Supportive and Palliative Care 1st Consultation – Stakeholder comments
Date??

National Institute for Clinical Excellence

Organisation	Section Number	Comment	Response from Guideline developers
Association for Palliative Medicine of Great Britain and Ireland		This organisation was approached but did not respond.	
Association of Surgeons of Great Britain and Ireland		This organisation was approached but did not respond.	
Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Breakthrough Breast Cancer		Breakthrough Breast Cancer is a charity committed to fighting breast cancer through research and awareness, in order to obtain our vision . We welcome the opportunity to comment on the draft of this guidance. As an overall comment Breakthrough feels that this first part of the guidance (Part A) is thorough and addresses many of the needs and concerns of women with breast cancer, and we welcome many of the recommendations. However, we are concerned about how the guidance will be implemented at a local level. A high level of standards need to be ensured across the country so that all patients receive the necessary information they require, rapid access to all available treatments, and the best form of support and palliative care that they may wish for.	Noted – covered in text.
Breakthrough Breast Cancer	3. Co-ordination of Care	C.2 Assessment: specific recommendations Some form of assessment should be made throughout treatment and at routine visits, and not just at the key points listed in section 3.14.	Text altered in line with comment.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Breakthrough Breast Cancer	4. Face-to-Face communication	We feel very strongly with the points raised in section 4.4 that there is a real need for good communication skills, and that this is significantly lacking. Mechanisms should be in place to ensure that all health professionals who are identified as needing training are made to do so. Service providers should ensure that all health professionals, who are in a position where they may need to communicate sensitive information, have the necessary qualities.	Addressed in text.
Breakthrough Breast Cancer	5. Information	Patients and carers should also be made aware of how and where they can access the information so that is available to them when they need or require it. Assistance in understanding information should be as unbiased as possible.	Addressed in text.
Breakthrough Breast Cancer	5.20	It would be very helpful if Networks provided supportive / voluntary organisations with the information they recommend to patients and their carers.	This is a local implementation issue.
Breakthrough Breast Cancer	6. Psychological support services	Some form of assessment of psychological well-being should be made throughout treatment and at routine visits, and not just at key points.	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Breakthrough Breast Cancer	7. Specialist Palliative care services	Specialist multi-professional palliative care teams (hospital and community). The palliative care team should also be able to recommend recognised and approved complementary therapies, should this be required.	Comment noted but decision made by Guidance Development Team not to alter text – complementary therapies will be included in Part B.
Breakthrough Breast Cancer	8. General palliative care services.	'NHS Direct is being proposed as the first main contact for all out-of-hours care by 2004.' We feel that NHS Direct is too general for the level of need / care required by cancer patients needing palliative care. Provision should be made for out-of hours access to the palliative care team. Thank you for allowing us to comment and we hope that due consideration is taken to the issues that we have raised. We look forward to seeing the next draft in September of this year.	Addressed in text.
Breast Cancer Care		This organisation responded and said that it had no comments to make.	
British	Section 6	BACP welcome this as a model of good practice. We particularly	Comment noted with thanks.

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Association of Surgeons of Great Britain and Ireland		This organisation was approached but did not respond.	
Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Association for Counselling & Psychotherapy	'Psychological Support Services':	appreciate the accuracy of the reference to counselling and the insistence on trained, supervised and accredited counsellors/psychotherapists, and are pleased that the needs of carers and relatives, and the demands placed upon staff working with cancer patients, are recognised.	
British Association for Counselling & Psychotherapy	Section 6 'Psychological Support Services':	There is mention of 'an explicit theoretical framework' and BACP would be interested in examining such a framework or collaborating its development if it is not already in existence.	This refers to the specific training/psycho-therapeutic approach taken by the professional.
British Association for Counselling & Psychotherapy	Section 6 'Psychological Support Services':	We have no negative comments to make - other than to mention that many counsellors are also Cognitive Behavioural Therapy (CBT) practitioners and often incorporate such techniques into an integrated approach in their counselling. BACP look forward to the second consultation in September 2002.	Comment noted.
British Association for Nursing In Cardiac Care		I notice that the manual has been prepared for the supportive and palliative care for people with cancer. However, the needs of people for supportive and palliative care for non-cancer, also requires addressing, although this may be outside the scope for	Outside the scope of the Guidance which is specifically for people with cancer – while acknowledging that the recommendations may impact on others with chronic disease.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		this document. Representing the British Association for Nursing in Cardiac Care, it is important to highlight that such services are required for the person with heart failure and perhaps it was our error to register as stakeholders for a document that is specific to the person with a diagnosis of cancer.	
British Association for Parenteral & Enteral Nutrition (BAPEN)		We were pleased – as stakeholders – to have had the opportunity to review the draft version of Part A of the Supportive and Palliative Care Guidance document, on behalf of the British Association for Parenteral and Enteral Nutrition. Unfortunately we were less happy when we read the document, as there appears to be no attention given, at any point that we could identify, to the importance of nutrition and nutritional support to this vulnerable group of patients. Clearly there are many other important concerns with the incurable and ultimately dying patient, but it is our experience that eating and drinking (and difficulties therein) come high in the priorities of many patients and their carers. Additionally there are some very complex ethical issues around the question of artificial	This will be covered in Part B of the Guidance.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		nutritional support in the palliative care patient population. These issues have attracted a great deal of attention in the professional and lay media and we were surprised that they are neglected in your first draft. We should be happy to identify source materials and individuals who could help you redress these important omissions.	
British Association of Head and Neck Oncologists		This organisation was approached but did not respond.	
British Committee for Standards in Haematology		This organisation was approached but did not respond.	
British Dietetic Association		The overall feeling is positive, we welcome the guidance. Many of the comments that follow are supporting and emphasise the important aspects from the point of view of dietitians. The sections are listed as in the document.	Thank you for your comments.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
British Dietetic Association	2. Background 2.13	It is useful to define and explain supportive and palliative care. It is of concern that additional training and qualifications are not easily accessible for dietitians. Higher degrees are often nurse orientated, courses need to be developed on broader basis.	Comment noted but decision made by Guidance Development Team not to alter text.
British Dietetic Association	2.13	(N.B. 'Dietitian' has been misspelt)	Spelling altered
British Dietetic Association	2.18	Questionnaire results of what patient and carers want from services need to be widely disseminated; all health professionals in general as well as specialised services would benefit from this insight.	Comment noted but outside scope of Guidance.
British Dietetic Association	2.22	There are deficiencies in the dietetic service available nationwide. The outcome is that many patients needing advice are not receiving it and the timeliness and quality of care of others is below the standards we would like to see.	Noted. This will be addressed in Part B of the Guidance.
British Dietetic Association	3. Co-ordination of care. 3.11	A unified assessment tool will be welcomed as long as services are consulted on their own aspect and guidelines on referral are linked to results from assessment.	For local implementation and decision re. assessment tool
British Dietetic Association	3.16	Agreed guidelines on referral to all disciplines are essential and particularly useful for services like Dietetics where resources are	Noted – a theme within the text.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		so limited.	
British Dietetic Association	3.17	Telephone access-points need to be carefully organised and personnel highly trained to recognise its limitations and to clearly apply agreed protocols.	Implications of introducing telephone access point are acknowledged, hence text suggests ‘consider’.
British Dietetic Association	3.22	We support the statement that an individual such as a therapist should be nominated to lead co-ordination for individual patients. This task need not rest solely on nursing staff.	Comment noted with thanks.
British Dietetic Association	3.24	There is a need for medical staff to have a clear understanding of the nature of multi-professional teams/meetings. These are too often accepted as being solely made up of doctors of different disciplines. Treatment plans are often medically orientated rather than holistic in approach.	Beyond scope of Guidance.
British Dietetic Association	4. Face-to-face communication. 4.17	The environment in which communication takes place should be emphasised - privacy and limiting numbers of people present is also key.	Comment noted and addressed in text.
British Dietetic Association	4.19	Summaries of key points of consultations are a routine part of dietetic practice and one which we believe should be widely adopted by other professionals.	Noted – but outside the scope of the Guidance.
British Dietetic	5. Information.	It is the aim of all Dietetic Services to provide written information	Addressed in text.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Association	5.5	of appropriate level and high quality to patients. Poor resources are a stumbling block. Much misleading and in some cases dangerous information about diet exists on the Internet. All professionals need to have skills in assessing information needs and preferences.	
British Dietetic Association	5.6	Availability of information and assistance to understand it is vital but it is important to recognise the possibility of information overload.	Addressed in text.
British Dietetic Association	5.20	A lead on information may help prevent excessive and contradictory information being made available locally.	Addressed in text.
British Dietetic Association	6. Psychological support services.	We do not feel competent to comment on much of this section.	
British Dietetic Association	6.19	It is essential that professionals understand their own limitations and that boundaries of care are clear. Validated screening tools should be used.	Local implementation point.
British Dietetic Association	6.20	Appropriate routine support for all professionals should be encouraged e.g. clinical supervision. In our experience there are huge gaps in support available to staff.	Text clarified.
British Dietetic	7. Specialist	We agree that specialist services have an important function in	Thank you.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Association	palliative care services.	education and training of generalists. This must have a high profile.	
British Dietetic Association	7.13	There are no standards of service provision for Dietetics. This is unhelpful in making a case for the service or for ring-fencing time.	This is outside the scope of the Guidance.
British Dietetic Association	7.24	We endorse the range of specialist expertise listed and would add Speech and Language Therapy. Sadly unless staff are full time members of the team or operate on ring-fenced time they cannot be expected to develop the expertise required.	Text altered in line with comment.
British Dietetic Association	8. General palliative care services.	We endorse this section. Access to paper medical notes out of hours can be problematic. IT investment is needed to facilitate records. Shared notes (by all professionals involved) and patient held records should be explored. From experience we find resuscitation status is often unclear.	IT issues outside the scope of the Guidance but comment regarding shared notes covered in text.
British Dietetic Association	8.41	Care pathways should be developed and agreed by Cancer Networks.	Comment noted but decision made by Guidance Development Team not to alter text.
British Geriatrics Society – Special Interest group in		This organisation was approached but did not respond.	

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Diabetes			
British Liver Trust		This organisation responded and said that they have no comments to make.	
British Lung Foundation		This organisation was approached but did not respond.	
British Medical Association		This organisation responded and said that they have no comments to make.	
British National Formulary (BNF)		This organisation was approached but did not respond.	
British Oncology Pharmacy Association	2. Background	General typographical error: There appears to be no section B? Sections go straight from A to C.	Text altered in line with comment.
British Oncology Pharmacy Association	3. Co-ordination of care B. Objectives 3.8	To ensure that care is from as few professionals as possible, perhaps bullet no. 3 should read, "Care provided by an optimum number of providers in different locations is seamless yet non-overlapping from the perspective of patients and carers"	Text altered in line with comment.
British Oncology Pharmacy Association	3.9	With reference to the statement in bullet no. 7, we would envisage that the Government's plans for the electronic patient record (EPR) will make a significant impact on the development of	Beyond scope of Guidance.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		systems aimed at presenting up to date clinical information on patients and carers. Targets by the Government focus on 35% of all NHS acute Trusts having instigated an EPR to level 3 by the end of 2002, and all acute hospitals by 2005. Any foundations made now by palliative and support care networks should future-proof themselves by considering the impact the EPR initiative will have on other systems that may be considered for disseminating patient information between health and social care professionals. Perhaps energies would be better channelled to developing this one system than several other, less durable "paper/hard copy" systems that would inevitably become redundant or add to inconsistencies in the continuity of information transfer were they retained to run parallel to EPR. This comment applies to several other sections throughout section 3, particularly with respect to co-ordination of services within and between teams, which will obviously rely heavily on a durable information transfer system.	
British Oncology	C.	Related to the comments above, the unification of an assessment	Beyond scope of Guidance.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Pharmacy Association	Recommendations C2 Assessment: specific recommendations 3.11	tool could be easily facilitated by building a suitable template within an EPR software specification. Assessment criteria and results could then be available to a range of health and social care professionals. Access rights could be incorporated to define those professionals suitable to perform all or only parts of the assessment tool. Read-only rights would then allow access by those professionals who require the data to proceed with the patient's therapeutic intervention(s) along their cancer journey.	
British Oncology Pharmacy Association	3.14	In addition to the assessment points mentioned it may be appropriate to allocate assessment "throughout the course of treatment" in addition to the beginning and end. Many treatments are inherently symptomatic and can lead to quite distressing adverse drug reactions if left unattended to. Many are resolvable with effective medications i.e. nausea and vomiting, diarrhoea, or reductions to existing anticancer doses. Left unattended these symptoms my lead a patient to express a change to the course of their treatment, and one which may adversely effect their symptom free survival, autonomy and overall prognosis. Often patients will be reluctant to bring such symptoms the attention of	Text emphasises these points are a minimum, but it does not negate the value of assessments at other times.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		the clinician through fear of stopping or reducing a life-saving treatment. Some nurse-led clinics result in the patient not being required to see the clinician for extended treatment intervals. Consultation periods may also be rushed and the patient may not want to burden the clinician with such “minor problems” and that they usually associate with the cancer drugs working properly. We would suggest that specialist pharmacists and nurses be best qualified to probe for these adverse symptoms. They spend comparatively longer with the patient as they receive their treatment and can take time to question the patient appropriately. Any intervention may then be facilitated further by the advent of dependant prescribing. Either nurse or pharmacist can then work within defined group directives to instigate or adjust certain therapies e.g. anti-sickness medication / diary card schemes, mouth care treatments etc.	
British Oncology Pharmacy Association	3.18	Presumably this role may be taken on by NHS Direct. This service is now well publicised which would facilitate introduction of the service.	Beyond scope of Guidance at this time.
British Oncology	4. Face-to-face	In addition to stating persons whose first language is not English	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Pharmacy Association	communication Introduction 4.4	additional comment needs to draw reference to the requirements of different cultures during and after death. Some culture's physical outpouring of grief around the bereavement process requires extreme skills in communication that must not be underestimated or ignored.	
British Oncology Pharmacy Association	C2 Service configuration and delivery: specific recommendations 4.17	We would suggest that in cases of breaking bad news, with the experienced clinician and certainly the inexperienced clinician, provision should ensure that an experienced second health and social care professional is available within the consultation. This allows better support for most eventualities that can occur in such an acute situation, providing a “back-up” to the breaker of the news. Patients may often find a second attendee (and one which they may know and relate to better from earlier and more regular encounters in their cancer journey) comforting and more empathetic to their needs at that point in time.	Text altered in line with comment.
British Oncology Pharmacy Association	4.22	In addition to that stated, provider organisations should ensure suitable services for people with learning disabilities, as well as the children or grandchildren of the dying patient.	Text altered in line with comment.
British Oncology	5. Information	5.10 general typographical error: “Box 3.1” should read “Box 5.1”	Text altered in line with comment.

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Pharmacy Association	C. Recommendations C.2 Service configuration and delivery: specific recommendations 5.11	Any paper-based information materials should be strictly controlled documents. Effective control logging of their distribution and retrieval, coupled with copyrighting restrictions should ensure only updated procedures and guidance are available by this format, and that rapid withdrawal of expired information follows immediately after any review / update.	
British Oncology Pharmacy Association	5.18	The population aimed at should also include children or grandchildren of the dying patient.	Text altered in line with comment.
British Oncology Pharmacy Association	6. Psychological support services C. Recommendations C.2 Service configuration and delivery: specific recommendations 6.16	An effective drug history analysis should be included as one of the interventions that may be most appropriate to a patient's needs. Specialist pharmacists should therefore be considered as the most appropriate healthcare professional identified in the service provision guidelines for this purpose, and should be accessible by any professional situated in levels 1-4 of the model proposed. Most cancer patients receive polypharmacy. Whilst many of their drugs act directly on or via the CNS for their effect, this can lead to troublesome adverse drug reactions, which can	Comment noted but decision made by Guidance Development Team not to alter text.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		initiate or worsen existing CNS morbidity.	
British Oncology Pharmacy Association	Table 6.1.	There is a logical extension to include pharmacists as one of the health groups that might be trained to be involved at level 1. Better psychological care could reduce the need for CNS medication in-patients who are often already taking a variety of drugs, many of which will have some or all of their effect in the CNS. Side effects from these drugs are often troublesome.	Included as health care professionals.
British Oncology Pharmacy Association		Pharmacists (both in hospital, hospice and in the community) are often involved in giving information about medicines to patients and carers but should be able to respond more effectively to patients' questions and identify those questions that could lead to issues affecting that patient's cancer journey. The pharmacist would then need to be able to pass onto the cancer team such concerns and respond to the patient or carer in a sensitive and appropriate manner.	Comment noted but decision made by Guidance Development Team not to alter text.
British Oncology Pharmacy Association	7. Specialist palliative care services C.	Clarify the statement: Presumably, eligibility criteria refer to the criteria used to make a patient eligible for referral? These should be agreed network-wide.	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
	Recommendations C.1 Overview 7.12		
British Oncology Pharmacy Association	7.14	Bullet no. 1 should include mention of providing ease of access to specialist devices and medications for patient in all locations.	Comment noted but decision made by Guidance Development Team not to alter text.
British Oncology Pharmacy Association	7.24	We would lay particular emphasis on the role of the pharmacist in the multidisciplinary team. Unnecessary and inappropriate medication can complicate drug regimens, increase the risk of clinically important adverse drug reactions and drug interactions and decrease the individual's quality of life in their remaining days. We are able to make early contributions to more effective treatment by recommending alternative products and dose forms where necessary. Pharmacists are also aware of other sources of unusual or difficult to obtain drugs and dose forms both nationally and internationally.	Comment noted but decision made by Guidance Development Team not to alter text.
British Oncology Pharmacy Association	7.24	In patient palliative care in NHS hospitals is, as previously noted in the report, particularly poor and better use of existing staff who are trained and experienced as part of the MDT can only help to	Outside the scope of the Guidance.

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		improve patient care whilst national responses to the dearth of specialist registrars are considered. The availability of dependent prescriber status to nurses and pharmacists from March 2003 can help patient care by working with care plans and care pathways. The (at the time of writing undefined) training programme should emphasise prescribing for symptom control in palliative and terminal care for this purpose. Those universities already offering programmes in palliative care for doctors should consider extending their client group to other professions active in palliative care and perhaps become part of the workforce confederation funding plans nationally. Additionally, the advent of dependant prescribing for both pharmacists and nurses will forge working relationships in cancer care even closer than they already are. Pharmacists will be required to part-authorise all group directives. Taking on this prescribing role, their immediate access to both the patient and medications within directives, particularly in the community would allow a valuable pooling of skilled resources. Combined, this could make a strong case for pharmacists assuming a more valid	

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		position within the core member team.	
British Oncology Pharmacy Association	7.24	Should the list of specialist access include "oncology" as per the list in 7.31?	Text altered in line with comment.
British Oncology Pharmacy Association	8. General palliative care A. Introduction	Community pharmacists are an integral part of the primary health care system. Patients and carers regularly visit community pharmacies and in rural or suburban areas families are well known to the pharmacist. Most community pharmacies use medication records.	Comment noted but decision made by Guidance Development Team not to alter text.
British Oncology Pharmacy Association		Where medicines (including complementary therapies) are bought and prescription medicines supplied then this information should be available to be shared with the cancer team. Medicines bought over the counter may be an indication of a changing symptom pattern and this could be important information for the overall care. Community pharmacists should be part of the MDT in the community but need further education to help their activities. The Centre for Postgraduate Pharmacy Education (University of Manchester) has a distance learning pack that is useful but needs updating. There is evidence that a sound education programme	Comment noted but decision made by Guidance Development Team not to alter text.

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		increases confidence and changes behaviour amongst community pharmacists in palliative care (Colin Hardman, Lincoln County hospital pharmacy department. Unpublished data 1986).	
British Oncology Pharmacy Association	8.7	Many systems are used to improve access to medicines for palliative care out of hours. Where controlled drugs are supplied (especially the range of diamorphine strengths needed for syringe drivers) some of the systems are almost certainly illegal. Colleagues in Grantham, Lincolnshire have been in correspondence with the Royal Pharmaceutical Society of Great Britain and the Home Office for many months to produce a legal supply system. They hope to have a final opinion this year and when available the information and guidance will be made public. Access to controlled drugs (CDs) out of hours is a general problem. However, adequately trained staff can plan a patient's likely requirements for most overnight and weekend periods, ensuring suitable prescription of CDs with PRN dosing, or syringe drivers with dose ranges are met with enough supply of medications on site for carers or district nurses to administer.	Text altered to reflect comment – and working group established at DoH to address these issues.

