University of Sheffield

ScHARR
School of Health and Related Research

Analysis of the Potential Economic Impact of Guidance on Improving Supportive and Palliative Care for Adults with Cancer

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1. Introduction

Evidence-based guidance has been developed to define the service models needed to ensure that patients with cancer and their families and carers receive the support they need to help them cope with cancer and its treatment. Before commissioners and trusts can implement this guidance they need to assess the resource and cost implications. The School of Health and Related Research at the University of Sheffield (ScHARR) has been commissioned to analyse the potential cost implications of implementing the guidance recommendations for supportive and palliative care.

2. Objectives and Scope

The objective of this economic analysis is to:

- estimate the cost implications for England and Wales of adopting the cancer guidance
- estimate the cost of implementing the guidance at a cancer network level with the use of scenarios to explore the potential variation between networks.

The Economic Review considers the cost implications of guidance implementation for England and Wales and covers all settings in which care may be delivered. The primary focus of the guidance is on commissioning services for adults. The Economic Review does not however seek to provide a definitive answer as to the cost implications of the guidance for specific service providers.

The Economic Review does not attempt to cost all aspects of the guidance. Major issues are identified and prioritised, based on their likely scale of the economic consequences of implementation. The Economic Review does not attempt to consider the cost-effectiveness of guidance implementation, but rather only the cost of implementation.

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, and not where the costs will fall.

Social support services, such as respite care and assisted transport, which straddle both 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 NICE.

The Economic Review does not address in detail the training and workforce implications of the draft guidance.

Costs associated with audit and monitoring activities are not considered within the Economic Review costings, 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.

3. Methods

3.1 Integration of Economic Review with the Cancer Guidance

The research on cost implications was developed in parallel to the production of the guidance on improving supportive and palliative care for adults with cancer. Members of the ScHARR team attended the Editorial Board meetings, facilitating a full understanding of the guidance as it developed.

3.2 Literature and Data Searching

Literature searches were carried out in order to identify any existing costing exercises, audits of cancer activity, cost of illness studies or models of treatment pathways. Limited costing data was found in the literature for the UK. There are some non-UK studies of costs, but their treatment patterns and service, funding and cost structures are likely to be quite different.

Other data sources used include the Minimum Data Set.[1] Clinical and nurse staff costs are taken from Netten at al[2]. Costs include not only wages and salaries, but also overhead costs.

3.3 Discussions with Clinicians and other Key Professionals

Advice from members of the Editorial Board and the Guidance Development Team was sought to ensure that appropriate assumptions were made in the modelling of future activity and staffing levels, to identify data sources and to assist in the interpretation of data. Numerous clinicians and business managers were contacted to discuss activity and resource implications of various aspects of the guidance.

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 4.1 to 4.12 set out the key cost issues associated with each chapter of the guidance.

Key cost issues that are addressed in the report are broadly as follows:

(a) staffing levels: wtes by grade required to deliver the guidance recommendations
(b) workforce development: education and training of health and social care professionals, and others such as local clergy and users
(c) set-up and ongoing/recurrent costs of establishing and running the services recommended in the guidance
(d) future activity levels
(e) volume and mix of services required to deliver the services recommended in the guidance.

Expansion of the workforce has not been addressed explicitly. However, the assumptions that have been used around wtes required for delivery of high quality supportive and palliative care services, will imply growth in staff numbers for some networks. This will depend on each network's baseline position with respect to the workforce volumes.

3.5 Cost Analysis and Modelling Approach

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

Previous economic modelling work by ScHARR[3] on the cost of providing a high quality specialist palliative care service in England has been 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.

Staffing costs are the key cost component for supportive and palliative care services. For each individual service component, the model estimates the volume of clinical staff (nursing, medical and other health professionals) required to deliver the services recommended as per the guidance. Assumptions on appropriate staffing levels are taken from published recommendations where available (e.g. Palliative Care 2000; Cameron Report 1996). Where recommendations are not available, advice has been taken from a number of experts in the fields of supportive and palliative care. All staff costs are based on NHS salaries. In general, the mid point of the pay spine per staff type grade is taken as the salary level per professional staff group, unless indicated otherwise. The model provides a crude estimate of other costs (including ancillary staff, overheads, depreciation etc) by estimating the proportion of total costs made up by other costs for each service component. Further details of the model are included in Appendix 1.

Estimates of future provision are based on working assumptions regarding the level of service provision, staffing levels within individual services, and the model of service provision adopted. The cost of implementation of guidance will vary by network, depending on current service levels.

Current expenditure on specific elements of palliative and supportive care services is not known with certainty. For Specialist Palliative Care services an estimate of the total future cost of service provision for all service component is made and compared with the best estimate of the total cost of current provision in order to determine the overall incremental cost of provision resulting from implementation of the guidance. For supportive and general palliative care services the majority of costs presented relate to the total cost of service provision rather than the cost impact of the guidance.

Given the complexities of service configuration and the lack of data on the volumes and costs of current service provision, it will be possible to provide cost estimates of a crude order of magnitude only. In some instances preliminary estimates only will be provided, with areas identified for future work, beyond the scope and timeframe of this project, to allow more robust estimates to be produced.

3.6 Structure of the Report

The report addresses the cost implications of each chapter within the guidance (section 4.1 to 4.12). As many aspects are interrelated and cross over between chapters, issues are considered in the chapter where the topic is most central. Workforce development issues identified within each of the chapters of the manual are considered in section 4.13. Those workforce development issues with a significant cost implication are, however, listed in sections 4.1 to 4.12. In section 5 the costs of supportive and palliative care provision from the economic model are presented together, along with a discussion of the results.

4. Economic Issues

4.1 Co-ordination of Care

4.1.1 Background

Patients with cancer will need to access a range of health and social care services throughout the patient journey. 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 patients' needs to be recognised and met by whichever service they require.

Current services are inadequate for a number of reasons:

- Unnecessary duplication of services leading to confusion between service providers and waste of resources.
- Poor communication between different care sectors leading to problems through delays in services.
- Inadequate assessment of patients' needs leading to patients not accessing services they require.

4.1.2 Cancer network lead for development of supportive and palliative care services.

The guidance recommends that cancer networks should establish a structure and process to plan and review local supportive and palliative care services, including nomination of an individual to lead the development of supportive and palliative care services.

Cancer networks are already working to co-ordinate and improve local supportive and palliative care services (SPCS), although the degree to which a structure and process to plan and review services is in place will vary between networks. The main financial implication of this element of the guidance is likely to be in the appointment of an individual to formalise the establishment of the structure and process to plan and review services.

Currently, this is largely being undertaken by staff at the cancer networks, within the remit of their job, or on a 'goodwill' basis. The implications of the guidance may be that this role is formalised and a full-time post to plan and review services is created for each network. It is unlikely that networks will have a person in post full-time to cover this cost currently, although some people may be carrying out the work within the remit of their job. Also, some networks have employed project workers on a sessional basis to carry out work on the development of SPC services. We have therefore considered the cost of employing an extra person half-time or full time for each network (Table **1**).

Table 1: Annual cost of nominated individual to lead development of SPCS

Cost element	Assumptions / sources	Cancer Network	England & Wales
Individual to lead development of SPC services	Assuming need 0.5 - 1 FTE person per network. Assume Whitley pay scale I grade (£34,721 inc on-costs).	£17,400 - £34,700	£642,000 - £1,285,000

4.1.3 Network-based service directories

A network-based service directory including information about national and local SPCS provided by the NHS, voluntary organisations and self-help groups should be available to health and social care professionals, patients and carers.

For some networks, these service directories already exist and the costs involved will be those of updating and redistributing the directories. Other networks need to set up the service directories from scratch and may not have any of the infrastructure for setting up a directory in place. The following cost elements have been identified for setting up and maintaining a network directory.

- Setting up a directory initially
    - Planning and consultation stage
    - Information gathering
    - Setting up artwork and typesetting

  - Printing costs
  - Dissemination costs
  - Setting up network website
- Maintaining the information
  - Updating the database
  - Updating the website
  - Reprinting and disseminating booklets

The South West London and West London cancer networks have developed a database and infrastructure for setting up network service directories. This was developed along with a web-based directory, the CancersupportUK resource directory as part of the Diana Princess of Wales Memorial Fund Project, based at the Royal Marsden NHS Trust[4]. The CancersupportUK 'How to' Guide describes the processes used to create a printed or web based directory from scratch and sets out the structure and format of the printed directories and website. The infrastructure for both the paper and web-based directories are intended to be generic for any cancer network and therefore to be transferable to other networks. If this model is followed, the infrastructure costs for other networks will be reduced.
The principal costs for setting up a network directory would therefore be the cost of time for initial data gathering. Printing and dissemination costs will 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 (£3000), 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 groups 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. Although costs above suggest annual updating of information, it is estimated that a new, updated directory will be produced every 1-2 years. Assuming that 50%, 75% or 100% of networks do not yet have a network service directory and that every network prints and distributes a new directory every 1.5 years, the annual costs for England and Wales are estimated as follows:

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

	Assumptions	Cost
Year 1	50 % of networks do not yet have a service directory	£680,000
Years 2+		£351,500
Year 1	75 % of networks do not yet have a service directory	£844,000
Years 2+		£351,500
Year 1	100 % of networks do not yet have a service directory	£1,008,000
Years 2+		£351,500

This is the cost of a full network service directory which will be available at all services, for patients to consult. Shorter subsets of these directories may be developed within each network, with details of how to access key services and aspects such as local support groups and information services.

4.1.4 Assessments

The guidance recommends that structured assessments should be undertaken at key points in the cancer journey, using a unified assessment tool. Mechanisms should be developed to enable different healthcare professionals to share the data and prevent duplication of assessment.

Assessments will already be occurring but are unlikely to be undertaken in a uniform, systematic fashion or to be shared between professional groups. They will be undertaken principally by nursing staff, although other healthcare professionals will also undertake assessments at different points in the pathway. The ‘key worker’ will need to co-ordinate assessments as part of their role.

It is assumed that changes to the assessment process will not lead to increases in workload, but a more effective use of current resource. Whilst an increase in numbers of ‘formal’ assessment might be incurred (particularly around the end of treatment and at recurrence as this does not routinely occur in many settings presently), this will be offset by effective sharing of data, resulting in reductions in those involved in less systematic and thorough assessment. Improvements to the assessment process are therefore considered to be resource neutral for the purpose of this study.

There could be additional indirect cost implications resulting from improved and co-ordinated assessments. Improved assessments are likely to identify increased need for services (e.g. social services), which could have a significant cost impact. However, no attempt has been made to quantify this change.

4.2 User Involvement

4.2.1 Introduction

Much of the input for this section has been provided by Macmillan Cancer Relief and user representatives for the User Reference Group.

4.2.2 Background

People whose lives are affected by cancer can make significant contributions to the planning, evaluation and delivery of services. Mechanisms should be in place 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 and demands that views be 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. Various initiatives have resulted in greater user involvement in cancer services, but full integration of users' voices will require a major change in the culture of the NHS

4.2.3 Scope

The following key resource issues have been identified, based on the guidance recommendations.

- payment to users for their time and travel expenses
- establishment and support for Partnership Groups that involve patients, carers and clinicians

- lead individual to develop and sustain user involvement for each provider organisation
- 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 for patients/carers
- provider organisations support for Self-help and Support groups.
- Education and training for all health and social care professionals in the importance, general principles and methods of user involvement.

4.2.4 User expenses

One cancer network estimated that a realistic assessment of reimbursement of users travel expenses alone, was approximately £10,000 per annum. In addition to travel, many people living with cancer have other carers responsibilities (for more elderly relatives or children) which would need to be paid for if the informal carer is absent – this is also an important consideration.

Cash reimbursements should be available for those who need it, to ensure greater equity of access to user involvement opportunities. In practice, some users do not claim expenses or payments even if these are available, as they feel they are ‘doing their bit’.

Assumption 1: £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.

4.2.5 User time

Information needs to be gathered on different schemes for payment of users or user representatives for their time and expenses; an example is that of CancerVOICES Regional Contacts receiving £100 a day for their time in giving presentations and workshops.

Payments to users (rather than for reimbursement of expenses), presents more challenging issues. In a recent survey [5] amongst users themselves, there was little consensus on this topic. However, when specific examples were discussed, e.g. membership of a ‘professional committee’, often where advance preparation, reading time, analysis of lengthy and complex papers is required, a fee for participation was considered appropriate. The Department of Health already has guidelines on fees for 'lay'/voluntary sector participants in its own committees and this could be used as a guide (approximately £130 per day).

Speaker fees to users at conferences, was also considered appropriate in some circumstances. It is likely that users asked to participate in such ways are likely to be more experienced (some would say 'expert' user representatives), and some resource should be allocated.

Some users are also engaged in teaching and education programmes for medical student and other health professionals and these activities should be appropriately reimbursed.

It is assumed that each network will allocate a modest sum to 'pay' experienced user representatives for involvement in activities requiring a greater degree of expertise.

Assumption 2: One expert activity every week will be required in every cancer network: approximately £ 100 x 50 weeks = £ 5000 per network per annum.

4.2.6 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 [6]. Currently this is provided through the Cancer Partnership Project, a joint initiative between Macmillan Cancer Relief and DH. Macmillan Cancer Relief contributed £5,000 p.a. [a], and DH contributed £10,000 p.a. to each Partnership Group. The expectation was that the network would match this with a further £10,000 p.a. to help recruit a facilitator. In practice, this has been patchy and many networks have felt significantly under-resourced.

