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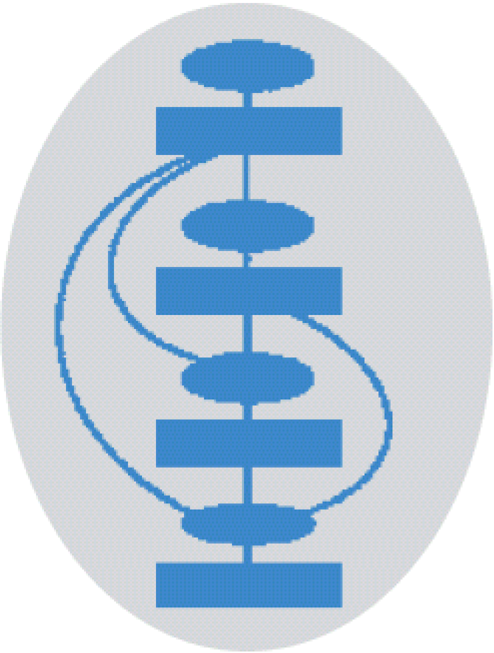
Clinical Excellence

Guidance on Cancer Services

Improving Supportive and Palliative Care for Adults with Cancer

Economic Review



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Related Research

Guidance on Cancer Services

Improving Supportive and Palliative Care for Adults with Cancer

Economic Review

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1. Introduction

1.1 Background

Evidence-based Guidance has been developed to define optimal service models to ensure that patients with cancer, their families and other carers receive high quality support to help them to cope with cancer and its treatment. Before commissioners and Trusts can implement this Guidance, they need to assess the cost implications of the recommendations. This report sets out this information.

1.2 Aims and Scope

This Economic Review estimates the cost implications of adopting the Guidance both at a Cancer Network level and for England and Wales as a whole. Like the Guidance itself, it focuses solely on adults with cancer and covers all settings in which care may be delivered.

The Economic Review does not attempt to cost all aspects of the Guidance. Major issues are identified and prioritised, based on the likely scale of the economic impact of implementation. It does not attempt to consider the cost-effectiveness of Guidance implementation, given the limited available evidence on outcomes.

Funding issues relating to the split of funding between the NHS and voluntary sector are beyond the remit of this report. The review considers the cost of implementing the Guidance, but not where the costs will fall.

Social support services, such as respite care and assisted transport, which straddle Social Services and NHS-funded provision as well as voluntary sector provision, are not costed, as Guidance in this area (and its consequent cost implications) is not solely the remit of the National Institute for Clinical Excellence (NICE).

Training and workforce implications of the Guidance are not addressed in detail. Costs associated with audit and monitoring activities are not considered, since specific audit and measurement requests are not mandatory in the Guidance. It is assumed that any costs related to audit and monitoring activities will be borne by providers and commissioners as part of their general activity.

1.3 Methods

1.3.1 Integration of Economic Review with the Guidance

The research on cost implications was developed in parallel with the production of the Guidance. Members of the ScHARR team attended the Editorial Board meetings, facilitating a full understanding of the Guidance as it developed.

1.3.2 Literature and data searching

Literature searches were carried out to identify any existing costing exercises, audits of cancer activity, cost of illness studies or models of treatment pathways.

Limited costing data were found in the UK literature. Although there are some non-UK studies of costs, their relevance is questionable due to differences in treatment patterns and service, funding and cost structures. Reviews of the literature on cost effectiveness found extremely limited evidence. There was also insufficient evidence on which to base a calculation of health benefit, quality of life or other benefits arising from implementation of the Guidance.

Key data sources included the Minimum Data Set[1]. Clinical and nurse staff costs are taken from Netten *et al*[2]. All staff costs include salaries and on-costs.

1.3.3 Discussions with clinicians, other key professionals and service users

Advice was sought from the Editorial Board and the Guidance Development Team to ensure that appropriate assumptions were made and data sources identified, as well as to assist in the interpretation of data. Numerous additional clinicians and business managers were contacted to discuss their current activity and the likely resource implications of Guidance implementation.

Input for the section on user involvement was provided by Macmillan Cancer Relief, including user representatives involved with its User Reference Group.

1.3.4 Identification of key cost issues

ScHARR used the Guidance, Editorial Board discussions, preliminary data analysis and consultations with both clinicians and service managers to identify and prioritise the key cost issues. Sections 2.1 to 2.12 set out the key cost issues associated with each chapter of the Guidance. In many, but not all, cases these match the key recommendations identified in the Executive Summary of the Guidance Manual.

1.3.5 Cost analysis and modelling approach

For each of the key issues, an estimate of the local and national cost consequences is made. The approach adopted for each issue is detailed in the relevant section.

Previous economic modelling work by the School of Health and Related Research (ScHARR) at the University of Sheffield[3] on the cost of providing a high quality specialist palliative care service in England was extended to consider the overall cost of providing a full range of supportive and palliative care services. The supportive and palliative care model estimates the cost of service provision for a hypothetical Cancer Network with a population of 1.5 million. Further details of the model are included in Appendix 1.

Staffing costs represent the principal cost component for supportive and palliative care services. For the majority of service components, the model estimates the volume of clinical staff (nursing, medical and other health professionals) required to deliver the services recommended. Assumptions regarding appropriate future staffing levels are taken from published recommendations, where available (e.g. Palliative Care 2000[4]; Cameron Report 1996[5]), or from a range of experts in supportive and palliative care. All staff costs are based on NHS salaries, using the mid point of the pay spine per staff type grade unless indicated otherwise. The impact of the Agenda for Change and the European Working Time Directive on future staffing levels is not known with certainty and will vary by Cancer Network.

Other costs (including ancillary staff, overheads, depreciation etc) are estimated for each service component as a fixed proportion of the total costs.

The cost of implementing the Guidance will vary by Cancer Network, depending on existing service levels and configurations. Estimates of the cost of future provision are based on a series of working assumptions regarding the level of service provision, the model of future provision adopted and the associated staffing levels required to achieve the recommendations. Inevitably, it has been necessary to make more detailed assumptions than those in the Guidance itself. These assumptions should not be taken as recommendations regarding the appropriate service configuration for all Networks, but rather as illustrations of one option for achieving the Guidance recommendations. It is anticipated that different Networks will meet the recommendations in different ways.

Current expenditure on many elements of palliative and supportive care services is not known with certainty. For specialist palliative care services, an estimate of total current costs of provision is given. The predicted total future cost of all service components is then compared with this estimate, in order to identify the overall incremental cost of implementing the Guidance recommendations. However, for general palliative care services, as well as for supportive care services, the current cost of provision is not known. Therefore, the costs presented for these services represent, unless otherwise stated, the total cost of service provision, rather than the incremental cost (cost impact) of the Guidance.

Given the variety and complexity of service configuration and the lack of data on the volumes and costs of current provision, it has been possible to provide only crude cost estimates. In some instances, only preliminary estimates are provided, with areas identified for future work, beyond the scope of this project, to allow more robust estimates to be produced.

All costs are adjusted to 2002-03 levels.

1.3.6 Structure of the report

This report addresses the major cost implications of each chapter within the Guidance (sections 2.1 to 2.12). As many issues pertain to more than one chapter, they are considered in the chapter where the topic is most central.

Education and training issues are considered in section 2.13, but those with a potentially significant cost implication are listed in sections 2.1 to 2.12.

In section 3, the costs of supportive and palliative care provision from the economic model are presented together, along with a discussion of the results.

2. Economic Issues

2.1 Co-ordination of Care

2.1.1 Background

Patients with cancer need to access a range of health and social care services throughout the patient pathway. They may come into contact with service providers in primary care, secondary care and social care, as well as various voluntary organisations. Well co-ordinated services are essential to allow the needs of patients to be recognised and met by whichever service they require.

Current services are inadequate for a number of reasons:

- Inadequate assessment of patients' needs, leading to patients not obtaining services they require;
- Lack of services in some localities, alongside unnecessary duplication of services in other areas, leading to confusion between service providers and the waste of resources;
- Poor communication between different care sectors, leading to service delays and failure to meet patients' needs.

2.1.2 Cancer Network lead for development of supportive and palliative care services

Guidance Key Recommendation: Within each Cancer Network, commissioners and providers (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.

Specifically the guidance recommends that Cancer Networks should nominate an individual (or individuals) at Cancer Network-level to lead on supportive and palliative care, reporting to the Cancer Network management board. Cancer Networks are already working to improve local supportive and palliative care services, although the degree to which a planning structure and process is in place varies between them. The main financial implication here is likely to arise from the appointment of an individual to formalise this structure and process.

Currently, this task is largely being undertaken by staff within the remit of their job or on a 'good will' basis. Following implementation of the Guidance, this role may be formalised with the creation of a part-time or full-time post to plan and review services in each Network. The cost of employing an extra person half-time or full time for each Network is therefore included (Table 1).

Table 1: Annual cost of a nominated individual to lead the development of supportive and palliative care services

Cost element	Assumptions/sources	Cancer Network	England & Wales
Individual to lead development of specialist palliative care services	0.5 - 1 wte person per Network. Whitley pay scale I grade (£34,721 incl on-costs).	£17,400 - £34,700	£0.6m - £1.2m

2.1.3 Network-based service directories

Guidance Recommendation: 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, other statutory and voluntary organisations, professionally-led support groups, self-help and peer-to-peer support groups, and local and national telephone helplines.

Some Cancer Networks already have local directories and the costs involved will be those of updating and redistributing the directories. Other Networks need to set up service directories from scratch and may not have any infrastructure for doing so.

A database and infrastructure for setting up Network service directories, together with a web-based CancerSupportUK resource directory, has been developed by the South West London and West London Cancer Networks[6]. This sets out the processes needed to create a printed or web based directory from scratch, as well as the structure and format of the printed directories and website. The infrastructure is intended to be generic for any Cancer Network. If this model were followed, the principal costs for setting up a Network directory would be the cost of time for initial data gathering. Printing and dissemination costs would be similar for the initial directory and for updated directories.

The costs below are those identified for the production of a Network service directory from scratch. The costs of purchasing a server, setting up a web template and hosting the website have been omitted, as an alternative package is detailed below.

Table 2: Costs per Cancer Network of setting up, disseminating and maintaining Network service directories.

Cost element	Assumptions/sources	Cost
Planning stage	Consultation with clinical staff consultation groups, co-ordination of working group, development of contracts for writing and collating data	£3,200
Implementation stage	Identification of organisations to contact for details, purchase of database software and PC for data input, questionnaire design and administration, database design, data input, data validation and editing of content supplied by members of clinical team.	£7,700
Production stage (hard copies)	Print design (£3,000), print production (£5,000 - £6,500), promotion (£500), dissemination (£4,000).	£13,250
Setting up Network website	A package, including training for the data entry procedure and help with setting up an individual Network website, is available from the website team who developed CancerSupportUK.	£1,500
Evaluation stage	Consultation group assessment.	£1,600
TOTAL		£27,250
Updating information	Annual questionnaire and data input. Updating website.	£4,500
Production stage	Print production (£5,000 - £6,500), dissemination (£4,000).	£9,750
TOTAL		£14,250

Source: Macmillan Cancer Relief. March 2003

There will be a significant set-up cost in year one, with ongoing maintenance required in subsequent years. The above costing is based on an annual updating of information, but it is assumed that a new, updated directory will be produced every one to two years.

Assuming that 75% of Networks do not yet have a Network service directory and that every Network prints and distributes a new directory every eighteen months, the annual costs for England and Wales are estimated as follows:

Table 3: Annual costs for setting up and maintaining Network service directories

	Assumptions	England and Wales
Year 1	75% of Networks do not yet have a service directory	£844,000
Years 2+		£351,500

The proportion of Networks currently without a directory is not known with certainty. On the assumption that 50% to 100% of Networks do not currently have a directory, the estimated cost would be between £0.7 m and £1.0 m respectively. The ongoing year 2+ costs of maintaining directories would remain the same.

This is the cost of a full Network service directory, available at all locations where patients access services, for patients to consult. Shorter directories, with details of how to access key services, such as local support groups and information services, might be developed within each Network, but these have not been costed.

2.1.4 Assessments

Guidance Key Recommendation: Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (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.

Assessments are currently carried out, but it is assumed that few are undertaken in a uniform, systematic fashion or shared between professional groups.

Future assessments are likely to be undertaken primarily by nursing staff, although other healthcare professionals may also carry them out at different points. It is assumed that changes to the assessment process will not lead to increases in workload, but will bring about a more effective use of current resources. Whilst there may be an increase in the number of 'formal' assessments (particularly around the end of treatment and at recurrence, as these are not routinely undertaken in many settings at present), this is likely to be offset by more effective sharing of data, resulting in reductions in the number of less systematic assessments. Improvements to the assessment process are therefore assumed to be resource neutral.

Effective inter-professional communication is required, both within teams and between them and other service providers with whom the patient has contact. Nomination of individual staff to take on the role of 'key worker' for individual patients will assist in the co-ordination of assessments and ensure continuity of care.

Indirectly, there may be additional – potentially substantial – cost implications from improved assessments, arising from better identification of patients' need for services (e.g. Social Services), which could have a significant cost impact. However, no evidence is available on which to quantify this change.

2.2 User Involvement

2.2.1 Background

It is widely felt that people whose lives are affected by cancer can make significant contributions to the planning, evaluation and delivery of services. Mechanisms are therefore required to ensure that the views of patients and carers are taken into account in the development and evaluation of cancer services. Patient and carer-led activity (such as peer-to-peer support schemes) should be supported as an integral part of cancer care.

Effective user involvement should reflect the diversity of those whose lives are affected by cancer, with views elicited from a range of groups. Service users need to be heard in a range of care settings, including community, acute and hospice settings, and at local, regional and national levels. User involvement may be direct (where users are personally involved in decision making) or indirect (where health professionals gather information about user views). Integrating user voices requires guidelines, resources and an infrastructure to support the process.

The following key resource issues arising from these recommendations have been identified:

- establishment of and support for Partnership Groups, involving patients, carers and clinicians
- the nomination of a lead individual to develop and sustain user involvement for each provider organisation
- payment to users and carers for their time and expenses
- support by provider organisations for self-help and support groups
- training and support for users and professionals in Partnership Groups, including confidence building, representational and committee skills and information about how the NHS is organised and managed with respect to services for patients and carers
- education and training for all health and social care professionals in the importance, general principles and methods of user involvement.

Cost estimates for education and training are considered in Section 2.13: Workforce Development.

2.2.2 Partnership/user groups and self help & support groups

Guidance Key Recommendation: 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 provide one potential mechanism. Systems should be devised to support patients and carers to participate in their own care, featuring a range of informal support opportunities such as self-help activities and peer support schemes within community settings.

Partnership/user groups

Partnership and user groups require funds to pay users' expenses, venue costs, publicity, administration and facilitation. The cost of supporting a Partnership Group was estimated at £25,000 in 2001[7]. Currently, this is provided through the Cancer Partnership Project, a joint initiative between Macmillan Cancer Relief and the Department of Health (MCR contributing £5,000 p.a.[a], and DH contributing £10,000 p.a., to each Partnership Group, with an expectation that local Cancer Networks would provide a further £10,000 p.a.). In practice, funding has been patchy and many Cancer Networks have felt significantly under-resourced. The Department of Health funding ends in April 2003 and the project comes to a close in March/April 2004.

It is assumed that funding for a Partnership Group at Cancer Network level is maintained at £5,000 p.a., and funding for the Partnership Group facilitator is increased to £30,000 p.a. to ensure appropriate support to the Group. The total funding assumed for the Partnership Group is therefore £35,000 p.a., covering venue costs, publicity, administration, and facilitation.

Table 4: Cost estimates for partnership/user groups

Partnership/User Groups	Cancer Network	England and Wales	Assumptions/sources
support	£0.005m	£0.17m	£5,000 per annum provides for support for venue costs, publicity, administration and facilitation.
support for facilitator	£0.030m	£1.04m	1 wte on Whitley pay scale G/H (assumed to be £30,000 p.a. including on-costs) would carry out the following roles: • user involvement facilitator for the Partnership Group • work through others nominated at unit and centre level who will have overview/oversight at the local provider level

Self help and support groups

Guidance Recommendation: Provider organisations should work with local self-help and support groups to establish the most effective ways of supporting their activities. Such support might help to pay for meeting rooms as well as training and support for group leaders, co-ordinators and managers.

Self-help and support groups are voluntary organisations, ranging from small groups of users who meet regularly to large organisations employing a number of staff. They carry out a range of activities to

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[a] The £5000 from Macmillan was to pay for members' individual expenses, publicity, venues such as a local community centre, support for outreach and to encourage both new members and more diverse user involvement.

support people with experience of cancer. Across the UK, there are over 700 such organisations; approximately 550 of these are in England, with 12,000-15,000 active members. The services provided by such groups include peer-to-peer support, advocacy, carers support, level 1 psychological support, social support and services for families. Larger groups may run projects, such as providing advice on welfare benefits. Groups often meet needs not assessed as priorities by others, such as transport to and from hospital or low cost complementary therapies.

Although most groups seek to raise their own funds, raising core costs can be a particular difficulty; this can deplete energies and take time away from supporting people. Smaller groups may require funding to help them to start-up, as well as meeting the costs of a venue and general administration. Larger groups may require funding for premises, staff, administrative costs, service delivery and project support. They may also require support for capacity building, such as advice, training, or consultancy in fund-raising.

A recent study[8] found that the costs of running self help groups varied enormously, between £750 and £400,000 per annum, depending on the type of support offered. Typical costs were £10,000 - £60,000 per annum. Simple meeting costs varied from nil, where small groups used NHS facilities, to £5,000-£7,000 per annum for community facilities. Larger groups employ staff to facilitate service development; salaries then become the most significant component of expenses. A medium level group with some service development could have salary costs of £25,000-£40,000 per annum. Further research on the costs of such groups in relation to their level and quality of service provision would be useful. There will also be costs for training professionals to facilitate these groups, where desired.