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Organisation	Section Number	Comment	Response from Guideline developers
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Association of Surgeons of Great Britain and Ireland		This organisation was approached but did not respond.	
Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		Specialist guidelines on site and access to other specialist resources out of hours will help inexperienced staff and supplement any training they should be getting in caring for these patients. Although there will always be exceptions to this, adequately trained staff working within the improvements proposed throughout section 8 will reduce the incidence of problems arising. In some areas problems are faced getting access to specialist palliative care medicines within hours. These are often syringe driver admixtures that are considered less common on the high street chemist shelf. This is particularly so for intravenous opioids, mostly argued on a security basis. Many areas now run schemes whereby dedicated chemists agree to hold a limited stock of these drugs, and which are known to community palliative care teams. Additionally some areas encourage stock rotation with high user centres i.e. local hospices that can guarantee use of expiring stock from a community source, replacing it with longer expiry material.	

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		It would be worthwhile to consider supply initiatives that would allow access to specialist medications, particularly CDs from high user centres. This would be both within and outside normal hours and could guarantee the stock was available and in the quantities required which, for CDs, can often not be the case in the community setting. Whilst improving patient care, any such initiative would improve the current security burden placed on the community pharmacy holding stocks of intravenous CDs.	
British Oncology Pharmacy Association	C. Recommendations C.2 Service configuration and delivery: specific recommendations Community-specific issues.	There should be some statement that proposes systems are in place that encourages the prompt removal and appropriate depositing of medications no longer required, either following change to therapy or patient death. This is particularly relevant for CDs.	Text altered to reflect comment – and working group established at DoH to address these issues.
British Psychological Society		This organisation was approached but did not respond.	

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
British Psychosocial Oncology Society		I would like to congratulate the team on the effort and commitment shown in what must have been a difficult and complex task. As ever when commenting on such a document there is an emphasis on disagreements and differences, but I would like it noted that I am in broad agreement with the vast majority of the Draft. The fact that I have been so detailed in my comments reflects the importance that I give to the topic and the fact that this represents a golden opportunity (and probably the only opportunity) that we have to get this right for patients, carers and relatives. I have not commented on Chapters 7 and 8 as I feel that they are outside of my area of expertise.	Thank you for your comments.
British Psychosocial Oncology Society		Much of this strategy applies throughout medicine. Perhaps there is an opportunity to identify it as a model of good practice for all medicine.	Thank you.
British Psychosocial		I am unhappy about the frequent and automatic linking together of supportive and palliative care. They are different and what may	Comment noted but decision made by Guidance Development Team not to alter text.

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Oncology Society		apply to one does not necessarily apply to the other. Whilst it might make to document slightly more cumbersome, identifying what is unique and what is common might help. The document already does this by having two separate chapters on palliative care.	
British Psychosocial Oncology Society		Without wishing in any way to be personally critical of members of the Editorial Board I am very disappointed that of the 17 members, six are explicitly in palliative care posts. There is no more than one member of any other grouping either lay or professional. This represents an imbalance which, I believe, undermines the supportive care element of the strategy. There are a large number of people involved in supportive care who would have been more than willing to contribute to this important endeavour.	The Editorial Board is not constituted to be representative of different professional groups. Other relevant experts are requested to input as required and as appropriate.
British Psychosocial Oncology Society		I am on record as noting that supportive care is a term which I believe is unhelpful, despite its widespread use. One of its common uses - as in the phrase best supportive care - (to the control arm in trials of chemotherapy for advanced cancer) as meaning 'normal' care simply does not reflect the breadth or the	Comment noted but decision made by Guidance Development Team not to alter text.

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		depth of this multi-professional, multi-disciplinary exercise. Its other use is a definition both by exclusion (everything that is not surgery, radiotherapy or chemotherapy) and inclusion (everything else) is ill-focussed. It also feels to be a weak word implying that it is little more than being a friendly kind individual who communicates well. What is wrong with a stronger phrase such as psychosocial care? This phrase is well established, is not profession-specific and ties the concept into two important realms of people's lives - the psychological and the social. To argue that any word beginning with the letters '..psyc..' is off-putting no longer holds water. All sorts and conditions of groups and individuals happily use a variety of such words without alarming or alienating potential and actual recipients of such services. You will note that I have used the phrase psychosocial care throughout my detailed comments as it reflects my strongly held view that any other term is actually devaluing of the work that psychosocial workers do and the professional service that I aim to give.	
British Psychosocial		Whilst on the subject of nomenclature, I have another serious concern with the phrase 'The Cancer Journey'. Apart from the	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Oncology Society		inappropriate use of the definite article (it cannot be the journey, only a journey) the whole idea of a journey seems misplaced. A journey often has a defined start and end, clear direction and is undertaken for a particular purpose. None of these apply to the person living with cancer. It is more Virgin Trains or Connex South East than Orient Express. It is uncomfortable, frightening, unpredictable and undertaken unwillingly. There is an additional aspect that alludes to an almost spiritual sense of 'passage' and 'growth'. I would support the idea that this can and does happen frequently, but this is an epiphenomenon of the illness, not its purpose. Again, I understand that this is common phraseology (particularly amongst cancer professionals) and the number of alternatives is limited (trajectory - too militaristic; experience - too mild) but I would suggest that this is an opportunity for being proactive and radical (as with the term supportive care). I wonder whether the user groups may have a view on this? I would be happy to be guided by their views in this. I would add that I do not believe that this is mere pedantry or some convoluted form of political correctness. Language is a powerful determinant of how we see and deal with people - how many people with cancer like	

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		being called a 'cancer victim', for example? Words matter because of the meaning and concepts that are associated with them. If we believe in a service that really values and respects people, then our language and terminology must reflect that belief.	
British Psychosocial Oncology Society	3/1.3	Why is there no commitment for developing draft National Standards for Supportive Care paralleling that for Palliative Care (bullet point 6)?	Covered in text – standards will be derived for all aspects of care covered by the Guidance.
British Psychosocial Oncology Society	4/Box1.1	The needs of children are clearly important and appropriate services need to be accessible to them. I cannot find further reference in the document to this. In view of the inappropriateness of referring such children to CAMHS Teams is there a need for some further comment here. I would suggest that consulting with expert groups in child development (rather than child pathology) would be helpful.	Will be included in Part B.
British Psychosocial Oncology	6/1.11	The lack of information concerning resources and measurement is disappointing. To have to wait until the final round of consultations seems to be adding an unnecessary delay	This relates to the guidance development process rather than content - it will be included when parts A and B are combined.

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Society		especially when trying to integrate with financial and business planning system. This will benefit from wide early consultation.	
British Psychosocial Oncology Society	7/1.18	In order to avoid checkbox standards that have limited utility, I would suggest that some effort is put into consulting with a variety of different professional and user groups about developing meaningful standards that can be assessed by a variety of different people.	Beyond the scope of the Guidance.
British Psychosocial Oncology Society	7/1.19	The phrase starting 'encouraged to' in sentence 2 is difficult to follow.	Text altered in line with comment.
British Psychosocial Oncology Society	9/2.2	Suggest phrase 'people with cancer' as being more inclusive that 'patients with cancer' especially in view of the statistic quoted in 2.1.	Change made where appropriate throughout text.
British Psychosocial Oncology Society	9/2.4	Include words 'and treatment' after 'the effects of the disease'	These are quotes from another source.

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British Psychosocial Oncology Society	9/2.4	Suggest use the phrase 'integrated with' rather than 'equal priority alongside'.	These are quotes from another source.
British Psychosocial Oncology Society	9/2.5	I find this paragraph verges on the pious and sentimental and almost impossible to operationalise (thinking of evaluation). I would strongly recommend that it is omitted entirely.	Text altered in line with comment.
British Psychosocial Oncology Society	10/2.6	This omits entirely any idea that psychosocial care might be based on any thing other than some feelgood approach to care. There are strong theories, models and data which underpin psychosocial care. To omit such a linkage will maintain the idea that supportive care is just about being kindly.	Text altered in line with comment.
British Psychosocial Oncology Society	10/2.9	This paragraph starts by talking about 'these definitions' and then goes on to talk only about palliative care.	Text altered in line with comment.
British Psychosocial	10/2.10	The bullet points apply to psychosocial care as well as to palliative care.	Agreed – 'supportive' includes 'psychosocial'.

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Oncology Society			
British Psychosocial Oncology Society	10/2.11	I would question whether the principles of psychosocial care and palliative care are broadly the same. This is an opinion which needs to be justified. There are clearly similarities between the two and some overlap, but that is as far as it goes.	Contradiction to point made above – this table identifies the salient differences between the two approaches to care.
British Psychosocial Oncology Society	11/2.11	Patients and relatives will also need access to well-defined areas of expertise within psychosocial care. Why be specific about one and not the other?	Comment noted but decision made by Guidance Development Team not to alter text.
British Psychosocial Oncology Society	12/2.13	Why use 'supportive care' in line 1 and then 'palliative and supportive care' in line 6?	Text altered in line with comment.
British Psychosocial Oncology Society	12/2.13,2.14	There are some professional in psychosocial care (such as myself) who would regard themselves as specialists. Certainly there is a hope in both clinical psychology and psychosocial oncology to develop a proper training and CPD programme to allow people to work effectively in this area.	Specialist is defined throughout the Guidance as someone with training and/or experience in a particular field.

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British Psychosocial Oncology Society	12/2.15	I welcome the inclusion of the role of the non-statutory sector.	Thank you.
British Psychosocial Oncology Society	13/2.16	Why specify fear and anxiety? Why not a more global term psychological or emotional distress which recognises a range of responses. The connotation of specific terms can too easily lead to psychiatric labelling.	Text altered in line with comment.
British Psychosocial Oncology Society	13/2.17	Suggest words 'experiences....' rather than the phrase 'emotions and symptoms'.	Text altered in line with comment.
British Psychosocial Oncology Society	14/2.18	This is very helpful.	Thank you.
British Psychosocial Oncology	15/2.21	I would mention the important work of the Cancer Collaborative here. Personally I would strengthen the statements on reducing the psychological iatrogenicity of the system as a key element of	Text altered in line with comment to include this.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Society		this strategy.	
British Psychosocial Oncology Society	15/2.22	Yet another identification of gaps in palliative care services (bullet point 5) with no equivalent note about lack of specialist psychosocial services.	Text altered in line with comment.
British Psychosocial Oncology Society	16/2.29	Generally a helpful statement (but see later comments about organisation).	Thank you.
British Psychosocial Oncology Society	18/3.4	What evidence is there that there is a lack of co-ordination of psychosocial care? My experience suggests that the problems in this area relate to a lack of resources rather than their organisation. I would agree that lack of organisation of the system causes psychological distress, but that does not necessarily apply to the organisation of those specific services.	Supported by CHI/AC audit.
British Psychosocial Oncology Society	18/3.5	I would like to see evidence of any unnecessary duplication of psychosocial services, as this is not my experience in the service delivery settings in which I and similar colleagues work.	Sentence does not imply reference to any particular domain of care. No change made to text.

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British Psychosocial Oncology Society	18/3.6	How will planning and organising psychosocial services better lead to better assessment of patients' needs? Surely that is a training issue?	Text altered in line with comment.
British Psychosocial Oncology Society	19/3.7	In view of my initial general comments I would want to see a proper balance between psychosocial care and palliative care in such a group.	Noted - but beyond scope of Guidance.
British Psychosocial Oncology Society	19/3.11	Excellent.	Thank you.
British Psychosocial Oncology Society	20/3.12	I don't think it helpful to link supportive and palliative care in this way. They may need differing elements.	Comment noted but decision made by Guidance Development Team not to alter text.
British Psychosocial Oncology	20/3.13	Proper formal training is absolutely essential.	Stressed in text.

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Society			
British Psychosocial Oncology Society	20/3.14	In general I agree, but there will be particular issues of confidentiality that need to be addressed [see comment on paragraph 6.23]	Text altered in line with comment.
British Psychosocial Oncology Society	20/3.16	Referral must be discussed with the patient and agreed with them.	Text altered in line with comment.
British Psychosocial Oncology Society	21/3.18	I am unsure as to what the actual need is for a 24/7 service. I understand that one or two groups have set this up and is has had to close because of lack of use. Has CancerBACUP or any Macmillan Centre any data on this? I query it as it has enormous resource implications.	Will be covered in economic review – and user representatives considered this to be essential.
British Psychosocial Oncology Society	21/3.21	I am not clear about what record is being referred to here. Is this a unified record for each patient or is the psychosocial one a separate entity?	‘Record’ is a verb in this context not a noun.
British	21/3.24	There will be enormous resource implications in attending all	Noted - but not suggesting that everyone need

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Psychosocial Oncology Society		MDTs.	be present. Teams have to find ways of sharing information.
British Psychosocial Oncology Society	22/3.33	This could be made stronger in that the word 'will' be substituted for 'are likely to' (line 5) and 'essential' for 'warranted' (line 7).	Text altered in line with comment.
British Psychosocial Oncology Society	25/Chapter 4	I think this whole chapter is a very helpful and well written one.	Thank you.
British Psychosocial Oncology Society	25/Title	Why not use the term 'Interpersonal communication' throughout as the whole process letters; phone calls etc should be included?	Noted – principles apply to all forms of communication.
British Psychosocial Oncology Society	25/4.3	replace 'empowering' with 'enabling'	Text altered in line with comment.

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British Psychosocial Oncology Society	25/4.4	Insert 'Good' at the beginning of the paragraph.	Text altered in line with comment.
British Psychosocial Oncology Society	26/4.7,4.14	I am not sure of the meaning of the phrase 'need for face-to-face communication'	Phrase deleted.
British Psychosocial Oncology Society	26/4.9	Include the word 'trained' Is this the point to note that significant amounts of such activities take place outside of the oncology team. There needs to be some mention of the fact that oncology units/centres often have to pick up the pieces of appallingly bad communication in the primary and secondary sector.	Text altered in line with comment.
British Psychosocial Oncology Society	26/4.10	Replace the word 'should' with the word 'must'	Comment noted but decision made by Guidance Development Team not to alter text.
British Psychosocial	26/4.12	Why list these particular people? There are many possible people that could be accessed including other healthcare professional	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Oncology Society		and volunteers.	
British Psychosocial Oncology Society	27/4.17	Whilst I understand what is being got at here the way is it presented could be very undermining of junior staff. It also assumes seniority and better skills always go together - my experience suggests that this may not always be the case.	Text altered in line with comment.
British Psychosocial Oncology Society	27/4.22	Include people with cognitive/intellectual deficits [see also 5.18]	Text altered in line with comment.
British Psychosocial Oncology Society	27/4.23	Support the idea of accredited training course. Where are these? Who accredits and how?	Work being done on this outside the scope of the Guidance at this point in time.
British Psychosocial Oncology Society	28/4.25	This statement is important but is it the intent in the final document grasp the nettle of what to do with 'untrainable' poor communicators, some of whom may be senior clinicians? Whilst this is an enormously difficult issue, there is an opportunity here to underline the critical importance of competence communication	Text altered in line with comment.

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		as being as least as important as all the other clinical skills the effective performance of which are essential for continuing practice.	
British Psychosocial Oncology Society	30/Chapter 5	I think this whole chapter is a very helpful and well written one.	Thank you.
British Psychosocial Oncology Society	31/5.11	There seems to be potential for conflict and duplication between what is expected locally and what is done nationally (see 5.6, 5.8, 5.9). There is a danger that there will be much unnecessary work unless it is made very clear who does what.	Text altered to clarify roles and responsibilities.
British Psychosocial Oncology Society	32/5.12	Why specify the CNS here? Whilst s/he may be appropriate there may be others (see, for example, para 5.20). There is also the problem that in many areas the CNS already has a massive workload.	Text altered in line with comment.
British Psychosocial Oncology Society	32/5.14	Why use the word 'trained' here and not elsewhere when referring the health and social care professionals? And in what should they be trained?	Text altered in line with comment.

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British Psychosocial Oncology Society	32/5.15	Consider the use of properly trained and supported volunteers.	This will be considered in Part B of the Guidance.
British Psychosocial Oncology Society	32/5.17	This would be very expensive and difficult to do at a local level. There are major difficulties in translating especially when the languages share neither words nor concepts. Is there a role for a national initiative here?	Text altered in line with comment.
British Psychosocial Oncology Society	32/5.18	See comments under 27/4.22. [In my copy, Chapter 6 starts with a new page 1, hence the re-numbering.]	
British Psychosocial Oncology Society	1/6.1	Are these data correct? Recent studies have shown lower levels of distress. Also, I think there needs to be a comment about transient, 'normal' distress. We need to challenge the idea that tears in outpatients is a diagnostic index for a psychiatric disorder or even psychological distress that requires specialist attention.	Text altered in line with comment.
British Psychosocial	1/6.2	Delete the word 'may' (line 1).	Text altered in line with comment.

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Oncology Society			
British Psychosocial Oncology Society	1/6.3	This paragraph has a very pathological/medical orientation when it uses words like morbidity which implies illness. What's wrong with the word distress?	Text altered in line with comment.
British Psychosocial Oncology Society	1/6.4	Suggest that you could make a recommendation that the psychosocial professionals must work toward getting agreement on who does what. We have started doing this locally and it is proving an essential process for workforce planning.	Text altered in line with comment.
British Psychosocial Oncology Society	1/6.4	Does it follow that lack of co-ordination means that services are not available? Surely there is a problem of actual availability?	Text altered in line with comment.
British Psychosocial Oncology Society	2/6.5	Omit the words 'facing difficult circumstances' (bullet point 2).	Text altered in line with comment.
British	2/6.6	Insert the phrase 'at least' between 'at' and 'all'.	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Psychosocial Oncology Society			
British Psychosocial Oncology Society	2/6.9	Whilst I am in favour of having accessible services, a 24/7 emergency service will be enormously resource intensive. Could I suggest that this merits some further research so that we can plan according to data rather than supposition? A short-term audit of a number of services over a 6-month period would give enough data to begin to make sensible decisions.	Noted – beyond scope of Guidance.
British Psychosocial Oncology Society	2/6.10	Please delete the word 'convivial' - it implies happy socialising Jovial and festive in my dictionary). The surroundings could be 'peaceful or calming'. However, privacy and quiet would be more than adequate.	Text altered in line with comment.
British Psychosocial Oncology Society	2/6.12	Delete the word 'unmet' (line 6).	Text altered in line with comment.
British Psychosocial	3/6.14	This is a helpful model, but I would suggest that it is made clear that there will be some overlap between the levels and that they	Text altered in line with comment.

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Oncology Society		are not rigidly definable boundaries.	
British Psychosocial Oncology Society	3/Table 6.1	I am very unhappy with the phrase 'counselling and simple CBT' (level 3). First some would argue that there is a real and necessary distinction between counselling and therapy. Second, what is simple CBT as opposed to complex CBT? Third, why specify simple CBT and not simple IPT or Solution-Focussed Therapy, for example? The phraseology runs the risk of reducing a coherent, structured and evidence-based approach to a simplistic 'cook-book' of techniques.	Text altered in line with comment.
British Psychosocial Oncology Society	4/6.17	There should be some reference to the balance between patient preference and professional advice. In this area people may have relatively little experience and information on which to base their judgements.	Comment noted but decision made by Guidance Development Team not to alter text.
British Psychosocial Oncology Society	4/6.18	The word adjustment has all sorts of unhelpful connotations and implies a norm to which patients ought to aspire. It also leads onto the idea of an 'adjustment disorder' thus both reifying and pathologising what may be a human, normal and understandable reaction to a life-threatening event. Suggest that the word 'state' is	Text altered in line with comment.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		substituted.	
British Psychosocial Oncology Society	5/6.20	See comments on 2/6.9.	Outside the scope of the Guidance.
British Psychosocial Oncology Society	5/6.21	Delete the word 'made'.	Text altered in line with comment.
British Psychosocial Oncology Society	5/6.23	There is an important issue of confidentiality here. Patients may reveal highly personal and sensitive information which they may not wish to be shared and which is unlikely to affect their overall care. I suggest that some phrase about 'professionals must ensure that they follow their professional guidance on issues regarding confidentiality' could be used. There may need to be an agreed, formal process within teams about managing sensitive and private issues.	Text altered in line with comment
British Psychosocial	6/6.27	Suggest a recommendation is made concerning the need for a systematic approach to training - possibly accredited.	Text altered in line with comment.

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Oncology Society			
British Psychosocial Oncology Society	6/6.31	Being completely pedantic, the model of levels of intervention is not strictly novel. Similar models have been used in the MAS review of the future of clinical psychology and in the NHS review of psychotherapy services. There is also a good deal of information available on training of nurses in psychological intervention techniques ranging from relaxation to therapy (including some in cancer).	Text altered in line with comment.
British Psychosocial Oncology Society	6/6.33	What do the percentages in brackets mean?	Text altered in line with comment
British Society of Rehabilitation Medicine		This organisation was approached but did not respond.	
Cancer Black Care		This organisation was approached but did not respond.	
Cancer		This organisation was approached but did not respond.	

