Supportive and Palliative Care 1st Consultation – Stakeholder comments
7 July 2003 – 15 August 2003

National Institute for Clinical Excellence

Stakeholder	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 Professional Music Therapists			This organisation was approached but did not respond.	
Association of Surgeons of Great Britain and Ireland			This organisation was approached but did not respond.	
Aventis Pharma			This organisation was approached but did not respond.	
Bard Limited			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	General	Please find below the response from Breakthrough Breast Cancer regarding the Supportive and Palliative Care Cancer Service Guidance. We welcome this guidance and the opportunity to comment on these documents. We hope that due consideration will be given to the points we have raised. Overall, Breakthrough feels that this guidance is comprehensive and addresses many of the needs and concerns of women with breast cancer. As such, we welcome many of the recommendations made.	Comments noted with thanks.
Breakthrough Breast Cancer	All	General	Despite welcoming the guidance, we do remain concerned that many of the recommendations will be difficult to implement at a local level. Further clarification is needed particularly with regard to the processes that need to be in place to implement the recommendations and the resource implications of this guidance. It is anticipated that various organisations (listed in paragraph 147 of the Introduction) will need to identify which recommendations to prioritise at a local level. Breakthrough is concerned that this may result in a ‘postcode’ lottery of care. We feel that every effort should be made to ensure that the care you receive does not depend on where you live.	This point is understood – but the implementation of the Guidance is the responsibility of the Department of Health and National Assembly of Wales – through their respective NHS organisations. This is in line with other site-specific cancer Guidance. All the Cancer Networks will however be expected to assess their current levels of service against the recommendations in the Guidance – and prioritise according to that assessment. This assessment should take note of all the local variables that may impact on the manner in which services are configured and delivered. Standards will also be derived from the Guidance for the Manual of Cancer Services Standards – and the

				peer review process as a part of this will mitigate against patchy implementation
Breakthrough Breast Cancer	Full	General	We are also still concerned that the length of the guidance will make it unusable. We would therefore recommend that further efforts be made to reduce the length and repetition of this document.	This comment was discussed at a recent Editorial Board meeting and a decision taken not to alter the Guidance in line with this comment. Considerable efforts have been made to limit the length of the Guidance without loosing the value of the document being taken as a whole, or taken in its component parts.
Breakthrough Breast Cancer	Full	General	It would be useful for future consultations for any changes that are made to the document as a result of the current consultation to be highlighted. This would make it easier for stakeholders who wish to respond to appreciate where changes have been made.	All responses are to be returned to reviewers so they can see where changes have been made.
Breakthrough Breast Cancer	Evidence Review and Full	General	Whilst we understand that guidelines must be based on good evidence, we are concerned that not enough weight is given to the views and experiences of patients and carers. We believe that more effort should be made to consider patient and carers views as evidence and incorporate them into the guideline development process and final guidance.	The Guidance includes a separate chapter on carers as well as on user involvement. In the consultation process a user group is involved and in the editorial board two user representatives are included. This was done particularly with the purpose to give enough weight to the experiences of patients and carers and to incorporate their views in the guidance.
Breakthrough Breast Cancer	Full	2	We particularly welcome the inclusion of the 'User Involvement in Planning, Delivering and Evaluating Services' chapter in the guidance. We strongly agree that people whose lives are affected by cancer can make significant contributions to the planning, evaluation and delivery of services, but feel that whilst the views of users are integral they are often under represented. Every effort should be made to ensure that service users are given the opportunity, support and confidence to become involved.	Comment noted. The majority of the research evidence was drawn from studies with patients, and so their opinions about aspects of services and interventions have been included in the Guidance.

Breakthrough Breast Cancer	Full	3	We feel that the chapters on Face-to-Face Communication and Information could be combined. As stated in paragraph 3.1 "face-to-face communication is the process of information exchange". As such, we feel it would be better if these topics were discussed as a single chapter. This could also help reduce the overall length and repetition of the document.	These sections will not be combined – but the links between them will be made clearer.
Breakthrough Breast Cancer	Full	4	All patients should have access to accurate, up-to-date and high quality information. We feel that the important role played by voluntary organisations in providing much of the information available about cancer should be emphasised more within this chapter. Breakthrough would also like to emphasise the need for information standardised to a high quality national level. The development of patient and carer information should be according to agreed quality criteria. The information Cancer Networks / individual trusts provide should be regularly assessed against these criteria to help ensure high standards across the country.	The role of voluntary sector per se is recognised, particularly in the introductory section to the Guidance. The Coalition for Cancer Information involves representatives from voluntary sector. The Coalition will address these issues and the recommendations endorse these aspirations.
Breakthrough Breast Cancer	Full	12	We particularly welcome this chapter on 'Services for Families and Carers, Incorporating Bereavement Care' and welcome many of the recommendations made. The needs of families and carers are important, but often overlooked. In addition to this chapter we feel that the needs of families and carers should also be further highlighted in other sections of the guidance.	Links are to be made between all the relevant sections of the Guidance.
Breast Cancer Care	Full guidance	ES18	Key recommendation 6 suggests the patient should be offered a permanent record of important points	This is for local implementation and audit.

Also Joint response at the end of the table			raised during key consultations. We support the recommendation however; we feel it is important that health professionals are trained how to write a written record of consultations that is appropriate for the patient. We have heard that patients sometimes find these records difficult to understand and confusing, particularly if they use complicated medical terms, and this can cause increased anxiety. Trusts should monitor whether patients are satisfied with the written records they receive.	
Breast Cancer Care	Full guidance	ES21	Key recommendation 10 This recommendation should include the voluntary sector under partnership arrangements as this sector may also provide forms of social support.	Text altered in line with comment.
Breast Cancer Care	Full guidance	I5	'Why are patients' needs not always met? Another bullet needs to be added which says: • because of poor signposting of information and support services by health or social care professionals. • patients being unsure of what different support organisations provide in terms of services.	This is implied in the first bullet point Decision made not to add this
Breast Cancer Care	Full guidance	I6	Introduction – B16 page 13 'What needs to be done' add: • Better signposting of information and support services, including voluntary sector services, by health and social care providers. • Information and support services need to provide clear information about exactly what type of	Text altered in line with comment.

			services they provide to enable patients to access the most appropriate service for their needs.	
Breast Cancer Care	Full guidance	I18	Introduction BI18 page 17. This paragraph discusses the importance of patients being involved in decisions about their care and the need for health professionals to help patients participate in decisions. It also encourages health and social care professionals to be sensitive to the needs of patients without close family and carers. We think these are excellent recommendations. However we are aware that some older people may need extra support from health professionals to enable them to participate in decisions about their care, particularly older people without close family and carers. Health and social care professionals sometimes assume that older people will want less information or are less likely to wish to participate in treatment decisions. We believe the guidelines should state that in particular health and social care professionals should be sensitive to the needs of older patients and ensure they are given the information and support to be able to participate in treatment decisions if they wish.	Text altered - a paragraph highlighting needs of several different groups of patients has been added - however, we would continually have to cite specific examples, and feel if assessment is undertaken sensitively, all these things should be taken up.
Breast Cancer Care	Full guidance	F	Introduction F 147 page 23. The guidance states that it is not anticipated that all the recommendations will be achieved in all areas immediately, or in the short term. It also states that organisations at a local level will need to identify which recommendations to prioritise. We understand that local needs differ and that	The Editorial Board considered this at some length – and a decision made not to prioritise any further than the 20 key recommendations. Further prioritisation should be for local determination and agreement. Standards are being derived from the Guidance and will be included in the Manual of Cancer Services Standards.

			different areas will be at varying stages of development in terms of supportive and palliative care. However, we are concerned that without guidance on which recommendations to prioritise a postcode lottery in terms of supportive and palliative care could develop across the country. We believe it would be appropriate for a set of recommendations from the guidance to be named as priorities for implementation so that patients have a set of minimum standards they can expect for supportive and palliative care regardless of where they live. While we understand that NICE guidance cannot set targets it could contain a suggested set of minimum standards. We are aware that the key recommendations listed in the executive summary do provide some idea of priorities. However they are not specific or detailed enough to be a set of minimum standards in terms of what patients can expect.	
Breast Cancer Care	Full guidance	1.20	We believe that a service directory is an incredibly important tool. However, this point should stress that the service directory needs to be kept up to date and should be updated annually at a minimum.	Text altered in line with suggestion.
Breast Cancer Care	Full guidance	3.8	This point should state more clearly that a patient should always be able to request another health professional if they feel that their communication needs are not being met by the health professional they are dealing with.	It is considered that this point is clear in the text as it stands.

Breast Cancer Care	Full guidance	3.17	The following sentence should read: ..'ideally in the company of a close relative or friend (if the patient so wishes).	Text altered in line with suggestion.
Breast Cancer Care	Full guidance	3.24	We feel that perhaps this paragraph should mention the needs of older people who may need extra help to fully participate in the process of information exchange, possibly because of sensory disabilities.	A paragraph has been inserted in the text drawing attention to the people with special needs – which includes the older people.
Breast Cancer Care	Full guidance	4.16	Although we agree that information materials should be available in a variety of formats and that an electronic format does allow information to be updated quickly, we believe the guidance should be careful about suggesting that electronic format is the optimum source. Many individuals in the UK do not have easy access to electronic information because they do not own computers.	The Guidance makes it clear that other media should be available.
Breast Cancer Care	Full guidance	5.35	This section suggests that mechanisms should be in place to ensure patients can access sources of support once treatment has ended and discusses the use of a key worker to access help. While we agree that access through a key worker is an excellent idea, we are also aware that some patients may want to access forms of psychological support themselves without going through a key worker. The guidance should state that when a patient finishes active treatment they should be informed about the range of support services that are available to them after treatment has ended so that they can access these services directly themselves.	Text altered in line with comment.
Breast Cancer Care	Full guidance	5.40	Under this point on staff receiving appropriate training and ongoing supervision to provide	This is included within the Guidance – and the suggestion that patient and carer feedback is obtained

			psychological assessments and interventions the guidance should state that: • a system should be established to evaluate how effectively staff provide psychological assessments and interventions (for instance through a performance appraisal process, which should involve a means of gathering the views of patients and carers).	on service delivery is included in the Guidance.
Breast Cancer Care	Full guidance	6.15	This point should read that patients with cancer need health, social services and the voluntary sector to work together to deliver....	Text altered.
Breast Cancer Care	Full guidance	9.30	Community specialist palliative care teams might also want to develop links with residential homes for the elderly, or ensure staff in these settings know how to contact and access palliative services.	This is not precluded.
Breast Cancer Care	Full guidance	10.6	We believe this point should highlight the fact that older patients who are already frail might have more complex rehabilitation needs after treatment.	It is considered that this should be part of a comprehensive assessment process.
Breast Cancer Care	Full guidance	B	Add Rehabilitation onto this section: All patients should have access to rehabilitation services (10.19).	Added as requested.
Breast Cancer Care	Full guidance	C	Under co-ordination of care it should stress that up to date service directories should be available. This paragraph should also say that service directories should include information on helplines.	Changes made – and telephone helplines included.
Breast Cancer Care	Full guidance	D	Under Information it should state that people should have access to high quality information materials in a variety of formats... Under Information an additional point should be	Text altered Text altered but included in existing paragraph on ‘teams’

			added: • Teams should ensure that patients and carers have the opportunity to talk through the information they have been given with health or social care professionals. Patients should also have their attention drawn to other sources of assistance to help them understand and interpret information such as voluntary sector helplines or information services (4.20) Under psychological support an additional point should be added: • Patients should be made aware of the wide range of support services available. • Systems to evaluate how effectively staff carry out psychological assessments and interventions should be established (such as performance appraisals).	Text altered but included in existing paragraph on 'teams' This is included elsewhere in the Guidance.
Breast Cancer Care	Full guidance	E	Under rehabilitation and additional point should be added: • Arrangements should be made for patients to have their rehabilitation needs assessed.	Text altered in line with suggestion.
Bristol Cancer Help Centre	All	General	It is extremely encouraging to see that we are moving away from an emphasis on palliative care and that supportive care is now included in the title of this document. However given that more people will be living with cancer in the coming decades it would be better to resource this area far more thoroughly than is evident in this document. Supportive care still seems to be taking a back seat. Consistent references were made to what appeared to be important recommendations in the supportive care	The estimated costs of future supportive care are a key component of the Economic Review and are summarised in Table 35. We are unclear as to which important recommendations have not been considered within the Economic Review. It is however acknowledged that the Economic Review is not totally comprehensive and has focused on the areas where the most significant cost implications are

			category, which were not backed up in the economic review. There appears to be a big gap between the recognition of the importance of psycho-social support and the resourcing of this.	anticipated. Further more detailed work will be required within each Network to establish the local resource implications.
Bristol Cancer Help Centre	Full and economic review	5.0	Very little extra resource appears to be going to be provided in this area of care and support With the compelling evidence emerging from Professor Leslie Walker's work (Director of the Institute of Rehabilitation in Hull) It would seem important to include in this model Health Care Professionals who are trained in teaching patients self-help techniques. This could be included at Level 2 of the recommended 4 level model in this section. His publications report the many beneficial effects on mood, symptoms and coping of self-help strategies this may well prevent psychological morbidity developing. If psychiatric problems could be prevented not only would there be a vast improvement in patient's quality of life, but also for the cost of service provision. (References can be provided of required).	The resource implications of psychological support are being revisited with feedback being obtained from a number of clinicians around the country. A revised model will be included in the version for second consultation. Self-management is now included in the rehabilitation section
Bristol Cancer Help Centre	Full	8.0	Staff training needs to include education re supportive care (including psychological care and complementary therapies) for lead staff.	Comment noted.
Bristol Cancer Help Centre	Full and economic review	10.0	Although rehabilitation is described as attempting to maximise function, promote independence and help people adapt to their condition – a VITAL aspect of ongoing supportive care - it seems there are minimal resources being put into this crucial area. It appears that people will be supported if they have severe symptoms but no support for ongoing lifestyle or stress-management recommendations. As treatment	Issues relating to areas such as nutritional advice and guidance re smoking cessation, exercise etc are part of cancer prevention strategies and are not within the remit of this guidance. The evidence about the nature of issues that people confront both in their treatment and in delivery of care and services is not yet available. It would have been premature to make stronger recommendations in the

Comment [S1]: Okay to leave name in?

			regimes are improving more people with cancer will be rehabilitating. The key worker could have an important role here in reviewing lifestyles etc. Nutritional advice and guidance re smoking cessation would be of particular importance. As the WHO states that 30% of cancers are probably related to diet and nutrition it would seem an important area to address to help prevent secondary recurrence. Links with community resources to promote health (exercise facilities etc) need more emphasis.	Guidance. This is recognised by the Developers as an important area for service development in the future once more evidence becomes available.
Bristol Cancer Help Centre	Full and economic review	11.0	It was alarming to read in the economic review that as there are no firm recommendations that complementary therapy services are to be provided by the NHS that no attempt has therefore been made to provide any resource implication for this crucial area. The initial definition of supportive care (p14 full document) clearly indicated that complementary therapies were a key dimension of supportive care and up to 30% of people turn to complementary therapies it would seem an area of key importance to address. It seems very puzzling that with the newly released 'National Guidelines for the Use of Complementary Therapies in Supportive and Palliative' from FIGH and the National Council for Hospice and Specialist Palliative Care Services there will be no resources allocated for this area. • the preface to the above guidelines [stated] that they would usefully complement the forthcoming guidance on supportive and palliative care – it	The primary purpose of the economic review is to cost recommendations made in the supportive and palliative care guidance. Given that the guidance is making no specific recommendations in this area, no resource implications have been identified. The recommendations in the Guidance have been derived from the evidence available. The national guidelines complement the Guidance in that the Guidance recommends the development of policies for example, and the guidelines provide substantive information on what these might entail.

			therefore feels like an area that needs to be reconsidered as a priority.	
British Association for Counselling and Psychotherapy	All	general	We commend the overall breadth of this guidance and especially the inclusion and full description of the often undervalued and/or overlooked aspects associated with psychological and spiritual support.	Comment noted with thanks.
British Association for Counselling and Psychotherapy	Full	3.25	The value and necessity for good face-to-face communication skills is paramount. Specific training should be mandatory for those with key responsibility for ensuring psychological, social and spiritual support.	Comment noted.
British Association for Counselling and Psychotherapy	Full	5.25	Health and social care professionals, who provide level 2 psychological support, would benefit from counselling skills training. Such training does not relate to fully qualified counselling/psychotherapy practice in anything other than very basic understanding and proficiency in supportive communication.	This is implied within the model.
British Association for Counselling and Psychotherapy	Full	5.27	We commend the accuracy of reference to the importance of counselling delivered by trained, accredited and supervised counsellors. It is worth noting that the terms counselling and psychotherapy are often perceived as interchangeable. As BACP embraces all mainstream approaches to therapy and chooses to call its members ‘Practitioners’, we would suggest that a short note to this effect is included in this paragraph.	Comment noted but decision made not to alter text as requested.
British Association for Counselling and Psychotherapy	Full	5.34	The last sentence should exclude the word ‘may’. Agreed formal processes for sensitive and private issues should be clear in all cases, both for the patient and health professionals, at the very start of	Text altered.

			psychological support being given.	
British Association for Counselling and Psychotherapy	Full	5.39	We note the inclusion of 'psychotherapists' but suggest this should be mentioned in paragraph 5.27 – in particular to avoid any confusion between the terms counselling, psychotherapy, psychology and psychiatry.	These are included as examples only in 5.27
British Association for Counselling and Psychotherapy	Full	7.11	We would draw your attention to the Association for Pastoral and Spiritual Care and Counselling, which forms a part of BACP. Its members are practitioners who specialise in providing counselling therapy within a spiritual or religious framework. By taking this into account, psychological and spiritual support for patients can be provided by one individual and we therefore suggest this is worth noting as an extra point within this paragraph.	Comment noted but decision taken by Developers not to alter text.
British Association for Counselling and Psychotherapy	Full	12.30	We would suggest that the second sentences in Component 3 of Bereavement Support should read; 'This will involve….specialist counselling/psychotherapy services…'	Text altered in line with suggestion.
British Association for Counselling and Psychotherapy	Full	B	B. Commissioners for Cancer Care – this section should include the recommendation: 7.14: 'Patients...and carers should have access to different forms of spiritual support…'	Text altered in line with comment.
British Association for Counselling and Psychotherapy	Full	General	BACP are please to have the opportunity to respond to this excellent guidance. The attached response is collaboration between staff and members of the BACP Public Consultation Network.	Thank you.
British Association for Nursing in			This organisation was approached but did not respond.	

Cardiac Care (BANCC)				
British Association for Parenteral & Enteral Nutrition (BAPEN)	Full	General	Thanks for the opportunity to comment on these draft guidelines. BAPEN had originally returned some comments on nutrition for the second draft of Part A. These comments registered our dismay that no attention was given to the importance of nutrition/ nutrition support but in your response were were told that these would be covered in part B. This is not really the case. Only passing reference to nutrition e.g. the inclusion of a Dietitian in MDTs is made. Nevertheless, we at BAPEN had not really appreciated that these guidelines were primarily about Service provision rather than specifics of 'best means of pain control', nutritional support etc. Our comments on this draft are therefore less critical and more limited.	Comments noted.
British Association for Parenteral & Enteral Nutrition (BAPEN)		Page 16	The document states that palliative care should neither hasten nor postpone death but in the case of nutrition/hydration support, this is clearly not the case. The provision of food and fluids by oral, enteral or (in exceptional cases) parenteral routes may delay death by days, months or even years yet is often palliative.	This is a WHO statement reproduced in the Guidance.
British Association for Parenteral & Enteral Nutrition (BAPEN)		Box 8.1 and general	Connected to the point above are questions of ethics. The document doesn't really address ethical issues at any point yet certainly in the case of palliative food and fluid, because of their potential to prolong life, this is of great importance and we would imagine that similar issues pervade many aspects of palliative and supportive care. We therefore suggest that such issues are mentioned specifically, perhaps	Comment noted – but decision made by Developers not to alter Guidance.

			with reference to relevant information.	
British Association of Art Therapists			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	Chapter 10	All	The spelling of ‘dietitian’ is incorrect throughout.	Noted – apologies.
British Dietetic Association		10.3	Better to list disciplines in alphabetical order.	Thank you – text altered as suggested.
British Dietetic Association		10.11	First bullet point, in brackets, should also refer to diagnosis /early treatment planning stages.	Text altered.
British Dietetic Association		10.14	The document is consistent and refers here to rehabilitative therapists instead of Allied Health Professionals.	Text altered.
British Dietetic Association		C3	Refers to national AHP Strategy. It needs to be clarified if this is a national document or an English one.	The Strategy covers Wales and England – the text has been altered.
British Dietetic Association		10.19	We welcome the proposal that Cancer Networks identify Lead Advanced Practitioners. This will represent a huge advance in developme.	Comment noted.
British Dietetic		10.19	The last bullet point about audit refers only to access	Text altered.

Association			and timeliness. Quality is a key word to include here.	
British Dietetic Association		10.20	This is very prescriptive about time. Perhaps better to say 'normal' working hours	Text altered throughout Guidance.
British Dietetic Association		Table 10.1	Level 1 Under Group providing Input there needs to be clarification of the bullet point 'patients and carers assessment'. Does this mean self assessment? How is it to be interpreted in context of the heading 'Group Providing Input'?	It is self-assessment – text not altered. This recognises the contribution patients and carers make to the assessment and intervention process.
British Dietetic Association		Table 10.1	Level 4 Under Group Providing Input 'higher level training' would be better than 'higher level qualifications'	Text altered.
British Dietetic Association		10.24	Suggest including here the need to manage services to provide a comprehensive service with clearly defined roles which avoids conflicts when boundaries are unclear and repetition when different disciplines are involved.	Comment noted – but a part of local implementation.
British Dietetic Association		10.32	It is essential that such training needs are met.	Comment noted.
British Dietetic Association	Chapter 11	11.14	It would be helpful if guidance is given on an appropriate person to fulfil this. Proper training for the role would be essential.	Text altered.
British Dietetic Association		11.8	Suggest an additional sentence at the end of paragraph: 'There are also studies to show that patients find it difficult to follow some treatments'.	Comment noted – but text not altered.
British Geriatrics Society-Special Interest Group in			This organisation was approached but did not respond.	

Diabetes				
British Liver Trust			This organisation was approached but did not respond.	
British Lung Foundation	All	general	Overall this is moving in the right direction. It is always difficult to pick up issues for individuals with lung cancer because of their very low survival rates and therefore their inability to give comments in a coherent way. But because of this extremely short time space between diagnosis and death there is a great need for supportive and palliative care to be given quickly and with true understanding of the likely short life span left. As a general point it is also important to realise that there are all kinds of other diseases like COPD that need palliative care and that are not offered this level of help at present. Ensuring that services provided deal with all the different diseases necessary on the basis of greatest need should be the main priority.	Comment noted. Although the scope of the Guidance is for those with cancer and their carers there is considerable interest in looking at the service configuration recommendations for those with non-malignant disease.
British Medical Association			The British Medical Association received your email on the above consultation. Please note that we will not be submitting a response.	Noted. Thank you.
British National Formulary (BNF)			This organisation was approached but did not respond.	
British Oncology Pharmacy Association	Full	1. Co-ordination of care	Assessment and discussion of the carer and family's requirements should be integrated into this section in some way. Their inclusion is vital to ensure a best understanding and delivery of overall co-ordinated care. This is fully detailed in section 12 but should at least be acknowledged as a key inclusion here to allow better understanding by the reader.	Comment noted – this is included in the text.
British Oncology			The service model identifies the role of the family	Comment noted – this is included in the text.

Pharmacy Association			and carer in looking after the dying patient. There should be some acknowledgement of these members as potential stakeholders to this co-ordination of care, either in a formal or informally recognised agreement. 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.	
British Oncology Pharmacy Association	Full	3. Face-to-face communication	The service model identifies the role of the family and carer in looking after the dying patient. This has prompted my suggestion to include these members in the co-ordination of care as outlined above. Inclusive to this would be the requirement for these members to receive the same information transfer as imparted to professional persons required to best look after the issues delegated to them for the patient under their care.	Comment noted. Included in section on services for families and carers.
British Oncology Pharmacy Association			The above argument if accepted needs to acknowledge the often-greater demands to co-ordinate care of a close or family member of ethnic culture. Information-transfer and of a suitable presentation may then become inherent and require boosted resources.	Comment noted.
British Oncology Pharmacy Association	Full	5. Psychological support services	Assessment and discussion of the carer and family's requirements should be integrated into this section in some way. The patient's psychological requirements must not be seen in isolation, as the dynamic will integrate the family and carer issues as well. Their inclusion is vital to ensure a best understanding and delivery of overall care. This is fully detailed in	This is acknowledged in the introduction, and is considered to be sufficiently important to highlight as an issue that there is also the separate section. The links between each of the sections are made continually throughout the Guidance.

			section 12 but should at least be acknowledged as a key inclusion here to allow better understanding by the reader.	
British Oncology Pharmacy Association	Full	6. Social and support services	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 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.	Comment noted – and see response above.
British Oncology Pharmacy Association	Full	9. Specialist palliative care services	No additional comments to those submitted in last consultation round.	Noted. Thank you.
British Oncology Pharmacy Association	Full	10. Rehabilitation services	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	Comment noted. This has not been excluded and the role of family members in providing care is endorsed.

			optimal both during and, importantly after the experts have withdrawn their services.	
British Psychological Society, The			This organisation was approached but did not respond.	
British Psychosocial Oncology Society	Full Guidance	General	BPOS Welcomes this Guidance as it strengthens the case for the provision of high quality psychosocial care for people with cancer - reflecting one of the aims of our organisation. Furthermore we are pleased that so much evidence underpinning the review comes from the UK and from many of our members. BPOS has been arguing for many years for a greater acknowledgement of the psychosocial issues in cancer and this document gives strong support to that plea. As a multi-professional group we are please to see the inclusion of a wide range of psychosocial topics. This response will not detail specific issues as these are likely to come from individual members through the consultation process. We feel that this document will allow service planners and practitioners at network, Trust and community levels to develop services that are integrated and enmeshed in the total care process. We would welcome a stronger sense of identity, however. Whilst acknowledging that the delivery of high quality psychosocial care is everyone’s responsibility, it is clearly more of a central responsibility for some. The document would give considerable support to a variety of different professional groups if it made a stronger	Comments noted with thanks.

			acknowledgement of this. We accept that there is not a structural parallel with palliative care (where you distinguish the ‘specialist’ parts from the ‘everyone’s responsibility’ part) but this could be the start of it. As we have noted before, this is also an opportunity to strengthen the case for the development of a more structured and systematic training in this area, both for the primary providers as well as for others.	The Developers consider that the levels of service provision in the psychological support section assist with this process. We anticipate that the Guidance may act as a catalyst for the further development of education and training in many areas.
British Psychosocial Oncology Society	Full Guidance	General	BPOS wishes to thank the Team for their hard work.	Comment noted – thank you!
British Psychosocial Oncology Society	Economic Review	General	BPOS feels that this document requires more work and significantly more consultation with current service managers and providers. We would be happy to facilitate this process and play an active part in it.	The resource implications of psychological support are being revisited with input obtained from additional clinicians. This will be included in the version for second consultation.
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 Research UK	All	general	Overall the guidance is welcomed. However, there is a tendency to oversimplification and generalisation about the necessary services.	Comment noted.