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

The Department of Health funding ends in April 2003 and the project comes to a close in March/April 2004.

Assumption 3: it is assumed that the funding to the Partnership Group at the network level is maintained at £5,000 p.a., and that funding for the Partnership Group facilitator is increased to £30,000 p.a.[b] to ensure appropriate support to the group (see also Assumption 4). The total funding assumed for the Partnership Group is therefore £35,000 p.a. covering venue costs, publicity, administration, and facilitation.

4.2.7 Lead individuals

The guidance recommends that provider organisations should nominate an individual to take the lead on developing and sustaining user involvement. It is assumed that the person(s) carrying out the role of facilitator for the partnership/user groups referenced above will work through others nominated at unit and centre level who will have overview/oversight at the local provider level.

Assumption 4: It is assumed that no additional monies are required for the lead user involvement individuals nominated by each provider organisation.

4.2.8 Training for user involvement

The guidance recommends that cancer networks should ensure that members of Partnership Groups (users and professionals) have access to training and support. Users and professionals might be trained together where they are working as part of a group.

To be effective, users need to be trained to work with health professionals. Evidence for this comes from the National Childbirth Trust's VOICES Project and College of Health's VOICES in Action Project.

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[b] Approximately £ 30000 p.a. would pay for 1 wte employed on Whitley pay scale H or G including on-costs.

Training for users is currently provided through CancerVOICES which is supported by Macmillan Cancer Relief among others.

Health Professionals also require training for user involvement as evidenced by the research conducted by Avon, Somerset and Wiltshire Cancer Network.

Cost estimates are provided in Section 4.13 Workforce Development.

4.2.9 Self-help and support groups

The guidance recommends that provider organisations should work with local self-help and support groups to establish the most effective ways of supporting their activities, such as for the provision of accommodation for their meetings and/or offering training and support for group leaders, co-ordinators and managers.

Self-help and support groups are voluntary organisations of varying sizes and carrying out a range of activities to support people with an experience of cancer. Across the UK there are over 700 such organisations with approximately 550 in England, with between 12000 – 15000 active members.

Additionally, there is a growing network of Black and Ethnic (BME) organisations whose sole or partial interest is in supporting people affected by cancer. This sector has been given a boost in recent years as New Opportunities Fund resources have been targeted at socially or economically disadvantaged groups.

Larger groups provide services and run projects such as out-reach, welfare benefits advice, and peer-to-peer support. There is a distinction to be made between the activity of involving users and with users being the provider of services. The types of services self-help and support groups provide may include peer-to-peer support schemes, advocacy schemes, carers support schemes, level 1 psychological support, social support, and services for families among others.

Larger groups may require funding for premises, staff, administration, service delivery and project support. Smaller groups may require funding to help start-up, and for a venue and general administration. Most groups make great efforts to fundraise to support their needs. Raising core costs can be a particular difficulty, and this can deplete their energies and take time away from their role of supporting people affected by cancer.

Groups can and do fill gaps and meet needs that others have not assessed as priorities – these are often ‘hidden’ and undervalued: for example, transport to and from hospital, financial benefits advice, advocacy, access to one to one peer emotional support and free/low cost complimentary therapies.

These groups require capacity building support to enable them to respond most effectively to people living with cancer in their communities; this might be in the form of advice, training, and consultancy in obtaining funding. Smaller groups require start-up funding and resources to assist with administration, venue etc.

It is recommended that further consideration be given by commissioners about possible frameworks for supporting activity of this type. One option would be to make statutory funding available to self-help and support groups who are prepared to be formally accredited in relation to the service they provide. One route to achieve this might be through the Community Network Team at Macmillan Cancer Relief.

Flexible resources may need to be made available locally to allow the network of cancer self-help and support groups and local organisations to play an active and complementary role to that of health professionals. Particular attention, may also need to be paid to the role of groups and networks for people from socially or economically disadvantaged areas (including BME communities), where outreach work is vital to ensure people access appropriate services.

Some of these groups are run by professionals as part of services, such as site specific CNS or counsellors. With an increase in activity for self-help and support groups, there may be cost implications. These will include the need for the training of professionals to facilitate these groups. This will require skills often not inherent in a CNS such as for group processes. Joint working between health care professionals and user groups could be an effective means of group facilitation. The majority of groups prefer to meet in a neutral and impartial non-medical community setting as opposed to using NHS facilities.

Assumption 5: Work in progress: A method of costing accommodation is being explored and could reflect assumptions around the cost of rental accommodation in community settings, with each unit and centre requiring at least 1 meeting per month. It is unclear as to the level of funding required for capacity building and for establishing and running services provided by these groups. At this stage, no assumptions have been made for the resource implications of self-help and support groups in the economic review.

4.2.10 Cost estimates

Table 4: Cost estimates for user involvement recommendations

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
1. Users expenses	£ 0.010 m	£ 0.35 m	£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.
2. Users time	£ 0.005 m	£ 0.17 m	One expert activity every week in will be required in every cancer network: approximately £ 100 x 50 weeks = £ 5000 per network per annum.
3. Partnership/User Groups			
- support	£ 0.005 m	£ 0.17 m	It is assumed that £5000 per annum provides for support for venue costs, publicity, administration and facilitation.
- support for facilitator	£ 0.030 m	£ 1.04 m	It is assumed that 1 wte on Whitley pay scale H or G (about £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
4. Lead individual on developing and sustaining user involvement per provider organisation	£ 0.000 m	£ 0.00 m	No additional monies assumed for this role.

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
5. Self help and support groups	N/A	N/A	Work in progress: A means of costing accommodation required for the regular meetings of self-help and support groups is being explored. It is recommended that further consideration be given by commissioners about possible frameworks for supporting the activity of self-help and support groups.
Total	**£ 0.050 m**	**£ 1.73 m**	

4.3 Face to Face Communication

4.3.1 Background

High-quality face-to-face communication with skilled health and social care professionals is essential to providing patients and carers with information throughout the patient journey. Good communication will increase patients' ability to participate in decision-making, improve their understanding of the disease and enhance quality of life. Health and social care professionals therefore need excellent communication skills. Professionals may especially lack the necessary skills to communicate effectively with patients from minority ethnic backgrounds or those with hearing, sight or combined sensory disabilities or learning disabilities.

4.3.2. Scope

Recommendations identified as requiring significant additional resources are detailed below.

- Permanent record of important points of consultations
- Provision of skilled interpreters and services for people with hearing, sight or combined sensory disabilities.
- Staff to receive training in communication skills.

4.3.3 Permanent record of important points of consultations.

The guidance recommends that patients should be offered a permanent record of important points of consultations. Earlier drafts of the guidance suggested that these would be recordings or summaries of consultations in which key information is imparted or discussed.

The permanent record could take three forms:

- A copy of the letter written to the referring doctor/GP
- An individualised summary letter
- An audiotape recording of the consultation

Current use of permanent records

The use of permanent records currently appears to be limited. A study of practice of oncologists, surgeons and general practitioners in Australia showed that fewer than 4% of oncologists or surgeons offer any of the three options to patients in all or most[7]. A copy of the letter written to the referring doctor/GP was provided in at least some cases by 27% of doctors, an individualised summary letter was sometimes provided by 21% and an audiotaped recording of the consultation by 15%. Although practice and perspectives may be changing, there is currently opposition by a significant proportion of doctors to offering patients records of consultations, and the uptake of routine provision of recordings may be slow [7, 8].

Uptake of recordings and patient preference

We have not identified any studies reporting the uptake of recordings. Personal communication suggests that not all patients will want to have recordings or summaries of key points of consultations. Some patients do not wish to hold a recording of their conversation and tape recorded consultations are not always required, as many people do not have access to a tape player at home.

The guidance does not state which form of record should be used. Studies comparing the use of consultation audiotapes and summary letters in cancer patients suggest that both are useful to patients in reviewing information and communicating information to family and friends and there was no significant difference between recall, anxiety or depression between the two groups [8, 9]. When offered six communication options following a consultation, patients ranked a tape of the consultation first, a personal letter from the oncologist second and a letter from the oncologist to their doctor third.

There is therefore no clear evidence as to what option should be provided to the patient; doctors prefer to provide a copy of the letter to the referring doctor/GP first, and favour an audiotape recording least, while patient preferences are the reverse.

For the purposes of this report we will provide estimates of the cost of providing the three different permanent records to all patients. It is not yet clear what proportion of patients will be offered each type of consultation, nor how many patients will require a permanent record of the conversation.

The number of consultations at which key information is imparted or discussed depends upon the type of cancer and the course of treatment required. We estimate that there will be an average of five consultations per patient at which key information about diagnosis or treatment will be imparted, where the patient may wish to refer back to the consultation.

The cost of offering a copy of the letter written to the referring doctor/GP is estimated as follows:

- Cost of secretarial support for copying and sending out letter (assume 1 hour per 10 letters)
- Postage and stationery costs

The cost of offering individualised summary letters is estimated as follows:

- Cost of clinician time in dictating letter (assume 1 hour per 10 letters)
- Cost of secretarial support for typing up and sending out letter (assume 2 hours per 10 letters)
- Postage and stationery costs

The cost of offering taped consultations is estimated as follows:

- Tape machine for each clinician who will be discussing key information. Assume one tape machine for each consultant and registrar in palliative medicine, clinical oncology and medical oncology in England & Wales. Assumptions regarding volumes of consultant and registrar are detailed in section 3.13.
- Tapes (assume 2-3 tapes per patient, as can use same tape again. Average 28 minutes consultation[9]).

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

Assumptions	Cost

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

4.3.4 Provision of interpreters and services for people with hearing, sight or combined sensory disabilities.

Provision of Interpreters

The guidance states that patients who cannot understand or speak English should have access to professional healthcare interpreters at consultations where key information is communicated and discussed and important choices have to be made. 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 significant proportions of people from ethnic minorities do not have difficulties speaking English or prefer to make use of friends or family as interpreters. Patients may prefer to use family members in some situations, but use professional interpreters where the subject is of a sensitive nature.

Difficulty in speaking English is greatest among people from Pakistani and Bangladeshi backgrounds, and is higher among the older population. Gerrish et al found that 54.4% of South Asian patients in their study had little or no understanding of spoken English, increasing to 96.8% for patients aged 65 and over [10]. Although numbers in the study were small, these figures provide estimates for the potential need for interpreters, if we assume all those patients who have little or no understanding of English will require interpreters. We have considered three minority ethnic groups: South Asian, Black and Chinese, as these are the main groups reported within the census. Assuming the estimates of patients who had little or no understanding of spoken English are representative of the three minority ethnic groups may result in an overestimate of need, as other ethnic groups have lower need. Also, we do not consider the other ethnic groups reported within the census (mixed and other) but it is likely that the numbers involved will be very small within these groups.

The number of consultations for which patients will require an interpreter will vary considerably depending upon the degree to which patients wish to use family and friends. However, we estimate that if patients require an interpreter for the main consultations where important information is imparted, then patients may require an interpreter for between 3 and 5 consultations.

Table 6**:** 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.[10]	1407	694	127
I	Estimated no patients needing interpreter <65	As above	3986	2278	388

Total no. patients needing interpreter	8881
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	1582.5
wte interpreters required per network	0.81
cost per network assuming social worker salary including oncosts (per annum cost)	£ 18,231
estimate for England and Wales (per annum cost)	£ 633,028

We have been unable to ascertain the level of current unmet demand for interpreting services.

Services for people with hearing, sight or combined sensory disabilities.

The guidance recommends that provider organisations should ensure that suitable services are available for people with hearing, sight or combined sensory disabilities and for people with learning disabilities. Patients with learning disabilities should have access to carers with whom they can communicate and it is not clear what additional services they may require. Services such as sign language services should be available currently upon request and the numbers 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 the section on Information. It is unlikely that there will be significant cost implications to improvements made to services for these patients and we have therefore not considered these costs.

4.3.5 Staff to receive training in communication skills

The guidance recommends that cancer networks should decide which staff groups should be given highest priority for advanced skills training courses for senior personnel (e.g. consultants, specialist registrars, nurse specialists and GPs). All health and social care professionals who come into contact with patient and carers should be offered accredited training courses in communication skills.

Three levels of training needs have been identified by Fallowfield et al : level 1 - receptionists, medical secretaries, porters etc, level 2 - those providing direct clinical care, level 3 - senior clinicians who may have to handle particularly complex situations. A pilot study evaluating an advanced communication skills course for senior health care professionals (SHCPs) (i.e. level 3) is currently underway nationally and is expected to report in February 2004. Courses for junior personnel (level 2) or non-clinical staff (level 1) are not yet being piloted.

Within the advanced communication skills programme, two levels of training are provided. One programme, ‘training the trainers’, involves a three day course to train SCHPs to be able to facilitate communication skills training courses for other SHCPs. The second programme involves these trained SHCPs to then run a three day training course in communication skills for other SHCPs.

The costs of training senior personnel is considered in Section 4.13.

4.4 Information

4.4.1 Background

Patients and carers require high quality information at all stages of the patient pathway and the level and type of information required is the prerogative of the patient. Materials should be free at the point of delivery. Professionals should be prepared to respond appropriately to the different information needs of patients.

