanisms should be developed and implemented to ensure that all patients who may benefit from specialist palliative care services have access to them at each stage in the patient pathway. To achieve this, the following measures should be taken:

- Cancer Networks should be able to list the locations and care capacity of the different types of inpatient accommodation in their area – hospitals, hospices, community hospitals and care homes which provide care for people with advanced cancer
- all patients with advanced cancer should have their needs for palliative care assessed by a competent healthcare professional (see Topic 8, *General Palliative Care Services, incorporating Care of Dying Patients*); the findings of this assessment should be shared with the specialist palliative care team, if appropriate
- service directories related to supportive and palliative care should include information on specialist palliative care services and should be made available to all health and social care professionals and to patients and carers (see Topic 1, *Co-ordination of Care*)
- Cancer Network-wide referral guidelines and eligibility criteria should be developed and disseminated
- specialist palliative care teams in hospitals, hospices and the community should work in close partnership with teams who refer patients to them; collaborative working might include participation in joint clinics (for example, with oncologists), multidisciplinary meetings and joint ward rounds
- teams should ensure that points of contact are clearly defined and widely known.

9.23 All specialist palliative care service providers within a network should develop common approaches to assessment, treatment and care of patients. This should lead to

the publication and dissemination of guidelines, protocols and care pathways as appropriate, and will facilitate the delivery of high quality care and comparative audit.

Specialist multidisciplinary palliative care teams (in any setting)

9.24 Each multidisciplinary team should be able to provide specialist advice, support and care for patients and carers. The service should be provided in conjunction with the GP and primary care team and specialties within a hospital, as relevant. The level of intervention will vary according to assessed needs of the patient and carer, and will range from a purely advisory role to taking a lead in providing care. The team should also be in a position to provide advice and support to, and education and training for, professional colleagues.

9.25 To provide this level of service, a specialist palliative care team requires, <u>as a minimum</u>, the following core members:

- palliative medicine consultants
- palliative care nurse specialists
- team secretary/administrator.

It is undesirable for a specialist palliative care team to be staffed by a single-handed medical consultant. Cross-cover arrangements may need to be developed where consultant cover is shared with neighbouring specialist teams or units.

9.26 Each specialist palliative care team should have arrangements in place to access a range of specialist expertise to enable them to deal with complex problems. This might be provided by relevant staff acting as full members of the team, and includes:

- psychological support services (see Topic 5, *Psychological Support Services*)
- social support services (see Topic 6, *Social Support Services)*
- rehabilitation support services (see Topic 10, *Rehabilitation Services)*
- spiritual support services (often provided by a chaplain) (see Topic 7, *Spiritual Support Services)*
- input from site-specific cancer multidisciplinary teams
- services for families and carers (see Topic 12, *Services for Families and Carers, incorporating Bereavement Care)*
- anaesthetists with expertise in nerve blocking and neuromodulation techniques
- pharmacists with expertise in cancer and palliative care.

9.27 In many settings, specialists who are part of the 'extended' team are regular attendees at team meetings. This may be highly desirable and beneficial, and the team definitions set out above are not intended to diminish the impact of their involvement in any way.

9.28   Each multidisciplinary team should work to agreed network guidelines/protocols. The care of individual patients should be reviewed at multidisciplinary team meetings held at least weekly. Records of attendance at meetings and of patients discussed should

be maintained by the team secretary/administrator. The outcome of decisions on care should be recorded in the patient's notes[Q].

9.29 The team should be staffed to a level sufficient to undertake direct assessment of people with cancer (at home or in hospital) 09.00-17.00, seven-days-a week. In addition, there should be access to telephone advice at all times (24 hours, seven days a week). This is considered a minimum level of service. It is desirable that provision be made for bed-side consultations in exceptional cases outside the hours of 09.00-17.00, Monday-Friday.

9.30   The team should have access to office space to enable the safe storage and efficient retrieval of records and information materials and effective communication within and between teams.

9.31 Community specialist palliative care teams should develop effective links with community hospitals and care homes and should ensure that staff working in these areas have up-to-date information on how to contact and access specialist palliative care services.

Inpatient specialist palliative care services
9.32 Commissioners should ensure that specialist palliative care beds (in hospices or hospitals) are available in each Cancer Network and are sufficient in number to meet the needs of the population served.

9.33 Inpatient specialist palliative care facilities should be served by a specialist palliative care team (as described at 9.25) enhanced with nursing staff who have completed at least an introductory programme in the principles and practice of palliative care. Palliative medicine consultants should be supported by experienced medical staff so that medical cover can be provided 24 hours, seven days a week.

9.34 Around this core, the extended team will consist of a range of health and social care professionals to provide services, listed at 9.26. It is recognised that this full range of expertise may not be available within each inpatient facility. Where this is the case, it will be necessary to establish formal arrangements between providers of neighbouring services to ensure access. Staff in these cases will be likely to be members of several services simultaneously.

9.35 Cancer Networks should establish guidelines which set out eligibility criteria for patients who warrant admission to specialist palliative care inpatient facilities.

9.36 Inpatient specialist palliative care facilities should adhere to specifications set out in the Care Standards Act (2000)[4]. While the Act does not specifically relate to the NHS,

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[Q] Help the Hospices is leading a programme of work – Hospice Connect – that aims to link all independent hospices in England to the NHSnet, so they may access and contribute to the electronic health record of the NHS Integrated Record Service.

statutory providers should strive to ensure that their facilities match the standards described within the Act.

Specialist palliative care day therapy facilities

9.37 Specialist palliative care day therapy facilities offer opportunities for assessment and review to be undertaken and enable the provision of a range of physical, psychological and social treatment and care interventions within the context of interaction, mutual support and friendship. A range of different types of services is already in existence, including provision of:

- medical care, such as blood transfusions and medication adjustment
- nursing care, such as bathing and dressing changes
- emotional and spiritual support
- social support
- services for families and carers.

9.38 Many of these services can be provided on an individual basis in patients' homes, care homes, hospitals and hospices. Specialist palliative care day therapy does, however, offer the opportunity to bring all these services together in the same setting. It also brings patients together, providing social support and access to facilities and equipment, and is a means of providing respite to carers. While initial research reports suggest that patients appreciate the social contact that day therapy provides, there is as yet insufficient evidence to support a recommendation on the adoption of any particular model (or models) of service delivery. For example, such interventions might be delivered during the course of day attendance at a dedicated facility or by appointment at a more formally arranged clinic (which might be located in a hospital, hospice or dedicated day therapy facility).

9.39 Commissioners, working through Cancer Networks and in partnership with existing providers of specialist palliative day care, should agree the objectives of local service provision and the types of interventions to be offered. This service might be delivered alongside (and have significant interfaces with) other supportive care services such as complementary therapy and rehabilitation, and should take account of other community-based services. The skills, expertise, activities and facilities necessary to support service delivery will depend upon the agreed function of individual day therapy facilities.

9.40 Providers of specialist palliative day care should have mechanisms in place to ensure effective communication and co-ordination between different service elements (both specialist and general) involved in the care of individual patients.

9.41 As further evidence becomes available on access to day therapy, its acceptability and its contribution to quality of life, psychological and social well-being, service objectives should be reviewed.

C.3 Workforce development: specific recommendations

9.42 Cancer Networks should assess their needs for each of the professional groups contributing to specialist palliative care teams (as core or extended members). Workforce development should be planned in collaboration with Workforce Development Confederations in England and the Workforce Development Steering Group in Wales.

9.43 The role of specialist palliative care teams (based in hospices, hospitals and the community) in delivering education and training to general staff should not be underestimated. A network-wide education and training plan should be developed, identifying priority staff groups. Specialist palliative care services should be sufficiently resourced to enable them to contribute to network-wide education and training programmes.

C.4 Research and development: specific recommendations

9.44 Research is needed to compare different models and components of palliative care services such as skill mix, method of working, mix of services (for example day care, home care, education and direct care) and their relative merits in different situations and for different patient groups.

9.45 Research is needed to determine cost-effective ways of providing specialist palliative care to patients and families outwith the hours of 09.00-17.00, Monday-Friday.

D. Evidence

D.1 Multidisciplinary teams

9.46 Studies and systematic reviews have demonstrated quantitative and qualitative benefit from adopting a multidisciplinary approach with specialist input [A]. This leads to a higher quality service than conventional care being offered alone.

9.47 Reviews also provide support for specialist palliative care teams working in different locations, such as homes, hospitals and in-patient units or hospices, as a means to improve outcomes for patients with cancer. Teams have a positive effect on patient outcomes, independent of team (or service) make-up or study design. Similar or improved outcomes for patient satisfaction, pain and symptom control and family anxiety when compared with conventional care for hospices and home care have been demonstrated.

9.48 There are neither systematic reviews nor randomised controlled trials to provide evidence of specialist palliative day care services' effectiveness. A number of observational studies, however, offer information on their structure, process and outcomes for patients [B]. Surveys reveal a wide variety of models of care and patients tend to report high levels of satisfaction on the grounds that a visit provides social contact, some new activities and a chance to get out of the home; there is also some evidence of symptom control [B]. Studies have been hampered, however, by difficulties in evaluating an ongoing service and by the vulnerability of the patient population. The

best model of care and most appropriate skill mix have not yet been determined. Issues of access also need to be addressed.

9.49 There is great variation in the 'type' of intervention reported, and specific activities of teams are often not clearly defined. There is no strong evidence to support a particular team composition in each of the various settings, and no research evidence on the level of specialisation required for team members. Better outcomes tend to be observed, however, where the teams are categorised as 'specialist' and consist of multidisciplinary trained staff, compared to those which have a nurse only and/or have had limited training. There is no evidence on the number of team members from each profession required to enable provision of an effective and efficient service.

D.2 Organisation of care

9.50 Patients with cancer who have complex needs can receive high quality care in a variety of settings, providing there is adequate input from specialist palliative care services.

9.51 The need for effective communication, co-ordination and continuity of care becomes more prominent with the involvement of increasing numbers and categories of practitioners.

9.52 Given the complex nature of service provision, it is essential that mechanisms for co-ordination and communication are in place to ensure appropriate and timely access to specialist palliative care services. The multidisciplinary palliative care team approach is one means by which continuity of care can be achieved. Few studies have specifically examined continuity of care *per se*, but some have looked at aspects of care that are thought to improve as a result of achieving continuity.

9.53 The importance of effective communication and co-ordination between in-patient and home care teams has been demonstrated in terms of reducing number of days spent in hospital and the number of home visits; nurse co-ordinators appear to be particularly advantageous for this function [A].

9.54 The availability of a 24-hour telephone intervention (when combined with specialist nurse co-ordinator, home care team linked with hospital, home care dossier and care protocols) has been shown to reduce re-hospitalisation, enable more patients to die at home and improve quality of life [A]. Systematic reviews also suggest that specialist palliative care teams facilitate access to other services and co-ordinate care.

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10. Rehabilitation Services

A. Introduction

10.1 Cancer and its treatment can have a major impact on patients' activities of daily living and on their ability to lead a normal life. Activities that healthy people take for granted, such as mobilising, speaking, engaging in sexual activity, eating, drinking and swallowing, can be severely impaired. Treatment of cancer may involve amputation of a limb or removal of a breast or the creation of a stoma (an opening onto the body surface). The capacity of patients to care for themselves, to undertake activities of daily living, to work and to pursue their previous interests, may all be affected.

10.2 Cancer rehabilitation attempts to maximise function, promote independence and help people adapt to their condition[1]. It offers a major route to improving quality of life for people with cancer no matter how long or short the timescale, and aims to maximise independence and dignity and reduce the extent to which cancer interferes with an individual's physical, psychosocial and economic functioning.

10.3 This topic area concentrates on patients' needs for a range of interventions that may be considered to have a physical focus, but which can also have major psychological, social and spiritual benefits for patients. Services are provided by a range of allied health professionals (AHPs) and other professionals, including:

- appliance officers
- dieticians
- lymphoedema therapists
- occupational therapists
- oral health specialists such as dental hygienists
- physiotherapists
- psychosexual counsellors
- speech and language therapists
- stoma therapists.

10.4 There is an increasing emphasis being placed on the importance of rehabilitation in cancer and palliative care services and a growing recognition that it should be integral to the process of caring for people with cancer. Rehabilitation has a vital part to play in improving the lives of people with cancer over the weeks, months or years ahead.