Cancer Research UK	Full	general	Concern has been raised that considering limitations in resources, it is unclear how so many priorities for key staff, specific services, education and training needs can be addressed by commissioners and services providers. Whilst prioritisation would be difficult to agree across so many disciplines those interventions ensuring patient safety and addressing basic needs could be given a greater focus.	The Guidance identifies 20 key recommendations to assist with this process.
Cancer Research UK	Full	general	The term ‘psychological support services’ conceals the need for expert intervention from psychologists and psychiatrists. More appropriate representation of the work that these services perform should include the term ‘intervention’. We recommend that the term ‘psychological support services’ is changed throughout the document to ‘psychological intervention and support services’.	Comment noted – but it is the Developers opinion that ‘support’ includes assessment and intervention.
Cancer Research UK	Full	general	More emphasis is needed not only on general statements about support but clear statements are needed on the provision of specific multidisciplinary teams for patients with clearly identifiable psychological and psychiatric disorders.	There is no evidence to support this explicit recommendation, but it is stressed that a team approach is needed.
Cancer Research UK	Full	general	There are a number of significant omissions in this guidance. There is no reference to the need for clear access to emergency cover for patients at suicidal risk, assessment and management of patients with severe confusional states and behavioural problems, or use of the Mental Health Act.	The Developers consider that access to emergency services is covered by text in the Guidance. The use of the Mental Health Act is not within the scope of the Guidance.

Cancer Research UK	Full	general	Data shows that patients with more severe psychiatry disorders, particularly depression, are not recognised and not treated, and may need more intensive intervention that that provided by supportive and simple psychological services. Available evidence suggests that such patients are best managed by active protocol-based multidisciplinary teams.	This is supported in the Guidance with the model of access according to need and the importance of assessment. See comment below.	
Cancer Research UK	Full	general	There is also a need for less urgent access to psycho-oncology experts to assess and advise on cognitive impairment, capacity for consent and antidepressant prescribing, especially for complex problems in patients with medical co-morbidity.	Referral criteria and effective working practices between providers cover patient management issues.	
Cancer Research UK	Full	general	The need for experienced staff to be available for the supervision of medical, nursing and support staff and counsellors providing psychosocial care is not adequately emphasised. In contrast, due emphasis is given to more general aspects of supportive care, but the top level of the model for services is given inadequate recognition.	Developers consider that access to support of this nature at level 4 is given equal weighting.	
Cancer Research UK	Full	general	It is disappointing that referral to a health professional with expertise in oncology is not recommended. Clinical psychology services have long waiting lists and psychiatric services are overburdened with serious mental illnesses. Both routes therefore can result in inadequate access to psychological intervention or advice for palliative patients. Additionally, many psychiatry services would find it difficult to address people with co-morbidities.	The service identified at Level 2 includes professionals of this nature. The Guidance supports availability of services at level 4 from professionals with specific experience of managing patients with cancer	
Cancer Research	Full	ES16	Key Recommendation 2 and 3	This is acknowledged within the main text of the	

UK	Executive summary		The recommendations are of particular importance as they underpin multidisciplinary care. However, the assessment of a patient's needs (especially psychological needs) requires training and staff to provide intervention.	Guidance.	
Cancer Research UK		ES18	Key Recommendation 5 This recommendation is also vital. Access, including funding, to training and appropriate study leave should be regarded as high priorities for staff to achieve this recommendation.	Comment noted.	
Cancer Research UK		ES20	Key Recommendation 9 This point is too superficial and general. Delivery of this recommendation will be heavily resource dependent. Key staff, such as counsellors and psychologists often lack adequate infrastructure support. The guideline could help prioritise the need for securing resources in this area of care. Cancer Networks and commissioners need to consider the best model of provision in their area so that scarce resources can be optimally deployed.	Comments noted – the model is a suggestion for service configuration. Cancer Networks will need to do a needs assessment taking local variables into account.	
Cancer Research UK		ES26	Key Recommendation 16 Patients should also be given information about centres offering support and rehabilitation in the voluntary sector. These centres can help provide services not available in cancer centres, or in a more convenient locality	Comment noted - but this is considered to be too specific to be addressed in the Guidance.	

Cancer Research UK	Evidence Review	Section 7	Clearer distinction is needed between patients with an identified need and those without, since resources may need to be prioritised for those with higher levels of morbidity	The assessment process will identify patients with psychological care needs. The evidence focuses on ways of delivering psychological therapies. Further research is needed which considers different patient groups.	
Cancer Research UK	Evidence Review	Section 7	Research studies of drug interventions are not covered in this section. This is an important omission.	The guidance focuses on models of service delivery. The effectiveness of the provision of drugs is beyond its scope.	
Cancer Research UK	Evidence Review	Section 7	The need for preventive interventions for patients and carers, especially those delivered by non-specialist staff should be highlighted	This is indeed an important point. However, the only evidence that adopts a preventive approach is the literature on burnout in staff.	
Cancer Research UK	Evidence Review	Section 7	Priorities for future research should be collated in a single paragraph.	This will be included in the Guidance Manual.	
Cancer Services Collaborative 'Improvement Partnership' (CSCIP)			This organisation was approached but did not respond.		
Cancer Services Co-ordinating Group			Please find attached additional comments from the CSCG in relation to the current draft guidance on supportive & palliative care.	Thank you.	
Cancer Services Co-ordinating Group	all	general	The vast majority of clinicians in cancer units may see this document as concerning specialist palliative care staff. I would recommend that consideration is given to how this is guidance is launched to ensure that all clinicians dealing with patients with cancer understand that this guidance has implications for them.	This will be discussed with NICE.	
Cancer Services Co-ordinating	Full	5.26 & 5.27	Text does not include the registered mental health nurses and you should be aware that as" psychological services" replace "mental health	RMNs are not excluded from this reference and mentioned in several places in the text. The Developers have taken the decision to retain the	

Group			services" as the accepted name it may be forgotten by some that psychiatrists and mental health nursing staff also have a role to play	phrase 'psychological services' but to continue within the Guidance to include the range of professionals that this type of service will include.
Cancer Voices			This organisation was approached but did not respond.	
CancerBACUP Also Joint response at the end of the table	Full	General	CancerBACUP welcomes the opportunity to comment on the first draft of the Supportive and Palliative Care Cancer Service Guidance from the National Institute for Clinical Excellence. Our comments focus primarily on the section of the guidance that deals with cancer information, as this is CancerBACUP's particular area of expertise and interest. We have had the opportunity for substantial input into this guidance. CancerBACUP welcomes the emphasis in the guidance on good communication with patients, on the importance of information and on the need for effective coordination of care. We welcome the recognition given to the role of all health and social care professionals in contributing to good supportive care for people with cancer. We also welcome the chapter on User Involvement in planning, delivering and evaluating services following our request, in a joint response with other charities, for greater and more consistent emphasis on user involvement and joint decision making. Above all else, we welcome the recommendation that information should be free at the point of delivery.	Comments noted with thanks.
CancerBACUP	Full	General	Information and Resources As this draft Guidance acknowledges, access to	Comments noted.

			information for people affected by cancer has been patchy and inadequate. The 1999/2000 Department of Health National Survey of 65,000 cancer patients found that more than 60% received no written information at the point of diagnosis, for example. Cancer charities' ability to provide information has depended on their resources and the reach of particular groups; or on the wherewithal of people affected by cancer to seek out support directly from them. Many of those who contact CancerBACUP explicitly state that they wish they had known about the charity earlier in the patient pathway. Healthcare providers purchase our booklets, which they display with 'do not remove' stickers. Informal visits to hospitals by CancerBACUP staff suggest that patient information on display is often seriously out of date. Anecdotally, ward level staff access small pots of local charitable monies in order to purchase sample copies of national patient literature. In the apparent absence of sufficient resources to purchase or commission high quality patient information, NHS staff continuously reinvent the wheel by writing clinical, as well as genuinely local, information. Arguably, this is a greater waste of resources than those needed to purchase or commission nationally accredited materials. CancerBACUP welcomes the recommendation in the draft Guidance that information should be free at the point of delivery. We believe that in the light of the above comments the guidance should be unambiguous about the need for commissioners and providers to allocate the relatively modest expenditure of resource needed to	

			purchase/commission high quality patient information. CancerBACUP has written a separate commentary on the analysis of the potential economic impact of guidance on improving supportive and palliative care for adults with cancer.	
CancerBACUP	Full	General	CancerBACUP welcomes the emphasis in the guidance on the information needs of black and ethnic minority groups. We note that the guidance variously mentions 'black and minority ethnic groups' and 'black and ethnic minority groups' and suggest that these phrases be consistently worded. We also recommend that the guidance should emphasise that the needs of black and ethnic minority groups should be regarded as part of mainstream services and not as an adjunct service. This recommendation is reflected in our comments.	Text has been altered to be consistent throughout. This has been emphasised throughout the Guidance.
CancerBACUP	Full	General	CancerBACUP welcomes the emphasis in the guidance on the need to address inequities in access to information and to include information as an integral aspect of patient care. We also welcome its emphasis on the need for high quality information, in a variety of formats, at all stages of the patient pathway. We recommend, therefore, that the information section of the guidance contain a definition of high quality information, and that this definition is referred to throughout the document. We have suggested a wording for this definition (see below).	Text altered to include suggestions.
CancerBACUP	Full	General	The Guidance acknowledges that the lack of co-ordination of care between sectors and within	Comment noted.

			individual organisations has repeatedly been reported in studies of patients' experience of care. Anecdotally, users of CancerBACUP's information services reflect these findings. Callers to our national freephone helpline report significant variations in the range of services available and opportunities to access them. Service users are also frequently unaware of the services available to them. Information can play a key role here in supporting coordination of care by ensuring people are aware of all local and national services and sources of information and support.	
CancerBACUP	Full	ES14	We suggest that an additional line is added to this paragraph reflecting the importance highlighted elsewhere in this Guidance on service users being integral to the decision-making process.	Developers consider that this is covered in the text of the Guidance. .
CancerBACUP	Full	ES15	We would suggest an additional bullet point is inserted here acknowledging that the service model recognises: "the value of high quality information, as defined in the information section of this guidance, for patients and carers at all stages of the cancer journey"	Text altered as suggested – thank you.
CancerBACUP	Full	Key Recommendation 2	We suggest that the words "and information" should be inserted after the word "support" in line two of this paragraph. We also suggest that "during treatment" be added to the list in parentheses in line three of this paragraph. We further suggest that this Recommendation emphasise that health professionals, patients and carers working in collaboration should carry out an assessment of a patient's needs.	Text altered as suggested.

CancerBACUP	Full	Key Recommendation 4	We suggest that the word “informed” be added before the word “views” in this Recommendation.	Comment noted – text not altered.
CancerBACUP	Full	Key Recommendation 5	We suggest that the second line of this paragraph incorporate the words “assessed as being” before the words “an effective communicator”. We also suggest that the words “be supported to enable them “should replace the words “be able “in the fourth line of this paragraph.	Text altered as suggested. Comment noted but decision made not to alter text as suggested.
CancerBACUP	Full	Key Recommendation 8	We strongly recommend that this Recommendation be amended as follows: “Commissioners and provider organisations should ensure that patients and carers have easy access to a comprehensive range of high quality information materials about cancer and about cancer services. These information materials should be free at the point of delivery and patients should be offered appropriate help to understand them within the context of their own circumstances.”	Text altered.
CancerBACUP	Full	Key Recommendation 17	We suggest that the words “high quality” should be inserted after the words “At a minimum…” in line three of this paragraph.	Text altered.
CancerBACUP	Full	Key recommendation 19	We suggest that the words “reflecting cultural sensitivities” be added to the third line of this paragraph following the words “the needs of families and carers.”	Text altered.
CancerBACUP		ES30	ES30 and Key Recommendations 19 and 20, page 10 CancerBACUP welcomes the emphasis in the Guidance on workforce development and the need	Thank you.

			for enhanced training in several areas. We suggest that this section should specify that systems should be in place to ensure such training needs are met. We also suggest that this section should reflect the need for staff to receive training in cultural sensitivity and diversity. We further suggest this section should address the training and support needs of non-professional paid care workers provided by social services as they often have considerable contact hours with the patient.	Developers consider that this is included in the text of the Guidance. This will be included in the 'face to face' section. This is not within the scope of the Guidance.
CancerBACUP	Full	I3	We welcome the bullet point here stating that patients want and expect to receive detailed information about their condition and possible treatment. We would suggest that the words "high quality" be inserted here before the word "information" and that the words "at all stages of the patient pathway" are inserted at the end of this sentence. We also suggest that a bullet point in an earlier draft be reinserted in this paragraph. This bullet point related to choice and to patients knowing "what options are available to them under the NHS, voluntary and private sectors, including access to self-help and support groups and complementary therapy services". We would also suggest that access to information be added to this sentence.	Text altered.
CancerBACUP	Full	I6	We suggest the addition of a bullet point reflecting the need for better provision of high quality information as defined in the Information section.	Text altered in line with suggestion.

CancerBACUP	Full	I15	We suggest that this paragraph acknowledge the important role played by healthcare assistants provided by the Homecare team or the local authority. We would suggest that an extra bullet point be added to this paragraph to reflect this.	Comment noted – but the Developers consider that this is implied in the term ‘usual professional carers’.
CancerBACUP	Full	I18	We suggest that this paragraph reflect the need for health and social care professionals to check with patients whether their decisions about their own care remain the same, or have changed.	Text altered as suggested.
CancerBACUP	Full	1.10	We suggest that a further bullet point be added here, as follows: “ensuring information needs are coordinated according to patients requirements, utilising a comprehensive range of high quality materials”	Comment noted – Developers consider that this is covered within the text.
CancerBACUP	Full	1.14	We suggest that the last sentence of this paragraph should be amended to read as follows: “Mechanisms should be developed to enable the sharing of assessment data at key points (as listed in 1.17) among different members of the multi-professional team involved in planning and delivering care to an individual patient.	Text altered to take comments into account.
CancerBACUP	Full	1.21	CancerBACUP welcomes the recommendation that patients and carers are given information about who they can contact at any time of the day or night for advice, support and provision of services. In accordance with our earlier submission, we would again suggest that this paragraph should also emphasise the need for patients to be given information about both local and national sources of information and support and details of other, confidential sources of information and support.	This is included in the text of the Guidance.

			We also suggest that the words "bearing in mind specific issues relating to black and ethnic minority communities, and the needs of those with sensory impairment" should follow the words "meeting local community needs" in the 5th line of this paragraph.	Text altered.
CancerBACUP	Full	1.23	We suggest that the words "whilst taking full account of national guidelines" be inserted at the end of the first sentence in this paragraph.	Text altered.
CancerBACUP	Full	1.26	We suggest that patients should be given written telephone contact details for the administrative contact identified in this paragraph	Text altered.
CancerBACUP	Full	1.40	It should be noted here that key workers would need relevant training and support to fulfil their role.	Comment noted – but Developers consider that at this stage it is inappropriate to specify what the training and support could be as the nature of the role should be further developed and evaluated.
CancerBACUP	Full	2.13	National organisations are often good sources of information about local support groups. We would suggest that this paragraph be reworded as follows: "Patients with cancer and their carers should be given information about relevant local and national self-help and support groups."	Text altered in line with suggestion.
CancerBACUP	Full	2.15	We suggest that an additional sentence be added here stating that Partnership Groups should specifically include people from diverse communities and/or the organisations who represent them.	Developers consider that this point is covered.
CancerBACUP	Full	2.31	We suggest that diversity training be added to the types of training listed in line four of this paragraph.	This refers to evidence - it is not a recommendation.
CancerBACUP	Full	3.0	The Guidance refers throughout this section to "good communication". We suggest that an additional paragraph be added here defining "good	Developers consider that this is implied throughout the Guidance.

			communication" and suggest that this definition is: "The ability to meet the needs of patients and carers in a confidential and supportive environment and to give them the option of anonymity and/or other services."	It is also covered in the introduction to this topic.
CancerBACUP	Full	3.2	CancerBACUP welcomes the insertion into this paragraph of a reference to telephone communications as a supplementary mode of communication with patients and carers. We would suggest that this paragraph also emphasises that the telephone offers the benefits of anonymity and confidentiality, which people often want in addition to face-to-face communication.	Comment noted – decision taken not to alter text to include this point.
CancerBACUP	Full	3.3	CancerBACUP agrees with the emphasis on good communication as a prerequisite for enabling patients and carers to make informed decisions about their care. The guidance could also point out that good communication is also likely to lead to greater compliance with treatment regimes.	Comment noted - references for evidence to support this statement would be very useful.
CancerBACUP	Full	3.11	We suggest that if patients want to take up this opportunity to discuss matters further, an appointment should be made immediately with the professional of their choice. If the offer is declined, the patient should be made aware they could request it at a later stage of their choosing. We also suggest that patients are offered the opportunity to have an advocate present if they so wish.	This is covered in the text to some degree – and could be left to local implementation.
CancerBACUP	Full	3.12	We suggest the first words of this paragraph be changed to: "For those individuals whose first or preferred language is other than English," rather than "For those individuals who cannot understand or speak	Text altered throughout Guidance – thank you.

			English…”	
CancerBACUP	Full	3.13	We suggest that the last line of this paragraph be supplemented by the words: “or be supported by someone who has those skills.”	Text altered.
CancerBACUP	Full	3.20	CancerBACUP welcomes the guidance’s recommendation that suitably skilled interpreters, such as a professional healthcare interpretation service, be made available for patients who want or need them. We suggest, however, that the words “who cannot understand or speak English” be removed as patients should be encouraged to communicate in their preferred language.	See comment above.
CancerBACUP	Full	3.21	CancerBACUP welcomes the recommendation that although the potential role of family members as interpreters is acknowledged, services should not over-rely on family members to fulfil this role and should only seek their participation in extraordinary circumstances or when the patient specifically requests it. We suggest that the words “and/or family member” be deleted from the last line of this paragraph.	Text altered to reflect this.
CancerBACUP	Full	3.23	We suggest that the following words be added to the end of the first sentence of this paragraph: “and of the cultural sensitivities relating to cancer and to cancer treatment.”	Text altered.
CancerBACUP	Full	3.25	It should be acknowledged that junior staff and other workers often communicate ‘significant news’. We suggest that the words “including junior staff and other workers” are added to the end of this paragraph. We would also suggest that this paragraph recognise	Developers consider that the reference to ‘all staff’ covers this point.

			the need for health professionals to undergo diversity/cultural awareness training to ensure appropriate communication with people from ethnic minorities.	New paragraph inserted.
CancerBACUP	Full	4.1	We suggest that this paragraph reflects paragraph 3.3 (page 41) by including the words “Professionals should ask patients what they want to know, and not make assumptions about the level of information they require.” In accordance with our earlier general point regarding the definition of high quality information, we would suggest that the following paragraph be incorporated here after 4.1: “In order to inform, support and reassure, information needs to be of high quality. High quality is defined here as: nationally accredited, independent, evidence-based, peer reviewed, regularly updated, culturally sensitive, and available in a variety of formats. “	Text altered in line with comments.
CancerBACUP	Full	4.3	We suggest that the words “Culturally sensitive” be added to the beginning of the third sentence of this paragraph. The sentence would then begin: “Culturally sensitive materials in languages other than English….”	Text altered in line with suggestion.
CancerBACUP	Full	4.3	Paragraph 4.3 makes the point that there is currently unnecessary duplication of effort in the production of information. We would suggest, therefore, that an additional paragraph is incorporated into this section emphasising that existing sources of nationally accredited, high quality information should be the preferred choice of commissioners and providers in order to ensure that unnecessary duplication of effort	This is covered in the recommendations section.

			is avoided.	
CancerBACUP	Full	4.0	Further sources of information We would strongly recommend that these sections of the guidance emphasise more strongly the need for patients to be given information about both local and national sources of information and support. We would suggest additional paragraphs are incorporated into these sections stating that written information given to patients should include details of who they can contact nationally and locally if they have particular questions about their own treatment and care, plus details of other reliable and confidential sources of information and support.	Text altered in line with these comments.
CancerBACUP	Full	4.0	Culturally sensitive information materials We recommend that this section emphasise that information should be culturally sensitive towards the local community. We would suggest an additional paragraph stating this.	Text altered to include this.
CancerBACUP	Full	4.7	We suggest that the words “a comprehensive range of” replace the words “an adequate range of” in the first line of this paragraph, and that the words “high quality as defined in Paragraph 4.2” (as per new paragraph suggested by CancerBACUP) be inserted before the words “information materials” in the second line of this paragraph.	Text altered.
CancerBACUP	Full	4.8	In accordance with the general point made above under Further sources of information, we would suggest that the last line of this paragraph should read “They should direct patients and carers to other reliable and confidential local and national sources of information.”	Text altered.

CancerBACUP	Full	4.10	We suggest that this paragraph should state that patients and carers should be given written contact details of the person who is able to offer further help.	Text altered as suggested.
CancerBACUP	Full	4.14	We suggest that an additional bullet point be added to this paragraph as follows: “updated on a regular basis and out of date material destroyed.”	Suggestion included – but not as a bullet point.
CancerBACUP	Full	4.15	We suggest that this paragraph states that the Coalition for Cancer Information should ensure that commissioners of cancer services and other health providers are made aware of such nationally accredited information products.	Text altered.
CancerBACUP	Full	4.16	We would suggest that this paragraph begins with the words “High quality…. We would also suggest that the words “a comprehensive range of” replace the words “an adequate range of” in the third sentence of this paragraph.	Text altered.
CancerBACUP	Full	4.17	We would recommend that this paragraph place stronger emphasis on the need for user involvement. We would suggest that the final sentence of this paragraph be placed at the beginning of the paragraph, and that the words “representing the community” be inserted after the words “Service users”	Text altered in line with suggestion.
CancerBACUP	Full	4.18	We would suggest that the words “a comprehensive range of high quality information materials” after the words “easy access to” in line two of this paragraph.	Text altered.
CancerBACUP	Full	4.21	CancerBACUP notes comments by the Guidance Development Team that the role of NHS Direct needs to be reviewed in this context.	Comment noted.

CancerBACUP	Full	4.22	In line with our earlier point regarding paragraph 3.20, we suggest that the words “into a language the patient can understand” are replaced by the words “into the patient’s preferred language”. We also suggest that the words “culturally sensitive” are inserted before “information materials” in the second line of this paragraph. We also suggest that the words “nationally” be inserted before the words “accredited information provider” in the third line of this paragraph.	Text altered.
CancerBACUP	Full	4.30	We suggest that the words “cultural orientation” in the second line of this paragraph be changed to “cultural needs”.	Text altered in line with suggestion.
CancerBACUP	Full	4.34	Given the point made earlier in the Guidance (4.3) that there is currently unnecessary duplication of effort in the production of information, we would suggest that the last line of this paragraph states that “the number of people contacting and using them suggests a need for health providers to promote increased access to existing sources of high quality information” rather than “ a need for more sources of information”.	Text altered.
CancerBACUP	Full	4.35	We suggest that details of NOF projects taking place throughout the UK be listed in the Guidance Appendix.	Footnote with link to NOF project site inserted.
CancerBACUP	Full	7.18	We suggest that this paragraph should be amended to recommend that multi-professional teams ensure that their awareness of local community resources for spiritual care is kept up to date.	Text altered.
CancerBACUP	Full	10.29	We suggest that the word “appropriate” be included in the second line of this paragraph before the words “wigs, stoma bags” in order to ensure cultural needs	Text altered as suggested.

			are met.	
CancerBACUP	Full	12.7	We suggest that an extra line be added to this paragraph reflecting the need for cultural sensitivities to be acknowledged.	Text altered.
CancerBACUP	Full	12.14	We suggest that the following words be added to the end of this paragraph: "in accordance with the patient's wishes".	Text added as suggested.
CancerBACUP	Full	12.26	We suggest that the words "the relevant health advocates, where available," be added to the fifth line of this paragraph	Text altered.
CancerBACUP	Full	12.30	We suggest that these components should also reflect cultural sensitivities.	This is covered in the text in this section.
CancerBACUP	Full	F	We suggest an extra bullet point is added to the list, reflecting the need for training in cultural diversity	Text altered.
CancerBACUP	Full	Appendix 2.4	Point of information: Ms J Mossman is no longer the Chief Executive of CancerBACUP.	Thank you.
CancerBACUP	Economic Review	4.4.1	In the second paragraph, the draft refers to the need to "produce" high quality information. Whilst there are still gaps in the production of information to meet the needs of particular groups, in the main the need is to purchase or commission and disseminate rather than to produce high quality information.	The text in section 4.4.1 has been revised to reflect the fact that the main need is to purchase or commission and disseminate rather than to produce high quality information.
CancerBACUP	Economic Review	4.4.2	The reference to six booklets per patient in the third paragraph of this section is for those patients who stay in touch with CancerBACUP throughout their cancer journey. At any one point of contact, the average number of booklets sent to an individual is two. We therefore think it realistic to base the economic model on an average of five booklets per	No change required.