There are currently concerns that patients are not receiving sufficient information from health and social care professionals. Although there is a high volume of material available, there is considerable duplication and a lack of quality assessment of information. Information may not be available where it is required, particularly materials for minority ethnic groups or for patients with sensory deficits. High quality information therefore needs to be produced and disseminated to locations where patients and carers can access it as required.

The guidance recommends that patients be provided with all the information they wish to receive and offered support to help them cope with the emotional impact of the information they receive. This issue of psychological support for patients is dealt with in section 4.5 and therefore not costed here. With regards to provision of information, specific recommendations identified as requiring significant additional resources are as follows:

- Patients should be offered high quality information products relating to the disease, treatment options and available services – perhaps given a core information pack.
- Provider organisations should ensure 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.

These three areas are not mutually exclusive, as the cancer information centres will contain some of the written information, and be the point of access to alternative information formats.

4.4.2 High quality information products

There is a wide range of information booklets available to patients. For the purposes of this report, we consider the costs of providing CancerBacup information to patients. This should indicate the scale of costs involved, even if other sources are used.

CancerBacup is one of the main providers of information to patients, currently having around 60 booklets and 190 factsheets covering the main types of cancer as well as rarer forms of cancer, treatments and practical aspects of living with cancer. The information is revised and the booklets updated every 12-18 months.

However, access to this information is not uniform and patients are not all made aware of the information that is available to them. It is difficult to assess what proportion of people are receiving the information they need, and what the scale of additional need is. CancerBacup currently produce 181,000 booklets of various titles, with an average of 6 booklets per patient during their illness. This number may not be entirely representative of the average patient, and is likely to be slightly higher than the average number required. Assuming all patients would require a core information pack of 5 booklets on average, over the course of their cancer journey, the potential costs are summarised in the table below.

Table 7**: 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

These are the costs of providing all patients with 5 booklets. Some patients will download information from the website and not require booklets. These costs do not represent additional costs, given that over 180,000 booklets are currently being funded and distributed p.a.

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

There is currently a wide range of high quality information available from a variety of sources on the internet. Set-up costs to having information available are therefore unlikely to be significant. For example, all of the CancerBacup booklets and factsheets are available on the website, along with around 800 'Questions and Answers' about 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 (table in 4.4.2 above), including medical input, editorial input and technical services.

The use of video and audio-based materials is important particularly for people with sensory deficits and for people from some ethnic groups. As access to video, audio-based materials and also access to computer facilities will need to be provided, we have considered the cost of equipment within the costs of dedicated cancer information centres.

4.4.4 Network Cancer Information Centres

The guidance recommends that provider organisations should ensure that patients and carers have easy access to a range of different materials. This may be achieved by having dedicated cancer information centres within larger hospitals, and smaller satellite units at local PCTs, and community-based facilities.

The changes required to set up information centres within each network will differ depending upon the current information provision available. Some networks may have to set up centres from scratch, while others may need to add additional resources

For this exercise, we provide the costs of setting up dedicated cancer information centres for a cancer network. We consider the costs associated with providing one major centre and 4 satellite centres per network.

Table 8**: Cost of equipping dedicated cancer information centres**

Cost element	Assumptions / sources	Cost per network
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.	£13,620
Materials – yrs 2+		£6,218
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.	£7,525
Equipment yrs 2+	Assuming 25% of equipment costs of year 1.	£1,881

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

These costs are assuming that there is currently no service available. However, information centres will already exist to some degree within cancer networks.
We have assumed there is one dedicated full time information lead for the network, one FTE information manager at each of the major information centres and 0.5 FTE information managers at each of the satellite centres.

Table 9**: Cost of information leads for Network and Trusts.**

Cost element	Assumptions / sources	Cost per network
Information lead at network	One full-time person based at the network. Nurse specialist grade. Assume Whitley pay scale I grade (34,721 inc on-costs).	£34,721
Information managers at each centre	Assuming need 1 FTE person for a major centre and 0.5 FTE for small centres patients, i.e. 3 FTE per network. Assume Whitley pay scale nursing I grade (34,721 inc on-costs).	£104,163
Admin staff to support information managers	Assuming need 1 FTE person per for major centre and 0.5 FTE for small centre i.e. 3 FTE per network. Assume Whitley pay scale clerical grade 3 (mid-point - £13,736 inc on-costs).	£40,128
Total per network		£179,000

4.5 Psychological Support

4.5.1 Background

Psychological distress is common among people affected by cancer and is an understandable and natural response to a traumatic and threatening experience. 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 levels of anxiety and depression around the time of diagnosis severe enough to adversely affect their quality of life. In addition 10% of patients at any one time in the first year will experience levels of psychological morbidity severe enough to warrant a specific psychological therapy. Psychological symptoms are not being identified by professionals, and therefore patients and carers are not getting sufficient access to psychological support services. Insufficient numbers of professionals are equipped to offer support for patients and carers in psychological distress.

4.5.2 Scope

The following key resource issues have been identified:

- Development and implementation of a four-level model of professional psychological assessment and support in each cancer network to ensure that all patients undergo systematic psychological assessment at key points in the care pathway and have access to an appropriate level of psychological support
- Emergency psychological support services should be available for patients who have developed acute psychiatric problems and are potentially a danger to themselves and/or others
- Workforce development including:
    - training in screening for psychological distress and delivering of basic psychological interventions for those working at level 2

- supervision and training by psychological care experts with extensive experience in cancer particularly of those delivering other aspects of psychological care at levels 3 and 4.

For workforce development issues see section 4.13

It is assumed that the cost of level 3 bereavement support interventions for carers (see the section 4.12 for families and carers) provided by the psychological assessment and support services are already included here under psychological support services. This ensures that costs are not double counted under both chapter headings.

4.5.3 Methods and process

4.5.3.1 Emergency psychological support service

The guidance recommends that emergency psychological support services should be available for patients who have developed acute psychiatric problems and are potentially a danger to themselves and/or others. It is assumed that this cost would be borne by the local mental health team and is not costed in the Economic Review.

4.5.3.2 Four-level model of psychological assessment and support

The cost estimates in the Economic Review are based on the Psychological Support service run by the Richard Dimbleby Cancer Information and Support Service [11]. This is a service akin to the 4 level model of psychological assessment and support that is described in the guidance.

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).

Work in progress: For level 2 interventions, the guidance recommends that an individual (or individuals) should be identified within each cancer site-specific team to take responsibility for providing level 2 care. Clinical Nurse Specialists, social workers, or GPs might undertake level 2 assessments and interventions. Further work on the costing of for level 2 component is ongoing. The main resource implications for individuals operating at level 2 are around the training, education, and ongoing support and supervision required, as this will be incorporated into the existing role of health and social care professionals as opposed to being a dedicated role.

Assumptions for levels 1, 3, and 4 of the model are set out in the table below.

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

Level	**Group**	**Assessments**	**Interventions**	**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 L1 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)	
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 L3 and L4 support
4	Mental health specialists – clinical psychologists and psychiatrists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions	

The number of wte staff and grades at each level of the model were obtained directly from the service for level 3 and level 4 support. These are detailed in the table of cost estimates below.

Staffing costs are scaled up by a factor of 1.5 to extrapolate the cancer centre costs to that of the network; this is based on 5000 new patients seen at the cancer centre each year, and an average per network incidence rate of cancer of 7676 new cases per annum

Professionals operating at levels 3 and 4 have training costs of £1285 pa, and supervision costs of £1500 pa. These costs are not included in this section as workforce development issues are covered in section 4.13.

4.5.4 Cost estimates

Table 11: Cost Estimates for psychological support recommendations

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	£ 0.00 m	£ 0.00 m	- L1 no additional staff required
Level 2			- work is ongoing and costs are being sought
Level 3	£ 0.05 m	£ 1.6 m	- 1wte counsellor per Cancer Centre
Level 4	£ 0.14 m	£ 4.7 m	- 1wte psychologist (0.5 wte clinical, 0.5 team co-ordinator) per Cancer Centre - 0.5wte consultant psychiatrist per Cancer Centre
Other Assumptions			*Salary assumptions:* - Councellor salary is £27000 - Psychologist salary is £43600 - Psychiatrist salary is £66796 *Scale Factors:* - costs scaled from cancer centre to network using the ratio of cancer incidence rate per 1.5 million population p.a. to number of new patients per annum seen at the Cancer Centre = 7676 / 5000 = 1.5 - 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	£ 0.18 m	£ 6.3 m

4.6 Social Support

4.6.1 Background

The social impact of cancer is considerable. A MORI survey in 1992 highlighted that for a considerable proportion of people, the onset of cancer left them unable to carry out many of the functions they were capable of pre-diagnosis [12].

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 – 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 social workers can supply.

4.6.2 Scope

The following key resourcing issues have been identified:

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

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

1. undertaking social care assessments (only social workers can do many aspects of these)
2. benefits and welfare rights advice
3. bereavement counselling

4. general counselling
5. provision of professional psychological assessment, intervention, and support
6. care of families and children.

Functions 1 and 2 listed above are carried out mainly by social workers, or by welfare rights advisors who are not social workers. These aspects are not necessarily an NHS cost, and lie outside the remit of guidance produced by NICE. Functions 3 to 6 can be provided by social workers, and also by other health care professionals.

For services that straddle both NHS and social services sectors, such as respite care, the guidance cannot make firm recommendations, and consequently these services have not been costed as part of the economic review.

4.6.3 Methods and process

4.6.3.1 Social care assessments carried out by healthcare workers

Social support assessments to be carried out by healthcare workers consist of an initial examination of needs identifying where a more in-depth assessment might be needed, and "sign-posting" to services outside the immediate healthcare environment.

The main resource implication in relation to carrying out social care assessments for healthcare professionals, is the training and education that will be required in the social needs of individual patients and carers.

It is assumed that once healthcare professionals have undergone training and education in social needs assessments, that such assessments are then 'resource neutral', in the sense that no extra wte staff will be required to carry out assessments, and that the assessments will then become part of normal working practice.

Training and education requirements for health and social care professionals in general are covered in section 4.13 Workforce Development.

4.6.3.2 Social workers for high quality Specialist Palliative Care services

The assumptions for wte social workers in the previous ScHARR model for SPC 3 were reviewed by the editorial board member with particular expertise in Social Support Services. These are set out in the Cost Estimates table below.

The wte social worker figures presented by component of service within SPC represent staffing ratios required for delivery of high quality SPC services. The component of bereavement support costs presented in this section relates solely to the wte social workers required for implementation of the 3 level model of bereavement support. See section 4.12 on Families and Carers for the full description of the cost basis for the bereavement support model recommended in the guidance.

4.6.3.3 Estimate for social care assessments and welfare rights & benefits advice in supportive and palliative care

The component of supportive and palliative care cost related to undertaking of social care assessments and benefits and welfare rights advice by social care workers was separately estimated.

The editorial board member with particular expertise in Social Support Services advised using a figure of 50% of patients requiring social care assessments and welfare and benefits input based on discussions with colleagues in the field.

The total theoretical number of assessments was based on the 50% figure applied to the number of patients estimated to use specialist palliative care services in a year. A figure of 2752 for a hypothetical network with population of 1.5 million was derived based on the following assumptions:

- at least 75% of all people who die of cancer have used the SPC services (minimum figure); for England & Wales in 2001 the figure is calculated to be 102,000

- most patients using the home care services have previously used inpatient palliative care services or day care services [c]
- the total number of patients using home care services in England & Wales in 2001/02 is estimated to be 127,320 (Minimum Data Set1as this figure is higher than the minimum estimate, home care services have been used as the proxy for patients using any of the SPC services
- the total number of assessments required per cancer network with 1.5 million population is calculated as set out in the table below.

The final step in arriving at the estimated number of assessments under the guidance recommendations for social workers, is to apply a scale factor to the SPC net estimate representing the expected supportive care component of social workers caseload for adults with cancer.

The scale factor has been set at a value of 2 reflecting an assumption that the workload of social workers in the supportive care setting is at least equivalent to that in the SPC setting. This recognises the lower complexity of cases, and a level of 'unmet need' in that some patients and carers are not currently receiving social care services when they need them.

Table 12: Estimate of number of assessments required

	SPC: Maximum Theoretical Assessments	SPC: Number of assessments required	Supportive & Palliative Care: Number of assessments required
new patients using the home care services in 2001/02	2521	1260	2521
20% of other patients to cover those who deteriorate and require more help over the course of their illness	229	115	115
Total	2750	1375	2750

Further assumptions used to derive the estimate are set out in the table of Cost Estimates below.

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[c] Assumption provided by Ann Eve and Peter Tebbitt, NCHSPCS.

