Supportive and Palliative Care 2nd Consultation – Stakeholder comments

8 October – 4 November 2003

National Institute for Clinical Excellence

Organisation	Document version	Section number	Comments Please insert each new comment in a new row.	Developers' response Please respond to each comment
Abbott Laboratories Limited (BASF/Knoll)			This organisation was approached but did not respond.	
ADSS			This organisation was approached but did not respond.	
Afiya Trust, The			This organisation was approached but did not respond.	
Amgen UK Ltd			This organisation was approached but did not respond.	
Association for Palliative Medicine of Great Britain and Ireland			This organisation was approached but did not respond.	
Association of Hospice and Specialist Palliative Care Social Workers	Full Document	General Comment	Overall this draft is impressive in the comprehensive range of issues addressed. However it is very detailed. The comparable guidelines produced in Scotland are more concise, concentrating more on general principles and therefore likely to be more readily used. From a social work perspective the representation of social work as a discipline/profession on the Editorial Board and associated groups. (e.g The Allied Health Professional Reference Group, the Guidance Development Group and so on), is disappointing. Very few members of any of these groups have social work affiliations, but social workers play an important role in supportive and palliative care services. We welcome the emphasis on social care and the	Comment noted – the length of the Guidance has been constantly considered and reviewed, and a decision taken after the last round of consultation that the length and content would remain as it stands. The brief for the English and Welsh Guidance documents is very different to that for Scottish Guidance documents. The Editorial Board for the Guidance had expert input from an eminent social worker. The Guidance was reviewed by other experts in social work and also by the Social Care Institute for Excellence. The role of the specialist social worker is acknowledged in the Guidance.

			constant reference to health and social care professionals but are disappointed by the comparatively slight acknowledgement given to the role of the specialist palliative care social worker, who works at the interface of health and social care.	
Association of Hospice and Specialist Palliative Care Social Workers	Full Document	Section 5	The model of psychological assessment and support over-simplifies the situation of many patients whose problems are often a mix of social, emotional and practical issues. There is not enough recognition of the interconnectedness of the issues affecting patients and how social and financial problems may lead to psychological distress. The experience of palliative care social workers demonstrates the need to integrate practical assistance and emotional support, and to see individuals in their social context.	A unified assessment tool should assess these features simultaneously, but we have had to represent them in the Guidance as separate topics.
Association of Hospice and Specialist Palliative Care Social Workers	Full Document	Section 6 general comment	This section does not adequately address social inequality. The social impact of cancer is recognised, but not the impact of social inequality on the experience of cancer. Nor are the difficulties that may be experienced by marginalised groups acknowledged. The provision of support to such groups is much more challenging and complex than this chapter suggests. What is needed are workers who understand the social impact of having cancer for particular individuals, as well as the impact of social inequality on their cancer pathways.	The Guidance cannot address or redress social inequalities, nor the difficulties groups may experience. This point is recognised however in the section on Co-ordination of Care, as needing to be a part of any Network based needs assessment.
Association of Hospice and Specialist Palliative Care Social Workers	Full Document	Section 6 Key Recommendation 10	We welcome the need for explicit partnership arrangements between health and social care and note specialist palliative care social workers are well placed to facilitate such arrangements and identify gaps. Partnership arrangements alone will	Comment noted – but while a social worker may take a lead, the Guidance stresses that this is everyone's role. The Developers consider that the level of detail is sufficient for the executive Summary.

			not provide integration at an individual level and that is the role of the specialist palliative care social worker – to integrate formal with informal care, health and social care.	
Association of Hospice and Specialist Palliative Care Social Workers	Full Document	Section 6 6.5	We see social support as being firmly located within the provision of specialist palliative care services. Clearly not all a patient's needs, whether medical or social can be totally met by any one team, for example a patient may access radiotherapy or a home help from a different service, but we are concerned by the implication that social support is largely the remit of local authority social services and hence not covered by this document.	This is not what is being implied. The Social Support Services section of the Guidance stresses the need for communication and inter-relationships to be developed between all those providing social care and social support, and it is clearly acknowledged that this may come from a wide variety of sources. The Guidance is concerned with all aspects of care, not solely the delivery of specialist palliative care.
Association of Hospice and Specialist Palliative Care Social Workers	Full Document	Section 9.25	We would like to see palliative care social workers added as a core member of the specialist palliative care team. Social workers are well placed to make an assessment of a patient's needs across a wide range of psychosocial areas. It is important for holistic care that specialist palliative care services give equal weight to people's social, emotional, and practical support needs as to their physical needs. The social worker's training and expertise lies in working with and understanding people and their families / social units in the context of their communities. Social workers are trained to recognise and challenge discrimination and disadvantage and to value and respect the views of a diverse group of people.	Paragraph 9.25 has been altered to reflect this.
Association of Hospice and Specialist Palliative Care Social Workers	Full Document	Section 9.25, bullet point 3	We welcome the recognition of the importance of benefits advice but would point out that there is often a wider range of practical advice and emotional support which people need as part of	Paragraph altered to reflect comment.

			social care – and which is acknowledged in section 6.3.	
Association of Hospice and Specialist Palliative Care Social Workers	Full Document	Section 10	Again our concern would be that no reference is made to the role a specialist palliative care social worker might play in the rehabilitation of a patient. Many hospices offer rehabilitation services to patients and the social worker will be an integral part of the multi-disciplinary team working with that patient. For example patients planning a return to work may well find that the social worker is best placed to help negotiate with employers, advise on and help access benefits, help find suitable housing and so on.	The Developers consider the role is sufficiently highlighted in Social Support, but that does not preclude their role in other settings, as is the case with several other disciplines included within the guidance.
Association of Professional Music Therapists			This organisation was approached but did not respond.	
Association of Surgeons of Great Britain and Ireland			Thank you for your email. There will be no comment from the Association of Surgeons.	Thank you.
Aventis Pharma			This organisation was approached but did not respond.	
Bard Limited			This organisation was approached but did not respond.	
Bard Limited - 2nd contact			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	All		Please find below the response from Breakthrough Breast Cancer regarding the final draft of the Supportive and Palliative Care – Service Guidance. Breakthrough Breast Cancer is a charity committed to fighting breast cancer through research and awareness.	Thank you for your comments.
Breakthrough Breast	Full	General	Breakthrough believes that overall this guidance is	Comment noted with thanks.

Cancer			comprehensive and has the potential, if implemented successfully, to make a real difference to patients and their families and carers who are affected by cancer. We feel the guidance addresses many of the needs of those affected by breast cancer and particularly welcome the fact that NICE has taken on board many of the comments Breakthrough has made to the first consultation. However, there are still some areas where we feel that further clarification would be beneficial.	
Breakthrough Breast Cancer	Full	General	As stated in our previous response we are concerned about the length of the guidance, which may make it unusable. We do understand the difficulty faced by the Editorial Group in limiting the length without loosing the overall value of the guidance. However, we do still feel that there are areas where length and repetition could be reduced. We strongly recommend that this is looked at before publication.	Comment noted – the length of the Guidance has been constantly considered and reviewed, and a decision taken after the last round of consultation that the length and content would remain as it stands. Work is now underway to make using the Guidance easier to navigate through the use of hyperlinks within the electronic version of the document, for example. A final edit is now taking place, which may reduce some of the duplication and some of the length.
Breakthrough Breast Cancer	Public version	General	Breakthrough welcomes the development of a public version of the guideline. However, we are concerned that because of the way in which a number of recommendations have been incorporated together as more general statements, vital messages may have been lost in some areas. For example, whilst recommendation 17 in the full guidance states "as a minimum, high quality information should be made available to patients about complementary therapies" less emphasis is given to this in the public version of the guidance. It	The Developers consider that the balance in terms of messages and weight given to this issue and area of care/service is appropriate. Attention is drawn to making available information on all the variety and range of services included in the Guidance.

			is important that key messages are not lost.	
Breast Cancer Care	Full	Co-ordination of care. 1.12 (pg 31)	The brackets in the final sentence of this paragraph should read (health, social care and **voluntary**). It is important to make it explicit to commissioners that voluntary sector organisations should be included in the planning and review of local supportive and palliative care services.	Text altered to reflect suggested change.
Breast Cancer Care	Full	Co-ordination of care. 1.14 (pg 31)	Breast Cancer Care believes that nominating an individual at cancer network level to lead on supportive and palliative care will be a key factor in helping to ensure implementation of the guidance. We therefore believe the guidance should recommend more strongly that cancer networks should nominate an individual to lead on supportive and palliative care.	This is a key recommendation and so has considerable prominence within the Guidance.
Breast Cancer Care	Full	Co-ordination of care. 1.23 (pg 33)	We believe the guidance should suggest appropriate waiting times for referral to support services, particularly psychological support, rehabilitation and social support. There is evidence that patients can wait up to 8 months for referral to NHS psychiatric services, this is not an acceptable waiting time for this type of essential support (CHI & AUDIT, (2001) National service frameworks assessments No.1 – NHS Cancer Care in England and Wales.) At the very least the guidance should recommend that cancer networks set their own maximum waiting times for services. This will ensure that waiting times for support services are monitored and resources increased if necessary.	The Developers do not consider that it is within the remit of the Guidance to set waiting times. It is anticipated that this might be highlighted through the peer review process, as access will be a key feature that will need to be demonstrated. This is also for local implementation.
Breast Cancer Care	Full	User involvement. 2.25 (pg 43).	Breast Cancer Care welcomes the recommendation that teams should develop mechanisms to enhance patient access to different forms of peer-to-peer support. However, we	The Developers recognise this may be a useful way of developing these relationships and systems, but consider that this is for local practice and implementation.

			believe the recommendation should also state that teams should liase with voluntary organisations who offer peer-to-peer support. For example, Breast Cancer Care runs a peer support service, with over 350 volunteers who have had personal experience of breast cancer and are trained to offer emotional support and practical advice, face-to-face or by telephone.	
Breast Cancer Care	Full	Psychological care. 5.12 pg 63.	We believe the guidance does not go far enough in stating that patients should have a prompt referral to psychological services. It should recommend how long the maximum wait should be for an appointment with specialist psychological services. There is evidence that patients can wait up to 8 months for referral to NHS psychiatric services and this is not an acceptable waiting time for this type of essential support (CHI & AUDIT, (2001) National service frameworks assessments No.1 – NHS Cancer Care in England and Wales.) It is not enough to be promptly referred to a service, they also require a prompt appointment.	The Developers have not provided maximum waiting times for any service identified in the Guidance. This is for local implementation in line with any defined waiting times for accessing these services in use at the current time.
Breast Cancer Care	Full	Psychological care. 5.24 (pg 65)	Another bullet point should be added which states that staff should be able to inform patients and carers about the wide range of emotional and support services available. This should include professional and volunteer-led support groups, helplines, peer support systems and other types of support offered by the voluntary sector. It is important that staff inform patients about the range of support services available because many individuals prefer to self-manage psychological problems, particularly in the early stages and this information will give them the option to self refer. If	Text altered to reflect the comments made.

			patients receive emotional or psychological support in the early stages it may help prevent them from developing more severe psychological problems.	
Breast Cancer Care	Full	Psychological care. 5.39 (pg 67).	This paragraph should include peer support as one of the services that should be included in service directories related to supportive and palliative care. Breast Cancer Care has over 300 peer support volunteers who can offer support throughout the UK.	Text altered in the Co-ordination of Care section.
Breast Cancer Care	Full	Psychological Care C.1 Overview pg 63	It is essential that health professionals inform patients about the range of support services available to them so that they can access emotional and psychological care directly themselves when they need it. An additional overview recommendation should be added which states: • Health professionals should inform patients about the wide range of support services available at key points in the patient journey. This should include information about professional and volunteer-led support groups, helplines, peer support systems and other types of support offered by the voluntary sector. Patients should also have access to service directories for supportive and palliative care services.	The Developers consider that this point is adequately covered in the Social Support Services section of the Guidance.
Breast Cancer Care	Full	Social support. 6.18 pg 74	This bullet should re-iterate that further to an initial assessment of social care needs, patients should have their social care needs re-assessed at critical points in the patient journey. E.g. start and end of treatment, at recurrence and at diagnosis of secondary cancer.	Text altered to reflect these suggestions.
Breast Cancer Care	Full	General	A paragraph should be added which recommends	The Developers consider that this is too

		palliative care services. C.3 pg 92.	that health professionals and in particular specialist nurses are provided with training on communicating with and supporting patients diagnosed with secondary cancer. Some health professionals can find this a particularly difficult area of work.	specific a recommendation, and believe that this would be adequately covered in any communication skills training programme developed for those working with people with cancer.
Breast Cancer Care	Full	Rehabilitation services. General point.	In terms of access to dietary advice and dieticians the guidance only appears to refer to individuals whose nutritional status may be impaired or may be experiencing malnutrition following cancer treatment as being in need of dietary advice. However, we know from our work with women with breast cancer that many people are concerned that their diet may impact on the chances of recurrence and therefore make radical changes to their diet following diagnosis. We also know that many people with cancer make changes to their diet as a way of retaining some over what is happening to them. Many women with breast cancer tell us that they would like to have access to dietary advice. We believe it is important that individuals with cancer have access to dietary advice from the health professionals involved in their care and if requested dieticians. In certain cases it is particularly important that health professionals discuss diet with patients. For example earlier this year Breast Cancer Care produced a report which highlighted the concern that some women with breast cancer are at increased risk of developing osteoporosis as a result of their breast cancer treatment. In particular younger women who are put into an early menopause through their treatment can experience	The Developers consider that this is covered in the Rehabilitation section. The first point in the assessment model proposed is nutritional status.

			significant loss in bone density. Our research found that women are also removing dairy products from their diet without taking measures to replace the loss of calcium, which could further impact on their bone health. Women should be informed that they could be at risk of bone health problems so that they can take steps to protect their bones. We found that fewer than five per cent of women participating in a survey on this issue had received information or advice about bone health or diet from a health professional. In the case of breast cancer new treatments such as certain types of aromatase inhibitors may lead to increases in bone fractures associated with loss of bone mineral density. Women given this type of treatment should also be given advice about ways to protect their bones through their diet. Breast Cancer Care believes that the need for all patients to have dietary advice from health professionals involved in their care and access to dieticians should be included in the rehabilitation section.	
Breast Cancer Care	Full	Rehabilitation – General comment	The section on rehabilitation does not adequately highlight the problem of fatigue. This is a major problem for a large proportion of cancer patients and is an important issue. We believe it should be discussed in the introduction to this section and the recommendations should contain something about supporting people to cope with fatigue.	The Developers consider that fatigue is adequately covered in the Rehabilitation section of the Guidance alongside the variety of other symptoms patients may experience as a result of their disease and/or treatment. This is service guidance rather than symptom guidelines.
Breast Cancer Care	Full	Services for family and carers. 12.22	In the sentence ‘they should be ‘signposted’ to further sources of information etc.’ Sources of emotional and psychological support should be added.	Text altered to reflect comment.