Comment [S2]: Ok to leave name in?

			patient.	
CancerBACUP	Economic Review	Table 7	The figure of £1.50 per booklet includes the core costs of a publications nurse, editorial assistant and fulfilment officer. These are, of course, fixed costs. There would therefore be economies of scale involved in the production of five booklets per patient with 266,650 diagnoses each year.	The fact that there would be economies of scale has been reflected in the text.
CancerBACUP	Economic Review	Table 7	We think you are right to assume that these increase pro rata with increasing numbers of booklets.	No change required.
CancerBACUP	Economic Review	Table 7	Although CancerBACUP staff estimated the costs of keeping the website up to date as £57,000, this figure excludes some of the core staffing costs without which we could not undertake the updating work. This figure is therefore unrealistically low.	The economic review does not seek to provide detailed costings but rather to provide a crude order of magnitude estimate of the most significant costs. This assumption is not likely to have a significant impact on the total costs for information provision for the network.
CancerBACUP	Economic Review	Information, page 34	Nevertheless, we think the overall analysis of the costs of information based on our model does indicate the affordability of providing high quality patient information and the costs are significantly lower than the accumulating costs of NHS staff time spent in producing similar information over and over again at hospital or community level.	No change required.
Cephalon UK Ltd			This organisation was approached but did not respond	.
Chartered Society of Physiotherapy	Full	General	We welcome this guidance document and appreciate the time and effort that has gone into producing it. It has the potential to make a significant contribution to how services are organised, in reducing variations in care across the country, and the make up of that care.	Thank you.
Chartered Society	Full	General	We are pleased this document reflects the physiotherapy perspective so well, and recognise the	Comment noted – thank you.

of Physiotherapy			hard work of the two physiotherapy representatives on the AHP panel.	
Chartered Society of Physiotherapy	Full	General	In would be helpful to make a more specific link between each specific recommendation, the grade of evidence for that recommendation, and the evidence and thinking behind how the evidence has been used to create the recommendation. For example, section 10.36 makes four statements each with a Grade 'A'. These are not linked to the underpinning evidence and so it is not possible to know how these statements were devised. There is no explicit link between the recommendations in section C and the evidence paragraphs in section D.	The process of producing recommendations and testing those against the evidence is not always easy to represent. The evidence is not only based on published studies. Where such evidence was lacking, experience and knowledge from health professionals and users was consulted.
Chartered Society of Physiotherapy	Full	General	We noted the intention to do so, but because of its importance would stress that wording related to staff and grading should reflect the new Agenda for Change pay spine terminology.	The table this comment refers to has been re-drafted..
Chartered Society of Physiotherapy	Full	C2	This section should reflect a need to ensure minority groups and those with issues to do with literacy are included in this process.	Additional text has been inserted into the Guidance highlighting the needs of special groups.
Chartered Society of Physiotherapy	Full	3.24	Add: 'Provider organisations should ensure clinicians are aware of these services and have direct access to them'	Text altered.
Chartered Society of Physiotherapy	Full	3.34	This is an example where it is unclear from where this 'A' grade derives. What evidence was used to inform this statement? Depending on circumstances and the setting other healthcare professionals could also provide this service, for example, allied health professionals. Unless the evidence is specific, suggest remove	This is referred to in the relevant section of Evidence Manual. The evidence is specific and derived from the evidence tables, which have summarised sessions given by nurses, and which was high level evidence from randomised control trials – Allied Healthcare

			‘’usually provided by nurses’.	Professionals could do this type of intervention but little or no examples have been found in research.
Chartered Society of Physiotherapy	Full	5.24	‘…designated professionals’ should include allied health professionals.	Comment noted but Developers consider that the text will remain unaltered.
Chartered Society of Physiotherapy	Full	9.20	Fourth bullet point: Could include allied health professionals here: ‘support from other services such as those provided by allied health professionals and social services departments.	Additional bullet point inserted as suggested.
Chartered Society of Physiotherapy	Full	9.25	We recognise this ‘core team’ from the other site-specific cancer documents, however we would encourage a reconsideration of this. Allied health professional should be core members of the ‘specialist palliative care team’ to ensure, for example, the physical and movement problems of a patient are addressed early and expertly.	Point discussed at Editorial Board meeting – decision made that Allied Healthcare Professionals would not be identified as core members of the team but their expertise would be drawn from the extended team as appropriate to meet the needs of the patients/carer.
Chartered Society of Physiotherapy	Full	10.9	A recent national conference presented research findings on the lack of cancer related education at undergraduate level (Improving cancer care through better professional education, 13 May 2003, London. Coles CR, Fleming WG, Goulding LG (2003) Baseline review of cancer education in four professions – short report; Full report available from: mail@soundingsresearch.co.uk. There are limited physiotherapy clinical placements in oncology for undergraduates. Both result in a lack of exposure to oncology and palliative care by students and junior therapists, impacting on interest in specialist roles later.	This reference will be included in the Evidence Manual thank you. Comment noted.
Chartered Society of Physiotherapy	Full	10.9	There is one course “Oncology for AHPs, modules 1&2 in association with Liverpool University and Clatterbridge Centre for Oncology”	Comment noted.

Chartered Society of Physiotherapy	Full	Table 10.1	The wording of this table will need to reflect Agenda for Change terms, to ensure universal currency and understanding.	Table altered.
Chartered Society of Physiotherapy	Full	10.0	North-West England Care Pathways publication could be used here in the absence of higher level evidence.	Reference added to text.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	General	In general this guidance is too woolly to be of any use in guiding commissioners as to developments than need to take place to develop services to an acceptable national standard. There is far too much use of words such as “appropriate” or “sufficient” without defining what “appropriate” or “sufficient” means in this context. It reads rather like nutritional guidance that advises people to “eat sufficient vitamins and calories appropriate to their activities”	The Developers have been guided by a reference group of commissioners in producing this Guidance. This is not their view! Careful editing of the Guidance has taken place to remove these words or clarify their meaning.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	ES21	Why not national approach to assessment and recording of patients needs that can feed into shared EPR/HER developments. Patients move across Cancer Network boundaries and many SPC services serve patients from more than one cancer Network.	This would be welcomed – but is beyond the scope of the Guidance.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	ES25	Should read “appropriate range and volume of specialist palliative care services.” Range is not enough.	Text altered in line with comment.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	1.16	Why not national approach to assessment and recording of patients needs that can feed into shared EPR/HER developments. Patients move across Cancer Network boundaries and many SPC services serve patients from more than one cancer Network. It would be more economic to develop a database	This would be welcomed – but is beyond the scope of the Guidance.

			programme for these assessments nationally.	
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	1.29	Why not more national guidance on which of these approaches patients might reasonably expect e.g. which joint clinics.	Comment noted – but not within the scope of the Guidance.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	2.C2	There needs to be some recommendation on the representation of those who are too ill, communicationally challenged or dead to have a voice through the methods mentioned	This is covered in the text.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	3.9	Should read “received training on an accredited training course and is”	This is covered in a later paragraph.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	3.19	“and/or” should read “and” – all patients should at least be offered a second appointment to come back to discuss these key communications as questions often arise in the days following a consultation.	Comment noted but decision made not to alter text.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	5.14	Some definition of adequacy of training, supervision and support is required to make this meaningful.	This is included in the overview paragraphs in this section of the Guidance.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	5.23	This item says that Level 2 professionals should be able to screen but does not state that all patients should be routinely screened for psychological distress at these key points. This should be stated here or elsewhere.	This is referred to within this section.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	5.25	Palliative physicians are also important in this role and have a particular place in the management of mild to moderate depression in this patient group.	Text altered to identify this role.

Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	5	There is no statement of what constitutes adequate access to Level 3 & 4 services in this regard. Whereas we have a waiting time of two weeks for these services locally a neighbouring unit has a waiting time of six months. Both would say they have all levels of service! A waiting time target for assessment and intervention would seem appropriate.	It is not within the scope of the Guidance to define acceptable waiting times for services. These issues may be addressed in the standards that will derive from the Guidance.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	6.17	“Speedily” needs to be defined. Waiting times for equipment such as beds and mattresses vary from hours in some districts to weeks and months. Stairlifts often do not get put in as in the months of waiting for them the patient has died. Unless standards are set then “delivered speedily” will continue to be interpreted flexibly.	Comment noted but decision made not to alter recommendation.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	8.20	Why should eligibility for Specialist Palliative Care be a local matter – if service provision is to be equitable then surely we need a national definition of eligibility for SPC. This is what national guidance is there for.	This might be an issue for national bodies to take up as a result of the recommendations in the Guidance.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	8.28	As per comment on 6.17 “without delay” needs tighter definition. For example “within one working day for equipment that does not need specialist installation, within one working week for equipment that does need specialist installation.” Also the same standards of provision need to be provided for those who wish to be discharged from hospital or hospice into the community.	Comment noted but considered to be outside the scope of the Guidance.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	8.37	The DoH District Nurse programme provided education rather than training.	Comment noted.

Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	8.44	It would be helpful if the guidance included a definition of dying and the diagnosis of dying.	Comment noted – but decision made not to add further definitions on aspects of care.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.11	This seems to imply agreements with each individual GP/DN etc on co-ordination of care.	Text altered.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.12	Unless the guidance gives some indication of how commissioners should be assessing that "-the level of service provision (is) appropriate to the needs of the population" then this will be completely meaningless in the context of cash starved PCTs struggling to make budgets balance. We all know that in today's NHS (except for ring-fenced allocations) investment is only made in "must be dones." Likewise use of "appropriate" in 9.17	Text altered to take this comment into account.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.17	Unless the National Guidance provides some benchmark against which to assess adequacy "need" will be defined flexibly according to available resources.	Text included regarding audit and eligibility.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.18 & 9.31	The guidance about the availability of Specialist inpatient facilities is completely meaningless without some definition of accessibility. All Cancer Networks could point to a Specialist in-patient facility however for some there are long waiting times or are only practicably accessible from part of the Network served while others have units on the doorstep with beds lying empty for immediate access. A minimum for the guidance should be to	See response above. This is for local implementation – this is likely to depend on local needs and local variables. The work being done to produce standards for the Manual of Cancer Services Standards from the Guidance may address this issue.

			define appropriate access times for urgent referrals e.g. "that SPC beds are sufficient in number to provide access a specialist in-patient bed within two working days of urgent referral as a minimum standard." An alternative may be to define number of beds per million in each cancer unit district.	
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.25	There is a need for a standard definition of a Palliative Care Nurse Specialist (required training and experience and level of working.) The national guidance should be providing this.	Developers consider that this is an issue for the national nursing bodies to determine.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.25, 9.33 &9.37	Rehabilitation services should be core at least for Community teams, specialist in-patient units and daycentres.	Point discussed at Editorial Board meeting – decision made that Allied Healthcare Professionals would not be identified as core members of the team but their expertise would be drawn from the extended team as appropriate to meet the needs of the patients/carer.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9	Where is the guidance on Specialist palliative Care outpatient provision?	Outpatient services are referred to in the Guidance as a part of the range of services offered by day care facilities. This does not preclude specialist teams delivering aspects of service through provision of out patient clinics.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	9.25, 9.33	Some guidance on minimum standards for volume of each of the staffing components of the team based on population covered, size of cancer centre/unit etc should be within the scope of this guidance e.g. on consultant in palliative medicine for the population of Birmingham would not be adequate but might be for the population of Rotherham.	There is no evidence to support this. Text has been inserted underlining the need to assess the adequacy of services at local level with some criteria against which to assess this.
Chesterfield and North Derbyshire	Full	9.28	Normal working hours, seven-days-a-week including bank holidays – I assume this means 9-5 seven days	Text altered throughout Guidance to clarify this.

Royal Hospital NHS Trust			a week (and not the definition within the first consultant contract framework.) It would be better if it said precisely what it means.	
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	Table 10.1	Should include reference to graded exercise for those with cancer related fatigue as increasing evidence continues to be published on it's efficacy.	Comment noted – but table includes examples only..
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	10.28	It is useful to have a specific timescale for equipment provision but "Approaching the end of life" needs definition. At one extreme it could mean that a patient diagnosed with unresectable lung cancer should have their stairlift within 24 hours on a Bank Holiday weekend. I encourage the definition of timescales but the definitions need broadening out with reasonable timescales for different types of equipment and different patient state.	Comment noted - but this would be for local implementation.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	10.34	I would encourage the development of clinical specialist and consultant specialist posts but perhaps this guidance should specify that these are for AHPs with appropriate higher level education and training.	This is covered in this section of the Guidance.
Chesterfield and North Derbyshire Royal Hospital NHS Trust	Full	11.11	Would not National review of the evidence relating to best practice be more appropriate rather than expecting each cancer network to re-invent the wheel? This is the role of NICE surely.	This is covered in the footnote to this paragraph.
Cochrane Pain, Palliative Care and Supportive Care Group			This organisation was approached but did not respond.	
College of Occupational Therapists	Full	general	This document has been a long time in its generation and will be greatly welcomed by all occupational therapy practitioners working in oncology and	Comment noted, with thanks.

			palliative care.	
College of Occupational Therapists	Full	10	The College's specialist section for HIV/ AIDs, Oncology, Palliative Care and Education (HOPE) has been involved in the editorial team for the Rehabilitation section, chapter 10. This has been a valuable process, which we feel has produced a document of depth and quality. By having a whole section on rehabilitation this document allows a greater understanding of the role and contribution of AHPs to the rehab process.	Comment noted. Thank you.
College of Occupational Therapists	Full	10.28	We welcome the text in point 10.28 addressing the speed of equipment supply and look forward to this defined standard impacting patient care.	Comment noted. Thank you.
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	General	Important that output is linked to other ongoing pieces of work, such as communication skills project, and any relevant work Skills for Health are taking forward	Advice as to the specific pieces of work by skills for health would be helpful please. References have now been made to communication skills pilot in topic on face to face communication.
Department of Health	Full	3	Would you consider making investment in team working training at local level a priority?	The Evidence Review Team found one study (Nash & Hoy 1993) which evaluated a residential workshop for general practitioners/district nurse pairs from the same practice. A survey indicated that this workshop had a potential for affecting practice. The findings showed raising confidence in some areas of palliative care, and increasing awareness of the roles of other professionals within the team. More research is needed in training for teams.

Department of Health	Full	General	Could you clarify whether NICE will provide a carer/user version of the guideline?	Yes, this will be a part of the second consultation.
Department of Health	Full	ES	Would you consider indicating the weight of evidence?	Developers have taken the decision not to do so.
Department of Health	Full	3.10	Presentation of permanent records of communicated information seems wise.	Comment noted.
Department of Health	Full	4.0	Recommendations on information are good, but would you consider repeating the fact that not all people want the same amount of information and that things change?	Comment noted - but Developers taken the decision not to alter the text as requested.
Department of Health	Full	5.5	Refers to clinical health psychology (whereas clinical and health psychology are different). Could you consider re-phrasing this please?	Text altered.
Department of Health	Full	5.19-5.36	In checking the evidence we could not see where this particular number of levels was derived from. Could you consider making this clearer?	This model is based on professional consensus.
Department of Health	Full	5.43	Please could you present more evidence as to why the model proposed would/could reduce the risk of occupational stress.	Text altered – point deleted.
Department of Health	Full	5.0	No particular linkage to levels of mental health skills in primary care made in various documents. Would you consider making such links?	Advice as to the specific documents would be helpful please.
Department of Health	Full	5.0	Role of liaison psychiatry is not clear. Could you clarify this please?	Liaison psychiatry is referred to in the text. The Developers are considering producing a glossary and liaison psychiatry could be included in this. It is not within the scope of the Guidance to spell out the role of any specific service.
Department of Health	Full	5.0	No reference made to pre-existing psychological problems.	This is covered in the introduction to the Guidance.

Department of Health	Full	12.0	Learning could be gained from mental health carer work. Focus on social networks seems very sensible. Interesting that psychotherapy offered to carers not taken up – is this due to focus on sick relative and the individual work may be needed later in some cases?	A study has been carried out (Harding & Higginson 2001) which showed that informal carers of patients at the end of life have high-level information and support needs themselves. However caregivers are highly ambivalent with regard to their needs. The design and delivery of an intervention aimed at caregivers should take account of this by addressing their lack of identification with their role, enhancing existing coping strategies, and ensuring that interventions are accessible and acceptable.
Department of Health	Evidence review	3.0	P15, 2nd para, 1st sentence Please could you make the meaning of this sentence clearer?	We deleted the word “patient” which should not have been there.
Department of Health	Evidence review	4.0	P27 1st para Please could you check the numbers in the systematic reviews?	We checked the numbers in the systematic reviews.
Department of Health	Evidence review	7.0	P111 Could you check the calculations in the meta analyses?	The Evidence Review Team does not check calculations in meta-analyses as this has been done during the process of publication.
Department of Health	Evidence review	General	Please could you clarify the distinction between a critical review and a systematic review?	The difference between a traditional literature review and a systematic review is that the latter uses explicit criteria and methods to identify, critically appraise, and synthesise relevant literature.
Department of Health	Evidence review	13.0	Complementary therapy services Are there any comparisons with mainline therapy services?	As far as we know there are no comparisons with mainline therapy services.
Department of Health	Evidence review	13.0	Is a mood score being reduced a good or bad thing?	A mood score reduced is a good thing.
Department of	Full	ES14	Network model an excellent idea, could easily apply	Comment noted.

Health			to other areas, and is reminiscent of the Care Programme Approach in Mental Health	
Department of Health	Full	ES20	Good in that it sees psychological sequelae as normal not pathological. However, perhaps recommendation 9 could identify where 4 level model can be seen.	This cannot be done at the present time – but may be able to be done as a part of final editing. It may however be impractical to continually cross reference to other sections of the Guidance.
Department of Health	Full	E22	An unusual style, appealing, but incongruous with the rest of this document's style. Would you consider amending this?	Text deleted.
Department of Health	Full	ES24	It seems unusual that there is only this one named example of good practice.	One example considered to be sufficient.
Department of Health	Full	3.22	Is this strong enough? Surely the use of children as interpreters in this setting would be exceptional.	Part of the paragraph referring to this issue deleted.
Department of Health	Full	Figure 5.1	Would you consider including Specialist MH nurses here?	Added to text.
Department of Health	Full	5.28	Please could you consider rephrasing to *complex psychological problems, severe affective disorders , psychotic illness and substance misuse*	Text altered to clarify what is included in the description of complex psychological problems and psychotic illnesses added to list.
Department of Health	Full	5.29	Again could you please add *mental illness* to this list	This list describes various forms of mental illness – referred to within the Guidance as mental health problems.
Department of Health	Full	5.0	Perhaps Mental Health and psychological services would be a more inclusive title?	Comment noted but decision taken by Developers to retain original title for the section.
Department of Health	Full	5.12	Paragraph that says that emergency psychological services should be available when necessary. Do such services exist? Perhaps you could consider the following re-drafting: 'Anyone in acute distress and/or a mental health emergency should be able to access help quickly	Changes made to certain paragraphs – but this not altogether relevant for the level of psychiatric distress being referred to in this section of the Guidance.

			through NHS Direct and be referred to the appropriate specialised service. Anyone already in contact with specialised services should have a Care Plan identifying the person to contact in an emergency.’	
Department of Health	Full	5.15	For the most part, routine screening for psychological and/or mental health problems does not take place in general medical settings; this being something that is only undertaken on demand/referral. Is routine screening is desirable in the mental health context? Is this is a commissioner responsibility? Are there are instruments that exist with the appropriate predictive validity? It might be better to say: `Clinicians should ensure that risks are accurately judged and early signs of psychological distress are assessed in each individual case.’ This would also mean that the centre box in table 5.1 should be changed from `screening’ to `early detection’.	All the research says it should, and indicates that unless it is done in general medical settings, problems are missed. It is desirable – all Peter Maguire’s work suggests this. Screening assessment allows the formulation of the most appropriate care for individual patients.
Department of Health	Full	5.35	Survivorship issues are central to the MH user experience, too.	Text altered to acknowledge this issue.
Department of Health	Full	7.12	Would you consider mentioning the role of faith healers in minority black communities here?	Broader statement about belief systems added into this section.
Department of Health	Full	12.16	Seems to take a much harder tone than other sections, implying use of services a last resort. Is this intentional?	Comment noted. No intention meant.
Department of Health	Full	12.7	Would you consider replacing psychiatric and psychological therapy with *mental health services intervention*? Would you also consider removing the phrase *serious* from the last sentence?	Text altered.

Comment [S3]: Should name be removed?

Department of Health	Full	12.30	This is the preferred phrasing for mental health/psychological services. Would you consider adopting this throughout the document?	The Developers are not quite sure what comment is being made here.
Department of Health	Full	12.42	Perhaps this could be made clearer?	Text altered.
Department of Health	Research evidence	3.0	Please could you mention co ordination across statutory & non-statutory services?	Text altered.
Department of Health	Research evidence	4.0	Perhaps stronger recommendations for user involvement could be made. At times this chapter reads as if there is ambivalence around the issue. Is this intentional?	The reason for this is that the evidence shows that the involvement of patients in the planning and delivery of health care has contributed to changes in the provision of services across a range of different settings, but the effects of this process on the quality and effectiveness of services is still unknown.
Department of Health	Research evidence	5.0	There is a clear link between autonomy, involvement and outcome.	Communication skills training for patients, has an effect on their autonomy and involvement and in turn has a beneficial effect on patient outcomes.
Department of Health	Economic review (Applies to All as well)	2.0	• The guidance *should* be based on cost-effective evidence (in conjunction with the clinical evidence presented) in order to make sure that the NHS is receiving value for money. Just costing the guidelines is not enough, because it means the guidelines are not based on economic evidence of best practice. Cost-effective analysis aids in the decision of the best way to deliver a service/intervention. • It is also not clear why the guidance does not include cost-impacts where there is likely to be a fall in costs. It is suggested that information on cost reductions is included in order to accurately calculate the net costs of implementation of the guidance.	A literature search was undertaken to identify evidence on cost effectiveness and this was used where available. However, this was extremely limited. The economic review did not explicitly exclude cost savings. However, no areas were identified where significant cost savings might occur.

			• It would be helpful if the guidance could calculate what the health benefits, quality of life and other benefits of the guidelines are in order to support the extra expenditure • It would be useful if the guidance looked at cost implications of social support services such as respite care'.	There is no evidence on which to base calculation of health benefit, quality of life or other benefits of the guidance. Social support services, such as respite care, which cover both the services and NHS funded provision, as well as voluntary sector provision were not costed, as guidance in this area is not solely the remit of NICE. Costings for these areas would need to be undertaken as a separate exercise.
Department of Health	Economic review	2,3.4,4.5.3.1,4.13,5.1.1, table 35 0	• Is it really true that generalist staff groups such as GPs, community staff nurses and emergency psychological support service would be able to incorporate the recommendations into their existing workload? Can this issue be explored/researched in more detail and any staff expansion costed.	This is a complex area and a range of factors need to be taken into account. For instance, there will be additional time implications, due to longer, more detailed assessments taking place. However, improved sharing of information will avoid duplication of assessments and improved assessments may well reduce future workload, by identifying and responding to problems at an earlier stage. There is currently no robust evidence on which to base this assumption, but rather it is based on clinical opinion of members of the Editorial Board. Future research is recommended to explore this issue further
Department of Health	Evidence Review	8.0	The review mentions a study by Higginson et 2001, which is the only article that actually examines cost-effective evidence (alongside effectiveness evidence). However, this review section does not say whether the article found the palliative care team model to be cost-effective or not, it just says that 'there appears to be some substitution of hospital for home costs' – does this mean that the palliative care model provides a cost-saving? If so, could this be	This review did not find strong evidence for the overall cost-effectiveness of palliative care teams, but there was some evidence to suggest that there may be some substitution effects between hospital and home care, mostly by reducing the number of inpatient days.

			included in the guidance.	
Department of Health			Thank you for the opportunity to comment on the first draft of the supportive and palliative care guideline. This letter and supporting proformas (Annexes A, B and C) reflect the comments of the Department of Health and the Welsh Assembly Government. As with the development of all guidelines, we would find it helpful if you could identify the top 5 or 6 recommendations on clinical or cost effectiveness grounds. It would be helpful if you could also evaluate the cost impact to the NHS of the top 5/6 recommendations.	Thank you. This point was discussed at a Guidance Editorial Board meeting and it was decided that further refining of the 20 key recommendations identified in the summary was not helpful.
Department of Health		ES9	Perhaps the developers could make it clear that the NHS Plan and NHS Cancer plan are for the NHS in England only. The Strategic plan for the NHS in Wales 'Improving Health In Wales' published in January 2001 set out the priorities for the delivery of cancer care services in Wales. Where there are references to the NHS Plan in the guidelines, please could you refer to it as the “NHS Plan in England”.	Text altered.
Department of Health		1.30	Would you consider expanding "These should be consistent with the Information for Health strategy of the NHS Information Authority" to include reference to “Informing Healthcare“ the Welsh Assembly Government's strategy for transforming healthcare in Wales.	Text altered.
Department of Health		6.7	Would you consider replacing the first sentence with the following two sentences: 'New targets for assessment and receipt of services have been announced and new performance indicators for these targets will be published in October 2004. As a result of the Community Care (Delayed	Text altered.

			Discharges) Act 2003 social services will be required to provide services within a specified time limit or reimburse the NHS Trust for the consequential delay in hospital'.	
Department of Health		6.15	It might be helpful to expand the section about collaborative options to mention what the options are under section 31 of the Health Act. Perhaps after "... meeting local needs." You could insert: "The options for partnership working provided by section 31 of the Health Act 1999 are pooled budgets, lead commissioning and integration of services." You could then start the next sentence "Networks should ..." As JIPs have been largely superseded by local delivery plans, and are no longer required to be made, perhaps you could omit part of the last sentence from "in particular ..." Alternatively you might wish to run the first part of the last sentence into the end of the penultimate one. This would then read: "A range of different ...to meeting local needs while seeking to build on existing arrangements for planning and commissioning services." You could then finish the paragraph with the new sentence about S31 options. If the reference to JIPs is left in, you may wish to bear in mind that in Wales, Local Health Boards are required to develop Health and well-being strategies.	First option taken into revised text.
Department of		6.17	After the first sentence would you consider inserting	Added as footnote.