Flexible resources may need to be made available locally to help cancer self-help and support groups to play an active part in helping patients and carers. It is recommended that commissioners consider possible frameworks for supporting their activity. One option would be the provision of statutory funding to self-help and support groups who are willing to be formally accredited, possibly through the Community Network Team at Macmillan Cancer Relief.

No specific assumptions have been made regarding the resource implications of self-help and support groups in this Review. However, it is recommended that Commissioners give consideration to possible frameworks for supporting the activity of self-help and support groups within their local area. Further research is needed in this area.

2.2.3 Lead individuals

Guidance Recommendation: Provider organisations should nominate an individual to take the lead on developing and sustaining user involvement.

It is assumed that no additional monies are required for the lead user involvement individuals nominated by each provider organisation.

2.2.4 User expenses and time

Guidance Recommendation: Provider organisations should develop mechanisms to ensure that 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, available resources and expertise available and preferences of users involved.

User Expenses

In order to ensure that equity of access to systems for user involvement is achieved, it is assumed that cash reimbursements for expenses should be available for those who need it. In practice, some users do not claim expenses or payments even if these are available, as they feel they are 'doing their bit'.

An estimate from one Cancer Network suggests that reimbursement of users' travel expenses alone costs approximately £10,000 per annum. Many users also have caring responsibilities (for elderly relatives or for children) which would need to be paid for.

It is assumed that £10,000 p.a. is a minimum sum needed to cover users' expenses (for travel, childcare etc.) for a hypothetical Cancer Network of 1.5 million population.

Users' time

The question of payment for users' (or carers') time is more problematic. A recent survey[9] amongst users themselves found little consensus, but a fee for participation was considered appropriate where advance preparation, such as analysis of lengthy papers, is required of members of a formal committee. Speaker fees for users at conferences, was also considered appropriate in some circumstances. Information might usefully be gathered on existing practice. The Department of Health's guidelines on fees for 'lay'/voluntary sector participants in its committees could be used as a guide (approximately £130 per day).

Some users are also engaged in teaching programmes for medical students and other health professionals and these activities should be appropriately reimbursed. CancerVOICES Regional Contacts receive £100 a day for giving presentations and workshops.

It is assumed that Cancer Networks will allocate a sum to pay a modest fee to experienced user representatives for involvement in activities requiring a greater degree of expertise. The cost estimate is based on the cost of one expert activity per week in every Cancer Network, with the overall cost of £5,000 per Network per annum.

Table 5: Cost estimates for user expenses and time

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
Users’ expenses	£0.010m	£0.35m	£10,000 p.a. is assumed as the minimum amount for users’ expenses (for travel, childcare etc.) for a hypothetical Cancer Network of 1.5 million population.
Users’ time	£0.005m	£0.17m	One expert activity every week required in every Cancer Network: approximately £100 x 50 weeks = £5,000 per Network per annum.

2.3 Face to Face Communication

2.3.1 Background

High-quality face-to-face communication with health and social care professionals is essential for patients to obtain good information about their disease and its treatment at all stages. It is also important for family and other carers. Good communication will increase patients' ability to participate in decision-making, improve their understanding of the disease and enhance their quality of life. Professionals may lack the necessary skills to communicate effectively with patients from minority ethnic backgrounds or those with hearing, sight or combined sensory disabilities, learning disabilities or speech and communication disabilities/difficulties.

Recommendations identified as requiring significant additional resources include:

- Offering patients a permanent record of important points arising from consultations;
- Provision of skilled interpreters and services for people with hearing, sight or combined sensory disabilities, or speech and communication disabilities/difficulties;
- Training for staff in communication skills.

2.3.2 Permanent record of consultations

Guidance Key Recommendation: The outcome of consultations in which key information is 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.

The use of permanent records appears to be limited, both in the UK and elsewhere. The permanent record could take a number of forms, including a copy of the letter written to the referring doctor/GP, an individualised summary letter, an audiotape recording of the consultation or a video recording of the consultation. Although practice may be changing, many doctors seem to oppose the idea of offering patients a record of their consultation, so that the introduction of routine provision of such records may be slow [10,11].

The number of consultations at which key information is discussed depends upon the type of cancer and the course of treatment required. It is estimated that there will be an average of five consultations where the patient may wish to refer back to the consultation. Personal communication suggests that not all patients want records of consultations, nor do they want summaries of key points. No studies on the uptake of records by patients were identified.

The Guidance does not state which form of record should be used. Studies comparing the use of consultation audiotapes and summary letters suggest that both are useful to cancer patients in reviewing information and communicating information to family and friends[11,12]. There is therefore no clear evidence as to what option should be used; doctors assign greatest value to providing a copy of the letter to the referring doctor/GP and least value to an audiotape recording, while patient preferences are the reverse. The proportion of patients who might be offered each type of consultation is therefore not known.

Estimates are provided of the cost of providing three types of permanent record to patients:

- copy of the letter to the referring doctor/GP - estimated as the cost of secretarial support for copying and sending out letter (assumption of one hour per 10 letters) plus postage and stationery costs;
- individualised summary letters - estimated as the cost of clinician time in dictating letter (assumption of one hour per 10 letters), the cost of secretarial support for typing up and sending out letter (assumption of 2 hours per 10 letters), plus postage and stationery costs;
- taped consultations - estimated as the cost of a tape machine for each clinician discussing key information (assumption of one tape machine for each consultant and registrar in palliative medicine, clinical oncology and medical oncology - see section 2.13. for staff numbers), plus the cost of tapes (assumption of 2-3 tapes per patient, as can re-use tapes, with an average 28 minutes consultation[12]).

Table 6 provides estimates of the total cost of all patients taking up each option and therefore should not be totalled.

Table 6: Cost of providing every patient with a recording of 5 key consultations – three alternative scenarios.

	Assumptions	Cancer Network	Cost England and Wales
Copy of written letter	No additional consultant time. Additional secretarial time: 0.1 hours per letter (Admin Whitley 3, mid point @ £8.70 per hour incl. on-costs). Postage and stationery costs £0.25 per letter.	£43,000	£1,493,000
Individualised written summary of consultation	Additional consultant time: 0.1 hours per letter (@ £54.46 per hour incl. on-costs). Additional secretarial time: 0.2 hours per letter (Admin Whitley 3, mid point @ £8.70 per hour). Postage and stationery costs £0.25 per letter.	£285,500	£9,914,000
Taped consultation	Tape machines for each clinician @ £25 each. 2.5 tapes per patient @ £0.50 each	£10,400	£360,000
	Subsequent years (cost of tapes alone)	£9,600	£333,000

Not all patients will wish to receive records and a mix of options will be used in practice.

Assuming 75% uptake, with one third of patients taking up each of the options, the total cost would be £84,700 per Cancer Network and £2.9 million for England and Wales. Based on uptake rates of 50% and 100% the total cost would be £2.0 million and £3.9 million respectively.

2.3.3 Provision of interpreters and services for people with hearing, sight or combined sensory disabilities or speech and communication disabilities/difficulties

Provision of interpreters

Guidance Recommendation: Provider organisations should ensure that for consultations where key information is discussed and important choices made involving individuals whose preferred language is not English or Welsh, or where patients have made a specific request, professional health care interpreters or advocates are always present.

Access to interpreting services may need to be improved in some areas, so that patients are not over-reliant on family or friends to act as interpreters.

Estimating the need for interpreting services accurately is difficult, as many people from ethnic minority groups do not have difficulties speaking English. Moreover, some prefer to use friends or family as interpreters, at least in those situations where the information is not sensitive.

Difficulty in speaking English is greatest among people from Pakistani and Bangladeshi backgrounds, and is higher among older people. One study found that over 54% of South Asian patients had little or no understanding of spoken English, increasing to over 96% for patients aged 65 and over[13]. Although the study's numbers were small, these figures give preliminary estimates for the potential need for interpreters, on an assumption that all patients with little or no understanding of English will require one. For illustrative purposes, three minority ethnic groups have been considered: South Asian, black (including African, Caribbean and other black background groups) and Chinese, as these are the main groups reported within the census. This is likely to overestimate the overall need for interpreters, as the other groups will have lower need than the South Asian group.

The number of consultations for which an interpreter is required will vary considerably, depending upon the degree to which patients wish to use family and friends for this purpose. If this is limited to the main consultations where important information is imparted, this is likely to involve between 3 and 5 consultations.

Table 7: Estimates of need for interpreting service for ethnic minorities.

		Source of evidence	South Asian	Black	Chinese
A	Proportion of population	From Census (NB – for UK, not England)	4.4%	2.2%	0.4%
B	Population	Total England population (Census 2001) * A	2,289,844	1,144,922	208,168
C	% people aged over 65	Age concern (Website address)	8%	10%	9%
D	No. people aged <65	B*(1-C)	2,097,497	1,035,010	189,433
E	No. people aged >65	B*C	192,347	109,913	18,735
F	Estimated incidence for <65	Using incidence per 100k calculated for <65 from cancer statistics	4,291	2,117	388
G	Estimated incidence for 65+	As above	4,119	2,354	401
H	Estimated no. patients needing interpreter <65	Using % S Asian patients with little or no understanding of English from Gerrish *et al.*[13]	1407	694	127
I	Estimated no. patients needing interpreter <65	As above	3986	2278	388

Total no. patients needing interpreter	8,881
Total annual no. consultations requiring presence of interpreter (assuming 5 consultations per person)	44,400.=
Assuming 1 hour per consultation: hours of interpreting service required per Network	1,279
Assume the interpreter will be on the same pay scale and hours as a social worker	1,582.5
WTE interpreters required per Network	0.81
Cost per Network assuming social worker salary including on-costs (per annum cost)	£24,887
Estimate for England and Wales (per annum cost)	£698,411

These assumptions are for medical consultations only. The services of interpreters may also be required in other areas, particularly social support services, including welfare rights advice, detailed discussions on family relationships or contact with family overseas. The provision of interpreters for these consultations has not been costed.

There is no information available on the current level of unmet demand for interpreting services.

Services for people with hearing, sight or combined sensory disabilities or speech and communication disabilities/difficulties

Guidance Recommendation: 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 enable them to participate fully in information exchange.

Patients with learning disabilities are likely to have access to family or other carers with whom they can communicate and it is not clear what additional services they might require. Sign language and similar services tend to be available currently on request; the number of cancer patients who may need such a service is likely to be small. Audiocassette-based and Braille information for patients with sight problems may be available within information centres and is discussed in the section on Information. It is not anticipated that there will be significant cost implications to improvements to services for these patients and the costs have therefore not been considered.

2.3.4 Staff to receive training in communication skills

Guidance Key Recommendation: 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. As this is not always practical, all staff should be able to respond appropriately to patients' and carers' questions in the first instance before referring to a senior colleague.

Cancer Networks 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 must frequently break significant news, explain complex treatment options or discuss end-of-life issues. A national pilot study evaluating an advanced communication skills course for senior health care professionals is currently under way and is expected to report in February 2004. Courses for junior personnel or non-clinical staff are not yet being piloted.

The costs of communication skills training for senior personnel is considered in Section 2.13.

2.4 Information

2.4.1 Background

Patients and carers require high quality information at all stages of their experience with cancer, although different people may want different levels and types of information. There are current concerns that patients are not receiving sufficient information from health and social care professionals. Information may not be available where it is required, particularly materials for minority ethnic groups or for patients with sensory difficulties. In addition, although a lot of material is available in some areas, there is considerable duplication and no assessment of its quality. High quality information therefore needs to be made available and disseminated to locations where patients and carers can access it, as required.

Specific recommendations requiring significant additional resources are as follows:

- Patients should be offered high quality information relating to the disease, treatment options and available services, possibly through the provision of a core information pack;
- Provider organisations should ensure that patients have access to a range of different information materials, perhaps through dedicated Cancer Information Centres in larger Trusts;
- Cancer Networks and Trusts providing cancer services should nominate a lead for cancer information.

2.4.2 High quality information materials

Guidance Key Recommendation: Commissioners and provider organisations should ensure that patients and carers have easy access to a range of high quality information materials about cancer and cancer services. These 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.

Local policies will be required detailing the information materials to be routinely offered at different stages to patients with particular concerns. Nationally developed and accredited information materials will be required. The Guidance recommends that the Department of Health and National Assembly for Wales should oversee the commissioning, design, quality assurance and compilation of a comprehensive range of high quality information material for people affected by cancer. In England, the Coalition for Cancer Information will undertake this role.

Commissioners will need to purchase or commission information materials and ensure that they are disseminated appropriately. Currently, access to information is not uniform and not all patients are made aware of the information available. It is, however, difficult to assess the scale of additional need.

Cost estimates for information provision are based on CancerBacup figures. CancerBacup is one of the main providers of information to patients, with roughly 60 current booklets and 190 fact sheets covering the main types and rarer forms of cancer, as well as treatments and practical aspects of living with cancer. The booklets are updated every 12-18 months. In total, approximately 180,000 booklets are produced each year, with an average patient receiving six booklets during an illness. This figure may not be representative of all patients; some download information from the web and do not require booklets. For costing purposes, it is assumed that on average patients require five booklets over the course of their experience with cancer. The potential costs are summarised in Table 8 below.

Table 8: Cost of disseminating high quality information to all cancer patients

Cost element	Assumptions / sources	Total annual cost (E&W)
Development costs	£1,600 per booklet for staff time, advisors, editorial input. Average of 41 booklets produced per annum (new, revised or reprinted)	£65,600
	Assuming 5 booklets per patient, with 266,650 new cancer diagnoses each year.	
Cost per booklet	Approx £1.50 per booklet (production cost, typesetting, design, printing, paper).	£2,000,000
Distributor costs	Approximately £3,500 per month (producing 181,000 booklets). Assume these increase pro-rata with increasing numbers of booklets.	£309,400
Website	Cost of keeping website up-to-date (medical/editorial input plus technical services)	£57,000
General overhead costs	General overheads of publications/website dept.	£47,700
Total		£2,480,000

This corresponds to £71,400 per Cancer Network.

Translation of Written Material

Guidance recommendation: The Coalition for Cancer Information should lead the development of a national core set of accredited information materials, available in translation, for people from black and ethnic minority communities.

Translation of written information is important to support the services provided by face-to-face interpreters. The costs of translation are not included within this Economic Review, but a national study is being carried out both to identify the need for translated material and to ensure that this need is met efficiently. *The NHS Plan* set out a commitment to 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 it – and the wider NHS – will be able to access for a wider, quality assured service at a negotiated rate. More information will be available during 2004-05. A 'content bank' of core information on cancer is currently being produced, to be available on the NHS Direct Online website. Materials will be available in translation; work is currently being undertaken by NHS Direct to identify appropriate languages for specific materials. More information will be available during 2004-05.

2.4.3 Access to alternative information formats e.g. video, web-based materials.

Guidance Recommendation: Provider organisations should ensure that patients and carers have easy access to a comprehensive range of high quality information materials including books, leaflets, audio and videocassettes, Internet websites, CD-ROMs and DVDs.

A wide range of high quality information is currently available from a variety of sources on the internet. Set-up costs for making such information available locally are therefore unlikely to be significant. For example, all CancerBacup booklets and fact sheets are available on its website, along with around 800 'Questions and Answers' on a range of topics. These are updated regularly following feedback from patients. The cost of updating this website has been estimated as £57,000 per annum (see table in 2.4.2 above), including medical input, editorial input and technical services.

The use of video and audio-based materials is particularly important for people with sensory difficulties and for people from some ethnic minority groups. As access to video and audio-based materials, as well as to computer facilities, will need to be provided, the cost of equipment is considered within the costs of dedicated Cancer Information Centres below.

2.4.4 Distribution of information

Guidance Recommendation: The materials should be available in sufficient quantities to ensure that patients at all stages of the patient pathway are able 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 through a dedicated cancer information centre, or through a facility that encompasses information for a broader range of diseases.

The cost estimates below are based on a Cancer Network setting up dedicated Cancer Information Centres to ensure that patients have easy access to a range of materials. The costs are based on providing one major centre and four satellite centres. However, the establishment of dedicated information centres is only one way of meeting the Guidance requirement and some Cancer Networks may follow different routes to achieve the same objective.

The changes required to set up information centres within a Cancer Network will differ depending upon existing arrangements for information provision in each area. Some Networks may need to set up centres from scratch, while others may only need to add particular resources

Table 9: Cost of equipping dedicated cancer information centres

Cost element	Assumptions / sources	Cost per Network	Cost England and Wales
Materials for each service – yr 1	For a major centre serving approximately 2,500 people, handing out leaflets, the cost is £10,000. Costs obtained from the Macmillan information materials starter kit 2002, including booklets and leaflets, reference books, CD-ROMS and videos, journal subscriptions etc. A minimum budget for a satellite centre with reference-only booklets is £905.	£13,600	£472,900
Materials – yrs 2+		£6,200	£215,900
Equipment for services	For each major centre, 2 computers (one for the manager, one for public access), one TV, one video and one tape recorder. One computer per satellite centre.	£7,500	£261,300
Equipment yrs 2+	Assuming 25% of equipment costs of year 1.	£1,900	£65,300

It is assumed that there will be one dedicated full time information lead for the Network, one wte information manager at each of the major information centres and 0.5 wte information manager at each satellite centre.

Table 10: Cost of information leads for Network and Trusts.