Breast Cancer Care	Full	Summary D. Provider organisations pg 142	Under 'psychological support' the following should be added: • Access for patients and carers to information about the range of support services available should be facilitated (5.38). An up to date service directory of psychological support services should be available (5.39)	The Developers consider that this is adequately covered in the Guidance.
Breast Cancer Care	Full	Summary. E. Multidisciplinary teams	Under' information' a bullet should be added which states: • Health and social care professionals should assess on an ongoing basis the information needs and preferences of patients and carers. (4.9).	Text altered to reflect this point in the Summary of Recommendations.
Breast Cancer Care	Full	Summary G. Workforce development confederations	In the paragraph about 'making provision for skills training in assessment of needs', add a bullet point for rehabilitation needs.	Text altered in line with this suggestion.
Bristol Cancer Help Centre			This organisation was approached but did not respond.	
British Association for Counselling and Psychotherapy			BACP does not have anything to raise within this excellent document.	Thank you.
British Association for Nursing in Cardiac Care (BANCC)			This organisation was approached but did not respond.	
British Association for Parenteral & Enteral Nutrition (BAPEN)			This organisation was approached but did not respond.	
British Association of Art Therapists			This organisation was approached but did not respond.	
British Association of Art Therapists - 2nd contact			This organisation was approached but did not respond.	
British Association of Head and Neck Oncologists			This organisation was approached but did not respond.	

British Association of Otolaryngologists, Head & Neck Surgeons			This organisation was approached but did not respond.	
British Dietetic Association	Full	General	Thank you for responding so positively to the comments made on the first draft of the guidance. We are pleased to see that the majority of these have been included in the second draft of the guidance.	Comment noted with thanks.
British Dietetic Association	Full	General	Incorrect spelling of 'Dietitian'. This was acknowledged as incorrect in the response to the comments made by the BDA on the first draft of the consultation.	Apologies.
British Dietetic Association	Full	Chapter 10 10.20	This remains prescriptive about time referring to '9-5 Monday to Friday' Unfortunately the alteration made in response to the comments made by the BDA on the first draft of the consultation has made this point more, rather than less prescriptive. The word '**Normal**' needs to be reinstated and ***'9-5'*** needs to be removed.	More comments were received requesting that the Guidance be more specific about time frames rather than less. Text to remain unaltered.
British Geriatrics Society-Special Interest Group in Diabetes			This organisation was approached but did not respond.	
British Liver Trust			This organisation was approached but did not respond.	
British Lung Foundation			This organisation was approached but did not respond.	
British Medical Association			The BMA has received this consultation. Please note that we will not be submitting a response.	Thank you.
British National Formulary (BNF)			This organisation was approached but did not respond.	
British Oncology Pharmacy Association	Full	6. Social and support services	Original submission: The service model identifies the role of the family and carer in looking after the dying patient. There should be some acknowledgement of these members as potential	This was responded to from the first consultation: Comment noted – this is included in the text.

			support stakeholders to a range of social activities they are, by the fact they do them everyday, expert in providing / helping others to reinstate. This should be either in a formal or informally recognised agreement. Formal agreements are recognised in other European countries. It is well acknowledged that the psychological morbidity of both the carer / family member and the quality of the patient's death can be optimised by interplay of effective roles during the cancer journey and, in particular the terminal phases of the patient's life. The way in which the patient dies lives on in those left behind.	
			Although there is mention of support from "family and friends or other social networks" this has been classed as an informal arrangement and impacts minimally within the body of the section.	The Developers consider that this is adequately covered in the Guidance- see specifically the Services for Families and Carers Section.
			I feel that close carers, whether family of friends should, through a recognised assessment tool be included as potential "key workers" (defined in section 1, Co-ordination of care) for the patient. Where appropriate they may be able to take part or full role(s) away from professional practitioners and care directly for the patient. The positive dynamic this can lead to for both carer and patient is well documented and important during terminal, after-death and rehabilitation phases. We want patients wherever possible to die (or recover) at home with close family and friends. We should acknowledge the roles these members could play, not least of all because they will likely be available around the clock. Formal arrangements of this kind are evident in other European countries.	This is not being precluded.

			Throughout the guidance document as a whole there seems to be limited acknowledgement of the ownership of "key worker" status we could endow to close family members and friends. Isolation from input into the dying process could lead to a negative dynamic which, whilst potentially resulting in a less than optimal death, could imbalance the grievance process afterwards.	Key workers have considerable prominence within the Guidance – and are identified as one of the Key Recommendations in the Executive Summary.
British Oncology Pharmacy Association	Full	10. Rehabilitation services	Original submission: The service model identifies the role of the family and carer in looking after the dying patient. This should also include a role in their recovery, whether partial or complete. Family members and carers should be able to work closely with the experts and where possible take over mutually agreed roles. The benefits of a positive dynamic with close carer or family members are real. It can promote good morbidity and overall relationships that need to be optimal both during and, importantly after the experts have withdrawn their services. My comments for this are along the same arguments as above for section 6.	This was responded to from the first consultation: Comment noted. This has not been precluded, and the role of family members in providing care is endorsed.
British Psychological Society, The, and Clinical Psychologists in Oncology & Palliative Care Special Interest Group	All	General	As noted before, this document will be extremely helpful for those of us planning and delivering services. Its various drafts have been more and more structured and focussed and it should give us the basis on which to develop high quality services. Again, thank you for your hard work.	Comment noted with thanks.
British Psychological Society, The, and Clinical Psychologists in Oncology & Palliative Care Special Interest Group	Full	General	There is an important issue regarding the workforce which I feel needs a comment somewhere. Much of the expertise in the psychosocial arena is only recently developed and will require some real expansion. Its not a matter of	Text altered to reflect suggestion.

			modernising existing services - the services are not there in the first place. Many places are still without appropriate expertise and it would be a pity if commissioners felt that these services could be delivered without some expansion of the workforce. I know the work in the associated document will address this, but it may benefit form an explicit statement in the main document (e.g. para I50, p24). And at the risk of sounding like a broken record….	
British Psychological Society, The, and Clinical Psychologists in Oncology & Palliative Care Special Interest Group	Full	I11	Whilst noting the response to my repeated comments about specialisation and noting that elsewhere in the document there is an acknowledgement that there are those who spend much or all of their time only delivering psychosocial care of people with cancer as the main part of their job, this statement misses, I feel, an opportunity to both acknowledge that this is becoming a reality (although much less developed than in palliative care) and that it needs active development in terms of training so it can become a more systematically applied speciality. The paragraph as it stands could mean that because its everybody's responsibility (something I would certainly not dispute) then everybody is an expert (a sort of 'psychology is just applied common sense' argument. It is a shame that the comments later in the document which do acknowledge some special skills and expertise is not more strongly reflected here. Thought that it was worth one last try!	Text altered in line with comment.
British Psychological Society, The, and Clinical Psychologists in Oncology & Palliative Care Special	Full	General	I would hope that there will be some national launch of this important guideline identifying both elements (*i.e.* psychosocial and palliative care). We are planning something within our network but this	The launch of the Guidance is being discussed with NICE at the present time.

Interest Group			is worth making a splash about both locally, nationally and internationally. In that context, some notice of when the launch might take place would enable us to promote issues locally.	
British Psychological Society, The, and Clinical Psychologists in Oncology & Palliative Care Special Interest Group	Full	General	Well done and thank you.	Comment noted with thanks.
British Psychosocial Oncology Society	All	General	As noted before, this document will be extremely helpful for those of us planning and delivering services. Its various drafts have been more and more structured and focussed and it should give us the basis on which to develop high quality services. Again, thank you for your hard work.	Repeat of above.
British Psychosocial Oncology Society	Full	General	There is an important issue regarding the workforce which I feel needs a comment somewhere. Much of the expertise in the psychosocial arena is only recently developed and will require some real expansion. Its not a matter of modernising existing services - the services are not there in the first place. Many places are still without appropriate expertise and it would be a pity if commissioners felt that these services could be delivered without some expansion of the workforce. I know the work in the associated document will address this, but it may benefit form an explicit statement in the main document (e.g. para I50, p24). And at the risk of sounding like a broken record….	Repeat of above.
British Psychosocial Oncology Society	Full	I11	Whilst noting the response to my repeated comments about specialisation and noting that elsewhere in the document there is an acknowledgement that there are those who spend much or all of their time only delivering	Repeat of above.

			psychosocial care of people with cancer as the main part of their job, this statement misses, I feel, an opportunity to both acknowledge that this is becoming a reality (although much less developed than in palliative care) and that it needs active development in terms of training so it can become a more systematically applied speciality. The paragraph as it stands could mean that because its everybody's responsibility (something I would certainly not dispute) then everybody is an expert (a sort of 'psychology is just applied common sense' argument. It is a shame that the comments later in the document which do acknowledge some special skills and expertise is not more strongly reflected here. Thought that it was worth one last try!	
British Psychosocial Oncology Society	Full	General	I would hope that there will be some national launch of this important guideline identifying both elements (*i.e.* psychosocial and palliative care). We are planning something within our network but this is worth making a splash about both locally, nationally and internationally. In that context, some notice of when the launch might take place would enable us to promote issues locally.	Repeat of above.
British Psychosocial Oncology Society	Full	General	Well done and thank you.	Repeat of above.
British Society of Rehabilitation Medicine			This organisation was approached but did not respond.	
Cancer and Leukaemia in Childhood (UK)			This organisation was approached but did not respond.	
Cancer Black Care			This organisation was approached but did not respond.	
Cancer Equality	Full	General	I make the following points on behalf of Cancer Equality an organisation which is working to address the inequity in cancer care faced by	Text altered in line with suggestion.

			people from Black and Minority Ethnic (BME) Communities. The guidance needs to make detailed recommendations re: (a) BME communities. Nationally there should be a core set of recommended information for BME communities to include written and audio visual materials, all networks should have this core set of information for dissemination to cancer centres, unit and information services	
Cancer Equality	Full	General	(b) At specific points in the patient pathway ie diagnosis, treatment planning, relapse, palliative care, qualified interpreters should be used not family members.	Text altered in line with suggestion.
Cancer Equality	Full	General	(c) Information and support centres, should have outreach workers attached targeting specific communities - they should go out to the community but also encourage the community to use the hospital facilities - two way process. Adopting the model oft information and support centres that are based in Primary Care/Health Centres which are doing outreach work in community groups - estates etc.	The Developers recognise that it is a model that could be encouraged at a local level. This is considered to be for local implementation.
Cancer Equality	Full	General	(d) Training for specific members of the BME Communities - general awareness around cancer - where to access information and support - so they can support the BME communities to access the support they need.	Text altered in line with comment.
Cancer Equality	Full	General	(e) Training for Health Professional in cultural awareness, communication skills and how to make services more appropriate.	This is covered in the Face to Face Communication section.
Cancer Equality	Full	General	(f) User Involvement - making sure BME communities are represented and they have the opportunity to influence services. Cancer services have to adopt innovative ways of working with the community to get their views ,such as shadowing	This is covered in the User Involvement section of the Guidance.