4.6.4 Cost estimates

Table 13: Cost Estimates for social support recommendations

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Estimate Social Worker Costs for Specialist Palliative Care Services			
Cost of social workers required per type of service:			Social Worker/Counsellor cost is £22,557 including on-costs (PSSRU 2001 Social worker (adult))
SPC beds	£ 0.08 m	£ 2.8 m	- 50 beds / million population - 0.8 wte /17 bed unit
Day Care	£ 0.01 m	£ 0.5 m	- 4 day care centres - 13000 place / million pa - 1.5 social worker session / week for a 20 place unit
Home Care	£ 0.03 m	£ 0.9 m	- 3 teams at level 3 support operating 9.00am till 5.00pm 7 days/week plus 24 hours telephone advice 7 days/week - 0.8 wte per million population
Hospital Support Team	£0.07 m	£ 2.3 m	- 1 cancer centre and 4 units at level 3 support operating 9.00am till 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	£ 0.15 m	£ 5.3 m	- 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	**£ 0.35 m**	**£ 12.2 m**	
Estimate for Social Care Assessments/Welfare Benefits advice within Supportive and Palliative Care			
Sub-Total [B]	**£ 0.2 m**	**£ 6.8 m**	- Minimum Data Set 1 data for 2001/02 was

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
			analysed to determine the total number of patients using SPC services for England & Wales - this produced an estimate of approximately 2752 patients per hypothetical cancer network of 1.5 million population using SPC 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 SPC 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

Note: some of these costs overlap with services covered and costed elsewhere in the economic review: namely bereavement support, specialist palliative care,. Social workers are also included in the 4 level model of psychological assessment and support where they provide assessments, interventions, and support mainly at level 2.

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[*] 5 hours represents the minumum time required for a social care assessment. It would take at least one hour to set up and undertake the meeting and for discussions 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. Then the package 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 in relation to 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 that has to be done 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.

4.7 Spiritual Support

4.7.1 Introduction

Much of the input required for this section of the Economic Review was provided to ScHARR by the editorial team member with particular expertise in spiritual support. This followed on from:

- review of assumptions provided by ScHARR from the previous modelling exercise for wte chaplains required for the various service components within specialist palliative care (SPC) 3 [13]
- discussions held by the editorial team member with particular expertise in spiritual support with various hospice/palliative care chaplains and receipt of data from the Chair of the Association of Hospice and Palliative Care Chaplains (AHPCC).

Within this section of the Economic Review the word "chaplain" where it appears, should be understood as meaning:

> *Chaplain-spiritual care giver appointed by the Health Care provider and authorised by the relevant Faith group.*

4.7.2 Background

'Spiritual' relates to the search for existential or ultimate meaning within a life experience. There are indications that spiritual needs are not being met within cancer and palliative care service services:

- Many health care professionals are confused as to what is exactly meant by 'spiritual care' and how best to approach this area with patients and their carers
- In the hospice sector, there is disparate provision of spiritual care, with some units having to rely on the services of 'on-call' faith leaders
- Within the hospital sector, there are insufficient numbers of chaplains to meet needs. A hospital-based chaplain has responsibility for supporting patients and carers across an entire service, and not just those receiving cancer treatment or palliative care
- Patients have insufficient choice in people to whom they can turn for spiritual care

- Health and social care staff have insufficient awareness of how to access individuals who can provide spiritual care
- Health and social care staff may be reluctant to call for chaplain's services or may not detect the need for spiritual support at key stages of the patient pathway. Some feel awkward and vulnerable when broaching spiritual issues with patients and may also feel awkward about discussing, or even considering, their own spiritual needs as professional carers.
- Palliative care by its very nature may require more input by chaplains than in some other areas as patients and families are preparing for the end of life. The time required per patient will be greater and likewise involvement with staff in terms of support.

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

4.7.3 Scope

The following key resource issues have been identified:

- spiritual care providers are available as a resource to in-patient and community teams and are appointed and paid in accordance with NHS criteria
- training and education in basic skills in offering spiritual support, understanding spiritual need, and training on specific religious needs and rites of patients from different faith groups, for health and social care and other staff dealing with patients with cancer and their carers including local community clergy.

As indicated above in the sub-section *"Care Setting"*, the provision of spiritual support can extend beyond the specialist palliative care services to general palliative care. As with other areas of the guidance (e.g. see section 4.8. General Palliative Care), it is assumed that the main resource implications will relate to the training and education needs of health and social care professionals in order to carry out assessments of the spiritual needs of patients and their carers. Once trained, there is then an assumption of resource neutrality in that no extra staff will be required, rather, this will then be an activity which is part of the normal workload of health and social care professionals working with cancer patients. This assumption applies also for core members of the SPC team that are not chaplain-spiritual care givers. As in other ‘psychosocial’ areas 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 4.13 Workforce Development.

For the SPC team, it is assumed that the major resourcing implication relates to the appointment of a sufficient number of wte chaplain-spiritual care givers to meet the guidance recommendations on provision of spiritual support services.

4.7.4 Methods and process

Assumptions used in the previous ScHARR model 3 for chaplains within the SPC services were reviewed by the member of the Editorial Board with particular expertise in spiritual support. The conclusion was that there is no current costing model that could replace the ScHARR mode 3.

In reviewing and amending the previous ScHARR assumptions for wte chaplains, account was taken of the funding implications of the new guidelines for multi-faith chaplaincy-spiritual care referenced [iv].

The salary rate for chaplains assumed is £25,282 + £3,292, where £3,292 is the housing allowance payable under Whitley terms and conditions. With oncosts of 13% this gives a gross cost per chaplain of £ 32,543. Chaplains are the only NHS group who may receive a housing allowance up to £3,292. In the future the housing allowance will be subsumed within the salary, but at present most chaplains receive the housing allowance especially if appointed under Whitley terms & conditions.

Detailed assumptions on wte chaplains required and their costs by SPC service component are set in the cost estimates table below. The scale factor used to extrapolate from the cancer network to England and Wales figures is the ratio of the 2001 census population (52.041 million) to a hypothetical cancer network population of 1.5 million.

There are some elements of spiritual support cost which are not included in the cost estimates:

1. The time required for on-going CPD for the chaplain
2. The nature of 'specialist' palliative care in terms of time required for chaplaincy Input per patient and staff support
3. There is no time provision for the chaplain's own supervision.

4.7.4.1 Care setting

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/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.

4.7.3.2 Demands for spiritual support services

The South Yorkshire Workforce Development Confederation (SYWDC) is the lead confederation for chaplains-spiritual care givers in the NHS. SYWDC 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 [14].

Within Palliative Care the issuing of the new guidelines for multi-faith chaplaincy-spiritual care [15] within the NHS will carry with it the following funding implications:

- there may be a need for some SPC units to employ and pay additional spiritual care givers of other faiths than Christian where numbers warrant specific appointments

- this will probably be on a sessional basis in the case of the major world faiths that are well represented in the community
- where the need is only occasional, a SPC unit may have to pay a 'call out' fee for a chaplain-spiritual care giver authorised by the relevant Faith group.

4.7.5 Cost estimates

Table 14: Cost Estimates for spiritual support

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
wte spiritual providers	£ 0.12 m	£ 4.1 m	Salary figures used are from Advanced Letter (SP) 3/2002 Based on a central scenario of 50 inpatient SPC 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 SPC* 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 Centres and 1 session per week in Cancer Units ie 0.65 wte chaplains *Day Care* 1 session per week for a 20 place unit (note with the growth of Day Care and Out-Patient clinics within palliative care this could be an under-estimate)

4.7.6 Cost impact analysis

In England and Wales there are currently 410 wte chaplains within the NHS covering acute, mental health, and community chaplaincies, and approximately 3000 part time chaplains. All of these will be from a variety of Christian denomination and other faith groups. Some of these chaplains will already provide a service to cancer patients (especially chaplains within the acute sector) alongside 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. Many chaplaincies have absorbed the increased or changed workload as a cost-pressure. It is estimated that for NHS units the shortfall figure is often in the region of 60%.

Anecdotal information from a selection of chaplains in post, indicates that in the voluntary sector many part-time chaplains 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 in the estimates table above of £ 4.1 m 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 £ 4.1m, which corresponds to £ 2.46m.

4.8 General Palliative Care

4.8.1 Background

Patients with advanced cancer require a range of services to ensure 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 coordinated and some need to be available on a 24-hour basis to prevent 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 are and who may have received little training in this area.

4.8.2 Scope

The following key resourcing issues have been identified, based on the guidance recommendations and discussions with experts in the field of community services.

- medical and nursing services available 24 hours a day for patients with advanced cancer living at home
- provision of continuous support at the end of life by trained carer and nursesmeans of identifying patients with advanced cancer who have palliative care needs through, for example, establishing a register or database
- agreed framework or managed plan of care provided by the primary care team, such as the Gold Standards Framework [16]
- protocol for the dying, such as the Liverpool Care Pathway [17]
- training of community nursing staff in palliative care so that at least 1 team member has undergone post-registration education and training

- education and 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

The guidance recommends that equipment such as mattresses, commodes, and wheelchairs needed to enable patients to stay at home should be available without delay, and should be removed promptly when no longer required. It is recognised that 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 the Economic Review since funding is from pooled budgets and equipment stores that are run jointly between health and social care. Therefore the cost of the equipment is not solely within the remit of NICE.

Workforce development issues are considered in section 4.13.

4.8.3 Methods and process

4.8.3.1 Assessments

The guidance recommends that each patient with advanced cancer should have his or her palliative care needs systematically assessed on a regular basis across the domains of physical, psychological, social and spiritual needs, using agreed assessment tools. As needs at this stage of the patient pathway can change rapidly, the need for re-assessment should be revisited at frequent intervals.

Assessments should be made by appropriately trained healthcare professionals who have received further education and training in palliative care or, where this is not available, members of the local specialist palliative care team, or in conjunction with the specialist palliative care team.

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

4.8.3.2 Implementation of Primary Care Planned Protocol/Framework and Protocol for the Dying

The guidance recommends that in line with other measures, teams should agree means of identifying patients with advanced cancer who have palliative care needs through, for example, establishing a register or database. An agreed framework or managed plan of care provided by the primary care team, such as the Gold Standards Framework (GSF), is also recommended.

The guidance also recommends that provider organisations should ensure that managed systems to ensure best practice in care of dying patients are implemented by all clinical teams. This might, for example, be achieved through implementation of the Liverpool Care Pathway (LCP) for the Dying Patient.

The GSF and LCP are used as the basis for the costing of these recommendations in the guidance. The protocol for the dying, e.g. the LCP, is already integrated into the GSF [d] for the community so is not separately costed.

In regard to implementation of the GSF, there are 2 requirements that have evolved [18]:

1. 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

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[d] The GSF includes as one of the 7 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.

costs will be required, as there will be minimal ongoing running costs once the registers and systems are integrated into PHCT/GP practice systems. A small "start up" budget for administration only is assumed per practice reflecting a view that money is not required to maintain GSF at a practice level, as this is integral to primary care, improves the quality of patient care, and in the end can save practice time by reducing crises [19].

2. Payment or secondment of a facilitator to run the GSF for each PCT. The PCT facilitator would also cover the LCP and other palliative care issues within primary care. The role could be carried out by a nurse, GP, or Macmillan GP facilitator etc. It is assumed that facilitation of palliative care in each PCT would amount to 1 day per week for a minimum of 3 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.

4.8.3.3 24 hour community care

4.8.3.3.1 24 hour medical services

NHS Direct can offer advice about any medical problem and are 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, there are the usual procedures to access the emergency acute services 24 hours a day via ringing 999 for an ambulance.

It is assumed that there will be no additional cost impact related to the guidance recommendation on provision of 24 hours a day medical services availability.

4.8.3.3.2 Continuous support for dying patients

The guidance recommends that as the end of life approaches, commissioners should ensure that continuous support can be provided for patients in their homes, in compliance with the wishes of patients and carers. This may involve either trained carers and / or trained nurses, according to the patient's needs. This cost is included in the costing of specialist palliative care services per network (see section 4.9).

4.8.3.3.3 24 Hour nursing services

There is much variation throughout the UK and between PCTs in the provision of 24 hours 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 community nursing services [20] contend that community care is cheaper than acute care and if 24 hour cover were introduced it would quickly begin to shoulder the burden currently falling on expensive hospital beds.

There are different models of care for 24 hour community nursing support including:

- 24 hour district nursing support
- 24 hour nursing support provided by a mix of providers including district nursing services, agency nurses, Macmillan nurses, and Marie Curie nurses
- level 5 support by the community team within the specialist palliative care services providing for 24 hour nursing support 7 days a week including 24 hour telephone advice.

For the purposes of the Economic Review, the cost for 24 hour nursing support is based on the model of 24 hour district nursing support.

However, to illustrate the costs associated with a different model of provision, the incremental costs of moving from level 1 support to level 5 support [e] for the SPC Home Care team are also presented (see sub-section 4.8.5).

Finally, cost impact analysis is carried out to determine the estimated incremental cost of moving to 24 hour community nursing across England and Wales (see sub-section 4.8.6).

4.8.3.3.4 Estimating the costs of 24 hour district nursing services

The approach taken to cost 24 hour district nursing services was as follows:

- derive an estimate of the cost of out-of-hours district nursing services per 1000 population
- apply the estimated component of workload that is palliative care
- scale to the population of England and Wales.

Four estimates of the cost of out-of-hours district nursing services were obtained. The estimates are averages for the entire PCT and are not broken down by rural and urban areas. There may be a need to refine the costing assumptions used in the Economic Review to reflect the cost of implementation of out of hours services in rural and urban areas.

Estimate 1 : A study conducted in Buckinghamshire in 1995 by Brogan et al [21] measured the use of out-of-hours community nursing over a two-month period from 1 March to 30 April 1995.

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[e] Levels of support are as follows: Level 1: Monday-Friday 9am to 5pm availability; Level 2: Level 1 with 24 hour telephone support; Level 3: Level 2 with 9 am to 5 pm availability extended to 7 days per week; Level 4: Level 3 with availability extended to 10 pm; Level 5: 24/7 availability.