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Research Care			
Cancer Research UK		This organisation was approached but did not respond.	
Cancer Services Co-ordinating Group		This organisation responded and said that they have no comments to make.	
CancerBacup		CancerBACUP welcomes the opportunity to comment on Part A of the draft service configuration guidance from the National Institute for Clinical Excellence on supportive and palliative care for patients with cancer. Our comments focus primarily on the section of the guidance that deals with cancer information, as this is CancerBACUP's particular area of expertise and interest. As a member of the Cancer Information Advisory Group, CancerBACUP has had the opportunity for substantial input into this guidance.	Thank you for your comments.
CancerBacup	2.12	CancerBACUP welcomes the emphasis in the guidance on good communication with patients and on the need for effective coordination of care. We also welcome the recognition given to the role of all health and social care professionals in contributing	Text altered in line with comment.

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		to good supportive care for people with cancer. However, we suggest that paragraph 2.12 should include volunteers and therapists, as well as health and social care professionals.	
CancerBacup	2.13	We further suggest that the third bullet point on the list given in paragraph 2.13 should refer to "cancer information nurses and other professionals" rather than "cancer information officers".	Text altered in line with comment.
CancerBacup	Information	The problems some patients experience in obtaining the information they need are highlighted in the National Survey of Cancer Patients.[1] The survey found that only 51 per cent of breast cancer patients were given written information at the time of their diagnosis, with this figure falling to 26 per cent at the worst performing trust – and patients with breast cancer reported receiving more information than patients with other types of cancer. We welcome the emphasis in the guidance on the need to address inequities in access to information and to include information as an integral aspect of patient care.	Thank you.
CancerBacup	1.14	The final sentence of paragraph 1.14 refers to "recommendations	Text altered in line with comment.

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[1] National Survey of NHS Patients: Cancer: National Overview 1999/2000 (July 2002)

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		generated by the Coalition for Cancer Information". We suggest that this should be amended to "recommendations generated by the Cancer Information Advisory Group", as the Coalition's remit is in fact to implement those recommendations.	
CancerBacup	Figure 2	It would be helpful if figure 2, which portrays the relationships between different types of supportive and palliative care, could include specialist information services alongside self-help support, user and advocacy groups.	Diagram redrawn.
CancerBacup	2.18	Paragraph 2.18 summarises what patients and carers want from services. We believe that the fourth bullet point on this list, regarding "having choices", should include access to information as well as the other services listed.	Text altered in line with comment.
CancerBacup	3.18	We would like the guidance to emphasise more strongly the need for patients to be given information about both local and national sources of information and support (paragraph 3.18). Written information given to patients should include details of who they can contact locally if they have particular questions about their own treatment and care, plus details of other, confidential sources of information and support.	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
CancerBacup	3.1	Levels of information We suggest that the second bullet point in box 3.1 should include information on specific types of cancer – such as that provided by CancerBACUP – as well as information on types of treatment and aspects of living with cancer.	Text altered in line with comment
CancerBacup	4.2	Paragraph 4.2 refers to the close relationship between the provision of information and emotional support. This is confirmed by CancerBACUP's experience, as reflected in data collected about users of our telephone helpline and local information centres, and deserves to be emphasised. The relationship between information and support could usefully be reflected in paragraphs 5.4 and 5.7, which refer to patients needing help to understand the information they have been given but do not acknowledge that people may need emotional support to help them cope with the impact of the information they have received.	Text altered in line with comment
CancerBacup	4.2	While we would not disagree with the emphasis in paragraph 4.2 on the value of good face-to-face communication, CancerBACUP's experience indicates that patients and carers also value the telephone as a means of communication. The	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		telephone offers the benefits of anonymity and confidentiality, which people often want in addition to face-to-face communication with the health professionals responsible for their treatment and care. The telephone also offers people the opportunity to raise personal issues that they may be reluctant to discuss face-to-face.	
CancerBacup	4.20	Paragraph 4.20 addresses the need for interpreting services for patients who cannot understand English. While family members have a role to play in interpreting information, we would not wish provider organisations to be directed by the guidance to over-rely on family members as interpreters. Independent interpreting services should be available to patients who need or want them, as patients do not always feel comfortable asking questions in front of family members. In addition, relatives may prevent patients receiving all the information they want because of a desire to protect them or because of cultural sensitivities that may make it difficult to discuss issues such as sexuality.	Text altered in line with comment.
CancerBacup	5.3	We would like paragraph 5.3 to emphasise that providing information to patients and carers is an ongoing process, not a	Text altered in line with comment.

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		one-off product. While it is important that the right products should be available to people at the time they are required, patients also need to know that their information needs will continue to be met at each stage of the cancer journey.	
CancerBacup	5.13	There appears to be some discrepancy between paragraph 5.11 and paragraph 5.13 regarding the extent to which information should be available in a choice of formats. Paragraph 5.11 emphasises the need for information to be available electronically, while paragraph 5.13 suggests that information should be available to patients in a range of formats. We believe it is essential to offer patients a choice of formats, to ensure that information is as accessible to as many people as possible.	Text altered in line with comment.
CancerBacup	5.12	Information that is tailored to the patient's personal needs should be balanced with generic information that helps people put their own experiences in context. We suggest that paragraph 5.12 should make this clear as part of the recommendation on cancer information packs for new patients.	Text altered in line with comment.
CancerBacup	5.16 and 5.28	Paragraph 5.16 refers to information accessed through the Internet. It may be appropriate in this paragraph to refer explicitly	The role of NHS Direct needs to be reviewed in this context by the Guidance Development

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		to the key role that NHS Direct Online will play as a gateway to sources of accredited information. Again, in paragraph 5.28, reference could usefully be made to NHS Direct Online's accreditation scheme and information partners programme.	Team - thank you for this information – text not to be altered at the request of NHS Direct.
CancerBacup	5.17	We welcome the recommendation that information should be available in a language the patient can understand. However, we would prefer paragraph 5.17 to recommend that provider organisations purchase materials from an accredited information provider, unless these are not available in the appropriate language.	Text altered in line with comment.
CancerBacup	5.26	The second bullet point in paragraph 5.26 refers to the need to reinforce verbal information with written information. We suggest that additional information could be provided by means of video or audiotape instead of in writing, where appropriate.	Text altered in line with comment.
CancerBacup	5.26	We have some concerns about references in paragraph 5.26 to patients' "readiness to receive information". Earlier paragraphs refer to the need for information that reflects patients' preferences. Our experience as an information provider suggests that health professionals may under-estimate patients' desire for	Text altered in line with comment.

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		information, with the result that people with cancer do not always receive as much information as they wish. Patients should be encouraged to express their own preferences and health professionals should be wary of making their own assessment of what information patients are ready to receive.	
CancerBacup		While it is desirable that patients should receive information that reflects local circumstances and is tailored to their particular needs, the guidance should discourage local service providers from developing their own information if good quality information has already been produced at national level.	Text altered to support this statement.
Chartered Society of Physiotherapy		The development of service configuration guidance on supportive and palliative care for patients with cancer is very welcome, and we congratulate the authors on the work so far undertaken.	Noted with thanks.
Chartered Society of Physiotherapy	2.13	Specialist physiotherapists with expertise and training in oncology should be included in the list; however what about including all AHPs: ‘Specialist Allied Health Professionals’?	Text altered in line with comment.
Chartered Society of Physiotherapy	3 C2 Assessment	This section could be strengthened. The Department of Health has included within the National Service Framework for Older People an ambitious single assessment process, elements of	Comment noted but decision made not to alter text.

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		which could be included here.	
Chartered Society of Physiotherapy	7.23	The suggested minimalist team can barely be described as specialist with this limited range of expertise. This very minimalist description is in danger of encouraging commissioners to fund inadequate teams.	Comment noted but decision made not to alter text.
Chartered Society of Physiotherapy		There is no mention of lymphoedema management in this document. All cancer patients who are at risk of developing this distressing condition should have access to a health-care professional with specialised training in this area.	To be included in Part B.
Chartered Society of Physiotherapy	7.24	If it is accepted that specialist palliative care is provided by a multi-professional team, the members of which have undergone specialist palliative care training, then none of the professions listed should require the adjective ‘specialist’. If the qualification is deemed necessary in the list e.g. psychological support, then it should also be given to physiotherapy, occupational therapy, etc, otherwise there is a danger of misinterpretation and an assumption being made that a generalist will do.	Text altered in line with comment.
Chartered Society of	7.24 and 7.31	It needs to be clear that the expertise of a specialist palliative care allied health professional (AHP) is more than the general	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Physiotherapy		expertise of an AHP.	
Chartered Society of Physiotherapy	7.28	Commissioners will have to take into account that the total emphasis on cancer has to be qualified by acknowledging that many providers of palliative care additionally offer services to patients with non-malignant disease. This is a growing part of their remit mirroring the importance given to palliative care in all other NSFs so far published. For example, a needs assessment at one hospice has shown that more in-patient beds are required, but that takes into account both cancer and non-cancer patients. If account were taken of cancer patients alone there would be enough beds. However, in the current situation, cancer patients still have to wait for admission because they have to take their turn with everyone else – in effect there are not enough beds for cancer patients.	Comment noted but decision made not to alter text.
Chartered Society of Physiotherapy	7.30	Chronic oedema is frequently a distressing symptom of advanced cancer. In-patient specialist palliative care services should have access to a lymphoedema specialist (who may also be a specialist nurse, specialist physiotherapist or specialist OT).	Will be included in Part B.
Chartered	7.31	See comment on 7.24.	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Society of Physiotherapy			
Chartered Society of Physiotherapy	8.23	Will undo all the good of 8.22 and will render it non-existent.	Comment noted but decision made not to alter text.
Chartered Society of Physiotherapy	Research Evidence Manual Page 173	Implications of the evidence for recommendations The first line should include physiotherapists.	Text altered in line with comment.
Cochrane Pain, Palliative Care and Supportive Care Group	Chapter 3, page 5	We have one small comment based on a quick skim through Part A. Chapter 3, page 5, Review Methods (a) states that the researchers searched the "specialist register" of the "Cochrane Pain and Palliative Supportive Care". As far as we are aware, this has not been done.	The specialist register was not searched – this was an error and has been corrected by the Evidence Review Team
College of Occupational Therapists		The College of Occupational Therapists welcomes the opportunity to comment on this cancer guidance document. Overall comments The document is clearly structured and written. The language used is practical and straightforward, which will promote	Thank you for your comments.

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		acceptance and compliance. The recognition of possible variations in the achievement of the recommendations, and the allowance for modification to its implementation, to incorporate local circumstances, is likely to gain a more positive response than a highly dictatorial document.	
College of Occupational Therapists	Assessment	The guidance document recommends a number of systematic and formal assessments and re-assessments, at key points in the cancer journey. It is unclear from the document whether the assessments are to be done by the relevant professionals for each domain, or whether trained professionals are expected to assess all domains. If this were the proposal we would not support it. In order to ensure that assessments are made fully and accurately, we recommend that the relevant professions for each domain make them.[1] As the domains of supportive and palliative care, as defined in the document, are so wide ranging, a single assessment tool may not be a practicable solution to repetitive assessments. However, a single assessment process, whereby information can be shared,	This is to be determined at a local level.

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		maintained and updated by the multi-professional care team, is a realistic option as part of integrated care along the patient journey.	
College of Occupational Therapists	Psychological Support Services	All health and social care professions involved in supportive and palliative care have a role in providing psychological support to varying degrees. Experienced occupational therapists are able to provide specialist support at levels 2 and 3 of the recommended model of psychological assessment and support. (Table 6.1) Occupational therapy is of critical value in facilitating a person's sense of mastery and competence and in putting substance into quality of living. The occupational therapist addresses physical, functional, psychological and social components of the patient's problems.[2] The anxiety, distress and depression associated with cancer are inextricably linked with the practical and physical problems occurring as a result of the illness or treatment. The occupational therapist can assist the patient with he effects of both the disease and the treatment, offering anxiety management strategies: relaxation; patient education and advice; identifying	Text altered in line with comment.

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		triggers and coping strategies. [3]	
College of Occupational Therapists	Specialist care services	The document differentiates between specialist and general palliative care. This approach tends to promote the perception that specialist palliative care is the ‘cream on the cake.’ Specialists arise when services are dedicated to a particular field, so there may also be specialist acute services in cancer care, which have an equally valuable supportive role to play in the cancer journey of a patient.	This is made explicit in the text.
College of Occupational Therapists	Specialist care services	The document describes the minimum requirement for supportive and palliative care teams as the inclusion of medical and nursing staff. There needs to be a balance of relevant professional skills within the team if the patient is to receive the best care by the right professional.[4] We would recommend that the minimum for any specialist team needs to be extended to include Occupational Therapists and Physiotherapists, who have additional experience and training to offer at a high level.	This is made explicit in the text.
College of	Workforce	The College of Occupational Therapists welcomes particularly the	Thank you.

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Occupational Therapists	Development	emphasis laid on education, training, continuing professional development and support for health and social care professionals within this document, with the recognition that this needs designated time in order to fulfil the learning requirements.	
College of Occupational Therapists	Evidential Support	We would like to propose that the consideration of evidence takes a broader view of professions that do not yet have a sufficient body of evidence to meet the grading criteria as set up for the production of the guidance document. The body of literature on occupational therapy in palliative and supportive care is small. While the value of occupational therapy is comprehensively described, there is relatively little empirical evidence. References: [1] Soderback I, Paulsson EH (1997) A Needs assessment for referral to occupational therapy, Nurses' judgement in acute cancer care. Cancer Nursing 20(4) 267-273. [2] Armitage K, Crowther L (1999) The role of the occupational therapist in palliative care. European Journal of Palliative Care	These references have been passed the Evidence Review Team for consideration for Part B – higher level evidence is sought first – qualitative studies will be reviewed if this higher level evidence is lacking.

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		6(5) 154-157. [3] McVey G (1998) Occupational therapy in stress and anxiety management. In: Cooper J (ed) Occupational Therapy in Oncology and Palliative Care. London: Whurr. [4] Ford G (1998) Multi professional education. In: Doyle D, Hanks GWC, MacDonald N (Eds) 2nd Edition Oxford Textbook of Palliative Medicine. Oxford: Oxford Medical Publications.	
Department of Health and Welsh Assembly Government		Thank you for the opportunity to comment on the first draft of the supportive and palliative care guidance. This letter reflects the views of the Department of Health and the National Assembly for Wales.	Thank you for your comments.
Department of Health and Welsh Assembly Government	General	NAW are concerned that the guidance covers cancer only. Palliative care is also applicable to non-cancer patients who are often overlooked. They also suggest that you should be alerted to the NAW draft palliative care strategy.	The scope of the Guidance was for adults with cancer – but it is acknowledged that the recommendations may impact on other groups of patients with similar needs.
Department of Health and	Chapter 2 – Background	Do these figures cover both England and Wales? Would it be possible to clarify this?	Figures checked - text altered in line with comment.

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Welsh Assembly Government	2.1		
Department of Health and Welsh Assembly Government	Chapter 3 - Co-ordination of care	The draft indicates that Cancer Networks should have a clear lead and responsibility for ensuring that a structure and process is in place to plan and review local supportive and palliative care services. This responsibility actually rests with StHAs and PCTs who review support and fund services. The best way for them to review and plan palliative care developments (and indeed all their cancer development) is through cancer networks. Perhaps the draft could make this clear. The NHS Cancer Plan indicated that supportive care networks would be developed alongside cancer networks. This was not intended to imply that these should be separate organisational structures. It would be helpful, therefore, if you made some reference to why the responsibility should rest within the cancer network.	Text altered in line with comment.
Department of Health and Welsh Assembly Government		You may wish to note that the Scottish Partnership for Palliative Care & the National Council for Hospices and Specialist Palliative Care Services have just published a randomised, prospective trial report 'An Evaluation of a Patient Held Record in Cancer and	Reference requested.

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		Palliative Care'.	
Department of Health and Welsh Assembly Government	Chapter 5 – Information 5.10	The Coalition for Cancer Information has already been established. You may wish to clarify what is meant by the coalition being responsible for dissemination of information products. We believe this could be open to more than one interpretation.	Text altered in line with comment.
Department of Health and Welsh Assembly Government	5.21	There is a recommendation for training for each level. We are concerned that this may be too rigid.	Paragraph deleted.
Department of Health and Welsh Assembly Government	Chapter 6 – Psychological support services 6.24	The development of service directories appears here and elsewhere. We suggest that guidance to should make clear that this would be a composite directory of services.	Text to make this clearer.
Department of Health and Welsh Assembly Government	6.25	Cancerlink is now part of Macmillan Cancer Relief.	Document referred to written by Cancerlink.
Department of	6.26	Are there links that should be made between this	Text altered where appropriate – but specific

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Health and Welsh Assembly Government		recommendation and the chapter on face to face communication? Would some of the training be the same and provided by similar people? 'Psychological care experts' needs more clarity, would a palliative care specialist fall into this category?	training issues/requirements outside the scope of the Guidance.
Department of Health and Welsh Assembly Government	6.31	Although there is no formal evidence on the potential benefits of implementing the model of psychological assessment and intervention, a strong case is put forward for its use. Before such a recommendation was taken on board by the NHS, we suggest that it would be necessary for the model to be piloted.	This will be considered as a part of the economic review.
Department of Health and Welsh Assembly Government	6.42	Would it be possible to make it clearer that part of the role of psychological support services is to provide direct support to staff to reduce 'burnout'.	Text altered in line with comment.
Department of Health and Welsh Assembly Government	Chapter 7 – Specialist Palliative Care 7.37	Day care is not recommended as there is currently no evidence on the efficacy of specialist palliative care day therapy. However, most specialist palliative care inpatient units (hospices) have day care facilities. A clear recommendation needs to emerge to guide commissioners on a service that already is quite well established.	Day care now included in this section- on the basis that it is an existing service – for which there is little or no evidence to support it as a part of service configuration – but – it is anticipated that further evidence may be forthcoming in Part B of the Guidance as

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
			issues such as social support, complementary therapy, rehabilitation and carer support are examined.
Department of Health and Welsh Assembly Government	Chapter 8 – General palliative care services 8.4 and 8.34	One point for correction – the district nurse project is a DH funded project. We have worked in partnership with Macmillan Cancer Research and other key stakeholders.	Text altered in line with comment.
Department of Health and Welsh Assembly Government	8.5	The new GP contract will have an impact on the provision of out of hours services. The Department of Health have commissioned the National Prescribing Centre (NPC) to develop a good practice guide for practitioners and health bodies about the management of controlled drugs in primary care. The guide will not cover clinical decisions (e.g. drug selection). It will instead concentrate on process, framework and action required to ensure the safe, secure and cost-effective management of controlled drugs. It is envisaged that the guide will be in two parts: the first, a short, concise and user-friendly "toolkit" for front line	Text altered in line with comment.