			of patients, interviews, focus groups, committees, asking them to comment on papers etc.	
Cancer Equality	Full	General	(g) Peer support / buddy system with people from similar ethnic background or trained in cultural awareness. We believe this would work to provide support and gives the patient a choice.	Text altered in line with comment.
Cancer Equality	Full	General	(h) Cancer services should make contact and build working relations with spiritual and faith centres so that they are able to meet and support patient requests. Where there are significant BME populations, the relevant religious leaders should be part of the 'chaplaincy' service provided	This point is referred to in the NHS Chaplaincy Guidelines, which in turn are referenced in the Spiritual Support section of the Guidance. The text in this section has been amended to refer providers to this national guidance.
Cancer Research UK			This organisation was approached but did not respond.	
Cancer Services Collaborative 'Improvement Partnership' (CSCIP)			This organisation was approached but did not respond.	
Cancer Services Co-ordinating Group			This organisation was approached but did not respond.	
Cancer Voices			This organisation was approached but did not respond.	
CancerBACUP	Full Guidance	General	CancerBACUP welcomes the opportunity to comment on the second draft of the Supportive and Palliative Care Cancer Service Guidance from the National Institute for Clinical Excellence. Our comments again focus primarily on the section of the guidance that deals with cancer information.	Thank you.
CancerBACUP	Full	General	CancerBACUP welcomes the positive response by the guidance developers to many of the points we made in our previous submission – thank you.	Comment noted with thanks.
CancerBACUP	Full	4. Information C Recommendations, page 54	In our earlier submission, we suggested that in order to ensure that unnecessary duplication of effort in the production of information is avoided, an additional paragraph be incorporated into this	The text in the Information section of the Guidance has been altered to give prominence to what constitutes high quality information, and stresses that it should be accredited. The

			section emphasising that existing sources of nationally-accredited, high quality information should be the preferred choice of commissioners and providers. Guidance developers have responded that this issue is covered in the recommendations section. Although this is most certainly true, the guidance is inconsistent on this issue. Given the significance of this recommendation, CancerBACUP believes that the use of existing sources of nationally-accredited, high quality information in preference to locally-produced, unaccredited information materials should be made explicit in this section of the guidance.	Developers consider that this is adequately covered in the section on Information.
CancerBACUP	Full	4. Information C.2 Dissemination 4.27, page 55	The fourth and fifth lines of this paragraph refer to the need for information materials to be produced in a variety of formats. In order to reflect the concerns mentioned above, CancerBACUP suggests that this line be amended to read "Materials should be *made available*, where possible…."	Text altered in line with comment.
CancerBACUP	Economic Review	4.4. Information 4.4.1 Background, page 32	This second paragraph refers to the fact that there is currently considerable duplication of information materials and a lack of quality assessment. In our earlier submission we suggested that in the main the need is to purchase or commission and disseminate rather than to *produce* high quality information. Although guidance developers say that section 4.4.1 has been revised to reflect this, CancerBACUP is still concerned that the last line of the second paragraph states that high quality information to be "produced and disseminated". We	Section 4.4.1 second paragraph and section 4.4.2 first paragraph have been revised to emphasise the need for purchasing or commissioning information, rather than producing this information

			would suggest that this should read "purchased or commissioned, and disseminated."	
Cephalon UK Ltd			This organisation was approached but did not respond.	
Chartered Society of Physiotherapy	Full	General	We are pleased to see the amendments to the first draft following our previous submission.	Thank you.
Chartered Society of Physiotherapy	Full	General	The whole document has been improved, and is a powerful and clear one. We welcome the clear placement of rehabilitation within cancer care.	Comment noted with thanks.
Chartered Society of Physiotherapy	Full	General	To our grave disappointment, the site–specific service configuration guidance documents have largely excluded rehabilitation and the work of nursing and allied health professionals. We have been left hoping this document would rectify this serious omission. To some extent it does that, and we welcome this. However one section causes us some concern (item 9.25). We have addressed most of our comments to this point.	Comment noted with thanks.
Chartered Society of Physiotherapy	Full	8.1	Bullet point 5: alter text to: 'allied health professionals in the community, hospitals, and in hospices.'	The Developers do not consider it appropriate to add hospices to the list as this section is about general rather than specialist palliative care - text not altered.
Chartered Society of Physiotherapy	Full	Section 9.20	Fourth bullet: Suggest add: "allied health professionals working at the correct level (see chapter 10, figure 10. 1)."	This bullet point has been deleted – as it is considered that the Allied Health professionals are a part of the specialist team referred to in the first bullet point.
Chartered Society of Physiotherapy	Full	9.25	We welcome the emphasis the document gives to multi-disciplinary teams throughout document. In fact, to borrow an indicator from the national media, we note multi-disciplinary teams are mentioned 57 times in the document. In view of this we firmly repeat our request to see	Paragraph 9.25 has been altered to reflect this request. Access by specialist palliative care teams to a range of expertise has been added which includes certain defined allied health care professionals.

			allied health professionals placed within the core team. In light of the NCC reply to our first response (which gave no reasons) we strongly urge the Editorial Board to include physiotherapists in the core team. Our reasoning for this is cited below.	
Chartered Society of Physiotherapy	Full	9.25	It is at odds with the ethos of the whole document to reduce the core team to doctors and nurses. While we are pleased to see cross-referencing to other elements of the document, this does not go far enough in supporting the key role that physiotherapists have in the management of this patient group.	See response above.
Chartered Society of Physiotherapy	Full	9.25	Physiotherapists and occupational therapists are key players in specialist palliative care teams and excluding them from the core team runs the risk of commissioners doing the same. In addition we are concerned service managers may consider the exclusion of physiotherapists as members of the core team to be an appropriate way of reducing staffing costs.	See response above.
Chartered Society of Physiotherapy	Full	9.25	Other national evidence-based documents have recommended a broader core team. For example, the Clinical Standards for Specialist Palliative Care, June 2002, NHS Scotland state: • Standard statement: “specialist palliative care is provided by a highly qualified multidisciplinary team.” • Criteria: Essential • “The core team comprises dedicated sessional input from the chaplain, doctors, nurses, occupational therapists, pharmacist, physiotherapist, social worker”	See response above.

Chartered Society of Physiotherapy	Full	9.25	The added value of physiotherapists has been identified in the document 'The Role of Allied Health Professions in Cancer Care' (see 'R', page 110). The key attributes of physiotherapists are: • A unique perspective developed from a detailed knowledge of functional anatomy, ergonomics and human movement • Detailed knowledge and understanding of the patho-physiology of cancer and its treatment • Use of applied critical thinking and advanced clinical reasoning to adapt this knowledge to the cancer patho-physiology, to identify and treat the likely disabilities that patients may suffer from • Use of skilled physical approaches to promote, maintain and restore physical, psychological and social well being, taking account of variations in health status • A preventative, educative and supportive role throughout the cancer journey. If these attributes are excluded from the core specialist palliative care team it will be to the detriment of patient care, outcome and choice.	See response above.
Chartered Society of Physiotherapy	Full	9.25	We would add that specialist physiotherapy intervention has a key role in: • facilitating timely and appropriate discharge from an inpatient setting to meet the needs of the patient and family • prevention of inappropriate admission to an inpatient setting through supporting the patient to remain at home, if that is the wish of the patient/family • identification and diagnosis of oncological	See response above.

			emergencies, such as spinal cord compression that require immediate treatment to preserve optimal physical functioning • In addition specialists physiotherapists in palliative care are highly skilled in facilitating patient choice, providing clear relevant information, breaking bad news, maximising potential and offering an alternative approach to some medical treatments e.g. TENS for pain.	
Chartered Society of Physiotherapy	Full	9.25	It is current practice. There are many sites throughout the country that already have physiotherapists as core members of a specialist palliative care team across all health care settings. For example, Countess Mountbatten House, Southampton St Catherine's Hospice, Scarborough Dorothy House Hospice Care, Bradford-on-Avon The Physiotherapy Service at the Royal Marsden Hospital, London The Beacon Community Cancer and Palliative Care Service, Guildford	See response above.
Chartered Society of Physiotherapy	Full	Section 9.26	The list is not ranked and the relative referral rates are unclear. There is a considerable difference in input between specialist physiotherapists and anaesthetists: referral to physiotherapy would be made several times a day in a specialist unit and in infrequently to an anaesthetist.	The list is not ranked in any order or by any factor.
Chartered Society of Physiotherapy	Full	Section 9.34	Reference needs to be made to accessing the correct level of expertise. Suggest add to last sentence "It is important the correct level of expertise is accessed."	The Developers consider that this is implied in the sentence.
Chartered Society of	Full	Section 10.6	Last sentence: A large majority of palliative care	Text altered in line with comment.

Physiotherapy			patients are omitted who are neither in active treatment nor at the end of life but do have advancing disease. It should therefore read "in active treatment, have advancing disease or those requiring support."	
Chartered Society of Physiotherapy	Full	Section 10.24 Level 4	Add: "Specialist Palliative Care Units should have access to practitioners capable of working at Level 4."	The Developers consider that this is not required to be added. The rehabilitation model is considered to be clear, and all providers, including specialist palliative care units should have access to all levels of the model.
Chartered Society of Physiotherapy		Page 117, References	In ref 13 there are several typing mistakes: Chartered Society of Physiotherapists. *CSP Position Statement: the role of physiotherapy for people with cancer*. London: CSoP. 2002. It is the Chartered Society of ***Physiotherapy***, not Physiotherapists. The Society abbreviates its name to CSP, not CSoP.	Thank you – text altered.
Chartered Society of Physiotherapy		11.8	Add 'allied health professionals' to this sentence: "with the exception of osteopathy and chiropractic, whose practitioners achieve registration in a similar way to medical practitioners, dentists, allied health professionals and nurses.	Text altered in line with comment.
Chartered Society of Physiotherapy		11.8	Massage is a core skill of the physiotherapy profession, as recognised in its rules of professional conduct (CSP (2000) Rules of Professional Conduct, London). Formal national occupational standards are provided by the Chartered Society of Physiotherapy and the Health Professions Council. As such it is regulated and employers should ensure they are employing appropriately trained personnel. We suggest either you remove massage from this list, or make a	Physiotherapists are one group of health care professionals able to provide massage amongst a number of others.

			comment to this effect.	
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	General	I commented in the first round that I felt this guidance was rather too woolly to give clear guidance to commissioners. You responded that commissioners didn't think so. This does not surprise me as in my experience of commissioners they would rather have wider discretion to decide what not to invest in at a local level rather than a list of "must be dones". They would much rather NICE said that "an appropriate range and volume of chemotherapy should be available to patients with breast cancer" than that NICE specified any particular chemotherapies which might be of benefit. So in general I still feel that this guidance is too long, too general and too non-specific.	Comment noted – the length of the Guidance has been constantly considered and reviewed, and a decision taken after the last round of consultation that the length and content would remain as it stands. Work is now underway to make using the Guidance easier to navigate through the use of hyperlinks within the electronic version of the document, for example. A final edit is now taking place, which may reduce some of the duplication and some of the length.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	ES16	Key Recommendation 2. I do not understand why recommending the development of a national unified approach to assessing and recording patients needs is beyond the scope of national NICE guidance. With the future development of national electronic patient records it is important that we move towards unified approaches for recording our assessments so that these can be shared when patients move from one cancer network to another cancer network and so that specialist palliative care services who serve patients from more than one network do not have to work with different systems for different patients. Developing a unified national approach to assessing and recording patients needs will be an important precursor to codifying this electronically. It would be a great shame if this NICE guidance missed this unique opportunity to recommend such national work.	This has now been included as a recommendation in the main body of the text.
Chesterfield and North	Full	2.C2	I suggested that there needed to be some	The Developers consider that the role of the

Derbyshire Royal Hospital NHS Trust			recommendation on the representation of those who are too ill, communicationally challenged or dead to have a voice. You responded that this was in the text. I did find a mention in 2.5 of the problem but I did not read of any recommendation for solutions to this problem. Ideally guidance should not simply tell us that there is a problem but also guide us as to approaches to solving the problem.	Guidance is to provide recommendations regarding what should be achieved rather than necessarily suggesting how that is then done. The Developers understand that Macmillan Cancer Relief is undertaking work to look at how the views of those at the end of life can be obtained.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	3.9	I suggested this should read "received training on an accredited training course and is …." You suggested that this was covered in a later paragraph. I note that there are recommendations about accredited training courses being available in later paragraphs but not specifically that there should be any expectation that those communicating significant news should have attended these courses.	Text altered in line with comment.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	3.19	I recommended that all patients who have had significant news communicated to them should at least be offered a further appointment to discuss these key communications further. You did not think they should. While not every patient will take up the offer it really is lowest common denominator guidance if patients cannot expect at least an offer of an appointment to come back and ask further questions when they have had an opportunity to think about what has been communicated to them.	The Developers consider that this can be covered in a variety of ways of which one way is a further outpatient clinic appointment.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	5.15	I suggested some definition of adequacy of training, supervision and support to make the recommendations in 5.15 meaningful. You suggested that this is included in the overview paragraphs in this section of the guidance. Perhaps a reference to where you think this is covered would be helpful.	Paragraph 5.15 in the overview for this section – the recommendations defining adequacy are covered later in the same section – see paragraphs 5.42-5.44.

Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	5.28/5.30	I suggested that Palliative Physicians were important in this role and had a particular place in the management of mild to moderate depression in this patient group. You responded that the text had been altered to identify this role. I find no mention of Palliative Physicians in the text.	Please see paragraph 5.18.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	5	I suggested that there should be some definition of adequate access to level 3 and 4 services. You responded that it wasn't within the scope of the guidance to define adequate access and that we would have to wait even longer from some standards that will derive from this guidance. It would seem that services have been in planning blight for too long because of the promise of this guidance which, when it arrives, is just another stalling procedure waiting on some standards that may take several more years to produce. Unless guidance developers are willing to come off the fence and make recommendations then this "guidance" will not influence service developments and patients will continue to die without having received services they needed.	This will need to be determined and agreed locally as a part of the implementation of the Guidance. Assessment for, and access to, psychological support services are a key recommendation, which gives this considerable prominence within the Guidance - and prominence for local implementation plans. Standards are being derived from these key recommendations and will be included as a part of the peer review process to be repeated in 2004.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	8.20	I do not understand why after so many years of deliberation and evidence review the guidance development team are so reticent to provide us with any guidance but rather suggest that so many things should be decided at network level. I had always assumed that NICE guidance on supportive and palliative care was part of the Calman Hine process to produce more equitable delivery of cancer care on a national basis. If so then the one thing that NICE guidance should be able to decide is eligibility criteria for specialist palliative care if this cannot be decided at national level then what is the point of having any national guidance at all?	These concerns have been passed to the Department of Health – other respondents have also suggested that should be co-ordinated nationally and this is being considered.