Cost element	Assumptions / sources	Cost per Network	Cost England & Wales (£ m)
Information lead at Network	One full-time person based at the Network. Nurse specialist grade. Whitley pay scale I grade (34,721 incl on-costs).	£34,700	£1.2
Information managers at each centre	One wte person at major centre and 0.5 wte for small centres, i.e. 3 wte per Network. Whitley pay scale nursing I grade (34,721 incl on-costs).	£104,200	£3.6
Admin staff to support information managers	One wte person per major centre and 0.5 wte for small centre i.e. 3 wte per Network. Whitley pay scale clerical grade 3 (mid-point - £13,736 incl on-costs).	£41,200	£1.4
Total per Network		£180,100	£6.3

Hospices and other services, such as standalone drop-in centres or complementary therapy services, may also be important sites for information giving. Where available, these will add to the overall cost of information provision.

Capital costs have not been included. The infrastructure requirements will vary considerably depending upon existing arrangements for the provision of information. Assuming most information centres will be set up within Trusts, local libraries etc, the cost of premises may also need to be considered, particularly in community-based settings.

These costs assume that there is no existing service available. However, information centres already exist to some degree within Cancer Networks.

2.5 Psychological Support

2.5.1 Background

Psychological distress is common among people affected by cancer and is an understandable and natural response to a traumatic and threatening experience. Many 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 support and intervention.

Nearly 50% of patients with early stage cancer experience sufficiently severe levels of anxiety and depression around the time of diagnosis to affect their quality of life adversely. In addition, 10% of patients at some time in the first year will experience levels of psychological morbidity severe enough to warrant a specific psychological therapy. Psychological symptoms are not always identified, and therefore many patients and carers are not offered psychological support services. Moreover, many professionals are not equipped to offer support for patients and carers in psychological distress.

The following key resource issues have been identified:

- Emergency psychological support services for patients who have developed acute psychiatric problems and are potentially a danger to themselves and/or others;
- Each Cancer Network should develop and implement a four-level model of professional psychological assessment and support, to ensure that all patients undergo systematic psychological assessment at key points in the care pathway and can obtain an appropriate level of psychological support;
- Workforce development issues, including training in screening for psychological distress and the delivery of basic psychological interventions and supervision; training should be provided by experts in psychological care with extensive experience in cancer, particularly those delivering more complex aspects of psychological care.

Education and training issues are addressed in section 2.13.

The costs of level 3 bereavement support for families and carers with complex problems requiring specialist intervention by the psychological assessment and support services are included here, rather than in the section on families and carers (section 2.12), so that costs are not double-counted.

2.5.2 Emergency psychological support service

Guidance Recommendation: Emergency psychiatric services should be available when necessary. Patients with severe mental health problems may require these services in and out of normal working hours.

It is assumed that this cost would be borne by the local mental health team and is not costed in this Economic Review.

2.5.3 Four-level model of psychological assessment and support

Guidance Key Recommendation: 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.

Current provision of psychological services is extremely limited in the majority of Cancer Networks. There are insufficient numbers of professionals available, so that psychological support services are neither available to – nor accessed by – many people with cancer who have psychological care needs.

Assumptions underlying the four level model of psychological assessment and support are set out in the table below. This suggests that professional psychological support at Levels 1 and 2 is provided by health and social care professionals directly responsible for the care of people with cancer. More severe psychological distress (Levels 3 and 4) should be managed by a variety of psychological specialists, including counsellors, clinical 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.

Table 10: Four Level Model of Professional Psychological Assessment & Support

Level	Group	Assessment	Intervention	Economic Review Assumptions
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support	Once heath and social care professionals have received training and education and are in receipt of CPD in this area, then assessments and interventions at Level 1 will be absorbed as a normal part of workload, ie no extra wte staff are required
2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological interventions (such as anxiety management & problem solving)	CNS, social workers and GPs with specialist training provide screening and interventions.
3	Trained & accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Counselling & specific psychological therapies, such as cognitive behaviour therapy (CBT) and solution-focused therapy, delivered according to an explicit theoretical framework	Psychiatrists, psychologists, psychotherapists and counsellors provide Level 3 and Level 4 support
4	Mental health specialists – clinical psychologists and psychiatrists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions	

The Richard Dimbleby Cancer Information and Support Service[14] offers a service akin to the four level model of psychological assessment and support described in the Guidance and is used here as the basis of cost estimates. The team serves Guy's and St Thomas' Cancer Centre directly, as well as taking a few particularly complicated referrals from other cancer service providers in the South East London Cancer Network (SELCN).

It is assumed that psychological assessments and interventions at level 1 will be part of the normal workload of health and social care professionals and that no extra staff will be required. The impact on workload for staff providing level 2 services is not known. No assumptions about additional staff to support level 2 services have been made, but this may need to be reviewed as further evidence becomes available. The main resource implications for existing health and social care professionals operating at level 2 arise from the training, education, and ongoing support and supervision they will require, as they will take on such work, with no new dedicated role created.

At levels 3 and 4, specialist staff, including psychiatrists, psychologists, psychotherapists and counsellors, are required. The mix of these staff is likely to vary between Cancer Networks. The Richard Dimbleby service for level 3 and level 4 support includes a team comprising one wte counsellor, one wte psychologist and 0.5 wte consultant psychiatrist. Using this as a model, it is assumed that 2.5 wte staff are required at the cancer centre. As the Richard Dimbleby service does not serve its entire Network, the staff volumes assumed to be necessary for a Cancer Network as a whole have been doubled. It is therefore assumed that a team of 5 specialist staff is required to serve a Network with a population of 1.5 million. On this basis, the total number of specialist staff required for England and Wales is estimated to be around 174 wte.

Staff volumes are assumed to be related to the size of the population served; a large Network with a population of 3 million are assumed to require a team of 10 wte specialist staff.

It has been assumed that a Network will need a minimum of 3 administrative support/clerical staff at a total cost of £72k including on-costs. Overheads, including office accommodation, travel, I.T. support and telephone expenses, are assumed to be 15% of total costs. These costs will vary, however, according to the model of provision adopted.

Professionals operating at levels 3 and 4 are assumed to have training costs of £1285 pa, and supervision costs of £1500 pa. These costs are not included here, as workforce development issues are covered in section 2.13.

The cost estimates for meeting the Guidance recommendation on this model of psychological support are given below.

Table 11: Cost estimates for 4 level model of psychological assessment and support

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
Operation of a four-level model of professional psychological assessment and support in each Cancer Network			
Level 1			no additional staff required
Level 2			no additional staff required
Level 3 and Level 4	£0.24m	£8.3m	1 wte counsellor, 1 wte psychologist (0.5 wte clinical, 0.5 team co-ordinator) and 0.5 wte consultant psychiatrist per cancer centre staff volumes scaled from cancer centre to Network by factor of 2 *Salary assumptions:* Counsellor salary is £27,000 Psychologist salary is £43,600 Psychiatrist salary is £66,796
Other Assumptions	£0.07m	£2.5m	Minimum of 3 admin staff per Network Overheads 15% of total costs
	£0.05m	£1.9m	costs scaled from cancer centre to England & Wales using the ratio of the population of E&W to 1.5 = 52.085/1.5 = 34.7
Total	£0.36m	£12.7m	

The exact model of service provision is not defined within the Guidance and will depend on the characteristics of the Cancer Network. For instance, Cancer Networks with a high population density within a small geographical area may be able to operate an outreach service, with specialist staff based at the cancer centre who can travel out to provide services to the rest of the Network. This model would not be appropriate for a large rural area with a widely dispersed population. The model of service provision adopted will affect the level of staff required.

These estimates are based on crude assumptions about the level of specialist staff required to offer a four-level model of professional psychological assessment and support. As noted, the Richard Dimbleby Cancer Information and Support Service has been used as the basis of these estimates. It is recognised, however, that there are alternative models of provision, which will have different costs. For instance, the two Oncology Health Centres at Kingston upon Hull provide drop-in facilities for patients with cancer and their relatives. In addition, health care professionals can refer patients and relatives experiencing clinically significant difficulties in coping with the diagnosis and/or treatment of cancer.

Very few dedicated staff currently operate within this model of care; the manpower implications will therefore be substantial and the implementation of this model will need to take place gradually over the medium to long term.

Further work is required to provide more detailed and robust cost estimates, in particular to explore possible options for service delivery and optimal methods of implementation over the next few years. It is recommended that the current assumptions are subject to a comprehensive consultation exercise.

2.6 Social Support

2.6.1 Background

The social impact of cancer is considerable. A MORI survey in 1992 highlighted that the onset of cancer left a considerable proportion of people unable to carry out many of the functions of which they were capable before their diagnosis[15].

Patients and carers commonly do not experience a coherent, integrated system of social support. The number of agencies involved in planning and delivering services makes collaboration difficult and 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 a social assessment and access to the services that social workers can supply.

The emphasis of the Guidance is on identifying the needs of patients and ensuring that patients are supported in finding ways to address them. Explicit partnership arrangements should 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.

The following key resource issues have been identified:

- staffing a specialist palliative care service, in terms of numbers of wte social workers per hypothetical Network with 1.5 million population;
- in-depth social care assessments, including welfare and benefits rights advice;
- education and training for the healthcare workers likely to be involved in carrying out a front-line assessment, on the social needs of individual patients and carers.

Social workers in supportive and palliative care teams fulfil a number of functions in a variety of care settings in hospitals and in the community, including in a patient's own home, in care homes, or in hospices, namely:

- social care assessments (only social workers can undertake many aspects of these)
- benefits and welfare rights advice
- bereavement counselling
- general counselling
- professional psychological assessment, intervention, and support
- care of families and children.

The first two of these functions are carried out primarily by social workers or by welfare rights advisors. The remainder can be provided by social workers, but are also undertaken by a range of other health care professionals.

Services that straddle both NHS and social services sectors, such as respite care and transport, are excluded from this Review and have not been costed here. The cost estimates for social services are therefore not comprehensive and some service issues will need to be addressed elsewhere.

2.6.2 Social care assessments carried out by healthcare workers

Guidance Recommendation: Each patient with cancer will need his or her social care needs initially identified as part of a routine assessment.

Such assessments consist of an initial examination of needs, identifying where a more in-depth assessment might be needed, and 'sign-posting' the person to services outside the immediate healthcare environment. Local collaborative arrangements should ensure that this assessment is undertaken by – or with the help of – social care professionals.

The main resource implication here is the required training and education of health and social care professionals in the social needs of individual patients and carers. It is assumed that after completion of training, these assessments will become resource neutral, in the sense that no extra staff will be required and the assessments will become part of normal working practice.

Training and education requirements for health and social care professionals in general are covered in section 2.13 Workforce Development.

2.6.3 In-depth social care assessments and welfare rights & benefits advice

Guidance recommendation: The patient's usual health care professional should arrange for access to more specialist assessment if required.

Specialist social care assessments should be undertaken by the most appropriately qualified professional. The cost estimates below are based on the cost of a social worker.

Assumptions about the total number of assessments required are based on the number of patients estimated to use specialist palliative care services in a year. This figure is scaled up to reflect the supportive and general palliative care component of assessments. It is assumed that 50% of these patients require specialist social care assessments and welfare and benefits input based on input from the Editorial Board member with particular expertise in social support services, following discussions with colleagues in the field.

At least three quarters of all people who die of cancer have used specialist palliative care services; this leads to an estimate of 102,000 people in England & Wales in 2001. However, the number of patients using home care services in England & Wales in 2001-02 is estimated to be 127,320[1]. As this figure is higher, home care services have been used as a proxy for the use of any specialist palliative care services.

An estimated 2,750 patients use specialist palliative care services per year. This figure was doubled to take account of the expected supportive care component of social workers' caseload for adults with cancer, on the basis that social workers' workload in the supportive care setting is at least equivalent to that in the specialist palliative care setting. This recognises the lower complexity of cases, and a level of unmet need arising from the fact that some patients and carers do not currently receive needed social care services. It is assumed that 50% of these patients may require a detailed assessment.

The cost estimates for social care are considered to be preliminary estimates only and will need to be refined in future.

Services that straddle both NHS and social services sectors, such as respite care and transport, are excluded from this Review and will need to be considered elsewhere.

Table 11: Cost estimate for in-depth social care assessments and welfare rights & benefits advice

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Sub-Total [B]	**£0.2m**	**£6.8m**	Minimum Data Set 1 data for 2001-02 was analysed to determine the total number of patients using specialist palliative care services for England & Wales. This produced an estimate of approximately 2752 patients per hypothetical Cancer Network of 1.5 million population using specialist palliative care services in 2001-02. - an estimated 50% of patients require social care or welfare and benefits input - assuming 5 hours per assessment * and 1582 hours per wte social worker per annum, provides an estimated 4.3 wte social workers per Cancer Network to carry out this role within the specialist palliative care setting - 1582.5 hours per wte is based on 7.5 hours per day for 211 working days, assuming 40 days for annual leave, sick days, training days, and statutory holidays. - multiply by scale factor of 2 to reflect the workload of social workers in the supportive care setting for adults with cancer

* 5 hours represents the minimum time required to carry out a social care assessment. It would take at least one hour to set up and undertake a meeting with the patient and any relatives, given that the social worker is not directly based on the ward or must travel to the patient's home. The package then needs to be negotiated with the providers (usually an independent provider, possibly more than one if the package is complex), agreed with a Senior, and recorded. During this process, there will be checking with nurses and other care professionals on the team about what is appropriate and further discussions with patients and relatives regarding details of the package. Practitioners in the field estimate that it takes about 7 hours to set up a care package. This excludes any monitoring after one month to assess if any change is required. The 7 hour figure has been reduced to 5 hours to reflect those initial discussions that do not issue in any action because the patient's condition changes.

2.6.4 Social worker input to high quality Specialist Palliative Care services

Assumptions used in the previous ScHARR model[3] for social worker input within specialist palliative care services were reviewed by the member of the Editorial Board with particular expertise in social support.

The wte social worker figures shown by component of service represent staffing ratios required to deliver high quality services. The component of bereavement support costs presented relates solely to the wte social workers required for implementation of the three level model of bereavement support. See section 2.12 on Families and Carers for a full description of the cost basis for the bereavement support model recommended in the Guidance.

Table 12: Cost estimates for social worker input to specialist palliative care services

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Cost of social workers required per type of service:			Social Worker/Counsellor cost is £22,557 including on-costs (PSSRU 2001 Social worker (adult))
specialist palliative care beds	£0.09m	£3.0m	50 beds/million population 0.8 wte/17 bed unit
Day Care	£0.02m	£0.5m	4 day care centres 13,000 places/million pa 1.5 social worker session/week for a 20 place unit
Home Care	£0.03m	£1.0m	3 teams at level 3 support operating 9am -5pm 7 days/week plus 24 hours telephone advice 7 days/week 0.8 wte per million population
Hospital Support Team	£0.07m	£2.6m	1 cancer centre and 4 units at level 3 support, operating 9.00am - 5.00pm 7 days/week plus 24 hours telephone advice 7 days/week 1 wte social worker per cancer centre 0.5 wte social worker per unit
Bereavement	£0.29m	£10.0m	Level 2 35% of bereaved require support 6 services/million population cancer deaths = 3600 per Network (1.5 million) 1wte/300 clients for bereavement lead social worker 0.6 wte/300 clients for part-time social worker/bereavement counsellor
Sub-Total	**£0.49m**	**£17.2m**	

Note: some of these costs overlap with services costed elsewhere in the Economic Review, namely bereavement support and specialist palliative care. Social workers are also included in the four level model of psychological assessment and support, where they provide assessments, interventions and support mainly at level 2.

2.7 Spiritual Support

2.7.1 Background

The term 'spiritual' is used to refer to the search for existential or ultimate meaning within a life experience. There are indications that spiritual needs are not being met within all cancer and palliative care service services. Many health and social care professionals are confused as to what exactly is meant by 'spiritual care' and how best to approach this issue with patients and their carers. They may not detect needs for spiritual support or be unaware of how to access people who can provide it; some may simply be reluctant to call for a chaplain's services[b]. Patients often have insufficient choice in people to whom they can turn for spiritual care, or may be unaware of what is available to them.

Provision for spiritual care is, in any case, variable. Within hospitals, there are often insufficient numbers of chaplains to meet needs, given their responsibility to support *all* patients and carers, and not only those receiving cancer treatment or palliative care. Within the hospice sector, there is disparate provision of spiritual care. As a result of these difficulties, patients and carers may not have their spiritual needs appropriately assessed or, in consequence, met.

Spiritual support is understood to be relevant at all stages of the patient pathway from diagnosis to end of life care. Palliative care by its very nature may require more input by chaplains or other spiritual care givers, as some patients and families are preparing for the end of life. The time required with each patient will be greater, as will involvement in providing support to staff.

Most aspects of spiritual care can be offered in any setting where patients with palliative care needs and their carers are cared for – at home, in hospitals, hospices or care homes. 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 or community nursing services, with additional support from a specialist palliative care service;
- Officially appointed and authorised faith leaders within a local community, or a healthcare chaplain.

The following key resource issues have been identified:

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[b] Within this section, the word 'chaplain', should be understood as meaning: 'Chaplain or other giver of spiritual care, appointed by the health care provider and authorised by the relevant faith group, with the ability to facilitate spiritual care provision in a religious or non-religious context'

- spiritual care providers should be available as a resource to in-patient and community teams, appointed and paid in accordance with NHS criteria;
- training and education in basic skills in offering spiritual support, understanding spiritual need, and specific religious rites of different faith groups should be provided to health and social care professionals working with patients with cancer and their carers, including local clergy.

It is assumed that the main resource implications will arise from the training and education needs of health and social care professionals in the assessment of spiritual needs of patients and their carers. Once trained, an assumption of resource neutrality is then appropriate, as this will become part of their normal work with cancer patients, with no extra staff required. This assumption applies also for core members of the specialist palliative care team, other than chaplains or other spiritual care givers. Many clinically trained staff will need updating and refresher training. When new staff arrive, it will be necessary for these staff to be trained. Training and education requirements for health and social care professionals in general are covered in section 2.13 Workforce Development.