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		healthcare professionals and managers outlining what is required of them to ensure controlled drug management is appropriate; the second, a more detailed resource with examples of existing good practice, signposts to useful information and expertise, checklists for action and an overview of the legal and regulatory frameworks underpinning controlled drugs.	
Eisai Ltd		This organisation responded and said that it had no comments to make.	
Elan Pharmaceuticals		This organisation was approached but did not respond.	
Faculty of Dental Surgery		Despite my providing information, with evidence in support of the importance of oral care for patients with cancer, admittedly based upon a guideline produced predominantly in relation to Head and Neck Cancer, there is nothing in the guidance that even acknowledges that oral care has any value to the patient. Anyone who has cared for a patient with cancer in the terminal stages of the disease will be aware of the importance the patients' oral comfort is.	Comments noted but decision made by Guidance Development Team not to alter text.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		I would be grateful if this could be drawn to the attention of the Guidance Development Group. At the very least there should be an acknowledgement of the importance of secondary care providers of dental services in the support of the core group in Section 7 Paragraphs 7.24 and 7.31 and in 8.3 there should be reference to the essential input of Community Dental Practitioners	
Foundation of Integrated Health		Thank you for your reminder. Here are the Prince of Wales's Foundation for Integrated Health comments: (Complementary and alternative medicine is abbreviated to 'CAM').	Thank you for your comments.
Foundation of Integrated Health	Part A	"Health and social care professionals" are referred to throughout the document. It is not specified what criteria is used to determine what is meant by a "health professionals". Does these include qualified, registered complementary and alternative healthcare practitioners (and if so on what basis, registered with whom). For example this might include professional homeopaths,	Examples of the professionals are included wherever thought appropriate to define who is being referred to in specific sections of the text.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		acupuncturists, reflexologists, etc. amongst a group likely to deliver CAM services within palliative care.	
Foundation of Integrated Health		Physiotherapists, OTs, dieticians, speech and language therapists, and other such therapists register with the Health Professions Council. The HPC have indicated that CAM professions are not eligible for registration with the HPC. As the NICE guidance is commissioned by DoH, this means that CAM professionals are not recognised as 'health professionals' when it comes to official govt papers/guidance etc. If this is the case for the Guidelines, perhaps this should be made clear in the documentation? However, the Foundation would recommend that some category for including CAM healthcare professions be incorporated into the Guidelines.	Complementary therapy is a topic in its own right to be included in Part B of the Guidance and so many of the comments from this stakeholder will be addressed in that section.
Foundation of Integrated Health	Chapter 7	The Foundation would also like to recommend an addition to the following sections: Under Chapter 7 Specialist Palliative Care Services 7.24	See above.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		Complementary therapy should be listed alongside physiotherapy, occupational therapy, etc as part of the 'range of other specialist expertise'. Complementary therapy is an expertise, i.e. more than just a range of techniques. 7.30 As above, complementary therapy should be listed.	
Foundation of Integrated Health	Chapter 4 Face-to-face Communication 4.12	Does 'experienced therapist' include an experienced complementary therapist? If complementary therapists are not included, perhaps there could be some criteria by which they could be included? Perhaps such criteria might include minimum qualifications, registration with a professional body, insurance, etc. The Foundation would strongly recommend that complementary therapists be included in some way in this category.	Text altered to reflect comment – patient choice is the determining factor.
General Medical Council		This organisation responded and said that it had no comments to make.	
GlaxoSmithKline UK		Thank you for the opportunity to comment on these guidelines from a GlaxoSmithKline perspective. Having gone back to the scope it was suggested that symptom control would be included as a topic. However having reviewed the 1st draft it does not	Symptom control has been included in both the general and specialist palliative care sections of the Guidance – the scope of the Guidance is to review and assess service configurations

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		seem to have been considered in any detail. We would suggest that some form of guidance as to what symptoms patients are likely to have needs to be covered. Many oncologists believe that symptom control is crucial in ensuring treatment success as these two quotes highlight; "Patients and health professionals agree that chemotherapy-related nausea and emesis are among the most distressing adverse effects of chemotherapy treatment for cancer, contributing significantly to several aspects of lowered quality of life during that stressful period, and often exacerbating negative physiological and psychological effects caused by the disease itself." Morrow GR, Roscoe JA, Hickok JT et al. Oncology 1998;12(Suppl.4):32-37 "'The effective prevention of chemotherapy induced emesis is a major achievement in cancer treatment. Among the research areas in oncology, developments in supportive care, including the prevention of emesis, have made possible many of the advances	and not individual treatments. The papers and references cited appear to relate more to individual drug regimes.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		in the approach to the patient with cancer." Gralla RJ. The evolution of antiemetic treatment. Medical Management of Cancer Treatment Induced Emesis. Ed Dicato MA. Pub. Martin Dunitz Ltd 1998.	
Haven Trust, The		This organisation was approached but did not respond.	
Health Technology Board of Scotland		This organisation responded and said that it had no comments to make.	
Help Adolescents with Cancer		This organisation was approached but did not respond.	
Help the Hospices		Additional evidence from Help the Hospices Introduction Help the Hospices submitted a summary of evidence to NICE	Help the Hospices are thanked for providing these sources of information. Many of the issues identified in the PROMARK survey are covered in the introductory chapters of the Guidance and are also identified in the issues

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		when evidence was invited in spring 2002. On reading the first draft of the guidance, it has become clear that the following documents may also be of relevance to the review. We are therefore submitting them at this stage, and have referred to them where appropriate in our response to the first draft. Evidence summaries 1. Charitable Funding and State Responsibility Help the Hospices/Independent Hospice Representative Committee, November 2001 Aim: to clarify the legal position on statutory and charitable funding of voluntary hospices. Conclusion: The Charity Commission advise that charities should not be spending charitable funds on providing a service which a statutory body has a legal responsibility to provide.	sections of the specific topics. Many of the other references cited here relate to implementation and to funding arrangements – which are outside the scope of the Guidance.

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		2. Chapter 30 of the 2002 Spending Review: Summary recommendations of the Treasury's cross-cutting review of the role of the voluntary sector in delivering public services. H.M. Treasury, July 2002 The full report of this review will be made available on 12 September 2002. This summary sets out the main recommendations. It states that: "The Government accepts that it is legitimate for service providers to factor in the relevant element of overhead costs into their cost estimates for services delivered under contract. All government departments will reflect this recommendation in their procurement policies." 3 Public Perception of Hospices Help the Hospices/PROMARK, Autumn 2001 Aim: to understand how the public perceive and understand	

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		the role of independent hospices. Method: Qualitative research: 30 in depth telephone interviews. Sample designed to be broadly representative of the whole population by age, region, and contact with hospice. Quantitative research: 600 face-to-face interviews with a statistically valid representative sample of the UK population. Response rate: 100% Results: • 92% of the adult general public are aware of the term hospice • Higher social grades and older age groups understand the term best	

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		• A high proportion of people, when prompted, associate “hospice” with “care”, “comfort”, “support” and “kindness” • Few people, when prompted, associate the term “hospice” with “fear” or “darkness” • 71% of people, unprompted, think hospices provide care for the terminally ill • 68% of people don’t know what palliative care means • Of the 32% of people who think they know, 11% think it means making people feel comfortable, 9% think it means care of the terminally ill and 7% think it means pain relief. 4 Compact on relations between Government and the Voluntary and Community sector in England Home Office, November 1998 Aim: To set out the key principles and undertakings which should underpin the relationship between Government and the voluntary and community sector in England.	

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		The Compact was signed by the Prime Minister and the then Home Secretary on behalf of the Government, and by Sir Kenneth Stowe, Chair of the English voluntary and community sector's Working Group on Government Relations, on behalf of the voluntary sector. The Compact Working Group, based at the National Council for Voluntary Organisations are responsible for ensuring that the Compact is implemented. The Compact is reviewed in Parliament on an annual basis. 5 Compact between the Government and the Voluntary Sector in Wales Welsh Assembly, December 1998 Aim: To set out the key principles and undertakings which should underpin the relationship between Government and the voluntary and community sector in Wales. 6 Compact and Policy Appraisal: a Code of Good Practice	

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		Home Office Aim: To make a positive impact on the way the Government consults and appraises its policies in respect of the voluntary and community sector. This is a supplement to the Compact for England listed above. Recommendations: The Code advises, amongst other things, that it is good practice for statutory bodies to assess the impact of proposals on the voluntary and community sector and to make this information available as part of the consultation process.	
International Myeloma Foundation (UK)		Many thanks for sending me these draft documents. I would like to congratulate you and your team for your excellent work so far.	Thank you for your comments.
International Myeloma Foundation (UK)	Recommendations	I have read through these documents and the only point I have is this. There doesn't seem to be a recommendation for the setting for a diagnosis. The recommendation could read. 'a diagnosis needs to be communicated honestly to the patient	Text altered to include this.

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		with the minimum of delay. Uncertainty about the condition is generally more distressing to a patient and his or her family. This information should be communicated in a quiet area with privacy, ideally in the company of a close relative and with the presence of a specialist nurse where possible' If this is in fact in the document and I have overlooked it please accept my apologies. I have no references for this other than feedback from patients and family members.	
Janssen-Cilag Ltd		This organisation was approached but did not respond.	
Macmillan Cancer Relief	General	Thank you for inviting Macmillan Cancer Relief to comment on the draft version of Part A of the Supportive and Palliative Care Guidelines.	Thank you for your comments.
Macmillan Cancer Relief	General	We welcome the opportunity to comment on these Guidelines. You asked us to respond specifically at this stage on the practical applications of the Guidelines, the interpretation of evidence, and	See specific responses.

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		any evidence overlooked. In our response we have based our comments around four main themes: the Evidence Base, the Process for developing the guidelines, the Content of the guidelines, and how they will be Implemented. Where we have commented on the content of the report, we have tried to provide an alternative approach or structure where we believe it would be helpful. Our main concerns centre around the methodology and framework; the lack of emphasis given to users' own skills and knowledge; the need for decisions about a patient's care to be made together with the patient and their carer; and the need for shared management between the statutory and voluntary sectors contributing to sustainable services.	
Macmillan Cancer Relief	General	We are also concerned that the views of the independent user involvement group, which we helped to set up, have not been sufficiently reflected in the document. A separate response has been sent to you by this group which we would urge you to give due consideration to.	See specific responses.
Macmillan Cancer Relief	General	We very much regret that your timescale has been too short to allow detailed comments at this stage. We hope that you will	See response to 3.1 regarding Macmillan's proposed re-structuring of the Guidance.

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		reflect our key concerns as laid out here in future redrafts. We would recommend that the work continues on Part B, but that Parts A and B should then be considered as a whole within a revised framework, as indicated in section 3.1.	
Macmillan Cancer Relief	Part One: Executive Summary	Although we welcome the emphasis by NICE on robust evidence to support patient treatment and care, we are concerned that insufficient weight has been given to patient-led research and qualitative studies that focus on users' experiences of supportive and palliative care services. As a result, the guidelines do not consider users' needs holistically and do not draw on recent/current studies.	The process followed is to search for the higher level research studies in the first instance - and where evidence is lacking then search the 'lower' level evidence databases. A considerable volume of higher level evidence has been available to determine recommendations for service configuration. The Evidence Review Team doubts whether the result of a qualitative review would substantially change may of the recommendations. It is important to note that the higher level evidence e.g. RCTs do not exclude patient experience measures and findings. Studies which have focussed on

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			'needs' have been drawn upon in the introductory chapters and in the 'issues' section at the start of each specific topic.
Macmillan Cancer Relief	Part One: Executive Summary	We believe that the framework used for the production of this guidance is not suitable for the topic area (apart from possibly specialist palliative care which deals with the more medical aspects of symptom control and pain management). We are concerned about users' needs being split into ten domains and the guidelines being divided into Parts A and B. We recommend that NICE continue work on Part B, but then consider Parts A and B together as a whole within the context of a revised framework as indicated in section 3.1 of our response below. This will help to cut down the length and repetition in the document, and will facilitate integrated service provision.	These concerns are shared by the Guidance Development Team, but for practical reasons each of the domains need to be considered individually. It is however acknowledged in the introduction that this may not be how users experience or perceive their care.
Macmillan Cancer Relief	Bacjground	We welcome the reference in the "Background" section of the document to the inner skills and resources of patients and carers. However, we do not believe that the guidelines recognise sufficiently the knowledge and expertise that patients and carers bring to the table about their condition, and the importance of user	Text has been amended in consultation with Macmillan to reflect this, and the model has been redrawn.

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		empowerment as a key principle underpinning good supportive and palliative care. We would like to see greater recognition of this throughout the document and would like to see the model shown in section 2.5 re-drawn with information and support, self-help and user involvement integrated into the network of support, not shown as separate services.	
Macmillan Cancer Relief		We are concerned about the paternalistic nature of some of the recommendations and the inference that “the professional knows best”. We would like to see greater emphasis given to the important role of professionals in listening to patients and carers, empowering them, and enabling the right decisions to be made about what services to access based on a genuine partnership with the patient and their carer.	Text altered in line with comment.
Macmillan Cancer Relief		We are confused about the purpose and audience for these guidelines and this should be more explicit. We would also recommend that their link with other policy documents, in particular the Manual of National Cancer Standards, is clarified.	This is covered in the text.
Macmillan Cancer Relief		We are concerned about the lack of realism of some of the guidelines, particularly those affecting assessment, and the huge	It is the view of the Guidance Development Team that assessment is a part of professional

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		cost in terms of time, people and money that would be needed for implementation. We would urge NICE as a matter of priority to consider the resource implications and to make recommendations that are practical, will require real partnership working between health and social care and the statutory and voluntary sectors facilitated through the Cancer Networks, and will result in services that are sustainable in the long-term.	practice – the Guidance is not making recommendations above and beyond that practice other than to suggest that this is done in a more rigorous way. Impact on time etc. may depend on how well and how thoroughly assessments are being made and documented at the present time.
Macmillan Cancer Relief		Part Two: General comments on the Guidelines 1. EVIDENCE We welcome the fact that diverse sources and types of research have been used in formulating these Guidelines. However, we are concerned that the Guidelines are weighted towards the use of quantitative and professionally-led peer-reviewed research, particularly randomized controlled trials – rather than qualitative and patient-led studies (see Appendix 1). We are particularly surprised that the lower cut-off for evidence is Class IV, so eliminating expert consensus and systematically collected oberservational data.	See comment above.

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		While quantitative statistical evidence is vital to underpin many areas of modern medicine, the nature of palliative and supportive care does not lend itself well to this kind of evaluation. Palliative and supportive care is about making patients 'feel better' and is inherently subjective and qualitative. The lack of experiental evidence in the document means that it fails to grasp the unique opportunity to reflect the authentic voice of patients and to show how their interests interact with those of professionals, which could have been done by for example quotations from patient studies or by commissioning some limited opinion research. We recognise that these facts may be due in part to the fundamental constraints of the NICE process itself, with its focus on clinical statistical evidence. Macmillan has, however, lobbied consistently for NICE to give 'patient experience' a higher priority when formulating advice, notably in its two most recent submissions, 'Timing and Selection of Topics for Appraisal' (June 2002) and its response to the Health Select Committee's Inquiry into NICE (January 2002).	

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Macmillan Cancer Relief		We urge you to revisit the evidence we submitted to NICE in May. We have also attached in Appendix 2 a list of other studies on the psychosocial impacts on cancer patients which are relevant to these Guidelines. We believe that the lack of focus on users' experiences as part of the evidence base means that the guidelines are skewed towards the needs of professionals, rather than the needs of users.	These references will be of considerable use when such topics as social support and carers support and bereavement are reviewed for Part B of the Guidance.
Macmillan Cancer Relief	Process For Developing Guidelines	The Guidelines divide patients' needs into separate categories, evaluating each in turn independently. Similarly, the separation of the document into Parts A and B would appear to be artificial, and driven by the practical needs of the report writing team, rather than in response to patient need. From the patient's perspective, it is not possible to separate out needs so cleanly. Studies led by patients, such as the study commissioned by the Department of Health to inform the development of these Guidelines, demonstrate that patients prefer to speak of needs as a whole.	See comment above – the completed set of documents comprising the Guidance will include a public version which Macmillan have been commissioned to write for the Guidance Development Team as a part of their input on user involvement for the project.
Macmillan Cancer Relief	2.25-6	We welcome the statements made in sections 2.25-6 about the importance of involving users and carers in shaping the delivery	Macmillan were requested to gain the permission of the users for their names to

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		of services. We are troubled; however, that the contribution of the user involvement group set up to help develop these guidelines does not appear to have informed the detailed thinking or to have been integrated into the document as a whole. This is manifested by the lack of reference to these users in the acknowledgments section of the appendices.	appear in the document prior to consultation – but this was not received in time to include the names of the user representatives.
Macmillan Cancer Relief		We recommend that NICE continue working on Part B, but then that Parts A and B should be considered together as a whole, within the context of a revised framework as indicated in section 3.1 of our response below. This will help to cut down the length and repetition in the document, and will facilitate integrated service provision.	Parts A & B will be considered together during the consultation that is to take place during July/August 2003 and then again in October 2003.
Macmillan Cancer Relief	3.1 Purpose and Structure of Guidelines	The purpose of the Guidelines is not entirely clear from the outset, and indeed, the objectives are presented inconsistently throughout the document (see sections 1.1, 1.7, 1.14 and 2.29). For example, are the Guidelines intended to detail minimum standards, or pointers for good practice? They currently appear to be a mixture of both. We welcome the excellent description of patients' and carers'	Macmillan are thanked for their suggestions regarding restructuring but the Guidance Development Team have made the decision not to alter the format of the document and topics. The final document will include aspects of structure, process and outcomes of care which can be monitored and a set of standards

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		needs in section 2.18. However, the document as a whole is not structured around enabling those needs to be met. We would recommend that the document is completely restructured as follows: Section 1: A description of users' needs. Section 2: A description of the care needed to meet these needs. Aspects of good practice would also be included here. Section 3: Guidance on how to undertake a stock-take or review of local services mapped against the user needs and the ideal standards, and a framework for action planning for the development / improvement of services in the future.	will be drawn from the Guidance for the Manual of Cancer Services Standards. The points made regarding stocktaking and action planning relate to local implementation and are therefore outside the scope of the Guidance.
Macmillan Cancer Relief		The Guidelines do not currently link with other important policy initiatives, including the Manual of National Cancer Standards, the COG Guidelines, the emerging primary care cancer standards, the recently agreed user involvement mechanisms, and the Expert Patients Programme.	These sources are referenced where appropriate within the text.
Macmillan Cancer Relief		Macmillan recommends that NICE clarifies the purpose, audience and intended usage of the document, and makes explicit its relationship with other policy documents. Consideration should	Macmillan are thanked for their suggestions regarding restructuring but the Guidance Development Team have made the decision

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		be given to restructuring the document around the identified needs of users. The document should be shortened in length and the repetition cut out.	not to alter the format of the document and topics.
Macmillan Cancer Relief	3.2.1 Definitions	Fundamental Assumptions We are concerned that the definitions for general palliative care and specialist palliative care have still not been formally confirmed, despite the extensive consultation exercise undertaken by the National Council of Hospices and Specialist Palliative Care to which we submitted a lengthy response in March 2002. We also do not understand what is meant by the term “Specialist Supportive Care Services” referred to in section 2.15.	The Guidance has drawn on the most recent definitions from the National Council. Text altered in paragraph 2.15.
Macmillan Cancer Relief	3.2.2 User Empowerment	We welcome the reference in the “Background” section of the document to the inner skills and resources of patients and carers. However, we do not believe that the guidelines recognise sufficiently the knowledge and expertise that patients and carers bring to the table about their condition, and the importance of user empowerment as a key principle underpinning good supportive and palliative care.	Text altered to reflect this.

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		Similarly the role of informal networks in offering support, referred to in section 2.5, are barely mentioned in the report as a whole, and yet for most people, in practice, they are the bedrock of supportive care (excluding the more medicalised 'end' of palliative care).	
Macmillan Cancer Relief		Paragraph 2.15 discussing the self-help, support and advocacy groups appears to display fundamental misconceptions about the role of self-help, support and advocacy (although the description could be applied to Cancer Service user groups in a meaningful way and their role is adequately described in section G; 2.25 – 2.28). Self-help and self-help and support groups provide opportunities for people to gain strength through shared experience, informal information sharing and the chance to feel more in control or 'empowered.' It is a holistic approach, with no professional boundaries and has little in common with a 'service delivery' model. User groups, on the other hand, provide a forum where patients may come together and influence change in the health service, and advocacy groups provide mutual support to	Text altered in line with comment.

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		enable people who have cancer to speak on their own behalf in order to get their needs met. Descriptions of the different kinds of groups are set out clearly in the study conducted by Cancerlink (see page 109, Self help, support, user and advocacy groups and volunteers).	
Macmillan Cancer Relief		We would like to see greater importance given to decision-making in partnership with patients as a fundamental philosophy throughout the document. We would also like to see the model shown in section 2.5 re-drawn with information and support, self-help and user involvement integrated into the network of support, not shown as separate services. We would also like to see the role of the different types of informal support structure clarified, as per the Cancerlink Study referred to above.	Macmillan were commissioned from the start of the project to provide a user perspective –the Guidance Development Team is working with Macmillan to review this input and to raise the profile of the user perspective and input. Diagram redrawn.
Macmillan Cancer Relief	3.2.3 Partnership between User and Professional	We are concerned about the paternalistic nature of some of the recommendations and the inference that "the professional knows best". We would like to see greater emphasis given to the important role of professionals in listening to patients and carers, empowering them, and enabling the right decisions to be made about what services to access based on a genuine partnership	Text altered to reflect this.

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		with the patient and their carer.	
Macmillan Cancer Relief	3.2.4 Carers	We welcome the recognition in section 2.18 that the needs of the carer should also be considered, but feel that the needs of carers are under-represented in the remainder of the document.	Part B will include a specific section on carer support and bereavement issues.
Macmillan Cancer Relief	Assessment	We welcome the focus on assessment throughout the document. However, we do not believe that the guidelines take sufficient account of the current situation, namely that professionals are continuously assessing users' needs. We do not believe that assessment always needs to be formalised/written down or that it needs to be undertaken as frequently as suggested in the document (if needs are to be wholly assessed across ten domains at six stages of the cancer journey and there are 200,000 new cancer diagnoses each year, there could be as many as 1.5 million assessments per year!). We believe that the obsession with professionals' assessment of user needs is likely to exacerbate some of the existing problems inherent in trying to develop effective supportive care, and could indeed gridlock the entire system.	See comments above relating to assessment.