Health			the following: 'As a result of the Community Care (Delayed Discharges) Act 2003 social services since June 2003 the discretion for social services to charge for community equipment services has been removed. This should make integration of NHS and social services community equipment services more straightforward.'	
Department of Health		8.24	It can be difficult to offer 24-hour care from the district nursing services in some areas, particularly in rural locations. While an 'on -call' service could be an effective way of managing this, one then incurs lone worker considerations. These problems are not insurmountable, but PCTs may find implementation presents challenges. This is especially so, where district nursing services are under pressure from rising demand and efficient use of resources is paramount.	Comment noted.
Department of Health		8.25	This paragraph refers to use of other workers such as trained carers, when district nursing care is unavailable out of hours. However, there is equal need for greater availability of 'sitting services' during the night, as it is often this lack of support that prevents carers from keeping relatives at home. In some parts of the country, sitting services from social service departments have limited availability, while in others, nothing exists at all.	Text altered.
Department of Health		11.4	Perhaps the second "and" could be amended to "through the". This would make clearer the main role of CAM therapies in relieving symptoms which, in turn, offer psychological and emotional benefits. Could you also consider amending "spiritual" to "emotional". Perhaps there could be a clearer	Text altered. Text altered in response to first suggestion – use of the word ‘emotional’.

			distinction between support provided by CAMs, and the services being discussed in Chapter 7. While Chapter 7 does not completely rule out spiritual healing of the sort offered by some CAM practitioners (and in use in the NHS), it focuses on more orthodox sources of spiritual counselling. In order to minimise the risk of confusion perhaps you might wish to avoid the use of the word "spiritual" in Chapter 11.	
Department of Health		11.8	Would you consider removing 'aromatherapy' and 'homeopathy'? We do not believe that there are plans to bring those therapies into statutory regulation. Perhaps you would consider inserting the following: "Work is in hand to strengthen the responsible voluntary regulation of aromatherapy, homeopathy, massage, reflexology, and others, based on the adoption of formal national occupational standards."	Text altered.
Department of Health		11.13	As in 11.11, would you consider including a footnote that says: "The Department of Health has commissioned the Prince of Wales's Foundation to provide a Guide for Patients. This should be available shortly."?	Footnote included.
Department of Health		11.18	There are a number of difficulties with the first sentence. One difficulty is that the national guidelines quoted at the foot of page 108 quote a quite significant body of evidence to support the use of the therapies they evaluate. Another is that it would seem strange to announce in the second footnote on page 108 that the RCCM is preparing an information resource, and then in para 11.18 appear to dismiss the evidence base as practically non-existent. Similar problems exist with the wording of	Text altered in line with comments.

			para 11.22. To overcome these problems, perhaps you could consider the following drafting suggestions.	
Department of Health		11.18	"In common with many non-pharmacological clinical interventions, the evidence base of the effectiveness of CAM therapies does not offer the same level of assurance that can be secured for interventions that are supported by the existence of numerous, well-conducted randomised controlled trials that have subsequently had favourable systematic reviews. Such reviews that exist are mentioned below. However it should be noted that, in its Report published in November 2000, the House of Lords Select Committee on CAM recommended that therapies that claimed to relieve rather than cure certain conditions should be subject to less stringent standards of evidence. While it may not be as rigourous as might be desired, there is a body of evidence of the effectiveness of CAM therapies in palliative care, and this is currently being assembled by the RCCM. Until this work is completed, the fact that these therapies are already in wide and effective use in hospices and NHS oncology departments may be taken as a significant indication of their value."	Text altered in line with comments.
Department of Health		11.19	Having said in paragraphs 11.4 and 11.18 that CAM is best used to supplement, rather than replace, orthodox medicine, this paragraph seems to contradict this by quoting, without distinction or evaluation, patients' expectations that CAM can stop cancer spreading or even bring remission. This may give readers the impression that NICE supports the use of CAM for these purposes. Perhaps you would	Text altered to include first drafting option.

			consider the following drafting amendments: You could completely omit the section beginning "expectations include" or else insert the words: "unfortunately some are unwilling to come to terms with their diagnosis and build unrealistic expectations about CAM that include.................. cure. Such expectations need to be handled sensitively, and the patient and his/her carers need sympathetic help to accept reality."	
Department of Health		11.20	Would you consider replacing "A sizeable minority" with "almost half"? The research quoted found that almost half of all GP practices (49%) offered some access to CAM therapies.	Text altered.
Department of Health		11.22	Would you consider removing the first words? Perhaps you could amend the sentence to say: "In conclusion, the best research, where it exists, offers some support for the use of certain CAM therapies in palliative care. But the same cannot be said for claims that CAM therapies cure cancer. A very few determined patients have found remission after following a very strict unorthodox regime. But there is no reliable evidence that these results are generally reproduceable, and patients and their carers should be strongly advised against placing any hopes in such measures"	New paragraph inserted.
Eisai Limited			This organisation was approached but did not respond.	
Elan Pharmaceuticals Ltd			This organisation was approached but did not respond.	
Eli Lilly and			This organisation was approached but did not	

Company Ltd			respond.	
Faculty of Dental Surgery		General	There is no comment anywhere in this document about oral health care. Good oral care is an issue of considerable significance for the patient during palliative care - and not only for those who have had head and neck cancer. It is an issue that is frequently forgotten - and has been completely neglected in this draft. It is clear you have no-one on the guidance development group who has any knowledge of dental - or other oral health care issues.	Oral heath care is now referred to in various sections of the Guidance in line with this comment.
Faculty of Dental Surgery		8.1	There should be a reference in this para to either general dental or community dental practitioners - or both - in relation to oral health care management.	Text altered in line with comment.
Faculty of Dental Surgery		8.7	Bullet point 4 - should include medical and dental out of hours care.	Comment noted – but decision taken not to alter text.
Faculty of Dental Surgery		9.9	The physical assessment must include an oral health care assessment and there should be specific reference to this.	An oral health assessment is a part of a comprehensive physical assessment for patients with cancer.
Faculty of Dental Surgery		9.26	This para should recognise the need for an oral health care input.	Included in the section on rehabilitation.
Faculty of Dental Surgery		9.34	Oral rehabilitation is an important component of general rehabilitation and should be specifically referred to in this paragraph.	Included in the section on rehabilitation.
Faculty of Dental Surgery		10.1	There is reference in this paragraph to the importance of being able to eat speak and drink in comfort as an important contributor to overall well being so at least this has been recognised - however to achieve this predictably there must be good oral health and oral health needs should be recognised	Included in the section on rehabilitation.

			as an important contributor to well being.	
Faculty of Dental Surgery		10.6	This para refers to appearance contributing to well being - appearance is also supported by a good facial appearance - requiring oral health needs to be recognised as an important contributor from the patient's viewpoint.	This is covered in the text.
Faculty of Dental Surgery		10.8	Rehabilitation is discussed in this paragraph with no specific reference to oral rehabilitation - it is important that this is included.	Included in this section.
Faculty of Dental Surgery		10.17	There needs to be a specific bullet point here to include a dental hygienist.	Text altered.
Faculty of Public Health		10.18	There should be a specific reference here to oral hygiene.	Text altered.
Faculty of Dental Surgery		Table 10.1	There is no mention in this Table to oral health care input from a general dental or community dental practitioner.	Oral care is covered in the text of this section.
Faculty of Dental Surgery		10.39	It is essential that there is an extra paragraph here that refers to intraoral obturators / prostheses - patients with such appliances should be recognised as being likely to need the support of a consultant in restorative dentistry - who will most probably - but not always - hence the need for a specific reference - be part of the head and neck cancer team.	This paragraph is a summary of available evidence – oral health issues are now included in the text of this section.
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 guidance	General	Statutory/charitable funding It would be helpful to have greater clarity that NICE recommendations are intended to guide services which are commissioned and funded by the NHS. We note Box 1.1 of the guidance which explains that the primary audience is those who commission services using NHS resources. However, it would be helpful to state more explicitly that NICE recommendations would need to be funded from NHS funds. Funding of voluntary-sector managed services is not outside the scope of the guidance – funding for self-help groups is addressed on page 23 of the economic analysis. It might therefore be helpful if the guidance could make clear that existing funding arrangements for hospice services are unsustainable, and against Charity Commission and Treasury guidance.	This has been clarified through the addition of text identifying the role of the NHS in commissioning and funding services. This is not within the scope or remit of the Guidance Development Team.
Help the Hospices		General	There are now some brief references to respite care and we welcome this. However, there is no explicit reference to inpatient respite care, to give carers short breaks from their caring responsibilities. We recommend there should be a short section on the range of services which should be covered under the umbrella respite care and that evidence on the impact on patients and carers of different types of respite care be considered. If specific evidence relating to people with cancer is not available, we suggest that evidence from other healthcare sectors be considered. It would be helpful if the guidance could clarify when	There is no evidence of the best way to provide respite care – in-patient or home-based. Therefore the Developers have not been specific about respite arrangements; other than to suggest that they should be in place – this is for local implementation.

			respite care is the responsibility of NHS commissioners and when it is the responsibility of social services.	
Help the Hospices		General	Role of the voluntary sector It would be helpful if the guidance could be explicit that the voluntary sector may be commissioned to provide any service. We welcome the attempts that have been made to show the role played by the voluntary sector, especially in running self-help groups and bereavement support. However, at present the impression given is that the voluntary sector provides a particular type of care – generally the less medical, more social end of service provision. In fact, voluntary hospices are involved in the provision of the full range of supportive and palliative care services, including the most highly specialist medical care. It would be helpful for this to be reflected in Chapter 9 and throughout the guidance.	See comment above regarding additional text. This is covered in the introductory section to the Guidance rather than in section 9.
Help the Hospices		General	Sector-specific evidence We understand that the Evidence Review Team have been asked to clarify which evidence relates to both the voluntary and statutory sectors and which is sector-specific. It would be helpful if this could be clarified in the guidance.	The specific examples highlighted by Help the Hospices in the last round of consultation were checked and this information returned to the organisation. It will not be possible to differentiate between sources of evidence as requested. Details regarding the studies are however available in the accompanying Evidence Manual.
Help the Hospices		General	There is currently no reference to continuing care in the guidance. However, HSC 2001/015 includes palliative care as one type of care which can be funded as part of a continuing care package and most Strategic Health Authorities' continuing care criteria reflect this. If the main audience for the	The Developers consider that these are links to be made locally.

			guidance are commissioners of NHS-funded services, then they need to be able to see how supportive and palliative care relate to other care packages such as continuing care, intermediate care and respite care. Where there are existing guidelines on these, the guidance needs to refer to them. In relation to Continuing Care, there needs to be reference to how assessments for supportive and palliative care needs relate to assessments for continuing care needs. Otherwise there is a danger that the processes won't be joined up, which could result in patients being treated differently in different parts of the country, or being means-tested for care which should be NHS-funded. Continuing Care is within the scope of the guidance, because it is funded by PCTs and is often available to people with cancer. It is health care and is not covered by the social support chapter. We make some further comments on continuing care in relation to specific sections of the guidance.	Text has been inserted referring to the need to integrate generic assessments with continuing care assessments.
Help the Hospices		General	The separation of Psychological Support Service, Social Support Services and Services for Families and Carers into separate chapters means there is no discussion of "psychosocial needs". For most patients, the psychological and social needs are closely intertwined and cannot really be separated. Although there may be a need for specific psychological counselling intervention for patients, there is often a greater need for more complex work to be undertaken to address the complex needs of patients within the context of their family. This more psychosocial approach will include not	The Developers have considered various structures for the Guidance, but a decision was taken by the Editorial Board that the structure of the Guidance should retain as it is at present. This allows for each service component to be considered in detail. The Guidance acknowledges the need for services to address complex family situations This paper was used as a part of the literature review

			only the psychological aspects but also the broader social context within which patients and families live their lives. This is not the same as social care, which is described in later parts of the document, which is primarily the assistance with personal care and practical care, but rather the wider psychological and social needs within patients and families. Has the Guidance Development Team considered the discussion paper produced by the National Council for Hospices and Specialist Palliative Care Services on "What do we mean by psychosocial?" (Briefing Paper No. 4, March 2000)	for this section of the Guidance. Comment noted – but changes will not be made to this section. It is considered that these elements of care and service delivery are covered in the Guidance
Help the Hospices		Key Rec 7	Why not have a national policy on what information should be available, rather than lots of Networks re-inventing the wheel? Networks would still need to collect the local information.	This is covered in the text.
Help the Hospices		Key Rec 17	Replace "provided within NHS facilities" with "commissioned by the NHS". Services commissioned by the NHS from the voluntary sector should also meet these standards.	Text altered in line with suggestion.
Help the Hospices		I1	Replace "patients" with "adults."	Patient is the preferred term to enable the Developers to be consistent throughout the Guidance.
Help the Hospices		I8-I22	It would be helpful if the relationship between supportive and palliative care could be made clearer. The definition of supportive care could equally be read as a definition of palliative care (apart from the fact that palliative care is currently included in the list of services it covers, and we are told that supportive care is not a distinct specialty – see next comment). It is not clear what the concept of supportive care adds to the equation, given that palliative care is holistic, covers all the same elements, and can start	The Developers consider that this has been achieved. Supportive care is the all-embracing term not palliative care.

			from the point of diagnosis.	
Help the Hospices		I11	I11 says that supportive care is not a distinct specialty. However, I20 seems to suggest that there are specialists in supportive care.	Text altered.
Help the Hospices		I20	It is not straightforward to categorise professionals into generalists and specialists. There may be some professionals who have qualifications in supportive or palliative care, but who are involved in the provision of general services. There may be others who are working in a service which specialises in providing palliative care, but who do not have specialist qualifications. This paragraph needs to be more tightly written to explain what is meant by generalist and specialist. It may help to be clear whether it is services, teams or individuals which are being categorised. NICE's response to our earlier comments states that "It is expected that specialist palliative care services will work towards the inclusion of the professionals identified in the core team lists in paragraphs 9.25 and 9.33 in the current version. The availability of these professionals as a minimum within a specialist service in any setting differentiates a specialist service from a general palliative care service." This is quite a different definition to that given in I20, which is more based around the role and qualifications of the individual professional. We appreciate that there may be more than one context in which the terms generalist and specialist could be used, but it would be helpful if the definition given in the Introduction corresponded to that used in the chapters on generalist and specialist palliative care. One option would be to describe individuals as	The Developers acknowledge this point. The Guidance has identified a minimum core team of specialists.

			specialist, but to describe services as specialised. This would recognise that specialist implies certain experience and qualifications, but that not all staff in a specialised service will necessarily have these and that specialists may work in general services. It is also not clear whether this paragraph is defining specialists in cancer care or in supportive or palliative care. A specialist in palliative care would not necessarily spend all or most of their time caring for people with cancer.	This point was discussed at an Editorial Board meeting where it was agreed that the definition of a specialist services 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. This implies that the services have expert professionals working within it to achieve this. The Editorial Board rejected the notion of a 'specialised' service. This paragraph identifies the spectrum of professionals involved in proving supportive or palliative care.
Help the Hospices		Box I2	Replace "independent" with "private". The independent sector includes the voluntary and private sectors.	The Developers have taken advice on this proposal and have taken the decision to retain the use of the word 'independent'.
Help the Hospices		1.11	We are pleased that, in response to our earlier comments, the Guidance Development Team have agreed to make reference to the Compact in this section. Further to our previous comments, we would suggest that the main reference here should be to the development of local Compacts, rather than the national Compact. Local NHS bodies are required to sign up to local Compacts by March 2004. More information on this is available on the Department's web site at http://www.doh.gov.uk/compact/index.htm	Text has been inserted suggesting that the process should be guided at a local level.
Help the Hospices		1.15	Assessments should where possible link in with other assessments such as continuing care assessments.	See comment above regarding assessments.
Help the		1.17	"… at each of the following key points *recognising that for some patients, several of these points may*	Comment noted but decision made not to alter text as

Hospices			*be reached at the same time in which case one assessment will cover several of these stages*."	suggested.
Help the Hospices		1.20	It would helpful to say "Local directories should draw on national sources of information as appropriate, such as the Hospice Directory published by *hospice information*." Effort should not be wasted on collecting information that already exists.	The text suggests that national information is available – text not altered.
Help the Hospices		1.22 & 1.25	"whether hospital, *hospice* or primary care based"	Text altered.
Help the Hospices		1.28	Replace "health, social care and voluntary agencies" with "NHS, local authority and voluntary agencies."	Text altered.
Help the Hospices		5.5	"More specific and specialised services include counselling …" i.e. delete "in the statutory sector". Specific and specialised services are not only provided in the statutory sector. Shouldn't the possible locations of care include patients' homes?	Text deleted as suggested.
Help the Hospices		5.17	What is meant by "services provided by the voluntary sector" here? Is it intended to describe a type of care? Any of the services listed in the table could be provided by the voluntary sector, so if a particular type of care is being described then that needs to be made clear. Or should it read "services funded by the voluntary sector"?	Phrase deleted.
Help the Hospices		Chapter 6	It would be helpful if this chapter could recognise the current shortage of nursing home places, and in particular of nursing homes registered to care for people under 65 or to provide terminal care. The commissioning of residential placements for personal care and not continuing care may be outside the scope of this guidance, but the shortage of places has implications for the commissioning of	This is neither within the remit nor scope of the Guidance Development Team. The local planning process alluded to throughout the Guidance should cover this point.

			healthcare services.	
Help the Hospices		6.4	Last sentence: Replace "social services, health services or voluntary organisations" with "local authority, NHS or voluntary organisations". Voluntary organisations may provide social or health services so the original wording is confusing.	Text altered.
Help the Hospices		6.7	The Community Care (Delayed Discharges etc) Bill will not cover palliative care patients in the first set of regulations. In fact, it is likely to lead to further delays for those patients who wish to be discharged from specialist palliative care services, because local authorities are likely to prioritise social care packages for other acute patients over palliative care patients. Are the new targets referred to here for social care or for continuing care? The new targets for continuing care should probably be addressed under specialist and generalist palliative care rather than social care, but in any case they will not apply to palliative care patients in the first instance, because they only relate to patients covered by the Community Care (Delayed Discharges, etc.) Bill. This is also likely to lead to more delayed discharges from specialist palliative care services, because continuing care assessments for other acute patients will be prioritised. Help the Hospices is holding a workshop with hospice staff on 20 Oct which should help to identify issues around discharge from hospices and action that could be taken nationally and locally to reduce the number of delays.	The Guidance covers all patients with cancer – not solely those with palliative care needs.
Help the Hospices		6.16	7th bullet point. "Care home placements" describes a setting or a type of provider, not a type of care.	'Care home' is used in the Guidance as a generic term. Advice has been taken on the appropriateness of

			Some care home placements provide NHS-funded continuing care, which is health care and should probably not be covered in the social support chapter. However, other care home placements would constitute personal care and might more appropriately be considered part of social support.	such a term and the Developers informed that this is correct.
Help the Hospices		6.16	8th bullet point. What is meant by appropriate responses to crisis situations?	Bullet point deleted.
Help the Hospices		6.17	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. If there are questions about this, we would encourage the Guideline Development Team to contact the policy lead for continuing care in the Department of Health.	This paragraph refers to equipment.
Help the Hospices		6.19	Is it always clear who is “the patient’s usual healthcare professional”?	The Developers believe that it is.
Help the Hospices		6.29	We don’t understand the first sentence. In the second sentence, what is meant by “conventional care”?	Text altered in line with comments.
Help the Hospices		7.3	Replace “are” with “tend to be”	Text altered.
Help the Hospices		7.11 & 7.23	The first bullet point suggests that it is bad if hospices rely on “on-call” faith leaders. However, 7.23 states that spiritual care providers do not need to be represented in every team. It would be helpful to clarify what level of support is considered acceptable.	Text amended.

Help the Hospices		8.11 & 8.16	These duplicate each other.	The former paragraph is a part of the overview of current services – the latter a recommendation based on this.
Help the Hospices		8.19	"Community, *hospice* or hospital based"	Text altered.
Help the Hospices		8.22	What are "generic" palliative care services? Also, palliative care referral criteria should relate to the local continuing care criteria (Strategic Health Authorities are required to have these in place by November 2003)	'Generic' deleted. It is anticipated that this will be taken into account.
Help the Hospices		8.29	The hospital *or hospice* specialist palliative care team should be asked to advise on management. It's not clear why this is a hospital-specific issue.	This paragraph refers to hospital services – secondary care in the acute sector – not hospice in-patient units.
Help the Hospices		8.34	"A patient's wishes concerning *location of care* and place of death".	Text altered.
Help the Hospices		8.49	It would be helpful to specify that, while 56% of patients want to die at home, 24% want to die in a hospice and 11% want to die in a hospital. A significant minority of people do not wish to die at home. Currently, only 17% of people with cancer die in a hospice so there may be a need to increase the provision of hospice beds to meet this demand. It would also be helpful to recognise that even if people die at home, they may still want to access inpatient care during the advanced stage of illness for symptom control or respite care. 30% of people cared for in a hospice do not eventually die there.	Text altered to reflect part of these comments – the text refers to people changing their mind about the preferred place of care.
Help the Hospices		8.51	What are "usual care" and "standard home care"?	These are terms used in the research papers.
Help the		8.52	What is the "palliative phase"? Palliative care can be	Altered to 'advanced' phase.

Hospices			provided at any stage of the illness alongside other treatments.	
Help the Hospices		Chapter 9	It would be helpful if the significant role currently played by the voluntary sector in providing specialist palliative care in people's homes, in inpatient, outpatient and day care specialist units, and providing support to generalist teams in hospitals and care homes, could be made clear in this chapter.	Text altered in section to reflect this point.
Help the Hospices		Chapter 9	This chapter does not recognise the range of providers who may contribute to an overall specialist palliative care service. Local health communities should be encouraged to plan services flexibly around the different needs of patients, recognising that there will be more than one way of achieving this and it may involve a range of teams with different levels of specialism and different ranges of healthcare professionals and volunteers. It may be more helpful to talk about specialised care in this context, to reflect the fact that not all staff involved in providing care will necessarily be specialists, but the key point is that the service specialises in providing palliative care. It may be helpful for the guidance to specify particular elements of services which need to be present across the Network as a whole in order to meet specific types of need, but this chapter as it stands could be read as being quite restrictive as to how care is organised because it addresses the requirements at specific team level, rather than giving guidance for the Network as a whole and leaving Networks to decide how they will organise the service.	Additional text inserted to cover these points. The Developers consider that the planning and delivery of care and services as being across a network is clear in the text. This point was discussed at an Editorial Board meeting. It was considered that a consultant is an integral part of a specialist core team.

			This could create problems for a number of Networks who currently commission teams (especially for home and day care) which do not employ a consultant, but provide nursing and/or psychosocial support as part of a wider overall service. These teams may have access to consultant advice when they need it, but they do not necessarily need to employ a consultant as a core member of the team because they are contributing to the wider service across the Network. It would not make sense for these teams to be considered as generalist providers because they specialise in providing palliative care and are likely to employ specialist staff.	Please see earlier response to suggestion regarding 'specialised' services.
Help the Hospices			This chapter needs to recognise more than one form of specialist palliative care. For some people, the primary need will be acute medical palliative intervention, which will need to be overseen by a consultant or other physician with equivalent experience. Others will need intensive holistic specialist nursing care, possibly over a longer period of time, either in an inpatient unit or at home. Their professional health and social care workers may benefit from advice from a consultant, but the consultant may not need to be a member of the core team. Chapter 9 currently describes teams providing acute medical care who will have a consultant as a core member of the team, but does not allow for teams providing intensive holistic nursing care. There are likely to be a range of packages falling under this umbrella, depending on patients' needs. They could be characterised broadly as "higher-dependency palliative continuing care" and an example of this	Please see earlier comment regarding the definition of a specialist service – one able to meet the needs of the patient and carer across all domains and with the ability to meet complex needs. The Guidance is clear regarding the inclusion of a consultant in palliative medicine being a part of a specialist core team. See comments above regarding the inclusion of a consultant in palliative medicine.

			might be the continuing care provided by St Peter and St James Hospice and Continuing Care Centre in Lewes (this centre also provides acute medical palliative care). A Network is likely to require both specialist acute palliative care beds/community care places and specialist continuing care beds/community care places. In some cases these will be provided by one service, but this need not always be the case. Higher-dependency continuing care differs from the continuing care provided in most nursing homes in that it involves a multi-disciplinary healthcare team, is provided by healthcare professionals who care for a significant number of people with palliative care needs, and is likely to incorporate bereavement and other support for families. It is not generalist palliative care, because it is best provided by services which specialise in providing palliative care. Cancer patients who might need higher-dependency palliative continuing care at a time when they do not need acute medical intervention include those with: • brain metastases • large sarcoma causing mobility problems • mental illness • learning disabilities Help the Hospices is in contact with a range of hospice professionals who could offer expert advice on the need for higher-dependency palliative continuing care. Please contact us to discuss this	The Guidance is clear that this is not a specialist palliative care service under the definitions being used.

			further.	
Help the Hospices		9.8	“hospitals, *hospices* and the community”	Text altered.
Help the Hospices		9.15	Replace “Each service should have sufficient staff to enable it to” with “Across a Network, there should be sufficient staff to”. Not every provider needs to deliver 24-hour care. For example, this would not be appropriate for a day care service.	Text altered.
Help the Hospices		9.18	This reads as though inpatient units do not employ multi-professional teams. Also, the need for 24-hour care from a specialist palliative care team is not only about the setting, but about whether the patient could benefit from continuous specialist input. Our understanding is that some hospice at home services aim to provide this care at home, so that it doesn’t always have to be provided in an inpatient unit. A clearer wording might be: “The range of services provided by specialist multi-professional palliative care teams should include: • Assessment and advice for people being cared for by generalist teams in any setting (including in acute hospitals, community hospitals, care homes and at home) • 24-hour hands-on care at home or in inpatient units (hospices or hospitals) for patients with complex problems who would benefit from the continuous support of a multi-professional specialist palliative care team.”	The text refers to multi disciplinary teams. Text altered.
Help the		9.21	“The Marie Curie Nursing Service, *and equivalent*	Text altered with Marie Curie given as an example.

Hospices			*services run by independent hospices*, …”	
Help the Hospices		9.24-9.41	It would be helpful if these two sections could start by setting out the requirements which apply to all multi-professional teams and then list the additional requirements for a team providing hands-on care (in inpatient units or in peoples’ homes), rather than just advice and support. With this structure, there would be no need to list the entire team twice – it would be clearer just to explain that a team providing hands-on care will need extra medical and nursing support. This proposed new structure would make clear that one team may often provide advice and support to generalist teams, as well as offering hands-on care for patients who need it. The present structure reads as though these two functions should be provided by two separate teams. The new structure would also help to clarify that, for example, 9.27 and 9.29 would apply to all teams including those providing inpatient services.	Some alterations made to text in line with suggestions.
Help the Hospices		9.32	Should this be eligibility criteria or referral criteria rather than admission criteria? Cancer Networks cannot necessarily determine admission criteria for independent providers.	Text altered.
Help the Hospices		9.33	The wording doesn’t seem to fit with the idea of patients being able to be cared for or die in their place of choice. It seems to suggest that a patient could only get access to inpatient care if they could not be cared for anywhere else. If this is the intention, then the statements about choice in other parts of the guidance should be qualified.	Text altered in line with comment.
Help the Hospices		9.33	It is still not clear what is meant by “served by the following core staff.” How much input is needed from	Text deleted.

			a particular member of the team in order for them to be considered a core member of staff?	
Help the Hospices		9.33	In the light of our general comments on Chapter 9 relating to Continuing Care, there needs to be recognition that the requirement for a consultant as a member of the core team is dependent on the casemix of that team. Not all teams will require a consultant in the core team (although they may benefit from a consultant being available to offer advice when appropriate) if they are not caring for patients who need acute medical care.	Please see comments regarding the inclusion of a consultant in palliative medicine in a specialist core team.
Help the Hospices		9.33	There are currently a number of hospices who do provide specialist medical palliative care, but who do not employ a consultant because they employ one or more experienced and competent physicians who are able to provide the equivalent level of specialism that would be expected from a consultant. Because palliative medicine is a relatively new specialism, there are a number of very experienced physicians working in the field who are not formally qualified as consultants. However, if the opportunity was made available through a proposed amendment of Article 14 of the European Specialist Qualifications Order, could be eligible for the specialist register. It would be helpful if the guidance could allow for Cancer Networks to recognise certain individual physicians as equivalent to consultants for the purposes of planning and commissioning services.	This point was discussed at an Editorial Board meeting and a decision taken that the Guidance will stress the need for local arrangements to be in place, as an interim measure, to provide specialist consultant input and advice where there is no specialist in palliative medicine available. Suggesting an amendment to an Act is not within the scope or remit of the Guidance.
Help the Hospices		9.34	The Guidance Development Team made clear in response to our previous comments that it is considered preferable if the staff providing the	This has been clarified.

			services listed in 9.34 are part of the core team. It would be helpful if this could be stated explicitly.	
Help the Hospices		9.42	Delete “and for hospice staff”. The only hospice staff who are relevant here are those who are contributing to specialist palliative care teams.	Text deleted as suggested.
Help the Hospices		9.44	What is “conventional care”?	Conventional care is where the patient is not receiving any specialist input. This is defined in the research papers.
Help the Hospices		9.45	What is “conventional care for hospices and home care”?	Conventional care is where the patient is not receiving any specialist input. This is defined in the research papers.
Help the Hospices		11.2	2nd bullet point suggests that commissioners don’t need to fund any complementary therapy services. However, 9.34 states that specialist palliative care inpatient facilities need access to complementary therapy services. It is difficult to see how this can be a requirement if there is no requirement for commissioners to fund these services.	This anomaly has been deleted – thank you for identifying this.
Help the Hospices		11.10	Replace “within an NHS setting” with “on behalf of the NHS”. Care commissioned by the NHS from voluntary organisations and others should meet these standards.	Text altered.
Help the Hospices		11.20	What is meant by “the voluntary sector”? Most hospices are in the voluntary sector, so this sentence is confusing.	Sentence deleted.
Help the Hospices		12.8	Replace “provided” with “funded”. It reads as though there is a problem with services being provided by the voluntary sector. There is only a problem if the NHS is not funding those services to an acceptable level.	Text altered.

