

**Supportive and Palliative Care 1st Consultation – Stakeholder comments
date**

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Organisation/Individual name	Section Number	Comment	Response/Changes made by Guideline developers
Association for Palliative Medicine of Great Britain and Ireland		This organisation was approached but did not respond.	
Association of Surgeons of Great Britain and Ireland		This organisation was approached but did not respond.	
Beating Bowel Cancer		This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd		This organisation was approached but did not respond.	
Breakthrough Breast Cancer		See Joint response at end of table	
Breast Cancer Care	General	<p>Breast Cancer Care is the leading provider of breast cancer information and support across the UK.</p> <p>From our work at Breast Cancer Care we know how important supportive and palliative care services are for people with cancer. A diagnosis of cancer can have a huge impact on an individual's life and those of their family. The social, emotional and psychological support that patients and carers receive is as crucial in helping them through their cancer journey as medical treatment. Breast Cancer Care welcomes the production of these guidelines by NICE as an acknowledgement of the importance of supportive and palliative care.</p>	Thank you for your comments.
Breast Cancer Care	General	Breast Cancer Care hopes that targets and milestones will follow from this guidance to ensure that the recommendations given for supportive and palliative are implemented throughout the UK.	Work has commented on producing standards for the peer review process from the recommendations included in the Guidance.
Breast Cancer	General	We would like to thank NICE for giving us the opportunity to	Thank you

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Care		comment on these guidelines and look forward to continuing to be involved in the production of these guidelines.	
Breast Cancer Care		<p>Breast Cancer Care's main areas of expertise are the provision of information and support services to people affected by breast cancer. Our main observation about this guidance is its failure to acknowledge the contribution of organisations like Breast Cancer Care in the provision of supportive and palliative care. The voluntary sector provides a wide range of unique services that often form an integral part of the supportive care received by cancer patients.</p> <p>Our primary concern is that the guidance does not contain enough information about the alternative sources of support provided by voluntary organisations. For example the helpline at Breast Cancer Care receives 16,000 calls a year from people affected by breast cancer. The helpline gives people the opportunity to discuss treatment options, fears, anxieties, and side effects of treatment helping them to gain greater understanding and clarity of what they have been told by health professionals. In 2001 Breast Cancer Care carried out an evaluation of our helpline by surveying of callers. The key findings are given below and clearly highlight the importance of the helpline:</p> <p>People commented that they had originally rung the helpline for written information but were very pleased to also receive emotional support.</p> <p>Callers felt empowered by the information and knowledge provided and were able to use the information to help them cope better with their diagnosis and feel more in control of the</p>	<p>The roles of voluntary sector and self-help groups are included in the sections covering co-ordination of care, psychological support and services for families and carers.</p>

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		<p>situation.</p> <p>Callers commented on the merit of discussing their situation and feelings with someone they did not know personally.</p> <p>Callers appreciated receiving information from the helpline that was complementary or extra to what they had received from their hospital or health professional involved in their care.</p> <p>Callers commented that they felt more able to ask questions about their treatment and better understand the different treatment options available after calling the helpline.</p> <p>Some callers commented that they wished they had been informed of the helpline earlier as it would of helped lessen their mental distress and made them feel less alone and unsupported.</p> <p>98% of respondents were satisfied with the service they received from the helpline.</p>	
Breast Cancer Care		<p>Individuals affected by breast cancer can find it incredibly useful to have the opportunity to share experiences with other individuals who have had breast cancer and experienced similar treatments. While the guidance mentions self-help groups it does not mention other opportunities for this type of support which can be very important if people have difficulty accessing support groups because of a rural location or ill health. Breast Cancer Care has developed several initiatives to overcome this problem. First is the peer support system which involves a network of 350 volunteers who have had breast cancer throughout the UK. Individuals who contact Breast Cancer Care</p>	See comment above.