			Your response to my initial suggestion was that this might be an issue for "national bodies" to take up but you do not suggest which national bodies are better placed than the NICE guidance development team after extensive consultation and evidence review.	
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	8.29	The guidance gets worse with revision! Now rather than patients getting their equipment "without delay" they get it "within an agreed time scale" the guidance seems to be going out of its way to ensure that it doesn't define anything that could make a commissioner have to commission a better service that is more responsive to patients.	The Developers consider that 'agreed timescale' is stronger wording than 'without delay'.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.12	I do not understand how changing "appropriate to" to "sufficient to meet" helps commissioners identify that they are providing an inadequate range and volume of specialist palliative care services. Unless you provide a formula for taking into account cancer death rates, deprivation in levels and other key factors then those comments are fairly meaningless. Commissioners do need some guidance in how to assess this as the traditional method of size of waiting list does not work for these patients. If they wait too long they die. Response times may be a better way to measure adequacy of services e.g. response time for out-patient assessment, response time to request for a specialist in-patient bed.	Please see paragraph 9.17 that covers the variables the respondent identifies.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.17	I note the inclusion of audit of patient access which is welcomed. Is there any evidence to suggest that volumes of service are interdependent and that an increase in the resources of a community specialist palliative care team may lessen the need for in-patient care? I thought the evidence such as it is	A paper by Constantini et al. (2003) "Effect of a palliative home care team on hospital admissions among patients with advanced cancer." has recently been published and not yet included into the review.

			suggested that community specialist palliative care teams improve quality while not affecting admission rates. A reference to any other evidence would be helpful.	However the studies by Zimmer et al. (1984, 1985), later replicated by Hughes et al. (1992) have been reviewed, which found a reduction in time in hospital and an associated reduction in costs for patients in the care of home care teams. Data from the National Hospice Study, using a quasi-experimental design supported this (Greer et al. 1986, Kidder 1986, Mor et al. 1985). However, a multicentre RCT of home care support in the USA found a reduction in hospital readmission at 6 months but not at 12 months, and higher costs (Hughes et al.2000). Findings from American services may not be relevant to other countries. There is also: Serra-Prat et al.(2001) Home palliative care as a cost saving alternative: evidence from Catalonia. Palliative Medicine 15:271-78.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.32	I noted that the guidance about the availability about specialist in-patient facilities is completely meaningless without some definition of accessibility. You said that this is for local implementation I therefore suggest that if you are unwilling to give any guidance about in-patient specialist palliative care services that you take this whole section out of the guidelines.	Accessibility is to be determined locally, based on a needs assessment. The volume and range of specialist services will therefore need to meet that local population profile.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.25	I suggested that you needed to define what you meant by a palliative care nurse specialist in terms of required training, experience and level of working. You suggested that national nursing bodies should determine this. You will be aware that they don't. Therefore, in the absence of any such definition you may as well simply put that a nurse should be a core member of the specialist	The Developers have not specified this with respect to any other profession in any of the other topics and so do not propose to specify training, experience and level of working for nurses as one professional group. The term is used to suggest that some level of experience and training beyond a basic level

			palliative care team as the phrase “palliative care nurse specialist” is open to wide interpretation.	qualification will be necessary to fulfil this role. The role is clearly differentiated from basic grade in-patient nurses in section 9.33 where nurses have has access to introductory level education in palliative care. There has now been publication by the Royal College of Nursing – A Framework for Nurses Working in Specialist Palliative Care. This outlines the knowledge, competencies and behaviours expected of a specialist nurse.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.29	I do not understand why the ability to undertake a direct assessment on seven days a week is within the scope of the guidance whereas the timeliness with which assessments are made is not. This guidance suggests that as long as you could be seen on a Sunday it doesn’t matter if you are seen on a Sunday on the day of referral or a month after being referred. Seven days working will compromise access within the week unless this is a “must be done” also. Therefore the guidance should be specific about both or neither. I prefer both.	The Developers are not clear of the point being made here. The recommendation is encouraging specialist palliative care providers to be able to provide a seven-day a week service, so patients with specialist palliative care needs do not have to wait to be seen until Monday morning for example.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.25/9.34/9.37	I find it difficult to envisage an in-patient specialist I am disappointed that your editorial board felt that Allied Healthcare Professionals were not core members of the specialist palliative care team. I did think that as this guidance was developed by the National Institute for Clinical Excellence and not the National Institute for Clinical Mediocrity it would be setting standards of excellence. Palliative care service that considers itself as achieving standards of excellence but does not meet regularly as a multi-professional team with	Paragraph 9.25 has been altered to reflect this comment. Access by specialist palliative care teams to a range of expertise has been added which includes certain defined allied health care professionals.

			Doctors, Nurses, Physiotherapists, Occupational Therapists and Social Workers. The National Institute of Clinical Excellence needs to decide whether it is about defining standards of clinical excellence that all teams should aspire to and commissioners be encouraged to support or whether it simply wants to say that Cinderella can come to the ball but she has to wear the rags she is wearing.	
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full and Economic Review	5	First is with regard to staffing levels. I note that the main document has rightly identified a number of important roles for those providing psychological support services including psychological therapies (for between 10% and 25% of all patients!), for staff training, for staff support, for consultation, for providing services local to patients, including D.V.s (with an implication for time spent travelling) and for continuing professional development and supervision. Given this, the estimate of 1 wte counsellor, 1 wte clinical psychologist and 0.5 wte psychiatrist per cancer centre within the economic review seems a gross underestimate. As I read it, the authors (SCHARR) estimate that, across the network, this should be scaled up by a factor of 2. Quite frankly to have 2 psychologists, 2 counsellors and 1 psychiatrist to provide all the above services across the whole Cancer Network seems farcical.	These staffing levels apply to level 3 and 4 psychological support services only. The existing assumptions are based on current practice in one institution. A brief consultation exercise has been carried out to obtain feedback on the acceptability of assumptions made from a small number of clinicians in the field. However these figures are considered to be provisional only and significant further work is required to obtain feedback from a wider audience and to explore potential variability between Cancer Networks.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	5.42	Secondly, I am concerned about the focus on a network level organisation of psychological support services (see 5.42). Given, the positive valuing in other parts of the document of effective co-ordination, effective support mechanisms, localisation of services and working in an integrated way, the danger is that will be lost if psychological support providers are effectively	This is not the intention of the Guidance.

			distanced from local palliative care services and from local psychology teams. There are also potential risks for recruitment and retention. While I would strongly commend the sharing of expert knowledge and skills across traditional service boundaries, it is my opinion that this is best done by locating psychologists (and other psychological support providers) within locally cohesive services.	There is no evidence for this model – it would need to be tested and evaluated.
Cochrane Pain, Palliative Care and Supportive Care Group			This organisation was approached but did not respond.	
College of Occupational Therapists			This organisation was approached but did not respond.	
Coloplast Limited			This organisation was approached but did not respond.	
Community District Nurses Association			This organisation was approached but did not respond.	
Department of Health	Full	ES23 (page 8)	There is an issue of affordability here. In its current form this recommendation will place a considerable burden on the NHS. Could it be softened to refer to “progressing” towards the provision of 24/7 care?	With service guidance, there is no fixed time-scale for implementation. The Developers anticipate that networks would develop their action plans to implement the guidance and that these would be signed off by SHAs – clearly, the milestones set locally will reflect achievability.
Department of Health	Full	129 (page 20)	Should topic 13 (as referenced on page 2) be added to the list?	Text altered to reflect comment.
Department of Health	Full	156 (page 26)	Would it be possible to provide a more detailed time scale?	The Developers thought long and hard about whether it would be possible to provide a more detailed time-scale; clearly different networks will be starting form a different baseline. Some will have larger workforce development issues

				than others, and that is likely to be one of the key rate-limiting steps. Consequently, that's why local planning, signed off by the SHA, is necessary, as indicated in response above.
Department of Health	Full	3.21 & 3.22 (page 49)	Would you consider changing the suggestion that family members may be used as interpreters? This is generally considered poor practice and we suggest that the draft should reflect that point more strongly. Similarly, where it says 'it is not recommended that children be asked' …it is suggested that this should be strengthened to be clear that children ought not to be asked.	Paragraphs amended in the light of the comments.
Department of Health	Full	8.25 (page 89)	We welcome the clarity that has been introduced here, but could a reference be made to care homes also being able to have access to specialist palliative care advice as appropriate?	This is covered in the following section on specialist palliative care services.
Department of Health		Economic review – applies to all as well	Further to our comments on cost effectiveness in the first consultation, we feel it would be useful if you could state that cost-effective literature has been reviewed but that the evidence found was extremely limited. Could you also state that there is no evidence on which to base a calculation of health benefit, quality of life or other benefits of the guidance?	A statement to this effect has been added to section 3.2
Department of Health	Full	General	There is a view that almost all of the principles in the draft can be applied to patients with heart failure and possibly other chronic advanced terminal conditions. Have you considered this?	The Developers did consider this, and think it is pertinent, but this would need to be supported by a separate systematic evidence review.
Eisai Limited			This organisation was approached but did not respond.	
Elan Pharmaceuticals Ltd			This organisation was approached but did not respond.	
Eli Lilly and Company Ltd			This organisation was approached but did not respond.	
Faculty of Dental Surgery			This organisation was approached but did not	

			respond.	
Faculty of Public Health			This organisation was approached but did not respond.	
Foundation for Integrated Health			This organisation was approached but did not respond.	
General Medical Council			This organisation was approached but did not respond.	
GlaxoSmithKline UK			This organisation was approached but did not respond.	
Help Adolescents with Cancer			This organisation was approached but did not respond.	
Help the Hospices	Full	General	We are pleased to note that many of the earlier comments that we have made have been taken into account in the development of this version of the guidance. There are many areas in which implementation of this Guidance will represent a significant step forward in terms of the supportive and palliative care available to patients. We especially welcome the emphasis on the role of patients and carers in managing their own symptoms and treatment. There are a number of issues which we have raised in previous comments which we do not yet feel have been adequately resolved. Our key concerns relate to: • The need to show how Continuing Care relates to supportive and palliative care • Allowing diversity in the range of teams that contribute to a specialist palliative care service across a Network • Identifying respite care as an area for further research	Comments noted. The comments regarding the passing on of comments from an earlier consultation process, and the composition of the Editorial Board have been covered in previous responses to Help the Hospices.

			We are concerned that, overall, there has been inadequate involvement of independent hospices in this Guidance. Independent hospices are not well represented on the Editorial Board and the Independent Hospice Representative Committee has not been invited to give expert advice on any issues in relation to the guidance. This problem has been compounded by NICE's failure to pass our first two responses to Part A on to the Editorial Board, meaning that input from independent hospices was not considered until very late in the process. We understand that this is an evidence-based review and that the Editorial Board is made up of experts rather than being a representative group. However, as the review is about service configuration, it is very important to understand perspectives of the diverse providers who contribute to the service under consideration. This is the last opportunity for the Editorial Board to consider the key concerns of independent hospices and we would urge you to give the points below your full consideration. We have highlighted what we consider to be the key issues in the text below. If anything that we have written is not clear, we would encourage you to contact us to discuss these issues further.	
Help the Hospices	Full	general	In our discussions with independent hospices, a question has recently arisen about how the perspective of ethnic minority service users has been taken into account in the development of the guidance. The concern has been raised that, although some efforts have clearly been made to	Representatives of ethnic minorities groups were included within the user reference group. The Developers will ensure that NICE are aware of these comments.

			reflect the needs of minority groups, the Guidance may not adequately reflect their needs, or the need for training for staff in working with ethnic minorities. We recognise that it may be too late to undertake any in-depth work with ethnic minorities at this stage. We would, however, be interested to know how the needs of these groups have been identified. We would also like to encourage NICE to consider how the needs of ethnic minorities can be taken into account in the development of future guidelines.	
Help the Hospices	Full	general	We welcome the recommendation that continuing care assessments should be integrated with supportive and palliative care assessments. We think there are some further links that need to be made with the Continuing Care framework. We understand that to some extent these links will need to be made locally, because continuing care criteria are determined by StHAs. However, we still think that it is helpful for national guidance to be joined up where possible and, as there is national guidance on continuing care, it is possible to make some statements nationally about the relationship between palliative and continuing care. In the last year, both the Health Service Ombudsman and the Local Government Ombudsman have identified cases where eligible patients have not been able to access continuing care, because the criteria were too restrictive, or were not applied correctly. It is therefore very important for this guidance to be clear about PCTs'	The Developers have included the following, not in 8.4 (introduction) but in 8.23: Commissioners have a responsibility to commission fully NHS-funded care packages that cover all an individual's care needs, including palliative care (where needed). This could be provided in any setting.

			responsibility to commission continuing care for cancer patients in a range of settings, including care homes, for eligible patients, and that these continuing care placements should sometimes include palliative care. Guidance on Continuing Care is available in HSC 2001/015, which makes clear that PCTs should commission palliative care as part of continuing care packages. We recommend that a paragraph on Continuing Care be included in Chapter 8 on Generalist Palliative Care. We would suggest that wording should be agreed with the Department of Health, but possible wording might be as follows: (Insert after 8.4) "PCTs have a responsibility to commission Continuing Care packages which include palliative care. These can be provided in any setting, including a patient's home, a care home, hospice or hospital. Continuing Care criteria are determined by Strategic Health Authorities. There may be a need for higher-dependency Continuing Care packages for patients with palliative care needs." (Insert at the end of 8.17 first sentence) "… who have received education and training in palliative care *and who have an understanding of how palliative care fits into the local Continuing Care criteria*." (Insert after 8.21) "Cancer Networks should ensure that appropriate Continuing Care packages are available to meet the needs of patients with cancer and at the end of life. These should be available in a range of settings (e.g. the person's home, a care	Comment noted but decision taken after taking further advice not to alter text. Paragraph 8.23 revised – Developers consider that revised text includes this point.