Some elements of the cost of spiritual support are not included in the cost estimates:

- The nature of 'specialist' palliative care in terms of time required for chaplaincy input per patient and staff support;
- The time required for a chaplain's own supervision;
- The time required for a chaplain's on-going Continuous Professional Development.

2.7.2. Access to staff who are sensitive to spiritual needs

Guidance key recommendation: Patients and carers should have access to staff who are sensitive to their spiritual needs. Multi-disciplinary teams should have access to suitable qualified, authorised and appointed spiritual care providers who act as a resource for patients, staff and carers. They should also be aware of local community resources for spiritual care.

Spiritual care provision is seen as a responsibility of the *whole team*, but one individual, such as a hospice or healthcare chaplain[4-6], may hold specific responsibility for ensuring that such care is provided to an acceptable standard. For the specialist palliative care team, it is assumed that the major resource implication arises from the appointment of a sufficient number of chaplains or other spiritual care givers to meet the Guidance recommendations.

Assumptions used in the previous ScHARR model for chaplains within specialist palliative care services were reviewed by the member of the Editorial Board with particular expertise in spiritual support. In addition, discussions were held with various hospice/palliative care chaplains and data were provided by the Chair of the Association of Hospice and Palliative Care Chaplains (AHPCC). It was concluded that no current costing model that could replace the ScHARR model[3].

The new guidelines for multi-faith chaplaincy/spiritual care[16] within the NHS have the following funding implications:

- some specialist palliative care units may need to employ additional spiritual care givers, covering faiths other than Christian, where numbers warrant specific appointments;
- such employment is likely to be on a sessional basis for the world faiths well represented in the community;
- for other faiths, where the need is likely to be only very occasional, a 'call out' fee may instead be paid for a spiritual care giver authorised by the relevant group.

In reviewing the previous ScHARR assumptions for wte chaplains, account was taken of the funding implications of these new guidelines.

Detailed assumptions on the number of chaplains required and their costs by service component are set out in the cost estimates table below. The salary rate for chaplains assumed is £25,282 plus £3,292, the housing allowance payable under Whitley terms and conditions. With on-costs of 13%, this gives a gross cost per chaplain of £32,543. Chaplains are the only NHS group who may receive a housing allowance; although this is due to be subsumed within their salary in future, at present most chaplains receive the allowance, especially if appointed under Whitley terms and conditions.

Table 13: Cost estimates for spiritual support

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
wte spiritual providers	£0.12m	£4.1m	Salary figures used are from Advanced Letter (SP) 3/2002 Based on a central scenario of 50 inpatient specialist palliative care beds per million population, and for each Cancer Network: 1 cancer centre and 4 DGHs/cancer units, 4 day care centres with 20 places operating 5 days per week. *Inpatients specialist palliative care* The formula adopted here matches the formula used for whole time appointments of health care chaplains. ie. 1 session for every 35 acute beds = 0.5 for 17 beds • 1 session other faiths/bereavement work • 1 session for staff support & volunteers support • 2 sessions for palliative care work • 0.5 session for mgt. Admin etc This gives a total of 5 sessions = 0.5 wte for a 17 bed unit. *Home Care Team* 0.375 wte per 1.5million population *Hospital Support Team* 2.5 sessions per week in cancer centre s and 1 session per week in cancer units ie 0.65 wte chaplains *Day Care* 1 session per week for a 20 place unit

2.7.3 Cost impact analysis

There are currently 410 wte chaplains within the NHS, covering acute, mental health and community chaplaincies, and approximately 3000 part time chaplains in England and Wales. These are from a variety of Christian denomination and other faith groups. Some, especially those within the acute sector, already provide a service to cancer patients alongside their other work within Trusts.

The development of chaplaincy in the NHS has not always kept pace with the development of Cancer (and other) Networks and it is difficult to obtain figures for the current shortfall. The South Yorkshire Workforce Development Confederation (SYWDC) is the lead confederation for chaplains or other spiritual care givers in the NHS. It has indicated that, within NHS chaplaincy as a whole, current chaplaincy levels are absorbing approximately a 30% shortfall in covering the growing demands on their service and cover for all Faiths[17].

Many chaplaincies have absorbed the increased or changed workload as a cost-pressure. It is estimated that for NHS units, the shortfall figure is frequently about 60%.

Anecdotal information from a selection of chaplains in post indicates that many part-time chaplains in the voluntary sector are either not remunerated or provide far more sessions than they are actually paid for. It would require a confidential survey of hospices to ascertain the true scale of this problem.

It is estimated that enhancing chaplaincy/spiritual care to the level of £4.1 million (see table above) for England and Wales, and to address the shortfall in chaplains across the NHS and voluntary sectors, requires funding in the region of 60% of the £4.1 million, i.e. £2.5 million.

2.8 General Palliative Care, including Care of Dying Patients

2.8.1 Background

Patients with advanced cancer require a range of services to ensure that their physical, psychological, social and spiritual needs are met as well as possible 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, 7 day a week basis to prevent both unnecessary suffering and unnecessary emergency admissions to hospital.

Much of the professional support given to patients with advanced cancer in their own homes, in hospitals and in care homes 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.

The following key resource issues have been identified, based on the Guidance recommendations and discussions with experts in the field of community services:

- means of identifying patients with advanced cancer who have palliative care needs, for example by 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[18];
- a protocol for people who are dying, such as the Liverpool Care Pathway[19];
- medical and nursing services available 24 hours a day, seven days a week, for patients with advanced cancer living at home;
- provision of continuous support at the end of life by trained carers and nurses;
- training of community nursing staff in palliative care, so that at least one team member has undergone post-registration education and training;
- training programmes for health and social care professionals to enable them to conduct assessments of palliative care needs, deliver general palliative care services, and recognise when to seek advice or refer to specialist services: these programmes should include staff working in all care settings, including care homes, community hospitals, and acute hospitals.

Training and education issues are considered in section 2.13.

2.8.2 Implementation of Primary Care Planned Protocol and Framework and Protocol for the Dying

Guidance Key Recommendation: Primary care teams should institute mechanisms to ensure that the needs of patients with advanced cancer are assessed, and that the information is communicated within the team and with other professionals as appropriate. The *Gold Standards Framework*[18] provides one mechanism for achieving this.

Guidance Key Recommendation: 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 (LCP) [19] *provides one mechanism for achieving this.*

Assessments should be made by appropriately trained healthcare professionals (who have received further education and training in palliative care); where this is not possible, they should be made by members of the local specialist palliative care team or in conjunction with the specialist palliative care team. Teams should agree means of identifying patients with advanced cancer who have palliative care needs through, for example, establishing a register or database.

Assessments are assumed to be resource neutral, with no extra staff required, as this activity should form part of the normal workload of health care professionals working with cancer patients, i.e. GPs, hospital doctors, district nurses, cancer site-specific nurse specialists, and nurses on hospital wards dealing with considerable numbers of patients with cancer.

The *Gold Standards Framework* (GSF) and *Liverpool Care Pathway* (LCP) are not the only means of providing these activities, but are used as the basis for costing the recommendations for illustrative purposes. The protocol for the dying, e.g. the LCP, is already integrated into the GSF [c] for the community, so is not separately costed.

Implementation of the GSF requires :

- Development of GSF registers and systems in each practice. Practices will require a payment for the initial administration time required. It is assumed that only initial set-up costs will be required, as there will be minimal ongoing running costs once registers and systems are integrated into the ongoing PHCT/GP practice systems. A small 'start up' budget, for administration only, is assumed per practice, reflecting a view that maintaining the GSF at practice level is an integral

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[c] The GSF includes as one of the seven key Gold Standards – the 7 C's: Care in the Dying Phase; The Gold Standards Framework for Community Palliative Care, Summary Keri Thomas + GSF Central Team, May 2003.

part of primary care, improving the quality of patient care and saving practice time by reducing crises[20].

- Payment for - or secondment of - a facilitator to run the GSF for each PCT. This facilitator would also cover the LCP and other palliative care issues within primary care. The role could be carried out by a nurse, GP, Macmillan GP facilitator or other person. It is assumed that facilitation of palliative care in each PCT would amount to one day per week for a minimum of three years and could be carried out by a senior manager or I grade nurse at an approximate cost of £7000 per annum, including on-costs.

Detailed assumptions and estimates for implementation of the GSF and LCP are set out in the table of cost estimates below.

Table 14: Cost estimates of implementation of primary care planned protocol and framework and protocol for the dying

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
Development of GSF registers and systems	£0.081m	£2.8m	in each practice, assume £300 for admin time: set up costs only are included 9334 practices in England and Wales [d]
Facilitation in each PCT	£0.064m	£2.2m	0.2 wte facilitators required per PCT Whitley I grade senior nurse/ manager at approximately £35,000 p.a. including on-costs; 302 PCTs in England[21] Population of England 49.181 million and population of Wales 2.903 million End of life protocol is also covered by the PCT facilitator
Total	**£0.15m**	**£5.0m**	

2.8.3 24 hour medical and nursing services

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

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[d] DoH: general and medical services statistics England & Wales, September 2001; figures relate to Partnerships of Unrestricted Principals and Equivalents (UPEs).

Equipment

Equipment, such as mattresses, commodes, wheelchairs and physiotherapy to enable patients to stay at home, should be available without delay, and should be removed, but not hastily, when no longer required. In order to ensure that this equipment is available within 24 hours, there may be a need to increase the total stock. This will need to be reviewed on a local basis. The cost of equipment is not covered in this Economic Review, since funding is from pooled budgets and equipment stores are run jointly by health and social services, and therefore is not solely within the remit of NICE.

24 hour medical services

NHS Direct can offer advice about any medical problem and is available 24 hours a day.

For GPs, there are already existing out-of-hours cover arrangements in place including:

- night visits reimbursed by the system of night visit fees;
- local cooperatives funded by GPs through their capitation budgets;
- primary care out-of-hours emergency centres.

For secondary care, emergency acute services can be accessed 24 hours a day via 999 services.

It is assumed that there will be no additional cost arising from the Guidance recommendation on provision of general medical services 24 hours a day.

24 hour Nursing Services

There is much variation throughout England and Wales in the provision of 24 hour community nursing support. Such services cater for the needs of all patients at home and not just cancer patients. The Community District Nursing Association (CDNA), which has a longstanding campaign for 24-hour, seven day a week, community nursing services[22], contends that community care is cheaper than acute care and, if 24 hour cover were introduced, it would quickly reduce the burden currently arising from the use of expensive hospital beds.

Where 24-hour district nursing services are not available, alternative means of providing patients with advanced cancer with access to trained nurses around the clock should be agreed between commissioners and the Cancer Network. These have not been costed.

Estimating the costs of 24 hour district nursing services

The estimated cost of out-of-hours provision of district nursing services is based on the costs provided by the Calderdale PCT[e]. The 24 hour district nursing service, begun in 2000, has 25-30 nurses, comprising a mix of part-time staff, bank staff, and unsocial hours staff. It runs from 16:30 p.m.- 08.30 a.m. during the week, as well as at weekends and on bank holidays. The annual full cost of running the out-of-hours service, including overheads, is budgeted at £345,000, equivalent to a cost of £1,725 per 1000 population. The service estimates that 10-15% of its out-of-hours workload is for palliative care. Some of this work is for patients with other forms of progressive life-limiting disease, such as end-stage cardio-respiratory failure.

The Calderdale PCT service provides the most comprehensive estimate for the running costs of services and is an up-to-date figure. A number of other sources were also identified. A 1995 study in Buckinghamshire[23] measured the use of out-of-hours community nursing over a two-month period. The authors found that 7% of nursing services related to palliative care, and that total nursing costs amounted to £1588 per 1000 population per year (adjusted to 2002-03 prices). Barking and Dagenham PCT currently provides 24 hour community nursing, with an estimated total cost of £568,000 per year, equal to £1472 per 1000 population per year. Huddersfield South and Central PCT runs a near 24 hour service, although there are some gaps in the morning and evening of about 1.5 hours. There are 9.69 wte F and G grade nurses employed in the evening nursing services, and 5.56 wte F and G grade nurses in the night nursing services. Salaries, plus on-costs for the out-of-hours nursing service, amounts to £1,810 per 1000 population per annum. The estimated palliative care component of workload is about 20%.

Halton PCT has two out-of-hours nursing teams: the evening team works 18.00 pm - 22.00 pm and the night team works 22.00 pm - 08.00 am. The teams visit the patients of several GP practices and cover a large rural and urban area with a population of 147,500. A breakdown of visits during the period January - June 2003 showed that approximately 44% of visits related to palliative care. No cost information was provided. A recent audit of workload of the overnight district nursing team (one RGN and one Health Care Assistant 22.30 p.m. - 08.30 a.m.) at the same PCT in May–July 03 (inclusive) has shown a total of 527 contacts over the three month period, with 293 (55.6%) being for palliative care[24].

Estimates of the proportion of out-of-hours workload attributable to palliative care vary considerably. Although some earlier estimates are as low as 5 - 10%[23], more recent estimates from Halton and Calderdale PCTs suggest that the proportion is much higher, perhaps 45 - 55%.

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[e] Budget for out-of-hours district nursing services and catchment population provided by Calderdale PCT (Halifax West Yorkshire), Ian Carey, Head of Older People Services.

It must be recognised that a 24 hour district nursing service could not be implemented for patients with cancer only, but would need to be available for all patients and therefore the full cost of implementation must be taken into account when planning future services.

Table 15: Estimates of 24 Hours Community Nursing Services

Key Economic Issue	Cancer Network	England and Wales	Key Assumptions
24 Hours Community Nursing: full cost of service	£2.59m	£89.8m	cost per 1000 population p.a. of £1725 for out-of-hours district nursing services; these costs cover the full budgeted amount of out-of-hours service for one PCT [e] cost scaled to the population of E&W

These figures are based on costs taken from one PCT and are therefore subject to significant uncertainty. The cost of provision in any given Network will depend on the configuration of the service and the level of demand. For instance, the sums do not take into account the potential differences in the cost of out-of-hours services between rural and urban areas. Further work should be undertaken to explore likely variations in out-of-hours nursing costs between Cancer Networks.

It is recommended that a full costing exercise is undertaken by the Department of Health to provide a more robust estimate of the staffing implications and costs of service provision across the country.

Cost impact analysis for 24 hour nursing services

The total cost of providing 24 hour community nursing support is estimated at £89.9 million across England and Wales. Some PCTs already provide this service. A cost impact analysis was therefore carried out to estimate the incremental cost of moving to 24 hour community nursing for those PCTs who do not currently provide this level of support.

A 1999 Audit Commission study of district nurses found that one third of all Trusts in England and Wales provided no district nursing services overnight[25]. Provision of evening and night services was noted to be patchy, with gaps leading to otherwise unnecessary hospital or nursing home admissions as well as delayed discharges. The same study also found that 57% of Trusts had staff on duty until midnight, while the remainder had a mix of on-call arrangements (5%) or a combination of on-call and dedicated services (38%). These services were not necessarily available in all areas, or even within one Trust, and they were not seen to reflect an assessment of need.

The figures are summarised in the following table.

Table 16 : Coverage Levels for Out of Hours District Nursing - Audit Commission Survey of Trusts 1999

	time slot:	**EVENING SERVICE**	**NIGHT SERVICE**
	Day duty	Twilight	overnight/after midnight
combination (on-call and dedicated service)	n/a	38%	23%
dedicated service	100%	57%	29%
on-call	n/a	5%	15%
no service		0%	32%
Total		100%	100%

Other data sources were also identified. A CDNA Survey[26] (circa 2001) of 32 Trusts in England indicated that about 41% were providing an overnight service and about 94% had a twilight or evening service. The survey did not have full coverage, however. A Department of Health survey estimated that just under half of England and Wales is served by 24 hour nurses[f]. Of these, many may not be strictly 24 hour coverage, e.g. they may have a half hour gap in the late afternoon or before 9am. A 2002 survey of nurses in over eight Cancer Networks found that 93% had evening or twilight coverage and 78% had access to some form of night service. In London, seven of the 31 PCTs provide 24 hours coverage; all provide some evening/twilight coverage, 14 have a gap between day and evening and ten have no night service. There is no information on what these services comprise; there may, for instance, be one nurse to cover a wide geographic area, which may be inadequate for patient needs.

The Audit Commission figures are the most comprehensive and are therefore used to estimate existing 24 hour community nursing coverage levels across England and Wales. The key steps in the cost impact calculation and the cost impact results are set out in the tables below.

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[f] Information provided by Cathy Shipman, Senior Research Fellow, Department of Palliative Care & Policy, King's College, London. The DH district nurse project is being evaluated by Kings College, London.

Table 17: Assumptions for estimation of Out-of Hours District Nursing Cost Impact

Step	Key Assumptions
1. Calculate unit cost per PCT for out-of-hours provision	- 302 PCTs in England - population of England 49.181 million - cost of out of hours provision per 1000 population £1725 p.a. - therefore unit cost per PCT = £280,920
2. Calculate distribution of workload between twilight/evening to midnight and after midnight services	- estimates are derived from BMJ study (Brogan *et al*) - based on contacts and unit costs for the twilight/evening and night services - estimate of workload for the evening/twilight services is 63% and for the night service is 37%
3. Calculate unit cost per PCT for the evening/twilight service and night service	- twilight service 7pm -12 am unit cost per PCT estimate = £177,672 - night service 12am - 8.00am unit cost per PCT estimate = £103,248
4. Apply the percent distribution across twilight/evening and night services to the number of PCTs in England	- use figures from the Table on Coverage Levels for Out of Hours District Nursing - Audit Commission survey of Trusts 1999 - apply to 302 PCTs in England
5. Assume cost impact weights for each level of service	- combination (on-call and dedicated service): ½ cost impact - dedicated service: no cost impact - on-call: full cost impact - no service: full cost impact
6. Calculate cost impact for England and scale results to England and Wales	- use the ratio of the population of England & Wales to that of England = 52.084 million/ 49.181 million

Table 18: Out-of-Hours District Nursing Cost Impact Estimates for England & Wales (£ million)

	EVENING SERVICE	NIGHT SERVICE	OUT OF HOURS SERVICE	
	7 pm to 12.00 am	Midnight to 8.00 am	England Estimate	England & Wales Estimate
combination (on-call and dedicated service)	£10.2	£3.6	£13.8	£14.6
dedicated service	£0.0	£0.0	£0.0	£0.0
on-call	£2.7	£4.7	£7.4	£7.8
no service	£0.0	£10.1	£10.1	£10.7
Total	£12.9	£18.4	£31.3	£33.2

The full cost of the out-of-hours service provision was estimated to be £89.9 million. Based on the Audit Commission data on existing levels of service, it is estimated that £33.2 million is required, over and above current levels, to ensure that all the remaining Cancer Networks can provide full coverage. There may, however, have been improvements to service provision since the study was carried out, so that the analysis may overestimate the true cost impact.