10.5 The need for particular aspects of rehabilitation will vary throughout the patient pathway. Some groups of patients have traditionally had their rehabilitation needs more readily recognised than others - patients with cancer of the head and neck and those with bone tumours, for instance. For other groups, such as people whose disease is progressively deteriorating and those who are in clinical remission of cancer following arduous treatment, rehabilitative approaches are just beginning to evolve.

10.6 While the need for rehabilitation will differ among patient groups, all patients are likely to need rehabilitation at some stage in the patient pathway. Patients may have problems with mobility, function and activities of daily living as a result of cancer and its treatment. These can contribute to feelings of loss of control, compromising well-being and impacting on feelings of self-worth. Problems can persist long after treatment has concluded, so access to rehabilitative services for patients in long-term remission or those whose cancer has been cured needs to be considered alongside the needs of patients in active treatment or those requiring support at the end of life.

10.7 Expressing sexuality remains important to many people with cancer, regardless of age, and can be fundamentally compromised by the condition and its treatment. Cancer impacts on intimate relationships, can cause specific sexual dysfunction, and affects how people perceive their sexual identity through, for example, a changed body image. Sexuality is an issue that many people find difficult to address. This can result in failures to offer information and support in this area.

10.8 Rehabilitation is not just the responsibility of professionals with specialist rehabilitative expertise. All health and social care professionals can play a role as patients may benefit from approaches that promote well-being whatever their stage of illness, and whether care is being provided at home, hospital, care homes or hospices.

10.9 Rehabilitation has often been seen as an optional extra. AHPs in the rehabilitation disciplines in particular make a major contribution to services, a contribution that has often gone unnoticed. There are currently few examples of integrated multidisciplinary teams that include professionals with particular rehabilitation expertise in the areas of cancer and palliative care, but there are exceptional examples, with some providers developing rehabilitation units or rehabilitation services that include (among others) nurses, doctors, physiotherapists, occupational therapists, dieticians, speech and language therapists, lymphoedema therapists and oral health specialists.

10.10 There are currently no clearly defined career pathways linked to post-registration education and training programmes for AHPs wishing to develop their clinical expertise in cancer care. The establishment of such programmes would enhance the knowledge and skills of practitioners at all levels and would encourage movement into specialist posts at a higher level.

10.11 No formal evaluation of rehabilitation services for cancer patients has been undertaken nationally. There is nevertheless widespread consensus among practitioners and patients that current rehabilitation services are inadequate at several levels:

- front-line practitioners frequently do not recognise patients' needs for rehabilitation and may be unaware of the benefits that could be derived from assessment and intervention by a skilled AHP
- availability of AHPs may be limited
- AHPs may be inadequately trained in dealing with the problems faced by people with cancer in specific situations

- delays in accessing equipment and facilities may occur with failure to prioritise the services required, particularly for patients at the end of life.

B. Objectives

10.12 The objectives are to ensure that:

- all patients have their needs for rehabilitative services assessed on a continuous basis throughout the patient pathway, with particular attention being given to points that are recognised as being especially challenging to patients and carers (such as at the time of diagnosis and early treatment planning, the end of treatment, recurrence, preparation for discharge after in-patient admission, and towards the end of life)
- patients receive an active and planned approach to rehabilitation that involves assessment, goal setting, care planning and evaluation and, for patients who might benefit, timely referral to specialists in rehabilitation
- all patients who need rehabilitation services access them when and where they need them, and services are provided without undue delay
- an education and training programme is available to all staff involved in the recognition and provision of rehabilitation services for patients with cancer.

C. Recommendations

C.1 Overview
10.13 The rehabilitative needs of patients should be assessed at key points in the patient pathway using an assessment tool that has been agreed across the Cancer Network

10.14 Rehabilitation services should be organised to ensure a range of expertise is available within a Cancer Network and close working relationships with site-specific multidisciplinary teams, specialist palliative care and primary care teams are enabled.

10.15 Access to AHPs should be clearly defined and delineated at each stage of the patient pathway through referral and treatment criteria, including self-referral routes of access.

10.16 Education and training programmes should be provided to enable defined levels of input to be achieved.

10.17 All specialist rehabilitation service providers within a Cancer Network should develop and implement evidence-based guidelines against which practice can be audited.

C.2 Service configuration and delivery: specific recommendations[R]

10.18 Commissioners, working through Cancer Networks, should ensure they can provide the range and volume of rehabilitation services appropriate to meet the needs of the local population. This will include providing services from the following:

- appliance officers
- dieticians
- lymphoedema therapists
- occupational therapists
- oral health specialists such as dental hygienists
- physiotherapists
- psychosexual counsellors
- speech and language therapists
- stoma therapists.

10.19 Commissioners, working through Cancer Networks, should ensure that patients with rehabilitation needs are identified and can access an appropriate level of rehabilitative support/input. This might be achieved through the use of a Cancer Network-wide assessment tool to ensure that functional needs that might benefit from rehabilitative interventions are recognised. The assessment tool will include assessment of the following, and would be used in all care settings, including the community:

- nutritional status
- mobility
- self-care, including dressing and personal hygiene
- oral health
- coping at home
- work and leisure activities.

10.20 Each Cancer Network should identify a Lead Advanced Practitioner AHP to work with the network management team. Cancer Networks will also need to identify a lead for each of the main therapy groups to work with the Lead Advanced Practitioner AHP. These individuals will lead a programme of work that should include:

- developing and implementing a Cancer Network-wide strategy to ensure that patients' rehabilitative needs are recognised and met through the use of a network-wide assessment tool
- establishing referral and treatment criteria to ensure that needs are met at the appropriate level of expertise. These should include strategies that generalist

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[R] The first national allied health professional cancer strategy will be published in 2003, covering recruitment, retention, education, training and professional development. Those involved in providing specialist advice to the guidance development team on this topic (see Appendix 2.5) have also been involved in the development of the strategy. Implementation of the strategy will be critical to the implementation of these recommendations.

healthcare professionals can initiate and the provision of contact details for identified specialists to whom the patient can be referred (or can access through self-referral processes in specific circumstances)

- identifying target times for access to services, equipment and facilities in all care settings
- overseeing the provision of specialist input across the Cancer Network
- agreeing an education and training programme to meet the levels of rehabilitative interventions required, and contributing to this programme
- auditing aspects of network rehabilitative services including, for example, quality, access and timeliness.

10.21 Commissioners should ensure that a comprehensive rehabilitation service is available in all care settings 09.00-17.00, Monday to Friday, and that once the need for referral to a specialist rehabilitative service is identified and made, it is provided within the target times specified.

10.22 It is recommended that within each care setting, a model of assessment of needs for rehabilitation and input be developed and implemented (a recommended model is shown in Figure 10.1). This would include the use of a Cancer Network-wide assessment tool and criteria for referral and treatment, and would be integrated with other assessment processes. The patient should be assessed at key points in the patient pathway such as at the end of treatment and towards the end of life, and when circumstances change.

Figure 10.1

Recommended model of rehabilitative assessment and support

Level	Patient Need (examples)	Group providing input	Assessments	Interventions
1	• Simple energy conservation techniques • Simple or first-line dietary advice • Advice to patients regarding skin care and risks of developing lymphoedema	• Patients and carers' assessment • General nursing staff • Therapeutic radiographers • Assistant practitioners/ Support workers	Recognition of needs for help and support based on assessment of function	Basic interventions, including self-management, and care strategies initiated by generalist healthcare professionals
2	• Post-operative physiotherapy following breast surgery • Dietary advice for patients having enteral feeding regime	Generalist allied healthcare professionals	Routine assessment of rehabilitative needs	Interventions provided for commonly presenting rehabilitative needs – post-operative input plus management of commonly presenting side-effects of treatment or functional impairment
3	• Management of significant weight loss/cachexia • Management of breathlessness caused by advanced disease • Management of mild or uncomplicated lymphoedema	Experienced allied health professionals with basic level training in cancer rehabilitation working at senior level	Specialist assessment from an experienced AHP	Interventions provided by professionals with knowledge and experience of effects of cancer treatment and aetiology. Interventions requiring knowledge of the impact of disease
4	• Management of a patient with spinal cord compression • Swallowing assessment for patient having had radical head and neck surgery • Management of severe/complicated lymphoedema	Advanced practitioner allied healthcare professionals working predominantly or exclusively with patients with cancer and with higher-level training as a specialist practitioner.	Highly specialist assessment from expert AHP	Highly specialist interventions for patients having radical surgery, patients with advanced disease, patients with severe functional impairment, patients undergoing combination therapies and/or patients with complex end of life issues.

10.23 Referral pathways between and to each level should be established, including the ability for the patient and carer to self-refer.

10.24 The function of each level is as follows:

Level 1 involves all those providing day-to-day care for the patient, including the patient and carer. The needs of patients are assessed using an agreed assessment tool with basic interventions initiated or a referral made to the next appropriate level of care.

Level 2 involves all generalist AHPs. Patients are identified as having rehabilitative needs and requirement for input that may be provided by the appropriate AHP working at this level, cross-referring to AHP colleagues as necessary or referring to a more experienced or expert colleague according to the needs of the patient.

Level 3 involves experienced AHPs who will have received basic-level training in approaches to managing cancer. These professionals may work across a care setting, such as a primary care organisation or acute Trust, and will also cross-refer as necessary.

Level 4 involves advanced practitioner AHPs who work predominantly or exclusively with patients with cancer and who provide expert advice and input for clearly defined rehabilitative needs. These expert AHPs will have received higher-level training in the rehabilitative needs of patients with cancer. Cancer centres should have practitioners capable of working at Level 4.

10.25 It is recognised that healthcare professionals other than allied health professionals will play a role at Levels 2, 3 and 4. For example, some nurse specialists have undergone a period of training in the assessment and management of lymphoedema and the management of breathlessness.

10.26 The end-result of assessment, at all levels, should be a set of individual goals recorded in the clinical notes and used as the basis of the plan of care. Patients should play a central role in setting these goals, which will be adjusted as repeated assessments identify changing need. Where rehabilitation needs that cannot be met in the patient's current setting are identified (due to lack of skills, lack or facilities, or both), onward referral to specialist rehabilitation therapists and/or facilities should be made.

10.27 Patients whose treatment is completed and/or are in long-term remission should continue to have access to rehabilitative therapies either through self referral or through their 'key worker' (see Topic 1, *Co-ordination of Care*) for an indefinite period, and should know how to initiate such access.

10.28 Providers should have mechanisms in place for patients to access user-led self-management programmes (in England, these should be in line with the Expert Patient Programme[2]). These would ideally be developed in partnership with patients' organisations and health and social care professionals.

10.29 Site-specific and specialist palliative care teams in cancer units, cancer centres, hospices and primary care teams should form close working relationships with professionals, based on this framework, to ensure that needs are being recognised and referral pathways are being used. AHPs should be part of site-specific multidisciplinary team meetings as appropriate – for example, a speech and language therapist participating in the head and neck cancer team meeting, or a dietician participating in the upper GI team meeting.

10.30 Providers should ensure suitable facilities and ready access to equipment to support effective and safe rehabilitation. They should ensure that equipment needed by patients to continue their rehabilitation plan in their home environment is made available and that priority is given to those patients who are dying. Equipment required by a patient approaching the end of life should be made available within 24 hours of the request being made.

10.31 Providers should be able to demonstrate robust systems of forward planning, with capacity to anticipate individual patient needs for appliances such as appropriate wigs, stoma bags, lymphoedema hosiery and other prostheses, anticipating order and delivery times. A ready supply of appliances commonly needed by patients with particular conditions should be available. Patients should be made aware of the appropriate person to contact to obtain fresh supplies or to discuss problems or concerns.

10.32 Providers should ensure that designated facilities are available for demonstrations and fitting of appliances with sufficient space to allow demonstrations and fittings to be carried out effectively. They should confer privacy and should be stocked with items such as mirrors, a couch, washbasin and storage cupboards.

10.33 Providers should ensure that appliances are fitted by skilled individuals who have an appreciation of the needs and concerns of patients with cancer and are knowledgeable about the relevant appliance.

10.34   Providers should ensure that the rehabilitation team has individuals with the necessary skills and knowledge to assess and offer support to enable people to resume their usual sexual practices or explore alternative ways to express their sexual preferences.