All evening nursing services in Buckinghamshire county were contacted and100% agreed to participate in the study. Nurses provided home visits that had been prearranged and planned. The authors found that 7% of nursing services related to palliative care, and that total nursing costs for all areas amounted to £1306 per 1000 population per year. Identified costs included staff plus transport and other expenses directly associated with out of hours calls. Inflation adjusting the amount per 1000 population observed in the study to 2003 costs, provides an updated estimate of £1588 per 1000 population p.a**.**

Estimate 2: A telephone interview was conducted with administrative staff of a PCT (Barking and Dagenham, 5 June 2003) which currently is providing 24 hour community nursing. It employs 1 Grade A nurse, 16 Grade B nurses, 3 Grade D nurses, 8 Grade E nurses and 3 Grade G nurses. Using approximate salary midpoints and including on-costs, the total cost of this community nursing is estimated at £568,000 per year. As this PCT serves a population of 385,600, this is equal to a cost of £1472 per 1000 population per year. The administrators estimated that palliative care accounted for approximately 5-10% of the out-of-hours workload.

Estimate 3: Calderdale PCT (Halifax West Yorkshire) provided figures for the annual amount budgeted for running its 24 hour district nursing service. The service has 25-30 nurses being a mix of part time staff, bank staff, and unsocial hours staff. It runs from 16:30-08.30 during the week and at weekends and on bank holidays. The 24 hour district nursing service was initiated in 2000. The catchment population of 200,000 is larger than the average PCT. The annual full cost of running the out-of-hours service including overheads is budgeted at £ 345,000. Converting this to a cost per 1000 population provides an estimate of £1,725. The service estimates that between 10-15% of its out-of-hours workload is for palliative care. Some of this work is for other forms of progressive life-limiting disease, such as patients with end-stage cardio-respiratory failure.

Estimate 4: Huddersfield South and Central PCTs [f] run a 24 hour service; although there are some gaps in the morning and evening of about 1.5 hours. They do not deal with emergencies and patients need to go to the GPs out-of-hours services instead. 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. The population served is 221,000. 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%.

Summary of Estimates

The figures chosen for the cost of out-of-hours provision of district nursing services are as follows:

- £1,725 per 1000 population p.a.: this was the most comprehensive estimate for the running costs of services and is an up to date figure
- 15% of the out-of-hours workload is assumed to be for palliative care; this figure is towards the high end of the range of estimates provided for palliative care out-of-hours workload from the 4 services described above. It is likely that this figure will include a component for palliative care for patients with forms of life-limiting progressive disease other than cancer.

It is recognised that it is unlikely that PCTs would be able to implement a 24 hour district nursing service for cancer patients only. An out-of-hours service may need to be implemented for all patients in order for cancer patients to gain 24 hour access.

4.8.4 Cost estimates

Table 15: Cost Estimates of general palliative care

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
Implementation of Primary Care Planned Protocol/Framework and Protocol for the Dying			

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[f] Information provided by Chris Hedgecox, Senior District Nurse, South and Central Huddersfield PCTs, 01484 347855.

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
i) Development of GSF registers and systems	£ 0.081 m	£ 2.8 m	- in each practice assume £300 for admin time: set up costs only are included - 9334 practices in England and Wales [g]
ii) Facilitation in each PCT	£ 0.064 m	£ 2.2 m	- 0.2 wte facilitators required per PCT - assume Whitley I grade senior nurse/manager at approximately £35000 p.a. including on-costs - 302 PCTs in England [h] - cost per network £ 64,676 - Population of England 49.181 million and Population of Wales 2.903 million [i] - end of life protocol is also covered by the PCT facilitator
24 Hours Community Nursing: full cost of service	£ 2.59 m	£ 89.8 m	- 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 [j] - this PCT provided the most accurate out-of-hours costs for running a 24/7 out-of hours service - cost scaled to the population of E&W (52.084 million [4])
24 Hour Community Nursing: Palliative Care only	£ 0.39 m	£ 13.5 m	- the full cost of 24 hours district nursing x 15% estimated palliative care workload
Total based on palliative care component of out-of-hours	**£ 0.53 m**	**£ 18.5 m**	

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

[h] Source, http://www.info.doh.gov.uk/doh/intpress.nsf/page/2002-0167?OpenDocument
Monday 1st April 2002, DEVOLUTION DAY FOR THE NHS, Half a century of centralised healthcare is drawing to close – Milburn.

[i] Source, mid 2001 population estimates, ONS, www.statistics.gov.uk.

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

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
community nursing			

4.8.5 Alternative model - community SPC care team model for 24 hour nursing support

There are other variations around the type of model that could apply for 24 hour community nursing such as the specialist palliative care home care team providing 24 hour visiting as well as telephone advice. The out-of-hours costs for the home care team at 5 support levels are set out in the table following. For a network which has no out-of-hours provision of community nursing, the approximate cost output by the ScHARR model for SPC of each home care team providing 24 hour visiting is estimated per network of 1.5 million population at £ 0.17 m or for England and Wales at £ 6.06 m.

Table 16: Out-of-Hours Community Nursing Costs for the SPC Home Care Team by level of support

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
SPC Home Care team: out-of-hours costs by level of support			- for the home care team the nursing costs vary according to the support level, both in terms of additional payments, and additional staff required to provide cover - 3 home care teams per network each serving a population of 500000 with their own administrative base and no outreach bases - scale factor from a network with 1.5 million population to England & Wales population of 34.7 - refer to the previous ScHARR model for SPC for full assumptions ii
Level 1	£ 0.00 m	£ 0.00 m	- 9 am to 5 pm Monday to Friday service
Level 2	£ 0.04 m	£ 1.24 m	- L1 + 24 hour telephone support
Level 3	£ 0.07 m	£ 2.55 m	- L2 + weekend nursing availability from 9 am to 5 pm
Level 4	£ 0.13 m	£ 4.37 m	- L3 + nursing availability from 9 am to

			10 pm 7 days a week
Level 5	£ 0.17 m	£ 6.06 m	- 24/7 availability

4.8.6 Cost impact analysis for 24 hour nursing services

4.8.6.1 CDNA survey

A CDNA Survey [22] (circa 2001) indicated for 32 trusts in England that about 41% are providing an overnight service while about 94% have a twilight or evening service. The survey was, however, ad hoc in that CDNA local branches were asked to establish the situation in relation to their local Trusts with results then collated from the responses of the local branches.

4.8.6.2 DH figures

DH was asked to provide figures in relation to coverage levels of 24 hour community nursing in England and Wales. The following information was provided on behalf of DH [k].

- 24 hour service coverage could be up to 49% nationally based on a survey of co-operative directors some time ago; many may not be strictly 24 hour coverage, eg have a ½ hour gap in the late afternoon and before 9am
- evening or twilight coverage; from a survey of nurses in over 8 cancer networks in 2002, 93% indicated access to some form of service
- night service; 78% indicated access to some form of night service
- in London, out of 31 PCTs: 7 provide 24 hours coverage, all provide some evening/twilight coverage, 14 have a gap between day/evening and 10 have no night service.

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[k] Information provided by Cathy Shipman, Senior Research Fellow, Department of Palliative Care & Policy, King's College London. Tel 0207 848 5567. The DH district nurse project is being evaluated by Kings College London. The person leading the research is Cathy Shipman who has already done some survey work with district nurses and GPs on what out of hours services are available.

- There is a lack of provision when nursing numbers/turnover are low – for example in inner London
- There is no information on what these services comprise – there may be one nurse to cover a wide geographic area which may be inadequate for patient needs.

4.8.6.3 Audit Commission study

The Audit Commission carried out a study of district nurses in 1999[23]. At that time 1/3 of all trusts provided no district nursing services overnight. The study found that provision of evening and night services is patchy and gaps can lead to otherwise unnecessary hospital or nursing home admissions and delayed discharges.

The Audit Commission's survey of trusts found that up to midnight, 57 % of trusts in England and Wales have staff on duty in the evening across trusts, while the others have a mix of on-call arrangements (5 %) or a combination of on-call and dedicated services (38%). These services are not necessarily available in all areas even within one trust and they do not reflect any current assessment of need.

The figures are summarised in the following table.

Table 17 : 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%

ScHARR has used the Audit Commission figures above to estimate existing coverage levels across England and Wales for 24 hours community nursing, in the absence of any definitive up to date figures being available. It is recognised that there may have been improvements in coverage levels in the 4 years since the study was carried out, so the cost impact analysis presented may be an overestimate of the true impact.

4.8.6.4 Cost Impact Calculation for Out-of-Hours District Nursing

The steps to the cost impact calculation are set out below.

Table 18: Assumptions for estimation of Out-of Hours District Nursing Cost Impact

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 the 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 to midnight unit cost per PCT estimate = £177,672 - night service midnight to 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 above 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

Assumptions on existing coverage for PCTs (n-302), based on the Audit Commission survey, are given below:

Table 19 : Out of Hours District Nursing: Estimate Coverage Distribution for PCTs

Audit commission survey of trusts	Day duty	**EVENING SERVICE** Twilight 7pm to 12.00am	**NIGHT SERVICE** Midnight to 8.00 am
combination (on-call and dedicated service)	n/a	115	70
dedicated service	302	172	88
on-call	n/a	15	46
no service		0	98
Total		302	302

The cost impact results are summarised below. The full cost of the service provision was estimated to be £89.9 m. Based on assumptions on existing levels of services in table 19 it is estimated that £33.2 m is required to ensure that all networks are providing full coverage.

Table 20 : Out of Hours District Nursing Cost Impact Estimates England & Wales (£ m)

	EVENING SERVICE Twilight 7 pm to 12.00 am	**NIGHT SERVICE** Midnight to 8.00 am	**OUT OF HOURS SERVICE** 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

4.9 Specialist Palliative Care Services

4.9.1 Background

Specialist palliative care (SPC) services offer support to patients with cancers suffering from a range of complex problems which can not be handled effectively by generalist services in hospitals or in the community.

Current SPC services are considered to be inadequate for a number of reasons:

- patients needs are not always adequately assessed
- access to and availability of SPC services is variable and inequitable
- full multi-disciplinary teams do not exist at many hospitals and many existing teams can not provide 24 hour access to advice
- community SPC services vary in their staffing levels and provision of out of hours support .

4.9.2 Scope

The guidance recommends the provision of a range of palliative care services - as a minimum this would include multi-professional SPC teams providing assessment, advice and care for patients in all locations, specialist inpatient facilities and bereavement support services (refer to section 4.12 for costing of bereavement support).

Recommendations identified as requiring significant additional resources are as follows:

- networks should provide an appropriate range and volume of SPC service to meet the needs of the local population
- hospital SPC teams should provide a seven day a week service with appropriate out of hours cover
- community SPC teams should provide a seven day a week service with appropriate out of hours cover.

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

The cost of enhancing SPC services within any given network will depend on the networks baseline position and the resultant priorities identified for improving services. Average levels of provision of some services in the cancer network may fall well below national average levels or there may be inequalities in provision within any given network (for instance some community SPC teams within a network may be operating a basic 9am to 5pm service with no out of hours cover whilst others may be offering weekend and evening visiting with 24 hour telephone support). Routine staffing levels in the network may fall well below optimal levels required for delivering a high quality service.

4.9.3 Methods and process

4.9.3.1 Current expenditure on SPC services

Expenditure on SPC services in England in 2001/2 is estimated at £ 320 million [1], an average of £9.4 million per cancer network. An additional £50 million has been allocated to SPC services over the next three years, resulting in an average expenditure of £10.9 million per network for 2003/4 onwards. The breakdown of current costs between services is not known.

Expenditure on SPC services in Wales is unknown. Extrapolating expenditure in England to Wales, based on the relative population sizes suggests that total expenditure in Wales in 2001/2 was around £19 million.

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[1] 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 £ 237 m. To this is added expenditure incurred by Marie Curie Centres and Sue Ryder Units – around £ 23 m. 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 £ 320 m (Source, NCHSPCS).

4.9.3.2 Future expenditure on SPC services

Previous modelling work, commissioned by the Department of Health in 2002, to identify the cost of providing high quality specialist palliative care service has been reviewed and updated3. The model has been extended to include supportive care and updated to reflect the guidance recommendations for health and social care professionals working within the specialist palliative care services. Education and training cost assumptions have been reviewed and are considered separately in section 4.13.

The core components of this service included in the model are: specialist palliative care inpatient beds, home care teams, hospital support teams, bereavement services, outpatient services, day care and “hospice at home” services. However given that no specific recommendations are made in the guidance in relation to day care it is assumed that day care services remain at current levels.

Staff costs are the major component of the total cost of SPC services. Assumptions on appropriate staffing levels are taken from published recommendation where available (e.g. Palliative Care 2000, Cameron Report 1996). Where recommendations are not available, advice has been taken from a number of palliative care experts. Staffing level assumptions take into account the need for SPC 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 in the model for each service component as a fixed proportion of total costs for that individual component.

The demand for SPC services within a cancer network is dependent on a wide range of factors, including the population of the network, the number of cancer deaths, the level of deprivation in the network, the volume and quality of general palliative care services such as nursing home beds, and district nursing services. The model takes into account some of the key variables such as population size and cancer deaths. However the model has not attempted to explore the impact of deprivation, and the provision of general palliative care services, due to lack of clear evidence on the exact nature of these relationships.