Help the Hospices		12.9	It is helpful to recognise the role played by the voluntary sector, but why is this not recognised in relation to specialist palliative care?	Text altered to reflect this.
Help the Hospices		12.12	Carers should be given the choice of whether they wish to be the carer. It should not just be assumed. Talk of "fulfilling the role of carer" could be seen as imposing responsibility on carers.	This is acknowledged in the text – and is also based on an assessment of the carer and their own needs etc.
Help the Hospices		12.15	All possible agencies, including GP practices and consultants, should make themselves aware of local sources of information and support and refer patients/families to these sources.	This is a statement in an overview section. The supporting recommendations identify actions needed to be taken to address these issues.
Help the Hospices		12.16	What are "existing support systems"?	This refers to family and friends etc.
Help the Hospices		12.17	Replace "specialist bereavement providers" with "providers of specialist bereavement support".	Text altered.
Help the Hospices		12.22	Carers may need to be referred to appropriate agencies, rather than just signposted to them. Carers are often reluctant to see themselves in need of support and if not encouraged fail to contact supportive organisations themselves.	This is covered in the text.
Help the Hospices		12.25	It would be helpful to explain why these services are ideally provided in partnership with the voluntary sector.	The Developers consider that this is sufficient.
Help the Hospices		12.25	It might be helpful to clarify that a service sufficient to meet patient needs should be funded by the NHS, even if the voluntary sector is involved in providing the service. At present, the voluntary sector sometimes funds the full service.	The Developers consider that this is covered in the text.
Help the Hospices		12.40 & 12.51	There are a range of different types of home care, including specialist advice and support for generalist	This refers to evidence, details of which can be found in the Evidence Manual.

			carers, 24-hour sitting services and specialist palliative hands-on care. What is being described in these sections?	
Help the Hospices		12.43	What type of “one-to-one interventions” does this paragraph refer to?	This refers to evidence, details of which can be found in the Evidence Manual.
Help the Hospices		12.46	The last sentence doesn’t seem to fit with the rest of the paragraph, which is about care before death.	Sentence deleted.
Help the Hospices		12.47	2nd sentence: What is “conventional care”? Is hospice care not conventional? What type of support was offered to carers in that hospice? The support offered in hospices varies, so this evidence needs to be more specific to be helpful.	This refers to evidence, details of which can be found in the Evidence Manual.
Help the Hospices		12.47	3rd sentence. Is it good or bad that the carers’ quality of life remained stable over a period of four weeks?	This refers to evidence, details of which can be found in the Evidence Manual.
Help the Hospices		12.47	Greater satisfaction than what?	This refers to evidence, details of which can be found in the Evidence Manual.
Help the Hospices		Summary of recs	The recommendations on palliative care would need to be changed to reflect our comments on chapter 9.	Any amendments to the text will be picked up in the summary.
Help the Hospices		Summary of recs F	Skills training should also relate to: • specialist palliative care • continuing care	These points are not made in the main body of the text.
Help the Hospices	Economic Review	2	If issues relating to the split of funding between the NHS and voluntary sector are beyond the remit of this report, why is NHS funding for self-help and support groups addressed on page 23? This is not a consistent approach. If the intention is to assess the cost to the NHS of implementing this guidance, then the economic analysis needs to address the issues relating to NHS funding of voluntary hospices which	The Guidance considers services commissioned and funded by the NHS. Self help and support groups are part of this and may be provided in liaison with or led by professional staff. We are concerned with the cost of provision rather than source of funding.

			we have raised in our previous sets of comments.	
Help the Hospices		4.6.3.1	Social workers play a key role in healthcare assessments, e.g. for continuing care. These need to be costed.	It is assumed that local collaborative arrangements will ensure that this assessment is undertaken by or with the help of social care professionals.
Help the Hospices		4.7.2	2nd bullet point: see our comment on Guidance Manual 7.11 and 7.23	Text has been amended.
Help the Hospices		4.7.2	The final bullet point doesn't seem to be an indication that needs are not being met.	This bullet point has been moved to a more appropriate section of the text within section 4.7.2
Help the Hospices		4.7.5	If NHS commissioners paid the voluntary sector the full costs of providing NHS services, it could require voluntary hospices to pay chaplains the full costs of the work they do for those services. It is unhelpful to raise this issue without addressing the issue of NHS funding for voluntary services.	We have focussed on the cost of provision rather than the source of funding. The level of staff required to provide a high quality service within the network has been identified and it is assumed that all staff are paid at NHS levels independent of the source of funding.
Help the Hospices		4.8.5	This describes care provided by services which specialise in palliative care – an example of a service which doesn't clearly fit into the "generalist" and "specialist" categories. It would be more "common sense" for this to fit in the specialist chapter. There are a wide range of home care services provided by specialist palliative care teams. More information would be needed about the level of support offered and how the costs have been calculated to be able to comment on the costings.	Agreed. This was included within this section for comparative purposes. A note has been added to the text to explain this more clearly. Information about the level of support offered is included in table 16. This relates to the services provided by a community specialist palliative care team and excludes services such as 24 hour sitting.
Help the Hospices		4.9	It is very difficult to comment on the costings in this chapter without more information about how the costs have been arrived at. A lot more information is given in other chapters. Given the variation in existing specialist palliative care services, it is important to explain what is being costed.	More details on costing have been added.

Help the Hospices		4.9.3.1	2nd sentence. Replace “over” with “in each of”	Amendment made.
Help the Hospices		4.9.3.3	See our comments on the Guidance Manual 8.49. While it is true that high quality, well staffed community services should offer the opportunity for more people to die at home, it is also true that better funded, more extensive hospice services would enable more people to choose to die in a hospice. It is also misleading to suggest that if more people die at home, fewer people will be cared for in a hospice. In fact many people are cared for in hospices who do not eventually die there. Even if everyone wanted to and was able to die at home (which they don’t and are not), there would be a need for inpatient beds for symptom control and respite care. We do not know enough about the demand for these services to make assumptions about future inpatient admissions.	Studies confirm that many people would prefer to die at home, yet only about 25% of people with cancer do so. It is also recognised that patients change their minds about preferences over location of care and place of death. Agreed - the text has been amended to reflect this – however people may spend less time in hospice care. Agreed.
Help the Hospices		4.9.3.7	We can see no reason to think there is likely to be a reduction in demand for hospice beds. At present, 24% of people want to die in a hospice. Only 17% of people with cancer do so. This impression appears to have been gained from service managers at Marie Curie and Macmillan. We would suggest that similar discussions should take place with service managers at independent hospices, in order to learn about the current picture in relation to demand for hospice beds	A reduction in inpatient beds it not assumed in the economic review. The text has been amended to ensure that this is not ambiguous.
Help the Hospices		4.9.4.1	Much more information is needed about what type of service is meant by Home Care. This figure is much lower than the figures we have been getting from our preliminary work on costings with independent	This relates to the service provided by a community specialist palliative care teams, offering visiting 7 days per week, 9am to 5pm and telephone support for generalist carers outside these hours. It excludes 24

			hospices. See our comments on the Guidance Manual 12.40 and 12.51 about the range of home care services provided.	hour sitting services. We would be interested to see your figures for validation purposes.
Help the Hospices		4.10.4.2	“hospital, *hospice* and community settings”.	Amendment made.
Help the Hospices		4.12.1	Last bullet point. It is not a problem if services are provided in the voluntary sector. It may be a problem if they are funded by the voluntary sector.	Reference to voluntary sector has been removed from last bullet point.
Help the Hospices		4.13.2	The requirement for NHS and voluntary organisations to work in partnership through Cancer Networks will require training for both sectors on the respective legal and financial frameworks within which they operate.	This point has been added to 4.13.2.
Help the Hospices		4.13.2	Why is workforce planning beyond the scope of the report? Recruiting new staff will be a key element of the cost of implementing the guidance.	Workforce planning involves detailed planning regarding how required future staffing levels will be achieved. This is a major task which will need to be considered by Department of Health over the coming months.
Help the Hospices		4.13.3	The guidance identifies a need for training in needs assessment in relation to specialist palliative care (see Guidance Manual 9.6)	The text has been amended to reflect this.
Help the Hospices		4.13.4.1	There are a significant number of physicians working in specialist palliative care, who are not consultants or SPRs but who are considered to be senior healthcare professionals. These staff should be reflected here.	Agreed. However we do not have an estimate of the number of these posts, therefore the text has been amended to reflect the fact that these posts are omitted from the calculations. Individual networks will need to identify specific numbers requiring training.
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.	
Joint Committee on Palliative Medicine			This organisation was approached but did not respond.	
Kings 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 listened to concerns of users and stakeholders and taken many of these on board in this new draft. We welcome the change in tone in sections previously included in Part A to make the document less professional and more patient centred, for example in the section on psychological distress and the new emphasis on self-help and support groups and the recognition that people affected by cancer have their own skills and knowledge.	Comment noted with thanks.
Macmillan Cancer Relief	All documents	general	However, despite the many improvements to the document, we still feel that the tone of the document remains too professionally focused and continue to have concerns about the structure of the document which is designed around different professional specialties rather than the needs of patients and carers. We are particularly concerned about the use of the word assessment and recommend that more emphasis be given to assessment as a partnership	The Developers consider that this is covered in the text of the Guidance.

			between healthcare professionals and patients, drawing on patients' own knowledge and expertise.	
Macmillan Cancer Relief	All documents	general	We are concerned that many of the recommendations in the Economic review are not mirrored in the Manual and vice versa. There is also a different tone and emphasis between the two documents. For example, the section on User Involvement in the Manual is very weak whereas the recommendations in the Economic Review are much stronger (see below).	This is partly accounted for by the fact that the Economic Review has had to make detailed assumptions on which to base cost estimates and therefore has had to provide greater detail than the manual. The two documents however should be consistent in terms of emphasis and the text within the Economic review User Involvement section has been adapted on this basis.
Macmillan Cancer Relief	All documents	general	In common with our comments on previous drafts, we believe that the document is far too long and unwieldy to use. We strongly recommend that the NICE Editorial Board seeks to cut out repetition through the document and make it more user-friendly.	This comment was discussed at the recent Editorial Board meeting and a decision made not to reduce the Guidance.
Macmillan Cancer Relief	All documents	general	We recommend that a glossary of terms be introduced including explaining who is part of Cancer Networks.	A glossary will be added as a part of the final version of the Guidance. Text has been inserted to denote membership of cancer networks.
Macmillan Cancer Relief	All documents	general	We believe that the Guidance has the potential to radically improve the quality of care provided for people affected by cancer but are concerned that NICE has no authority to ensure the guidance is implemented. The recommendations have huge resource implications and these must be met by the Departments of Health in England and Wales and by Local Council Social Services Departments through proper resourcing via the Local Government settlement; there are also huge implications for the voluntary sector. The Economic Review currently only takes account of the NHS perspective. We	Comment noted – but funding arrangements are beyond the remit of the Guidance Developers.

			recommend that NICE makes these resource implications clear in the Guidance and clear to the relevant Government departments and seeks assurance that adequate resources will be made available.	
Macmillan Cancer Relief	All documents	general	Monitoring of implementation will rely on standards. We are concerned about the current process of setting standards linked to the Guidance because of the lack of user involvement and the main focus of the standards on secondary care. We recommend that the process for developing standards is made as open and transparent as possible. The standards should also link with other work in the area, such as the standards being developed by the Cancer Nursing Advisory Group (CNAG).	Comment noted – but this is outside the scope and remit of the Guidance and the Guidance Development Team.
Macmillan Cancer Relief	All documents	general	The Guidance recommends significant increases in specialised nurses and social workers. At a time when the total workforce is declining, NICE must consider how it is to meet that need through training, recruitment and retention and by encouraging different ways of working. We recommend that NICE makes contact with the Workforce Development Confederations at an early stage to discuss implications.	This has been done – they have been kept abreast of the developments and recommendations in the Guidance.
Macmillan Cancer Relief	All documents	general	Other recommendations will also require considerable cultural changes within the workforce. These will take longer to implement than those relying on resources alone. Staff must be properly supported through these changes both through formal and informal training and feedback.	Comment noted.
Macmillan Cancer Relief	All documents	general	The guidance will take time to be implemented because of the resource implications. We	The Guidance has identified 20 key recommendations. Any further prioritisation will need to be done at a local

			recommend that NICE considers, through consultation with stakeholders, a prioritisation mechanism to enable implementation to be phased.	(network) level.
Macmillan Cancer Relief	Full guidance	general	Palliative care networks exist in many places and should be referred to in the document.	They are referred to in the co-ordination of care section of the Guidance.
Macmillan Cancer Relief	All documents	General	We believe that there is a need to make more explicit the links between supportive and palliative care and other care packages, such as continuing care and intermediate care, otherwise there is a risk o different assessment processes and some people affected by cancer falling through the gap.	Text altered in line with comment.
Macmillan Cancer Relief	Full guidance	general	We recommend that the Manual make reference to the particular needs of older people who may have other underlying chronic conditions in addition to cancer and so more complex palliative care needs.	Text inserted to identify the needs of special groups of people.
Macmillan Cancer Relief	Full guidance	Page 5	We welcome the overview of the Service Model which we think is a very helpful summary.	Comment noted.
Macmillan Cancer Relief	Full guidance	Paragraph 15	Patients' needs are not always met because sadly some professionals may not be aware of the existence of services or their benefit.	Comment noted.
Macmillan Cancer Relief	Full guidance	Paragraph 16	In addition to active promotion of self-help and support groups, we recommend that other local/national voluntary organisations who may help should also be promoted.	Text altered to reflect comment.
Macmillan Cancer Relief	Full guidance	Paragraph 16	This section should also make reference to the need for financial support and advice.	This is included in the section on social support.
Macmillan Cancer Relief	Full guidance	Page 15	We recommend that the Patient Pathway be redrawn to represent the fact that from the patient's perspective far more of their time is spent at home	Comment noted - the Developers are looking at ways of improving and refining this pathway to draw in the concepts identified.

			during the illness than in hospital. The voluntary sector also has a part to play in providing services, and not merely hospices. This should be represented on the pathway.	
Macmillan Cancer Relief	Full guidance	I15	This section should also make reference to the fact that palliative care is also provided by the patient's usual informal/non professional carers.	Text altered to reflect this comment.
Macmillan Cancer Relief	Full guidance	Box 1.1	This box should also make reference to the 'public' or user friendly version of the guidance which will be a key tool to help service users drive up standards.	The Developers consider that this would not be appropriate at this point.
Macmillan Cancer Relief	Full guidance	Executive Summary	We recommend that the mechanism for identifying key personnel to take forward the development of services, referred to in KR1, be clarified. This is likely to have enormous resource implications and key personnel will need to be trained.	It is outside the scope of the Guidance to state how recommendations might be implemented – please also refer to the Economic Review on this point.
Macmillan Cancer Relief	Full guidance	Executive Summary	We welcome the concept of the 'Key worker' which we have found to be helpful for patients struggling to navigate their way through a system. However, most of the cancer journey is spent in the community and so we recommend that the concept of a key worker be extended so that patients have one point of contact in primary, secondary and tertiary settings. This person should be the most appropriate individual to support the patient, and may be a physiotherapist or occupational therapist and not necessarily a nurse.	The location of the keyworker is for local implementation. Further feasibility work and evaluation is also required.
Macmillan Cancer Relief	Full guidance	Executive Summary and General	It is important to emphasise that assessments should be undertaken in partnership with patients not by professionals to patients, and that the real issue is about communication. We also recommend that self help and support groups should be involved in	Text altered.

			assessment and not just delivery of help.	
Macmillan Cancer Relief	Full guidance	Executive Summary	We recommend that the assessment of needs should also explicitly include financial needs and that staff should routinely consider sign-posting people affected by cancer to benefits advisors.	Text altered.
Macmillan Cancer Relief	Full guidance	1.2	We would like to see another bullet point added to the section on the role of the usual carer which is also to “know how to support and enable patients and carers to utilise their own knowledge and skills effectively.”	Text altered.
Macmillan Cancer Relief	Full guidance	ES17	We feel that KR4 is very narrow and does not reflect the high priority given to user involvement in the Economic Review. We recommend that the section ES17 is strengthened to include the 3 bullet points from p38 of the Economic Review recommendation and to refer to the Cancer Partnership Project. A suggested rewording is as follows: ES17 People whose lives are affected by cancer can make significant contributions to the planning and evaluation and delivery of services. However, to enable patients and carers to participate fully, it should be recognised that there are time, cost and training issues which affect effective involvement. User involvement may be direct (where users are personally involved in decision making) or indirect (where health professionals gather information about user views). People whose lives have been affected by cancer can also help other people affected by cancer through sharing experiences and ways of managing the impact of cancer on their lives.	Changes made to text to reflect much of the suggestions.

			Key Recommendation 4: Mechanisms should be in place to ensure the diverse views of patients and carers from a range of groups are taken into account in the development and evaluation of cancer and palliative care services. The Cancer Partnership Groups * provide a mechanism for achieving this. Guidelines, resources and infrastructure support are required to integrate user voices fully into the process. NEW Key Recommendation: Users should be actively supported in utilising and developing their unique experience, skills and expertise as equitable service providers. Systems should be in place so that patients and carers can participate in their own including self-help activities and peer support schemes offering a wide variety of informal support within community settings. * National Cancer Task Force Paper: User Involvement in Cancer Services April 2001	
Macmillan Cancer Relief	Full guidance	P37	In common with our comments on KR2, page 6, we recommend that the user involvement section explicitly refers to the need to refer patients and their families to benefits providers.	Comment noted – but decision taken not to alter text.
Macmillan Cancer Relief	Full guidance	P37	Paragraph 2.8 recognises the need to refer patients to sources of help and advice early enough. We recommend that this be at the point of diagnosis or very shortly afterwards, not on discharge from hospital as is more typical.	This paragraph is not a recommendation – it is a statement of the current position.
Macmillan Cancer Relief	Full guidance	2.24	We would like to see added to the end of this sentence ‘For example by inclusion in local service directories for patients.’ This section should make	Text altered.

			links with chapter 4 on Information.	
Macmillan Cancer Relief	Full guidance	Ch 3 and 4	We recommend that much stronger links be made between the communication and information sections. Service planners and providers need to consider these two topics together rather than in isolation.	Stronger links will be made between these two sections.
Macmillan Cancer Relief	Full guidance	Executive Summary	The need to keep records up-to-date should be mentioned in this section. KR6 opens the door to patient-held records but stops short of recommending they be implemented. We recommend that this section explicitly refer to patient held records in line with national cancer standards. We also recommend that consultants' letters use patient-friendly information.	The evidence to support this is not robust and it is conflicting – therefore this recommendation will stand as it is.
Macmillan Cancer Relief	Full guidance	3.10	The permanent record should be supported with written or audio material as appropriate for the patient and carer to take away from the consultation. Again this section needs to link with chapter 4 on information.	A permanent record may well include these materials.
Macmillan Cancer Relief	Full guidance	ES19	We recommend that the beginning of section ES19 be rephrased as it currently reads as patients not having the right to information. Suggested rewording: "To enable patients and carers to express preferences about their care and make choices on the extent to which they wish to be involved in decision making, it is important to ensure they have access to sufficient information at each stage of the patient pathway."	Text altered.
Macmillan Cancer Relief	Full guidance Information	ES19	We broadly welcome the recommendations on information, particularly that information materials should be free at point of delivery. We recommend that the recommendation on carers 4.15 p49 also be	Comment noted – but decision taken not to alter text as suggested.

			included in the Executive Summary and KR7. We recommend that the need for information to be appropriate and timely be recognised (ie, information needs differ at different points in the journey) and that KR8 in the Executive Summary make reference to the need for access to a 'range of high quality information materials'.	Text altered.
Macmillan Cancer Relief	Full guidance	ES19	We have some concerns about whether the delivery of information will be fragmented if it relies wholly on localised provision. We recommend that there be a national lead on information as well as Network level leads to co-ordinate between national resources (website and core booklets) and Network level resources (local directories; local content for national database; local cancer information and support services). We recommend that there also be a National Information Strategy.	This is in place.
Macmillan Cancer Relief	Full guidance		We recommend that there be a formal acknowledgement of the link between information and support (for training budgets, staffing costs etc.)	Apologies – the Developers are not quite sure what is being asked for here.
Macmillan Cancer Relief	Full guidance	P47	We welcome the emphasis on providing help with interpreting information in this section.	Comment noted.
Macmillan Cancer Relief	Full guidance	4.22	Approximately 25% of the population has low literacy levels and we recommend that this should be considered when producing written materials.	Comment noted.
Macmillan Cancer Relief	Full guidance	ES 20, KR9, ch5	The section on psychological support is much better in this draft than in previous versions. However, we still feel that is does not reflect the part that patients and carers and self-help and support groups play in alleviating psychological distress. We recommend that the word 'professional' in KR9 in the Executive	Comment noted – but decision taken not to alter text as suggested.

			Summary should be deleted in line with model on p57. We also recommend that Networks evaluate whether they can deliver services to meet the recommended four levels in this manual. We recommend that patients and carers be informed about the range of psychological services and support available to them so that they can access them individually without going through a health care professional is they prefer.	This would be a part of local needs assessment. Comment noted – but text not altered – not considered appropriate for patients to self-refer to psychological care services.
Macmillan Cancer Relief	Full guidance	ES21, KR10 ch6	We strongly welcome the section on social support which has historically been overlooked in an over-medicalised approach to palliative care needs. We recommend that a key recommendation in the Executive Summary should address the need for appropriate equipment in rehabilitation services.	Equipment added to recommendation.
Macmillan Cancer Relief	Full guidance	6.1	One of the key concerns for many elderly people who become ill or who are away from home in hospital is the welfare of pets. Help the Aged are able to provide further information on this point.	Comment noted.
Macmillan Cancer Relief	Full guidance	6.9; 6.10; 6.14	We strongly welcome these sections, especially the references to the need for financial support.	Comment noted.
Macmillan Cancer Relief	Full guidance	P69	We recommend that the Editorial Board also make reference to the following study: Ann Quinn. Macmillan Cancer Relief study into benefits advice for people with cancer. 2002. Published by Reading University.	The Evidence Review Team would welcome this paper – could it be sent to them please?
Macmillan Cancer Relief	Full guidance	ES 22, KR11,	We feel that this key recommendation, KR11, should be strengthened to include the role of patients and carers and to refer to the multi-cultural dimension.	Alteration made to text in line with part of this comment.

		ch7.	The section should also refer to the need for a wide range of staff in all settings to be sensitive to spiritual needs of patients and carers and for this to extend beyond death.	
Macmillan Cancer Relief	Full guidance	p.8	We recommend that the mention of the need for a 24 hour service in ES 23 should also make reference to the need for this to be available 7 days a week.	Text altered.
Macmillan Cancer Relief	Full guidance	P77	We recommend that 'self help and support groups' be added to the list in section 8.1.	Added into list.
Macmillan Cancer Relief	Full guidance	ES 26	This does not mention of training for AHPs in cancer. We recommend that this section should also mention the work of the voluntary sector in rehabilitation, e.g. laryngectomee support from the Laryngectomee Association and Expert Patient Programme.	Training issues are discussed in a later recommendation.
Macmillan Cancer Relief	Full guidance	P97	We recommend that this section make reference to the Expert Patients Programme (based on the work by Professor Kate Lorig at Stanford University and the Chronic Disease Self Management Course developed in the UK by the Long-term Medical Conditions Alliance (LMCA). This is also being piloted by Macmillan (see article by Catherine Tutton Towards self management programmes for cancer patients in Professional Nurse July 2003, Vol 18 (11), 658. This innovative approach to rehabilitation is more user-lead rather than the division outlined in this chapter framed around Allied Health Professionals areas of expertise.	This reference will now be included. Thank you.
Macmillan Cancer Relief	Full guidance	10.6	This section should also make reference to pain and fatigue as major problems facing many patients after treatment.	This list is intended as examples only.