C.3 Workforce development: specific recommendations
10.35 Workforce Development Confederations (the Workforce Development Steering Group in Wales), working with Cancer Networks, should assess the level of need for training and commission sufficient training places to meet the following requirements:

- all healthcare professionals should receive training in rehabilitative needs assessment
- a foundation course in approaches to cancer management should be established and provided for all experienced AHPs working at Level 3
- higher-level education should be established and provided for all advanced practitioner AHPs working at Level 4.

10.36 A 'cascade' model of training might be an effective way to ensure that rehabilitation experts play a key role in disseminating knowledge and skills across the Cancer Network. Experienced and advanced practitioners should have sufficient time rostered within their job plans to enable these activities to be undertaken.

10.37 'Clinical specialist' and 'consultant therapist' posts in cancer and palliative care should be developed across all AHP groups to ensure access for patients to the practitioners necessary to deliver high quality rehabilitation services. Alongside a review of the total number and skill-mix of AHP staff needed to support service delivery, clinical specialist and consultant therapy posts in cancer and palliative care should be developed.

C.4 Research and development: specific recommendations
10.38 Research is needed to explore the role, effects and components of rehabilitation, including the contribution of allied health professionals.

10.39 Research is needed to determine what models of rehabilitation are most effective for different patient groups, and how these are best integrated with other services.

D. Evidence

10.40 A number of individual studies have been undertaken on the effectiveness of various interventions to provide rehabilitation for patients with cancer. These have investigated the impact of interventions at different stages in patients' experience of cancer (initial diagnosis, treatment, recurrence, end of life) as well as with patients with different forms of cancer. Most studies are American, with little UK research in this area. No systematic reviews have been undertaken.

10.41 A small amount of research has focused on the functional recovery of hospital inpatients as a result of rehabilitation. Two studies found that patients with a wide variety of cancers made significant gains in motor function and, in one, most patients also made significant gains in cognitive function[3,4] [B].

10.42 Educational interventions have generally proved successful. Research suggests that a general training programme, providing information on physical exercise and coping skills, can improve the physical and emotional well-being of patients [A]. Similarly, specific training programmes, for instance to help people with cancer-related fatigue or breathlessness, can result in significant improvements in functioning [A]. Two studies of the impact of an intervention to provide walking exercise for cancer patients receiving adjuvant chemotherapy and radiotherapy respectively found this improved the physical functioning of patients and lowered their levels of fatigue and emotional distress [A]. A programme to assist compliance with vaginal dilation among women with gynaecological cancer was found to be effective both in increasing compliance and reducing fears about sex after cancer [A].

10.43 Research also demonstrates that self-administered stress management training for cancer patients about to start chemotherapy is particularly effective, at a much lower cost than professionally administered interventions [A]. Employing a self-help approach seems to bring positive outcomes in terms of self-care, psychological adjustment and confidence in cancer knowledge regardless of baseline resourcefulness [A]. Input from a dietician to avoid unwanted weight gain among women receiving adjuvant chemotherapy produced only small but statistically insignificant reductions in both calorie consumption and weight gain [A].

10.44 There is growing evidence to show that, compared to no intervention ('standard care'), self-management approaches can provide important benefits for participants. The benefits of self-management include reduced severity of symptoms, significant decreases in pain, improved life control and improved resourcefulness and life satisfaction[5-8] [B]. Macmillan Cancer Relief, through its *Living With Cancer* project, is exploring the outcomes of different models of self-management: a lay-led programme aimed at developing people's abilities in problem solving and self-care, and a professionally led programme aimed at developing people's knowledge of the illness[9].

10.45 Interventions involving combined approaches have also generally been found to be successful. These include a programme within primary care to increase contacts with home care nurses, including individual psychological support and, for some, help from a dietician; this found that the intervention was the strongest predictor of patients' contact with home care nurses six months after diagnosis [B]. Another intervention for patients with breast cancer, involving a team who provided support after surgery, including an oncology counsellor to provide support and information and a social worker to coordinate arrangements between hospital and the community, resulted in the expression of more emotional problems immediately and a greater sense of self-efficacy two months later [B]. A comprehensive intervention for women with breast cancer suffering from menopausal symptoms, consisting of a structured assessment followed by an individualised plan of education, counselling, pharmacological and behavioural interventions, support and referrals, was found to result in improvements in symptom management and sexual functioning [A].

10.46 There has been little research on patients' views of rehabilitation, but one study found that patients cared for on a rehabilitation ward specifically aimed at people with cancer welcomed direct help with their condition and the support gained from other patients; they also felt more involved in their own rehabilitation as a result[10] [B]. A study of patients with breast and bowel cancer found that only one quarter, generally those with physical or psychological problems, expressed an interest in having professional rehabilitation following treatment. Focus groups and interviews elicited that the kinds of help sought included information on the disease, diet and how to cope better in their new circumstances[11] [B].

10.47 One study of the appropriateness of professional assessments for rehabilitation suggests a lack of clear referral criteria among nurses[12] [B].There is evidence that education and training of those who are not specialists in this field is likely to result in

better recognition of patients' rehabilitation needs and a greater appreciation of the wider multidisciplinary team. An educational intervention for professionals proved to be effective for people from a wide range of healthcare disciplines (oncologists, nurses, mental health professionals), improving their knowledge of cancer pain, psychosocial issues and rehabilitation issues [B].

10.48 Interventions for cancer rehabilitation tend to be multi-faceted to address the often complex adverse physical and psychological effects of cancer and to promote adaptation to treatment. The importance of interdisciplinary teamwork is a common theme in professional guidance on this subject[13,14] [C]. More research is needed to investigate the particular impact of different interventions for patients with different types of cancer and at different stages.

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11. Complementary Therapy Services

A. Introduction

11.1 The complexity of decision-making regarding the provision of complementary therapy services for patients with cancer is acknowledged. A considerable proportion of patients express interest in the use of complementary therapies and a significant number report that they have used complementary therapies for their condition, yet it is recognised that there is little conventional evidence regarding the effectiveness of these therapies to the relief of pain, anxiety, distress or quality of life. In addition, some complementary therapies may present risks to patients with cancer, as well as benefits.

11.2 Against this background, the aim is to provide guidance that will:

- enable patients to obtain reliable information about complementary therapies and therapists, to empower them to make decisions for themselves
- assist commissioners in determining what, if any, complementary therapy services they should fund
- give providers advice on the measures they should take to ensure that patients can access complementary therapies safely, should they so wish.

11.3 This Guidance does not attempt to make recommendations regarding individual complementary therapies, just as specific recommendations have not been made for conventional treatments in other topic areas.

11.4 *Complementary* therapies are used alongside orthodox treatments with the aim of providing psychological and emotional support through the relief of symptoms. *Alternative* therapies purport to offer a distinct alternative to orthodox cancer treatments, and are not considered in this Guidance.

11.5 Complementary therapies encompass a diverse range of interventions, including physical, psychological and pharmacological approaches. Therapies may also be considered as self-care approaches (for instance, meditation), as techniques (massage) or as interventions with a range of clinical applications (homeopathy). Other popular therapies include touch and mind-body therapies. All are used in this context in addition to, rather than in place of, orthodox cancer treatments to help with symptom control and to enhance general well-being. The most widely used by patients with cancer are the touch therapies (aromatherapy, reflexology and massage) and psychological interventions (relaxation, meditation and visualisation)[1].

11.6 Patients with cancer may access complementary therapy services from a variety of sources in the statutory, voluntary and independent sectors. They are delivered in different settings such as general practices, hospitals, hospices and diverse community locations, including self-help and support groups.

11.7 Recent reports have indicated that between 9% and 30% of patients with cancer have used complementary or alternative therapies for their condition[2,3]. Two thirds of hospices and oncology departments in the UK offer at least one complementary therapy to patients[4]. Attitudes of doctors, nursing and allied health professionals have changed considerably over the last ten years, from a position of scepticism and frank antagonism in some cases, to a productive co-existence[5].

11.8 Under UK common law, no formal training is required to practice most forms of complementary therapy (with the exception of osteopathy and chiropractic, whose practitioners achieve registration in a similar way to medical practitioners, dentists and nurses). Work is in hand to strengthen the responsible voluntary regulation of aromatherapy, homeopathy, massage, reflexology and others, based on the adoption of formal national occupational standards.

11.9 Some NHS organisations have developed policies on qualifications, professional registration and indemnity in relation to complementary therapies. These are not unique to cancer services and it is widely acknowledged that issues related to training, qualifications and competence should be addressed at national level to ensure safety for patients.

B. Objectives

11.10 The objectives are to ensure that:

- patients are empowered to make their own decisions about complementary therapies and therapists through the provision of high quality information
- complementary therapies either commissioned by the NHS or provided in NHS facilities are provided safely by trained practitioners who are aware of the clinical problems or scenarios and psychological issues with which patients with cancer can present.

C. Recommendations

11.11 Commissioners, NHS and voluntary sector providers and user groups should work in partnership across a Cancer Network to decide how best to meet the wishes of patients for complementary therapies. The Cancer Network may choose to establish some form of complementary therapy interest group to:

- review evidence related to best practice[ST]
- agree policies to ensure safe practice
- develop complementary therapy components of a service directory.

[S] An evidence-based information resource in complementary medicine is currently under development by the Research Council for Complementary Medicine (with a specific section devoted to cancer).
[T] Cancer Networks might wish to consider the national guidelines for use of complementary therapies in palliative care developed by the National Council for Hospice and Specialist Palliative Care Services and the Prince of Wales Foundation for Integrated Health[6].

11.12 Commissioners should determine what complementary therapy services they wish to fund and in what setting and whether these should be made available for particular groups of patients. They should then work to ensure equal access for all patients meeting the relevant criteria.

11.13 Provider organisations should ensure that patients have access to high quality information about complementary therapy services and where they can be obtained[U].

11.14 Provider organisations should ensure that patients have access to a knowledgeable individual with whom they can discuss complementary therapies.

11.15 Provider organisations should ensure that any practitioner delivering complementary therapies conforms to guidelines agreed by the Cancer Network regarding training, qualifications and competence.

11.16 Provider organisations should ensure that facilities are made available for the delivery of those forms of complementary therapy that have been agreed at Cancer Network level.

11.17 Those involved with the provision of therapies within the context of the NHS should make every effort to contribute to ongoing evaluation of the therapies, participating in research designed to establish their efficacy and impact.

C.1 Research and development: specific recommendations
11.18 Evaluative research is needed into the cost-effectiveness and safety of different complementary therapies in supportive and palliative care.

11.19 Research is needed to determine the best ways to deliver and provide information about complementary therapy services.

D. Evidence

11.20 In common with many non-pharmacological clinical interventions, the evidence base for the effectiveness of complementary therapies does not offer the same level of assurance that can be secured for interventions that are supported by the existence of numerous, well-conducted randomised controlled trials that have subsequently had favourable systematic reviews.

11.21 Such reviews that exist are mentioned in the evidence review. However, it should be noted that, in its report published in November 2000, the House of Lords Select Committee on Complementary and Alternative Therapies recommended that therapies which claimed to relieve rather than cure certain conditions should be subject to less stringent standards of evidence[7]. While it may not be as rigorous as

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[U] The Department of Health has commissioned the Prince of Wales' Foundation to provide a Guide for Patients. This should be available shortly.

might be desired, there is a body of evidence of the effectiveness of complementary therapies in cancer care, and this is currently being assembled by the Research Council for Complementary Medicine (RCCM). Until this work is completed, the fact that these therapies are already in wide and effective use in the NHS and voluntary sector may be taken as a significant indication of their value.

11.22 Studies suggest that up to one-third of patients with cancer in the UK may visit therapists[2,8], most commonly for touch therapies (aromatherapy, massage, reflexology), mind-body therapies (relaxation and visualisation) or healing and energy work (reiki, spiritual healing, therapeutic touch)[9] [B]. Many more take remedies or use other products [B]. Use of such therapy also appears to be increasing, with most patients using complementary therapies alongside conventional medicine, rather than as a distinct alternative [B]. Patients have been found to be very satisfied with such treatments [B].