2.9 Specialist Palliative Care Services

2.9.1 Background

Specialist palliative care services offer support to patients with cancer suffering from a range of complex problems, which cannot be handled effectively by generalist services in hospitals or in the community.

Patients do not always receive needed specialist palliative care services for a number of reasons:

- patients' needs are not always adequately assessed;
- access to and availability of specialist services is variable and inequitable;
- full multi-disciplinary teams do not exist at many hospitals and many existing teams cannot provide 24 hour, seven days a week, access to advice;
- community specialist services vary in their staffing levels and their ability to provide out-of-hours support.

The Guidance recommends the provision of a range of palliative care services. At a minimum, this should include multi-professional specialist teams providing assessment, advice and care for patients in all locations, specialist inpatient facilities and bereavement support services.

Recommendations identified as requiring significant additional resources are:

- Cancer Networks should provide an appropriate range and volume of specialist palliative care service to meet the needs of the local population;
- hospital specialist palliative care teams should undertake direct assessment of people with cancer during normal working hours, seven days a week, with access to telephone advice at all times (24 hours a day);
- community specialist palliative care teams should undertake direct assessment of people with cancer during normal working hours, seven-days-a week, with access to telephone advice at all times (24 hours a day).

No specific recommendations relating to the provision of day therapy facilities are made and therefore no change to current service provision is considered here.

2.9.2 Provision of specialist palliative care services

Guidance key recommendation: 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, at a minimum, include specialist palliative care in-patient facilities and hospital and community teams. Specialist palliative care advice should be available on a 24 hour, seven days a week basis. Community teams should be able to provide support to patients in their own homes, community hospitals and care homes.*

Current expenditure

The cost of enhancing specialist palliative care services within any given Cancer Network will depend on its baseline position and the resultant priorities identified for improving services. Levels of provision of some services may fall well below national average levels or there may be inequalities in provision throughout the Cancer Network (for instance, some community specialist palliative care teams may not have out-of-hours cover, whilst others may offer weekend and evening visiting with 24 hour telephone support). Current staffing levels in any given Cancer Network may fall well below optimal levels specified for delivering a high quality service.

Expenditure on specialist palliative care services in England in 2001-02 was estimated at £320 million per annum [g], but the breakdown of costs between services is not known. An additional £50 million per annum has now been allocated to specialist palliative care services for three years, starting in 2002-03. Expenditure on specialist palliative care services in Wales is unknown. Extrapolating expenditure in England in 2001-02 to Wales, based on the relative population sizes, suggests that total expenditure in Wales in 2001-02 was around £19 million per annum.

Total expenditure for England and Wales is therefore estimated to be £398.5 million per annum, adjusted to 2002-03 prices. This corresponds to £11.5 million for a Cancer Network of 1.5 million.

Future expenditure

Previous modelling work[3], commissioned by the Department of Health in 2002 to identify the cost of providing a high quality specialist palliative care service, was revised. The model has now been extended to include supportive care and updated to reflect the Guidance recommendations for health and social care professionals working within specialist palliative care services. Education and training cost assumptions have been reviewed and are considered separately in section 2.13.

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[g] The Help the Hospices survey (NHS Funding of Independent Hospices 2001, Help the Hospices, Independent Hospice Representative Committee, February 2002) estimated that for 2001-02 the budgeted expenditure of the independent hospices in England was £237m. To this is added expenditure incurred by Marie Curie Centres and Sue Ryder Units – around £23m. Extrapolation for cost inflation of the figure for costs of NHS managed services (as included in the £300 m estimate in the Cancer Plan) produces a figure of £60m. Therefore, the total for 2001-02 is estimated to be around £320m. (£329.1 m, adjusted to 2002-03 prices) Source: NCHSPCS.

The core components of service included in the model are: specialist palliative care inpatient beds, community specialist palliative care teams, hospital support teams, bereavement services, outpatient services, day care and 'hospice at home' services.

Direct staff costs are the major component of the total cost of specialist palliative care services. Assumptions on appropriate staffing levels are taken from published recommendations where available (e.g. Palliative Care 2000, Cameron Report 1996). Where specific recommendations were not available, advice was taken from a range of palliative care experts. Staffing level assumptions take into account the need for specialist palliative care teams to offer a high quality service and to contribute to Network-wide education and training. All staff costs are based on NHS salaries, plus on-costs. Other costs, including ancillary and management staff, drug and food costs, building maintenance and depreciation costs, are included for each service component as a fixed proportion of total costs for that component.

There is a lack of evidence to support specified levels of service provision, such as the number of specialist inpatient beds or the level of bereavement support required per million population. The demand for specialist palliative care services within a Cancer Network is dependent on a wide range of factors, including the size of the population, the number of cancer deaths, the level of deprivation and the volume and quality of general palliative care services, such as nursing home beds and district nursing services. The model takes into account population size and cancer deaths, but does not explore the impact of deprivation nor the provision of general palliative care services, due to lack of clear evidence on the exact nature of their relative impact.

The demand for individual components of specialist palliative care services is inter-related. A Cancer Network providing a high quality community specialist palliative care service, for instance, may have a lower demand for specialist inpatient beds. A Cancer Network offering a full outpatient service may have a lower demand for medical input in the home or day care. Based on current evidence, it is not possible to quantify these relationships, but they need to be taken into account when interpreting the model for different Cancer Networks.

Components of Specialist Palliative Care Services

Specialist inpatient facilities

Current provision of inpatient facilities varies widely. The national average in 1999 was approximately 50 beds per million, with a range of 34 to 62 beds per million[27]. The demand for inpatient facilities will vary between Networks and will depend on a number of factors, including the level of local need and the level and quality of other services within the Network.

The cost estimates for inpatient specialist palliative care beds are based on the assumption of 75 beds (50 beds per million) in a Cancer Network. It is assumed that there are five units (one 20 bed unit, three 15 bed units and one 10 bed unit). The assumed occupancy rate of 85% and the average length of stay (12.6 - 16.3 days, dependent on size of unit) are used to calculate the annual number of occupied bed days, and the annual number of patients in inpatient services per network. The number of beds is the driver for staff numbers and corresponding costs.

Medical and nursing staffing level assumptions are as follows: one wte consultant per eight beds, one wte non-consultant medical staff per 10 beds, trained nurses (Grades E to G): one per three beds in morning and evening, one per six beds at night and untrained nurses (Grades A to C): one per four beds in morning, one per five beds in evenings and at night.

Additional staffing assumptions include administrative staff (two wte per 17 bed unit), social worker and physiotherapist (0.8 wte per 17 bed unit), pharmacist (0.6 wte per 17 bed unit), occupational therapist and chaplain (0.5 wte per 17 bed unit) and dietician (0.1 wte per 17 bed unit). These figures are assumed to linearly increase in ratio with the number of beds.

Other costs (including management staff, drug costs, food and equipment and travel and maintenance costs) are assumed to be 30% of the total inpatient costs. The costs of new facilities and upgrades are not considered.

Specialist multi-professional palliative care teams (hospital and community)

Full multi-disciplinary community and hospital support teams do not currently exist in many Cancer Networks; where teams do exist, they often do not offer a service at weekends or provide 24 hour access to advice. A move towards providing a seven day a week service with 24 hour telephone support has significant staffing implications, given that teams will need to have sufficient staff to allow sustainable rotas to be achieved.

Cancer Networks are likely to implement different models of provision and therefore the costs of implementation will vary between them. In order to illustrate the potential cost of future provision, a number of assumptions have been made: one nurse per team (hospital and community) works at weekends; 24 hour telephone support for hospital support teams is provided by the specialist inpatient unit ward staff with medical backup; and out-of-hours telephone support for the community team is provided by the home care team nurses, with one nurse from each team on telephone call 5pm - 9am seven days a week. These assumptions will clearly not be relevant for all Networks and alternative models of support will need to be developed and costed, based on the most appropriate assumptions for each Network.

Assumptions for Community Specialist Palliative Care Team

The cost estimates for future service provision assume that a Cancer Network operates with three community specialist palliative care teams, each covering 500,000 population and each with its own separate administrative base. For a basic Monday to Friday 9am - 5pm service, it is assumed that each team has 10 nurses (9 grade H and 1 grade I), based on a requirement of one CNS to 50,000 population, three wte consultants (one wte per 500,000 population) and three wte administrative staff (one per administrative base). The extended team includes input from the following staff: social worker, physiotherapist, occupational therapist, chaplain/spiritual care giver, pharmacist and a dietician. Non-staff costs are assumed to be 15% of total costs.

In order to extend such a service to one providing weekend visiting (9am-5pm) and telephone support at all times (24 hours a day), it is assumed that the number of nurses per team will increase from 10 wte to 11.5 wte, i.e. each of the three teams has an extra 1.5 wte. It is assumed that one CNS per team is available for weekend visiting and that one nurse per team is available each night for on-call telephone support 5pm-9 am. Medical cover is assumed to be provided by a consultant.

Assumptions for Hospital Support Team

The cost estimates for future service provision assume that a Network has one cancer centre and four cancer units (DGHs), two with 600 or more beds and two with fewer than 600 beds. It is assumed that one team is located at the cancer centre and a smaller team at each of four cancer units. To provide a basic Monday to Friday 9 am-5 pm service, it is assumed that four wte CNSs are required at the cancer centre (two H grades and two G grades) and two wte CNSs at the two smaller units and 3 wte CNSs at the two larger units (all H grade nurses). It is assumed that the cancer centre will require 1.5 wte consultants, with the support of one wte junior staff. For the extended team, input from physiotherapists, occupational therapists and dieticians is assumed to be five sessions per week in cancer centres and 2.5 sessions per week in cancer units; input from pharmacists and chaplains is assumed to be 2.5 sessions per week in cancer centres and one session per week in cancer units. Non-staff costs are assumed to be 10% of total costs.

In order to move from this Monday to Friday 9am-5pm service to a service providing weekend visiting (9am-5pm) and 24 hour telephone support at all times, it is assumed that the number of nurses at the cancer centre increases from four to five, to allow a sustainable rota to cover weekend availability. It is assumed that one CNS per team is available for weekend visiting. It is also assumed that the number of nurses increases by 0.5 wte at each cancer unit. This level of service is not likely to be sustainable at cancer units, however, unless teams work together with a neighbouring service. Medical cover is provided by a consultant on call.

Further work to investigate alternative options for providing weekend daytime visiting and 24 hour telephone support is required. This will need to take into account the likely impact of the Agenda for Change and the European Working Time Directive on working practices.

Bereavement services

Bereavement services are discussed in more detail in section 2.12 Families and Carers. The costs identified in section 2.12 for level 2 bereavement support are also incorporated within this chapter.

Day care

The Guidance offers no specific recommendations on day therapy facilities and therefore no change in current service provision (13,000 places/million) is considered.

Outpatients

Some Trusts offer dedicated specialist palliative care clinic outpatient appointments. Consultant input is assumed to be 0.3 WTE per population of 500,000. This may be offset, however, by reduced demand for medical consultations in the community or as part of a day care service. T he additional time required by palliative care consultants to support a range of cancer multidisciplinary teams is also included.

Continuous support for dying patients

Guidance Recommendation: 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 qualified nurses and/or trained carers, according to the patient's needs.

The assumed costs of continuous support for patients at the end of life are based on those of the main current provider of such support, Marie Curie Cancer Care. Its 2002-03 service costs arise from a complement of 10.5 wte nurses per 1 million population, of which 60% are registered nurses (£15.50 per hour) and 40% are health care assistants (£12.00 per hour).

Discussions with service managers at Marie Curie and Macmillan Cancer Relief suggest that it is extremely unlikely that future demand for Marie Curie and equivalent services will fall. The extent to which demand will change following implementation of the Guidance recommendations, however, is indeterminate at this stage.

Cancer Networks will need to consider the appropriate future balance of hospital and community services in order to allow patient choice in relation to place of death.

Table 19 shows that the total cost for the base case scenario for a hypothetical Cancer Network with a population of 1.5 million is £12.6 million. This corresponds to a total of £440.3 million for all Cancer Networks in England and Wales.

Table 19: Cost Estimates for Specialist Palliative Care Services

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Cost of high quality specialist palliative care services	£12.6m	£440.3m	Population of Network = 1.5 million Deaths in Network = 3,907 No of cancer centres = 1 No of cancer units = 4 Inpatient specialist palliative care beds = 50/million Community and hospital support teams: 9am - 5pm 7 days a week, with out-of-hours telephone support Bereavement support = 35% uptake (level 2) Day care =13,000 places/million Continuous support for the dying = 10.5 WTE nurses per million

Based on the assumption that expenditure in 2002-03 will be, on average, £11.5 million for a Cancer Network of 1.5 million population, the incremental cost of the Guidance recommendations on specialist palliative care services is estimated to be an average of £1.2 million per Cancer Network. This will vary significantly between Networks, given their differential baseline positions. This increase in costs for specialist palliative care services reflects the requirement to expand existing levels of service provision, to change the staff mix to ensure multi-disciplinary teams and to increase overall staffing volumes in order to ensure a high quality service.

It must be noted that the costs presented here include an element of double counting, as the costs included in the specialist palliative care service estimates are also covered in individual chapters (for instance, the cost of bereavement support is also covered in section 2.12 and the cost of social work input is included in section 2.6). The final estimates of the total cost of supportive and palliative care under the Guidance recommendations, set out in the summary tables, remove any element of double-counting (see section 3, Tables 35 and 36).

Cost breakdown of Specialist Palliative Care by service

The cost breakdown by service and cost per activity estimates derived from the model are given below.

Table 20: Cost Breakdown by Service Component

	Cancer Network Cost (£ m)	England and Wales Cost (£ m)	Cost as % of total
SPC Inpatient beds	£ 6.9	£ 237.9	54.0%
Community SPC Teams	£ 2.0	£ 68.1	15.5%
Hospital SPC Support Team	£ 1.7	£ 58.1	13.2%
Day Care	£ 0.9	£ 30.0	6.8%
Outpatient SPC services	£ 0.5	£ 17.1	3.9%
Bereavement services	£ 0.5	£ 16.1	3.7%
Continuous Support for Dying Patients	£ 0.4	£ 13.0	3.0%
TOTAL	**£ 12.7**	**£ 440.3**	**100%**

The key contributor to the estimated future cost of provision of specialist palliative care services is specialist inpatient beds (54%), followed by community specialist palliative care teams (16%) and hospital specialist palliative care support teams (13%).

Cost per activity

For validation purposes, it is useful to compare data on the cost of individual activities, derived from the model, with the costs of current units, where available. One example is the 8 Hospice Study a cost analysis of hospice and specialist palliative care services in 1998-99; these have been inflation-adjusted to 2002-03 prices to allow comparison with the results from the model.

Table 21: Cost Breakdown by Activity

	MODEL	8 Hospice Study	
		Mean	Range
SPC Inpatient beds - cost per bed day	£250	N/A	N/A
SPC Inpatient - cost per occupied bed day	£294	£243	£204 - £338
Home Care - cost per face to face contact	£103	£84	£26 - £143
Hospital Support - cost per face to face contact	£133	N/A	N/A
Day Care - cost per attendance	£66	£96	£61 - £125
Bereavement Service - cost per contact	£66	£78	£14 - £157
Average cost of SPC per cancer death per year	£3,236	N/A	N/A

Scenarios

The cost of meeting the Guidance recommendations for specialist palliative care will vary according to the existing level of service provision within an individual Cancer Network. To illustrate the potential cost of extending service provision within a Network, scenarios are presented for different service components, using low (A), central (B) and high (C), service provision.

For community and hospital support teams, Level B is set at the level recommended by the Guidance. For several services where specific recommendations about service levels are not made (inpatient beds; palliative day care places; Marie Curie Nursing Service provision), Level B has been set at current national averages. For bereavement support, Level B is set at the level of provision identified by the members of the Editorial Board with particular expertise in bereavement support. For inpatient beds, Level A and Level C have then been set to reflect known variation in current provision; for the other services, Level A and Level C are arbitrarily lower and higher.

The scenarios for a hypothetical Network of 1.5 million population are given in the table below. For example, the cost of a Cancer Network moving from providing a basic Monday to Friday 9am-5pm hospital and community specialist palliative care team service (scenario A for Community and Hospital specialist palliative care support teams in the table below) to providing a seven-day-a-week 9am-5pm service, with telephone advice at all times (Scenario B for Community and Hospital specialist palliative care support teams in the table below) is estimated to be £0.6 million per Network in total.