The demand for individual components of SPC services is inter-related. For instance a cancer network that provides a large high quality home care service may well have a lower demand for SPC inpatient beds. A cancer network that offers an outpatient service may have a lower demand for medical input into the home care or day care components of palliative care. Based on current evidence it is not possible to quantify these inter-relationships, however they need to be taken into account when interpreting the outputs of the model for different cancer networks.

The model results must be interpreted with caution and do not provide accurate costings for specific service developments. However, the model does show the crude order of magnitude of the costs of different levels of service provision. This may be useful when choices have to be made between, for example, expanding the number of specialist palliative care beds and expanding home care or hospital specialist palliative care services. It should be recognised that one of the key functions of the model is to inform future analytical and research work by identifying current data gaps, key cost drivers and key areas of uncertainty.

4.9.3.3 Specialist inpatient facilities

Current provision of inpatient facilities varies widely. The current national average is approximately 50 beds per million with a range of 34 to 62 beds per million[24].

The demand for inpatient facilities will vary between networks and will depend on a number of factors including the level and quality of services in the community. High quality, well staffed community services should offer the opportunity for more people to choose to die at home with adequate support and reduce the need for inpatient admissions.

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

The guidance recommends that hospital and community teams provide direct assessment of people with cancer (at home or in hospital) during normal working hours, seven days a week, along with telephone advice at all times.

Full multi-disciplinary teams do not exist at many hospitals and where teams do exist they often do not provide 24 hour access to advice. For hospital support teams, 24 hour telephone support is assumed to be provided by SPC inpatient unit ward staff with medical backup, at no additional cost. It is assumed that 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 from 5pm to 9am seven days per week. Nurses are paid on-call payments for each night and enhanced rates for time spent on the telephone. It may however be possible for telephone support to be provided by the local SPC inpatient unit ward staff at no extra cost. In addition it is assumed that one nurse per team (hospital and community) works at weekends.

4.9.3.5 Bereavement services

Bereavement services are considered as part of families and carers recommendations *(section 4.12).* This service overlaps between different chapters in the guidance and therefore bereavement services costs are included in the sections on: families and carers incorporating bereavement support, specialist palliative care, psychological support, and social support.

4.9.3.6 Social support

Social workers in specialist palliative care teams fulfil a number of functions, namely:

- undertaking social care assessments
- benefits and welfare rights advice
- bereavement counselling
- general counselling
- provision of professional psychological assessment, intervention, and support at levels 1, 2, or 3 (section 4.5 - psychological support)

- care of families and children.

The full cost of social workers for all of the above listed functions is included in the specialist palliative care cost estimate. However only the first 2 functions listed are included for the estimate of social workers costs in supportive care.

4.9.3.7 Continuous support for dying patients

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

For the existing main provider of end of life continuous support, Marie Curie Cancer Care, the existing services costs have been assumed (10.5 wte nurses per 1 million population), of which 60% are registered nurses (at rate of £15.50 per hour) and 40% are health care assistants (at a rate of £12.00 per hour).

Discussions with service managers at Marie Curie and Macmillan Cancer Relief, have revealed that it is extremely unlikely that demand for the Marie Curie or equivalent services will fall in future. The extent to which demand will vary once the guidance recommendations are implemented, however, is indeterminate at this stage. Cancer networks will need to consider the future balance of hospital and community services required in order to allow patient choice in relation to place of death. An expansion in community support services may be offset by reduced demand for hospice beds.

4.9.3.8 Day care

No specific recommendations relating to provision of day therapy facilities are made in the guidance manual and therefore no change to current service provision (13,000 places / million) is considered.

4.9.3.9 Outpatients

Some Trusts may offer dedicated SPC clinic outpatient appointments. Consultant input is assumed to be 0.3 WTE per population of 500,000. This may however be offset by reduced demand for medical consultations in the community or as part of a day care service. In addition palliative care consultants are increasingly required to support a number of cancer MDTs.

4.9.4 Cost estimates

The total cost for the base case scenario for the hypothetical Cancer Network with a population of 1.5 million is £ 12.6 m. This corresponds to £ 439.1 m for England and Wales.

Table 21 : Cost Estimates for SPC Services

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
Cost of high quality SPC services	£12.6 m	£439.1 m	Population of network = 1.5 million Deaths in network = 3,907 No of cancer centres = 1 No of cancer units = 4 Inpatient SPC beds = 50 / million Community and hospital support teams: 9am to 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 levels of expenditure in 2003/4 will be, on average £ 10.9 m per network (based on £ 370 m for England) the incremental cost of guidance on SPC service for a typical cancer network is estimated to be £ 1.8 m per network.

The increase in costs for SPC services reflects a requirement to expand existing levels of service provision, changes in the staff mix to ensure multi-disciplinary teams, and to increase the staffing volumes within SPC services in order to ensure delivery of a high quality service.

Cost presented in this section include an element of double counting, given that the costs included with the SPC services estimates are also presented within individual chapters (for instance, as already noted, the cost of bereavement support services is also presented in section 4.12).

The final summary table estimates of the total costs of supportive and palliative care under the guidance recommendations, are presented in such a way as to remove any element of double-counting of bereavement services (see section 5).

4.9.4.1 Cost breakdown by service and cost per activity

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

Table 22: Cost Breakdown by Service Component

	Cancer Network Cost (£ m)	England and Wales Cost (£ m)	Cost as % of total
SPC Inpatient beds	£ 6.8	£ 237.5	54.1%
Community SPC Teams	£ 2.0	£ 68.0	15.5%
Hospital SPC Support Team	£ 1.7	£ 57.9	13.2%
Day Care	£ 0.9	£ 29.9	6.8%
Outpatient SPC services	£ 0.5	£ 17.1	3.9%
Bereavement services	£ 0.5	£ 15.8	3.6%
Continuous Support for Dying Patients	£ 0.4	£ 13.0	3.0%
TOTAL	**£ 12.6**	**£ 439.1**	**100%**

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

Table 23: 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 contac	£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 yea	£3,236	N/A	N/A

Cost per activity figures derived from the model are useful for validation purposes to compare the future unit costs estimated by the model with current units costs, where available. Costs from the 8 Hospice Study, a cost analysis of hospice and SPC services in 1998/99, have been inflation adjusted to present day prices to allow comparison with the results from the model.

4.9.4.2 Scenarios

The cost of meeting SPC recommendations will vary according to the existing level of service provision within an individual network. Central, high and low scenarios are presented for different service components to illustrate the potential cost of extending service provision within a network.

For instance, there is a cost of a network moving from Monday to Friday 9am to 5pm provision of hospital and community SPC team services, to the guidance recommendation of providing direct assessment of people with cancer (at home or in hospital) during normal working hours, seven days a week, along with telephone advice at all times. This is shown as the difference in moving from scenario A to B in Community SPC Teams (service 2), and Hospital SPC Support Team (service 3), a cost of £0.6 m per network.

For several services Level B has been set at current national averages (inpatient beds; palliative day care places; Marie Curie Nursing Service provision). For inpatient beds Level A and Level C have then been set to reflect known variation in current provision, in other cases Level A and Level C are arbitrarily lower and higher. For bereavement support Level B is set at level of need identified by the members of the Editorial Board with particular expertise in families and carers services incorporating bereavement support.

The scenarios for a hypothetical network of 1.5 million population are given below.

Table 24: 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)	6.8m

	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	1.4m
	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	0.3m
	B	35% uptake by potential clients	0.5m
	C	45% uptake by potential clients	0.6m

These scenarios may not capture the full cost of expanding service provision in a particular network, given that they assume that scenario A provision is adequately staffed (the model assumes staff ratios per service component required for high quality provision of specialist palliative care services). If scenario A levels services are inadequately staffed the cost of moving to scenario B level services will be higher than indicated in the above scenarios.

4.10 Rehabilitation

4.10.1 Introduction

Assumptions for the Rehabilitation section of the Economic Review have largely been sourced from the member of the Editorial Board with particular expertise in rehabilitation.

4.10.2 Background

Cancer and its treatment can have a major impact on a patient’s ability to lead a normal life. Activities which healthy people take for granted such as mobility, speech, eating, drinking, and swallowing could be severely impaired. Cancer rehabilitation aims to maximise physical function, promote independence and help people adapt to their condition. A range of Allied Health Professionals (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 current rehabilitation services are inadequate at several levels:

- Front-line staff frequently do not recognise patients' needs for rehabilitation and may be unaware of the benefits that could be derived from assessment and intervention by a skilled AHP
- Availability of AHPs may be inadequate
- 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.

4.10.3 Scope

The following key resource issues have been identified, based on the Guidance recommendations and discussions with the member of the Editorial Board with particular expertise in Rehabilitation.

- Costs of staffing supportive and palliative care service in terms of numbers and grades of wte therapists per hypothetical cancer network with 1.5 million population in order that the four-level model for rehabilitation services recommended in the guidance can be implemented
- Each cancer network to establish 5 new expert posts at superintendent or chief level 3 grades; there are education and training costs also associated with these appointments
- One of these posts will assume a network lead AHP role
- Cost of education and training of therapists in the basics of cancer rehabilitation in order to implement the recommended cascade model where therapists training other health care professionals working with cancer patients in rehabilitative needs assessment

Workforce development issues are discussed in section 4.13.

4.10.4 Methods and process

4.10.4.1 Strategic posts per network

The guidance recommends that networks will need to identify a Lead AHP from one of the 5 appointed experts (physiotherapy, occupational therapy, dieticians, speech and language therapists, lymphoedema specialists) to extend their expert role to take a strategic AHP role, working with the network management team, on behalf of the 5 therapies. These individuals will:

- Work with their expert AHP colleagues to lead a programme of work including inter alia [m]:
    - development and implementation of network wide strategies to ensure that patients' rehabilitative needs are recognised and met through the use of a network-wide assessment tool
    - establishing referral and treatment criteria.

It is assumed in the Economic Review there will be 1 wte per therapy for the role of expert AHP per network with the posts graded at the Chief 3 or Superintendent 3 grade. It is also assumed that one of the post holders will also carry out the role of the Strategic AHP Lead per network.

4.10.4.2 Volumes of AHPs staff required per network

Assumptions have been made for requirements for wte staff per therapy group in both hospital and community settings. These were provided by the member of the editorial board with particular expertise in rehabilitation and are based on a modification of assumptions used in the previous ScHARR modelling 3 for specialist palliative care extended to include supportive care, speech and language therapists, and lymphoedema specialists.

The table of cost estimates below provides details of the assumptions used in terms of wte therapists required in cancer centres and units and in the community home care team setting. It is assumed that the wte figures will be sufficient to enable implementation of the 4 level model of rehabilitative assessment and support recommended in the guidance.

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 work, and seniority of staff working with cancer patients.
The exception is the expert AHP per therapy who is graded at Chief 3 or Superintendent 3 grade.

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[m] See guidance chapter 12 for a full list of the role of the 5 lead therapists per network.

4.10.4.3 Stoma-therapists and appliance officers

The guidance recommends that providers should ensure that designated facilities are available for demonstrations and fitting of appliances for patients. Appliances such as wigs, stoma bags, lymphoedema hosiery and other prostheses should be supplied by these therapist groups to patients in a timely manner. There are no additional costs assumed here since these posts generally already exist and the appliances involved such as breast prostheses and wigs and stoma bags come from NHS funds already.

4.10.4.4 National Agenda for Workforce Expansion for Therapists

The Economic Review considered whether a model could be built for the extra number of therapists required for supportive and palliative care under the guidance recommendations, based around the national agenda [n] for workforce expansion for therapists.

However, this approach was abandoned at an early stage, given that the growth figures are not specific to the professions, and staff working within the supportive and palliative care area are more likely to be senior grade staff, while the staff entering the professions as per the national agenda will be junior grade staff. The approach taken instead, to estimate the wte therapists required under the guidance recommendations, is set out above in sub-section 4.10.4.2.

4.11.5 Cost estimates

Table 25: Cost Estimates for Rehabilitation

Key Economic Issue	Cancer Network	England & Wales	Key Assumptions
5 expert posts per	£ 0.146 m	£ 5.1 m	- Salaries are at Superintendent 3 or Chief level 3 grades: these are the same. They are also

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[n] HR in the NHS Plan: July 2002: sets out targets for staff increases of 6500 extra therapists by 2004, and 30000 more therapists and scientists by 2008 than in 2001.

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
network			included in the total Staffing costs figures below
Total staffing costs	£ 0.68 m	£ 23.75 m	*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 1.5million 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 £ 25481 Chief III or Superintendent III Point 02 Salary level = £30037 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 £25.5m for England and Wales is for therapists working within the specialist palliative care services, and 2/3 for therapists working within supportive care for adult patients with cancer.

4.11 Complementary Therapies

4.11.1 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. On the other hand, it is recognised that there is 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.

4.11.2 Scope

Specific areas where there are NHS costs are:

- Specific posts or sessions dedicated to complimentary therapies with the support of commissioners
- provision of reliable and high quality information about complementary therapies, to empower patients to make decisions for themselves.

Resource issues in relation to guidance recommendations on information are considered separately in the section 4.4 of this report.

There are no firm recommendations that complementary therapy services should be provided by the NHS. Therefore, no attempt has been made to provide any resource implications in relation to this area.

4.12 Services for Families and Carers incorporating Bereavement Support

4.12.1 Background

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

Current services are inadequate 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 opportunity for contact with professionals to address 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 and much is provided by the voluntary sector.