11.23 Patients with cancer use complementary therapies because the remedies are felt to be non-toxic and holistic, give patients more participation in their treatment and involve supportive relationships with practitioners [B]. They also see complementary therapy as a means of improving their quality of life and controlling symptoms of cancer or cancer treatments [B]. Users tend to be women, are on average younger and come from higher socio-economic backgrounds than non-users [B].

11.24 Although much complementary therapy is provided privately or through voluntary organisations, its provision within the NHS is growing. Almost half of GPs in England provide access to some form of complementary therapy[10] and two-thirds of oncology departments claim to provide therapies[11] [B].

11.25 The evidence review to accompany the development of the recommendations has largely been confined to systematic and non-systematic reviews. These demonstrate that evidence on the effectiveness of complementary therapies is limited, with most therapies not having rigorous evaluations. One Cochrane review, however, suggests that aromatherapy and/or massage confer short-term benefits for patients with cancer in terms of psychological well-being and, probably, a reduction in anxiety and some physical symptoms[12] [A]. Another found positive benefits for patients with cancer from reflexology in breathing, reduction in anxiety and reduced pain[13] [A].

11.26 There have been three systematic reviews of randomised controlled trials and studies of other complementary therapies, not limited exclusively to patients with cancer. Two provide some evidence of the benefits of aromatherapy in reducing anxiety [A] and acupuncture in reducing nausea and vomiting [A]. Preliminary results on a systematic review on chemotherapy-related nausea and vomiting is also positive for acupuncture[14] [A]. There is some indication that therapies might have the ability to improve patients' general sense of well-being and quality of life through, for instance, reductions in distress, anxiety, pain and nausea [B].

11.27 Many studies have a considerable number of methodological limitations, making it difficult to draw definitive conclusions. The best research, where it exists, offers some support for the use of certain complementary therapies in cancer care, but the same cannot be said for claims that complementary therapies cure cancer. A very few determined patients have found remission after following a very strict unorthodox regime, but there is no reliable evidence that these results are generally reproducible.

11.28 The Department of Health has recently commissioned research that explores perceptions, preferences, expectations and outcomes about complementary and alternative medicine treatments in patients with cancer[15].

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12. Services for Families and Carers, incorporating Bereavement Care

A. Introduction

12.1 Cancer affects the whole family system and significant role adaptation is necessary when one member becomes ill. While the needs of family members and carers have to some degree been addressed within the other topics of this Guidance, this topic area focuses on their specific needs and the services required to support them.

12.2 A broad definition of 'family' is taken, which includes those related through committed heterosexual or same sex partnerships, birth and adoption, and others who have strong emotional and social bonds with the patient. Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management[1].

12.3 Families and carers provide crucial support for patients, yet their importance can go unrecognised by care professionals. Close family members usually try to keep things going within the family and try to normalise the experience, consequently remaining 'invisible' to care professionals. Because families and carers put the needs of the patient first, it is difficult to get them to express their own needs, which are likely to be different from those of the patient. Care-giving may not necessarily be viewed as 'burdensome' by family members; it has both positive and negative elements.

12.4 Family and carers can struggle to cope with watching their loved one suffer from the symptoms of the disease and treatment. Multiple issues come into play, including emotional strain, the physical demands of caring, uncertainty, fear, altered roles and lifestyles and matters of personal and sexual intimacy. While their emotional distress can be greater than that experienced by the patient, family members have less opportunity to express their feelings. This distress can manifest in a number of ways, including fatigue, weight loss, insomnia and vulnerability to infection.

12.5 Information and support needs will differ at discrete points in the patient pathway, with crucial times being identified at the point of diagnosis, the end of first treatment, disease recurrence and the terminal phase. Practical needs revolve around help with transport, maintaining the home and caring for any other dependents, financial matters, coping with distressing symptoms and dealing with the tiredness that accompanies caring. Help may also be needed in dealing with their own and others' feelings. Difficulties can arise if their choices and judgements are at variance with those of the patient and/or others in the same family group, raising the possibility of conflict and creating ethical dilemmas for professionals.

12.6 Families and carers have particular needs around the time of death that may only be fully realised after the patient's death. Grief is a normal response to human loss, and while bereavement represents a significant challenge, the majority of people have sufficient resources to enable them to respond and adapt to this life transition. Most find

a way of adjusting to the loss, but some may find it too difficult or traumatic without additional support.

12.7 Bereavement can give rise to a wide range of needs – practical, financial, social, emotional and spiritual. There might be needs for information about loss and grief, needs to pursue particular cultural practices, needs for additional support to help people deal with the emotional and psychological impact of loss by death or, in a small number of circumstances, specific needs for mental health services intervention to cope with a mental health problem related to loss by death.

12.8 Services for families and carers are poorly developed in many parts of England and Wales, although the situation is somewhat better in relation to specialist palliative care. Service delivery is fragmented and is commonly targeted at discrete groups, with much being funded by the voluntary sector. Sources of help, support, information and advice may be both insufficient and inappropriate. Many family members and carers have virtually no contact with professionals, leading to professionals making erroneous assumptions about their coping and often leaving families and carers unaware of additional resources, services or sources of support[V].

12.9 Different forms of support are available for those experiencing bereavement, ranging from information, through befriending and self-help groups, to more formalised psychological interventions such as counselling. These are provided by the statutory and voluntary sectors, with voluntary services often providing the lion's share.

12.10 Inequitable distribution of bereavement services and their varying quality are ongoing concerns. Families and carers, particularly those not receiving specialist palliative care, may never undergo screening to assess their level of vulnerability. They consequently may experience delays in receiving additional support, or may not receive support at all. Professionals are often not adept at assessing, predicting and responding to families' and carers' bereavement needs, both before and after death.

12.11 Professionals need to pay greater attention to the role played by carers and their psychological and social needs. Carers, however, tend to put the needs and interests of patients above their own. They will only be likely to accept services designed to support them if they are confident that in doing so, they are not diverting resources and attention away from services to the patient.

B. Objectives

12.12 The objectives are to ensure that:

- family members' and carers' needs are assessed, acknowledged and addressed
- carers have access to levels of practical and emotional support sufficient to enable them to fulfil the role of carer

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[V] Cancer Networks should be aware of the Department of Health[2] and National Assembly for Wales[3] strategies on caring for carers.

- those who experience bereavement receive support to facilitate grieving to prevent the detrimental consequences of bereavement
- health and social care workers can access support to enable them to come to terms with the loss and bereavement issues they encounter in their work.

C. Recommendations

C.1 Overview

12.13 Family members and carers should be offered the opportunity for their needs and preferences for support and information to be assessed separately from those of patients, particularly at stages in the patient pathway acknowledged as being especially demanding and when extra help might be needed, and taking into account cultural and ethnic preferences on family involvement.

12.14 Whenever possible and appropriate, family members and carers should be invited to accompany patients during clinical encounters and be involved in discussions about treatment and care, in accordance with the patient's wishes.

12.15 Family members and carers should be made aware of, and have easy access to, sources of local information, advice and support designed to meet their own needs.

12.16 Family members and carers who are bereaved should, in the first instance, be encouraged to use existing support systems. Where these prove insufficient, or it is predicted that family members or carers are likely to experience difficult grief reactions, there should be access to additional help and support.

12.17 Providers of specialist bereavement support should work closely with other care providers (both statutory and voluntary) to ensure carers and family members can access services when needed.

C.2 Service configuration and delivery: specific recommendations

12.18 Commissioners, working through Cancer Networks, should ensure that a range of information, support and bereavement services are in place to meet the spectrum of need. They will need to work with a range of statutory and voluntary health and social care agencies to achieve this. While not necessarily separate from many of the services provided to patients (indeed, most will be fully integrated), commissioners should ensure there is sufficient capacity to meet the distinct needs of this group.

12.19 Organisations providing cancer services should nominate a lead to oversee the development and implementation of services that specifically focus on the needs of families and carers. This role might involve:

- leading on the development of criteria and routes of referral to sources of specialist support and advice

- appraising written information currently provided to families/carers and, in conjunction with the Trust information lead, developing further resources where necessary
- regularly appraising teams of sources of local and national support for families and carers
- acting as a resource for teams considering the development of programmes of support for families and carers.

12.20 The patient's usual health and social care professionals should assess and address family members' and carers' needs on an ongoing basis. Teams should establish a system to ensure that family members and carers have regular opportunities to discuss their particular concerns. This might be achieved by an appointment being offered with the 'key worker' (see Topic 1, *Co-ordination of Care*) around times acknowledged to be particularly challenging (diagnosis, end of treatment, recurrence, palliation, time of death).

12.21 Where carers are providing a substantial amount of care on a regular basis, providers should ensure they are offered a separate assessment, in accordance with The Carers (Recognition and Services) Act 1995[4]. The practice guide that accompanies the Act recommends potential areas to be covered in an assessment to identify the types of support carers receive, which can then be used as the basis for planning timely and relevant interventions.

12.22 Teams should ensure that all family members and carers are offered information on a variety of topics, from a simple 'who's who' to more detailed accounts of cancer, its treatment and consequences and services available locally. They should be 'signposted' to further sources of information, advice and practical support in their local community and nationally. Services for carers and families should be listed in the directories developed at Cancer Network level.

12.23 Teams should provide families and carers with a clear indication of the personnel they might contact in relation to a range of needs.

12.24 If they wish, patients with young children or teenagers should be offered information by their usual health and social care professionals on how to talk with them in a way that will encourage the sharing of fears and concerns. Age-appropriate resources should be available to support this process (see Topic 4, *Information*).

12.25 Providers should make provision for families and carers to meet and speak with other families and carers who have experienced similar situations, if wished. Support groups for family members and carers, either professionally or peer-led, may also be welcomed by some. These services are ideally provided in partnership with the voluntary sector.

12.26   An awareness of the needs of family members from different ethnic populations, including differences in language, religious practice and culture, is necessary within a

multi-cultural society. Providers should ensure that teams have access to reference guides on the cultural differences that surround a diagnosis of cancer and death and dying, and that information on accessing interpreters, relevant health advocates (where available) and faith leaders is readily accessible (see Topic 3, *Face-to-Face Communication,* and Topic 7, *Spiritual Care Services*).

12.27 Providers should ensure that families and carers have access to professionals capable of providing confidential emotional support and, if there is variance between the needs, choices and judgements of a family member or carer and those of the patient, that the professional is independent of normal services offered to the patient.

12.28 Some family members and carers will require care and support from a health or social care professional capable of dealing with complex family situations. Providers should ensure they have access to individuals and teams with the requisite skills and knowledge through social support, spiritual support, specialist palliative care or psychological support services. Criteria and routes for referral should be agreed between the different services.

12.29 Teams should ensure they have the facility to offer information and training on practical issues to carers who are looking after patients who require extra help with activities of daily living and are approaching the terminal stage of their illness. This might include manual handling, managing distressing symptoms and dealing with incontinence and other body fluids. As death approaches, they should also be given information about what to expect and what to do after the death.

Bereavement support
12.30 A three-component model of bereavement support should be developed and implemented in each Cancer Network to ensure that people's individual needs are addressed through variety in service provision. Cancer Networks should take account of the standards for bereavement care developed by the National Bereavement Consortium[5]. The components should be flexible and accessible when needed around the time of bereavement:

Component 1 Grief is normal after bereavement and most people manage without professional intervention. Many people, however, lack understanding of grief after bereavement. All bereaved people should be offered information about the experience of bereavement and how to access other forms of support. Family and friends will provide much of this support, with information being supplied by families' usual health and social care professionals.

Component 2 Some people may require a more formal opportunity to review and reflect on their loss experience, but this does not necessarily have to involve professionals. Volunteer bereavement support workers/befrienders, self-help groups, faith groups and community groups will provide much of the support at this level. Those working in Component 2 must establish a process to ensure that when cases involving more complex

needs emerge, referral is made to appropriate health and social care professionals with the ability to deliver Component 3 interventions.

Component 3 A minority of people will require specialist interventions. This will involve mental health services, psychological support services, specialist counselling/psychotherapy services, specialist palliative care services and general bereavement services, and will include provision for meeting the specialist needs of bereaved children and young people (which is being developed as part of the National Service Framework on children and is not covered here).

12.31 Provider organisations should be equipped to offer the first component of bereavement support and have strategies in place to access the other components. Services should be accessible from all settings.