			home or hospice) and might include higher-dependency Continuing Care for patients with palliative care needs, but who do not need specialist palliative care.” We would encourage the Guideline Development Team to contact St Peter and St James Hospice and Continuing Care Centre in Lewes for an example of higher-dependency palliative Continuing Care services. Cancer patients who might need higher-dependency palliative Continuing Care include those with: • Brain metastases • Large sarcoma causing mobility problems • Mental illness • Learning disabilities	Thank you for this information.
Help the Hospices	Full	1.11	It is local Compacts rather than the national Compact which should really guide local partnerships. We suggest replacing the last sentence with the following: “Local Compacts between the statutory and voluntary sectors should guide these partnerships at local level. Local NHS bodies should have signed up to local Compacts by the end of March 2004.”	Text altered in line with suggestion.
Help the Hospices	Full	Chapter 6 C.4	In your response to our most recent comments, you state that there is no evidence on respite care and that this is why there is not more detailed guidance on what forms of respite care should be available. 6.4. does, however, recognise that NHS organisations may be involved in providing respite care. It would be helpful therefore if the guidance could specifically identify respite care as an area which could benefit from further research. We	The Developers have added a new point 6.30, with the following recommendation: Research is needed to determine the particular role and contribution of different models of respite care for patients and families in supportive and palliative care.

			suggest inserting a new item after 6.29 to say "Research is needed to assess the impact on people with cancer and their carers and families of respite care, and to compare the benefits of different types of respite care and care provided in different settings."	
Help the Hospices	Full	6.7	If the Community Care (Delayed Discharges) Act 2003 is mentioned here, it must be made clear that it does not currently apply to patients who are receiving palliative care. In your response to our previous comments, you said that this point was not made because the guidance does not only relate to people receiving palliative care. We understand this, but as the guidance specifically relates to supportive and palliative care, it is clearly relevant that palliative care patients are not covered by the Delayed Discharges Regulations even if some patients receiving supportive care are.	The precise details of any of the statutory instruments cited have not been provided in the Guidance.
Help the Hospices	Full	6.16	We remain concerned that this section gives the impression that all care home placements constitute social care. In fact, many care homes provide health care, such as continuing care placements or nursing care. At present, the guidance does not make clear that PCTs may have a responsibility to fund continuing care placements in care homes. We recommend the following wording to replace "care home placements": • "residential care placements in care homes"	The role of care homes is considered to be covered in the section of the Guidance relating to General Palliative Care. It is within the regulatory framework that 'care home' is defined as the generic category.
Help the Hospices	Full	6.18	Commissioners should ensure that a continuing care assessment takes place before a patient is referred to local authority social services. This is a requirement for patients who are covered by the Community Care (Delayed Discharges etc) Bill and should be considered good practice for all patients.	Continuing care assessment is a specialist assessment, and paragraph 6.19 refers to the need for 'the patient's usual healthcare professional to arrange for access to sources of more specialist assessment, if necessary.'

Help the Hospices Help the Hospices	Full	Chapter 9	This chapter could still be interpreted as restricting the range of services which may contribute to a specialist service across a Cancer Network area. There are a significant number of services which currently specialise in providing palliative care for patients with cancer, but which do not employ the staff members set out in this chapter as part of their full team. These services include home nursing services, hospice day care centres providing psychosocial support, and inpatient hospices offering inpatient higher-dependency palliative continuing care as distinct from acute palliative care. It would be confusing to describe these services as generalist, because they are provided by professionals who spend the majority of their time providing palliative care and who have specialist skills and/or qualifications in this area. In fact, the Guidance recognises this point in relation to the Marie Curie Nursing Service, which is included in the specialist chapter of the Guidance and the Economic Review, although it does not employ a consultant as part of the core team. We welcome the recognition of the Marie Curie Nursing Service as a specialist palliative care service, but the inclusion of that service means that there can be no argument for excluding other services on the basis that they do not employ the full team currently identified. It doesn't matter where these services fit in the Guidance, but they need to be mentioned somewhere. If the Guidance only recognises one	The Developers have considered these comments carefully. The section on Specialist Palliative Care Services has been re-drafted to make the meaning of the specialist service, the components of such a service and the ability of that service to meet specialist care needs clearer. The Developers consider that the definition of a specialist service is one that meets all the criteria as defined in section 9 of the Guidance.

			type of service, there is a danger that the diverse range of services which are currently available will not be seen as part of the service to be commissioned by PCTs and the choices available to patients will therefore be diminished. In your previous response to our comments, you argued against recognising “specialised” services on the basis that a specialist service “was one where the service had the capacity to meet the needs of a patient and carer across all domains, with the ability to meet complex needs.” If domains in this statement refer to, for example, spiritual, psychological, physical and social needs, then we would agree that this must be available across a Network. This doesn’t, however, mean that every team has to be able to meet all of these needs. There may be a range of teams (including home nursing services such as Marie Curie, day care centres and inpatient continuing care providers) contributing to this specialist service across the Network, who work together to create a continuous service for patients and carers.	
Help the Hospices	Full	9.21	The first sentence gives the impression that there is likely to be a reduction in the demand for inpatient beds. PCTs may interpret this as suggesting that they should reduce the (already very low) level of funding for inpatient beds. In fact, the evidence suggests that while 24% of people want to die in a hospice, only 17% actually do so at the moment, so there may in fact be a need to increase the level of provision of inpatient beds. We suggest replacing the first sentence with “To achieve the capacity set out in paragraph 9.20, commissioners might need to increase the level of	Sentence replaced as suggested.

			services provided in the home."	
Help the Hospices	Full	9.21	The insertion of "for example" in the third sentence has given the impression that the Marie Curie Nursing Service is a hospice at home service. Our understanding is that they are a home nursing service rather than a hospice at home service, because they do not employ a multi-disciplinary team. It might be helpful to move that sentence to the end of the paragraph, to clarify that home nursing is different from hospice at home.	This has been clarified.
Help the Hospices	Full	9.21	We suggest that the third sentence be amended to read "Practical nursing care and support for extended periods for patients with advanced cancer may be provided by a hospice or by the Marie Curie Nursing Service. In many cases home nursing and hospice at home services may work closely together and some providers may offer both."	Text altered as suggested.
Help the Hospices	Full	Summary of Recs G	Skills training should also cover assessment needs in relation to: • Specialist palliative care • Continuing Care The need for training relating to specialist palliative care is identified at 9.6 in the guidance. This is recognised in the Economic Review. The need for training in Continuing Care would follow from our suggested text above – see our general comment on Continuing Care.	The Developers consider that skills training relates to usual health and social care professionals in this context, and not to specialist professionals.
Institue of Physics and Engineering in Medicine			This organisation was approached but did not respond.	
International Myeloma Foundation (UK)			This organisation was approached but did not respond.	
Janssen-Cilag Ltd			This organisation was approached but did not	

			respond.	
Janssen-Cilag Ltd - 2nd contact			This organisation was approached but did not respond.	
Joint Committee on Palliative Medicine			This organisation was approached but did not respond.	
Kings Fund			This organisation was approached but did not respond.	
L'Arche UK			This organisation was approached but did not respond.	
Leukaemia Research Fund			This organisation was approached but did not respond.	
Link Pharmaceuticals			This organisation was approached but did not respond.	
Macmillan Cancer Relief	All documents	General	We welcome the fact that NICE has accepted a number of our earlier recommendations and that these are reflected in this new draft. The CancerVOICES network is pleased that the user's voice has been heard and is increasingly evident in the Guidance. We continue to be concerned, however, about the structure, tone and length of the document. We recommend that cross-referencing occurs throughout the Guidance to ensure that appropriate links are made between sections, as so many of these are interrelated. In particular we feel that carers' needs should not be dealt with in isolation as they are relevant to many other areas. On a practical note we presume that the contents page will include page references when published to make it easier to find the different sections.	Comment noted – the length of the Guidance has been constantly considered and reviewed, and a decision taken after the last round of consultation that the length and content would remain as it stands. Work is now underway to make using the Guidance easier to navigate through the use of hyperlinks within the electronic version of the document, for example. A final edit is now taking place, which may reduce some of the duplication and some of the length. Page references will be included in the final version.
Macmillan Cancer Relief	All documents	General	We are still concerned that NICE has no authority to ensure the guidance is implemented, and feel that the huge resource implications of what is proposed will significantly inhibit, or even prevent, their implementation. We recommend that NICE	Implementation is not within NICE's remit. The Guidance Developers cannot do more than draw attention to the scale of the economic impact of the Guidance.

			ensures that the Departments of Health in England and Wales, together with local authority Social Services Departments, discuss the implications to ensure that adequate resources are made available, and clarify responsibilities for implementing the recommendations.	
Macmillan Cancer Relief	All documents	General	We have stressed before that effective implementation of the Guidance relies on clear standards which are regularly audited. We would like to repeat our concern that the current process of developing standards is taking place without adequate user involvement. Standards are needed for primary care as well as for the secondary and tertiary areas. We would like to highlight a forthcoming publication from Macmillan Cancer Relief and the Cancer Services Collaborative on "Guidance for Good Practice for use in Primary Care", to be published by the end of January 2004.	Comments have been passed to those responsible for the development of the standards.
Macmillan Cancer Relief	Public Version	General	We welcome the concept of having a Public Version of the Guidance. However, we continue to have the concern that, without clear accountabilities for ensuring implementation of the recommendations, backed up with the necessary additional resources, such a document will be little more than a statement of ideals.	The Information for the Public is based on the key recommendations from the Guidance Manual. These are likely to be the basis for local implementation plans and are the basis for the development of standards. The Guidance Developers cannot do more than draw attention to the scale of the economic impact of the Guidance. Comments passed to NICE as above.
Macmillan Cancer Relief	Public Version	General	It is essential that all service providers working with patients and their families and carers fully understand the implications of a cancer diagnosis and its repercussions. This is especially important for those involved in assessing a person's needs.	Comment noted and agreed.
Macmillan Cancer Relief	Public Version	General	We would like to know what the intentions are for disseminating this document and ensuring that it is	This is being agreed with NICE at the current time.

			accessed by those who need it.	
Macmillan Cancer Relief	Full guidance	Page 3 ES3	We recommend that the National Cancer Patient Survey is repeated, as it should be able to demonstrate the impact of the Guidance on improving the patient's experience. To this end, we recommend that it is incorporated into Key Recommendation 4, adding as a new third sentence "Repeating the National Cancer Patient Survey regularly would also provide opportunities to do this."	This is not an issue for the Developers to consider. This will be referred to the Department of Health.
Macmillan Cancer Relief	Full guidance	Page 4 ES6	We recommend that this Guidance is linked to the development of childhood and adolescent cancer guidance.	Text altered to reflect suggestion.
Macmillan Cancer Relief	Full guidance	Page 4 ES8-11	These paragraphs contain assumptions about what is expected to happen to the Guidance and the recommendations. We recommend that this section should identify specifically who will be responsible for these actions.	The Developers consider that this would increase the complexity of the Executive Summary. Responsibilities are defined in the section summarising recommendations.
Macmillan Cancer Relief	Full guidance	Page 4 ES11	It is essential that primary care is also subject to standards and peer review.	To be referred to the Department of Health.
Macmillan Cancer Relief	Full guidance	Page 4 ES12	We welcome the suggestion that the National Cancer Patient Survey could form a basis for these audits. We believe that it should be repeated, and that the next survey should address care in the community. We also believe that the survey should be complemented by other local methods of assessing users' experience and satisfaction levels.	This is not for the Guidance Developers to comment on. The Guidance does however suggest that any national survey should be complemented by local surveys in the section on User Involvement.
Macmillan Cancer Relief	Full guidance	Page 5 ES13	When developing research, we recommend that consideration is given to a range of types of research evidence, not just clinical trial outcomes or formal research results.	The Developers consider that this is covered in the Guidance – see section 13 regarding research priorities.
Macmillan Cancer Relief	Full guidance	Page 5 ES13	We wish to inform the Editorial Board that we have noted areas identified as lacking in research	Thank you.

			evidence, and shall ensure that, where possible, our own research priorities are focused on these areas where they match the achievement of Macmillan's objectives.	
Macmillan Cancer Relief	Full guidance	Page 5 ES14-15	We wish to stress the value of retaining the Cancer Networks model.	Comment noted and agreed.
Macmillan Cancer Relief	Full guidance	Page 5 ES15, last bullet point	We recommend that the sentence be amended to read "the value of high quality information in a variety of media…" It is essential that information is provided in different formats to meet differing needs and preferences. No assumptions can be made about how people will choose to access information, and differing levels of ability place constraints on the formats people are able to use.	Text altered to reflect suggestion.
Macmillan Cancer Relief	Full guidance	Executive Summary	The need to keep records up-to-date should be mentioned in this section. We recommend that the statement "the outcome of consultations… should be recorded in patients' notes" should be supplemented by the wording "in user-friendly language".	This is not considered appropriate for the Executive Summary. The focus of this recommendation is inter-professional communication.
Macmillan Cancer Relief	Full guidance Information	Executive Summary	We welcome the recommendations on information, particularly that information materials should be free at point of delivery. This is applicable to many of the other sections, and there would be benefit in ensuring that there is appropriate cross-referencing to and from other sections where information has been mentioned. We would like to suggest that key recommendation 8 is amended to read "…materials about all aspects of cancer, its treatment and cancer support services." This could then encompass other topics such as, for example, self-help groups, financial advice and complementary therapies. We also recommend that such information is available in different	Text altered to reflect comments. This is not precluded – and would be a part of local implementation.