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		We believe that NICE should give greater emphasis to the important role that professionals play in recognising and drawing out the knowledge and skills that many users have to assess their own needs – this is consistent with the current emphasis on self-management and the Expert Patients Programme. We believe that the most important thing is for professionals to have the skills to facilitate an appropriate assessment of needs together with the patient and their carer, for the needs to be discussed in multi-disciplinary teams, and for the services to be available once the needs for a service have been identified.	
Macmillan Cancer Relief	3.4 Information	We welcome the emphasis on the importance of information in section 5. However, we do not believe that the guidelines have sufficiently emphasised the importance of information in empowering patients and carers, and helping them to feel in control. We also believe that the two separate chapters on “Face-to-face Communication” and “Information” need to be brought together because this is an artificial distinction.	Text altered to reflect this. The chapters will however remain as two separate topics as the Guidance Development Team believe they address two differing albeit inter-related areas.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Macmillan Cancer Relief		We have provided substantial evidence on the needs of users, yet these views are weak in the document.	Evidence relating to 'need' has been drawn on in the introductory chapters and in the 'issue' sections for each individual topics.
Macmillan Cancer Relief		We believe that information and support services need to be organised strategically to ensure economies of scale and links across the cancer network so that a continuum of support is available throughout the cancer experience – between hospital and the community. We believe that the provision of information and support needs to be seen as an integral part of every professional's work, and in addition, greater emphasis needs to be given to the value of Cancer Information and Support Services/Centres in providing a complementary independent service to people affected by cancer.	The Guidance reflects this.
Macmillan Cancer Relief	3.5 Psychological distress	Psychological distress is to be expected in people affected by cancer as a normal response to a traumatic experience. We believe that section 6.1 over-medicalises this distress. It is important that members of the healthcare team are able to distinguish between normal reactions and a pathological response	Section re-drafted.

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		and refer patients to services accordingly, ensuring that services are targeted at those in the greatest need. We feel that the role of non-professional structures, such as friends and family and self-help and support groups, are not sufficiently reflected in the guidelines. Macmillan recommends that this section be revised to take account of the normal range of psychological distress and to give greater emphasis to non-professional networks of support.	
Macmillan Cancer Relief	3.6 Coordination of care	It is important to stress in section 3.1 that most of the cancer journey takes place in the community, not in the hospital.	Text altered in line with comment.
Macmillan Cancer Relief	Coordination of care	There is no mention of respite care or day care within the document as a whole, an area which is vital for patients and carers alike.	Day care included – please see comments in response to DoH/NAW re. Day Care.
Macmillan Cancer Relief	Coordination of care	Discussion around teams within section 3.19 needs to stress the importance of those teams being multi-professional and multi-sectoral.	Text altered in line with comment.
Macmillan	Implementation	We are concerned that the resource implications for implementing	These comments will be addressed when parts

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Cancer Relief		the guidance will not be incorporated until the final draft in 2003. We are concerned about the lack of realism of some of the guidelines, particularly those affecting assessment, and the potential for gridlock in the system. We note that the availability of additional funding has not been highlighted at this stage. As much of the service delivery occurs within the voluntary sector. Macmillan recommends that, in line with the Compact recommendations, an appraisal be undertaken of the likely implications for the voluntary sector and appropriate funding made available.	A and B are completed and an economic review has been made of the implications of key recommendations. Local implementation and funding arrangements are outside the scope of the Guidance.
Macmillan Cancer Relief	Implementation	The document appears to confuse the roles and responsibilities between Cancer Networks, Supportive and Palliative Care Networks, Primary Care Trusts, etc. Macmillan proposes that all delivery should be channeled through Cancer Networks, with PCT Cancer Leads playing a key coordinating role to bring the key players from the different sectors together.	Text altered in line with comment.
Macmillan Cancer Relief	Implementation	We would like to see greater emphasis on the importance of partnership working between health and social care, and between	This is reflected in the Guidance in as far as the scope permits.

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		the statutory and voluntary sectors. We would urge NICE as a matter of priority to consider the resource implications and to make recommendations that are practical, will require real partnership working between health and social care and the statutory and voluntary sectors facilitated through the Cancer Networks, and will result in services that are sustainable in the long-term.	
Macmillan Cancer Relief	Appendix One	Research on the psychosocial needs of cancer patients and their carers **The Social Impact of Cancer** Macmillan commissioned this MORI poll in 1992. The poll consisted of 976 interviews with patient, primary carers and friends/relatives/colleagues, across 246 constituencies and identified: • The priority needs of cancer patients as being help with: caring for children; lifting heavy objects, cleaning, getting up and down stairs; emotional issues and home support during chemotherapy.	These references will be taken into account in the review of evidence of Part B.

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		• The priority needs of carers as being help and support with emotional issues and practical support such as shopping, cleaning, cooking and laundry. • Increases in expenditure are significant in a number of areas including: transport/fuel costs; heating; special foods; extra equipment and clothing. • That carers needs are less likely to be met than the patients'. • The majority of cancer patients require help from carers for between 1 month and 3 years. **Palliative Care at Home: A Cambridgeshire Study 1994**. This study gathered evidence from questionnaires distributed to GPs, district nurses, patients and carers. All the patients approached were terminally ill. The findings reflected many of those above, identifying that the main areas of difficulty include: • Outdoor mobility, transport, housework and personal care. • Increases in expenditure as a result of the illness. • The needs of carers being less well met than the needs of	

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		patients. **What are the psychosocial needs of cancer patients and their main carers? Lancaster University, 2001** This most recent study supports the findings above and identifies that carer needs are less well met than those of the patient and that significant area of unmet need for both patients and carers are: • Managing daily life, including finances and practical help with housework and children. • Managing emotions. • Managing changes in social identify and body image. **The Carers Resource** A study of 2,500 carers by the Carers Resource (reported in the spring 2002 edition of NHS magazine) revealed that: • 83% carers identified listening and emotional support as their greatest priority. • 60% need benefits advice and advice about money.	

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		• 47% want more personalized information. • 37% want more advice from other professionals. • 22% time off in their own home. • 16% identify needing time away from home.	
Macmillan Cancer Relief		Response on behalf of the User Focus Group BACKGROUND Cancerlink was commissioned to facilitate the user involvement in the NICE Supportive and Palliative Care Guidance by King's College London in spring 2001. The contract for this work transferred to Macmillan Cancer Relief when Cancerlink merged with Macmillan in summer 2001. Cancer Service Users have been involved as members of the Editorial Board and as participants in the focus groups for Part A. CONSULTATION WITH USERS Cancerlink asked those users if they had any comments on: the content of the Draft of Part A and on the process of	Thank you for your comments.

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		involvement so far. Some users have chosen to comment individually and separately to the Guidelines and Audit Co-ordinator. The comments below are a summary of the responses we received:	
Macmillan Cancer Relief		A welcome for the way in which user involvement in supportive and palliative care has been incorporated, particularly as it includes involvement in strategic level decisions about services, as well as decision making for individual patients, including the key components of good supportive care However it is evident that user views and experiences are given a comparatively low weighting by the NICE process in relation to other forms of evidence and therefore it is less likely that services will be based on the patient perspective.	Please see earlier comments regarding evidence review and inclusion of patient experience in RCTS and inclusion of 'needs' based evidence.
Macmillan Cancer Relief		The Guidance is not based on an 'empowering ' philosophy which puts the patient/carer in the centre of his/her care – as shown by the apparent proliferation of professional needs assessment.	Text altered to reflect this wherever appropriate. Macmillan asked to review their input to the project to ensure that this is being highlighted at the key stages in the future development of the document.

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Macmillan Cancer Relief		The Guidance could have included the role patients and carers can play in their own care and to recognise this important and complementary contribution. This was mentioned by users, particularly in relation to psychological support which appears to be a highly professionalised model. The model could be extended to include the role of self help groups and to patients/carers themselves in utilising resources within their own networks (section 6).	See above.
Macmillan Cancer Relief		Themes from the user focus group are applied to some but not all sections. These include • 24 hour contact/helpline • more patient friendly language • integration of services • the need to consider patients/carers in a social (as well has health) context • support for professional staff (not mentioned at all)	Text altered where appropriate to include these issues – and will be covered in Part B. Support for professional staff is included in the text.
Macmillan Cancer Relief		Emphasis placed on assessment and advice by professionals does not necessarily mean that patients will receive the care and support they need when resources are limited or unavailable.	Please see comments regarding assessment – the purpose of the Guidance is to identify service configurations best placed to deliver

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			high quality care – this should allow for priorities to be set at a local level to ensure delivery of such services.
Macmillan Cancer Relief		There should be more emphasis on the integration of services particularly health with social care and voluntary with statutory. Integration of services, a more holistic approach and having a link worker as a key contact were all strongly suggested by users. By dividing services into professionally determined domains, this need for integration has been ignored or lost.	It is acknowledged that the split of the document into two parts and into sections is artificial – but was done for reasons of pragmatism. There is a key chapter on integration of care – and further work pulling these strands together will emerge in Part B. The need for continuity of care and key contacts have been addressed in the text.
Macmillan Cancer Relief		Emphasis appears to be on hospital and hospice provision rather than community/other voluntary sector.	Community services are identified throughout the document There has been no sub-division of services as either statutory on voluntary as the configurations of both services should be exactly the same. No distinction has been made between hospital and community services for example, they are identified as providers of care. Specific services are only

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			identified where specific recommendations are made.
Macmillan Cancer Relief		Self help groups are characterised in a professional service delivery framework (which is inconsistent with user perspectives) rather than a self help, empowering and holistic framework.	Text altered to reflect this.
Macmillan Cancer Relief		User involvement is not mentioned as a topic area under Aims and Scope (section 1.8) which we believe is an omission.	This will be included in Part B.
Macmillan Cancer Relief		Finally, no reference is made to the membership of the user focus group in the Appendices to the Guidance, whereas the membership of the various Professional focus group members are listed in full.	Macmillan were asked to provide the names of the participants of the user focus group with the permission of the people involved – but this was not received in time for the draft.
Macmillan Cancer Relief		The Introduction to the Service configuration guidance leads one to assume that a set of standards for the provision for Supportive and Palliative care throughout England is being devised. However this is clearly not the case: 1.16 'It is not anticipated that all the recommendations will be achieved in all areas immediately, or in the short term…'	A set of key recommendations will be included once Parts A and B are complete. This may be used to determine priority areas for implementation. Work will follow on from the Guidance including for example, a set of standards which will be used to assess the levels of service provision across the country.

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		1.18 'Local circumstances will dictate modifications in the way the Guidance is implemented…' It is reasonable to conclude therefore that the Guidance will not lead to people with cancer receiving comparable levels and standards of care regardless of their location or local circumstances.	
Macmillan Cancer Relief		Table 1.1 Evidence Grades clearly identifies that the results of randomized trials are held to be of greater value – Grade 1 strong evidence - than the experience of people living with cancer, which is regarded as 'weak evidence' – in essence therefore that the views of patients and carers are deemed to be of little value in determining standards. This attitude toward the views of people with cancer is in marked contrast to the sentiments of the NHS Cancer Plan and the work going on throughout the cancer networks, which are actively engaging the views of patients and carers.	Please see comments regarding high level evidence and the inclusion of patient experience – and the use of 'needs' based sources throughout the Guidance. Where higher level evidence is absent the Guidance is drawing on other sources of evidence including consensus and expert opinion.

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		1.16' ……….It might seem reasonable to prioritise on the basis of the likely impact of change – as far as this may be judged from the evidence…..' 1.17 '….The amount and strength of supporting evidence available also varies, partly reflecting the fact that research into supportive and palliative care has tended to focus on specific issues' It is reasonable to question whether this ranking of evidence reflects best thinking or is a positive reflection of a decision to downgrade the views of people with cancer. 'Only a small fraction of therapeutic decisions in medicine can be supported by the results of randomized trials. Almost no managerial or policy decisions can be so supported. Almost no conclusions as to the causes and natural history of disease can be supported by such evidence. For most of our knowledge of medicine in terms of therapy, aetiology and health care planning, we must use observational studies, because of the ethical and	

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		logistical impossibility of mounting randomized trials in more than a tiny proportion of circumstances. We must therefore be prepared to consider such observational evidence and to gain skill in judging such evidence in terms of the extent to which it supports a causal relationship.' J. Mark Elwood, (Professor and Chairman, Department of Community Medicine and Epidemiology, University of Nottingham.) 'Causal Relationships in Medicine: a practical system for critical appraisal', Oxford, 1988, p.9: It may not be without significance that in recommending a structure and process to plan and review local supportive and palliative care service (C.1. page 19), 'ensuring the views of patients and carers are taken into account' is listed last of eight elements for consideration.	
Macmillan Cancer Relief		At D.1, page 22 it is both insulting and demeaning to the experience of people with cancer to write that ' Studies have reported that the assessment of patients' physical symptoms and	References now included.

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		psychosocial needs is often inadequate' but add that this statement is provisional on the evidence review team supplying data. What does the latter statement say about the attitude of the writers of the Guidance to the experience of patients and carers?	
Macmillan Cancer Relief	Communications.	People with cancer who attended the Cancerlink workshop, which submitted evidence to the preparation of the Guidance, represented the views of patients and carers from all over England. On the subject of quality of communications they were unanimous in their view that there were examples of good practice to which all professionals should aspire, but that generally poor communications were a major issue for the great majority of people with cancer.	
Macmillan Cancer Relief	4.8 and 4.9	*All health and social care professionals should be able to judge….etc* and 4.9 …….*who should be an effective communicator* are both unacceptable.	'Should' changed to 'must'.
Macmillan Cancer Relief		Unless health and social care professionals are required to achieve a minimum standard of professionalism in	See comment above regarding standards being derived from the Guidance to assess local

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		communications then quality standards will never reach acceptable standards.	services.
Macmillan Cancer Relief	5.5	Information *5.5 The information needs and preferences of individual patients and their carers should be assessed by a trained health or social care professional at key points in the cancer journey* It is not without significance that no evidence is offered to support this statement, possibly because the proposal is wholly untenable. It is unacceptable that anyone should seek to control how much information a patient may have about their own state of health and the options that may be available in the treatment of their condition.	Text altered in line with comment.
Macmillan Cancer Relief	5.8	*The adequacy of provision of information to patients and carers should be reviewed regularly, in association with groups of service users.* Patients and carers should lead on this requirement.	Text altered in line with comment.

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Association for Palliative Medicine of Great Britain and Ireland		This organisation was approached but did not respond.	
Association of Surgeons of Great Britain and Ireland		This organisation was approached but did not respond.	
Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Macmillan Cancer Relief	5.9	Decisions on local policy should be informed by surveys of patients' and carers' experiences *Local policy should be driven by patients' and carers' experiences.*	Text altered in line with comment.
Macmillan Cancer Relief	5.11	Information to people with cancer should be available in paper-based and electronic formats at all times.	Text altered in line with comment.
Macmillan Cancer Relief	5.12	All information should be all patients at all times with the need determined solely by the patient.	Text altered in line with comment.
Macmillan Cancer Relief	5.14	No evidence is offered to support the contention that withholding information from patients might be to their benefit, indeed evidence offered on P.77 and P.88 of the Research Evidence Manual positively contradicts the proposal. 'The patient has a right to know' is the only acceptable statement when determining policy on information distribution.	Text altered in line with comment.
Macmillan	Psychological	6.6 Requires that the psychological wellbeing of patients be	Section re-drafted.

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Cancer Relief	support services	assessed appropriately and 6.7 proposes that those who are found to have significant levels of distress (etc). This raises two critical issues. It would appear that the patients own view of how well they are coping with their illness, their treatment or their prognosis will not entitle them to receive any support unless their state of mind is deemed to meet some undescribed criteria. But what is significant to one patient or their assessor may be quite different to another patient or his or her assessor. The only acceptable measure of distress must be that of the patient.	
Macmillan Cancer Relief		Secondly 6.6 and 6.7, when read in conjunction with 1.6 and 1.8 raise the prospect of continuing variance in service quality and of rationing which cannot be the desired outcome of this Guidance?	Please see points above relating to key recommendations and national assessment.
Macmillan Cancer Relief		Throughout the Draft document we have referred to those on the Cancer Journey and those who need terminal care and bereavement counselling for Carers. I feel there is one category of patients that has been left out. They are those who, following their treatment are left with a poor Quality of Life. E.g. Those who have radiotherapy injuries or	The needs of people who are experiencing issues of this nature are reflected in the section on psychological support, and will also be identified in Part B in the rehabilitation section.

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		surgical damage etc. These injuries are there for life, as at the present time, there are no procedures or treatments to cure them. So expert help is required. I feel strongly that these should be included in the draft. Some may say that these people are covered and do not need to be written in to the draft but in my experience this is not always so. They need care and management of their difficulties for the rest of their lives. This could be described as continual Palliative Care. According to the Maher Report, 'Management of Adverse Effects following Breast Radiotherapy'. Each patient experiencing adverse effects should have their care co-ordinated and managed by a Clinical Oncologist Consultant at a Cancer Centre for the rest of their days. Although the Report was published in 1995 and distributed to all Clinical Oncologists it has still not been acted upon by all Centres. Many of those injured find themselves and their GP's trying to manage their problems alone.	

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		The Maher Committee was a multidisciplinary committee set up in 1994 under the auspices of the Royal College of Radiologists at the request of the Department of Health. I feel that the work being done for NICE is an opportunity to correct this.	
Marie Curie Cancer Care	Introduction	Marie Curie Cancer Care is pleased to have the opportunity to make initial comments on this draft Service Configuration Guidance. The charity looks forward to the second phase of consultation when a longer timeframe will allow a more in-depth consultation amongst the many senior clinicians within the charity.	Thank you for your comments.
Marie Curie Cancer Care		We wish to make the following general and specific comments. The Guidance states that its aim is to identify service models likely to lead to high quality care for patients with cancer. It describes drawing together work undertaken in many other initiatives in England and Wales in relations to aspects of care of the cancer patient. The resulting recommendations for service organisation, based on a critically appraised evidence review are helpful but not always consistent and in some cases contradictory	Text altered where specific contradictions have been identified.

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		when the text is read as a whole.	
Marie Curie Cancer Care	General themes	The Cancer Plan required the setting up of palliative and supportive care networks. These networks are now in place, mirroring the cancer networks, across England and Wales. These networks, whose membership includes providers from the voluntary sector (7.18), have already begun to evolve service delivery plans for their populations. The Guidance does not specifically refer to the palliative and supportive care networks. It is of concern that very considerable effort has been expended by hard-pressed clinicians and managers to establish such networks if now the Guidance is to suggest a change in the fundamental structure of the organisation of services. The charity recognises that there is no evidence for the concept of networks but notes that significant reference is made to the cancer network within the text of the Guidance. Reference is made in some parts of the text to individual organisations agreeing mechanisms for referral criteria, etc (7.11, 7.12) rather than on a network-wide basis.	Text altered highlighting the statement in the Cancer Plan and the local interpretation/implementation to deliver supportive and palliative care services.
Marie Curie Cancer Care		Recommendations are made concerning staffing levels within the setting of a cancer network. It is assumed that this advice may be	A full economic review will be included as a part of the final version of the Guidance.

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		extrapolated to the palliative and supportive care networks. However, there are recommendations (6.15) which require the involvement of large numbers of staff not currently designated as providers for cancer services. It is not clear how such staff will be consulted, engaged or resourced in terms of funding or manpower development within this Guidance.	
Marie Curie Cancer Care		Many recommendations are made throughout the Guidance on staffing levels required to provide various aspects of supportive care. At present, staffing assessments are made within the palliative and supportive care networks and approved by the Cancer Network Board. However, as funding for new post developments is not held within these networks, such developments may not always proceed. It would be helpful if the Guidance would be clearer about the relationship between funding bodies, in particular Primary Care Trusts, and the expert recommendations of networks.	Text altered to clarify this.
Marie Curie Cancer Care		This Guidance recognises that a strategy to provide support throughout a cancer patient's journey is extremely resource-intensive. There are no specific recommendations concerning	Specifying numbers of staff is outside the scope of the Guidance - but a full economic appraisal of key recommendations will be made

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		numbers of staff, but it is clear that in order to achieve the suggested levels of support, the enormous increase in education and training of generalist staff and even simply to provide 24-hour access to specialist care, a large increase in the number of healthcare professionals will be required. It is not clear where the funding for such posts, or indeed where the personnel, will come from.	as a part of the full and complete version of the Guidance
Marie Curie Cancer Care		Throughout the Guidance document, reference is made to the need for training of all levels of staff involved with the care of cancer patients. It is suggested that specialist palliative care practitioners would, in many cases, be the appropriate source of trainers for such education. Whilst this is undoubtedly considered by many practitioners to be a key part of their role, in reality small specialist teams are already significantly overburdened by their training and education commitments	Comment noted – but this may be a part of working collaboratively across providers which is identified in the text as being necessary to deliver a number of aspects of care identified in the Guidance.
Marie Curie Cancer Care		Reference is made within the document (1.19) to the Guidance being useful in determining priorities for the research agenda. No reference is made to the already established National Cancer Research Networks and the ongoing recruitment of a chairman for	Text altered in line with comment.