12.32 Within the context of family and social support assessments, usual healthcare professionals involved in delivering care in the terminal phase of illness should assess individual and family coping ability, stress levels, available support and actual and potential needs with respect to the anticipated or actual bereavement.

12.33 Cancer Network-wide protocols to inform the level of bereavement support offered and the need for follow up and specialist referral, particularly for those at risk of complicated grief reactions, should be developed. They should apply wherever the patient dies – at home, in hospital, hospice or care home – and should include a system to engage proactively with those assessed to be at risk, involving, for example, follow-up telephone calls or letters to individuals around eight weeks after death. Issues of consent and data protection should be considered carefully.

12.34 Providers should ensure that a leaflet is made available for families and carers around the time of the bereavement. Ideally, this should be developed locally, should be agreed by those involved in the provision of bereavement services, and should include information on anticipated feelings and how to access local and national services.

C.3 Workforce development: specific recommendations
12.35 Workforce Development Confederations in England and the Workforce Development Steering Group in Wales, working with Cancer Networks, should ensure all healthcare professionals involved in the delivery of supportive and palliative care services have access to basic training in understanding and meeting the needs of families and carers. This should include knowledge to underpin the delivery of ethnically and culturally sensitive care to this group of individuals. They should also ensure that ongoing education and training about bereavement and loss are available. The aim should be to enable professionals to develop a basic knowledge of the characteristics that increase vulnerability to the loss experience or which impede adjustment to bereavement, and to help recognise their own needs for further education and support.

12.36 Providers should ensure that all staff working with people who are dying have access to a range of opportunities to address concerns and explore the difference between

personal and professional responses to loss. This might involve a number of processes such as clinical supervision and one-to-one and group support.

12.37 Specialist bereavement services should be sufficiently resourced to enable them to contribute to the preparation and ongoing support of health and social care professionals in relation to this aspect of care.

12.38 Those who offer bereavement services that include volunteer support workers should ensure that mechanisms for recruiting, training, supervising and managing them are in place. It is desirable that the workforce reflects the gender, age distribution and ethnicity of the clients they serve.

C.4 Research and development: specific recommendations
12.39 Empirical research is needed to map the carer pathway, to identify views about different services and patterns of care received and how services can best meet their needs.

12.40 Evaluative research is needed to determine the cost-effectiveness of different models of providing support tailored to different groups of families and carers.

12.41 Evaluative research is needed to compare different models of bereavement support for different groups, in particular one-to-one versus group sessions and user versus professionally driven services.

12.42 Research is needed to determine in which situations and for which groups of people bereavement support is needed.

D. Evidence

12.43 There has been some research on services to meet the needs of carers during the time they are looking after a patient, when the cared-for person is terminally ill and at the point of bereavement. While there are a few randomised controlled trials (RCTs), many of the studies involve small sample sizes and insensitive outcome measures, with a reliance on descriptions and formative evaluations. One systematic review has examined interventions for carers of patients using home cancer and palliative care services.

D.1 Services for carers of patients with cancer
12.44 Home care services for patients generally include carer support in their aims. Carers report high satisfaction with such services and describe them as useful in helping them to look after patients, but they do not meet many of carers' own needs [B]. One RCT found that a home care nursing service raised the well-being of carers in the first three months after a patient was discharged, although this was lowered among those with physical problems of their own [A]. An education programme for carers of patients with cancer may have helped them to cope, with their perception of the burden of caring not worsening, even when caring tasks increased in intensity.

12.45 Respite services can take many forms. Research suggests that carers of patients with cancer can be very ambivalent about leaving the patient, and such care may not be accessible to those who wish to remain in the home. Evaluations of two sitting services nevertheless found a high degree of satisfaction among carers, with the great majority feeling able to leave the sitter with the patient [B]. Research on massage, intended to provide a form of respite to carers, found that it reduced emotional and physical stress, physical pain and sleep difficulty [B].

12.46 Social networks and activities can be an important source of support to carers. An 'activation programme' to increase the social activity of carers of patients with cancer was found to significantly increase their social activities during the treatment period [A].

12.47 One-to-one interventions are intended to provide a means of providing support and building problem-solving skills. The results of two RCTs of such services, however, are not promising: in one, the service appeared effective only for a distressed sub-sample; in the other (offering psychotherapy to spouses of patients with lung cancer), there was no visible impact. There was also low uptake of the latter service [A]. Research on a family education programme on the management of cancer-related pain, however, found significant improvements in knowledge, pain management, and carer burden following its completion [B].

12.48 There has been more research on group interventions for carers of patients with cancer or who need palliative care. Although carers' groups may not be appropriate for all carers, the benefits of sharing information, as well as practical and coping skills, can be great. One RCT of a stress and activity management group for spouses found that those who attended had significantly higher knowledge scores, became more active, coped better with medical situations and were more satisfied with the care provided than a control group, although psychosocial adjustment did not alter between the two groups [A]. Other research on various kinds of group sessions for carers of patients with cancer have had mixed results. Some have shown no difference in quality of life or coping strategies; some have been found to provide support, facilitate coping and reinforce confidence; and others have been found to increase the anxiety of at least a sizeable minority of participants [B]. There can be considerable difficulties in recruiting carers to take part.

D.2 Care at the point of terminal illness
12.49 Several studies have considered provision for carers at the time of terminal illness, together with its effectiveness. Carers' needs are viewed as part of palliative care, but many services did not assess carers' needs.

12.50 Three RCTs have assessed the impact of interventions to assist both carers and patients. They clearly suggest that good care prior to a patient's death, whether in hospital or at home, can reduce the carer's anger and distress during bereavement. Another study had similar results, although it focused on physiological changes among those involved [A].

12.51 Several studies have examined carers' responses to particular forms of terminal care. One found no difference in anxiety levels or social participation among carers of patients in a

hospice compared to those of patients using conventional care [B]. An evaluation of a home hospice service found that carers' quality of life remained stable over a period of four weeks [B]. An RCT of a hospital-at-home service for terminally ill patients found carers had greater satisfaction with the care provided, although there was no increased likelihood of patients remaining at home in the last two weeks [A].

D.3 Support in bereavement
12.52 The evidence on terminal care supports the view that it should be seen as part of bereavement care, as carers' levels of emotional distress are affected by the care provided before death. A few studies have examined the impact of particular strategies to offer support in bereavement, with mixed results. Research on bereavement counselling found no impact for those involved [B], whereas a study of telephone contact between ward nurses and grieving families found that this reduced sense of despair and detachment [B]. Involvement in a support group has been shown to have a statistically significant impact in terms of satisfaction and diminished needs for other support, although such positive effects may take time to appear [B].

12.53 Studies underscore the need to assess carers' needs with respect to bereavement along with the potential for experiencing difficulties adjusting to their loss. Individual clinical judgement is currently the most effective way of identifying those as risk, as risk assessment tools cannot be relied upon as a predictor of outcome [B]. This emphasises the need to ensure training and support for those involved in this process.

12.54 An RCT of a programme to prevent mental health problems in children who had experienced the death of a parent had encouraging results, in that the programme was able to modify the warmth of the parent-child relationship and decrease symptoms in the children [A].

D.4 General issues
12.55 A range of models for providing help to carers has been identified, but no single service model will be acceptable to all carers, or meet all needs of individual carers. The evidence of unmet need among carers using home palliative care services highlights the limited scope of this type of intervention for them. An expansion of such services to include multidisciplinary support for carers, independent of patient care, might help to meet carers' needs.

12.56 The evidence for one-to-one therapeutic interventions for carers is currently unclear. From the two published trials, only one found benefits for the intervention group, and this was for a significantly depressed sub-sample. Group interventions may be more successful, with the only controlled trial suggesting that carers gain both information and social activities. These tend to have fairly low uptake, however. The challenge of providing support may be greatest in rural areas, and it is important that carers are informed of the possibility of informal peer support, local and national telephone helplines and existing social networks.

12.57 Research suggests that practitioners planning to develop interventions for carers must ensure that these focus specifically on the needs of carers (that is, that they do not provide a

generic service), address issues of access and acceptability, have clear and modest aims and are evaluated using rigorous evaluation methods.

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13. Research in supportive and palliative care: current evidence and recommendations for direction and design of future research

A. Introduction

13.1 The nature of research in supportive and palliative care in cancer is somewhat different to that found in other areas of cancer care, particularly drugs and therapies. It was felt that a short section examining current conclusions about the best service configurations for supportive and palliative care and the evidence underpinning them would be valuable in developing services in the future. The section makes general recommendations about the direction and design of research in supportive and palliative care. Specific research recommendations are included in each topic area .

B. The quality of current research evidence

B.1 Nature of the evidence
13.2 Evidence in supportive and palliative care comes in three main forms. There is evidence of need, of importance (to those affected by cancer and to society), and of effective solutions.

13.3 Without doubt, there is ample evidence of need for effective supportive and palliative care among patients affected by cancer.   This is shown in studies over many years that have demonstrated concern and problems in communication, information, psychological support, symptom control, care of dying patients, bereavement support, care for patients and families, the need to involve service users, palliative care, spiritual support, social support, and the need to orientate services around the issues faced by patients and families.

13.4 Studies of the relative importance of supportive and palliative care have indicated that palliative and terminal care and good communication are among the top fifteen healthcare priorities identified by members of the general public.

13.5 These two forms of evidence demonstrate a healthcare concern that requires attention. The evidence is weaker in supportive and palliative care in determining the most effective solutions to meeting individuals' important needs. Research into supportive and palliative cancer care has received very low investment in the past, particularly in some fields, which may be partly responsible for the problem.

13.6 Nevertheless, there is extremely good evidence of effectiveness in some areas, particularly if both randomised and observational studies are included. In areas such as information giving, communication, specialist palliative care and psychological support, information from experimental randomised controlled trials and observational studies indicates that training, professional interventions and services can help to alleviate problems and difficulties for patients and families.

13.7 The evidence is less clear on the details of interventions, on the particular groups of individuals and problems that benefit, and in priorities for the future. Each of these areas and recommendations regarding future service configuration, support and research are discussed below.

B.2 Interventions

13.8 Two main difficulties were encountered in the systematic review of evidence. First, in many instances the intervention was not clearly described. This limitation is commonly a result of lack of publishing space within journals and the fact that it is often felt that providing detailed accounts of the intervention is not of great interest to an international readership.

13.9 However, lack of information about interventions makes drawing conclusions about their relevance in different circumstances and settings more difficult. It also makes it difficult for others to independently and accurately reproduce the interventions in another setting.

13.10 Second, when information about the intervention is available, it shows that they are often highly varied from setting to setting. This makes it difficult to draw conclusions about the overall effectiveness of a group of interventions. We can see this demonstrated clearly in the area of specialist palliative care, where teams work in different ways with different policies, different staff mixes and different training backgrounds. It is consequently difficult to make decisions about the best model of working.

13.11 There are few studies that compare different components of interventions to determine the best way of providing training or care. There is clearer development in some areas of supportive and palliative care, with earlier trials mapping the exact nature of the intervention and later studies testing it, rolled out in a wider framework. A good example is the development of studies examining communication skills training. In other areas, however, the research base underpinning the intervention is not so clear.

B.3 Populations

13.12 Many studies very clearly identified the populations included. Conducting research on patients who are highly distressed, have severe symptoms or who are dying is very difficult. Many of the studies made extremely bold and rigorous attempts to recruit from representative samples of patients and families and to collect data in an ethical, sensitive and meaningful way.

13.13 It was clear from some of the research that interventions effective earlier in care needed to be different or modified in advanced disease, or in groups of older people or those from diverse cultural or ethnic backgrounds. There was very limited research into the needs and preferences of effective interventions for individuals from different cultures and in the oldest age groups.

B.4 Study design

13.14 Although we did not specifically search for qualitative work, we found our strategy elicited both quantitative and qualitative research studies. Some studies have used the technique of triangulation, combining data from both quantitative and qualitative sources.

13.15 NICE guidance provides an hierarchy according to study design, with a well-designed experimental study - and in particular a randomised controlled trial - providing the highest-level evidence. Lowest-level evidence is drawn from consensus among professionals and/or service users. While this hierarchy is useful, it takes account neither of the relevance or pertinence of the individual studies to the question or problem affecting patients and families, nor of the healthcare context in which the service is operated.