			outlets, including public libraries and community centres.	
Macmillan Cancer Relief	Full guidance	Page 57 Section C3	We recommend that this section also includes recognition of the importance for health care professionals to received appropriate training to enable them to provide information, or to signpost patients and carers appropriately, and to have sufficient resources to support them to undertake this training.	Text altered in line with suggestion.
Macmillan Cancer Relief	Full guidance	General Executive Summary Key Rec 9	We believe that patients, carers and self-help and support groups can play a valuable role in alleviating psychological distress, and it is not always necessary to seek professional help. Both patients and carers should be informed about the full range of psychological services and support available. We note that the developers did not think it appropriate for patients to self-refer, but we still believe that patients and carers would welcome being able to access support without having to go through a health care professional if they prefer. This would be particularly relevant if psychological help encompassed an expanded range of support services. We therefore recommend that the word 'professional' is deleted from the last sentence of Key Recommendation 9.	The Developers have reviewed this on several occasions, and do not dispute that carers play a valuable role – in fact, this is underlined and endorsed throughout the Guidance. However, the Developers consider that it is important to present the model as a professional model.
Macmillan Cancer Relief	Full guidance	Page 71 Para 6.3	We recommend that the 'includes' is substituted for 'encompasses', as we believe the list of social care is not definitive. We also recommend the addition of two other elements: • Provision of personal care to patients when needed • Provision of respite care for carers	Text altered as suggested.
Macmillan Cancer Relief	Full guidance	Page 71 Para 6.5	Much of the Guidance will be delivered by social care providers, and, in line with our earlier comment, it is essential that social care	Comment noted and agreed.

			commissioners and providers are engaged in discussions about the implementation of the recommendations and the identification of resources.	
Macmillan Cancer Relief	Full guidance	Page 72 Para 6.6	We recommend that the last sentence be amended to read "…social workers and others can supply", since other agencies may be able to meet the needs of patients and their carers.	Text altered as suggested.
Macmillan Cancer Relief	Full guidance	Page 71 Para 6.7 and Page 73, Para 6.15	The Guidance places considerable stress on the assessment of a patient's needs. However, it is a meaningless exercise to carry out an assessment if the identified needs cannot be met. There will undoubtedly be financial implications for the commissioners of social support services and this must be recognised.	Comment noted.
Macmillan Cancer Relief	Full guidance	Page 72 Para 6.10	It is important to recognise the needs and wishes of patients and carers and we recommend that the last bullet point is amended to read: "Practical and financial support is made available to patients and carers where and when needed, and in a way that is acceptable to them."	Text altered in line with comment.
Macmillan Cancer Relief	Full guidance	Page 73 Para 6.14	It is essential to acknowledge the complexities of the benefits system, especially in respect of the cancer journey. We think it unlikely that all professionals will have sufficient knowledge to be able to help patients and carers access the benefits to which they are entitled. We recommend that patients and carers are referred to expert benefits advisors for this advice, and that health and social care professionals be helped to know how to access such experts.	Paragraph 6.14 is a part of the overview and as such does not provide the necessary level of detail – this is covered later in the topic. However the word 'expert' has been included to qualify 'advice' in the relevant paragraph (6.23)
Macmillan Cancer Relief	Full guidance	Page 74 Paras 6.18-6.25	Whilst we acknowledge the importance of ensuring that a patient's needs are met, we believe that it is essential to acknowledge that carers and family members also have support needs which must be	New paragraph inserted in line with suggestion.

			recognised, as their welfare will inevitably have an impact on the welfare of the patient. The Guidance should therefore acknowledge the importance of ensuring that the social support needs of carers and families are identified.	
Macmillan Cancer Relief	Full guidance	Page 75 Para 6.26	In accordance with our earlier recommendation that the financial support needs of patients and carers are often complex, particularly in relation to benefits, we recommend that people who are skilled in providing financial advice are also included in the range of professionals undertaking assessments.	This paragraph does not specify any specific group of staff. Such staff could be included.
Macmillan Cancer Relief	Full guidance	Page 107 Para 10.3 and Page 113 Para 10.28	We are pleased to see recognition of the fact that self-care/self-management is an important aspect of rehabilitation for many patients who wish to be active in their own care. However, we are disappointed that this is only mentioned in one paragraph and is not emphasised in the Executive Summary or in other recommendations, despite being highlighted a number of times in the Evidence Section. This is an issue which Macmillan Cancer Relief is particularly interested in. We recommend that this concept is strengthened in the Guidance and included in the Executive Summary, and suggest that people affected by cancer should be mentioned in the second sentence of paragraph 10.3.	There is not only one mention of self-care in the Guidance – it is highlighted in other areas, most specifically in psychological support at 5.19 and 5.38. The Developers consider that attention is drawn to it in the Executive Summary in Key Recommendation 4, but have altered the appropriate supporting text. Whilst there is interest in the provision of self-care, there is very little evidence of how services should be configured to meet wishes of patients with respect to this area. The evidence points to an acknowledged gap, and the recommendations set out an expectation that ways should be found to fill that gap, but not necessarily how this might be best achieved.
Macmillan Cancer Relief	Public Version	Page 3	People affected by cancer should be able to obtain free information about cancer and cancer services <u>First paragraph of this section</u> We recommend that complementary therapies are	Text altered in line with comment.

			included in the penultimate sentence, ie "…including self-help organisations and complementary therapies" to demonstrate that complementary therapies are part of the package of cancer care.	
Macmillan Cancer Relief	Public Version	Page 3	People affected by cancer should be offered a range of emotional, spiritual and social support Paragraph 2 Key workers should be contactable at any time to revisit patients' needs, not just at the defined key stages.	The Guidance Manual does not suggest this – and the two documents must be congruent.
Macmillan Cancer Relief	Full guidance	Page 13 Para I6 Last bullet	In addition to self-help and support groups, complementary therapies should also be actively promoted in the management role people with cancer have in their own care. We therefore recommend that a section on self-care/self-management is added to reflect the way in which complementary therapies are used, ie by allowing patients to be active in their care and to do something for themselves.	The Developers consider that better sign-posting of information and support services is implicit in bullet point 5. Text has been added to the section of the Guidance on Rehabilitation to stress this point.
Macmillan Cancer Relief	Full guidance	General comment	Consideration should be given to providing complementary therapy services to staff and carers. Many services currently provide therapies to carers and staff to beneficial effect (see item 9 in the list of references to section 11).	This would be for local implementation.
Macmillan Cancer Relief	Full guidance	Page 118 Para 11.1	We recommend that complementary therapies would be better presented within the context of integrated cancer care, as patients should be able to choose from a range of interventions including complementary therapies as part of a package of supportive care.	This would be for local implementation. There is no evidence at the current time suggesting where such services are best located.
Macmillan Cancer Relief	Full guidance	Page 118 Para 11.2	We are unclear as to how – and if – the Guidance meets the aim to provide guidance to assist commissioners to decide which, if any, complementary therapy services they should fund.	The Developers consider that this is stated in paragraph 11.11.

			It is evident that patients value complementary therapies, and we suggest that commissioners are guided by this fact when determining future service provision. Network complementary therapy interest groups would help with this process.	
Macmillan Cancer Relief	Full guidance	Page 118 Para 11.5	We suggest that the sentence *‘other popular therapies include touch and mind-body therapies’* should be removed, as these are already included in the preceding sentence. Other therapies commonly provided in the NHS and voluntary sectors should be added to show the range offered.	This sentence has been deleted. This second point is considered to be too specific for the Guidance.
Macmillan Cancer Relief	Full guidance	Page 119 Para 11.7	*‘Two thirds of hospices and oncology departments…’* The reference is incorrect. Using reference 9 (Macmillan Directory), it should read, ‘Many NHS and voluntary sector organisations offer complementary therapy services.’	Text and reference altered – thank you for pointing this out.
Macmillan Cancer Relief	Full guidance	Page 120 11.12	We recommend that users, practitioners, clinicians etc are involved with service commissioners in determining local provision of complementary therapies, assisted by network complementary therapy interest groups.	Text altered in line with comment.
Macmillan Cancer Relief	Full guidance	Page 120 11.13	It is also important to provide information on other resources, both local and national, for example the Directory published by Macmillan Cancer Relief in 2002 (item 4 in the list of references).	Comment noted but it is not possible to include all the available information on this subject.
Macmillan Cancer Relief	Full guidance	Page 120 11.13-11.4	We recommend that specific mention be made of the need to train health care professionals appropriately to enable them to support patients and carers in respect of complementary therapies.	The Developers consider that this is implied.
Macmillan Cancer Relief	Full guidance	Page 120 Section D	We believe that more evidence is available than is reflected in this section. For example, we would like to suggest that evidence for mind-body therapies be added, since there is strong evidence to support their use. For further information,	Evidence of mind-body therapies is included in the chapter on psychological support and supports the beneficial effect of these therapies. The Evidence Review Team have contacted Professor Leslie Walker and

			Professor Leslie Walker, Institute of Rehabilitation, University of Hull might be contacted.	discussed the evidence base of these therapies. They are awaiting the relevant studies.
Macmillan Cancer Relief	Full guidance	Page 121 Para 11.24	We recommend that the findings from the Macmillan Directory (reference 4) be added here, as it demonstrates the extent of provision UK-wide. Statistical analysis (reference 9) revealed that a comprehensive range of therapies was offered in the majority of places – over 50% of services offered more than five therapies.	Text altered in line with comment.
Macmillan Cancer Relief	Full guidance	General comments on research	Evaluative research to determine which interventions are most effective (and cost-effective for different patient groups at different stages of disease) should also be encouraged (as is recommended in the Guidelines for psychological interventions – see Section 5, page 68, item C4, paragraph 5.45).	New paragraph inserted.
Macmillan Cancer Relief	Full guidance	General comments on research	We recommend that future research is encouraged on outcome measures and tools which reflect the patient's experience.	Additional text inserted.
Macmillan Cancer Relief	Full guidance	General and Section 12	We are concerned at the presumption that a patient's family will be able and willing to undertake the care of the individual. This may not be possible or desirable in all cases, and family members may not wish to undertake the caring role. If they do opt to provide a caring role, they must be adequately supported to enable them to do this.	Text altered.
Macmillan Cancer Relief	Full guidance	Page 124 Para 12.8	This paragraph supports our view that there should be greater emphasis on the services supported by statutory providers and that families must not be regarded as alternative means of providing a service to a patient. Furthermore, the fragmentation of service delivery highlights our concern that there is little point in assessing a patient's needs (see our comments on Section 6) if	Comment noted.

			there are no service providers to meet these needs.	
Macmillan Cancer Relief	Full guidance	Page 125 Para 12.14	The wishes of the family members and carers also need to be considered, not just those of the patient. We recommend that this is specifically mentioned in this section.	The Developers consider that this is an issue for the patient to decide – not for the Guidance to make any statement regarding who should and should not be present at any clinical contact.
Macmillan Cancer Relief	Full guidance	Page 125 Para 12.18	It is important to acknowledge that the support needs of patients and their families are frequently practical, not just emotional. We recommend that the needs of carers are identified specifically in this paragraph.	Text altered in line with comment.
Macmillan Cancer Relief	Full guidance	Page 127 Para 12.29	It is important that carers are provided not merely with information and training to deal with these matters but also access to practical support to help them deliver this care. They should also be offered respite from their caring role. We recommend that these needs are specifically mentioned in this section.	Comment noted – and change incorporated into paragraph 12.18 not 12.29 as suggested.
Macmillan Cancer Relief	Economic Review	Section 4.6 General comment	We wish to express again our concern that the impact of these guidelines is severely compromised without additional financial resources being made available to service providers to enable them to implement the recommendations.	This concern is noted. The aim of the economic review is to quantify the cost impact of implementing the guidance. This is considered to be the first step towards identifying the scale of additional funds necessary to ensure successful implementation.
Macmillan Cancer Relief	Economic Review	Page 42 Section 4.6	This section does not address the issue of having to provide practical support services to help people fulfil a caring role.	These services, such as respite care and transport, typically straddle both NHS and social service sectors. It is acknowledged in the text that the Guidance cannot make firm recommendations for these services. And consequently these services have not been costed as part of the economic review.
Macmillan Cancer Relief	Economic Review	Page 42 Para 4.6.2	We would like to make the point that social workers are not trained to provide benefits rights advice nor is this a role they are keen to undertake. Patients	Point noted. It will be acknowledged that social workers are not trained to provide benefits advice, although in practice many social

			and their families should be referred to expert advisors for this information.	workers do provide this advice where there is not an easily available welfare rights advice service. Social workers do develop expertise in this area. However patients and their families should be referred to expert advisors where available
Macmillan Cancer Relief	Economic Review	Page 90 Para 4.12.3.1	This paragraph demonstrates the difficulty service providers are likely to have with implementing this Guidance, in that it recommends additional posts to undertake strategic development of services, without any indication of how these posts and developments will be paid for. It is also essential that these services include the provision of practical support services.	Agreed – implementation will not be straightforward. As above - the aim of the economic review is to quantify the cost impact of implementing the guidance. This is considered to be the first step towards identifying the scale of additional funds necessary to ensure successful implementation. It does not however answer the question of where the funding will come from.
Marie Curie Cancer Care	Executive Summary	General	We welcome the prioritisation implied by the 20 Key Recommendations, but wonder if there is scope for further refinement based on evidence of successful outcomes. This would encourage early concentration on Key Recommendations such as 13 and 14, and allow more consideration of those Key Recommendations which have large workforce implications and less sound evidence supporting their implementation.	This was very carefully discussed at some length during the last Editorial Board meeting. It was concluded that the Guidance should not attempt to prioritise, and that there was no logical framework for prioritising some recommendations over others. The Developers are aware that the Cancer Service Collaborative is prioritising certain of these key recommendations, including 13 and 14 and information delivery. The Developers believe the way the CSC is doing this achieves the objective Marie Curie is setting out, but it would not be appropriate for the Guidance to do more than this.
Marie Curie Cancer Care	Executive Summary	ES2 KR12 8.36, 8.37,	We welcome the emphasis placed on the right of individuals to die in the place of their choice, and note this aspect of care has recently been	Comment noted and agreed.