4.12.2 Scope

The guidance recommends assessment of the needs of family members and carers on an on-going basis. It is assumed that the patients' usual health and social care professionals will undertake assessment of needs and the cost impact of this will be minimal. 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 (see section 4.4 for costing of directories). A small proportion of families and carers may require access to professionals providing emotional support and capable of dealing with complex family situations (see section 4.5 for costing of psychological services).

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

1. organisations providing cancer care services should nominate a lead to oversee development and implementation of services that specifically focus on the needs of families and carers
2. implementation of the three component model of bereavement support
3. 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 4.13 Workforce Development).

Issues such as respite care, are not addressed within this section of the Economic Review. Because these services straddle both NHS and social services sectors, the guidance cannot make firm recommendations about future service provision, and consequently these services have not been costed as part of the Economic Review.

4.12.3 Methods and process

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

Additional posts will be required to undertake the role of strategic development of services for families and carers. It is assumed that there will be 1 wte per 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 £0.1m for a network with 1 cancer centre and 4 units, and £3.6 m in total for England and Wales.

The leads for families and carers will also deliver services and be involved in counselling in particular.

4.12.3.2 Bereavement services

Three component model of bereavement support

The guidance recommends a three-component model of bereavement support:

1. Component 1: all bereaved people should be offered information about grief and how to access support services
2. Component 2: a proportion of bereaved people require additional support to help them deal with the emotional and psychological impact of loss by death
3. Component 3: specialist interventions are required by a small proportion of bereaved people. This will 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.

1.Cancer Care Acute Trusts

The Department of Health survey on bereavement services (summer 2001) demonstrated that every NHS Trust provides support to the bereaved in some form, but the extent of this support varies considerably.

2. Hospices and SPC Services

Hospice and SPC services are generally better developed than services in acute trusts. There is however a range of models of service provision, and significant geographical variation in provision. Some areas of the country currently lack services working at component 2 and 3. Waiting lists for component 3 services are around 6 months in some parts of the country.

3. Community services

Community services, such as Cruse, tend to offer local services focussing on providing support for specific groups of bereaved people. They are not considered within the scope of the Economic Review.

Evaluating bereavement support provided to older people by hospices

Professor Sheila Payne (Professor in Palliative Care, Trent Palliative Care Centre, University of Sheffield) has recently undertaken a national survey of UK bereavement services listed in the Hospice Information Directory 2002 [25]. Responses were received from 253 bereavement services, of which 203 were based in England and 50 based in Wales, Scotland and Northern Ireland. Initial frequency statistics from the survey indicate that 95% of these services offer one-to-one support, along with telephone support (89% of services), and written information/advice (73% of services). Other services offered include: memorial, remembrance or anniversary service (71%), support group (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 services use volunteer workers. The mean number of paid staff is 2.8 and the mean number of volunteer workers is 9.6 per service.

Future provision of bereavement services

The editorial board members with particular expertise in services for families and carers incorporating bereavement support, advised figures of 100% of bereaved require level 1 support, 35% require additional support at level 2, and 5-10% require level 3 support.

Component 1

The information requirements of component 1 are included as part of the costing of information services (refer to Section 4.4 Information).

Component 2

It is assumed that component 2 support services are provided by volunteer bereavement services, managed by health and social care professionals. Some services, however, are run by health professionals alone, and these services may well have higher costs. The efficacy of volunteer bereavement services is determined by the quality of the relationship between volunteer and client. The effectiveness of bereavement volunteers reflects the quality of the co-ordination of their work [26]. Sufficient time and resources are required to select, train and supervise volunteers.

A bereavement lead (Administration and Clerical Grade 7) will spend the majority of their time on education, supervision, training and recruitment. For larger services, with 200 or more clients, it is assumed that this position is full- time; for small/ medium services, with less than 200 clients, 0.75 wte is assumed.

A part-time bereavement counsellor handles 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 6 providers per million population (based on 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 [o].

Component 3

Approximately 5 – 10% of bereaved people will have complex problems requiring specialist interventions. Component 3 services are included within the cost for psychological support services (refer to section 4.5).

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

4.12.4 Cost estimates

The cost estimates include the cost of provision of bereavement services (component 2 only) and strategic leads. The cost of current provision in not known and therefore the incremental cost of future provision, over and above current levels, cannot be calculated.

Table 26 : Families & Carers incorporating Bereavement Support: Cost Estimates of Implementing the Guidance Recommendations

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
Bereavement Support Services (component 2 only)	£ 0.5 m	£ 15.8 m	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
Strategic leads	£ 0.1 m	£ 3.4 m	- 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 is assumed to be grade I with salary of £30455 (2002 Grade I NP57 spine 3) - the unit people are assumed to be grade H with a salary of £27695 (2002 Grade H NP51 spine 3)
Total	£ 0.6 m	£ 19.2 m	

4.12.4.1 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 [27], and can therefore produce cost savings.

The study showed that those receiving support were significantly less likely to increase their use of health care services (p=0.02), particularly GPs (p=0.03). Only 25% of those receiving support reported seeing their GP more frequently than usual in comparison with 40% of the control group. However, 88% of those receiving support reported 4 visits or less during the first 14 months after bereavement, whereas 47% of the control group saw their GP at least 8 times (Personal Communication, Marilyn Relf).

These cost savings have not been taken into account in the Economic Review.

4.13 Workforce Development

4.13.1 Background

A significant number of recommendations in the guidance relate to workforce development - the education, training and support requirements staff will 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 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 (2001-2004) to train and support over 10,000 district and community nurses (one in four of all district nurses). Significant additional investment will be required for a range of other health professionals involved in the provision of supportive and palliative care.

4.13.2 Scope

Education and training needs identified within the guidance include:

- Skills training in the assessment of supportive and palliative needs, both generally and specifically in relation to social care, spiritual needs, psychological support and rehabilitative needs
- Accredited communication skills training programmes for clinical staff at advanced and foundation levels
- Information giving
- Training needs of specific groups
  - training and support for members of Partnership Groups (both users and professionals)
    - education in the principles and importance of user involvement, and training in user involvement methods and in how to act on user views for health and social care professionals
    - training staff to facilitate patient and carer support groups

- training of staff providing psychological support
- 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. Cost estimates for a limited number of training programmes are given to illustrate the potential scale of costs associated with meeting these training needs.

Consideration of workforce planning is beyond the scope of this report. The implications of implementing the recommendations contained within the guidance 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.

4.13.3 Methods and process

4.13.3.1Types of training

Training in communication skills.

The guidance recommends all health and social care professionals who come into contact with patient 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 have been identified by Fallowfield et al*:*

Level 1 - receptionists, medical secretaries, porters etc,
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 the requirement for training in needs assessment in relation to many aspects of service provision: psychological support, social support, spiritual support, general palliative care and care of the dying, rehabilitation and families and carers.

Other Education and Training requirements

Specific groups of professional and voluntary workers and patients will have particular training needs. For instance in spiritual support - training for local faith leaders in the assessment and delivery of spiritual care for patients and carers.

4.13.3.2 Current Training Programmes

Department of Health (DH) programme to train and support district and community nurses [28] [29]

The NHS Cancer Plan sets out a £ 2 m per annum investment for each of the 3 years 2001/02 to 2003/04. The funds available are £ 60 k for an average network p.a.

- Programme funding covers both the provision of education and backfill costs
- It applies to district nurses or other community and nursing home staff
- Networks were required to submit proposals to DH including the numbers and types of nursing staff expected to benefit, with priority given to G grade nurses.

The DH stated aim is to train 10,000 (one in four) district and community nurses. The programme is ongoing and has built up since its first year. DH returns indicate that nearly 8,500 nurse training events had taken place by 31 March 2003 (note as some nurses are involved in more than one event this is not 8,500 individuals). There are various training courses, events, and placements organised under the programme. Each cancer network throughout England devised their own training programme and set their own targets for how many nurses they would train.

DH have encouraged networks to extend the programme to include other health care professionals as they consider appropriate. Up to 31 March 2003, there were 2010 training events for other health professional in the programme (this is not 2010 individuals as some will have been involved in more than one event). DH are now encouraging networks to build the programme into their routine education plans so that staff can continue to receive this training in the future.

Existing Continuing Personal Development (CPD) Courses

A wide range of courses is currently offered, including Care of the Dying and Palliative Care. These consist of study days, short courses and modules that form part of certificate/diploma, degree and MSc programmes. It may incorporate both academic and non-academic study.

The typical cost of CPD accredited units/modules for level II (diplomas) and level III (degrees) is around £550-£700 per person attending, with these courses typically running for 1 day per week over 10 weeks with 40 hours of study and 80 hours of self directed study. Both the provider and venue for such courses range widely, and are often dependent on the subject matter being taught and the nature of the skills training. This might range from but not be confined to a hospice education department, higher education establishment or hospital department. Very few courses attract backfill costs.

4.13.3.3 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 a clear leadership and direction to workforce planning and development, and to manage the Multi-Professional Education and Training budget and other relevant budgets (these will be allocated from the DH to Strategic Health Authorities which will act as paymasters for the Confederations).[30] The WDCs ensure that the guidance is known to trusts, assist the trusts in meeting the guidance, providing 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 the NHS more widely. It acts as the Champion of 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; disseminates examples of good practice within the field. Where it has been decided that education & 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, skill-mix etc

Training Needs Assessment

The Kent Cancer Education Project [31] 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 that needs to be commissioned to implement the workforce development recommendations in the guidance. In 1997 the Kent Education Consortium funded a TNA of nurses and professions allied to medicine (PAMS[p]) within the cancer workforce across Kent. This was a major project running from August 1998 to July 1999.

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

The types of nurses and PAMS selected for the Kent Cancer Education Project survey illustrate the diverse range of HSCPs working in cancer whose training and education needs will need to be assessed by networks to address the guidance workforce development recommendations.

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

The Kent Cancer Education Project also recommended consideration for training be given to the following groups who did not participate in the survey- GPs, GP care managers, medical staff, clinical psychologists, social workers, bereavement counsellors, palliative care assistants, health care assistants, nursing home staff, pastoral care/chaplaincy, complementary therapists, consultant secretaries, support workers, appliance officers, porters.

Work in progress

Additional references to be added:

- *Current project by NELWDC on developing a training needs analysis in cancer and palliative care. Source: Danny Kelly . UCLH*
- *South West London project with funding from South West London Education Consortia (replaced by WDC). Details in European Journal of cancer care 2000 , 9, 191-196 by Wood,C and Ward,J A general overview of the cancer education needs of non-specialist staff*
- *Cancer Care Alliance in Yorkshire - in EJCC 2000, 9, 30-35 A cultural change in cancer education and training by Boal et al – includes details of needs assessment survey.*

4.13.4 Illustrative costing exercise

A full cost analysis is beyond the scope of this project. However preliminary estimates of the cost of training are given to illustrate the means of calculating workforce development costs for generic training and education programmes for health and social care professionals and for a limited number of specific programmes of training and education. 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.

4.13.4.1 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) (i.e. level 3) is currently underway 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 SCHPs to be able to facilitate communication skills training courses for other SHCPs. The second programme is a three day SCHP 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 SCHP training course.

Costs of training senior personnel only 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.

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 [32] (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[33].	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 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

*Input from S.Wilkinson suggests that this cost should be approximately £1000 – to be confirmed.

Table 29: 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 patient of £722 the total cost of training senior staff is estimated to be £3.1 m in England and Wales (£7.6 m with backfill costs). Assuming that one third of these staff undergo training in the first year the number of senior personnel receiving training in year 1 would be 1230, an average of just over 33 places per network. At a cost of £722 this equates to approximately £1.0 m in year 1 (£2.5 m with backfill costs).

Additional costs would be incurred if GPs undertake 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 required for training sufficient trainers.

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

4.13.4.2 Needs assessment training

Training programmes for needs assessment will need to be developed, along with an assessment tool. There are no examples of dedicated needs assessment training programmes at present. Where training in needs assessment is available currently, it 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 would be £ 400. Base 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 extended to frontline nurses (Grade E & F in first instance), perhaps targetting 10 nurses per acute trusts - approximately 2000 places per annum

Assuming that 2000 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: Costs of Needs Assessment Training

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

acute hospitals

4.13.4.3 Information Giving

Training in meeting peoples health information needs, based on a one day non-residential course at cost of £100 per day and assuming 3000 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	£ 8 K	£ 0.3 m	3000 places per year undergoing training at £100 per place

4.13.4.4 Specific Training Requirements

Rehabilitation

Specific training requirements for therapists include both training of AHPs in the basics of cancer rehabilitation so that a cascading model of therapists training other healthcare professionals rehabilitative needs assessment can be implemented and post graduate 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 £9000 p.a. Upper £18000 p.a.	£ 0.5 m per annum (using averaged network figure)	15 – 30 therapists per year undergoing training per network at £600 per therapist
education and	Set up costs:	Set up costs: £ 0.5	Specialist course (post graduate

training for the expert 5 designated posts per network	£12500 Ongoing costs Lower £2500 Upper £5000	m Ongoing per annum costs (using averaged network figure) £ 0.1m	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 £12500 Ongoing costs Lower £11500 Upper £23000	Set up costs £ 0.5 m Ongoing costs £ 0.6 m	

User Involvement

Both users and health professionals require training to support the user involvement process.

Assuming 6 training sessions per year per network at cost of £10,000 p.a.