13.16 A further consideration is the integration of qualitative studies. Qualitative designs can examine the effectiveness of interventions, or can provide more detailed interpretations of need or descriptions of interventions. Currently, no robust hierarchy of qualitative studies that examine the effectiveness of interventions is available. It is possible to use qualitative research to compare interventions.

B.5 Outcome measurement

13.17 Devising outcome measures that are sensitive and appropriate to the intangible nature of critical issues such as symptom control, psychological well-being, quality of life, quality of death and quality of care is a major challenge in the field of supportive and palliative care.

13.18 Great progress has been made in developing robust and sensitive outcome measurement, but in many areas these are still relatively crude. In addition, many services do not routinely collect information about their important outcomes in the way that biological markers and clinical parameters are recorded in other clinical settings.

B.6 Systematic review methods

13.19 Some specific difficulties were encountered with the systematic review. First, the electronic database searches and our search strategy did not detect all important studies, even some important randomised controlled trials. It is likely that some of the key words and search terms used to detect studies in supportive and palliative care do not always detect the important studies. Our search therefore had to be augmented by consultation with experts, grey literature searches and follow up of references. The database of evidence should be a resource for others in the future, but it will require updating as even during the course of this project we are aware of new studies that required inclusion.

13.20 Given the number of qualitative studies in this field, we feel that it would be timely to conduct some qualitative reviews, particularly in those areas where the quantitative data is not so apparent. These could include, for example, spiritual support, user

involvement and social support. Such work would require not only a new review, but also development of qualitative systematic review methodologies, such as the conduct of a meta-ethnography.

C. Recommendations

C.1 Direction of research
13.21 Future research should focus on determining effective solutions rather than re-determining need; there is a wealth of evidence on need and importance, and a relative dearth regarding effective solutions.

13.22 Research funders should invest in longitudinal studies of patient and carer experiences and expectations of both illness and health and social care, to describe change in perspectives as illness evolves and best ways of meeting needs at different points in time.

13.23 New services and many existing services should be developed (or continue to be developed) within a rigorous and properly funded evaluation framework.

13.24 Research funders should invest in research programmes in both supportive and palliative care. These should be sufficiently substantial, sustained and robust to ensure studies involve and measure aspects of services important to users, determine effectiveness and experience, and achieve appropriate power.

C.2 Interventions
13.25 Detailed descriptions of interventions and service configurations should be made available when evaluations are published.

13.26 Wherever possible, studies should use a research base to develop interventions, building on existing research and indicating where interventions deviate from those already established.

13.27 Future research should compare different service configurations and interventions.

C.3 Populations
13.28 Clear descriptions of populations seen by individual services and comparison of how these compare with the general population need to be made.

13.29 Future research should investigate effective care for those from diverse cultures.

C.4 Outcome measures
13.30 A system of routinely collecting some limited outcome information should be included in the care of cancer patients, in addition to biological markers.

13.31 Prospective measures of outcome for patients at all stages of disease and their carers should be further refined and developed.

13.32 Work to develop a core set of person-centred outcome measures robust enough to capture changes over time, for worse or better, should be pursued.

C.5 Systematic review methods
13.33 Future reviews should explore ways to combine scores of a traditional hierarchy of evidence based on study design with an estimate of the pertinence or relevance of the study using, for example, some kind of signal score.

13.34 Systematic review methods and hierarchies that can include high quality qualitative research need to be developed and tested.

DRAFT FOR 2ND CONSULTATION

Summary of Recommendations

A. The Department of Health and the National Assembly for Wales

The Department of Health and the National Assembly for Wales should:

Oversee the implementation of this guidance by:
- developing standards related to supportive and palliative care for patients with cancer which take account of the recommendations in this Guidance
- ensuring that quality assurance programmes are in place to monitor progress towards the achievement of the recommendations
- ensuring that mechanisms are in place to monitor changes over time in patients' experience of care
- ensuring that the necessary workforce and accredited training programmes are in place to achieve these recommendations.

In addition, they should ensure that:

Research is commissioned in areas pertinent to supportive and palliative care (1.38)

A comprehensive range of high quality information products is available for people with cancer (4.16).

A process is in place to accredit organisations producing information related to cancer (4.16).

Nationally accredited information materials are disseminated to locations where they are needed (4.17).

B. Commissioners of cancer care

Health Service Commissioners of Cancer Care, working through Cancer Networks, should ensure that:

Co-ordination of care
Structures and processes are in place to plan and review local supportive and palliative care services (1.12).

All relevant stakeholders are involved in the planning and review of services. These include (1.12):
- patients and carers (through Partnership Groups)
- voluntary sector providers
- NHS organisations and teams
- Workforce Development Confederations/the Workforce Development Steering Group

- councils with social service responsibilities
- representatives of the Cancer Services Collaborative Improvement Partnership.

Cancer Network-wide audits of patients' experience of care are undertaken (1.37).

Strategies that seek to engage with and identify service planning needs of people within local communities who are socially excluded and who have difficulty accessing services are developed (1.12).

Information
An adequate range of information materials is available to patients, free at the point of delivery (4.17).

Psychological support
All patients have access to an appropriate level of psychological support, as described in the four-level model of professional psychological assessment and intervention set out in this Guidance (5.17).

Emergency psychological support services are available and that healthcare professionals have 24-hour, seven days a week access to advice on caring for patients who have acute psychological and/or psychiatric problems (5.35).

Social support
Collaborative working relationships with local authorities are established to facilitate the delivery of social care to patients and carers (6.15).

Different components of social support are available within a Cancer Network and are accessible from all settings, domestic or institutional (in conjunction with social care services) (6.16).

Spiritual support
Multidisciplinary teams have access to suitably qualified, authorised and appointed spiritual care providers (7.21)

General palliative care, incorporating care of dying patients
Policies for the provision of out-of-hours palliative care to patients with cancer are developed, underpinned by assessment of local needs and deficiencies (8.24).

Medical and nursing services are available 24 hours, seven days a week for patients with advanced cancer living at home (8.25).

Specialist palliative care
Teams are sufficiently staffed to undertake direct assessment of people with cancer (at home or in hospital) during the hours of 09.00-17.00, seven-days-a week (9.29).

Specialist palliative care beds (in hospices or hospitals) are available in each Cancer Network and are sufficient in number to meet the needs of the population served (9.32).

Rehabilitation
All patients who need them have access to rehabilitation services (10.19)

Complementary therapies
Decisions are made on what, if any, complementary therapies should be funded for particular groups of patients (11.12).

Services for families and carers, incorporating bereavement care
Information, support and bereavement services are in place for families and carers (12.18).

C. Cancer Networks

Cancer Networks, as partnerships of organisations, should ensure that:

Co-ordination of care
A unified approach to the assessment of patients' needs is adopted across the Cancer Network. This will require agreement on which tools should be used in specific circumstances (1.17).

Up-to-date service directories are available. These should include information on local self-help and support groups, user groups and advocacy groups, information services, psychological support services, social support services, spiritual care, specialist palliative care services, rehabilitation, complementary therapies, services for families and carers and local and national telephone helplines (1.24).

User involvement
Partnership Groups that involve patients, carers and practitioners are established and supported, and their views are taken into account when services are planned (2.15).

Members of Partnership Groups (users and professionals) have access to training and support (2.26).

Information
A lead for cancer information is nominated (4.25).

Local policies regarding cancer information materials are developed (4.18).

Psychological support
Referral criteria for specialist psychological support services are developed (5.23).

Social support
Joint reviews of community equipment services for people with cancer are performed (6.17).

General palliative care, including care of dying patients
Protocols/guidelines on symptom control, palliative interventions and care of dying patients are developed (8.21).

Specialist palliative care
All specialist palliative care providers within the network develop common approaches to the assessment, treatment and care of patients. This should lead to the publication and dissemination of guidelines, protocols and care pathways as appropriate (9.23).

Guidelines that set out admission and referral criteria for specialist palliative care are developed (9.35).

Rehabilitation
A Lead Advanced Practitioner Allied Health Professional is identified to work with the Cancer Network management team on devising a Cancer Network-wide strategy for rehabilitation and a network-wide assessment tool (10.20).

Assessments of patients' rehabilitation needs are based on the four-level model of rehabilitative assessment and support described in this Guidance (10.22).

Complementary therapies
Guidelines on acceptable levels of training, qualifications and competence for practitioners practising complementary therapies within NHS organisations are developed (11.15).

Support for families and carers, incorporating bereavement care
The three-component model of bereavement support described in this Guidance is developed and implemented (12.30).

Cancer Network-wide protocols on bereavement support, follow-up and specialist referral are developed (12.33).

D. Provider organisations

Individual provider organisations should ensure that:

Co-ordination of care
An individual is nominated to lead on supportive and palliative care services (1.15).

User involvement
An individual is nominated to take the lead on developing and sustaining user involvement (2.20).

Mechanisms are developed to ensure the views of patients and their carers are elicited and taken into account (2.21).

Work is progressed with local self-help and support groups to establish the most effective ways of supporting their activities (2.23).

Face-to-face communication
Interpretation services are available when key information is communicated (3.20).

Services are available for people with hearing, sight, speech or combined sensory difficulties and for people with learning disabilities (3.24).

Members of staff who may benefit from communication training are identified (3.28).

Systems to evaluate how effectively staff communicate (such as performance appraisal) are established (3.28).

Information
A nominated lead for cancer information is appointed (with Cancer Networks) (4.25).

Mechanisms to ensure that patients and carers have access to a range of high quality information materials about cancer and its treatment are developed in a variety of formats (4.19).

Arrangements are in place to translate information materials (4.23).

Psychological support
Appropriate facilities, fit for purpose, are available for undertaking psychological assessments and interventions (5.36).

Social support
Patients, carers and healthcare professionals have ready access to social workers (6.20).

Healthcare staff know how to secure specialist social care assessments (6.27).

Access for patients and carers to information about social care (6.23) and to the different types of social support available to them (6.24) is facilitated.

Spiritual support
A staff member is nominated to take responsibility for liaising with local faith leaders (7.22).

Patients, carers and staff have access to authorised spiritual care advisers (7.21).

An appropriate room is available for use by various faith groups (7.24/25).

General palliative care, including care of dying patients
All multidisciplinary teams implement managed systems of caring for dying patients (8.34).

Rehabilitation
Suitable facilities are available and equipment is readily accessible to support effective and safe rehabilitation (10.30).

Robust systems of forward planning which account for patient needs for appliances such as wigs, stoma bags, lymphoedema hosiery and other prostheses are in place (10.31).

Complementary therapies
Patients have access to high-quality information about complementary therapy services (11.13).

Any practitioner delivering complementary therapies conforms to guidelines agreed by the Cancer Network (11.15).

Services for families and carers, incorporating bereavement care
A lead is nominated to oversee the development and implementation of services for families and carers (12.19).

Families and carers are offered a separate assessment when they provide substantial amounts of care, in accordance with the Carers (Recognition and Services) Act 1995 (12.21).

Provision is made for families and carers to meet with others who have had similar experiences, if wished (12.25).

Families and carers have access to personnel who can offer support for complex needs (12.27).

A leaflet providing key information is available for families and carers around the time of bereavement (12.34).

Staff working with people who are dying have access to appropriate support (12.36).

Primary Care Organisations/Local Health Boards should ensure that:
Means are developed to identify patients with advanced cancer who have needs (8.28).

Provision is made for continuous support in patients' homes for those who are approaching the end of life and wish to die at home (8.37).

Equipment needed to enable patients to live in the community is available without delay (8.29).

Access to medications that may be required in patients' homes is available on a 24-hour, seven days a week basis (8.38).

Acute NHS Trusts should ensure that:
Flexible systems are in place to obtain rapid discharge of patients who wish to die at home (8.36).

Inpatient specialist palliative care service providers should ensure that:
They can provide care for patients with complex needs (9.25).

They have levels of core staff sufficient to provide a specified level of service and access to a range of other specialist expertise (9.25/26).

E. Multidisciplinary teams/services

Each multidisciplinary team (such as breast, colorectal and lung cancer teams and primary care teams) and each specialist service (radiotherapy, chemotherapy and palliative care, for instance) should ensure that:

Co-ordination of care
Referral guidelines for the services they offer are developed (1.23).

Patients and carers are provided with information on whom to contact locally if they have particular questions about their treatment and care (1.25).