		8.38	highlighted in government policy statements. We hope that the requirement for 24 hour generalist medical and nursing services which will support home deaths will be given due weight.	
Marie Curie Cancer Care	Executive Summary	General	We note your comments that manpower resourcing is outside the scope of this guidance, but remain concerned that many of the Key Recommendations place unrealistic expectation on the availability of the current limited numbers of specialist palliative care clinicians, and the rate at which such individuals will be trained in the future.	Comment noted – the Developers will ensure that this is brought to the attention of the National Workforce Group.
Marie Curie Cancer Care	Full Document	9.19, 9.38, 9.46	As requested, we have supplied details of a recent study of the benefits of Day Care provision. As many of the interventions provided to patients attending a modern day therapy unit will be similar in clinical content to those available to in-patients, we suggest that it would be helpful to distinguish between the efficacy of specific interventions, given regardless of the precise location of the patient, and the efficacy of the social benefits of attendance at day care.	It is beyond the scope of the Guidance to focus on specific interventions. However, the study will be included in the literature list.
Marie Curie Cancer Care	Executive Summary	ES 31 (ref 8)	We request the inclusion of the web address for the Liverpool Care Pathway for the Dying www.lcp-mariecurie.org.uk.	Details added.
Medicines and Healthcare Products Regulatory Agency (MHRA)			This organisation was approached but did not respond.	
Merck Pharmaceuticals			This organisation was approached but did not respond.	
Napp Pharmaceuticals			This organisation was approached but did not respond.	
National Alliance of Childhood Cancer Parent Organisations			This organisation was approached but did not respond.	
National Cancer Alliance			This organisation was approached but did not	

			respond.	
National Cancer Network Lead Clinicians Group	Full	9.29	Thank you for clarifying the "normal working hours seven days a week". However, we feel that paragraph 9.29 is still not entirely clear. It suggests that services should be staffed to a level sufficient to undertake direct assessment of people with cancer at home and hospital 0900 – 1700, seven days a week in the first sentence, but in the last sentence says it is desirable that provision be made for bedside consultation in exceptional cases outside 09.00 – 1700 hours Monday to Friday. Should this latter sentence read "seven days a week" rather than "Monday to Friday"?	Text altered.
National Care Standards Commission			This organisation was approached but did not respond.	
National Council for Disabled People, Black, Minority and Ethnic Community (Equalities)			This organisation was approached but did not respond.	
National Council for Hospice and Specialist Palliative Care Services	All	General	After four separate consultations it is considered that the documents as a whole are very close to being as good as they can be at this time. There are therefore very few further comments to be made.	Comment noted with thanks.
National Council for Hospice and Specialist Palliative Care Services	Full guidance	1.13	The principles on which palliative care is based include the statement 'neither hasten nor postpone death'. In the consultation paper on definitions circulated by the National Council in 2002, it was suggested that such a statement be deleted since, whatever the intent of the statement, it was not factual. In the responses to the paper there was almost unanimous agreement to that suggestion. The statement was therefore omitted from the definition contained in Council's Briefing Number 11 of September 2002 on Definitions of Supportive	Changes made to I13, and reference 4 updated as requested.

			Palliative Care. Accordingly, it is suggested that it should also be omitted from the NICE definition.	
National Council for Hospice and Specialist Palliative Care Services	Full guidance	9.25	It is understood that consideration may be given to providing a precise definition of a 'palliative medicine consultant'. If that is considered to be necessary then it is recommended that consultant be defined as a consultant who is on the GMC specialist register for palliative medicine. It is recognised that until such time as there is a sufficient supply of such consultants, some specialist teams may not be able to satisfy this criterion. Consequently, any team in this position will have to make interim arrangements until the appointment of a consultant as defined can be made.	New text inserted to reflect this point.
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.9	The comment made on the first consultation document was to the effect that it was not possible to comment on the estimates of costs of specialist palliative care services without knowing how the costs have been built up in detail. As a result of that comment some additional information has been provided about the assumptions made in building cost estimates for community and hospital teams. There is also a note in the text to the effect that some further description of assumptions used will be included in the final text. There is however no additional information about how the costs of in-patient care have been arrived at and yet this is the principal consumer of resources. While it is recognised that it may not be appropriate	Additional details have been added to the final draft including details of the costing approach for inpatient care. The original report was undertaken for the Department of Health and it is not with the public domain. ScHARR are however happy to answer questions from interested parties if the details given within the final report are not sufficient.

			to include all the detail of assumptions made in this review, it is suggested that readers of the review need to be able to access the work completed for the Department of Health referred to in this section. In other words that work needs to be referenced and available. Only then will it be possible to make any meaningful comment on the estimates of costs contained in this review for specialist palliative care services.	
National Council for Hospice and Specialist Palliative Care Services	Information for the Public	General	It is considered that this is a suitably concise document that summarises for the general public what the Guidance aims to do and how both patients and other users together with professionals can work to achieve its aims – improved support and care throughout the patient journey.	Comment noted with thanks.
National Guidelines & Audit Patient Involvement Unit			This organisation was approached but did not respond.	
National Guidelines & Audit Patient Involvement Unit			This organisation was approached but did not respond.	
National Guidelines & Audit Patient Involvement Unit			This organisation was approached but did not respond.	
National Nurses Nutrition Group			This organisation was approached but did not respond.	
National Public Health Service			This organisation was approached but did not respond.	
NHS Direct	Full Guidance	Paragraph 1.25 and 9.29	Since NHS Direct fits the description of a single, common, 24-hour, seven day a week telephone access-point for patients and carers, it would be helpful to clarify whether paragraph 1.25 is intended to refer to telephone access to the multidisciplinary team as stated in paragraph 9.29	The Developers consider that this is for local decision-making. In one location, a hospice may act as the night-time focal point because they have on-site, specialist expertise. In another location they may choose to have NHS Direct as the first filter, or have an arrangement

			or whether it is intended to refer to a service such as NHS Direct that could provide assessment and advice but is not part of that multidisciplinary team and does not have access to individuals' management plans.	with the GP co-operative. This is for local implementation.
NHS Quality Improvement Scotland			This organisation was approached but did not respond.	
North Tees and Hartlepool NHS Trust	Full	2.9	It is strongly questioned the proposal of linking assessment to defined points in the cancer pathway evident in both of these recommendations. As everyone is aware, patients/carers experiences of any cancer pathway are subjective and extremely individual and needs can vary enormously. It is strongly felt that assessment of need should be patient-focused, based on the clinical judgement of the key worker at each phase of the pathway. Assessment activity should not be a tick-box exercise performed at specific times which may be totally inappropriate to individual situations.	The Guidance does not suggest that assessments be performed to a rigid timetable – and very much supports the notion that the assessment process is patient-led and patient focussed.
North Tees and Hartlepool NHS Trust		3	Communication channels between nursing and some allied health professionals are probably well in place and working well. An important issue is inter-hospital transfer of patient information which remains extremely slow in many cases.	Comment noted.
North Tees and Hartlepool NHS Trust		7.8	There are difficulties in producing patient information which is relative to our patient group and which meets the extensive and very exacting criteria demanded by the Patient Information Group. This is a very time-consuming activity which cannot be performed in addition to a busy clinical caseload.	Comment noted.
North West Wales NHS Trust			This organisation was approached but did not respond.	
Novartis Consumer Health			This organisation was approached but did not	

(Novartis Medical Nutrition)			respond.	
Novartis Pharmaceuticals UK Ltd			This organisation was approached but did not respond.	
Ortho Biotech	All	General	We have sent in documentation in earlier consultations supporting the need for this service guidance to give some explicit attention to a key element of supportive care: chemotherapy related anaemia and fatigue. However, his latest version once again almost completely fails to even mention it (except very briefly). This is a disappointment given the published evidence that shows the importance of anaemia, and anaemia management, to cancer patients.	The Guidance does not cover any aspect of symptom control or treatment – it is service configuration Guidance as opposed to a clinical guideline. Please see I28 for clarification of this point.
Ortho Biotech	All	General	Cancer service guidelines are being inconsistently produced. Other service guidelines, such as the recent haematological outcomes guidance, have briefly covered treatments to complement and give context to the core service delivery/configuration recommendations. In my mind this improves the value of such service guidance as it contextualises it better. However, the supportive and palliative care guidelines almost exclusively exclude treatments, and hence seems imbalanced.	Please see comment above. The Supportive and Palliative document is generic in nature. The haematological guidance and other site specific cancer service guidance have short sections on treatment, in relation to the particular cancer in question. As these documents are about service configuration and are not clinical guidelines it would be inappropriate to have a large amount of detail in the treatment section.
Peterborough Hospitals NHS Trust		General	We have reviewed the 2nd Consultation, and accept the responses you have given to us in respect of issues raised from the 1st Consultation by Peterborough Hospitals NHS Trust. Some of these have been referred to within the 2nd document. No further comments.	Comment noted.
Pfizer Limited			This organisation was approached but did not respond.	
Prodigy	All	5.3	This section needs to be referenced.	This section is drawn from several sources, and in keeping with style of the introductory sections they are not necessarily referenced. The proportions quoted are well established

				and a consensus amongst professionals.
Prostate Cancer Charity, The	All	General	This draft guidance continues to improve. The Prostate Cancer Charity is pleased to see the increased number of references to the Voluntary sector and helpline support services. And the inclusion of 'sex'.	Comments noted with thanks.
Prostate Cancer Charity, The		General	We remain concerned about the length of the document. We understand that you consider its format is fixed. We continue to register concern that the format may work in direct opposition to the valuable content.	Comment noted – the length of the Guidance has been constantly considered and reviewed, and a decision taken after the last round of consultation that the length and content would remain as it stands. Work is now underway to make using the Guidance easier to navigate through the use of hyperlinks within the electronic version of the document, for example. A final edit is now taking place, which may reduce some of the duplication and some of the length.
Prostate Cancer Charity, The		General	We also remain concerned about the resource implications of the Guidance. Whilst we realise that this is outside the responsibilities of NICE, we feel it is not beyond NICE to make some public observations about the importance of adequate resources to meet increasing service need. 'Not being within your scope' is a lame defence against an issue that will, we fear, undermine the effect that these guidelines are designed to have – and you have made great efforts to produce.	Comment referred to NICE and the Department of Health.
Prostate Cancer Charity, The	Full	3.27	This is a missed opportunity to include students – medical, nursing, and professions allied to medicine. Most patients spend a lot of time in the company of junior staff, who are therefore most likely to be asked unexpected and difficult questions at unpredictable times, and be least	This was considered – but decided to be outside the scope of the Guidance.

			likely, through knowledge or experience, to be able to address them in a satisfactory manner. There should be some recommendations on communication skills training for students, and for continuing professional development of communication skills. There may even be a case for a version of this training for auxiliary and assistant staffs. The top down approach for 'advanced skills' ignores reality, which is that patients will always bring up difficult issues at times other than on the occasions when specialists are to hand. Those questions emerge late at night, in the dark, when senior people have gone home, patients have had time to reflect and junior staff are left to deal with subsequent existential and medical queries on their own.	Training students is a part of the NHS Plan. The Developers acknowledge the role of Continuing Professional Development in relation to communication skills.
Prostate Cancer Charity, The		4.2	The definition of 'high quality' should also include reference to 'user evaluated' or 'demonstrates user involvement in design and development' or similar. 'Top quality' **has** to include the patient experience.	Text altered in line with comment.
Prostate Cancer Charity, The		4.19	We believe there has to be some financial encouragement to providers to offer these information services. As you are unable to make budgetary recommendations you can, at least, insert some reference to commissioning of services. We suggest recommending that commissioners recognise 'information' as an integral aspect of care, and specify the 'NICE guideline' level of expected information provision when they commission services for local communities. Commissioners should be held to account if they do not demand a specific commitment to information.	This is referred to in paragraph 4.17. This point is likely to be included in the standards that will derive from the Guidance.

Prostate Cancer Charity, The		10.7	As we have said, we are glad that sex has appeared in this section. May we suggest a minor wording change? The last two sentences read “Sexuality is an issue that many people find difficult to address. This can result in failures to offer information and support in this area.” Can these be altered to “Sexuality is an issue that many people, both health professionals and patients, find difficult to address. This can result in failures to offer, or seek, information and support in this area.”	Text altered as requested.
Prostate Cancer Charity, The		10.18	Perhaps include Erectile Dysfunction specialist nurses? Many work within diabetes services, but others work in Urology and may also have clients who have or had cancer.	This is considered to be too specific a point to include in the Guidance.
Relatives and Residents Association			This organisation was approached but did not respond.	
Royal College of Anaesthetists			This organisation was approached but did not respond.	
Royal College of General Practitioners	Full	(Para 1.25)	I look forward to the audits produced by individual service providers (and hope that these will include OOH services as well!)	Please note that for all the comments from the RCGP the Developers consider that the respondent was referring to a previous version of the Guidance – and not the one circulated for consultation in October 2003. Comment noted.
Royal College of General Practitioners	Full	General	It is important to acknowledge that Palliative Care covers other illnesses as well as Cancer (I acknowledge that this is a document written specifically for cancer patients)	It is acknowledged in the introduction to the Guidance that it may well inform services for other groups (see box I1). The definition of palliative care is not specific to cancer.
Royal College of General Practitioners		General	There is not enough in the document to cover the boundary between generalists and specialists- many generalists have a specialist interest. I feel the figure 2.2 does an injustice to the growing	The Developers think that the respondent may be referring to a previous draft of the Guidance and cannot see to what this comment relates.