Table 33: illustrative Costs of Training for User Involvement

Key Economic Issue	**Cancer Network**	**England & Wales**	**Key Assumptions**
Training for user involvement	£ 0.010 m	£ 0.35 m	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 6 training sessions per year costing £ 1500 per session).

Psychological Support

Education and training requirements include training in screening for psychological distress and delivering of basic psychological interventions for those working at level 2, along with supervision and training by psychological care experts with extensive experience in cancer particularly of those delivering other aspects of psychological care at levels 3 and 4.

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	£ 0.011 m	£ 0.371 m	Level 3: 1wte counsellor Level 4: 1wte psychologist (0.5 wte clinical, 0.5 team co-ordinator) - 0.5wte consultant psychiatrist Staff operating at levels 3 and 4 have training costs of £1285 pa, and supervision costs of £1500 pa. Above wte figures are per cancer centre, these are scaled to the network level, and then to E&W (see Psychological Support section 4.5)

5. Discussion

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 guidance recommendations.

5.1 Issues Relating to Presentation of Cost Estimates

In this section the costs from sections 4.1 to 4.12 are presented together to give a comprehensive picture of the cost of future provision of services under the guidance recommendations.

5.1.1 Supportive care and general palliative care

A number of issues existing in relation to the presentation of costs within the supportive and general palliative care:

- Generalist staff groups, such as GPs and community nurses, are not modelled in respect of their workload in relation to cancer patients. It is assumed that the palliative care needs assessments, interventions, and referrals that are 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.

  However this presents some inconsistencies in the cost estimates. For example, for Allied Health Professionals and social workers we present an estimate of staff volumes required in the supportive care setting; but not for other groups of health care staff providing supportive care such as GPs.

- In many areas within supportive care, the costs presented are an annual ongoing cost (e.g. for user expenses in the User Involvement Section 4.2 or the staff wte component of the annual cost of running a service, as for dedicated cancer information centres in units and trusts Section 4.4). However in some instances the cost presented are a one off set-up cost (e.g. for production of a network-service directory in the Co-ordination of Care section 4.1)

- In the majority of cases the full cost of service provision is presented, rather than the incremental cost of guidance implementation. Generally 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.

- In a limited number of cases the costs presented are incremental costs, such as for the cost of out of hours community nursing, given that PCTs will already be providing in hours services; only the cost of extending the service to provide out-of-hours provision is estimated

The cost estimates for supportive and general care presented in Table 35 should be interpreted with caution. The reader is advised to refer back to the relevant sections when interpreting the figures presented for a full explanation of the basis of calculation.

5.1.2 Specialist Palliative Care

Current expenditure on specific elements of SPC services is not known with certainty. However the cost of future provision for all SPC services is totalled and is compared with the best estimate of the total cost of current provision in order to estimate the overall incremental cost of provision resulting from implementation of the guidance.

5.1.3 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 4.9 Specialist Palliative Care and section 4.12 Services for Families and Carers. However figures within the final summary table of estimates of the costs of supportive and palliative care under the guidance recommendations, are presented in such a way as to remove any element of double-counting between services.

5.2 Cost of Current Provision of Supportive and Palliative Care

The current expenditure on supportive and palliative care services across England and Wales is not known with certainty. Expenditure on SPC services only in England in 2001/02 was estimated at £ 320 million, an average of £ 9.4 million per cancer network *(see the footnote in the specialist palliative care section 4.9 for the reference for this cost).* An additional £50 million has been allocated to SPC services in England over the next three years, resulting in an average expenditure of £10.9 million per network in England for 2003/4 onwards. Expenditure on SPC in Wales is unknown. However extrapolation of expenditure on services in England in 2001/2 to the population of Wales suggests that expenditure in Wales in 2001/2 was around £19 million.

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. Work is required within individual networks in order to establish the baseline level of service provision and costs.

5.3 Cost of Future Provision of Supportive and Palliative Care

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. Staffing level assumptions have been made to ensure that a high quality service can be delivered. All staff costs are based on NHS pay scales.

The cost estimates are considered to be a crude order of magnitude only. There has been insufficient time within the scope and timeframe of this report to undertake detailed costing work on all components of supportive and palliative care. It has been necessary to make broad brush assumptions relating to the level and cost of future provision. The cost estimates do however provide an indication of key areas where additional funding will be required 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, and not where the costs will fall.

Workforce development costs, as outlined in section 4.13, are not included in these tables.

Cost estimates are split into two categories: general and supportive care (table 35) and SPC services (table 36).

General and Supportive Care Services

The figure of £68.5 million in table 35 is not the cost impact of implementing the guidance. In the majority of cases the current expenditure on these services 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. These figures are therefore an upper ceiling, assuming that there is no current service provision. However in most networks some level of service provision is likely to exist and these figures are therefore an upper ceiling.

Table 35: Cost Estimates for General and Supportive Care Services (excluding workforce development costs)

GENERAL/SUPPORTIVE PALLIATIVE CARE SERVICES	Cancer Network (£)	England & Wales (£ m)
Co-ordination of Care (Ch.3)		
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 (Ch.4)		
User Expenses	£10,000	£0.3
User Time	£5,000	£0.2
Partnership/User Groups - support for venue costs, publicity, administration	£5,000	£0.2
Partnership/User Groups - support for facilitation	£30,000	£1.0
Face-to-Face Communication (Ch.5)		
Records of consultations	£113,000	£3.9
Professional healthcare interpreters	£18,200	£0.6
Information (Ch.6)		
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)	£104,100	£3.6
Administration (Centre and satellite units)	£41,200	£1.4
Psychological Support Services (Ch.7)		
Psychiatrists (Level 3 / Level 4)	£59,000	£2.0
Psychologists (Level 3 / Level 4)	£76,700	£2.7
Counsellor (Level 3 / Level 4)	£47,200	£1.6
CNS Level 2- work in progress	*N/A*	*N/A*
Social Workers (Level 2) - work in progress	*N/A*	*N/A*
Service overheads - work in progress	*N/A*	*N/A*
Social Support (Ch.8)		
Social Worker: assessments/welfare benefits input	£196,000	£6.8

General Palliative Care (Ch.10)		
Out-of-hours community nursing: palliative care only **	£388,100	£13.5
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 (Ch.12)		
Physiotherapist	£89,200	£3.1
Occupational Therapist	£89,200	£3.1
Dietician	£89,200	£3.1
Lymphoedema Nurse	£25,500	£0.9
Speech and Language Therapist	£31,900	£1.1
Strategic leads for 5 therapy groups	£120,000	£4.0
Families & Carers (Ch.14)		
Family & Carer lead at cancer center	£34,700	£1.2
Family & Carer lead at cancer units	£63,000	£2.2
Supportive and General Care	**£1,972,400**	**£68.5**

* Set up costs - year 1 only .

** Total cost of out-of hours service is £2.6 m for network and £89.8 m for E & W. Palliative care workload assumed to be 15%

New strategic staff posts, such as network leads for 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 networks and therefore the full cost of provision given in the table may be considered to be the cost impact of the guidance.

For information provision, including network directories, networks will vary considerably in their baseline provision of these services and therefore the full cost of provision will over-estimate the cost impact of the guidance.

For psychological support, social support and rehabilitation services cancer networks are already likely to be providing some level of service provision and will therefore not incur the full cost of provision identified. It should be noted that the cost estimates in table 35 incorporate only the supportive and general palliative care component of these service; a significant proportion of the costs for these services will fall under SPC services in table 36.

For out-of-hours community nursing the total cost of service provision in estimated to be £89.8 m for England and Wales. The palliative care component is estimated to be £13.5 m, 15% of the total workload. However it is unlikely that those PCTs without an existing service would be able to implement a 24-hour district nursing service for cancer patients only. An out-of-hours service may need to be implemented for all patients in order for cancer patients to gain 24- hour access. In addition a cost impact analysis, taking into account estimates of current service provision, suggests that the cost impact of implementing out-of-hours provision in PCTs where this service does not currently exist is £33.2 m.

Specialist Palliative Care Services

The figure of £439.1 million is the estimated total cost of providing SPC services in England and Wales and not the cost impact of the guidance. Given that current provision is estimated to be £370 million per annum for England and approximately £19 million per annum for Wales (based on the extrapolation of the estimate for England), this suggests that the cost impact of the guidance for SPC services will be around £50 million per annum.

Table 36: Cost Estimates for Provision of Specialist Palliative Care Services (excluding workforce development costs)

SPECIALIST PALLIATIVE CARE SERVICES	**Cancer Network (£ m)**	**England & Wales (£ m)**
Medical Staff		
Consultants inc out-of-hours cover	£1,222,500	£42.4
Other Medical Staff (incl out-hours cover)	£844,300	£29.3
Nursing Staff		
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 SPC Team		
Social Care Assessments, Welfare Benefits Rights Advice, Counselling, Psychological Support, Care of Families & Carers (inc. bereavement support)	£466,900	£16.2
Administrative support	£581,200	£20.2
Chaplain-Spiritual Care Giver (Spiritual Support Services Chap 8.)	£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: SPC Staff Costs - Direct Medical, Nursing and Extended Team	**£9,564,400**	**£332.1**
B. SPC Overhead Costs	**£3,082,000**	**£107.0**
C. Total Cost of Future Provision (A + B)	**£12,646,400**	**£439.1**
D. Total Cost of Current Provision	**£11,231,800**	**£388.9**
E. Cost Impact (C - D)	**£1,414,600**	**£50.2**

5.3 Limitations and Uncertainties

Given the complexities of service configuration and the lack of data on the volumes and costs of current service provision, it is possible to provide cost estimates of a crude order of magnitude only. The model uses the existing evidence base, where available. Gaps in the evidence base have been filled using expert opinion. In some instances preliminary estimates only can be provided, with areas identified for further work, beyond the scope and timeframe of this project, to allow more robust estimates to be produced.

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

5.3.1 Staffing assumptions

The model is predominantly based on a series of assumptions concerning appropriate staffing levels within different components of a high quality SPC service. In many cases no published evidence was identified on which to base staffing level assumptions. In such cases the assumptions are based on expert opinion.

5.3.2 Estimation of other costs

Other costs for SPC inpatient services and day care services are key contributors to the total cost of SPC provision. Evidence on the appropriate level of other costs was not readily available. Assumptions relating to the proportion of total costs made up by other costs for these services are reliant on one or two examples of current practice. Further detailed work, beyond the scope of this project, would be useful in order to ensure that the current estimates are robust and to explore the extent of possible variation.

5.3.3 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 model between a small SPC inpatient bed unit, say 10 beds and a large unit, 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 the IP 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 be requiring 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 is employed additional staff may be recruited at a more junior grade

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

5.3.4 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 SPC 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.

5.4 Timeframe for implementation

Implementation of the guidance will not be immediate but will take place over the next few years. The speed of change is likely to vary considerably on a local basis, based on a large number of factors including the baseline position of individual network and extent of changes in service structure required to achieve the desired level and quality of service provision. The cost impact of the guidance will therefore build up over the next few years and the total cost impact of implementation will not be experienced for a number of years.

6. Conclusions

The economic modelling work provides an initial estimate of the scale of the cost of providing high quality supportive and palliative care services in England and Wales. The cost estimates are a crude order of magnitude only, allowing preliminary consideration of the scale of cost implications of adopting agreed levels of supportive and palliative care provision.

Appendix 1: Description of the Health Economic Model

The model is based on a hypothetical cancer network. The following characteristics of the network can be defined:

- Population size
- Cancer death rate for the population
- Number of cancer centres
- Number of cancer units
- Number of specialist palliative care (SPC) inpatient units; beds in each and occupancy rates
- Number of SPC home care teams and levels of support provided by these teams (based on hours of service)
- Number of Day Care units and places available in each per week
- Level of SPC outpatient provision
- Level of Marie Curie-type nursing service provision
- Level of bereavement support

For the purposes of this report certain parameters are fixed:

- Network population = 1.5 million
- Cancer death rate = = 2,605 per million
- Cancer Centres = 1
- DGHs/Cancer Units = 4

Service Components

Supportive and palliative care services included in the model are as follows:

- Specialist palliative care (SPC) inpatient bed providers

- Community SPC teams
- Hospital SPC support teams
- Psychological support
- Social support
- Rehabilitation services
- Spiritual support
- Bereavement support
- Care for the dying
- Day care services
- Outpatient services
- Information services
- User Involvement

Staff

For each individual service component the model estimates the volume of clinical staff (nursing, medical and other health professionals) required to deliver the service. Assumptions on appropriate staffing levels were taken from published recommendation where available (e.g. Palliative Care 2000; Cameron Report 1996). Where recommendations were not available advice was taken from a number of palliative care experts.
Staff groups in the model are:

- Medical
- Nursing
- Physiotherapist
- Occupational Therapist
- Social worker/rights advisor
- Counsellor

- Psychiatrist and clinical psychologist
- Dietician
- Pharmacist
- Chaplain/spiritual care giver
- Speech and language therapist
- Lymphoedema nurse
- Administrative support
- Strategic leads for network e.g. supportive and palliative care strategic leads, rehabilitation leads
- Information staff, including network information lead, information managers (based at information centres and satellites)

All staff costs are based on NHS salaries. In general, the mid point of the pay spine per staff type grade is taken as the salary level per professional staff group, unless indicated otherwise.

General palliative care staff including GPs, nursing home nurses, etc are not included with the model.

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