Structured assessments of patients' needs are undertaken and recorded at key points in the patient pathway. These assessments should encompass needs related to information, communication, psychological support, social support, spiritual support, palliative care and rehabilitation (1.18).

Individuals' needs for support are discussed at multidisciplinary team meetings and the outcomes of these discussions are recorded (1.26).

Policies/protocols in relation to communication, information and other key aspects of supportive and palliative care are developed (1.27).

They are able to identify patients under their care (1.28).

Mechanisms to promote continuity of care are promoted, including the possibility of nominating an individual to take on a 'key worker' role with respect to individual patients (1.29).

An individual is identified to act in the capacity of administrative contact for patients and professionals (1.30).

Other teams/services with which they most frequently interact are identified and joint plans to promote co-ordinated care are developed (1.33).

Mechanisms are developed to ensure timely transfer of information about patients (electronic transfer and patient held records, for instance) (1.34).

User involvement
Mechanisms are developed to gather the views of patients and carers on a regular basis (2.22).

Face-to-face communication
Face-to-face communication at key points in the patient pathway involves (wherever possible) a senior clinician. This clinician should have expertise in the relevant disease and in options for treatment and care and should have received advanced communication skills training (3.16).

Patients are enabled to review what they have been told during key consultations at a later date should they so wish (3.19).

Information
An individual is nominated to take a lead on information and to implement policy at local level (4.26).

Patients and carers have the opportunity to talk through the information they have been given with health or social care professionals. Patients should also have their attention drawn to other sources of assistance to help them understand and interpret information, such as voluntary sector helplines or information services (4.21)

They are familiar with local patient information resources and are able to provide relevant materials to patients (4.25).

Psychological support
Patients are systematically screened for psychological problems at key points in the patient pathway (5.26).

Patients are made aware of the wide range of support services available after cancer treatment has ended (5.38)

An individual (or individuals) who can provide Level 2 psychological care is (are) identified (5.41).

Social support
Patients' social needs are assessed as part of routine assessments (6.18).

Mechanisms are established to promote effective working relationships with social services departments (6.21).

Spiritual support
Patients and carers are offered information about spiritual support services (7.17).

General palliative care, including care of dying patients
Policies for the transfer of relevant clinical information between daytime and out-of-hours services are developed (8.27).

Rehabilitation
Arrangements are made for patients to have their rehabilitation needs assessed (10.22)

Allied health professionals are part of site-specific multidisciplinary team meetings as appropriate (10.29).

Services for families and carers, incorporating bereavement care
Families and carers have regular opportunities to discuss their concerns with team members (12.20) and are offered information on a variety of topics (12.22).

They can offer families and carers information and training on practical care issues (12.29).

F. Individual Health and Social Care Professionals

In order to help achieve quality care for patients and carers, individual health and social care professionals must:

Have necessary skills to conduct assessments in partnership with patients and carers, or ensure that another competent health or social care professional carries out relevant assessments, and work in partnership with patients and carers to meet their needs (1.18)

Document accurately patients' identified needs (1.19)

Make necessary referrals to other services (1.23)

Communicate with other members of the multidisciplinary team (1.26)

Ensure they have the necessary education and training and ongoing support and supervision to meet the needs of patients and carers under their care (1.22).

G. Workforce Development Confederations/the Workforce Development Steering Group

Workforce Development Confederations/the Workforce Development Steering Group (working with Cancer Networks) should:

Assess the need for, and plan the development of, each of the professional groups who contribute to supportive and palliative care.

Make provision for skills training in the assessment of needs of patients, families and carers both generally, and specifically, in relation to:
- psychological care
- social care
- spiritual care
- information needs and preferences
- cultural diversity.

In addition, they should ensure that:

Face-to-face communication
Accredited training courses on communication skills are made available for staff (3.25) and, in collaboration with Cancer Networks, staff groups are prioritised for communication training (3.27).

General palliative care services, incorporating care of dying patients
All relevant staff are trained in best practice regarding the care of dying patients (8.42).

Priorities for training community staff in palliative care are identified (8.39).

Rehabilitation
Education and training provision is adequate to meet the demands of the four-level model of rehabilitative assessment and support (10.32).

Appendix 1

How the Guidance was Produced

User involvement

A1 The involvement of people with cancer and their carers has been central to the process of producing the Guidance. Among their contributions has been:

- involvement in the initial proposal-generating event and a parallel survey of service users carried out by Cancerlink to guide and inform the Guidance development process
- active participation on the Editorial Board (Appendix 2.1) with two service-user members, including a representative from Cancerlink
- representation on a User Reference Group (Appendix 2.2) who met twice during the process and commented and contributed to successive drafts of the Guidance
- significant involvement at different consultation stages prior to publication of the Guidance.

Stages in the process

A2 The first stage was a two-day residential event at which a large group of relevant health and social care professionals, people with personal experience of cancer, healthcare commissioners and academics from around the country met to put forward structured proposals based on their experience and knowledge. The proposals were set out in a common format, which included key elements such as the evidence on which they were based, implications for the NHS, and relationships to outcomes.

A3 The proposals were sent to referees representing a spectrum of clinical opinion, those likely to use the eventual guidance, and organisations and individuals representing the concerns of patients and carers. The original proposals and referees' comments then went forward to the evidence review stage.

A4 The Editorial Board, who oversaw the development of the Guidance, reflected on the proposals and relevant comments from referees with the Guidance Development Team (Appendix 2.3) and drafted preliminary recommendations designed to inform and direct the task of reviewing the literature. This evidence was assessed by the Editorial Board and was used to further refine the recommendations. At a relatively early stage in Guidance development, the recommendations were also scrutinised by two sets of reference groups, one of representatives of commissioners and providers (Appendix 2.4) and the other of service users (Appendix 2.2). An Allied Health Professional (AHP) reference group (Appendix 2.5) was also established to review the Guidance during development.

A5 The guidance was subject to the NICE consultation process (see NICE website for details – www.nice.org.uk). In addition, a number of individuals were invited to comment by the Guidance Development Team (see Appendix 2.1).

DRAFT FOR 2ND CONSULTATION

The evidence review

A6 Systematic reviews of the research literature were then carried out by the Evidence Review Team (Appendix 2.6) based at the Department of Palliative Care and Policy, King's College, London.

A7 The task of the Evidence Review Team was to prepare a systematic assessment of the nature and strength of the evidence underlying the recommendations developed by the Editorial Board and Guidance Development Team, based on the original proposals. This work is summarised in *The Research Evidence*.

A8 The quality of individual research studies was graded following the criteria listed in Table A.1. This is the same system used in the reviews undertaken by the NHS Centre for Reviews and Dissemination at the University of York as part of the site-specific *Improving Outcomes* series[1].

Table A.1 Evidence grades	
Grade I (strong evidence) – randomised controlled trial or review of randomised controlled trials	
Ia	Calculation of sample size and standard definition of outcome variables
Ib	Accurate and standard definition of outcome variables
Ic	Neither of the above
Grade II (fairly strong evidence) – prospective study with a comparison group (non-randomised controlled study or good observation study)	
Iia	Calculation of sample size and accurate, standard definition of outcome variables and adjustment of the effects of important confounding variables
Iib	One of the above
Grade III (weak evidence)	
IIIa	Comparison group, calculation of sample size and accurate, standard definition of outcome variables
IIIb	Two or more of the above
IIIc	None of these
Grade IV (weak evidence) – Cross-sectional study	

A9 The quality of combined research was also graded using the hierarchy of evidence employed in the *Improving Outcomes* manuals[1]:

- A – evidence derived from randomised controlled trials (RCTs) or systematic reviews of randomised trials.
- B – evidence from non-randomised controlled trials or observational studies
- C – professional consensus.

A10 These are broad categories and the quality of evidence within each category varies widely. It should not be assumed that RCT evidence (Grade A) is always more robust than evidence from observational studies (Grade B).

A11 The quality of research evidence forms a continuum. It is categorised here for convenience, but there is overlap between categories. Much of the published research on supportive and palliative cares focuses on clinical evaluations of treatment and care; little direct research has been carried out on the organisation and delivery of services. Moreover, as previously recognised in the site-specific guidance series for many service delivery issues, randomised controlled trials (categorised here as the highest quality evidence) may not be feasible. Research designs that might be regarded as being of relatively poor quality for evaluating a clinical intervention may therefore be the most reliable available for assessing the effectiveness of service delivery.

A12 Complementary research, designed to quantify the potential cost of implementing key aspects of the guidance, was carried out by the School of Health and Related Research (ScHARR) at the University of Sheffield (see Appendix 2.3).

Outcomes of the process
A13 The process culminated in the production of three large sources of information: *The Guidance Manual*, which is based on all the available sources of information; *The Research Evidence,* a condensed version of systematic reviews of research used to inform the guidance and published in electronic format *[website address to come]*; and *The Economic Analysis,* also published in electronic format. The recommendations are also available in a version for the public.

A14 The production of the guidance was funded by the National Institute for Clinical Excellence (NICE).

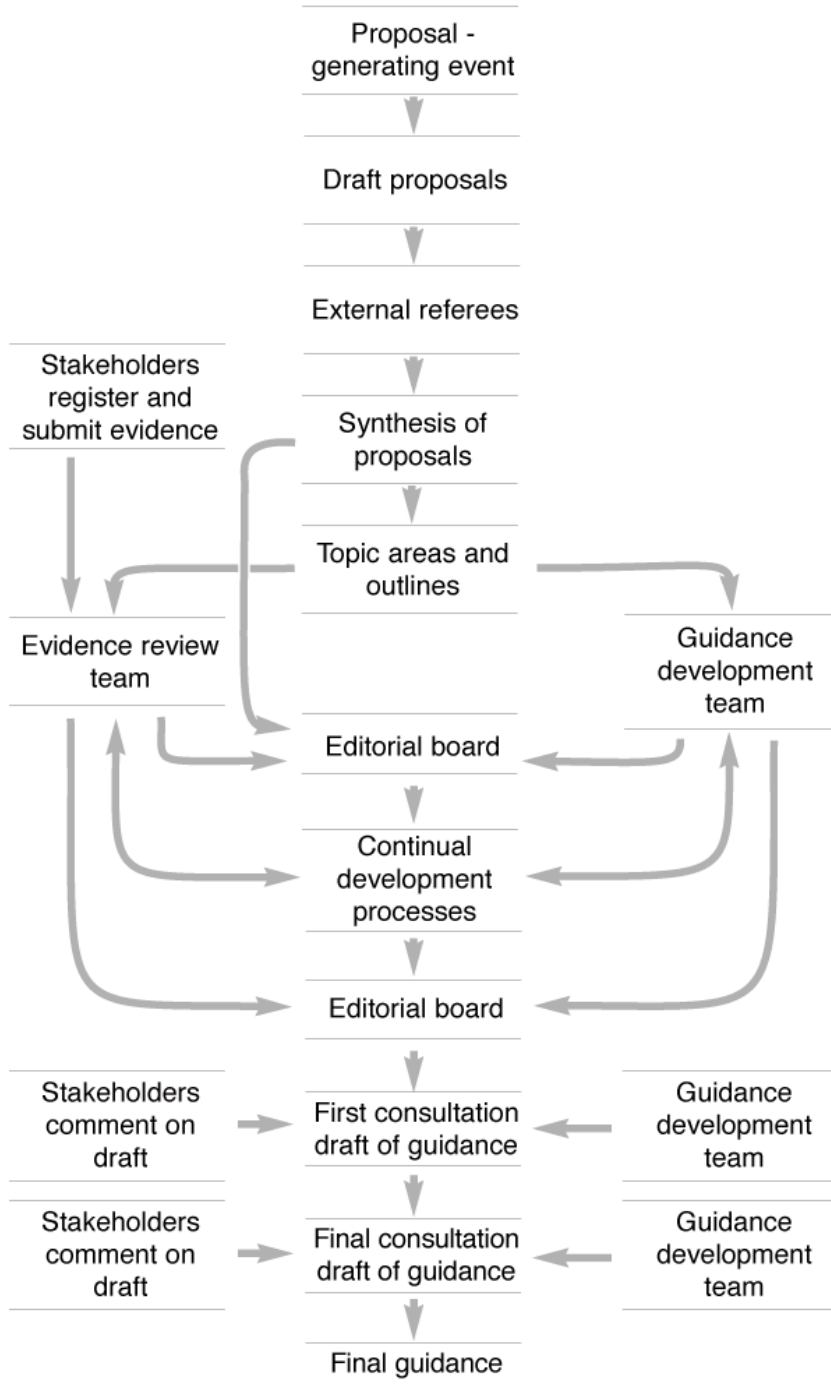A15 Figure A.1 (over) depicts key stages in the development of the Guidance.