Macmillan Cancer Relief	Full guidance	p.9 and chapter 11	We felt that the section on complementary therapies was rather weak and hampered by NICE's focus on randomised controlled trials. Many patients find complementary therapies to be of benefit and there is a body of evidence to support its use. We recommend that the Editorial Board consider the report by the Prince of Wales' Foundation for Integrated Health, Complementary and Alternative Medicine: the consumer perspective. 2003. We recommend that NICE consider and encourage the use of different models and exemplars to achieve good practice in service delivery of complementary therapies within mainstream healthcare. We also recommend that ES 28 make reference to the role of voluntary organisations and self help groups in providing complementary therapies. We recommend that priority should be to providing good information to enable patients to choose therapies which they feel may suit them.	Footnote and reference added to text.
Macmillan Cancer Relief	Full guidance	General and Ch 12	We are concerned that the needs of carers and families are considered separately in the document whereas patients want and need to be considered as a whole, which includes their informal support network. The needs of patients and their carers often overlap and supporting carers to support patients at all stages of the journey is vital. We recommend that the needs of carers be considered throughout the document.	This is reflected throughout the Guidance. The Developers wished to give prominence to a neglected area and so chose to have a separate chapter in addition to recognising throughout.
Macmillan Cancer Relief	Full guidance	ES29	We recommend that the section on families and carers should link with the social care section as many of the support structures relevant to patients are also relevant to families. This underlines our	It is clear in the text that these two sections are inter-related.

			view stated above, that the needs of families and carers should be considered throughout the document and not only in a brief stand alone section.	
Macmillan Cancer Relief	Full guidance	Executive Summary	We recommend that a lead person to focus on developing resources for the needs of families and carers (KR18) be community based rather than based within an acute setting.	The Developers do not wish to be restrictive about where this postholder might be – but simply to identify the usefulness of such a role.
Macmillan Cancer Relief	Full guidance	ES30	We feel that this section currently over-emphasises the role of professional services. We recommend that workforce issues reflect the role of the patient, carer and voluntary sector in meeting needs, as well as the NHS and social services.	This section is written predominantly about professional workforce issues.
Macmillan Cancer Relief	Full guidance	ES30	Much of palliative care is provided by generalist staff rather than specialist staff. The need for training for district and community nurses has already been prioritised through PCTs and we recommend that staff allied to health professionals be prioritised for training using a similar model.	This is covered in the text – and would also be a part of local implementation.
Macmillan Cancer Relief	Full guidance	KR20	Given the huge resource implications of this guidance we recommend that the Editorial Board considers suggesting that a key role/nominated person should gather and disseminate information about wider community resources/organisations that already exist.	Comment noted but decision made not to alter text. This might also be for local interpretation and implementation.
Macmillan Cancer Relief	Economic Review	p.22-3	The implications for user involvement on benefit entitlement should be covered in this section. Methods of making it easier to include users, such as the need for a float for immediate payment of expenses should also be covered.	This is not within the scope of the Guidance. This is too detailed to be included.
Macmillan Cancer Relief	Economic Review	4.4.2	We recommend that the CancerBACUP model for costings is probably the best available option here.	A proportion of patients are likely to use the internet to access information and therefore it is considered

			We are concerned that the internet may not be the right format for the core data. We recommend that costings be allowed for digital TV and other new media.	appropriate to ensure high quality core information is available through this outlet to support that provided by booklets. The Economic review does not seek to provide detailed costings but rather to provide a crude order of magnitude estimate of the most significant costs. On this basis the costs for digital TV and other new media have not been taken into account. The text has, however, been revised to reflect this.
Macmillan Cancer Relief	Economic Review	4.1.3	If there is a standard hosting arrangement, there should be a standard input database. We recommend that the costings on p16 include £600 database design. We recommend that local versions referred to here should have flexibility to present information to meet local needs – in line with local consultation groups.	The Economic review does not seek to provide detailed costings but rather to provide a crude order of magnitude estimate of the most significant costs. The impact of this omission will be negligible. It is however acknowledged in the text.
Macmillan Cancer Relief	Economic Review	4.1.3	We recommend that the costings on p16 include an adjustment for increased print costs every two years. We recommend that the Editorial Board consider whether family members should also be allowed to receive copies of information and so calculate for the impact of this on costings.	Costs estimates are crude order of magnitude only, and do not seek to take into account such detailed assumptions. Network Service directories are assumed to be available at all cancer service organisations within a cancer network for patients and their families to consult.
Macmillan Cancer Relief	Economic Review	4.4.4	We welcome the acknowledgement of the need for the role of Network information lead.	Comment noted.
Macmillan Cancer Relief	Economic Review	4.4.4	One main information centre and four satellites per Network (1 FTE and 4 0.5 FTE managers plus equivalent admin) Training costs for the centre managers and staff do not seem to have been allocated under the	Section 4.13 does not provide a comprehensive evaluation of training costs. However the text has been amended to specifically mention the need for training of centre managers and staff.

			communications skills training costs (4.13.4.1) here. We welcome the acknowledgement of need for administrative support and a budget for information materials.	
Macmillan Cancer Relief	Economic Review	4.4.2	Core booklets – 41 in production per year and average of 5 per person We recommend that the relationship between the content of the core booklets and the content for the national website should be clarified. We recommend that good quality information be made available with a range of formats with different levels of information and the costs calculated accordingly.	The text has been revised to reflect the requirement that information is required in a range of formats with different levels of information. A proportion of patients are likely to use the internet to access information and therefore it is considered appropriate to ensure high quality core information is available through this outlet to support that provided by booklets. It should be noted that the costs provided are illustrative only, given that there will be numerous ways of providing this information in any particular network.
Macmillan Cancer Relief		4.7	The Economic Review currently heavily emphasises the role of chaplains whereas many more staff need to be involved in line with the point above commenting on the Guidance emphasising the need for diversity and choice for patients in spiritual support services.	In section 4.7.1 it states that where the word "chaplain" appears, should be understood as meaning: *Chaplain-spiritual care giver appointed by the Health Care provider and authorised by the relevant Faith group* This definition has been expanded to include "….*with the ability to facilitate spiritual care provision in a religious and non-religious context"*
Marie Curie Cancer Care	Exec Sum	all	This section reads well with clearly stated recommendations. The recommendations are comprehensive and all carry significant resource implications. It will be essential for NICE to establish, in consultation with stakeholders, a mechanism for prioritising the implementation of the Guidance and to ensure that appropriate funding is linked to the implementation.	Comment noted.

Marie Curie Cancer Care	Exec Sum	KR 8	Much of information currently available is provided by charities; developed, quality assured and printed in large quantities. This existing work should be acknowledged and funded.	The role of the voluntary sector with respect to services is underlined at various points in the Guidance
Marie Curie Cancer Care	Exec sum	KR 9 & 16	It is noted that there is little evidence to support the complex, 4-tiered proposals for either psychosocial care or rehabilitation. These proposals have significant implication for both manpower and financial resources and we are concerned that lack of these resources may result in the return of 'post-code' provision of service as commissioners make choices about which parts of this strategy are funded.	These models are based on professional consensus as a suggestion for service configurations that might deliver better quality care than at present. The models are a guide only The development and monitoring of standards will mitigate against this occurring.
Marie Curie Cancer Care	Exec Sum	KR 11	The practice of specialist palliative care teams is to include providers of spiritual care as core members of the team, as this care is a fundamental component of palliative care. It is not necessary for a patient in this setting to specifically consent to a chaplain seeing their health records. Currently the NHS does not view chaplains as core and thus creates a barrier to them functioning as an integral part of the MD team. We wish to encourage the wording of the KR to be strengthened from 'access to' to 'part of'.	Chaplains are identified in the Guidance as a part of the extended specialist palliative care team.
Marie Curie Cancer Care	Exec Sum	KR 14	We welcome the emphasis placed on the introduction of the Liverpool Care Pathway for the Dying Patient. But see below: 8.33	See below
Marie Curie Cancer Care	Exec Sum	KR 19	Although voluntary sector providers are involved in Workforce Development Confederations, they are rarely selected from the palliative care field. We suggest that WDCs co-opt extra voluntary sector palliative care provider representatives to ensure that	This is outside the scope of the Guidance – but could be a part of local implementation.

			this vital KR becomes a reality.	
Marie Curie Cancer Care	Exec Sum	KR 15	We welcome the recommendation of equitable provision and 24 availablity of specialist palliative care advice, but would again point out the resource implications of this, particularly in view of the European Working Time Directive and New Deal requirements.	Comment noted.
Marie Curie Cancer Care	Exec Sum	KR 6	The complexity of care for patients in the palliative phase of their illness recommended in this guidance will result in large and increasing numbers of professionals requiring information about the management of individual patients. Current systems of communication are fragile and constantly fail. The proposed introduction of integrated healthcare records should ultimately improve communication, but early phase implementers will undoubtedly suffer considerable problems in coordination of information. NICE should ensure that the project team responsible for progressing the ICR is fully aware of these recommendations.	Comment noted. A footnote with a link to the ICRS system inserted.
Marie Curie Cancer Care	Full Doc	8.10, 8.33, 8.40, 8.43, 8.48, 8.58	We fully support the emphasis on the importance of recognising the onset of dying and the recommendation of the use of the Liverpool Care Pathway for the Dying Patient as a management and educational tool.	Comment noted. Thank you.
Marie Curie Cancer Care	Full Doc	Box 8.1	The identification of the individual components of the Liverpool Care Pathway for the Dying Patient is welcomed.	Comment noted. Thank you.
Marie Curie Cancer Care	Full Doc	9.15	See KR 15. It is unlikely that manpower resource will ever allow every specialist palliative care provider to deliver 24/7 cover. This recommendation should be	Comment noted – but this is to be worked towards – and the process of doing so is for local implementation.

			revised to acknowlege that crosscover arrangements within a network, or sub-division of a network, will be necessary and to consider the evidence related to patient dissatisfaction with such arrangements.	
Marie Curie Cancer Care	Economic Review	General	SCHARR are to be congratulated on producing this comprehensive document. It is, however, not easy to identify the point-in-time basis for the costs quoted.	Thank you. Costs are based on 2002 prices. The text has been revised in section 3.5 and section 5.3 to reflect this.
Marie Curie Cancer Care	Economic review	3.5	All staff costs are based on NHS salaries, but there is no recognition of the imminent implementation of the Agenda for Change or the European Working Time Directive and the associated significant cost implications for all groups of staff. Specifically, the cost estimates for provision of psychological support assume that the service will be linked to a Cancer Centre. In practice this recommendation will affect every specialist palliative care service, most of which are not linked. The costs are probably significantly underestimated.	The implementation of the agenda for change and the European Working Time Directive will have significant cost implications on the whole of the NHS. Taking this into account is beyond the scope of this costing exercise. Within the costing model the staff estimates for the cancer centre are scaled up to take account of staff requirements throughout the rest of the network
Marie Curie Cancer Care	Economic Review	4.9.3.7	The costs quoted for the Marie Curie Nursing Services are for the financial year 02/03. The costs for 03 /04 are: £16.70 for registered nurses and £12.90 for healthcare assistants.	The costs quoted for the Marie Curie Nursing Services have been identified as being costs for the financial year 2002/2003.
Marie Curie Cancer Care	Economic Review	4.8.3.2	Implementation of the Liverpool Care Pathway is incorporated into the costings of the GSFamework for PCTs. However, in other healthcare, primarily hospital, settings, dedicated time similar to that identified for the community is required. Therefore an additional point should be added costing a facilitator to implement the LCP in every institution. This could be either a CNS or a consultant in Palliative Medicine. The education and support programme	The costs included in the economic review for the gold standards framework for Primary Care Trusts are intended to be illustrative costs only. There is more than one way of providing this service. Individual networks will need to identify the most appropriate means of service provision and provide more detailed costings for their locality.

			needed should be costed at 2 days per week for 2 years at 'H' grade Senior Nurse.	
Marie Curie Cancer Care	Full Doc	9.38, 9.46	Evidence of the value placed by patients on the support mechanisms afforded by day therapy attendance is becoming available. The immediate availability of a variety of healthcare professionals is considered important, but the unique opportunity to share experiences with other patients scores very highly. This recommendation might be modified to recognise that evaluation of daycare services is on-going and that evidence to more stongly support this form of service may shortly become available. It should be recognised that conventional randomised controlled assessment may not be the most appropriate method now that day services are well established in many parts of the UK.	To our knowledge all the evidence available about day care was included in the review that was conducted. Could you perhaps send us the references of the studies that are lacking?
Medicines and Healthcare Products Regulatory Agency (MHRA)			This organisation was approached but did not respond.	
Mencap	Full	general	The full Supportive and Palliative Care documentation seems to deliver broadly what is required, in a field where there is less than total agreement on what constitutes good practice, and a very patchy experience of what is seen be good practice.	Comment noted. Thank you.
Mencap	Full	general	I would welcome greater emphasis on differentiation. Palliative care is basically a flexible response, varying over time, to the support needs of an individual in the context of their personal circumstances and networks. At one end of the	Comment noted.

			spectrum, there are people who are unemployed, homeless and socially isolated, with long-standing problems of e.g. addiction that pre-date and overshadow the condition requiring palliative care. Such people might hope to discover latterly significance for themselves and a meaning for their lives and some relationships that they have always lacked or lacked for many years. At the other end of the spectrum, there are people who are economically active and socially engaged, and who are mainly concerned to complete unfinished business. End stage illness can lessen and eventually remove life story differences, but palliative care needs to respect both the essential individuals and the differences.	
Mencap	Full	general	My particular interest is in the current mutual learning between palliative care and learning disability support, which is helping people with learning disabilities to secure tailored palliative care in whatever setting is most appropriate – family home, own home, shared home, hospices – without further undermining sometimes rather limited and fragile social networks.	Comment noted.
Mencap	Full	general	Palliative care needs always ran the risk of finally breaking down support arrangements from elderly family carers or from a residential home not geared to catering for high dependency. The shift from residential care to supported living has many advantages, but it can make the person with learning disability even more vulnerable when palliative care needs arise, because the support arrangements are more tenuous than in residential home and there is less safety margin. Moreover, in supported living, there is commonly a more dispersed circle of support	Comment noted.

			and friendship (if any) and people can more quickly become isolated.	
Mencap	Full	general	Crucial good palliative care in this context is good communication – the ability to interpret to people, some of whom are non-verbal, what is happening to them, and to gear what happens to them to an understanding of their needs and wishes. Even basic pain control is more difficult where someone's experience of pain has to be interpreted for them rather than explained by them.	Comment noted.
Mencap	Full	general	I have to leave it to you where some of this might find more forceful expression. Hopefully, the experts in this field will already be on the case.	Comment noted.
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 Care Standards Commission			This organisation was approached but did not respond.	
National Council for Disabled People, Black, Minority and			This organisation was approached but did not respond.	

Ethnic Community				
National Council for Hospice and Specialist Palliative Care Services	Full	general	The decision to publish the draft guidance as a complete document rather than in Parts A and B is welcomed. That allows for an overall view to be taken of the guidance. In general it is considered that the guidance presents a challenging but necessary agenda for supportive and palliative care over the next few years. For the most part it strikes the right balance between prescriptive recommendations and allowance for local flexibility in implementation of the guidance. The Council welcomes in particular the Chapter on user involvement and the new section containing the summary of recommendations.	Comment noted with thanks.
National Council for Hospice and Specialist Palliative Care Services	Full	ES	There is some doubt as to the value of yet another list of recommendations in addition to the detailed recommendations in each chapter and the summary of recommendations at the end. At best the key recommendations constitute an attempt to summarise in a few words the substance of all the detailed recommendations for each topic area. Implementation of the guidance is likely to be assessed not against these key recommendations but against the recommendations detailed in the summary. An alternative approach would be to include the summary of recommendations within the executive summary and to focus in the ES on key objectives rather than recommendations.	Comment noted – but the Developers have taken the decision that key recommendations will continue to be set out, as in other Improving Outcomes guidance. New text has been inserted to explain the reasons for the various summaries.
National Council for Hospice and Specialist	Full	General	The prime audiences for this version of the guidance are commissioners and providers of services. The language and method of presentation e.g. the map of	Comment noted.

Palliative Care Services			the patient pathway, the four levels of psychological support and rehabilitation services has these audiences in mind rather than patients and other users. It will therefore be very important in the drafting of the version for the general public to structure the document from the user perspective and to employ language in every day use rather than technical terms or jargon.	
National Council for Hospice and Specialist Palliative Care Services	Full	General	One of the principles underpinning the guidance is that of user involvement in the individual care of patients and other users. It should perhaps be more clearly stated that the philosophy of the Guidance is based on a concept of equal partnership between patient/carer and health or social care professional. Such a statement could be incorporated in the overview of the service model in ES 14/15 and emphasised in any foreword to the Guidance. This would emphasise the resources patients have themselves to meet their own needs and to meet with professionals on an equal footing, take joint responsibility for their treatment and utilise their personal experience in a positive and constructive way.	Text altered to include this.
National Council for Hospice and Specialist Palliative Care Services	Full	General	There is a need for inclusion of a glossary of frequently used terms.	The Developers are considering producing a glossary for the final version.
National Council for Hospice and Specialist Palliative Care	Full	I28	Box 1.1 indicates the scope of the Guidance. There is still some doubt in relation to the current wording as to whether voluntary hospices will be bound to implement the Guidance. In order to introduce absolute clarity on this point it is suggested that the	Text altered.

Services			following statement be included: the guidance relates to all services provided by non-NHS providers that have been commissioned by the NHS under the terms of service level agreements	
National Council for Hospice and Specialist Palliative Care Services	Full	I45	In the third sentence the final words need to be amended to '…primary care and services provided by the voluntary sector for the NHS'.	Text altered.
National Council for Hospice and Specialist Palliative Care Services	Full	1.9	The word 'optimum' has no meaning in the context of the sentence. Suggest that 'an optimum number of' be replaced by 'multiple'.	Text altered.
National Council for Hospice and Specialist Palliative Care Services	Full	1.10	It would be useful to list here as well as in the summary of recommendations all the principal stakeholders who should be involved. The list is on page 121. It will need some amendment and additions.	Comment noted and text altered within section as suggested.
National Council for Hospice and Specialist Palliative Care Services	Full	1.16	It is not only the responsibility of individual professionals to ensure that they have received training but also that of their employers. The point is made adequately elsewhere in the document but should be included here also.	New text inserted in line with comment.
National Council for Hospice and Specialist Palliative Care Services	Full	1.19	Teams should develop referral guidelines. The following should be added: 'in accordance with any relevant network guidelines'. There are references to guideline development elsewhere in the guidance where the same point would be relevant e.g. 1.23.	Text altered.
National Council for Hospice and	Full	1.25	Add 'social worker' to those who might be nominated as a key worker. This would reflect practice in	Text altered.

Specialist Palliative Care Services			community teams that have a social worker as a core member of the team.	
National Council for Hospice and Specialist Palliative Care Services	Full	General	In the document that set out the Scope for the development of the Guidance it was stated that one of the requirements would be to develop Level 1 audit criteria which would allow the objective measurement of whether the guidelines had been implemented. This requirement is not now addressed or mentioned in this draft. It may be that it is anticipated that the development of standards derived from the Guidance will fulfil this function. However, whatever the reason for the omission of reference to this, it is suggested that some explanation is required.	The original scope stated that one of the requirements would be to develop audit criteria that would allow the objective measurement of whether the guidelines had been implemented. This has not been addressed in the document, as it is no longer considered necessary, as the Manual of Cancer Services Standards will be updated in accordance with the Guidance. Text has been included in the Guidance to explain this.
National Council for Hospice and Specialist Palliative Care Services	Full	General	In the document that set out the Scope for the guidance development it was envisaged that services would be classified either as 'core' or 'non-core'. The latter were anticipated as services for which evidence was less strong but for which there was some evidence that patients found value in them. The guidance does in the event not use such classification although there are some possible candidates for 'non-core' e.g. complementary therapies. As with 'measurement' it is suggested that some note of explanation is required about deviation from the requirements set out in the Scope document.	New text inserted in introduction explaining that the evidence did not allow the Developers to pursue this.
National Council for Hospice and Specialist Palliative Care	Full	2.7/2.8	Council's user involvement group suggests that it is important to highlight benefit issues for users as a topic needing to be addressed in user groups.	Outside the scope of the Guidance.

Services				
National Council for Hospice and Specialist Palliative Care Services	Full	3.17	Council's user involvement group makes the point that significant news should be communicated to the patient without delay whether it is 'bad news' or 'good news'.	This is considered to be implicit ion the text.
National Council for Hospice and Specialist Palliative Care Services	Full	3.23	Employers also have a responsibility to ensure that professionals have understanding of cultural dimensions in communicating with patients	Text altered.
National Council for Hospice and Specialist Palliative Care Services	Full	4.0	Chapters 3 & 4 appear relatively isolated one from another whereas their topics are closely related. It may be desirable to make some cross referencing between the chapters or at least an acknowledgement that the provision of information materials to patients/users may best take place in the course of face-to-face communication.	Links between the two sections made clearer.
National Council for Hospice and Specialist Palliative Care Services	Full	5.16	The Association of Hospice and Specialist Palliative Care Social Workers takes the view that social workers specialising in palliative care are able to provide psychological support at level 3. If that view can be substantiated then such social workers need to be included in the list of those that can provide care at that level.	This is considered to be outside the scope of the Guidance – but might be considered as a part of local implementation.
National Council for Hospice and Specialist Palliative Care Services	Full	7.7	In spiritual care it is important for support to be offered within the framework of the patient's set of beliefs or philosophy of life. This further issue needs inclusion.	Text altered.
National Council	Full	8	The title 'General Palliative Care Services	Text altered throughout the Guidance.

for Hospice and Specialist Palliative Care Services			incorporating care of dying patients' is to be welcomed but it needs to be used throughout the guidance where reference is made to general palliative care services.	
National Council for Hospice and Specialist Palliative Care Services	Full	8	The sub-sectioning of the dying elements is helpful in promoting specific issues around care of the dying. Additional evidence and references may be obtained from the journal of the BMA published on 26 July 2003.	The Evidence Review Team will consult this journal for further evidence. Thank you for this.
National Council for Hospice and Specialist Palliative Care Services	Full	Box 8.1	The first box would be better with the addition of the words 'with the patient'. In the same vein it is suggested that the final phrase in the second box should end with 'care planned and agreed with the patient'.	This table comes from the Liverpool Care Pathway and is referenced. Although some minor changes have been made to the table further changes cannot be made without loosing the sense of the original. The notion of working in partnership with the patient is an overriding principle throughout the Guidance.
National Council for Hospice and Specialist Palliative Care Services	Full	8.22	The meaning of 'generic' is unclear in this context.	Altered to generalist.
National Council for Hospice and Specialist Palliative Care Services	Full	9.25	There are several points to make about this and the following recommendation. The first concerns what meaning should be attributed to the word 'core'. In the context of the Manual of Cancer Service Assessment Standards core members of the MDT are those members who have specific obligations relating to attendance at MDT meetings. Extended team members do not have such obligations. The question that arises from the recommendation in the guidance is 'Is the meaning of core and extended the same as in the Manual? If it does, then does the attendance of someone able to provide benefits	Text altered in line with these comments, and value of extended team members clearly identified in relation to attending MDT meetings.

			advice carry the same obligations of attendance as the consultant and specialist nurse? If it does not then what do the terms mean? Presumably core would mean those professionals that would constitute the minimum membership consistent with being a specialist multi-professional team in palliative care. This needs clarification.	
National Council for Hospice and Specialist Palliative Care Services	Full	9.25	The wording relating to social workers etc. would appear to mean that social workers are optional members of the core team. They are not however included in the extended team. This would mean that there would be no requirement for a social worker in the specialist palliative care team. Is this the intention?	This is not the intention - please see the social support section. Social workers have also been included in the extended team list rather than the core team.
National Council for Hospice and Specialist Palliative Care Services	Full	9.28	The definition of 'normal working hours' needs clarification. Is it 9 to 5 on seven days a week or something less than that? If so, what?	Altered throughout Guidance.
National Council for Hospice and Specialist Palliative Care Services	Full	12.0	It is suggested that it may be useful to construct a carer pathway that is related to the patient pathway but separate from it. Such a pathway might be helpful in encouraging consideration of carer needs at key points of the patient pathway.	Comment noted – but decision made not to alter text as suggested.
National Council for Hospice and Specialist Palliative Care Services	Full	B	The list of stakeholders needs amendment. Add NHS Commissioners, Care Homes, Social Services, Specialist Service providers e.g. psychology, specialist palliative care	The phrases 'Health Service Commissioners of Cancer Care' and 'Councils with Social Service Responsibilities' have been introduced into the text.
National Council for Hospice and Specialist	Full	Summary of recommen	It may be useful to add to the summary a statement of what is expected of individual health and social care professionals. There are numerous	New sub-section on individual health and social care professionals added.

Palliative Care Services		dations	requirements laid upon every professional throughout the text e.g. communication skills, assessment skills. Essentially this is about the construction of a picture of what the health and social care professional should be able to know and do in order to provide good supportive and palliative care as a routine part of their clinical practice. It is suggested that putting this together in summary form would be helpful to both individuals and those who are charged with arranging CPD.	
National Council for Hospice and Specialist Palliative Care Services	Economic Review	General	This is a valiant attempt to make some estimates of the costs of implementing the guidance. It reveals how little is known about the current costs of providing services and consequently demonstrates a need for the collection of cost data that are specific to the principal elements of supportive and palliative care. This review is therefore just a start that will need refining as more data becomes available.	It is agreed that the economic review is a starting point in defining the cost of future service provision. It will need refining as more data becomes available and this has been emphasised in section 5.3 Limitations and Uncertainties.
National Council for Hospice and Specialist Palliative Care Services	Economic Review	2.0	It is noted that the review does not consider where the costs will fall. There is however a need for a statement either in the guidance or in the review about where they will fall. It is suggested that the answer to the question is straightforward. The guidance relates to services provided for NHS patients whether the providing agencies are NHS, or in the voluntary or private sectors. The NICE guidance will in future be part of the service specification in all service level agreements. Logically therefore the cost of the specification will fall on those requiring the service i.e. NHS commissioners. It is suggested that a paragraph to this effect be inserted in either the guidance or the review or both.	Comment noted – but funding arrangements are beyond the remit of the Guidance Developers.