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		the Palliative Care Research Group, or how the priority in research agenda setting will be achieved.	
Marie Curie Cancer Care		In the introduction to the Guidance (1.16) brief mention is made of variable timeframes. However, within individual chapters recommendations are made for considerable investment in personnel and service development (6.27-6.30) which in most situations, will be developing from a minimal baseline. No suggestion for a suitable timeframe is given for these developments.	This will be a part of the economic review – and will be a part of local implementation which is outside the scope of the Guidance.
Marie Curie Cancer Care		The Guidance contains many recommendations for service configuration and delivery which are very specific and detailed. In some situations (6.31) recognition of the absence of formal evidence for the benefit of such recommendation is given. Some of these recommendations involve considerable manpower investment; without evidence, or funding, to support such developments, it will be difficult for commissioners to prioritise their investment.	This will be covered in part in the economic review. Where high level evidence may not have been available the Guidance has drawn on professional consensus or user views to determine the impact that certain recommendations might have in providing high quality services. Key recommendations will be identified in the final version of the document.
Marie Curie Cancer Care		It is important that the Guidance should be consistent about its use of terms and definitions. Supportive care is defined as the	The definitions used are drawn from the National Council for Hospice and Specialist

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		responsibility of all health and social care professionals (2.6) and not a distinct specialty. If, however, some healthcare professionals develop an expertise in aspects of supportive care, they are designated as specialists. From this, within the text and fig. 2, it would appear that there are, by definition, specialist supportive care services. Comment is made that these definitions in principle will evolve over time (2.9). It is not however clear in which forum this will happen in order that a co-ordinated approach to such terms may be developed. Many surveys of the general public and patients have shown that they are not familiar with the term 'palliative care'. It would seem necessary therefore, that healthcare professionals should clarify their use of terms quickly in order that general public education may be undertaken.	Palliative Care Services – and are the definitions current at the time of writing the Guidance. The National Council might be the forum for taking the debate forward regarding definitions – but this is outside the scope of he Guidance.
Marie Curie Cancer Care		Guidance is given on the development of specialist palliative care services (7). The introduction recognises that such services are specialist and have a clear role in the care of patients with cancer. It is therefore surprising that there are not also chapters on the	Oncology is identified as a part of the services comprising specialist palliative care services – and oncologists are identified as providers of both supportive care and general palliative care

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		role of medical and clinical oncology within a supportive and palliative care strategy.	to their patients. The Guidance Development Team has chosen not to delineate the input of individual professional groups in individual chapters or sections.
Marie Curie Cancer Care		A large proportion of specialist palliative care is carried out within the voluntary sector. Representatives of the voluntary sector are fully engaged members of the palliative and supportive care networks. Indeed many of these networks are chaired by representatives of the voluntary sector. It is inappropriate (7.18) for the Guidance to suggest that the voluntary sector is not fully engaged within the network structure.	Text altered in line with comment.
Marie Curie Cancer Care		Confusion about the proposed organisation of specialist palliative care services is demonstrated by reference to 'each specialist palliative care service' (7.12) and 'all specialist palliative care providers within a network' (7.21) making arrangements for relationships with referring services.	Text altered in line with comment.
Marie Curie Cancer Care		Reference is made to the core members of a specialist palliative care team (7.23). The presence of a specialist social worker or	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		counsellor able to provide psychological and social support has been established as a core component of a specialist team for some time and is supported by statements from the National Council for Hospice and Specialist Palliative Care Services. It would be a retrograde step to allow this component of care to be removed from the core of a team.	
Marie Curie Cancer Care		Guidelines setting out admission criteria to specialist palliative care units should be established by the palliative and supportive care network rather than the cancer network (7.29).	The supportive and palliative care network works alongside and in conjunction with the cancer network.
Marie Curie Cancer Care		Reference is made to the Care Standards Act (2000). Voluntary providers are already bound by this Act but changed requirements for the provision of single rooms have already occurred. These changes to significant parts of the Act are clearly not helpful for small, independent providers. Mention is made in the Guidance of the appropriateness of the physical surroundings in which care is undertaken. The Guidance could be more helpful in the way it interacts with the Care Standards Act.	Comment noted – but considered by the Guidance Development Team to be outside the scope of the guidance.
Marie Curie Cancer Care		Specialist palliative day care/therapy is now an established component of the provision of care. Whilst there maybe no	Included – please see earlier comments relating to inclusion and links to part B.

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		evidence for the cost effectiveness of such care (7.37), there is clearly a large component of patient satisfaction with such services. There are examples within the Guidance of patient satisfaction surveys being used as evidence. Why are these surveys not appropriate in this situation?	
Marie Curie Cancer Care	General Palliative Care (8)	No mention is made of the provision of inpatient beds in which general palliative care may be carried out. Clearly these are an important part of the overall provision of care within a network and should be mentioned.	This level of care is likely to be provided as a part of care wherever the patient is – hospital, home, nursing home etc.
Marie Curie Cancer Care		Reference is made in the text to education initiatives and specific examples are quoted. Reference to other services is made without reference to named providers. This approach is not helpful.	The initiative identified is a national initiative and is a part of the Department of Health supportive care strategy.
Marie Curie Cancer Care		Reference is made to variability of access to general palliative nursing care in the community (8.23, 8.25). The Marie Curie Nursing Service is clearly an example of a service available within a network setting.	Comment noted – but this is a part of local implementation and service delivery.
Marie Curie Cancer Care		The charity welcomes the specific mention of care pathways as an instrument for improving the delivery of care in all settings	Text altered in line with comment

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		(8.41). We note the strong recommendation (8.29) of involvement of a hospital specialist palliative care team in certain situations. The language implies that this recommendation is the most forcefully supported of all recommendations within the Guidance. There does not appear to be more sound evidence for this recommendation than for many others. It would be helpful, referring back to the general point about timeframes, for the Guidance to be consistent in its recommendations or suggestions of the development of services.	
Merck Pharmaceuticals		This organisation responded and said that it had no comments to make.	
National Cancer Alliance		This organisation responded and said that it had no comments to make.	
National Council for Hospice and Specialist Palliative care		The primary questions to be addressed are: Does the draft guidance appear broadly sensible? Does the draft guidance deliver what might have been expected	Thank you for your comments.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Services		from the Commissioning Brief and Scope? How might the draft be improved in detail? 1. The Guidance Overall In response to the first question the conclusion is drawn that overall the document is soundly based and reflects current majority professional opinion about supportive and palliative care. There are no major conflicts with guidance offered by the National Council. There are therefore no surprises in the recommendations although there may be several important omissions e.g. supportive and palliative care networks, day care, respite care. For the most part the recommendations are practical but some may need to be more detailed e.g. those relating to the continuing education of health and social care professionals.	
National Council for Hospice and Specialist Palliative care		While Box 1.1 describes the scope of the guidance and its limitations, it is suggested that the focus on adults rather than children could be made more specific. This could be achieved simply by incorporating the word ‘adult’ in the title of the Manual.	Title of Guidance altered.

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Services		It may also be helpful to refer to sources of guidance explicitly for children's services e.g. the forthcoming National Service Framework.	
National Council for Hospice and Specialist Palliative care Services		Similarly, there is a need to give greater prominence that the guidance may be useful for informing the development of services for the non-cancer groups of patients and their carers e.g. CHD, older people.	Reflected in scope of Guidance in first chapter.
National Council for Hospice and Specialist Palliative care Services		The final comment is that the Manual is already very long and will be even more so when Part B is added together with the economic analysis and the suggestions for adding a chapter on Education and Training and a Glossary (see below). It is suggested that consideration be given to editing the document.	There will be a public version of the guidance and the executive summary will also be printed as a separate document. The evidence may be available only in CD format.
National Council for Hospice and Specialist Palliative care Services		2. Delivery against the Commissioning Brief and Scope Consideration of the second question is more complex. It is first necessary to recall the key points from the Commissioning Brief and Scope.	

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		Commissioning Brief • The guidance will inform service configuration in both England and Wales.(7.4) • Preparation of guidance – describing recommendations for models of service delivery, the anticipated benefits, the levels of evidence supporting the recommendations and approaches to measurement and cost impact of recommendations. (8.4.3) • If possible a distinction should be drawn between ‘core services’ – most likely to have a major impact on patient/carer well being and ‘non-core services’ – which may be welcomed by patients, but for which the evidence of benefit is less well established. (8.5) • The Institute will consider the health economic analysis, to assess the likely resources needed to achieve the recommended configuration of services. (8.6) The Scope	

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		• The guidance will advise on the services needed to optimise the physical, psychological, social and spiritual well being of those affected by cancer. (1.3) • The areas covered by the guideline will include evidence-based recommendations for supportive care networks, information delivery and communication, inter-professional communication, symptom control and access to specialist palliative care, community supportive care, complementary therapies, models of psychological care, social inclusion, users' and carers' needs, social care and meaning and belief. (Fig. 1) • The guidance should cover care in all sectors in the NHS – i.e. in the community, in hospitals, in NHS hospices and other institutions (4.1) • The guidance will also be relevant to services provided outside of the NHS such as nursing homes and charity run hospices, but will not directly address these services. (4.2) • The guidance should cover all aspects of the care pathway	

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		– from the time that cancer is suspected through to death and bereavement. (4.3) • The guidance will provide a preferred model through which effective treatment/care should be delivered rather than clinical guidelines for the treatment/care of specific symptoms/conditions.(5.2.3) The following questions arise: Does the draft offer guidance on ‘service configuration’? What the draft does is, in its own words (Introduction 1.7), to describe the ‘organisational and professional interventions for the differing service components that make up supportive and palliative care, underpinned by effective co-ordination.’ It does not offer guidance on how they might best be configured i.e. how the service components should be brought together to provide a supportive and palliative care service for a population. It is probably wise not to attempt that since there are probably several	The Guidance Development Team will consider whether an overarching model for integration will be included once Parts A and B are completed.

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		different models of organisation and integration of the different service components that would deliver good quality services for patients/carers. It might be helpful if the guidance acknowledged this.	
National Council for Hospice and Specialist Palliative care Services		Does the guidance provide a basis on which an economic analysis can be made? The draft indicates (Introduction 1.11) that the measurement and resource implications have yet to be assessed. It is intended that they will be included in the final version when Part A and Part B have been completed. There will be two major impediments to achieving that: • There are no recommendations in this draft about the required volumes of each service component for specific populations. In order for the workforce implications to be assessed there would need to be some assessment of the numbers of the various professionals that may be required to deliver the defined service components. • The underlying premise of this guidance is that it is the	Defining precise service volumes is outside the scope of the Guidance (in line with other Improving Outcomes Guidance documents). The economic analysis will review the cost impact of key recommendations – and items such as staff costs are common to both statutory and voluntary sector services. Local implementation (and therefore voluntary sector payment arrangements) is outside the scope of the Guidance.

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		responsibility of the NHS to ensure that the service components defined are provided as mainstream NHS care for people with cancer and their carers. Some of the service components are currently provided for the NHS by non-NHS agencies e.g. voluntary hospices. Until such time as there is agreement about the arrangements for payment of non-NHS agencies for services delivered, the economic analysis cannot be completed.	
National Council for Hospice and Specialist Palliative care Services		Does the guidance make a distinction between core and non-core services? No distinction appears to be made at this point. Services that are not regarded as ‘core’ are merely omitted e.g. day care/therapy has been omitted on the grounds that there is ‘no evidence on the efficacy of specialist palliative day therapy’. If that conclusion is sustainable (and it may not be – see below) then day care seems to be an obvious candidate for designation as ‘non-core’. There is much evidence that it is ‘welcomed by patients’.	Day care is included – see other comments relating to day care.
National Council		Does the guidance include all the areas included in the Scope?	Text altered highlighting the statement in the

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
for Hospice and Specialist Palliative care Services		There are no recommendations concerning ‘supportive care networks’. There are also no references to them. It may be that the conclusion has been drawn that there is no evidence to support the efficacy of supportive and palliative care networks. However, such a conclusion could also be drawn in respect of Cancer Networks. The Cancer Plan is committed to the establishment of supportive care networks (later to be called ‘supportive and palliative care networks) and consequently the guidance does need reference to them.	Cancer Plan and the local interpretation/implementation to deliver supportive and palliative care services – and the role of supportive and palliative care network working alongside and in conjunction with the cancer network.
National Council for Hospice and Specialist Palliative care Services		Is there clarity in the guidance about how it will be relevant to services provided outside the NHS? This issue is not addressed in the draft document. There probably needs to be a recommendation that supportive and palliative care services supplied by non-NHS agencies for the NHS (and funded by the NHS) will need to comply with the	This is made clear in the scope of the Guidance in the first chapter.

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		recommendations in the guidance. It would also need to be acknowledged that such a requirement would not apply to services that were not supplied for the NHS.	
National Council for Hospice and Specialist Palliative care Services	Chapter 1 Introduction	Detailed Comment Box 1.1 – The first bullet point could be better worded as 'the primary audience is NHS commissioners of supportive and palliative care services (across health and social care sectors) whether supplied directly by the NHS or by non-NHS providers for the NHS'	First quote cannot be altered as published as the scope of the Guidance – but suggested text incorporated in chapter.
National Council for Hospice and Specialist Palliative care Services		1.11 – See comments above about economic analysis. 1.14 – The resource implications are not yet considered. Box 1.2 and 1.16 – Reference needs to be made to Supportive and Palliative Care Networks	See comment above.
National Council for Hospice and Specialist		1.18 – How is it proposed that 'standards will emerge from the recommendations'?	Structure, process and outcome measurements relating to key recommendations will be included in the final version of the Guidance –

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Palliative care Services			the work undertaken to produce a set of standards for the Manual of Cancer Services Standards is outside the scope of both the Guidance and the Guidance Development Team.
National Council for Hospice and Specialist Palliative care Services	Chapter 2 Background 2.1	In the year 2000 there were 537,877 death registrations in England and Wales. The underlying cause of death was neoplasms in 134,490 of these deaths. (source Office of National Statistics). This is considerably different from the statistics given. The data needs to be checked and its source referenced.	Text altered in line with comment
National Council for Hospice and Specialist Palliative care Services	2.5	The Cancer Journey. A note needs to be added at the foot of the figure stating that supportive care is provide throughout the whole journey.	Covered in the text.
National Council for Hospice and Specialist Palliative care	2.11	Add to bullet points 'complex psycho-social issues'	Text altered in line with comment

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Services			
National Council for Hospice and Specialist Palliative care Services		– Amend 'may' to 'should' in line 5. The problem with offering examples is that those professionals who are not mentioned wish to be. Requests include social workers, physiotherapists, psychologists.	The first point relates to the definition of specialist which the Guidance Development Team have taken to mean someone who may have received specialist or higher training and /or have specific expertise gained through time for example. The text provides examples only – but text altered to include AHPs.
National Council for Hospice and Specialist Palliative care Services		What are cancer counsellors? How are they defined? There needs to be a Glossary Of Terms as an Appendix to this guidance.	A glossary will be included in the final version of the Guidance when Parts A and B are brought together.
National Council for Hospice and Specialist Palliative care Services	2.15 & Fig 2	The weakness in the diagram lies in the separation of 'specialist palliative care services' from other specialist contributions to supportive and palliative care. Only one circle is required that should be called 'specialist contributions to supportive and palliative care.' A note could be added at the bottom of the Fig along the lines of 'this includes specialist palliative care services,	Diagram redrawn

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		information resource and advice centres ………' The problem with the term 'specialist supportive care services' is that it appears to be in conflict with the statement in 2.6 that 'supportive care is not a distinct specialty'.	
National Council for Hospice and Specialist Palliative care Services	Chapter 3 Co-ordination of Care 3.7 & 3.8	The word 'quality' is used in these two paragraphs and frequently elsewhere in the document. What concept of quality is being used by the Guidance Development team? Is there consistent use of the term throughout the document?	This comment is to some degree tautological in that the Guidance itself defines what is meant by quality.
National Council for Hospice and Specialist Palliative care Services	3.8	Delete the word 'appropriately' in the second bullet point.	Text altered in line with comment.
National Council for Hospice and Specialist Palliative care Services	3.9 & 3.10	These paragraphs need redrafting to take account of the role of Supportive and Palliative Care Networks. Particularly important is the membership of these networks that include commissioners, providers from NHS, voluntary and private sectors, social services, users and other key stakeholders. Good co-ordination	

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		of care will not be achieved unless the decision making process embraces all these interested groups who need to be regarded as partners. The sixth bullet point reveals a misunderstanding of what is required. It is not liaison that is required but true partnership working with joint decision making.	
National Council for Hospice and Specialist Palliative care Services	3.11	Somewhere in this or succeeding paragraphs reference needs to be made to assessment of patient and carer needs being made with patients and carers i.e. a shared professional/patient/carer function.	Text altered in line with comment.
National Council for Hospice and Specialist Palliative care Services	3.12	It is illogical to list 'palliative care' as a domain of palliative care. It should be omitted from the list.	Text altered in line with comment.
National Council for Hospice and Specialist Palliative care	3.13	There are numerous references to the workforce needs for training throughout the document. Many supplementary questions arise. For example in this recommendation – Training in precisely what? Who is going to provide the training and how?	Clear reference made to relationships with Workforce Development Confederations. Decision made by Guidance Development Team not to include separate chapter – as

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Services		Who accredits the training courses? There needs to be an additional chapter on Workforce Education & Training Needs.	largely beyond scope of the Guidance to answer these type of questions.
National Council for Hospice and Specialist Palliative care Services	3.19	Add to the first bullet point 'including Palliative Care Consultant and Clinical Nurse Specialist in Palliative Care.	This will be left to local implementation.
National Council for Hospice and Specialist Palliative care Services	3.22	There needs to be acknowledgement of the contractual responsibility for provision of 24 hour care when the patient is at home.	Comment noted – but decision made by Guidance Development Team not to alter text.
National Council for Hospice and Specialist Palliative care Services	3.25	There needs to be acknowledgement of the need to improve communication between the NHS and voluntary sector e.g. a recommendation that the NHS should ensure connection of voluntary providers to NHS Net would be very helpful.	Outside the scope of the Guidance.
National Council for Hospice and	3.32	See comments above about the omission of references to Supportive and Palliative Care Networks.	See comments above.

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Specialist Palliative care Services			
National Council for Hospice and Specialist Palliative care Services	Chapter 4 Face to Face Communication 4.4	There needs to be reference to the problems of communication with those from different ethnic and cultural backgrounds	Text altered in line with comment.
National Council for Hospice and Specialist Palliative care Services	4.10	As this recommendation stands it is probably impracticable as well unethical.	Text altered to make meaning clearer.
National Council for Hospice and Specialist Palliative care Services	4.12	Why is this list restricted? Equally important are GP, Community Nurse and Consultant.	Text altered in line with comment – patient choice is the deciding factor.
National Council	4.13	Although this may be desirable it may be impossible for 'all'	Text altered in line with comment.

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for Hospice and Specialist Palliative care Services		consultations.	
National Council for Hospice and Specialist Palliative care Services	4.14	The first sentence is unclear. What is it that staff are being asked to do? It needs to be spelled out.	Text altered in line with comment.
National Council for Hospice and Specialist Palliative care Services	4.25 & 4.26	Consideration should be given as to whether a stronger line should be taken. The whole thrust of this chapter is concerned with the importance of everyone involved in cancer care to have good communication skills. If that is right then is it not important to state that? If it is good that staff who have received training should continue to be evaluated, would it not be also good that there should be evaluation of those who have not received training?	Text altered in line with comment.
National Council	Chapter 5	This organisation responded and said that it had no comments to	

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for Hospice and Specialist Palliative care Services	Information	make.	
National Council for Hospice and Specialist Palliative care Services	Chapter 6 Psychological Support Services	There are considerable doubts about the widespread use of the term ‘psychological care’ when what most patients need is ‘emotional support’. In short, the overwhelming view is that this Chapter is focused overmuch on the minority of patients and carers who do need psychological care and to the detriment of the emotional support that the good Community Nurse, GP, Hospital Cancer Team or Palliative Care Team can provide for the majority of patients. 6.4 -There should be a reference to specialist palliative care teams. 6.11 – It is considered that the provision of clinical supervision for all staff providing psychological support is both impractical and unnecessary.	This entire section redrafted to include these and other comments.