Table 22: Specialist Palliative Care Scenarios for a Cancer Network

Service / Level			Cost
1		**Inpatient SPC beds**	
	A	30 beds/million	4.1m
	B	50 beds/million (national average)	6.9m
	C	70 beds/million	9.6m
2		**Community SPC teams**	
	A	9am - 5pm x 5 days/week	1.7m
	B	9am - 5pm x 7 days/week + 24hr telephone support	2.0m
	C	24hr visiting x 7 days/week	2.5m
3		**Hospital SPC support teams**	
	A	9am - 5pm x 5 days/week	1.5m
	B	9am - 5pm x 7 days/week + 24hr telephone support	1.7m
	C	24hr visiting x 7 days/week	2.5m
4		**Palliative Day Care**	
	A	8,000 places/million	0.6m
	B	13,000 places/million (national average)	0.9m
	C	18,000 places/million	1.2m
5		**Outpatient SPC services**	
	A	None	-
	B	Dedicated SPC clinics only	0.1m
	C	SPC clinics plus support to cancer MDTs	0.5m
6		**Marie Curie (or equivalent) Nursing Services**	
	A	6.7 WTE nurses/million	0.2m
	B	10.5 WTE nurses/million (national average)	0.4m
	C	16 WTE nurses/million	0.6m
7		**Bereavement support**	
	A	25% uptake by potential clients	0.2m
	B	35% uptake by potential clients	0.5m
	C	45% uptake by potential clients	0.7m

These scenarios may not capture the full cost of expanding service provision in any one Network, given that they assume that even in the lowest scenario (A), provision is adequately staffed to allow provision of a high quality service. (The model assumes staff ratios for each service component to achieve services of high quality). Therefore, if services in a Cancer Network are currently inadequately staffed, the cost of moving from scenario A to scenario B will be higher than indicated in the above scenarios.

The cost estimates should be interpreted with caution and are not intended to provide accurate costings for specific service developments. However, they do give a crude order of magnitude for the costs of different levels of service provision. This may be useful when choices are made, for example between increasing the number of specialist palliative care beds and expanding home care or hospital specialist palliative care services. One of the key aims in developing the original model was to inform future research by identifying current data gaps, key cost drivers and key areas of uncertainty.

2.10 Rehabilitation

2.10.1 Background

Cancer and its treatment can have a major impact on a patient’s ability to lead a normal life. Activities such as mobility, speech, eating, drinking, and swallowing can be severely impaired. Cancer rehabilitation aims to maximise physical function, promote independence and help people to adapt to their condition. A range of Allied Health Professionals (AHPs) and other professionals provide rehabilitation services. These include physiotherapists, occupational therapists, dieticians, speech and language therapists, lymphoedema specialists, stoma therapists, and appliance officers.

There is widespread consensus among clinicians and patients that patients with cancer are not currently receiving needed rehabilitation services. This is for several reasons:

- front-line staff frequently do not recognise patients' needs for rehabilitation and may be unaware of the benefits that could be derived from it;
- the availability of AHPs to staff services may be inadequate;
- the AHPs may be inadequately trained in dealing with the problems faced by cancer patients in specific situations;
- delays in accessing equipment and facilities may occur, with failure to prioritise the services required, particularly for those with palliative care needs and those at the end of life.

The following key resource issues arising from the Guidance recommendations have been identified:

- costs of staffing the four-level model for rehabilitation services, in terms of numbers and grades of therapists;
- cost of establishing five new expert posts at superintendent or chief level 3 grades per Network, together with education and training costs associated with these appointments;
- education and training of therapists in the basics of cancer rehabilitation, in order to implement the recommended cascade model (whereby therapists train health care professionals working with cancer patients in rehabilitative needs assessment).

Training and education issues are discussed in section 2.13.

National Agenda for Workforce Expansion for Therapists

The Economic Review considered whether a model could be built for the extra number of therapists required under the Guidance recommendations, based on the national agenda for workforce expansion for therapists [h].

This approach was abandoned at an early stage, as growth figures are not specific to the professions. Moreover, staff working within the supportive and palliative care area are more likely to be senior grade staff, while the staff entering the professions under the national agenda will be junior grade staff. Instead, the wte therapists required under the Guidance recommendations have been estimated, as set out below.

2.10.2 Four-level model of rehabilitative assessment and support

Guidance Key Recommendation: 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.

Staffing levels required to implement the four level model of rehabilitation are based on a modification of assumptions used in previous ScHARR modelling[3] for specialist palliative care, extended to include supportive care, speech and language therapists, and lymphoedema specialists. It is necessary to make assumptions regarding the number of wte staff needed for each therapy group in hospital, hospice and community settings.

The table of cost estimates below sets out the assumptions regarding the wte therapists required throughout a Cancer Network with a 1.5 million population. It is assumed that this staff complement will be sufficient to enable implementation of the recommended four level model of rehabilitative assessment and support. However, these are considered provisional estimates only, as little is currently known about what high quality services should look like and the level of staffing required. These assumptions will need to be revisited as more evidence becomes available.

As part of this model of care, Cancer Networks should identify one wte person for each therapy group – physiotherapy, occupational therapy, dieticians, speech and language therapists, lymphoedema specialists – to undertake the role of expert AHP in each Network, with the posts graded at the Chief 3 or Superintendent 3. One of the five appointed experts should carry out the role of strategic AHP lead, working with the Network management team, on behalf of the five therapies. These individuals should

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[h] HR in the NHS Plan: July 2002: sets out targets for staff increases of 6500 extra therapists by 2004, and 30,000 more therapists and scientists by 2008 than in 2001.

work with their expert AHP colleagues to lead a programme of work, including the development and implementation of a Network-wide strategy to ensure that patients' needs for rehabilitation are recognised and met through the use of a Network-wide assessment tool and the establishment of referral and treatment criteria[i].

In the rehabilitation model as a whole, half of the therapist posts within each Network are assumed to be senior 1 grade and half are assumed to be senior 2 grade, reflecting the balance of specialist and general cancer work, as well as the seniority of staff working with cancer patients. The one exception is the expert AHP for each therapy, graded at Chief 3 or Superintendent 3 grade.

Approximately one-third of service provision is assumed to be within specialist palliative care services and two-thirds within general and supportive care.

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[i] See Guidance chapter 12 for a full list of the role of the five lead therapists per network.

Table 23: Cost estimates for four level model of rehabilitative assessment and support

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
5 expert posts per Network	£0.146m	£5.1m	Salaries are at Superintendent 3 or Chief level 3 grades: these are the same. They are also included in the total Staffing costs figures below
Total staffing costs	£0.67m	£23.75m	*At cancer centres:* 1.5 wte for physiotherapists, occupational therapists, and dieticians 1 wte for lymphoedema specialists 0.75 wte for speech and language therapists *At cancer units:* 0.75 wte for physiotherapists, occupational therapists, and dieticians 0.5 wte for lymphoedema specialists 0.375 wte for speech and language therapists *For the home care team:* 2.25 wte per 1.5 million population for physiotherapists, occupational therapists, and dieticians 1.5 wte per 1.5 million population for lymphoedema specialists 1.125 wte per 1.5 million population for speech and language therapists A 'central' scenario is assumed of 1 cancer centre and 4 units per Network
Salary Assumptions			Therapists posts per Network are assumed to be 50% at senior 1 grade and 50% at senior 2, reflecting the balance of specialist and general cancer supportive work and seniority of staff working with cancer patients - average is computed of the Point 02 and 03 scales for senior I and senior II therapists *Expert posts for Physiotherapy, OT, SLT, and Dieticians* average salary, including on-costs, is £25,481 Chief III or Superintendent III Point 02 Salary level = £30,037, including on-costs Source Advance Letter PAM (PTA)1/2002

Note: costs for therapists overlap with specialist palliative care services: about 1/3 of the cost estimate of £23.75m for England and Wales is for therapists working within specialist palliative care services, and 2/3 for therapists working within supportive care for adult patients with cancer.

2.10.3 Stoma-therapists and appliance officers

Guidance Recommendation: *Providers should ensure designated facilities are available for demonstrations and fitting of appliances, with sufficient space for these activities to be carried out effectively. Such facilities should confer privacy and be stocked with items such as mirrors, a couch, washbasin and storage cupboards.*

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

There are no additional costs assumed here, since these posts generally already exist and the appliances involved, such as breast prostheses, wigs and stoma bags, are already paid for via NHS funds.

2.11 Complementary Therapies

2.11.1 Background

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. There is, however, little conventional evidence regarding the effectiveness of these therapies in relation to the relief of pain, anxiety, distress or other components of quality of life.

Specific areas where there are NHS costs are:

- specific posts or sessions dedicated to complementary therapies, supported by the NHS;
- provision of reliable and high quality information about complementary therapies, to empower patients to make decisions for themselves.

Resource issues in relation to information are considered separately in section 2.4 of this report.

2.11.2 Issues

Guidance key recommendation: 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, where there is evidence to support their use. 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.

As the Guidance does not make any specific recommendations regarding the availability of complementary therapy services within the NHS, no estimates have been made in relation to the cost of service provision. A Cancer Network may, however, choose to establish some form of complementary therapy interest group to review evidence related to best practice, agree policies to ensure safe practice and develop the complementary therapy components of a service directory. 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.

Patients will require access to a knowledgeable individual to provide high quality information on complementary services and this will have training implications.

2.12 Services for Families and Carers, including Bereavement Care

2.12.1 Background

Families and carers provide crucial support for patients, but often their own needs for support and information go unrecognised. Information and support needs of families and carers will differ at discrete points in the patient pathway. Carers may require access to practical and emotional support to address their own needs, to enable them to fulfil their caring role more effectively and to facilitate their grieving process.

Many carers do not currently obtain needed services for a number of reasons:

- services are underdeveloped in many parts of the country, with fragmented service delivery and services targeted at discrete groups;
- many family members and carers have little contact with professionals to discuss their own needs;
- sources of help and advice may be inadequate and/or inappropriate;
- bereavement services are of variable quality and are not available to everyone.

Guidance recommendations identified as requiring significant additional resources are as follows:

- organisations providing cancer care services should nominate a lead to oversee the development and implementation of services specifically focused on the needs of families and carers;
- implementation of the three component model of bereavement support;
- basic training in understanding and meeting the needs of carers and families for all health care professionals involved in the delivery of supportive and palliative care (refer to section 2.13 Workforce Development).

The needs of family members and other carers should be assessed on an on-going basis.
It is assumed that the health and social care professionals providing day-to-day care will undertake the assessment of needs and the cost impact of such work will be minimal.

Issues that straddle both the NHS and social services, such as respite care, are not addressed within the Economic Review, as there are no firm recommendations in the Guidance.

2.12.2 Strategic lead for development and implementation of services for families and carers

Guidance key recommendation: Provider organisations should nominate a lead person to oversee the development and implementation of services that specifically focus on the needs of families and carers during the patient's life and in bereavement, and which reflect cultural sensitivities.

New posts will be required to undertake the role of strategic development of services for families and carers. The leads for families and carers will also deliver services, especially counselling. It is assumed that there will be one wte in each Network (grade I) to lead on strategic development, likely to be based at the cancer centre, and supported by 0.5 wte per unit (grade H). This is estimated to cost £0.1million for a Cancer Network with one cancer centre and four units, and £3.4 million in total for England and Wales.

Table 24: Cost estimate of strategic leads for families and carers

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Strategic leads	£0.1m	£3.4m	1 wte per Network to lead on strategic development likely to be based at the cancer centre 0.5 wte per unit 1 cancer centre and 4 units assumed per Network the lead person assumed to be grade I with salary of £30,455 (2002 Grade I NP57 spine 3) the unit people assumed to be grade H with a salary of £27,695 (2002 Grade H NP51 spine 3)

2.12.3 Three-component model of bereavement support

Guidance Recommendation: 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.

The components should be flexible and accessible when needed around the time of bereavement:

- Component 1: all bereaved people should be offered information about grief and how to access support services;
- Component 2: a proportion of bereaved people will require additional support to help them deal with the emotional and psychological impact of loss by death;
- Component 3: a small proportion of bereaved people will require specialist intervention. This may involve a range of services including mental health services, psychological support services, specialist counselling services etc.

Current provision of bereavement services

A range of service providers currently offers bereavement services:

- Cancer care acute Trusts
  The Department of Health survey on bereavement services (summer 2001) found that every NHS Trust provides support to bereaved people in some form, but the extent of this support varies considerably
- Hospices and specialist palliative care services
  Hospice and specialist palliative care services are generally better developed than services in acute Trusts. There is a range of models and significant geographical variation in provision. Some areas currently lack services working at component 2 and 3. Waiting lists for component 3 services are around six months in some areas.
- Community services
  Community services, such as Cruse, tend to offer local support services for specific groups of bereaved people. They are not considered within the scope of this Economic Review.

A recent national survey of UK bereavement services[28] found that many services were offered, including one-to-one support (95%), telephone support (89%), written information/ advice (73%), memorial, remembrance or anniversary service (71%), support groups (61%) and drop-in support (43%). The mean number of newly bereaved people referred to one-to-one services per year is 160 (median = 90). Approximately two thirds of these services use volunteer workers. The mean number of paid staff is 2.8 per service and the mean number of volunteer workers is 9.6 per service.

Future provision of bereavement services

It can be assumed that all bereaved people require level 1 support, 35% require additional support at level 2, and 5-10% require level 3 support, based on input from Editorial Board member with expertise in this area.

Component 1

Family members and carers will require access to sources of information, advice and practical support. Network service directories should list services for families and carers. The information requirements of component 1 are included as part of the costing of information services in Section 2.4.

Component 2

For costing purposes it is assumed that component 2 support services are provided by trained volunteers, managed by health and social care professionals. Some services, however, are run by health professionals alone, and these services are likely to have higher costs.

The efficacy of bereavement services using volunteers is determined by the quality of the relationship between volunteer and client, but there is also a need for good co-ordination of their work[29]. Sufficient time and resources are therefore required to select, train and supervise volunteers.

A bereavement lead (assumed to be Administration and Clerical Grade 7) is likely to spend the majority of his or her time on education, supervision, training and recruitment. For small to medium sized services, with less than 200 clients, it is assumed that this position would be 0.75 wte per service. For larger services, with 200 or more clients, it is assumed that this position would be full- time. It is assumed that a part-time bereavement counsellor is employed to handle more complex cases (0.4 wte per service for small/medium services and 0.6 wte per service for larger services). Administrative support (0.6 wte per service for smaller services and 1.0 wte per week for larger services) is required. Other costs, including depreciation, maintenance etc, are assumed to be 10% of total costs.

It is assumed that there are six providers per million population (based on the number of services listed in the 2002 Hospice Directory). Assuming that 35% of bereaved people use these services, each provider would see an average of 152 clients [j].

Component 3

Approximately 5 – 10% of bereaved people will have complex problems requiring specialist intervention. Component 3 services are included within the cost for psychological support services (see section 2.5).

Table 25: Cost estimates of implementing three-component model

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Bereavement Support Services (component 2 only)	£0.5m	£16.1m	Cancer deaths = 3907 per Network (1.5million) Component 2: 35% (1368 clients per Network) of bereaved require support Provided by volunteers with co-ordination by health professionals

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[j] Based on an average cancer deaths per network of 3907 x 35% requiring L2 support ÷ 9 services.

The cost estimates in this section include the cost of strategic leads and the cost of provision of bereavement services at level 2. The majority of strategic lead posts will be new posts, as these services are currently poorly developed. The incremental cost of future bereavement service provision, over and above current levels, cannot be estimated because the cost of current provision is not known. However, the current cost is likely to be a relatively small proportion of the total future cost of service provision given in Table 25.

2.12.3 Cost savings from high quality bereavement support services

An unpublished study has shown that high quality bereavement support interventions for selected 'at risk' people significantly reduce the use of health services, in particular GP visits, and can therefore produce cost savings [30]. These cost savings have not been taken into account in the Economic Review.

2.13 Workforce Development

2.13.1 Background

A significant number of Guidance recommendations relate to workforce development – the education, training and support staff need to deliver services. Frontline clinical staff require enhanced training in the assessment of patients' problems, concerns and needs and in information sharing and communication skills. Additional specialist staff, with their own training and support requirements, will be needed in roles related to information delivery, psychological support, rehabilitation, palliative care and support for families and carers.

The Department of Health is currently investing £6 million over 3 years (2001-04) to train and support over 10,000 district and community nurses (one in four of all district nurses). Significant additional investment will be required to train a range of other health professionals involved in the provision of supportive and palliative care.

Education and training needs identified within the Guidance include:

- Skills training in the assessment of supportive and palliative needs, both generally and specifically for social care, spiritual needs, psychological support and rehabilitative needs;
- Accredited communication skills training programmes for clinical staff at advanced and foundation levels;
- Training in information giving, including training of managers and staff in information centres;
- Training of staff in the facilitation of patient and carer support groups;
- Training of staff in the provision of psychological support;
- Education for health and social care professionals in the principles and importance of user involvement, together with training in user involvement methods and in how to act on user views;
- Training for staff in both the NHS and voluntary organisations in the legal and financial frameworks of the NHS and voluntary organisations, arising from the requirement that they work in partnership through Cancer Networks;
- Training needs of specific groups, including
  - training and support for members of Partnership Groups (both users and professionals)
  - training for local faith leaders in the assessment and delivery of spiritual care for patients and carers.

A detailed analysis of national education and training needs is beyond the scope of this report. However, cost estimates for a limited number of training programmes are provided to illustrate the potential scale of costs associated with meeting these training needs.

Detailed consideration of workforce planning is also beyond the scope of this report. The implications of implementing the Guidance recommendations for the number and type of different care professionals will need to be considered at a national level by the Department of Health Workforce Planning Care Group board with responsibility for cancer, along with the Workforce Development Confederations in England and the Workforce Development Steering Group in Wales.

Types of training

Training in communication skills

The Guidance recommends that all health and social care professionals who come into contact with patients and carers should be offered accredited training courses in communication skills. Cancer Networks will need to decide which staff groups should be given highest priority for advanced skills training courses.

Three levels of training needs are recognised:

- Level 1 - receptionists, medical secretaries, porters and other ancillary staff;
- Level 2 - those providing direct clinical care;
- Level 3 - senior clinicians, who may have to handle particularly complex situations (e.g. consultants, specialist registrars, nurse specialists and GPs).