			Although there are no specific audit requirements contained in the guidance, the review overlooks the fact that standards are being derived from the guidance and that these will be subject to assessment.	
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.1.2	The identification of the need for management support at network level is welcomed. The development of such support has recently been encouraged by the National Partnership Group for palliative care.	No change required.
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.1.4	It is suggested that the assumption that changes to the assessment process will not lead to increases in workload is wrong. The requirement for assessments to be made with the patient and carers over all the potential domains of care need will take longer than at present simply because current assessments are not as comprehensive as those now required. Making assessments, communicating with patients takes time. There may also be a greater demand for services to meet these heretofore unknown and therefore unmet needs.	Changes to the assessment process may lead to increase in workload due to the requirement for assessment to be made which will take longer than at present. However, there will be other factors that may well reduce workload and therefore the net impact on workload not known with certainty. Further research is needed in this area. It is acknowledged that there may be a greater demand for services to meet previously unmet needs, however, the scale of this increase in demand is unknown and cannot be taken account of.
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.3.4	This is a good method for estimating costs of interpreters but the costs could be expected to diminish over time as people become more assimilated and develop their knowledge of English.	The fact that the costs of interpreters can be expected to diminish over time as people become more assimilated and develop their knowledge of English, has been acknowledged in the text.
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.5.4	Provision of more comprehensive support at Level 1 is not likely to be cost neutral (see comment above).	This is a complex area and a range of factors need to be taken into account. For instance, there will be additional time implications, due to longer, more detailed assessments taking place. However, improved sharing of information will avoid duplication of assessments and improved assessments may well

				reduce future workload, by identifying and responding to problems at an earlier stage. There is currently no robust evidence on which to base this assumption, but rather it is based on clinical opinion of members of the Editorial Board. Future research is recommended to explore this issue further
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.6.3.1	The same point arises. This is not likely to be cost neutral.	As above
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.7.3	The same point arises. This is not likely to be cost neutral.	As above.
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.7.5	There is a note about the supposed growth of day care. Since the guidance is not encouraging of day care expansion is this a reasonable supposition?	This note has been removed.
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.8.3.1	The assumption about cost neutral needs to be challenged.	As above (item 36)
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.8.3.2	Implementation of the Liverpool Care Pathway is incorporated into the costs for the GSF for Primary Care. However in other care settings, primarily hospital settings, the experience is that a dedicated time similar to that for the community is required.	The costs included in the economic review for the gold standards framework for Primary Care Trusts are intended to be illustrative costs only. There is more than one way of providing this service. Individual networks will need to identify the most appropriate

			Two days per week is required for a minimum of two years. Assume a Grade H nurse.	means of service provision and provide more detailed costings for their locality.
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.9	It is 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. This information should be provided in the review as it has for most other elements of the supportive and palliative care services.	More details have been provided in the specialist palliative care service in order to allow better understanding of cost estimates.
National Council for Hospice and Specialist Palliative Care Services	Economic Review	4.9.4.2	The presentation of this section appears to carry the assumption that it is good to move from scenario A to through to C. Clearly in some respects this is true e.g. increasing out of hours availability. In other respects it may not be true e.g. in relation to beds, spc teams, day care places. The volume of these services should be related to the population's aggregate need and this may vary within networks and between networks quite significantly.	It is agreed that the volume of services should be related to need within the network and that between networks this need might vary significantly. This has been emphasised in section 3.5 of the Economic Review.
National Council for Hospice and Specialist Palliative Care Services	Economic Review	Table 36	There is an assumption in this Table that variation in the need for resources is related solely to population size. There are in fact other important factors that would suggest the questioning of that assumption. Much more work is needed before reasonably reliable estimates can be obtained of likely future costs of providing services in compliance with NICE Guidance according to population need.	It is acknowledged that variations for resources is reliant upon a number of important factors and that more work is needed to provide reliable estimates of likely future costs for different cancer networks. This is now reflected in section 5.3 of the economic review.
National Network Lead Clinicians Group	Full	general	Clear structure and overview of supportive and palliative care issues for cancer.	Comment noted with thanks.
National Network Lead Clinicians Group	Full	general	There are a number of references to commissioners separated from networks and also a reference in the summary of recommendations that networks are merely groups of providers. We feel it should be	Addressed in new text in the introduction.

			made clear that commissioners are also members of networks.	
National Network Lead Clinicians Group	Full	general	The guidance focuses on commissioning services for patients with cancer and their carers, but suggests that it may inform development of effective service models for other groups of patients with similar needs (Box 1.1, Page 19). This is particularly relevant for palliative care services where expansion to include other illnesses is taking place. This obviously has impact on the economic analysis and costs of service developments. Is it intended that these will be addressed in other NSFs? It will be helpful to have a clear statement in this guidance on this, particularly in relation to the economic analysis and scope of service provision.	The Developers consider that this is beyond the scope of the Guidance. The Department of Health/Welsh Assembly would need to consider whether to commission work on this.
National Network Lead Clinicians Group	Full and Economic Review	general	Many of the recommendations in the guidance do not include specific details of recommended levels of service for a network, e.g. number of palliative care beds, number of clinical nurse specialists, number of AHPs. However, the economic analysis inevitably has made assumptions on which to base costs. It would therefore be helpful to have greater clarity about how the two sections, i.e. full recommendations and economic analysis link together. More specifically, there seem to be some inconsistencies, which are illustrated later.	The Developers apologise for any inconsistencies – these should have been ironed out in the nest version. The precise numbers of staff, beds etc. etc, is for local determination following a needs assessment. The Economic Review has provided a cost model that might be of use once such decisions are made to estimate cost impact.
National Network Lead Clinicians Group	Full	general	In a number of areas, e.g. ES 25, 9.12, 9.14, 9.15, 9.17, 9.23 the word "appropriate" is used, e.g. in terms of provision of an appropriate range and volume of specialist palliative care services. This is always a difficult term when it comes to recommendations as there can be a wide number of interpretations. It would be helpful if this guidance	Careful editing of the Guidance has taken place to remove these words or to clarify their meaning.

			could define what is meant by appropriate in these situations.	
National Network Lead Clinicians Group	Full	I17	This paragraph raises the difficult issue of needs versus wants and implies that patients should receive services wherever they want them. Whilst patients' wishes are clearly important, this could lead to an inefficient use of professionals' time with, for example, home visits by consultants rather than outpatient attendances by patients.	Text altered.
National Network Lead Clinicians Group	Full	I21	This paragraph implies that the use of the term generalist or specialist will depend on circumstances in which a social worker works. Usually a social worker employed by a hospice will have specialist skills and training in palliative care above those of a generalist social worker working in a local authority.	That is exactly the point the Developers are making.
National Network Lead Clinicians Group	Full	1.6	We feel it is important to include the fact that there may be circumstances where patients' needs are recognised with planning by the network, but a failure of commissioners to fund.	Text altered to reflect this.
National Network Lead Clinicians Group	Full	1.10	We feel there should be inclusion of the responsibility of commissioners to fund services.	This is outside the scope of the Guidance other than to highlight where there appears to be a clear role for commissioners – as a part of their role as funding services and service delivery.
National Network Lead Clinicians Group	Full	1.15	Whilst involvement in design and delivery of services is an important role for patients and carers, we would question whether it would need to be included in all assessments.	The text suggests that this might be included – it will be driven by individual needs.
National Network Lead Clinicians Group	Full	3.10	Although the possibility of use of taped records of consultations is mentioned in paragraph 3.34, it would be useful from the point of clarity to include reference to it in 3.10.	The former paragraph referred to is a synopsis of evidence. The permanent records referred to in the latter paragraph might include a tape.

National Network Lead Clinicians Group	Full	7.18	It would be helpful to clarify what is meant by “suitably qualified” in relation to spiritual care providers.	Text altered.
National Network Lead Clinicians Group	Full	8.22	As this section relates to provision of general palliative care services as part of care in generic settings, we are not clear as to what is meant by “referral criteria to generic palliative care services” in this paragraph.	The word ‘generic’ has been removed to clarify this.
National Network Lead Clinicians Group	Full	9.28	It would be helpful to clarify what “normal working hours, seven days a week” means. It seems that in the economic analysis this is 9.00 – 5.00 for seven days a week.	Text altered throughout Guidance to clarify this.
National Network Lead Clinicians Group	Full	9.31	It would be helpful to clarify what is meant by “sufficient in number to meet the needs of the population served” and how this may be calculated/measured. The economic analysis is based on the range of current existing bed numbers per million population, which is extremely wide. If there is no clear recommendation of bed numbers per million population should factors such as ‘that there is always a bed available in a specialist palliative care unit to admit a patient at any time of day or night including weekends without a waiting list and without patients having to be admitted to acute wards inappropriately’ be used as a measure of “sufficient”?	There is no evidence on optimal levels of service provision and the guidance therefore does not make specific recommendations. Local needs assessment is required, with locally agreed definitions of levels of service required to meet that need. Text inserted to clarify this.
National Network Lead Clinicians Group	Full	9.33	It would be helpful to clarify what is meant by palliative care nurse specialists in an inpatient specialist palliative care setting. This term if usually used to describe clinical nurse specialists, e.g. at grade H, who work as part of hospital or community palliative care teams. Presumably, here it means	This is considered to be outside the scope of the Guidance and is an issue for the national nursing groups to consider and define.

			nurses who have been trained beyond an introductory programme in palliative care and have special expertise in this area.	
National Network Lead Clinicians Group	Full	10.21	It seems to be suggested that a formal assessment of needs for rehabilitation should be carried out at each outpatient visit. If this is so, what form of assessment should be taking place? Is this intended to be level 1 or level 2 as in table 10.1? This would obviously have significant implications in terms of staffing of outpatient clinics, etc. if felt to be essential.	This refers to a general rehabilitation needs assessment – which then triggers referral to whatever level is appropriate for the patient's needs.
National Network Lead Clinicians Group	Full	10.24	The detail of discussion about the provision of lymphoedema services in the document is disappointing. Whilst it is recognised that lymphoedema affects people who do not have cancer as well as those who have malignancy or who have been treated for it, it is clear that nationally there are major inequalities in service provision for patients with lymphoedema and it would seem a good opportunity to begin to address this. At present most lymphoedema services for patients with cancer, and with lymphoedema not related to cancer, are provided by specialist palliative care services. Although much of the work is done by either nurse specialists or specialist physiotherapists, there is a recognised need for medical input to these services. It would therefore be useful to have a more detailed consideration of lymphoedema services in this document with recommendations to guide commissioners regarding service provision.	The Developers consider that lymphoedema has prominence within the Guidance – alongside the other rehabilitative needs a patient may have. This section of the Guidance was drafted with input from lymphoedema specialists.
National Network Lead Clinicians	Economic Review	4.11.5	The estimates of staffing in this do not seem to link clearly with those discussed in the full manual, e.g. lymphoedema specialists are costed in cancer	This is partly accounted for by the fact that the Economic Review has had to make detailed assumptions on which to base cost estimates and

Group			centres, units and in the home care setting, but this is not considered specifically in the manual. The costings are also not consistent with the cost estimates for lymphoedema staff in Table 35 of the economic analysis. In addition, lymphoedema nurses also appear in the extended SPC team in Table 36. This seems to be rather confusing. Perhaps a separate section specifically on lymphoedema service provision under the heading of rehabilitation in the full manual, with a corresponding section in the economic analysis, would be helpful.	therefore has had to provide greater detail than the manual. There were inconsistencies between section 4.10.5 and Table 35 and table 36 – these have been corrected. Costs appear in table 35 and 36 as services are provided both as part of supportive and general palliative care (table 35) and Specialist Palliative Care (table 36). Further explanation has been added in section 4.10
National Nurses Nutrition Group			This organisation was approached but did not respond.	
NHS Quality Improvement Scotland			This organisation was approached but did not respond.	
North Tees and Hartlepool NHS Trust	All	general	I wonder if there has been a reconnection with Providing patient centred care Topic 1 of the Manual of Cancer Service Standards and the supportive and palliative care strategy. Each site specific multidisciplinary team must provide this standard. It broadly involves a patient survey on the experience of the patient with the MDT. It highlights the need for support groups, patient involvement, and patient information and whole area of psychological support such as the breaking of difficult news. It is a micro level of the strategy but the connection needs to be established that each MDT should be thinking about how they can integrate the 20 recommendations to the work of the site specific MDT. Page 16 of (MCSS) suggest that it waiting for the strategy and possibly the standard will change. This work has a great opportunity to provide a framework for the	Standards for the revised sections of the Manual of Cancer Service Standards will be derived from the Guidance. This will include the current section on ‘patient centred care’.

			multidisciplinary teams as long as the reconnection is made.	
North Tees and Hartlepool NHS Trust	All	general	Under the key recommendation of specialist palliative care. It implies there should be specialist palliative care bed (facilities) in a hospital. How feasible is this? Is it in keeping with the modernisation agenda? For every six patients receiving treatment in these beds there could well be another twenty dying patients without access. Palliative care should be seen as a generic skill that the generalist should extend themselves to when required and focus on rehabilitation when improvements occur. It will be difficult to see how these inpatient facilities will be able to help all the non cancer palliative care patients. It is the structure of the specialist palliative care teams that should be more flexible and respond to where the need is not the adding of facilities. It is important that palliative care for non cancer patients have a share of the provision rather than setting facilities for cancer patients. At this time specialist palliative for all patients is too complex.	Comment noted – this is for local needs assessment using local variables – and then implementation according to such needs.
North Tees and Hartlepool NHS Trust	All	general	We recently had a discussion at our network to discuss how we can take the strategy forward. We worked from an organisational perspective. We decided to focus on those aspecst of the strategy that we felt confident with. The items that we left for a later date were: Psychological care Rehabilitation Social support	Comment noted.

			Spiritual care Complementary care These areas were seen as difficult to put in place because the network lack a comprehensive multi-agency team but more importantly I am sure these are the areas that a patient would developed first. I need someone who will help me cope with the feelings and ideas I have about my diagnosis. I want the care to be focus on my rehabilitation. I want to be demedicalised and my life back. It is getting hold of the individuals who can help me with the social side of my care. So it is the cross boundary working. I need organisations to be talking and collaborating with each other. I need some one who will help me explore the meaning of my illness to me so that I can get more control back in my life. I want to see the whole of my life and strengthen my faith. I think I would want someone to help me feel at ease and a little massage and healing may just help me that I can handle this disease inside of me. (These are my own thoughts on the issues but they might be closer to what patients most want) I took the liberty of suggesting that patients would want us to develop those areas that are the most difficult to put in place from a strategic perspective	
North Tees and Hartlepool NHS Trust	All	general	I wonder if there was an identified role for the nurse consultant in palliative care in making a major contribution for delivering the supportive and palliative care. Nurse specialists are mentioned but not nurse consultants. They could be an extra driving force. There are only about 8-10 across the country. To strengthen the strategic and leadership	Comment noted. It is anticipated that nurse consultants will have an increasingly important role.

			dimension of the role the nurse consultant in palliative care where present should have a function at Network level connected to the guidance. I have a meeting with [X] to see how we can be more integrated in the National Council for Hospice and Specialist Palliative Care. I suggested that we could be a major force in doing the frontier work of reaching over into non cancer areas such as Heat failure, COPD, dementia and the multiple pathology of the elderly. It is the practice development aspect of their role that will look at the application of this strategy into everyday practice. My suggestion is Nurse consultants in palliative care where available should play a key role at a network level in apply the strategy to practice. I already do this I am a part of the steering group for the strategy and a member of the palliative care working group.	
North Tees and Hartlepool NHS Trust	All	general	Under communication shouldn't the guidance identify what kind of advanced qualification is expected of clinicians?	This is being considered as a part of a pilot programme.
North Tees and Hartlepool NHS Trust	All	general	Is it possible that Cognitive Behavioural Therapy should be seen a competency of the clinical nurse specialist in palliative care. It would be nursing intervention at level three. There are post graduate courses that recognised the significance in palliative care.	It is possible, and does not preclude this if nurses have received the relevant training and have ongoing supervision
North Tees and Hartlepool NHS Trust	All	general	Is it possible to advocate the new project by the Lancashire Cancer Network call the 'Preferred Place of Care'. [X] has the details. It fits in with the Gold Standard and the integrated care pathway.	Thank you for this – this has been referred to in the text.

North Tees and Hartlepool NHS Trust	All	general	It is an amazing piece of work that will be a major step in ensuring quality of palliative care outside of the hospice setting well done.	Comment noted with thanks.
North West Wales NHS Trust			This organisation was approached but did not respond.	
Novartis Consumer Health (Novartis Medical Nutrition)			This organisation was approached but did not respond.	
Novartis Pharmaceuticals UK Ltd			Having reviewed the above document I can confirm that we will not be submitting any comments.	Thank you.
Ortho Biotech			This organisation was approached but did not respond.	
Peterborough Hospitals NHS Trust	Full	General	Overall we agree in principle with the comments, recommendations and evidence behind the document. We felt the document was very lengthy and repetitive, and could have been more user friendly using bullet points and shorter sentences, eg the Executive Summary was 10 pages long in its own right. The key points were picked out very well but there was also discussion within each key point which was then repeated later in the document. The document could have been structured more clearly to enable accessibility of the information contained. It is encouraging that needs for palliative care patients will be assessed so thoroughly and methodically providing equity for all patients and localities. The guidelines take a common sense and shared approach to palliative care. Care would be enhanced if, for example, the following main aspects	This comment was discussed at an Editorial Board meeting and a decision taken to retain the document as it is. However, text has been inserted to explain the reasons for the various summaries. Comment noted, thank you.

			were implemented. • More palliative care beds (acute unit, hospice, community) • Access to a psychologist • Multidisciplinary palliative care teams • Liverpool Care Pathway for the Dying • Gold Framework Several areas of the document refer to "appropriate" resources, levels of care, etc, and greater clarity would be helpful. If an individual patient basis is intended this should be specified. We realise that there is a planned hypothecated palliative care investment plan but to fully implement all of the recommendations would require considerable ongoing investment. We are assuming this is the complete document comprising Parts A & B as indicated in the enclosing letter.	This is intended to be assessed at Network level. Comment noted – and acknowledged – the Guidance identifies service configurations to work towards achieving. Yes. This is the complete Guidance.
Peterborough Hospitals NHS Trust	Full	8.8	3rd line – spelling of "failing".	Thank you.
Peterborough Hospitals NHS Trust	Full	8.33	2nd line – spelling of "multi".	Thank you.
Peterborough Hospitals NHS Trust	Full	6	Comment – Agree with the current difficulties in accessing social workers/support and that more support is required. Would further suggest that multidisciplinary palliative care teams require dedicated social worker/support,	Comment noted.

			occupational/physiotherapists, pharmacy, psychology, spiritual support, etc. These teams/members will then be familiar in working within palliative care thus building up expertise in the specialty. Rehabilitation needs to be promoted in this specialty to ensure the best possible quality of life.	
Peterborough Hospitals NHS Trust	Full	9.13	Palliative care service needs to have “appropriate range of staff” specified. Ie MDT skill mix – see comments for section 6 above.	The Developers consider that this is covered in the text – precise numbers must be left to local needs assessment and planning.
Peterborough Hospitals NHS Trust	Full	9.26	Would include lymphoedema services to this section, as a need for palliative care patients. Nationally we feel this is a service which is not widely available and could have a significant impact on quality of life for palliative care patients.	Lymphoedema services are included in this section.
Peterborough Hospitals NHS Trust	Full	3.34	It would be helpful to include guidance on the need for consent and confidentiality.	This is considered to be outside the scope of the Guidance.
Peterborough Hospitals NHS Trust	Full	4.1	It would be helpful to recognise that in some cases patients and carers may not wish to receive information and this should be assessed on an individual basis and patient and carer wishes respected.	This point is covered in the text.
Pfizer Limited			This organisation was approached but did not respond.	
Prodigy			This organisation was approached but did not respond.	
Prostate Cancer Charity, The	Full	general	Overall, this guidance a great improvement on the first document. Previous comments have been taken into consideration. However, there are still difficulties	Thank you.

			with it. 1. Its size 2. The resource implications of the guidelines – Will the Trusts etc have the resources to meet them? If no extra central support is forthcoming, and resources are allocated to meet the guidelines' recommendations, according to local need, the users' voice must be paramount in defining the priorities. 3. There seems to be a limited expectation of the role of the voluntary sector 4. As cancer is seen as a health problem, rather than something people need help to live with, the tone of the document is still 'health professional' rather than 'person with cancer' orientated.	Comment noted but Editorial Board decision to retain the Guidance in its current form. Funding issues are outside the scope of the Guidance. New text inserted stressing the relationship between NHS and voluntary sector providers. The Developers consider that the role of the person with cancer and their and carers have been given prominence throughout the Guidance.
Prostate Cancer Charity, The	Full	General	The document is huge. Its size is a liability, and could render the document almost useless. Who will have time to read it? As the Guidelines have to be practical, the size, as you already suspect, is a problem. Its size is due to two things a) there is a lot of information and b) the style is needlessly wordy. I realise that whoever wrote it has put a lot of work into the task. I apologise for reacting so strongly against the written style, but it is full of redundant phrases. As an experiment I have copied the random phrases and edited them to demonstrate how much	See above.

			redundant information is included. I suggest a ruthless re-edit of the whole document is required. Page 12-13 A. Aim of this Guidance I1 The aim of this Guidance is to define the service models needed to ensure that patients with cancer and their families and carers receive the support they need to help them cope with cancer and its treatment. Services may be needed at all stages of the patient's illness, from before diagnosis to the end of life and, for families and carers, into bereavement. B. Rationale for developing the Guidance Burden of cancer I2 Cancer affects a very large number of people each year in England and Wales. Around a quarter of a million people are diagnosed with cancer, many of whom have family, close friends and carers who are also affected by the diagnosis. An even larger number of people, probably well over a million, develop symptoms that could be due to cancer. These people and their families and carers may suffer significant levels of anxiety before they can be reassured that they do not have the disease. 164 words. My edit: A. Aim of this Guidance I1 This Guidance defines the service models to ensure that patients with cancer and their families and carers receive the support they need throughout the patient's illness, and families and carers are supported into bereavement.	

			B. Rationale for developing the Guidance Burden of cancer I2 Around a quarter of a million people are diagnosed with cancer, many of whom have family, close friends and carers who are also affected by the diagnosis. Well over a million other people develop symptoms that could be due to cancer. These people and their families and carers also need support. 101 words.	
Prostate Cancer Charity, The	Full	Executive summary ES16 Key Recommendation 2	This is also too long and wordy, though the format with Key Recommendations makes sense. (The word 'Key' may be redundant).	Comment noted.
Prostate Cancer Charity, The	Full	General	These guidelines are a 'statement of intent' or an 'aspiration' and one hopes work will begin immediately in all Trusts to deliver the services described. However, if they are not adequately resourced progress will not be possible, no matter how committed the Health Professionals on the ground are to the cause. Health Professionals may well be demoralised rather than empowered by the Guidelines, wanting to do as suggested but without the staff, time or money to do so.	The Guidance identifies service configurations to be worked towards achieving – it is acknowledged that this may take time and acknowledged that this will need to be based on local need and local variables. Funding issues are outside the scope of the Guidance.
Prostate Cancer Charity, The	Full	General	It is not clear that the potential role of the voluntary sector is fully appreciated. The voluntary sector makes a considerable contribution to palliative and supportive care for people affected by cancer. There	New paragraph inserted, recognising that NHS will want to work in partnership with voluntary sector to implement recommendations.

			is consistent mention of local self-support groups but that is not the only form of help available. Not all services are organised locally and not all support services are led and delivered by people with cancer. The Prostate Cancer Charity would like to see a less restricted view of ‘support’, otherwise the Guidelines themselves will be guilty of compounding a basic problem - which is that people do not know what sources of help could be available. We run a national Helpline and website for support and information, and provide written information free of charge to individuals – but we seem to be excluded by the way the guidelines are presented. Through our website we are an Information Partner of NHS Direct Online and we believe we offer something that is mainstream, highly regarded – and useful!	
Prostate Cancer Charity, The	Full	General	It is much improved and modified, though I still feel that the Health Professional point of view informs the tone of the document. This means that people with cancer are still peripheral, though not as obviously so as in the first version. It also tends to suggest that Health Professionals are in charge rather than in partnership. The tone obscures the wider social context of cancer, which is where the carers and people with cancer experience it, and substitutes a ‘health context’, which is where Health Professionals come across it. The word ‘signposting’ does not appear often enough in this document and we think that Health Professionals should be encouraged to ‘signpost’ people with cancer to all kinds of places which could	Comments noted.

			help. NHS staff needs to be reassured that this is commonsense, not a dereliction of care.	
Prostate Cancer Charity, The	Full	General	I can only recall one brief reference to ‘formats’ for information. I think this should be spelled out in full at least one. This ensures that all possible media are considered – audio, video, face to face etc. All ‘hard to reach’ groups should also be specifically acknowledged; people with learning difficulties, physical impairments, the frail elderly etc. They all have needs for support through information and communication and it would help to have them specifically acknowledged at least once.	The Developers consider that this has been covered in the text. The standards, which will derive from the Guidance, may address these issues and will ensure that this is monitored. Text has been included in the Guidance acknowledging the needs of special groups of patients and carers.
Prostate Cancer Charity, The	Full	General	There are no specific references to elderly people and their needs for palliative and supportive care. This may be a significant omission. Cancer is, generally speaking, a disease of later life. Older people may need more time to express their needs or may be less active partners in their own care, which puts them at risk of not having their supportive and palliative care needs met in a timely fashion, particularly by a service pushed for time and resources. Similarly, many men may need special acknowledgement of their palliative and support needs as they are often late to ‘present’ for all kinds of services. A quarter of 80 year old men live alone for example, and so they may need more active engagement by ‘services’ to ensure their needs are met. A truly ‘user centred’ service should not need to have ‘special needs groups’ identified but those people with cancer who fall through the net will	New text inserted referring to the needs of groups such as the elderly and also men.

			continue to do so in a resource limited NHS, when their ‘voices’ are not easily heard.	
Prostate Cancer Charity, The	Full	ES21	There are other wider issues that fall under this banner which should be acknowledged. Other financial advice is also required, and Health Professionals should become proficient in signposting to sources of good information on this. They DO NOT have to train as financial advisers. Insurance for holidays for example is not a health issue but it is a social one which affects people with cancer.	Wider issues are referred to in the section – the Guidance is suggesting signposting and not training.
Prostate Cancer Charity, The	Full	I3	The list of what people with cancer and carers need should be the template for any summary document that you produce for the Guidelines. In addition to:	Comments noted – and have been used as the basis of the Information for the Public version of the Guidance.
Prostate Cancer Charity, The	Full	I6	The section titled ‘What needs to be done?’ - though as I mentioned before, there are more voluntary sector services than just self help and support groups. National helplines, for example.	See above.
Prostate Cancer Charity, The	Full	I20	Do you include helpline nurses as ‘cancer information nurses’ as specialists in supportive or palliative care? If you do – good! If you do not, please can you add them as specialists?	Yes, they are included.
Prostate Cancer Charity, The	Full	I47	As a statement of fact this is probably true. However, there needs to be a set of key standards that have to be met, making sure that, even if a postcode lottery of supportive care does exist, people with cancer can be assured of a minimum acceptable level of supportive and palliative care that will be available to them.	Comment noted.