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		Table 6.1 Where does the specialist palliative care team fit into this categorisation? Where should it fit? What is the role of its core members in providing psychological assessment and support i.e. doctors, nurses, social workers, Allied Health Professionals?	
National Council for Hospice and Specialist Palliative care Services	6.15 – Level 2	Two additional points of crisis should be added i.e. entering the terminal phase and the point of actually dying.	Text altered in line with comment.
National Council for Hospice and Specialist Palliative care Services	Chapter 7 Specialist Palliative Care Services 7.12	The mechanisms and criteria should be consistent with Network standards.	Included in subsequent paragraphs.
National Council for Hospice and Specialist Palliative care Services	7.13	Add ‘and other key factors’ at the end of the paragraph.	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
National Council for Hospice and Specialist Palliative care Services	7.16 & 7.17	Unless guidance is given on numbers of staff, economic analysis will not be possible (see comments above).	See previous comment regarding this being outside the scope of the Guidance.
National Council for Hospice and Specialist Palliative care Services	7.18	The opening sentence assumes the voluntary sector is separate from the cancer network whereas, to achieve good service integration, the voluntary sector has to be within and part of the cancer network (see comments on networks above).	Text altered in line with comment.
National Council for Hospice and Specialist Palliative care Services	7.19	Advice and care has to be available in any institutional setting. Among those not mentioned are community hospitals, institutions for the mentally ill, prisons.	Text altered in line with comment.
National Council for Hospice and Specialist Palliative care		Either here or in the Chapter on general palliative care services there needs to be reference to and recommendations about the need for general palliative care beds that are often provided by nursing homes, community hospitals and some hospices. The	This level of care is likely to be provided as a part of care wherever the patient is – hospital, home, nursing home etc.

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Services		function of these beds is to provide general palliative care – terminal care, respite care. Without these facilities bed blocking will occur in both acute hospitals and specialist palliative care units. They should be linked to the specialist services that should be able to provide assessment, advice and care.	
National Council for Hospice and Specialist Palliative care Services	7.20 First bullet point.	The word 'discussed' may not be appropriate on its own. The following is suggested: 'this assessment should be sent to the named specialist palliative care team for discussion if appropriate'.	Text altered in line with comment.
National Council for Hospice and Specialist Palliative care Services	7.23	Palliative care consultant and palliative care nurse specialist should be in the plural. There is good evidence from the Royal College of Physicians that single handed consultants are not viable in the longer term.	Text altered in line with comment. It is made clear in the text that collaboration is likely to be necessary to provide the levels of care and service defined in the Guidance - this is an issue for local implementation.
National Council for Hospice and Specialist Palliative care	7.24 & 7.31	The epithet specialist should either be dropped from the first two bullets or inserted for all of them.	Text altered in line with comment.

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Services			
National Council for Hospice and Specialist Palliative care Services		What is existential support?	Text altered in line with comment – phrase deleted.
National Council for Hospice and Specialist Palliative care Services	7.30 and elsewhere in this chapter	There is no reference to the need for a lymphoedema service. Chronic oedema is frequently a common distressing symptom of advanced cancer. A requirement for this service should be included. It may be that it is more appropriately included in Rehabilitation but at least reference to it should be made here.	This will be included in Part B under rehabilitation services.
National Council for Hospice and Specialist Palliative care Services	7.31	Add radiotherapy to the list.	Text altered in line with comment.
National Council for Hospice and Specialist	7.37	It is stated that there is no evidence on the efficacy of specialist palliative day therapy. It is not clear what the basis for this statement is. Furthermore, given the widespread availability of	Day care included – please see earlier comments regarding inclusion and relationship to Part B.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Palliative care Services		day care services it is not sufficient to dismiss day care in one line. All the supportive and palliative care interventions carried out in day therapy (day hospice) settings are identical to many of those carried out in other settings e.g. home, hospital, specialist palliative care unit. Indeed paragraph 7.39 states that ‘patients can receive high quality care in a variety of settings, providing there is adequate input from specialist palliative care services.’ The message there is that variety of setting does not affect the efficacy of the intervention. Day care is widely acknowledged as providing a social context of friendship and mutual support in which palliative care interventions can beneficially be made. The benefits of mutual support are similar to those gained by patients and carers from support groups and are welcomed by patients. Day care also provides respite for the carers of the patient. All these benefits provide added value over and above the supportive and palliative care interventions that can be carried out effectively in a day care	

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		setting. Where evidence is lacking is in the cost effectiveness of day care/therapy. However there is no evidence in this document concerning the cost effectiveness of home care and yet that is clearly recommended as a core service. There appears to be inconsistency of appraisal of these two services. It is suggested that reconsideration be given to the statement that there is no evidence on the efficacy of specialist palliative day therapy/care.	
National Council for Hospice and Specialist Palliative care Services	Chapter 8 General Palliative Care Services 8.11	More than respect is required in respect to patient preference as to care. Preferences need to be met wherever possible.	Text altered in line with comment.
National Council for Hospice and Specialist Palliative care Services	8.29	This is the only time that the term strongly recommended is used. Are all the other recommendations to be regarded as weaker?	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
National Council for Hospice and Specialist Palliative care Services	8.46 to 8.49	Add the benefits of providing secondments and rotation of staff between general and specialist teams.	There is no evidence to recommend this.
Northern Cancer Network			This organisation was approached but did not respond.
Ortho Biothech		The NICE programme of Clinical Guidelines presents a great opportunity to deliver to the NHS a set of clinically relevant evidence based guidance on best practices across a range of diseases and conditions. In cancer, evidence based clinical guidelines are required to build on the service recommendations identified in the NHS Cancer Plan (1) and the National Service Framework Assessment for NHS Cancer Care in England and Wales (2). The current NICE programme for cancer, including the supportive and palliative care guidance, focuses on service delivery. We welcome this type of guidance but would like to stress the urgent need for complementary and timely clinical guidance on best treatment and care practices in cancer that will	Thank you for your comments.

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		directly improve the quality of the lives of patients with cancer. Guidelines based on good evidence on what treatments work best in which settings are essential to optimise the value of service configuration guidance. Ideally, we would like to see service guidance and clinical guidelines produced in tandem covering both adults and children, but in the absence of this we recommend the Department of Health and/or NICE issue clearer timelines for the production of cancer specific clinical guidelines through NICE.	
Ortho Biothech		Inclusion of symptom and fatigue control in the Draft Guidance Specifically addressing the draft Service Configuration guidance on supportive and palliative care for patients with cancer, we would like to draw your attention to a topic that seems to have been largely overlooked in the Guidance Manual and the accompanying Research Evidence Manual: that of symptom control. We suggest the Guidance Development Team and Evidence Review Team specifically reviews evidence and makes	Symptom control has been included in both the general and specialist palliative care sections of the Guidance – the scope of the Guidance is to review and assess service configurations and not individual treatments for specific symptoms.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		recommendations regarding service configuration and delivery for cancer related symptom management, in particular fatigue management. Symptom control is a key aspect of any supportive care service structure, and has been recognised as such in the National Cancer Plan Section 7.5, page 63) and the National Service Framework Assessment for Cancer (section 3.42, page 47). It is also encompassed within the definition used for supportive care in the draft supportive and palliative care guidance (section 2.5 of the Guidance Manual). Furthermore, the scope for the NICE guidance and the DoH/NAW remit contained within this lists symptom control as an area to be covered by the guidance. The National Cancer Plan reported that in surveys of cancer patients in addition to being treated with humanity, good communication with health professionals, being given clear information about the condition and receiving the best psychological support when needed, high priority is also given to receiving the best possible symptom control. These priorities are also listed in the Guidance Manual (section 2.18). We believe the recommendations contained within the draft guidance have covered sufficiently all these issues with the exception of	

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		symptom control. More precisely, there is no mention anywhere in the Guidance or Evidence Manuals of one of the most important symptoms associated with cancer treatment; that of cancer related fatigue. To date no guidance or planning frameworks have sufficiently addressed the issue of fatigue, either in terms of actual treatments that can make a difference to patient's lives, or in terms of supportive care. Chemotherapy-related anaemia is a major cause of fatigue in cancer patients, which can be effectively treated with erythropoietin (3). Cancer related fatigue is a serious clinical condition with a major impact on quality of life affecting the majority of patients undergoing chemotherapy, but which often goes unrecognised and untreated both in the UK and elsewhere (4, 5). In July 2002 the US National Institute of Health State of the Science Conference issued a statement on symptom management in cancer highlighting low levels of awareness and knowledge of the prevalence and causes of cancer related fatigue, lack of simple assessment tools, and barriers to service delivery that have contributed to the inadequate treatment of	

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		cancer related fatigue, pain and depression in the US (3). There is published evidence of the importance of cancer related fatigue to patients. In a large UK survey of 1307 patients with cancer published in 2000, 58% of patients responding reported fatigue affecting them “somewhat, quite a bit or very much”, compared with 22% for pain, and 18% for nausea/vomiting (6). Despite this, fatigue was not reported to the hospital doctor in 52% of patients with the symptom. Evidence suggests that fatigue is inadequately recognised by health professionals working in oncology. In the same UK survey, only a small proportion of patients with fatigue in the previous month received any treatment or advice from their doctor or nurse on managing the condition (14%), the most frequent advice being to “have a rest”. A US survey also reported fatigue as representing a more distressing problem than pain from the perspective of patients, whilst health professionals thought pain affected patients to a greater extent (7). These studies demonstrate a potential gap between patients and health professionals’ perceptions of the importance of cancer related fatigue, indicating a need to educate and inform clinicians	

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		of the importance of addressing fatigue in cancer treatment. We feel this evidence is relevant for the review, for instance in relation to section D.1 of the Guidance Manual, which states “Studies have reported that the assessment of patients physical symptoms and psychosocial needs is often inadequate”. Despite its importance to the patient, fatigue has been entirely omitted from both the manual and research evidence parts of the draft guidance. At a minimum, fatigue should be included in the list of symptoms within the patient and carer outcome measures defined on page 7 of the draft Research Evidence Manual. Fatigue does not appear to have been a keyword used in the literature search criteria on page 5/6 of this document.	
Ortho Biothech	Section C.2 of Co-ordination of Care	There are a number of recommendations within several of the sections of the Draft manual where revisions to deal adequately with cancer related fatigue would be appropriate: Assessment recommendations – we feel that missing from the list in 3.14 is that assessments at a minimum should also be	Text emphasises that these points are a minimum, and does not negate the value of assessment at other times.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		undertaken at a appropriate point during treatment, in order to identify important treatment related symptoms such as fatigue, identify potential interventions and develop an action plan (section 3.15).	
Ortho Biothech		Face to Face Communication, section 4: C.1 (5.5) of Information, and section 6: C.1 (6.6) of Psychological Support, the cancer journey should include a "during treatment" phase. During this phase the face-to-face communication/information needs and preferences, and psychological well-being of patients and carers should be identified and assessed, including the need for communication and information on fatigue and other treatment related symptoms.	Comment noted but decision made by the Guidance Development Team not to alter text.
Ortho Biothech	Section 4: C.3	Whilst, section 4: C.3 provides several recommendations around communication skills training. However, there does not seem to have been any attention given to recommendations on training of health professionals in symptom management in the Supportive Care part of the Manual (apart from psychological support training in section 6). One key training intervention is in fatigue management as (as we pointed out above) this represents a high	This is covered in the general palliative care section.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		priority issue for patients.	
Ortho Biothech		Symptom and fatigue management issues could be incorporated to some extent into the recommendation parts of the existing sections 3, 4 and 5 of the draft Manual, However, given the importance of this aspect of supportive care we feel that the structures, systems and interventions to support symptom management generally and fatigue management should be included as a separate section in the review, either in part A or within part B when drafted.	Comment noted but decision made by the Guidance Development Team not to alter text.
Ortho Biothech		Cancer related fatigue service interventions On page 7 of the Research Evidence Manual, the types of intervention included in the review is specified as any intervention strategy that improves supportive and palliative care for those affected by cancer, specifically: Professional interventions: strategies to provide professionals with information or training on appropriate practice.	The Evidence Review Team comment that their goal was to review studies on service configurations not on individual therapies and specific symptoms. OrthoBiotech are thanked for these references and for the information relating to various studies – these will be drawn on where appropriate to assess service configurations.

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		Organisational interventions: interventions about changes in organisational systems e.g. multi-disciplinary teams, skill mix changes, setting or site of service delivery. In terms of service configuration interventions for cancer related symptom control that could fall within these inclusion criteria, Ortho Biotech UK and Ireland sponsor or support a number of interventions relating specifically to fatigue and anaemia information, education and service delivery. Here we provide brief details of a number of these service interventions which we feel are within the scope of the guidance: • The Fatigue School, run since 2000, aims to train a maximum of 15 health professionals (e.g. nurses, physiotherapists) each year in fatigue management. Innovative teaching and learning methods are used on the course to educate and empower health professionals on issues such as changing practice behaviour, best multi-disciplinary working practice and leading changes in	

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		improving cancer related fatigue management. Health professionals apply and are selected by an expert selection panel to attend the “school” which consists of three 2-3 day modules run over the course of a year. The school has obtained RCN approval, and is operated in collaboration with cancer related fatigue experts at King’s College, London. Although this initiative has not been formally evaluated to date to provide evidence at grade 1-III level, given it has received professional accreditation it does seem to fit into the evidence grades at level IV according to the criteria in section A9 of the Supportive and Palliative Care Manual. • A “living everyday” patient information pack developed by CancerBacup. Through Cancer Backup, this pack is issued to patients with cancer on request to inform them, and via the patient their health professionals, about fatigue and anaemia. This pack has had an initial evaluation using a patient questionnaire, which included assessment of the	

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		relevance of the information, and whether fatigue was discussed with their doctor/nurse and outcome of that discussion. A total of 550 responses were received, the results indicating generally positive outcomes in terms of relevance and initiation of patient-health professional discussion over fatigue and anaemia. The results of the survey are not published but can be made available to the guidelines team. • Ortho Biotech sponsors the only magazine designed to provide information and news specifically to cancer patients and carers, called I Can. This has an editorial board of experts in the field of cancer care. The magazine comes out quarterly, the first issue in Spring 2002, and its initial impact is in the process of being evaluated (Uptake for the first edition was approximately 16,000, which exceeded expectations). When available, we would be happy to share the results of this initial evaluation with the Guidance Development Team. The magazine is primarily	

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		distributed through health professionals and can be used by them as part of a system of the provision of information to cancer patients and carers about all aspects of cancer and its treatment. All the above service interventions could fall under the remit of the guidance, either within a separate section on service configuration in supportive care for symptom/fatigue control (in part A or B), or within sections 3, 4 and 5 of the current draft guidance. None of these interventions have been fully evaluated to date and results published. However, we would welcome the opportunity to discuss with the NICE Guidance Development Team the value of setting up systems to more fully evaluate these schemes before the end of the development process to support their inclusion in the review.	
Ortho Biothech		Balance of evidence/recommendations. A further comment is there appears to be some imbalance in the guidelines, in that more attention is given to palliative care than	Supportive care includes information giving, psychological care for example which are covered in depth in this part of the Guidance – other topics will be included in Part B.

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		supportive care. That may be indicative of the greater amount of evidence that exists for the former. It may also be related to a fairly narrow scope for the types of supportive care intervention reviewed. Even if there is a lack of evidence due consideration should be given to all types of supportive care, including symptom management.	
Ortho Biothech		Overall, we are pleased that these guidelines are being developed and appreciate the hard work to date of the Evidence Review Team, the Guidance Development Team and associated groups. We recognise that the guidelines represent work in progress. However, we hope that when the resource implications of the recommendations have been incorporated stakeholders as promised will get an opportunity to comment in order to assess the economic and structural feasibility of the guidance. We would however like to stress our belief, supported by the NHS Cancer Plan, that comprehensive guidelines should be developed with the total care of the patient in mind. Ultimately, the effectiveness of the recommendations contained within the draft	See comments relating to the Guidance as a review of service configurations.

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		guidance needs to be measured through the improvements in patient and carer outcomes. These improvements can only be fully achieved through the use of best practice in treatment and care alongside optimal service configurations. Hence the need for complementary clinical guidelines on best treatment and care for cancer. In our original submission we presented evidence at grade 1 level that has demonstrated the benefits of appropriate anaemia management using erythropoietin for reducing cancer related fatigue and improving overall quality of life. Hence, although we welcome service delivery guidelines we strongly feel that these should be supported as soon as possible by clinical guidelines.	
Ortho Biothech		A final observation on the evidence review is that there is clearly a lack of evidence on the cost-effectiveness of the interventions included, especially for supportive care. We would be interested to know how the Guidance Development team intend to address this gap (we notice there does not appear to be a health economist on the Guidance Development Team). It would be useful if as in technology appraisals recommendations are put	An economic analysis is to be included in the final version.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		forward relating to gaps in the evidence base and how they may be filled (in particular to reduce the need for recommendations based on consensus opinion). References: 1. The NHS Cancer Plan. A plan for investment. A plan for reform. September 2000. 2. Commission of Health Improvement/Audit Commission. National Service Framework Assessments no. 1: NHS Cancer Care in England and Wales, CHI, Dec 2001 3. National Institutes of Health State-of the-Science Conference Statement. Symptom Management in Cancer: Pain, Depression and Fatigue, Draft Statement, July 15-17, 2002 4. Blesch et al, Correlates of fatigue in people with breast or lung cancer. Oncology Nursing Forum, 1991; 18(1): 81-87 5. Detmar et al. The patient-physician relationship. Patient-physician communication during outpatient palliative treatment visits in an observational study. JAMA 2001;	

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		285(10): 1351-1357 6. Stone et al, Cancer-related fatigue: Inevitable, unimportant and untreatable? Results of a multi-centre patient survey. Annals of Oncology, 2000; 11: 971-975. 7. Vogelzang et al, Patient, caregiver, and oncologist perceptions of cancer-related fatigue: Results of a tripart assessment survey. Seminars in Haematology, 1997; 34(2, Suppl 2): 4-12.	
Pharmacia Ltd		This organisation was approached but did not respond.	
Prodigy		This organisation responded and said that it had no comments to make.	
Prostate Cancer Charity, The		Thank you for sending the Supportive and Palliative Care Guidance for comment by The Prostate Cancer Charity. The document clearly represents a large amount of work and expresses significant 'notice of intent' for addressing this aspect of care for people with cancer. As requested we have confined comment to the recommendations themselves. We feel that they are practical so	Thank you for your comments.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		have just made suggestions on the tone and completeness of some of them. We have nothing substantive to offer on the interpretation of the evidence, or any additional items of evidence that we feel you should consider.	
Prostate Cancer Charity, The		There is one overarching comment, on tone, that we believe will be helpful. The whole document concentrates on 'delivery' of support and palliative care. On one level this is exactly as it should be. However, such is the concentration on 'delivery' the language of the document forces users into the role of 'passive receivers' of palliative and supportive care.	Text altered to reflect this comment.
Prostate Cancer Charity, The		Communication is not just for health professionals with a message or questions. It is also about the patients – who have questions and messages themselves. Their questions should drive care, not just those of the health professionals. As the document itself says on p16 2.25 patients 'want to feel in control of their own care, rather than being frustrated onlookers'.	Text altered to reflect this.
Prostate Cancer Charity, The		As a simple example of what we mean – the psychological assessment of patients does not necessarily start with the health professional assessing their patient. It could start with the	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		patient's assessment of themselves - 'I feel…. Can you help me deal with this?'	
Prostate Cancer Charity, The		Please add comments and observations about not just 'delivery' but 'responding' to patients - hearing their questions, listening to them and answering them. The Prostate Cancer Charity nurses, and many staff involved in cancer care work entirely this way around. They respond to patients' questions. They always start from that point.	Text altered in line with comment.
Prostate Cancer Charity, The		We also suggest that there needs to be more acknowledgement that supportive care can begin before diagnosis. It is mentioned in the definition of supportive care [2.4] but does not feature elsewhere. Indeed, the need for it may exist where there is a threat of a cancer diagnosis, which never materialises. This is something we find in our work and we can offer supportive care at this time. Concerned patients may perceive themselves as perhaps worrying needlessly, and are uncomfortable about diverting support from whom they see as more 'deserving' cases i.e. those people who have already been diagnosed.	The need for support from before the diagnosis is made has been identified in the text.
Prostate Cancer		Main commentary	Text covers this.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Charity, The		We understand the need to use a broad brush to illustrate what are huge variations in supportive and palliative care within and between patients' lives. However, we caution that the document may unintentionally promote an overly mechanistic approach to assessment. On p20 there should be an acknowledgement that a 'steady state' in palliative care is illusory, achieved by the right assessment at the right time. All services directed at the patients should be as responsive as possible and that this includes repetition of information already given, and also clarification, revision, and reassessment at many different times. Some of these will be patient driven.	
Prostate Cancer Charity, The	C2 3.14	Add 'and when the patient requests it.'	Text altered in line with comment.
Prostate Cancer Charity, The	C3 3.16	Clarify to whom the Service Directories will be circulated. Can patients have one if they want?	Text altered in line with comment.
Prostate Cancer Charity, The	C3 3.17	Are the service directories available for reference? If so, where from, and who can use them?	Text altered in line with comment.
Prostate Cancer	C4 3.19	Is there any specific reason for excluding patients or their carers?	It is recognised that the patient's voice needs to

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Charity, The			be heard – but no evidence of the benefit of including the patient in this context. Aware that some areas take the opportunity to do this – but did not want the Guidance to be overly prescriptive. Areas for further research.
Prostate Cancer Charity, The	C4 3.22	Should the patient be told of the co-ordinator's name and role?	Text altered in line with comment.
Prostate Cancer Charity, The	D1 3.33	The Prostate Cancer Charity is pleased to see an acknowledgement of the changing needs and preferences of patients over time.	Thank you.
Prostate Cancer Charity, The	C1 4.8	'All professionals should be able to judge whether they can address an individuals patients or carers communication needs.' Where is the patient empowerment in that statement? The patient themselves may have strong opinions about whether or not the professional can address an individual's communication needs.	Text altered in line with comment.
Prostate Cancer Charity, The	C1 4.9	How is an effective communicator assessed as such?	The work on standards will address this.
Prostate Cancer Charity, The	C1 4.10	We think the patients should also be informed of the outcome of consultations.	Text altered to make the meaning clearer.