Training in Needs Assessment

The Guidance identifies a need for training in needs assessment in relation to many aspects of service provision for patients: psychological support, social support, spiritual support, rehabilitation, specialist and general palliative care and care of the dying; in addition, training is needed in the assessment of the needs of families and carers.

Other Education and Training requirements

Specific groups of professional and voluntary workers, as well as patients, are seen to have particular training needs. For instance, within spiritual support, local faith leaders are seen to need training in the assessment and delivery of spiritual care for patients with cancer and their carers.

Identifying Future Training Needs

Workforce Development Confederations (WDCs)
Cancer Networks will need to work closely with WDCs in England (and the Workforce Development Steering Group in Wales) to determine training and education requirements.
The role of WDCs, as partnership organisations, is to give clear leadership and direction to workforce planning and development, and to manage the Multi-Professional Education and Training budget and other relevant budgets (to be allocated from the DH to Strategic Health Authorities, which will act as paymasters for the Confederations).[31] The WDCs ensure that the Guidance is known to Trusts, assist the Trusts in meeting the Guidance, and may provide funding if necessary. The Guidance recommendations will need to be reflected in Local Delivery Plans (LDPs).

The North East London Workforce Development Confederation (NELWDC) is the lead confederation for cancer and palliative care. It plays an essential role in communicating the work of the CGWT to other WDCs and to the NHS more widely. It acts as a champion for cancer services among WDCs; works with a national Network of WDC and other key leads for cancer; provides regular update reports to the CGWT on workforce developments; and disseminates examples of good practice within the field. Where it has been decided that education and training programmes are best commissioned nationally, the WDC will commission these on behalf of the NHS. The lead WDC, in conjunction with CGWT & CWP, will collate, analyse and disseminate examples of good practice and encourage innovation in relation to various human resources fields, such as recruitment and retention, pay, education and training, new roles and skill-mix.

Training Needs Assessment
The Kent Cancer Education Project[32] provides an example of the type of training needs analysis (TNA) that Cancer Networks may need to carry out to determine new training and education needed to implement the workforce development recommendations. In 1997, the Kent Education Consortium funded a TNA of nurses and professions allied to medicine (PAMS[k]) within the cancer workforce across Kent. This was a major project running from August 1998 to July 1999.

The types of nurses and PAMS selected for the Kent Cancer Education Project survey in Table 26, illustrate the diverse range of health care professionals working in cancer, all of whose training and education needs will need to be assessed by Cancer Networks to address the Guidance workforce development recommendations.

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[k] PAMS was the previous term used for AHPs (Allied Health Professionals).

Table 26: List of nurses and PAMs selected for inclusion in Kent Cancer Education Survey

Nurses	Nurse Managers, Practice Development Nurses, Clinical Nurse Specialists, Nurse Practitioners
	Nurses working in cancer centres, units, hospices, Macmillan nurses, Marie Curie nurses, senior nurses undertaking research
	General ward nurses (day/night/flexibank) working in day care, surgical, medical, gynaecological, outpatient, elderly and paediatric services
	Community nurses, district nurses, community psychiatric nurses, practice nurses, health visitors
PAMS	Radiographers (therapeutic and diagnostic) and dieticians, occupational therapists, speech therapists, physiotherapists, pharmacists

2.13.2 Illustrative costing exercise

Key Recommendation: 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.

Key Recommendation: 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.

A full cost analysis of meeting education and training needs is beyond the scope of this review. However, preliminary estimates of the costs of some training are given to illustrate the means of estimating workforce development costs for generic training and education programmes for health and social care professionals, as well as for a limited number of specific training programmes. Health and social care professionals need specific skills to allow them to do their jobs. Future training programmes, designed to prepare staff for their specific role, may include some of the elements outlined below.

It will not be feasible to meet all training needs in the short term. Cancer Networks will need to work closely with WDCs in England (and the Workforce Development Steering Group in Wales) to identify and prioritise training and education requirements.

2.13.2.1 Training in Communication Skills

Advanced communication skills course for senior health care professionals (SHCPs)

A pilot study evaluating an advanced communication skills course for senior health care professionals (SHCPs) is currently under way nationally and is expected to report in February 2004. Within the advanced communication skills programme, two levels of training are provided. One programme, 'training the trainers', involves a three day course to train SHCPs to facilitate communication skills training courses for other SHCPs. The second programme is a three day SHCP training course in communication skills run by the trainers. The communication skills programme pilot is training 28 SHCPs on the 'training the trainers' course and approximately 168 SHCPs on the SHCP training course.

Only the costs of training senior personnel are considered, as this is assumed to be the highest priority. Estimates of the potential numbers of senior doctors (consultants and specialist registrars), senior nurses (nurse specialists) and other SHCPs nationally who may potentially require communication skills training are given below. This table is not comprehensive; additional staff, including surgical oncologists and physicians working in specialist palliative care who are not consultants or specialist registrars, but who are considered senior health care professionals, could potentially be included.

Table 27: Potential numbers of senior healthcare professionals requiring communication skills training at level 3

Type of senior HCP	Source / assumptions	Numbers
Consultants in Palliative Medicine	Association of Palliative Medicine	249
Specialist Registrars in Palliative Medicine	Association of Palliative Medicine	117
Consultants in Medical Oncology	RCP Consultant census[33] (adjusted to exclude Northern Ireland)	146
Specialist Registrars in Medical Oncology	Estimated using ratio of consultants to specialist registrars, as in Palliative Medicine	68
Consultants in Clinical Oncology	Hospital and Community Health Services census 2001[34].	330
Specialist Registrars in Clinical Oncology	Estimated using ratio of consultants to specialist registrars, as in Palliative Medicine	155
Total no senior doctors		1065
Nurse specialists	Estimated using ratio of senior doctors: nurse specialists undergoing training in the pilot.	1331
Other senior healthcare professionals	Estimated using ratio of senior doctors: senior healthcare professionals undergoing training in the pilot.	1331
Total number of SHCPs requiring training		3727

Training costs were obtained from the three day communication skills course pilot, based on a course with 12 delegates. Costs per person are given in the table below.

Table 28: Cost per Person for Communication Skills Training

Cost element	Costs (per person)
Communication pack	£35
Delegate meals & accommodation	3 days @ £120 per day
Actors' costs	Fees, travel & accommodation £1,440 for the course (£120 per person)
Facilitators' costs	Fees, travel & accommodation £2,484 for the course (£207 per person)
TOTAL	£722

Table 29: Illustrative Cost of Communication Skills Training for Senior Staff

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
Communications skills course for trainers	£72,747	£2.7m	3 day training course – assume 1 trainer per 6 delegates.
	£151,811	£5.6m	As above, including backfill costs.
Communications skills course for senior HCPs	£12,124	£0.4m	3 day training course. Course alone.
	£25,763	£1.0m	As above, including backfill costs.

Based on a cost per staff member of £722, the total cost of training senior staff is estimated to be £3.1m in England and Wales (£7.6m with backfill costs). Assuming that one third of the above staff undergo training in the first year, the number of senior personnel receiving training in year 1 would be 1,230, an average of just over 33 places per Network. At a cost of £722, this equates to approximately £1.0m in year 1 (£2.5m with backfill costs).

Additional costs would be incurred if GPs undertook the communication skills course. The cost of 30,000 GPs undertaking the course would be £21.7 million in England and Wales for the course alone (£32.8 million if backfill costs were included). There would also be additional costs for training sufficient trainers.

Level 1 and level 2 courses would also need to be developed and made available in subsequent years.

2.13.2.2 Needs assessment training

Training programmes for needs assessment are required, along with an assessment tool. There are no examples of dedicated needs assessment training programmes at present, as all current training in needs assessment is part of a broader course.

Assuming a two day non-residential course – one initial training day, followed by one day follow-up, at a cost of £200 per day – the cost per place is estimated at £400. Based on a three day residential course – two initial training days, followed by one day follow-up – the cost per place would be £600. For residential courses, an additional £125 per day would need to be added.

It is assumed that the initial target group would be Clinical Nurse Specialists. Training would then extend to frontline nurses (Grade E & F in first instance), perhaps targeting ten nurses per annum per acute Trust - approximately 2000 places per annum

Assuming that 2,000 places are made available nationally for needs assessment training per annum (around 55 per Network), at a cost of £400 per place, the total cost for England and Wales is estimated to be £800,000 per annum.

Table 30: Illustrative Costs of Needs Assessment Training

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Needs Assessment Training	£21.6K	£0.8m	2000 places per year undergoing training at £400 per place Initial targeted at Clinical Nurse Specialist, then targeted at Grade E and F nurses in acute hospitals

2.13.2.3 Information Giving

The estimated cost of training in meeting people's health information needs is based on a one day non-residential course at cost of £100 per day, and assuming 3,000 places per year are made available nationally.

Table 31: Illustrative Costs of Training on Information Giving

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
Information giving	£8K	£0.3m	3000 places per year at £100 per place

2.13.2.4 Specific Training Requirements

Rehabilitation

Specific training requirements for therapists include both training of Allied Health Professionals (AHPs) in the basics of cancer rehabilitation, so that a cascading model of therapists training other healthcare professionals in rehabilitative needs assessment can be implemented, and postgraduate training for new strategic post holders

Table 32: Illustrative Costs of Training for Rehabilitation Services

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Education and training in the basics of cancer rehabilitation	Lower: £9,000 p.a. Upper £18,000 p.a.	£0.5m per annum (using averaged Network figure)	15-30 therapists per year undergoing training per Network at £600 per therapist
Education and training for the expert: 5 designated posts per Network	Set up costs: £12,500 Ongoing costs Lower £2500 Upper £5000	Set-up costs: £0.5m Ongoing per annum costs (using averaged Network figure) £0.1m	Specialist course (postgraduate Diploma/MSc) taking 2 years at £2500 per therapist Set-up costs assume all training costs accrue in the 1st year, although in practice, probably 2 per year would be trained until all are trained Ongoing costs consist of 1-2 per Network per year being trained to cover natural turnover, new posts; costs are spread over the 2 years
Total	Set-up costs £12,500 Ongoing costs Lower £11,500 Upper £23,000	Set-up costs £0.5m Ongoing costs £0.6m	

User Involvement

Cancer Networks need to ensure that both user and professional members of Partnership Groups have access to training and support. Users and professionals might be trained together where they are working as part of a group. Training for users is currently provided by CancerVOICES, an independent national organisation of users and user/partnership groups, supported by Macmillan Cancer Relief.

The cost estimate assumes that six training sessions per annum per Network are undertaken at a total cost of £10,000 p.a. per Network.

Table 33: Illustrative Costs of Training for User Involvement

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Training for user involvement	£0.010m	£0.35m	up to £10,000 p.a. is made available to users and health professionals in each Cancer Network to 'buy in' appropriate training for user involvement (based on about six training sessions per year costing £1500 per session).

Psychological Support

Education and training requirements include training in screening for psychological distress and delivering basic psychological interventions for those health care professionals working at level 2. There are also needs for training of those staff delivering psychological care at levels 3 and 4, by psychological care experts with extensive experience in cancer.

Table 34: Illustrative Costs of Training for Psychological Support

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Training and supervision costs for professional psychological assessment and support	£0.01m	£0.5m	Level 3: 2 wte counsellors Level 4: 2 wte psychologists - 1 wte consultant psychiatrist Staff operating at levels 3 and 4 have training costs of £1285 pa, and supervision costs of £1500 pa.

2.13.2.5 Discussion of illustrative costs

Given the number of Guidance recommendations relating to workforce development, the resource implications will be significant. It will not be feasible for Cancer Networks to meet all training requirements in the short term. The cost for any given Cancer Network will, however, depend on the priorities given to different types of training by individual Networks, the number of places made available on an annual basis and the format in which training is provided.

Detailed consideration of workforce planning will need to be given at a national level by the Department of Health Workforce Planning Care Group board with responsibility for cancer, along with the Workforce Development Confederations in England and the Workforce Development Steering Group in Wales.

3. Discussion and Conclusion

Economic modelling work has been undertaken to estimate the overall cost of providing a full range of supportive and palliative care services in England and Wales, based on the Guidance recommendations.

3.1 Issues relating to the presentation of cost estimates

In this section, the total costs from sections 2.1 to 2.12 are presented together to give a comprehensive picture of the estimated cost of future provision of services under the Guidance recommendations.

The costs are presented in two separate tables: Table 35 shows estimated costs for supportive and general palliative care and Table 36 shows estimated costs for specialist palliative care services.

These costs should be considered to be of only a crude order of magnitude and the results should be viewed with caution. Key limitations and uncertainties are discussed in section 3.3.

3.1.1 Supportive care and general palliative care

A number of issues arise in the presentation of costs within supportive and general palliative care:

- In the majority of cases, the full cost of service provision is presented, rather than the incremental cost of implementing the Guidance. This is because it has not been possible to determine baseline service levels or details of current expenditure for these services. Cancer Networks will need to undertake baseline assessment exercises in order determine their current level of service provision and estimate the difference between current and future costs.

- In many areas within supportive care, the costs presented are recurrent annual costs (e.g. for user expenses in the User Involvement section 2.2 or the staff wte component of the annual cost of running a service, such as dedicated cancer information centres in units and Trusts in section 2.4). However, in some instances, the costs presented are a one-off set-up cost (e.g. for production of a Network-service directory in the Co-ordination of Care section 2.1).

These costs are highlighted in Table 35 and account for only a small proportion of total costs.

- For generalist staff groups, such as GPs and community nurses, their total workload in relation to cancer patients is not modelled. It is assumed that the palliative care needs assessments, interventions and referrals recommended in the Guidance form part of their normal workload and that the cost impact for these staff groups is minimal, except in the relation to training and education requirements.

When interpreting the figures presented in Table 35, the reader is advised to refer back to the relevant sections for a full explanation of the basis of calculation.

3.1.2 Specialist palliative care

Specialist palliative care services offer support to patients with cancer, suffering from a range of complex problems which cannot be handled effectively by generalist services in hospitals or in the community. The core components of service are specialist palliative care inpatient beds, community specialist palliative care teams, hospital support teams, bereavement services, outpatient services, day care and 'hospice at home' type services.

Current expenditure on individual elements of specialist palliative care services in England and Wales is not known with certainty, but an estimate of total current expenditure on these services as a whole has been derived. In Table 36, the estimated cost of future provision for all specialist palliative care services is totalled and compared with this estimate of the total cost of current provision, in order to estimate the cost impact of provision of specialist palliative care resulting from implementation of the Guidance.

3.1.3 Double counting

The costs presented within individual chapters of the Economic Review include elements of double counting. For instance, the cost of bereavement services is shown in both section 2.9 Specialist Palliative Care and section 2.12 Services for Families and Carers. However, figures within the final summary tables are presented in such a way as to remove any element of double counting between services.

3.2 Summary of costs of supportive and palliative care services

3.2.1 Current provision

Current expenditure on all supportive and palliative care services across England and Wales is not known with certainty.

Expenditure on specialist palliative care services only in England in 2001-02 was estimated at £320 million (see footnote in the specialist palliative care section 2.9 for further explanation). Expenditure on specialist palliative care in Wales is unknown, but extrapolation of expenditure on services in England in 2001-02 to the population of Wales suggests that expenditure in Wales in 2001-02 was around £19 million. In 2002-03, an additional £50 million per annum was allocated to specialist palliative care services in England for three years, resulting in a total national figure of £398.5 million for 2002-03.

For a typical Cancer Network, with a population of 1.5 million, the cost of current provision is estimated to be £11.5 million. However, there is wide variation in the current levels of provision of supportive and palliative care services between Cancer Networks and therefore the baseline cost of provision will vary considerably.

Significant work is required within individual Cancer Networks in order to establish the baseline level of service provision and current expenditure. In addition, collection of national cost data relating to the principal elements of supportive and palliative care is essential, in order to build on the cost estimates presented within this report.

3.2.2 Future provision

The economic model estimates the potential scale of costs of future provision of high quality supportive and palliative care services, based on Guidance recommendations, within a hypothetical Network of 1.5 million. The assumptions on staffing levels are based on the requirement to ensure that a high quality service can be delivered and may be well above current staffing levels in many Networks. All staff costs are based on NHS pay scales.

The cost estimates are considered to be of only a crude order of magnitude. It has not been possible within the scope and timeframe of this report to undertake detailed costing work on all components of supportive and palliative care. It has therefore been necessary to make broad brush assumptions relating to the level and cost of future provision. These cost estimates are considered to be a starting point for discussion and will need to be updated as more data become available. The assumptions on which these costs estimates have been generated have been made explicit and it is anticipated that further work will be required in the future to build on this work. The cost estimates do, however, provide an initial indication of key areas where additional funding is needed to allow successful implementation of the Guidance.

Funding issues relating to the split of funding between the NHS and voluntary sector are beyond the remit of this report. The review considers the cost of implementing the Guidance, not where the costs will fall.

Education and training costs, as outlined in section 2.13, are not included in these tables.

Cost estimates are split into two categories: general and supportive care (Table 35) and specialist palliative care services (Table 36 and Table 37).

General and Supportive Care Services

The figures in Table 35 are estimates of the total cost of provision for these services, and not the cost impact of the implementing the Guidance. This is because, for the majority of these services, the current expenditure on the service is not known. Staff groups involved in delivering these services are providing services to a wide cross-section of patients and the proportion of their workload currently dedicated to cancer patients is generally unknown. In most Cancer Networks, some level of service provision is likely to exist for the majority of services and these figures therefore represent an upper ceiling for the predicted cost impact.