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		<p>for advice can be matched to a volunteer who has had similar experiences and can offer support and advice. Often the volunteer may just have one phone call with an individual but it can help individuals to feel less isolated and alone. Breast Cancer Care also runs telephone support groups for younger women who may find that normal support groups do not contain anyone in their age group.</p>	
Breast Cancer Care		<p>The guidance should also mention the opportunities the Internet offers for support. The Breast Cancer Care website has chat forums, where people can share fears, anxieties, treatment experiences and offer each other advice and support. Since the chat forums were set up 1000 users have registered and the forums receive 5 or 6 new posts a day. The Internet can be very useful for people that have difficulty attending support groups or prefer an anonymous forum.</p> <p>To summarise, we feel that the guidance does not provide enough emphasis on more informal methods of psychological support such as helplines, chat forums and peer support. These can often be incredibly important because what people need is immediate support when they are feeling anxious, upset or panicked. More formal structures such as psychiatrists cannot fulfil this need, as people have to wait for appointments. The guidance should stress the importance of both informal and formal interventions, as timely and rapid intervention can be as important as in-depth psychological help. It is essential that health professionals are aware of these informal methods of support and pass this information on to patients.</p>	<p>While the Guidance does not identify specific websites/internet services the role of this as a source of information is acknowledged in the information section of the Guidance.</p> <p>See comments above.</p>
Breast Cancer Care	Resource Implications	Breast Cancer Care feels that the absence of the sections on measurement and resource implications from this draft has made it difficult to make a full assessment of the guidance.	Measurement will be included in the standards, which will derive from the Guidance and will be a part of the Manual of Cancer Services Standards.

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		It is clear that if the recommendations within this guidance were implemented we would see an enormous improvement in the quality of supportive and palliative care. However, without knowing how the recommendations from the guidance will be measured or resourced it is difficult to tell if the guidance can be implemented effectively. It is clear that much of the guidance cannot be implemented using current NHS resources and that dedicated funds need to be allocated.	Resource implications are now included in the combined document coming out for consultation in July/August 2003.
Breast Cancer Care	Resource Implications	It would be useful to know whether the resource implication sections will include consideration of how voluntary organisations can help fulfil many of the recommendations. The voluntary sector is an enormous potential resource and already delivers information, support and palliative care services. We believe voluntary organisations such as Breast Cancer Care have a key role to play in ensuring the successful implementation of this guidance - although not without adequate funding. It is not sensible to put added pressure on the NHS to develop supportive services if the voluntary sector is already providing them, what is needed is better co-ordination between the statutory and voluntary sectors.	The economic review has been completed – and this has been included. It does not provide a detailed review of the respective contributions of the voluntary and statutory sectors – but further consideration will be given to the possible options for supporting self-help and support groups and other organisations contributing to service provision.
Breast Cancer Care		The guidance suggests that standards will emerge from the recommendations and be incorporated into the 'Manual of Cancer Services Standards in England'. We feel it is essential that recommendations do become standards if the guidance is to be implemented. The NHS is already overstretched with competing priorities and without clear timelines and targets the guidance may not be prioritised. As the guidelines contain such a large number of recommendations it might also be useful to have these prioritised. Implementation of all the recommendations cannot happen at once and commissioners	See above – this work is underway and will be a part of the peer review process to identify implementation and achievement of the recommendations.