			band of GPwSI's for instance. Application of the document Improving Communication in Cancer – will help some way towards the deficiencies noted in Para 2.25 User involvement Cancer networks are proceeding with this well, and in some areas the groups preceded the organisation of Cancer networks.	
Royal College of General Practitioners		3.2	Usual professional carers – at core of service- as recognised by the GP contract- Palliative Care is *and should be* a core service.	The Developers think that the respondent may be referring to a previous draft of the Guidance and cannot see to what this comment relates.
Royal College of General Practitioners		3.3	There will always be seams in any service- but we need to be aware of them so that the seams are in the inside and thus invisible to the patient. Again the DOCTOR acronym – (from the improving communication document) .	Comment noted.
Royal College of General Practitioners		3.4	Trying to ensure that there is effective communication from all sides is of primary importance – use of a key worker/coordinator may go some way towards ensuring effective use of resources. MDT meetings in primary care with representation from Specialist Care (in the form of a Clinical Nurse Specialist – CNS)	Comment noted.
Royal College of General Practitioners		3.5	Education and Training- this is being addressed by the Networks- and by local Palliative Care Implementation Groups. Using the Gold Standards Framework learn-as-you-go, GSF Facilitators/Macmillan GP facilitators are trying to improve the education of Primary Health Care Teams.	Comment noted.
Royal College of General Practitioners		3.6	I am concerned about how we commission the services for the patient groups listed. As a commissioner- the discussions should be	Comment noted.

			interesting!	
Royal College of General Practitioners		3.12	A Single Assessment Protocol is being trialled in part of Leeds and I would be interested to see how this fits in with what is envisioned in the document.	Comment noted.
Royal College of General Practitioners		3.18	Service directory will be compiled by Cancer networks (this will be in the form of information on a website- in YCN) as well as a limited amount within a symptom control guideline. The local Cancer Centre has produced a manual containing information for supportive and palliative care as required by the Manual of Cancer Services Standards.	Comment noted.
Royal College of General Practitioners		3.25 and following	Difficulties may well be encountered in co-ordinating services unless they are based with the patient's *usual* professional carers. I feel strongly that MDT meetings should take place within Primary Care with Specialist Palliative Care Nurses (CNS) acting as the conduit between Generalist and specialist care.	The Developers think that the respondent may be referring to a previous draft of the Guidance and cannot see to what this comment relates.
Royal College of General Practitioners		4.3 + 4.5, 4.13	I would be interested to know if funds would be made available from central sources to help to subsidise the delivery of education/refresher courses with an emphasis on communication skills.	The Department of Health is significantly investing in the development of communication skills programmes, via NHSU. The area of advanced communication skills in cancer care is a priority. The Department is still working through the feasibility of more widespread roll out of these programmes including funding models. The Workforce Development Confederations receive funding from the Department of Health to support the commissioning and delivery of Learning and Development programmes, they decide on local funding priorities in accordance with local delivery plans

Royal College of General Practitioners	**Face-to-face communication**	4.25, 4.26	As a representative on the YCN Palliative Care Education Group, I look forward to working with the Workforce Confederation – in helping to deliver some of the education.	Comment noted.
Royal College of General Practitioners		5.5	Accessing accurate and up-to-date information within a General Practice setting is fine for common cancers, but holding stocks of leaflets for uncommon cancers would not be practical however ensuring that PHCT's have access to leaflets on more practical aspects such as the Cancer link 'living with cancer that cannot be cured'.	Comment noted.
Royal College of General Practitioners	**Information**	5.9	Encouraging PHCT's to assess patients including information needs along the lines of the Gold Standards Framework GSF- with contact numbers of support centres etc will help.	Comment noted.
Royal College of General Practitioners		5.10	Locally agreed selection information…..nationally agreed leaflets such as Cancer link/cancerbacup are useful from a PHCT perspective.	Comment noted.
Royal College of General Practitioners		5.17	Disseminating information to GP's surgeries- my concern is that many leaflets/booklets may be produced and then languish in surgeries- a sample of what is available and then replenished may be more cost-effective??	This would be for local decision making and implementation.
Royal College of General Practitioners		5.18	Policies for distributing materials- as a Cancer Lead I would be interested in looking at this.	Comment noted.
Royal College of General Practitioners		General	I welcome the five-level model of psychological support – I hope the cancer networks can work towards ensuring that personnel are available to address the needs of the more distressed pts.	Comment noted.
Royal College of General Practitioners		7.16	Many areas exist with no out-of-hours cover for their hospice and no specialist staff to service it. The opportunity of new money has listed that 70 new consultants will be provided (latest news on DoH website) however these are not available- and will not be so for several years. Models to assist	This is for local implementation as implied by the respondent.

			with provision of cover in areas where there is a dearth of consultants with perhaps telephone advice applied across a network will need investigating. (See 7.32)	
Royal College of General Practitioners		8.3	Agree totally with the ‘pressing issues….demands on GP time, skill and expertise’	Comment noted.
Royal College of General Practitioners		8.4	Specialist Palliative Care teams are attempting to address the Nursing Homes educational needs.	Comment noted.
Royal College of General Practitioners		8.7	PCT Cancer Leads are concerned with the level of education / information available to OOH providers on managing patients provided by their GP and by managers of Co-ops/deputising services.	Comment noted.
Royal College of General Practitioners		8.8	I look forward to seeing what the National Prescribing Centre has to say about Controlled drugs. (The Carson Review on OOH stated that the drugs should be available at the time of consultation).	Comment noted.
Royal College of General Practitioners		8.9	This is exactly the point of the GSF developing improved in-hours care and anticipation to reduce problems developing OOH.	Comment noted.
Royal College of General Practitioners		8.14	Addressing these educational needs- symptom control and when to refer is a key role of Network Specialist Palliative Care groups.	Comment noted.
Royal College of General Practitioners		8.23	Provision of out-of-hours palliative care- This may well be restricted to telephone advice as some areas do not have access to specialists to cover their in-patient beds 24hrs a day. However the need for advice is not high (personal study of out of hours contacts with one hospice).	The Developers think that the respondent is referring to a previous draft of the Guidance. This is covered explicitly in the latest version of the Guidance.
Royal College of General Practitioners		8.24	New GP contract has 2 points for use of handover form to OOH provider for patients with special needs e.g. terminally ill etc.	Comment noted.
Royal College of General Practitioners		8.37	Education programmes: These are in the remit of both Specialist Pall care providers and a strong desire from PCT cancer leads. Collaborative	Comment noted.

			working will help to arrange delivery of such care.	
Royal College of General Practitioners		8.44-8.46	An emphasis on anticipatory care and access to night sitters (carers) supported by regular visits from DN night service helps to provide the necessary support for patients to remain at home. Comprehensive support of District Nursing is necessary to allow delivery of quality General Palliative care.	Comment noted.
Royal College of General Practitioners Wales			This organisation was approached but did not respond.	
Royal College of Nursing - Palliative Nursing Group			This organisation was approached but did not respond.	
Royal College of Nursing (RCN)			The RCN Supportive & Palliative Care Forum has no further comments to make at this stage. They commented on the first draft of part A of the guidance in August 2002, and have nothing to add to this. Thanks for the opportunity to comment.	Comment noted.
Royal College of Paediatrics and Child Health			This organisation was approached but did not respond.	
Royal College of Physicians of London			This organisation was approached but did not respond.	
Royal College of Psychiatrists	All	General	This is an excellent document, which the Royal College of Psychiatrists strongly endorses. It is particularly pleasing to see such well considered discussion of the psychological impact of cancer throughout the "cancer journey", and constructive comments on how best to ensure that common mental disorders are recognised and treated effectively. We are impressed with the emphasis on developing basic skills for clinicians to recognise and manage aspects of common mental disorders.	Comment noted with thanks.
Royal College of Psychiatrists	Full	General	Individuals with severe mental illness (e.g. psychotic illness), dementia and learning difficulties	The Developers agree that patients with problems and difficulties such as these may

			are potentially excluded groups in cancer care. Patients with psychotic illness are at high risk of cancer because of their risk profile, but disease in all three groups is often recognised late. Such individuals have special needs and it is not clear whether palliative care and oncology services currently are equipped to support them. Work is needed to determine whether they access services as effectively as other patients, and whether their needs are met appropriately, once they are engaged in services. Pre-existing mental illness may impact on understanding, mental capacity, and symptom control. Managing such difficulties might include the involvement of psychiatrists (especially in the disciplines of liaison, old age or learning difficulties).	well fall through the net – there are not inconsiderable issues regarding access and consent etc. See also comment below.
Royal College of Psychiatrists	Full	General	Patients with cancer are at a considerably increased risk of suicide and deliberate self harm. In this setting patients also sometimes request euthanasia or physician assisted suicide. Suicidal behaviour, or requests for euthanasia are difficult to handle. Providers should develop policies for the management of such patients. Patients with advanced cancer who have displayed suicidal behaviour may require hospital admission to ensure their safety. There is often a gap between psychiatric wards, which may be too disturbed for patients with frail physical health, and general hospitals or hospices which have insufficient expertise and resource to manage suicidal patients safely.	The Developers are not aware of any evidence to suggest that patients with cancer are at greater risk of suicide or self-harm; indeed, in general, evidence suggests patients with cancer value life greatly. There is evidence that patients with head and neck cancer have a greater risk, but this may be related to other vulnerability factors, such as social isolation and heavy alcohol and tobacco use. The Developers agree that euthanasia is an important issue, but not really for the guidance to discuss – assessment and management of patients expressing these kinds of thoughts are really clinical issues that need to be determined at local level between patients and professionals. There is undoubtedly a problem in determining

				where patients should be cared for, acute psychiatric wards are often not suitable for people with cancer, and it is also difficult to look after these patients in hospices or general hospitals. Liaison psychiatry wards may be an option, but they are very expensive and labour-intensive, and may not provide a practical option. When someone has a severe mental and physical illness, a clinical judgement has to be made where his or her needs would best be met at any particular time.
Royal College of Psychiatrists	Full	General	In our experience community mental health teams (CMHTs) are often not sufficiently responsive in handling patients with physical disease. For many hospices or patients in nursing homes it is difficult to persuade CMHTs or mental health trusts to take part in care, even in emergencies. A general comment stating that CMHTs and palliative care/oncology services may need to liase closely in the management of patients with advanced disease would be welcome. Mental health trusts and palliative care providers (especially in the voluntary sector) should be encouraged to develop closer links.	Text inserted to reflect these comments.
Royal College of Radiologists			This organisation was approached but did not respond.	
Royal College of Speech and Language Therapists	All	general	We are pleased to note that most of the comments we made for the first consultation especially in relation to the table have been taken up. We have no further comments for this second consultation.	Comment noted. Thank you.
Royal Pharmaceutical Society of Great Britain			This organisation was approached but did not respond.	
Sargent Cancer Care for	Full	general	Overall this guidance is very thorough in	The Developers understand that this will be

Children			addressing both the clinical and support needs of adult patients. While recognising that the needs of children under 19 will be covered by the specific NICE consultation on child & adolescent cancers, we remain concerned that there is a potential gap at the transition from paediatric to adult services that could impact significantly on the needs of patients for Palliative care	covered in the NICE Guidance on services for children and young people.
Sargent Cancer Care for Children	Full	Sec5	We welcome the recognition of the contribution of psychological services to supportive and palliative care	Comment noted.
Sargent Cancer Care for Children	Full	Sec 6	We would support recommendation 10 which proposes agreed partnerships between health, social services and voluntary organisations to deliver social support to patients and their families. Sargent Cancer Care for Children would be interested in piloting such agreements in relation to their work with young people up to age 21.	Comment noted.
Schering Health Care Ltd			This organisation was approached but did not respond.	
Schering Health Care Ltd - 2nd contact			This organisation was approached but did not respond.	
Scottish Intercollegiate Guidelines Network (SIGN)			This organisation was approached but did not respond.	
Social Care Institute for Excellence (SCIE)	Full	6.16	I commented in 1st consultation as follows: ‘carer support can be emotional/psychological as well as practical and the bracketed examples should show this’. The Developers responses did not comment on this point. I would go further and suggest that the text notes that a carer can request an assessment of their own need from the CSSR. This avoids narrow examples of help and emphasises legal rights and broad ranging assessment of need. A form of words could be: Carer support: Under the 1995 Carers (Recognition	This is considered to be covered in the section on Families and Carers, where the importance of carer assessment (see 12.21) is referred to. The Developers have amended the wording of 12.21 to: Where carers are providing a substantial amount of care on a regular basis, providers should ensure they are offered a separate assessment or respond positively when a carer asks for one, in accordance with The Carers

			& Services) Act, carers can ask for an assessment of their ability to care when the person they are looking after is being assessed for community care services request an assessment of their own needs from the local CSSR (e bracketed examples should go .	(Recognition and Services) Act 1995. The Developers have also added 'emotional support' to the second last bullet and deleted the last.
Society and College of Radiographers			This organisation was approached but did not respond.	
South Manchester University Hospitals NHS Trust			This organisation was approached but did not respond.	
Sue Ryder Care			This organisation was approached but did not respond.	
Teenage 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 Children's Cancer Study Group			This organisation was approached but did not respond.	
UK Clinical Pharmacy Association			This organisation was approached but did not respond.	
UK Myeloma Forum			This organisation was approached but did not respond.	
UK Pain Society			This organisation was approached but did not respond.	
Welsh Assembly Government (formerly National Assembly for Wales)			This organisation was approached but did not respond.	
Wessex Cancer Trust			This organisation was approached but did not respond.	
Worcestershire Acute Hospitals NHS Trust	All	General	Thank you for the amendments already made from our suggestions in the first consultation.	Comment noted. Thank you.
Worcestershire Acute Hospitals NHS Trust	Full	77.13 page 80	Spiritual Support Services The chaplaincy team have put forward the	The Developers have taken the decision not to alter the text in line with this comment. This is

			following comments: 'should have access …….according to their needs and wishes' Such access should be available 24 hours per day.	a part of the contract of employment for chaplains - it is outlined in the Scope of Chaplaincy Provision (DoH) that they should be available across organisations and available outside of normal working hours.
Worcestershire Acute Hospitals NHS Trust	Full	7.14 page 80	Spiritual Care is well described but religious expression is very important to some people. 'Patients and carers should have opportunities for their spiritual and religious needs to be assessed and met'. Action where possible should follow assessment.	The Developers have used the word spiritual to encompass religious beliefs and practices.