Table 35: Cost Estimates for General and Supportive Care Services (excluding education and training costs): Total cost (2002-03 prices)

GENERAL AND SUPPORTIVE PALLIATIVE CARE SERVICES	Cancer Network (£)	England & Wales (£ m)	% of total cost
Co-ordination of Care (section 2.1)	**£63,700**	**£2.2**	**3.7%**
Network lead for development of supportive and palliative care services	£34,700	£1.2	
Production of a network service directory	£29,000	£1.0	
User Involvement (section 2.2)	**£50,000**	**£1.7**	**2.9%**
Partnership/User Groups - support for venue costs, publicity, administration	£5,000	£0.2	
Partnership/User Groups - support for facilitation	£30,000	£1.0	
User Expenses and Time	£15,000	£0.5	
Face-to-Face Communication (section 2.3)	**£104,800**	**£3.6**	**6.1%**
Patient records of consultations (75% uptake)	£84,700	£2.9	
Professional healthcare interpreters	£20,100	£0.7	
Information (section 2.4)	**£272,600**	**£9.5**	**16.0%**
High quality information packs	£71,400	£2.5	
Information provision via dedicated cancer information centres - materials and equipment - set up costs *	£21,100	£0.7	
Network lead for information	£34,700	£1.2	
Information managers (Centre and Satellite units)	£104,200	£3.6	
Administration (Centre and satellite units)	£41,200	£1.4	
Psychological Support Services (section 2.5)	**£364,800**	**£12.7**	**21.4%**
Specialist staff (Level 3 / Level 4)	£238,100	£8.3	
Administration & Service overheads	£126,700	£4.4	
Social Support (section 2.6)	**£108,100**	**£3.8**	**6.3%**
Social Worker: assessments/welfare benefits input	£108,100	£3.8	
General Palliative Care (section 2.8)	**£145,100**	**£5.0**	**8.5%**
Out-of-hours community nursing **	£2,587,500	£89.8	
Gold Standards Framework: practice set up costs *	£80,600	£2.8	
Gold Standards Framework: 0.2 wte facilitator per PCT	£64,500	£2.2	
Rehabilitation (section 2.10)	**£500,700**	**£17.4**	**29.3%**
Physiotherapist	£89,200	£3.1	
Occupational Therapist	£89,200	£3.1	
Dietician	£89,200	£3.1	
Lymphoedema Nurse	£51,000	£1.8	
Speech and Language Therapist	£31,900	£1.1	
Strategic leads for 5 therapy groups	£150,200	£5.2	
Families & Carers (section 2.12)	**£97,800**	**£3.4**	**5.7%**
Family & Carer lead at cancer centre and units	£97,800	£3.4	
Supportive and General Care (excl. out-of-hours community nursing)	**£1,707,600**	**£59.3**	**100.0%**

* Set up costs - year 1 only

** This is the total cost of out-of hours service. Palliative care workload is only a proportion of the total workload. This cost is excluded from the total figures. The cost impact, based on estimates of current provision, is estimated to be around £ 33 m

It should be noted that the cost estimates in Table 35 incorporate only the supportive and general palliative care component of services; for some services, a significant proportion of the costs for the service will fall under the specialist palliative care costs, set out in Table 36 and Table 37.

Strategic staff posts, such as Network leads for the development of supportive and palliative care services, the new strategic posts for rehabilitation services and family and carer leads are likely to be new posts in many Cancer Networks and therefore the full cost given in the table may be considered to be the cost impact of the Guidance. However, for information provision, including Network directories, baseline provision will vary considerably between Cancer Networks and these costs are likely to over-estimate the cost impact of the Guidance in many Cancer Networks. For psychological support, social support and rehabilitation services, most Cancer Networks are already providing some level of service and will therefore not incur the full cost of provision identified here. However, particularly in the case of psychological services, current provision in most Networks is minimal and therefore the cost impact and staffing implications of the Guidance will be substantial.

For out-of-hours community nursing, the total cost of service provision is estimated to be £89.8 million for England and Wales. Estimates of the palliative care share of this service vary enormously, although the two most recent studies indicate that palliative care may be around 50% of the total workload. However, it should be noted that an out-of-hours service would need to be implemented for *all* patients in order for cancer patients to gain 24-hour access. Given the significant proportion of PCTs which currently offer an evening or full 24 hour service, a cost impact analysis was undertaken, taking into account estimates of current service provision. This analysis suggests that the cost impact of implementing out-of-hours provision in PCTs where this service does not currently exist is £33.2 million.

A variety of costs are excluded from this table. Services that straddle both the NHS and social services, such as respite care and transport, along with equipment such as mattresses, commodes, wheelchairs, are excluded from the Economic Review. The costs of translation of written information is not included on the basis that separate work is on-going on a national basis to ensure that requirements for translations are being met efficiently.

Specialist Palliative Care Services

The estimated total cost of providing specialist palliative care services in England and Wales, shown in Table 36 and Table 37, is £440.3 million. Given that current provision is estimated to be £398.5 million, this suggests that the cost impact of the Guidance for specialist palliative care services will be around £42 million per annum.

Table 36: Cost Estimates for Provision of Specialist Palliative Care Services (excluding education and training costs): Total Cost and Cost Impact of Guidance (2002-03 prices)

SPECIALIST PALLIATIVE CARE SERVICES (section 2.9)	Cancer Network (£)	England & Wales (£ m)	% of total costs
Medical Staff	**£2,066,800**	**£71.8**	**16.3%**
Consultants (incl. out-of-hours cover)	£1,222,500	£42.4	
Other Medical Staff (incl. out-hours cover)	£844,300	£29.3	
Nursing Staff	**£5,644,000**	**£196**	**44.5%**
Grade G / H / I	£2,133,900	£74.1	
Grade E and F	£2,232,000	£77.5	
Untrained Nurses	£1,107,600	£38.5	
Cover/Oncall Nurse Costs	£170,500	£5.9	
Extended Specialist Palliative Care Team	**£1,881,418**	**£65**	**14.8%**
Social Care Assessments, Welfare Benefits Rights Advice, Counselling, Psychological Support, Care of Families & Carers (inc. bereavement support)	£494,718	£17.2	
Administrative support	£581,200	£20.2	
Chaplain-Spiritual Care Giver	£118,200	£4.1	
Physiotherapist	£57,300	£2.0	
Occupational Therapist	£57,300	£2.0	
Dietician	£57,300	£2.0	
Speech & Language Therapist	£28,700	£1.0	
Lymphoedema Nurse	£38,200	£1.3	
Pharmacist	£160,400	£5.6	
Trained Carers and Nurses providing continuous support to the dying	£288,100	£10.0	
A. Subtotal: Specialist Palliative Care Staff Costs - Direct Medical, Nursing and Extended Team	**£9,592,218**	**£333.1**	**75.6%**
B. Overhead Costs	**£3,088,769**	**£107.3**	**24.4%**
C. Total Cost of Future Provision (A + B)	**£12,680,988**	**£440.3**	**100%**
D. Total Cost of Current Provision	**£11,477,900**	**£398.5**	**-**
E. Cost Impact (C - D)	**£1,203,088**	**£41.8**	**-**

A breakdown of the specialist palliative care costs by type of service is given in Table 37 below. Inpatient services, along with hospital and community specialist palliative care teams account for nearly 83% of total costs.

Table 37: Cost Estimates for Provision of Specialist Palliative Care Services (excluding education and training costs): Cost Breakdown by Service (2002-03 prices)

SPECIALIST PALLIATIVE CARE SERVICES (section 2.9)	Staff Costs	Other Costs	TOTAL COSTS	
CANCER NETWORK	**£m**	**£ m**	**£m**	**%**
Specialist Palliative Care Inpatient Beds	£4.8	£2.1	**£6.9**	54.0%
Day Care	£0.5	£0.3	**£0.9**	6.8%
Community Specialist Palliative Care Team	£1.7	£0.3	**£2.0**	15.5%
Hospital Support	£1.5	£0.2	**£1.7**	13.2%
Bereavement Services	£0.4	£0.0	**£0.5**	3.7%
Outpatient	£0.4	£0.0	**£0.5**	3.9%
Continuous Support for Dying Patients	£0.3	£0.1	**£0.4**	3.0%
Total Specialist Palliative Care Costs (Cancer Network)	**£9.6**	**£3.1**	**£12.7**	**100%**
ENGLAND & WALES	**£m**	**£ m**	**£m**	**%**
Specialist Palliative Care Inpatient Beds	£165.1	£72.8	**£237.9**	54.0%
Day Care	£17.9	£12.1	**£30.0**	6.8%
Community Specialist Palliative Care Team	£57.9	£10.2	**£68.1**	15.5%
Hospital Support	£52.3	£5.8	**£58.1**	13.2%
Bereavement Services	£14.5	£1.6	**£16.1**	3.7%
Outpatient	£15.4	£1.7	**£17.1**	3.9%
Continuous Support for Dying Patients	£10.0	£3.0	**£13.0**	3.0%
Total Specialist Palliative Care Costs (England & Wales)	**£333.0**	**£107.2**	**£440.3**	**100%**
% of total costs	75.6%	24.4%	100.0%	

3.3 Limitations and Uncertainties

Given the complexities of service configuration and the lack of data on the volumes and costs of current service provision, it has been possible to provide cost estimates of only a crude order of magnitude.

The model uses the existing evidence base, where available. Gaps in the evidence base have been filled using expert opinion.

In some instances, such as the psychological support model and social support, only preliminary cost estimates have been provided, with further work identified beyond the scope and timeframe of this Review, to allow more robust estimates to be produced.

A number of key data gaps and uncertainties have been identified and are discussed below.

3.3.1. Inadequate data on costs of current provision

Current cost data are limited. There is an urgent need to collect high quality cost data within this field. The cost estimates generated in this report should be considered in the light of this absence of robust costing data.

To this end, the NHS Information Authority is currently undertaking a project to develop Health Resource Groups (HRGs) for core specialist palliative care services. A range of draft HRGs for specialist palliative care is currently being piloted at three sites in England. The data collection for this pilot is due to be completed in December 2003. The project is expected to report in June 2004.

In addition, a project is under way to provide an analysis of current specialist palliative care costs. Detailed cost data has been obtained so far from about 20 units. The initial analysis shows that in-patient unit costs vary from £225 to £389 per occupied bed day and from £158 to £287 per available bed day. For day care, the cost per attendance varies from £41 to £240. For home care, the variation is from £59 to £290 per visit. Analysis of additional data on staffing resources employed to support these services is currently in progress. It is expected that the anticipated cost of providing a core service in accordance with the NICE specification will be reported in early 2004. Estimates of the costs of future provision of services within this Report will need to be revisited as this new cost data becomes available.

3.3.2 Inadequate data on current activity

Data on current activity and service provision by Cancer Networks is limited. Cancer Networks will need to undertake baseline assessment exercises in order determine their current level of service provision.

Cancer Networks with low levels of current service provision will require greater levels of additional funding to meet the Guidance recommendations.

3.3.3 Staffing assumptions

The assumptions on future staffing levels are based on the requirement to ensure that a high quality service can be delivered and may be well above current staffing levels in many Cancer Networks. In many cases, no published evidence was identified on which to base the assumptions of future staffing levels. In such cases, the assumptions used in the Economic Review were based on expert opinion.

The implementation of the Agenda for Change and the European Working Time Directive is likely to have a significant impact on working practices and will therefore affect staff costs, the key cost component of service provision. This will be particularly relevant in relation to the costs of providing 24 hour medical and nursing care. The impact will vary according to existing working practices within individual Cancer Networks and the strategies adopted to ensure that these guidelines are met. Detailed work will need to be undertaken at Cancer Network level to ensure the potential impact is fully understood and costed.

3.3.4 Estimation of non-staff costs

Non-staff costs for both specialist palliative care inpatient services and day care services are significant contributors to the total cost of specialist palliative care provision. Evidence on the appropriate level of these costs is not readily available. Assumptions relating to the proportion of total costs made up by non-staff costs for these services are reliant on one or two examples of current practice. Further detailed work is required in order to ensure that the current estimates are robust and to explore the extent of possible variation.

3.3.5 Local variations in demand for services

The demand for supportive and palliative care is not constant among populations of the same size. For instance, the demand for specialist palliative care services within a Cancer Network is dependent on a wide range of factors, including the number of cancer deaths, the level of deprivation, the volume and quality of general palliative care services such as nursing home beds, and district nursing services. Deprivation has been shown to have an impact on the workload of community specialist palliative care teams and on the demand for specialist palliative care inpatient beds. However, the exact nature of these relationships is not known with certainty and, although this relationship has been demonstrated at ward level, it is not known to what extent this relationship holds at Network level.

Cancer Networks will need to undertake local needs assessment to understand the level of demand within their own population. This will influence the level and type of services required within each Network.

The cost estimates in the Economic Review are based on a hypothetical Network with a population of 1.5 million, assuming an average cancer death rate and average levels of deprivation across the Cancer Network.

3.3.6 Future levels of service provision

The Guidance requires that commissioners ensure that they provide an appropriate range and volume of specialist palliative care services to meet the needs of the local population. There is, however a lack of evidence to support specified levels of service provision, such as the number of specialist inpatient beds required per million population. In addition, volumes of service are interdependent; for example, an increase in the resources for community specialist palliative care teams may lessen the demand for inpatient care services.

The Economic Review has made working assumptions on how future service may be structured and staffed in order to provide cost estimates. However, different Networks will seek to achieve the required level of service provision in different ways. The costs of future service provision should therefore be considered indicative only and expected to vary between Networks.

3.3.7 Economies of scale

The model does not fully take account of the possible impact of economies of scale on the cost of service provision.

For instance, there is little variation in the cost per occupied bed day predicted by the economic model between a small specialist palliative care inpatient unit, with say 10 beds, and a large unit, with say 40 beds. There is, however, a number of reasons why cost per occupied bed may decrease as unit size increases. For instance, when a patient enters or leaves an inpatient unit, the requirement on staff resources is greater than during the intermediate part of their stay. Smaller inpatient units operate with a shorter average length of stay and are therefore likely to require more staff per bed than larger units. In addition, larger units will employ more staff in the same occupation. It is likely that as more staff are employed, additional staff may be recruited at a more junior grade, reducing the average staff cost.

Further detailed work would be useful in the future to explore the relationship between service size and costs.

3.3.8 Impact of integrated services on costs

The model does not take account of differences in the service structure on total costs.
For instance, an integrated service providing specialist palliative care inpatient beds, a home care team and a bereavement service from one base may be expected to have lower costs than the total costs generated

when these services are provided independently. Given the limited data currently identified, it has not been possible to explore these issues.

Further work on the impact of different service configurations on costs is recommended.

3.4 Timeframe for implementation

It will not be possible to address all recommendations in the short term and prioritisation will therefore be necessary. The Guidance identifies 20 key recommendations. Further prioritisation is for local determination. All Cancer Networks will be expected to assess their current levels of service against the Guidance recommendations and prioritise according to that assessment. This assessment should take note of all local variables that may impact on the manner in which services are configured and delivered. The prioritisation process will affect the timeframe of implementation for different services within different Networks.

One of the main resource implications of the Guidance is the staffing levels required to implement the recommended models of care. The workforce planning implications are enormous and a significant time period will be required to gradually build up to the required staffing levels.

Implementation of the Guidance will be gradual and the speed of change is likely to vary considerably from one area to another, due to a variety of factors, including the baseline position of each Network and the extent of changes in service structure required to achieve the targeted level and quality of service provision. The cost impact of implementation will therefore build up over the next few years and the total cost impact will not be experienced for a number of years.

3.5 Further Work

The resource implications of the Guidance are significant. Substantial work is needed in the future to build on the costing work undertaken to date and to work towards effective implementation of the Guidance.

3.5.1 Baseline activity and cost data

Baseline service data are required. All Cancer Networks will need to assess their current levels of service against the recommendations in the Guidance. In addition, collation of high quality cost data is required for validation and potential updating of cost estimates provided in this report.

3.5.2 Staffing issues

The Guidance has major workforce planning implications. The implications of implementing the recommendations for the number and type of different care professionals will need to be considered at a national level by the Department of Health Workforce Planning Care Group board with responsibility for cancer, along with the Workforce Development Confederations in England and the Workforce Development Steering Group in Wales.

In addition, the education and training implications for both existing and new staff will need to be addressed.

The impact of Agenda for Change and European Working Time Directive on staffing levels and costs will vary by Network. Detailed assessments will need to be carried out on a Network-by-Network basis. This will need to include the impact on out-of-hours nursing and medical costs.

3.5.3 Models of care

In order to estimate the cost implications of the Guidance, it has been necessary to make working assumptions regarding the likely staffing implications of specific models of care, such as the four-level model of psychological support and the four-level model for rehabilitation services. These exercises have been undertaken under tight time-scales, with limited time available for consultation, to comply with the timescales of the Guidance development process. Further time and resources will be needed to allow more robust estimates of the staffing implications to be developed and to explore in more detail the possible options for service delivery and optimal methods of implementation over the next few years.

3.6 Conclusions

The economic modelling work provides an initial estimate of the scale of the cost of providing future high quality supportive and palliative care services in England and Wales, based on the Guidance recommendations.

Cost estimates are presented in two categories: general and supportive care and specialist palliative care services. For the particular general and palliative care services identified, the total cost of provision is estimated at just under £60 million. This is not, however, the cost impact of implementing the Guidance. For the majority of these services, the current expenditure on the service is not known and therefore the total cost of providing the services, rather than the difference between total and current costs is given. In most Cancer Networks, some level of service provision already exists for the majority of services and therefore the estimates represent an upper ceiling for the cost impact. For specialist palliative care services, the total cost of future provision is estimated at around £440 million. Current costs are estimated at £398.5 million. The cost impact of implementing the Guidance for specialist palliative care services is estimated to be around £42 million per annum, over and above current costs.

The cost estimates should be considered to be only a crude order of magnitude, providing a preliminary indication of the scale of cost implications of adopting agreed levels of supportive and palliative care provision. Further work has been identified to allow more robust estimates to be produced.

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