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		<p>need guidance on where to begin so that they are able to make changes gradually. We believe timescales and targets would make it easier to monitor implementation of the guidance.</p>	
Breast Cancer Care	Clarity of the involvement of the voluntary sector in the provision of information, supportive and palliative care services	<p>The voluntary sector is a key provider of information, support and palliative care services for people with cancer, and therefore is very well informed about what individuals affected by cancer want and need from these services. We feel that the guidance does not do enough to emphasise the importance of the voluntary sector in providing many of the services listed. It needs to be more specific about which services the voluntary sector can provide. This is concerning because the document is aimed at commissioners and we do not want them to overlook the voluntary sector, especially as it has some specialist areas of expertise.</p> <p>The guidelines often describe care provided by ‘health and social care professionals’. Often this seems to imply only professionals within the NHS or social services will be involved in delivering these services where as sometimes a voluntary organisation may also fulfil this role. However, in reality voluntary organisations are very involved in providing supportive and palliative care services. For example, in the background sections 2.6 and 2.7 it states that supportive care is a term for both generalist and specialist services and the responsibility of both health and social care professionals, but it does not stress that a large proportion of supportive care may be provided outside the NHS and social services in the voluntary sector.</p> <p>We also believe it is important that individuals have a choice of information and support services, from both within the statutory sector and outside. Commissioners need to ensure that different</p>	<p>Please see comments above – this is now included.</p> <p>This is acknowledged and included in those sections of the Guidance identified above.</p> <p>See above.</p>

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		service options are available in their area.	
Breast Cancer Care	Training and workforce development	Throughout the guidance there are recommendations about training needs and workforce development. However, there is no timetable or targets about when training should be introduced. Many of the recommendations for 'face-to-face' communication and psychological support cannot be effectively implemented until training has taken place. Therefore it is important that training programmes are introduced as soon as possible. Training and development also have enormous resource implications and we are very interested in how this will be funded.	The resource implications of this are being considered. Funding sources for the recommendations, time-tabling and target setting are not within the scope of the Guidance.
Breast Cancer Care	Identification of best practice	We believe for the guidance to be implemented effectively research will need to be carried out to identify examples of best practice, particularly in terms of co-ordination of services. Service models should be shared throughout the NHS and we would be keen to see the Cancer Services Collaborative examine this issue. The voluntary sector and patients and carers should also participate in the identification of best practice.	This is included in the work of the Cancer Services Collaborative – and the Guidance Evidence Review Team has also identified clear areas for continued or further research.
Breast Cancer Care	Commissioning	The guidelines contain good principles in terms of what is needed to improve supportive and palliative care. However we feel there is not enough detail or advice on how to commission these services.	This is not within the scope of the Guidance – however the section summarising the recommendations does identify the level of responsibility for the key recommendations.
Breast Cancer Care	Background	The guidance states (1.22) that it is 'not anticipated that all the recommendations will be achieved in all areas immediately or in the short term. And that some may be relatively straightforward to implement while others will be goals at which to aim. 'We recognise that different regions will have different requirements and services will always vary between regions. However, it is important that inequalities do not develop in access to supportive and palliative care between regions. To ensure this	This will be a part of the development of the standards derived from the Guidance manual.

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		<p>does not happen Breast Cancer Care would like to see targets and a timetable for implementation of recommendations for Strategic Health Authorities, Primary Care Trusts and cancer networks.</p> <p>The guidance should recommend that the involvement of patients and carers in the development of services be monitored and reviewed regularly to ensure their views are being given appropriate consideration.</p>	<p>This is included in the section on user involvement.</p>
Breast Cancer Care	Co-ordination of care	<p>Breast Cancer Care is concerned about the difficulty of co-ordinating care and ensuring that individuals have access to all the support and information services they need. We would like to see a named health professional as co-ordinator of care who has responsibility for ensuring that support and information needs have been assessed and addressed. For example a GP or specialists cancer nurse. We feel this should be a clearly defined role so that patients have a single point of contact in relation to assessments and do not get continually re-assessed by different professionals or miss being assessed at all because it is assumed that another professional has already assessed them. Other staff and relatives or carers should also be consulted about support needs and it is essential that they have a named contact. We understand that the individual co-ordinating care may have to change throughout the cancer journey. However, we would like to stress that changes should be kept to a minimum to ensure continuity of care for the patient and minimise confusion.</p> <p>Cancer networks or units should ensure that individuals responsible for co-ordinating care are regularly updated about support and information services available within the area from</p>	<p>This is included in the section on co-ordination of care.</p> <p>This should happen as a part of the updating of local service directories which are referred to throughout the Guidance</p>