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Prostate Cancer Charity, The	C2 4.18	Preferences for involvement should be recorded – and there should be some acknowledgement that preferences might change over time.	Text altered in line with comment.
Prostate Cancer Charity, The	C2 4.20	Interpreting services are important. Our observation about the underlying tone implies patients are in passive receipt of care is reinforced by the use of the word 'understand'. Are they only to receive information, rather than ask questions or impart it? Health professionals need to hear an opinion or a view or a question, not just make themselves understood. We think inserting 'understand or speak' English would solve this. It is mentioned elsewhere [C1 4.13].	Text altered in line with comment.
Prostate Cancer Charity, The		Family members – including children? This is generally an unsatisfactory arrangement and should be approached with caution – there is scope for coercion or invasion of privacy of both the patient and the prospective interpreter. It should be identified as deficient care in the absence of specific case assessment, except in the most extraordinary circumstances.	Change made to text.
Prostate Cancer Charity, The	C2 4.22	Patients with learning difficulties should be included in this list.	Text altered in line with comment.

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Prostate Cancer Charity, The	C3 4.25	What happens to staff who refuse communication skills training? Perhaps communication skills training should be part of the contractual obligations for a cancer team role. Patient satisfaction surveys etc may also identify poor performer. Does performance appraisal imply 'peers' alone? It should not. Using peer review places the patients outside the circle yet again.	This is for local implementation.
Prostate Cancer Charity, The	C1 5.5	The patients may be quite explicit in their requests for information. The Health Professionals may not need to wait for the assessment to gather what they are.	Text altered in line with comment
Prostate Cancer Charity, The	C1 5.6	The document acknowledges the problem of identifying quality information form all sources especially the WWW (section 5.3) Health professionals should be encouraged to offer guidance on information the patients and carers have found for themselves, rather than just making the local material available.	Both sources of information are identified in the Guidance- WWW plus written material. No change made to text.
Prostate Cancer Charity, The	C2 5.13	Voluntary sector involvement is also important and should be specified.	The Guidance does not distinguish between statutory and voluntary service providers
Prostate Cancer Charity, The	C2 5.18	Patients with learning difficulties should be included in this list.	Text altered in line with comment.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Prostate Cancer Charity, The	5.20	The Information Lead should not have responsibility for generating information unless they have particular relevant expertise in writing, the public understanding of science, layout, readability and design. This is a skilled job and should be out to tender, not attempted by health professionals most of whom do not have the required training and are, in any case, far too pressed for time. Because of the skills involved there are budgetary implications which will need to be addressed.	Change made to clarify this role.
Prostate Cancer Charity, The		In configuring services in palliative and supportive care a budget for information resources is fundamental. The Prostate Cancer Charity provides information for free. We ask for postage and packaging costs for bulk orders. As our information is highly regarded by many nurse specialists they are keen to provide it to their patients. They do not always have the budget for this and will ask us if they can photocopy materials. As we believe some of the message is in the medium, photocopies detract from the information that is being shared. Nurse specialists should have the budgets under their control to access the information they identify as the best available for their patients.	This is a local implementation point which might be covered by the suggestion that the individual is responsible for the implementation of an information policy at a local level.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Prostate Cancer Charity, The	D 5.26	Add or emphasise that Health Professionals should be prepared to repeat relevant information as often as the patient needs, or wants to hear it.	Text altered to reflect this.
Prostate Cancer Charity, The	Table 6.1	We suggest that there is a baseline level 0 (see earlier observation). The patient themselves – or their carer on their behalf - may well recognise that there some particular psychological needs and then ask for help and support. They must be included in this hierarchy as they have direct involvement in their own care.	Model altered.
Prostate Cancer Charity, The	C2 7.19	Patients should be prepared at some point for the fact that palliative care may become appropriate. The role of hospices is often misunderstood and patients may need some time to get used to the idea and reflect on the help that hospice care provides. In our experience this is also true of the involvement of Macmillan and Marie Curie nurses who do vital work at different stages of the cancer journey. The public perception we sometimes hear it is that their involvement is to be resisted, because of what they signify. This, we infer, means that some cancer patients may not get the comfort and care they need in a	Covered in introductory sections of the Guidance.

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		timely fashion.	
Prostate Cancer Charity, The		In the National Survey of NHS Patients – [National Survey of NHS Patients - Cancer- National Overview 1999-2000 Department of Health: 2002] several items came up which make the palliative and supportive guidance of particular relevance. Although the survey was completed before various changes in service configuration, there are still some things which will remain issues. Guidance should work in the real world. In the real world many patients are caring for others: 15% of all patients said they themselves were looking after friends or relatives who were sick, disabled or elderly. [p16] Many patients are elderly: 14% of respondents with prostate cancer were men under the age of 65. Nearly half (48%) of these men were 75 or over. [p15] And a significant number do not have their home circumstances	Findings of the National Survey are now included.

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		taken into consideration during discharge planning: About two thirds (65%) of people said their family or home situation had been taken into account during discharge planning. The proportion of people who said it hadn't been taken into consideration at all ranged from 9% of people with colorectal cancer to 18% of men with prostate cancer. [46] This demonstrates that care needs are often deeply complex. Eventual implementation of this Guidance will go some way to addressing them.	
Royal College of Nursing		Thank you for asking the Royal College of Nursing to comment on Part A of this guidance. We were unfortunately unable to identify a member with adult oncology expertise to comment, however the draft documents have been reviewed by one of our members with expertise in paediatric oncology. The views of the reviewer are that the guidance is extremely comprehensive and reflective of much of what is already considered to be good practice. Specific comments are as follows.	Thank you for your comments.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Royal College of Nursing		Although the primary focus of the guidance is on commissioning services for adult patients, it may be helpful to include 'adult' in the title to ensure the guidance is used appropriately, given the very different needs of children which commissioners of services may not always be conversant with.	Title altered.
Royal College of Nursing		With specific reference to Box 1.1, page 4 of the Manual, there is reference to the acknowledgement of the needs of children who may be affected by an adult carer or relative with cancer, yet there is no further mention of the child's needs. This is important to cover in relation to service provision, particularly as young people often assume the role of the significant carer in the home. Information and lines of communication would need to take account of the needs of the young person and their requirements for support from service providers. Whilst there is a dearth of literature in the area of cancer on provision of support for the dependent relatives of adult cancer patients, the social care literature does include numerous references to this.	Text altered to include the needs of children where felt appropriate to do so – and Part B will cover this in more detail.
Royal College of Nursing,		The recommendations are to be applauded. The RCNPCNG welcomes the Guidance.	Thank you for your comments.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Palliative Nursing Group		We have several specific comments to make and, for ease of reading, have chosen to raise any issues or comments following your numbered points. If comments have not been made on specific points please assume there is consensus/agreement.	
Royal College of Nursing, Palliative Nursing Group	General	The Group would like to have seen more emphasis on: - Day Care Services/initiatives	Day care included – please see previous comments.
Royal College of Nursing, Palliative Nursing Group		Respite breaks for patients Carer breaks – particularly evaluations of Marie Curie support services (both nurses and sitters).	Respite and care for the carers to be covered in Part B under carer support and social support.
Royal College of Nursing, Palliative Nursing Group		Little evidence was reviewed around actual nursing care of patients who are dying.	The emphasis of the Guidance is on service configuration rather than on specific or individual strategies for care.

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Royal College of Nursing, Palliative Nursing Group		Studies centred mainly on cost-effectiveness of home care and not quality of care.	See comment above.
Royal College of Nursing, Palliative Nursing Group		Little evidence was reviewed regarding access to services by minority groups	The needs of minority groups are identified throughout the Guidance where their needs are considered to require specific attention.
Royal College of Nursing, Palliative Nursing Group		Current understanding of "The New NHS" suggests that it must centre on patient choice and ease of access of services. We, therefore, welcome the emphasis on these issues in the Guidance.	Thank you.
Royal College of Nursing, Palliative Nursing Group	2.6/7	Supportive and palliative care need to be seen to be interlinked and not viewed as separate entities.	Comment noted but decision made by the Guidance Development Team not to later text.
Royal College of Nursing, Palliative	2.13	Definition of the word "specialist". Where is the criterion for what makes a specialist? There appears to be differing standards in different areas. Also, there is no standardisation in the quality of	See earlier comments regarding the definition of 'specialist' used by the Guidance Development Team – broader than simply

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Nursing Group		“specialist courses” with differing health care providers setting up courses of varying quality. Should the Workforce Development Confederation be able to influence this?	higher or ‘specialist’ educational qualifications. Reference made to relationship with Workforce Development Confederations.
Royal College of Nursing, Palliative Nursing Group	3. Co-ordination of Care 3.6	There is some concern about the level of symptom control knowledge and expertise demonstrated in some area by generalist workers. Also, in spite of the initiative by the DOH re district nurse education, there is no standardisation of the quality of the education being provided.	Considered to be outside the scope of the Guidance.
Royal College of Nursing, Palliative Nursing Group	3.18	There is concern here re telephone advice out of hours. RCN guidance states that telephone advice should not be given by nurses if they have no first hand knowledge of the patient. Accessing advice from NHS direct is not a viable option for this same reason. Currently the NHS Direct nurses have a set flowchart to follow – which does not take into account patient variability in palliative care. Is there also an insurance indemnity issue here?	Beyond the scope of the Guidance.
Royal College of Nursing,	4. Communications	The key to improved communications/information exchanged must rest with modern technology. No mention has been made of	Outside scope of the Guidance –a local implementation issue.

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Palliative Nursing Group		increased investment in information technology. (Wanless Report 2002).	
Royal College of Nursing, Palliative Nursing Group	4.29	Should communication skills training not be mandatory in all nursing and medical curricula to a defined standard – with regular re-assessment/upgrading of skills?	Beyond scope of the Guidance.
Royal College of Nursing, Palliative Nursing Group		Presumably these issues will also be addressed with the planned multi-professional core-skills training at the new NHS University? Communication has, of course, been high-lighted as one of the essential core skill for health service workers.	Beyond scope of the Guidance.
Royal College of Nursing, Palliative Nursing Group	5. Information	The RCNPCNG agree that information quickly becomes out-of-date and at present there appears to be duplication of effort. Here again modern technology could be used to great advantage.	Thank you for your comment.
Royal College of Nursing, Palliative Nursing Group	6. Psychological support services 6.9	It needs to be outlined exactly how "emergency psychological care be made available when necessary". Would "when necessary" assume 24-hour access to such services?	Outside scope of the Guidance.

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Royal College of Nursing, Palliative Nursing Group	6.10	“Adequately trained”. This needs to be specifically outlined. What is “adequate”?	Text altered in line with comment.
Royal College of Nursing, Palliative Nursing Group	6.16	“Appropriate out of hours service”. 24-hour services must be standard if we are to achieve patient choice.	Unsure what this comment relates to.
Royal College of Nursing, Palliative Nursing Group		In this section it would be helpful to include family and significant other rather than at present concentrating solely on patient’s needs.	Section redrafted.
Royal College of Nursing, Palliative Nursing Group	Specialist Palliative Care Services. 7.20	“All patients with advanced cancer should be discussed with a specialist palliative care service after assessment by a competent healthcare professional”. This should only be if appropriate as not all assessed patients would be appropriate and specialist services may be overwhelmed if all patients were discussed. We appreciate, however, that the Guidance is trying to ensure no patients fall through the net by not being referred even when it is	Comment noted but decision made by the Guidance Development Team not to alter text.

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		appropriate.	
Royal College of Nursing, Palliative Nursing Group	7.24	Please consider including access to day care services, respite care and additional nursing care (e.g. Marie Curie nurses).	Day care included – see earlier comments. Respite to be included in Part B.
Royal College of Nursing, Palliative Nursing Group	7.26	This has the potential for a huge impact on staff recruitment and retention.	Comment noted but decision made by the Guidance Development Team not to alter text.
Royal College of Nursing, Palliative Nursing Group	7.37	“Currently there is no evidence on the efficacy of specialist palliative care day therapy”. The RCNPNG would dispute this strongly. There is consensus that little research has been undertaken in day care therapy. However, patient and carer satisfaction has shown overwhelmingly the benefits of such services.	Day care included – see earlier comments.
Royal College of Nursing, Palliative Nursing Group	7.42	“Nurse Co-ordinators””. There is potential for confusion over this title. What does a Nurse Co-ordinator mean? And at what level would this nurse be operating?	This was the title given to the professionals in the research study.

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Royal College of Nursing, Palliative Nursing Group	7.43	Whilst acknowledging the usefulness of 24hour telephone intervention, standardisation of a 24hr nursing service must be recommended as standard if we are to significantly reduce the "out of hours" emergency admissions to hospital.	This is evidence for this recommendation.
Royal College of Nursing, Palliative Nursing Group	General Palliative Care Services. 8.3. -8.5	Are recommendations being made to address educational needs of GP's (similar to those currently being addressed for community nursing staff in England?)? Similarly, what specific recommendations are being made to address the educational needs of hospital staff?	This is addressed in the recommendations for all care staff without necessarily identifying any specific group.
Royal College of Nursing, Palliative Nursing Group	8.8-9	We cannot agree that "improvements in hours community services will reduce the burden of out-of-hours provision". Full 24-hr services (particularly nursing services) should be standard.	Comment noted but decision made by Guidance Development Team not to alter text.
Royal College of Nursing, Palliative Nursing Group	8.17	What type and level of post-registration education and training in palliative care should the healthcare professional have received?	Outside the scope of the Guidance.
Royal College of Nursing,	8.31	Whilst applauding the recommendation, it would be inappropriate in many instances to await "necessary support being in place".	The section of co-ordination of care should address these issues.

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Palliative Nursing Group		We are aware that patients are frequently prevented from spending precious time in their own home whilst awaiting services. Perhaps this should read “ideally” rather than “only”.	
Royal College of Nursing, Palliative Nursing Group		Finally, as a Group who have been lobbying for palliative care services and specialist palliative care services to be available for all patients regardless of disease, we wish to make the comment that this guidance excludes patients with non-malignancy, which creates an inequity of access and assistance to many dying of other life-limiting illness. When and how will the Guidance be extended for all patients and not just for those with a diagnosis of cancer?	See scope of Guidance in first chapter.
Royal College of Paediatrics and Child Health		This organisation was approached but did not respond.	
Royal College of Physicians		This organisation was approached but did not respond.	
Royal College of Psychiatrists		This organisation was approached but did not respond.	

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Royal College of Radiologists		This organisation was approached but did not respond.	
Royal College of Surgeons of England		This organisation was approached but did not respond.	
Royal Pharmaceutical Society of Great Britain		This organisation was approached but did not respond.	
Sargent Cancer Care for Children		This organisation responded and said that it had no comments to make.	
Scottish Intercollegiate Guidelines Network (SIGN)		This organisation was approached but did not respond.	
Society of Radiographers		The Society and College of Radiographers, SCoR, warmly welcomes the opportunity to comment on the first draft of Part A of the Supportive and Palliative Care Guidance.	Thank you for your comments.

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Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		General comment We found the Manual to be comprehensive with recommendations that are well supported by evidence. It is also our view that most of the suggested recommendations are entirely achievable provided that the recommended and necessary infrastructure, workforce and cultural changes can be enacted. Fundamental to this is the identification of adequate resources to support enhanced provision of services, enable the recruitment, training and development of staff and the development of relevant and timely patient information materials. Further, there is a need to ensure the equitable distribution of any available resources between the various professional groups and services. In this regard, The SCoR would wish to encourage the guidance development team to look towards developing a method that capture and better recognises the individual contribution of the wider team of professionals involved in cancer care. For example, therapeutic/therapy radiographers are specifically educated and trained in cancer care and radiotherapy and work exclusively with cancer patients yet the guidance fail to recognise them as a specialism or priority group in any of the exemplars of	

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		professions or groups for particular attention and specific support. We would like to suggest that inclusion of an appendix that contains a comprehensive list of the various professional groups with a brief summary of each of their roles would be helpful. Specific comments We endorse the view of the Editorial Board concerning the deficiencies in services and recognise that the current shortage of qualified radiotherapy staff to include clinical oncologists, medical physicists and radiographers is likely to lead to delay and variability in provision across England and Wales. For this reason, The SCoR is working closely with the Department of Health on a number of initiatives to improve recruitment and retention through skills mix changes and a new career progression structure that would provide more and better opportunities for career development and reward for existing staff. For this reason we are proposing the appointment of Consultant Practitioner posts within the Service, for example, Radiotherapy Palliative Care Consultant Radiographer.	

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Society of Radiographers	3. 11 Assessment	We would wish to suggest that this recommendation be extended to include the need for all supportive and palliative care staff to: • Have a sound knowledge concerning the efficacy of the various treatment modalities; • Develop good communication links with treatment centres for referral. The SCoR would like to congratulate the team on the hard work that has gone into preparing the guidance so far and believe that the finished document will be extremely helpful towards the continuing development of the service and improving the quality of patient care.	Text altered to include these points.
Sue Ryder Care		Having read the draft, which on the whole, is detailed and instructive I am rather disappointed that it is so exclusively cancer driven. There is little (no) acknowledgement for the needs of non-cancer patients, yet for many of us much of our work involves patients with diagnoses other than cancer. Sue Ryder Care has always been involved with these patients needs. Failing to acknowledge them in this document, I fear, will further	See scope of the Guidance in the first chapter.

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		discriminate against their largely unmet needs.	
Teenager Cancer Trust, The		This organisation was approached but did not respond.	
The Royal Society of Medicine		This organisation was approached but did not respond.	
UK Childrens Cancer Study Group		This organisation was approached but did not respond.	
UK Myeloma Forum		I would offer the following comments on the draft. They are perhaps of a more general nature rather than specific. In reading through I sense that the focus is on "advanced cancer" and end-of-life care rather than involvement of Palliative care at earlier stages in the "journey". This realistically is the case for the majority of situations, however, patients with myeloma, by definition, have "advanced cancer" but 50% will have a life expectancy of 3 - 5 years or more, sometimes with significant	Introductory sentences to both specialist and general palliative care altered to reflect this.

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Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
		morbidity from long term bony damage present before diagnosis. The engagement of Palliative Care early on in management is often beneficial in achieving effective symptom control pending the therapeutic impact of chemotherapy etc. In the recently published UK Myeloma Forum guidelines we did emphasise the accessibility of Palliative Care, because of its important role, from early on in the myeloma "journey". (Brit J Haem 115, 522-540 2001, Guidelines on diagnosis and management of myeloma).	
UK Myeloma Forum		I note that the consultation group does not appear to have included input from clinical haematology - the "journey" for patients with haematological cancers is different from most of the others; the same specialist team is usually involved from diagnosis to death; additionally, in the late stages of leukaemias and myelomas chemotherapy is quite often used as part of the palliative management of symptoms even though prognosis is often very limited indeed. Although Haematological cancers are a relative minority this dynamic of care is important and the guidelines would benefit from its inclusion..i.e. the concept of a "parallel" partnership focused on achieving the best quality of life	Comment related to process rather than content of the Guidance.

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		for the individual patient. These are relatively specific criticisms in relation to particular malignancies, the drafts otherwise are an extremely sound start I hope these comments are of some help.	
UK Pain Society		This organisation was approached but did not respond.	