Reference
1. Mann T. *Clinical Guidelines: using clinical guidelines to improve patient care within the NHS.* London: DoH. 1996.

Figure A.1

Overview of development of supportive and palliative care guidance

Appendix 2

People and Organisations Involved in Production of the Guidance

1. Editorial Board

2. User Reference Group

3. Guidance Development Team

4. Commissioner and Provider Reference Group

5. Allied Health Professionals Reference Group

6. Evidence Review Team

Appendix 2.1

Membership of Editorial Board

Ms Silvia Berry	Liverpool Cancer Support Centre
Ms Maggie Bisset	Nurse Consultant in Palliative Care, Camden and Islington Primary Care NHS Trust
Ms Jane Bradburn	Cancer Voices Consultant, Macmillan Cancer Relief
Dr Ged Corcoran	Macmillan Consultant in Palliative Medicine, University Hospital, Aintree
Prof. Lesley Fallowfield	Cancer Research UK Psychosocial Group, University of Sussex
Ms Kim Fell	Nottingham Cancer Centre Manager, Nottingham City Hospital and Queen's Medical Centre, Nottingham
Dr Rob George	Consultant in Palliative Medicine, Camden and Islington Primary Care NHS Trust
Ms Maureen Hunter	Assistant Director, Rehabilitation, The Royal Marsden Hospital NHS Trust, London
Dr Stephen Kirkham	Consultant in Palliative Medicine, Poole Hospital NHS Trust, Dorset
Prof. Sheila Payne	Professor in Palliative Nursing Care, Trent Palliative Care Centre, University of Sheffield
Prof. Amanda Ramirez	Professor of Liaison Psychiatry, Guy's, King's and St Thomas' School of Medicine, London
Prof. Mike Richards	National Cancer Director, Department of Health
Ms Frances Sheldon	Macmillan Senior Lecturer in Psychosocial Palliative Care, Department of Social Work Studies, University of Southampton
Mr Stewart Sinclair	Carer
Rev. Peter Speck	Former chaplaincy team leader, Southampton University Hospital NHS Trust and Hon.Senior Research Fellow, King's College, London
Dr Keri Thomas	Macmillan GP Advisor, National Clinical Lead for Palliative Care, Cancer Services Collaborative
Dr Rob Thomas	Consultant Oncologist, Addenbrooke's NHS Trust, Cambridge

In addition, the following people provided expert advice in relation to specific topic areas during the Guidance development process:

Dr John Ellershaw	Medical Director, Marie Curie Centre Liverpool and Consultant in Palliative Medicne/ Honorary Senior Lecturer, Royal Liverpool University Hospital NHS Trust
Mr Mike Fitzsimmons	Lead Therapist, Carer Services, Department of Palliative Medicine, Guys and St Thomas' NHS Trust, London

Ms Caroline Hoffman	Nurse Consultant (Rehabilitation), The Royal Marsden Hospital NHS Trust, London
Dr Sosie Kassab	Director of Complementary Therapy Services, Royal London Homeopathic Hospital NHS Trust
Ms Patricia Kearney	Director of Practice Development, Social Care Institute for Excellence (SCIE)
Dr Michelle Kohn	Complementary Therapies Medical Adviser, Macmillan Cancer Relief
Dr Barry Muir	Project Manager/Project Lead, Pathology Modernisation and National Cancer Workforce, North East London Workforce Development Confederation
Dr Marilyn Relf	Head of Education, Michael Sobell House, Churchill Hospital, Oxford
Mr Peter Tebbit	National Palliative Care Development Adviser, National Council for Hospice and Specialist Palliative Care

Appendix 2.2

Membership of User Reference Group

Louise Bass, Weston super Mare, Somerset
Tom Bass, Weston super Mare, Somerset
Sylvia Berry, Liverpool Cancer Support Centre
Andy Caswell, Rushden, Northants
Anna Craven, Skipton, North Yorkshire
Sara Crisell, Harwich, Essex
Jeremy Gambrill, Cuckfield, West Sussex*
Devi de Silva, London
Denise Fuller, Horsham, West Sussex
Heather Goodare, Horsham, West Sussex
Steve Hawley, Bromley, Kent
Denise Hodkin, Rotherham, South Yorkshire
Margaret King, UK Breast Cancer Coalition
Hannah Lynes, Special Projects Officer, Help the Hospices
Pete Madeley, Cottingham, East Yorkshire
Delyth Morgan, Breakthrough Breast Cancer
Joyce Pritchard, RAGE, Bromley, Kent
Lindi Shaw, Rotherham, South Yorkshire
Stewart Sinclair, London
Barry Stables, Scarborough, Yorkshire
Jayne Thomas, User Involvement Co-ordinator, National Council for Hospice and
Specialist Palliative Care Services

The User Reference Group was facilitated by Mrs Jo Luthert, Healthcare Consultant, London, and Ms Jane Bradburn, Cancer Voices Consultant, Macmillan Cancer Relief and attended by Damyanti Patel, Ethnic Minority Network Development Officer, Macmillan Cancer Relief.

*Sadly, Mr Gambrill died before the Guidance could be published.

Appendix 2.3

Guidance Development Team

Prof. Alison Richardson	Professor of Cancer and Palliative Nursing Care, The Florence Nightingale School of Nursing and Midwifery, King's College, London (Lead)
Ms Jane Bradburn	Cancer Voices Consultant, Macmillan Cancer Relief
Mrs Jo Luthert	Healthcare Consultant, London
Mr Alex Mathieson	Freelance Writer and Editor, Edinburgh
Dr Ann Richardson	Independent Research Consultant, London.

The economic analysis was commissioned from the School of Health and Related Research (ScHARR), University of Sheffield:

Ms Sue Ward	Senior Operational Research Analyst, Operational Research Department, School of Health and Related Research, University of Sheffield
Mr Stephen Salzano	Senior Operational Research Analyst, Operational Research Department, School of Health and Related Research, University of Sheffield
Ms Fiona Sampson	Research Fellow, Medical Care Research Unit, School of Health and Related Research, University of Sheffield
Ms Johanna Cowan	Operational Research Assistant, Operational Research Department, School of Health and Related Research, University of Sheffield

Appendix 2.4

Membership of Commissioner and Provider Reference Group

Dr Sheila Adam	Director of Public Health, North London SHA
Ms Elizabeth Andelin	Assistant Director of Patient Services, Bradford City PCT
Prof. Mark Baker	Director/Lead Cancer Clinician, Yorkshire Cancer Network
Dr Simon Balmer	Director of Public Health, Leeds North East PCT
Ms Judith Brodie	Head of Cancer Support Services, CancerBACUP
Mr Chris Bull	Chief Executive, Southwark PCT
Ms Penny Buchan	Director of Nursing and Health Improvement, Colchester PCT
Mr Derek Campbell	Chief Executive, Central Liverpool PCT
Ms Liz Cheesman	Senior Cancer Information Nurse, Cancer BACUP
Dr Jane Chidgey	Lead Cancer Nurse, North East London Cancer Network
Ms Lisa Christensen	Executive Director, Social Services and Health Improvement, Lambeth Social Services
Dr Susan Closs	Consultant in Palliative Medicine/ Clinical Director for Cancer Services, Swansea
Ms Maggie Crowe	Nurse Consultant, Royal United Hospital, Bath
Ms Moira Davison	Director, Northern Cancer Network
Dr Peter Elton	Director of Public Health, Bury PCT
Dr Andrew Fowell	Macmillan Consultant in Palliative Medicine, Bodfan Eryri Hospital, Caernarvon
Mr Mark Gilmore	Lead Nurse, North West Midlands Cancer Network
Ms Julie Gorry	Chief Executive, Willowbrook Hospice, Merseyside
Dr Jane Halpin	Lead Clinician, Mount Vernon Cancer Network
Ms Liz Holford	Assistant Director – Workforce Strategy (Acute), North East London Education and Workforce Confederation
Ms Katherine Hopkins	Lead Nurse for Palliative Care, The Royal Free Hospital, London
Mr Liam Hughes	Chief Executive, East Leeds PCT
Mr Patrick Keane	Head of Strategy, Policy and Planning, Northumberland, Tyne and Wear SHA
Mr Kevin Keogh	Centre Manager, Marie Curie Centre, Edenhall, London
Mr Mark Lyles	Cancer Lead, Bradford City PCT
Dr Chantal Meystre	Clinical Director, Myton Hamlet Hospice, Warwick
Mr David Oliviere	Director of Education, St Christopher's Hospice, London
Ms Joanna Paul	General Manager: Medical Directorate and Lead Cancer Manager, St Mary's Hospital, London
Prof. Malcolm Payne	Director of Psychosocial and Spiritual Care, St Christopher's Hospice
Mrs Judith Powell	Matron, Wakefield Hospice
Dr Cliff Richards	Primary Care Cancer Lead, Runcorn, Cheshire
Mr Steve Richards	Head of Service Development, Macmillan Cancer Relief

Mr Steve Salzano	Senior OR Analyst, School for Health and Related Research, University of Sheffield
Dr Richard Scheffer	Medical Director/Consultant in Palliative Medicine, Rowcroft Hospice, Torquay
Dr Greg Tanner	General Practitioner, Bridgwater, Somerset
Mr Peter Tebbitt	National Palliative Care Development Adviser, National Council for Hospice and Specialist Palliative Care
Dr Adrian Tookman	Lead Clinician, North London Supportive and Palliative Care Network
Dr Julia Verne	Consultant in Public Health Medicine, Government Office for the South and West
Ms Jan Watkins	King's College, London

The Commissioner and Provider Reference Group was facilitated by Ms Susan O'Toole, Consultant in Health Policy and Management, supported by Mrs Valerie Saunders, Manager, Northern and Yorkshire Cancer Registry and Information Service.

Appendix 2.5

Membership of the Allied Health Professionals Reference Group

Ms Caroline Badger	The British Lymphology Society
Ms Jo Bray	Occupational Therapists in HIV/AIDS, Oncology and Palliative Care (HOPE)
Ms Debbie Collins	Society and College of Radiographers
Ms Jill Cooper	Occupational Therapists in HIV/AIDS, Oncology and Palliative Care (HOPE)
Ms Lucy Eldridge	British Dietetic Association Oncology Special Interest Group
Ms Kim Fell	Guidance Editorial Board member
Ms Maureen Hunter	Guidance Editorial Board member
Ms Julie Neden	British Dietetic Association Oncology Special Interest Group
Ms Jo Patterson	The Royal College of Speech and Language Therapists Head and Neck Special Interest Group
Ms Gillian Percy	Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)
Ms Lena Richards	Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)

The Allied Health Professionals Reference Group was facilitated by Mrs Jo Luthert, Healthcare Consultant, London.

Appendix 2.6

Evidence Review Team

Prof. Irene J. Higginson	Head of Department, Department of Palliative Care and Policy, Guy's, King's and St Thomas' School of Medicine King's College London (Lead)
Dr Marjolein Gysels	Research Fellow, Department of Palliative Care and Policy Guy's, King's and St Thomas' School of Medicine King's College London (Lead Researcher)

Input to specific Topic Areas:

Ms Kirsty MacCormack	Research Fellow, Department of Palliative Care and Policy Guy's, King's and St Thomas' School of Medicine King's College London.
Dr Meera Rajasekaran	Specialist Registrar, Department of Palliative Care and Policy Guy's, King's and St Thomas' School of Medicine King's College London.
Dr Jean Potter	Research Fellow, Department of Palliative Care and Policy Guy's, King's and St Thomas' School of Medicine King's College London.
Dr Elisabeth Davies	Clinical Senior Research Fellow, Department of Palliative Care and Policy Guy's, King's and St Thomas' School of Medicine King's College London.
Mr Richard Harding	Research Fellow, Department of Palliative Care and Policy Guy's, King's and St Thomas' School of Medicine King's College London.