Prostate Cancer Charity, The	Full	I48	If this pragmatic approach is to be adopted it is imperative that systematic input from carers and people with cancer is gathered on their priorities for improving local supportive and palliative care services.	Comment noted.
Prostate Cancer Charity, The	Full	2.19	We hope that this includes, rather than excludes, service delivering organisations such as The Prostate Cancer Charity which happen to be based nationally.	Yes, they are included.
Prostate Cancer Charity, The	Full	2.24	Similarly to the above point, we hope that this does includes, rather than excludes, service delivering organisations such as The Prostate Cancer Charity which happen to be based nationally.	See above.
Prostate Cancer Charity, The	Full	4.20	Thank you! Our like is mentioned here!	Comment noted.
Prostate Cancer Charity, The	Full	5.35	We recognise this 'survivorship 'issue from our helpline work here. Please mention national voluntary sector helplines here, too.	Text altered to include helpline services.
Prostate Cancer Charity, The	Full	10.1	"Mobilising, speaking, eating, drinking and swallowing" This is an example of the Health Professional tone of which I complain. These are all conspicuous problems in which Health Professionals can expect to play a role. However, you have missed out SEX! Mention sex! This is a huge issue for men and women of all ages, during and after treatment for cancer. It is both a 'relationship' issue and also a 'treatment' issue. And it is tricky to bring up in conversation. Both health professionals and people recovering from cancer may be ambivalent about mentioning it. In particular, as we are a male cancer charity, we	Sex and psychosexual issues now included. Thank you for bringing its absence to our attention!

			emphasise erectile dysfunction and impotence – both common consequences of treatment for prostate cancer. And, naturally, this has a profound effect on their partners – who are usually their carers too. This a major ‘survivorship’ issue as mentioned in the previous point.	
Prostate Cancer Charity, The	Full	10.17	Who looks after ‘sex’ and ‘expressing sexuality’?	See above – text altered.
Prostate Cancer Charity, The	Full	12.2	We support the ‘all inclusive’ definition of family and carer, acknowledging the diversity of social contexts within which people with cancer live.	Comment noted.
Prostate Cancer Charity, The	Full	12.4	Do not forget that many voluntary sector national Helplines will offer support to carers as well.	Comment noted.
Prostate Cancer Charity, The	Full	12.52	Voluntary sector national Helplines should be signposted for people with cancer and their carers in rural areas, because self help and support groups might be difficult to access.	Text altered in line with this comment.
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			This organisation was approached but did not respond.	
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)	Full	General	Although the document specifically identifies that it is for adults, the majority of the principles and recommendations are applicable to paediatric palliative care services. Also there appears to be no evidence that the document identifies the needs of the adolescent and young adult (Age 16 and above) many of whom may be cared for by adult services. This group do have some specific needs in addition to adults.	NICE is currently compiling guidance on the care of children and young people with cancer. It will cover children (from birth) and young people in their late teens and early twenties who have cancer. Details can be found on the NICE website.
Royal College of Nursing (RCN)	Full	General	Although alluded to in several sections, perhaps a specific section that looked at the specific needs of health care professionals who work primarily in palliative and terminal care would have been relevant and appropriate.	Comment noted - but decision made not to alter text as suggested. This issue is covered in certain sections of the Guidance.
Royal College of Nursing (RCN)	Full	KR 9	To fulfil recommendation 9, commissioners and providers of cancer services will need to ensure comprehensive provision of specialist clinical psychology and psychiatry services to meet the standards.	Comment noted.
Royal College of Nursing (RCN)	Full	KR 9	Specialist palliative care advice available 24 hours should include 'for both health care professionals and patients and carers'.	A decision was taken at the Editorial Board meeting that the recommendation should suggest that this level of advice/support should be available to health care professionals as a minimum – anything more than this would be for local implementation.
Royal College of Nursing (RCN)	Full	116	Could include DNR orders.	The Developers consider that this is too specific to be included.
Royal College of	Full	120	Add CNS for children and young people with cancer.	See comment above. The scope of this Guidance is for

Nursing (RCN)				adults with cancer.
Royal College of Nursing (RCN)	Full	126	Should also include New Opportunities funding for palliative care and paediatric palliative care.	This is a list of examples. Paediatrics is not within the scope of the Guidance.
Royal College of Nursing (RCN)	Full	Box 1.1	Scope should include commissioning services for children and young people, as the majority of the issues/areas addressed are entirely relevant to this client group in developing services.	Please see comments above regarding scope.
Royal College of Nursing (RCN)	Full	C2 1.13 1.14 1.16	Could include the potential benefits of patient family held records, to facilitate documentation of assessment and minimise the need for repeated assessment.	This is highlighted in the evidence section.
Royal College of Nursing (RCN)	Full	C4 1.22	Patients also need to be informed as to who/how will be meeting their identified needs.	Comment noted – but decision made not to alter text.
Royal College of Nursing (RCN)		1.25	Teams ‘may wish’ - change to should. The key worker role is invaluable in the coordination of often complex care.	Decision taken at Editorial Board meeting not to alter recommendation regarding the key worker – however, text inserted identifying the need to evaluate this role to identify how it might best be used to facilitate patient care.
Royal College of Nursing (RCN)	Full	3.11	Could include in a setting of their choice ie. At home or in hospital.	Comment noted – text not altered.
Royal College of Nursing (RCN)	Full	5.8	Should state psychological needs of staff who are caring for patients and carers…. Are identified and met. There appears to be no further detail in this section or the whole of the document specifically aimed at meeting the needs of the health care professionals working in palliative care.	This is covered in the text.

Royal College of Nursing (RCN)	Full	6.16	Should include support to maintain mainstream and further education for young people and adults.	See comment s regarding scope.
Royal College of Nursing (RCN)	Full	6.16	Respite care should also be available in the patient's own home.	This is not excluded in the Guidance.
Royal College of Nursing (RCN)	Full	6.18	Joint assessment would seem imperative in line with coordination and communication sections.	Comment noted – but decision taken not to alter text.
Royal College of Nursing (RCN)	Full	6.21	Should also include citizen's advice and welfare benefit services.	Comment noted – but decision taken not to alter text.
Royal College of Nursing (RCN)	Full	8.24	24 hour support should be available for all patients including children and young people. Children's community nurses should be available in every area and provide 24 hour support in terminal care.	See comments regarding scope.
Royal College of Nursing (RCN)	Full	8.36	Individual palliative care drug boxes for children's palliative care at home have been extremely effective.	Comment noted.
Royal College of Nursing (RCN)	Full	8.49 & 8.50	In contrast the Paediatric Oncology outreach model has facilitated an average of 75% home deaths, for all children with cancer.	Comment noted.
Royal College of Nursing (RCN)	Full	12.29	Information written/verbal or both	This is implied.
Royal College of Nursing (RCN)	Full	12.30	Component 2: many families/carers may welcome the opportunity to reflect with the health care professionals involved in the care of their relative, particularly terminal care.	Comment noted.
Royal College of Paediatrics and Child Health			This organisation was approached but did not respond.	

Royal College of Physicians of London	All	General	While in general this guidance will be very helpful to commissioners of specialist palliative care, the lack of quantitative guidance on the services needed per head of resident population or in relation to specific indices of mortality means that the guidance will not be as useful as hoped in remedying inequities in service provision across the country and ending post code provision of services.	This point is understood – but the implementation of the Guidance is the responsibility of the Department of Health and National Assembly of Wales – through their respective NHS organisations. This is in line with other site-specific cancer Guidance. All the Cancer Networks will however be expected to assess their current levels of service against the recommendations in the Guidance – and prioritise according to that assessment. This assessment should take note of all the local variables that may impact on the manner in which services are configured and delivered.
Royal College of Physicians of London	Full	9.15	The lack of quantitative data is a particular problem in relation to this section.	This point is covered in the over view section.
Royal College of Physicians of London	Full	9.21	The lack of quantitative data is a particular problem in relation to this section.	The evidence base for this is not developed and further evaluation is needed. The next version of the Guidance will include a section on the needs for research in certain areas to support service configurations.
Royal College of Physicians of London	Full	9.31	The lack of quantitative data is a particular problem in relation to this section.	See comment above.
Royal College of Physicians of London	Full guidance	General	It is acknowledged in the introduction that the resource implications in terms of people and finance make this an aspirational document. This is true in relation to the supportive and palliative care needs of cancer patients, but equity will also require a similar intensity of resources for those with advanced non-malignant disease. The point is made in the document, but it needs more emphasis.	The scope of the Guidance is to identify service configurations for people with cancer and their carers. Non-malignant disease is therefore not within the scope. There is considerable interest however to use the Guidance for this group of patients and their carers where appropriate.

Royal College of Physicians of London	Full guidance	8.20	It is suggested that eligibility criteria for specialist palliative care should be developed at the level of the cancer network. This will result in significant duplication of effort. Could not a hierarchy of prioritisation be developed at national level? Local resources and decision making could then determine how many referrals could be accepted.	This might be an issue for national bodies to take up as a result of the recommendations in the Guidance.
Royal College of Physicians of London	Full guidance	8.21	It is suggested that cancer network-wide protocols and guidelines be developed and implemented in relation to symptom control and palliative interventions. Many such sets of guidelines already exist. There is widespread consensus around the appropriate first line management of most symptoms. To avoid duplication of effort, would it not be more cost-effective for such guidelines to be developed at national level and implemented locally?	See comment above.
Royal College of Physicians of London	Full guidance Economic review	8.24	While welcoming recognition of the need for medical and nursing services 24 hours a day, it would be helpful if the workforce implications of various models of care to meet this objective were explicitly stated. Workforce constraints, as much as financial constraints, often limit the provision of such services currently and are likely to do so into the foreseeable future. We would also challenge the model in the Economic Review which assumes that medical services can be available 24 hours a day at no additional cost. While pioneers of such services have often given their time for nothing, when such services are routinised there are significant additional costs incurred. This is likely to be exacerbated by the implementation of the European Working Time Directive. The document is also inconsistent. Some sections	Additional details have been included in the Economic review. The costs of medical cover are being reviewed. They will be dependent on local circumstances and the assumptions used to estimate costs will be explicitly stated.

			refer to the need for medical and nursing services 24 hours a day. Others merely refer to the 24 hour availability of specialist advice. These have different resource and workforce implications. It would be helpful if this could be clarified.	The inconsistencies have been ironed out and the language strengthened.
Royal College of Physicians of London	Full guidance	8.26	Electronic information transfer is the obvious solution to the need to make patient-specific data available to several providers of care both in working hours and out of hours. The transfer of patient-identifiable data between providers electronically is currently constrained, often to the detriment of good clinical care, by the requirements of the Data Protection legislation. This is insufficiently recognised in this guidance.	This is covered in the sections on information and co-ordination of care.
Royal College of Physicians of London	Full guidance	8.29	This paragraph is vague, not evidence-based and not thought through. People die in a variety of generalist settings throughout hospitals. Many do not have specialist palliative care needs. Hospital specialist palliative care teams should continuously assess the palliative care training needs of hospital healthcare teams caring for dying patients and seek to provide education and training appropriate to the needs identified. A number of educational and training models are employed by hospital specialist palliative care teams, but further research and examples of good practice, in this area are required. The aim should be to empower staff working in generalist settings, rather than to turn dying into a specialist area. Since it is uncommon for hospital wards to employ staff with post-registration training in palliative care, the implications of this objective would be a significant increase in workload for hospital specialist	The recommendation advises that the individual should have experience /training in palliative care (not necessarily specialist palliative care). The evidence base for this is not developed and further evaluation is needed. Changes have also been made to the text regarding ‘informing the ‘specialist team rather than advising on management and basing their interventions on a needs assessment.

			palliative care teams. (As an example, in one acute teaching Trust 4500 people die each year. Only 1500 are referred to the hospital specialist palliative care team, and only 300 die while on the team's caseload.) This should be explicitly recognised. It would be helpful if the nature of the recognisable post-registration training were made more explicit – for instance, would an in-house training course provided to ward staff by the hospital palliative care team be acceptable?	This might be an issue for local implementation as a part of training for generalist staff.
Royal College of Physicians of London	Full guidance	9.4	We welcome the recognition given to the importance of acute hospitals having full multi-professional palliative care teams, and the implication that commissioners will be expected to fund the creation of such teams in all acute hospitals.	Comment noted.
Royal College of Physicians of London	Full guidance	9.5	We welcome recognition of the workload imposed by the support of patients in care homes with palliative care needs. The remainder of the paragraph suggests the main deficit is in care out of hours; there should be greater emphasis on the need for additional staffing in order to meet the needs of patients during working hours, and the training needs of staff in care homes.	Text altered.
Royal College of Physicians of London	Full guidance	9.21	This section in particular raises many issues. On what basis should these models be reviewed? Are there any indicative numbers? Are there any models of the impact of development of one type of service, on the need for another? Practicalities of staff recruitment and economic evaluation of the models are also pertinent here.	There is no evidence available on which to define numbers for service components. This will need to be determined locally according to need, and appropriate services made available.
Royal College of Physicians of	Full guidance	9.26	The list should include specialist pharmacy input.	Text altered to include this point.

London				
Royal College of Physicians of London	Full	9.34	The list should include specialist pharmacy input.	Text altered to include this point.
Royal College of Physicians of London	Full	9.26	The last bullet point should be reworded to “anaesthetists with expertise in nerve blocking and neuromodulation techniques”.	Text altered as suggested.
Royal College of Physicians of London	Full	9.34	The last bullet point should be reworded to “anaesthetists with expertise in nerve blocking and neuromodulation techniques”.	Text altered as suggested.
Royal College of Physicians of London	Full	9.25	While this section alludes to “palliative medicine consultants” in the plural, there should be specific reference to the undesirability of any service or team being staffed by a single-handed consultant and the need to ensure appropriate cross-cover. There should also be specific recognition that many teams and services are still headed by a non-consultant non-training grade doctor without real consultant support. This is unacceptable for a specialist service.	This point was discussed at an Editorial Board meeting and a decision taken that the Guidance will stress the need for local arrangements to be in place, as an interim measure, to provide specialist consultant input and advice where there is no specialist in palliative medicine available. The text will also stress the undesirability of single-handed consultant services.
Royal College of Physicians of London	Full	10.21	It seems excessive to suggest that AHP assessment is necessary at every outpatient attendance. AHPs are likely to remain a scarce resource for the foreseeable future and need to be appropriately targeted.	Text altered.
Royal College of Physicians of London	Full	12.41	Should include the fact that the patient’s permission should be sought.	This is a précis of research evidence.
Royal College of Psychiatrists			This organisation was approached but did not respond.	
Royal College of			This organisation was approached but did not	

Radiologists			respond.	
Royal College of Speech and Language Therapists		General - 15	We recommend adding allied health professionals to this group – since for example SLTs have a role as listed below To assess, diagnose and treat speech, voice, language and swallowing difficulties, at all stages throughout the patient's cancer journey and in partnership with patients and carers. To hold a key role in the specialist rehabilitation of the head & neck cancer patient and to participate in combined head and neck cancer clinics. Patient and carers should be seen pre treatment if speech, voice or swallowing difficulties are anticipated. The consequences and side effects of the cancer treatment should be discussed in-depth. The speech & language therapist has a key role in the selection of voice prostheses and management of surgical voice rehabilitation following laryngectomy. The speech and language therapist has a role in assessing, managing and offering appropriate information about the choices and risks facing patients with swallowing difficulties. Management is discussed with patient, carer and multidisciplinary team. The speech & language therapist advises on communication difficulties through therapeutic/compensatory strategies, communication aids, modifying the environment or training carers in their communication style. The speech and language therapist plays an	The Developers are not quite sure to what part of the Guidance this comment refers to.

			important role in providing specialist support and advice to generalist speech and language therapists once a cancer patient has finished treatment and has been transferred out into the community. However, generally the care continues to be co-ordinated by the specialist speech and language therapist for oncology.	
Royal College of Speech and Language Therapists	Full	I - 21	Whilst we agree in principle with the description of generalist and specialists clinicians, our concern is that speech and language therapists may work part time in different areas whilst being specialists in 1 or more of these areas.	Comment noted.
Royal College of Speech and Language Therapists	Full	I – 28, Box I 1	We welcome the inclusive nature of the document ie. Care needs to address the needs of all people involved ie. Patient, family, including children.	Comment noted with thanks.
Royal College of Speech and Language Therapists		3-21, 3.13	We would suggest that health care interpreters are also trained in communicating complex and distressing information if they are to be used as interpreters in these situations.	This is not within the scope of the Guidance – but might be an issue for local implementation.
Royal College of Speech and Language Therapists		4.18 – 4.23	See above comments.	Thank you.
Royal College of Speech and Language Therapists		9.26	We welcome the multidisciplinary focus here since and speech and language therapy (appropriately skilled and experience) would be needed for patients experiencing swallowing difficulties.	Comment noted.
Royal College of Speech and Language		Table 10.1	We welcome this table for its clarity: it clearly shows the different levels of intervention and is thus transparent.	Comment noted with thanks.

Therapists			Our concern would be to ensure, that speech and language therapists and assistants are appropriately trained and experienced to deliver intervention, at whatever level, safely.	
Royal College of Surgeons of England			The RCS has replied to NICE stating that it does not wish you comment on this particular guideline. Is there any chance that you could remove me from the emails where I have informed you that the RCS will not be commenting on?	Thank you. We will remove you from the database where appropriate.
Royal Pharmaceutical Society of Great Britain			This organisation was approached but did not respond.	
Sargent Cancer Care for Children			This organisation was approached but did not respond.	
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)			This organisation was approached but did not respond.	
Society and College of	All	General	Overall this guidance will be very helpful to both specialists and generalists in cancer care. It is	Comment noted with thanks.

Radiographers			comprehensive in relation to the range of supportive and palliative services required.	
Society and College of Radiographers	All	General	Therefore it should support commissioners and providers in the design of service delivery models and should also be helpful to workforce development confederations, education providers and professional associations in clarifying the education and training and needs. We endorse all of the recommendations made.	Comment noted with thanks.
Society and College of Radiographers	All	General	It is our view that sufficient information is given to justify the recommendations. Although dense it is readable and easy to follow.	Comment noted with thanks.
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.	
Wessex Cancer Trust			This organisation was approached but did not respond.	
Worchestershire Acute Hospitals NHS Trust	Full	general	The Worcestershire Acute Hospitals Trust is glad to be given the opportunity to respond in this consultation. Overall the guidance will be very helpful to commissioners and providers in planning and delivering services. These are some questions and comments raised by professionals working in this Trust.	Comments noted. Thank you.
Worchestershire Acute Hospitals NHS Trust	Full	ES18	Key recommendation 5: would you specify what 'advanced level training' means	This is currently being assessed as a part of a pilot project in communication skills. This level of detail would not be appropriate in the key recommendation section.
Worchestershire Acute Hospitals NHS Trust	Full	151	Commissioners ultimately have responsibility?	Commissioners are identified as being a part of a cancer network.
Worchestershire Acute Hospitals NHS Trust	Full	1.10	Is it the Strategic Health Authority or Cancer Network who take responsibility for planning/monitoring Service Delivery Plans?	The Guidance suggests that both bodies need to work together.
Worchestershire Acute Hospitals NHS Trust	Full	3.13	'Enhanced skills' from further recognised training.	Text altered – but not quite as suggested.
Worchestershire Acute Hospitals NHS Trust	Full	3.22	We agree that children should not provide interpreting services for parents, but even in rare circumstances, the NSF for Children's Services forbids this.	Text deleted.

Worchestershire Acute Hospitals NHS Trust	Full	4.7	BACUP leaflets are purchased in this Trust. Will the commissioners be expected to fund information materials?	There is an expectation that they will.
Worchestershire Acute Hospitals NHS Trust	Full	5.12	Emergency psychological care will be a challenge to most organisations. Is it practical?	It is understood that this will be a challenge – but the Guidance recommends that this is achieved.
Worchestershire Acute Hospitals NHS Trust	Full	5.16 page	Whilst this model of psychological support is commendable, it is also probably undeliverable.	The Guidance provides suggested frameworks for service configuration which networks will need to work towards delivering – such delivery will be based on a needs assessment taking local variables into account.
Worchestershire Acute Hospitals NHS Trust	Full	6.17	The community equipment provision is being reviewed by NSF for Older People - there needs to be collaboration rather than duplication.	This is covered in a footnote that has been inserted into the text.
Worchestershire Acute Hospitals NHS Trust	Full	7.0	The chaplains of this Acute Trust welcome the place that spiritual care has, and the emphasis placed on it, in this document.	Comment noted.
Worchestershire Acute Hospitals NHS Trust	Full	7.2	Add 'Who am I now?' There is often confusion about the 'self' with a grieving process for the former 'self'	Text altered in line with suggestion.
Worchestershire Acute Hospitals NHS Trust	Full	7.3	Another bullet point: ♦ changes in relationships with significant others.	Bullet point added as requested.
Worchestershire Acute Hospitals NHS Trust	Full	7.4	're-affirm, abandon or initiate an exploration into them according…'	Text altered as requested.
Worchestershire Acute Hospitals NHS Trust	Full	7.6	Omit 'broadly'. '………re-establish hope, but can include aspects of fear, failure and uncertainty according to how their 'god' is perceived.'	Text altered as suggested.

Worchestershire Acute Hospitals NHS Trust	Full	7.7	We should like to emphasise the first sentence. bullet point two: omit 'in a broad way' Bullet point four: 'social, emotional and clinical care'. We believe that clinical care has a spiritual dimension too.	Text not altered but clinical component picked up in another paragraph in this section.
Worchestershire Acute Hospitals NHS Trust	Full	7.8	'..and in response to clinical care, inter and intra-personal… 'This means that an ongoing, accurate…'	See above – 'accurate' added into text as suggested.
Worchestershire Acute Hospitals NHS Trust	Full	7.11	What is meant by 'the whole team'? By definition, the palliative care team includes the chaplain. One of the results of the Information Commissioners decision on the Data Protection Act is that chaplains are excluded from the Care Team. In many areas chaplains have to leave meetings when clinical issues are discussed. Bullet three ♦ 'patients may be unaware of their choices in people to whom….'	Please refer to specialist palliative care section. 'Choice' added into text.
Worchestershire Acute Hospitals NHS Trust	Full	7.12	There is the need for Trusts to commit themselves to the importance of spiritual education for staff.	This is an introductory statement rather than a recommendation.
Worchestershire Acute Hospitals NHS Trust	Full	7.16	Who will be doing the scrutinising and monitoring?	This is outside the scope of the Guidance.
Worchestershire Acute Hospitals NHS Trust	Full	7.17	How does this fit in with 7.11 above?	Text altered in line with comment.
Worchestershire	Full	7.23	Spiritual care needs to have a structure within the	Developers consider that if the chaplain is working as

Acute Hospitals NHS Trust			team otherwise it tends to be forgotten.	a part of the multidisciplinary team this should provide a structure.
Worchestershire Acute Hospitals NHS Trust	Full	7.33	Caldicott standards suggest that chaplains should not have access to patients or their notes that patients need to consent in advance, therefore, is this possible?	New text added to cover this (complex) point.
Worchestershire Acute Hospitals NHS Trust	Full	9.28	Whilst acknowledging the minimum requirement of 24 hour availability of telephone advice, does 'normal working hours' mean working full days seven days per week? On-call availability should be sufficient at week-ends, with the possibility of bed-side assessment if required. Small teams could make this undeliverable.	Text altered throughout Guidance to ensure clarity.
Worchestershire Acute Hospitals NHS Trust	Full	9.32	Networks cannot set rigid admission criteria, only guidelines. Clinical judgement and local organisational constraints will apply.	Comment noted.
Macmillian, Breakthrough Breast cancer, Breast Cancer care, Cancer BACUP, Help the Hospices, Marie Curie Cancer Care, Prostate Cancer Charity – Joint Response			As organisations reflecting the views and priorities of users of supportive and palliative care services, we would like to make a number of comments on the 3rd draft of the NICE Supportive and Palliative Care Guidance.	Thank you for your comments.
Macmillian, Breakthrough Breast cancer, Breast Cancer care, Cancer			Tone and style of guidance • We welcome the fact that NICE has listened to concerns of users and stakeholders and taken many of these on board in this new draft. We	Comment noted, thank you.

BACUP, Help the Hospices, Marie Curie Cancer Care, Prostate Cancer Charity – Joint Response			welcome the change in tone in sections previously included in Part A to make the document less professional and more patient centred. • However, we are still concerned that the document remains too professionally focused, partly because the structure is framed around professional specialities but also because insufficient emphasis continues to be given to the skills and knowledge of patients and carers and the benefits of peer support. • As we noted in our last joint response, the guidance remains far too long and repetitive to be easy to use.	The Developers consider that they have emphasised the skills of patients, carers and peer support. However there is insufficient evidence on peer support services. Decision made at Editorial Board meeting to retain structure of Guidance as it stands.
Macmillian, Breakthrough Breast cancer, Breast Cancer care, Cancer BACUP, Help the Hospices, Marie Curie Cancer Care, Prostate Cancer Charity – Joint Response			Implementation of the Guidance • We are concerned that the Guidance is too NHS-focused referring too little to other providers who will have a part to play in implementing guidance such as local authorities and the voluntary sector. • As we stated in our previous joint response, if the benefits of the Guidance are to be experienced by patients the implementation must be adequately resourced, through the Departments of Health in England and Wales and through Local Authorities' Social Services Departments. We recommend that NICE makes these implications clear to the relevant Government departments and Commissioners of Cancer Services and seeks assurance that adequate resources will be made available. • The guidance will take time to be implemented	New text inserted regarding the need for NHS providers to work with the voluntary sector to implement recommendations. This is outside the scope of the Guidance.

			because of these implications for the workforce. We recommend that NICE considers, through consultation with stakeholders, a prioritisation mechanism to enable implementation to be phased. We also recommend that there be more voluntary sector representation on Workforce Development Confederations to ensure the voluntary sector is fully involved in working through the implications for the workforce.	This is the responsibility of the Workforce Development Confederations.
			• Monitoring of implementation will rely on standards. We are concerned about the current process of setting standards linked to the Guidance because of the lack of user involvement and the main focus of the standards on secondary care. We recommend that the process for developing standards is made more open and transparent, with user and voluntary sector involvement and consultation on the standards at an early stage.	This is outside the scope of the Guidance.
			• The Guidance recommends significant increases in specialised nurses and social workers. At a time when the total workforce is declining, NICE must consider the implications of its recommendations for training, recruitment and retention and how different ways of working might help providers to implement the recommendations.	This is the responsibility of the Workforce Development Confederations.
			• We believe that there is a need to make more explicit the links between supportive and palliative care and other care packages, such as continuing care and intermediate care, otherwise there is a risk of different assessment processes and some people affected by cancer falling	Text altered to reflect this concern.

			through the gap.	
Macmillian, Breakthrough Breast cancer, Breast Cancer care, Cancer BACUP, Help the Hospices, Marie Curie Cancer Care, Prostate Cancer Charity – Joint Response			Information • We welcome the emphasis in the Guidance on the need to address inequities in access to information and to include information as an integral aspect of patient care. • We recommend that the information section of the guidance contain a definition of high quality information (as per the one provided in Cancer Bacup's submission to NICE) and that this definition is referred to throughout the document. There should also be more emphasis on the need for high quality information, in a variety of formats, at all stages of the patient pathway.	Comment noted. Text altered to define what constitutes high quality information
Macmillian, Breakthrough Breast cancer, Breast Cancer care, Cancer BACUP, Help the Hospices, Marie Curie Cancer Care, Prostate Cancer Charity – Joint Response			Rehabilitation • We recommend that NICE also make reference to sex in the section on rehabilitation.	Text altered to include sex and psychosexual issues.
Macmillian, Breakthrough Breast cancer, Breast Cancer care, Cancer BACUP, Help the Hospices, Marie			Special groups • We recommend that NICE consider the needs of carers and families at all points during the document, alongside those of patients. While there are distinct needs, many are overlapping and part of considering the patient as a whole	This is reflected throughout the Guidance.

Curie Cancer Care, Prostate Cancer Charity – Joint Response			must include an automatic reference to the patient's normal informal support network. • We recommend that the needs of black and ethnic minority groups be regarded as part of mainstream services, not as an adjunct service and that special reference be given to the particular needs of older people.	Text has been inserted into the Guidance acknowledging the needs of certain groups of patients and carers. Comprehensive assessment of both the patient and carer - which underpins much of the recommendations in the Guidance, should elucidate any specific needs and preferences for care.
Macmillian, Breakthrough Breast cancer, Breast Cancer care, Cancer BACUP, Help the Hospices, Marie Curie Cancer Care, Prostate Cancer Charity – Joint Response			We look forward to continuing to be involved in the development of these guidelines which could make such a difference to the lives of people with cancer and other long-term conditions.	Thank you.