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		<p>both the voluntary and statutory sectors.</p> <p>We feel it is important that patients and carers have access to support services as quickly as possible once a need is identified. To enable this to happen local cancer networks or providers need to ensure a good communications strategy is in place to inform health professionals about the wide range of support services available in both the voluntary and statutory sectors. In particular where there are long waits for counselling or psychological care within the statutory sector health professionals should be aware of alternative services within the voluntary sector that could have shorter waits.</p>	<p>This is covered within the Guidance- referral pathways etc. see section on co-ordination of care.</p>
Breast Cancer Care		<p>Patients and carers should be informed about the wide range of support services available when they are assessed for support needs regardless of whether or not an immediate need is identified during the assessment. Psychological needs can change rapidly as patients often experience a 'rollercoaster' of emotions after being diagnosed with cancer. If they are well informed about the support available they are then empowered and able to access services when they need them.</p>	<p>The service directories referred to above should cover this.</p>
Breast Cancer Care	Section 3.15	<p>Lists points in the patient journey at which individuals should be assessed for support needs. While we agree that these are key points it is important to stress that assessment is an ongoing process as individual needs will fluctuate. We also feel it is important to highlight that many individuals experience psychological problems a few months after they have completed treatment. Often it is when individuals are returning to their 'normal' lives that the psychological impact and reality of what they have been through hits them. During the treatment programme patients are in touch with a wide range of staff who offer support, but after treatment they are suddenly alone and</p>	<p>This is why the Guidance stresses the need for regular assessment and review – and also why the Guidance stresses the need for the local service directories and local information/support services.</p>

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		<p>have to adjust to living with breast cancer and the fear of reoccurrence. Individuals at this point can benefit from being shown alternative support and coping mechanisms. This highlights why it is essential that patients are given information about the wide range of support services available so that they can access these once they have left the hospital system.</p> <p>The guidelines stress that prompt referral to support services is important. This is true, but will be dependent on there being adequate provision of support services to cope with need. At Breast Cancer Care we know of at least one case where someone with breast cancer had to wait a year for an appointment with a psychiatrist in the NHS. Individuals experiencing psychological distress need immediate help and if this is not available within the statutory service health professionals should be aware of potential alternatives in the voluntary sector. While the recommendations are sound we are concerned whether resources are available to fulfil the recommendations.</p> <p>While we are encouraged by the emphasis on continually re-assessing patients for support needs we are concerned that there is capacity to carry this out. We are aware that health professionals such as breast care nurses are already overstretched and they may not have time to keep re-assessing needs. This is why it is important to ensure patients are well informed about the support services available from the beginning of their treatment and know how to access them.</p> <p>We are concerned that different groups of cancer patients currently experience different levels of care. Women with breast</p>	<p>This is being addressed in the economic review.</p> <p>See comments regarding service directories etc.</p> <p>The role of the Guidance is to ensure consistency and equity in the whole range of services associated with providing support and palliation.</p>

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		<p>cancer have good access to breast care nurses who can help address their needs. However when individuals develop secondary breast cancer their treatment often falls outside the breast cancer service and they can feel that the level of support has dropped dramatically. Women with secondary breast cancer are often symptom controlled and “well” for a long time. However, they still have complex psychological and physical needs but do not fall into the boundaries of any one cancer service area and are therefore commonly unsupported and isolated. As treatments become more effective more people will live longer with cancer, particularly in the secondary stage, it is important that the needs of these patients are adequately supported.</p>	
Breast Cancer Care	Face to Face Communication	<p>The guidance states that the ‘patient should be offered opportunity to discuss matters further with a professional of their choice’ (4.11). This is very important as patients may feel more comfortable or have developed a better rapport with a particular professional and communications skills can vary. We also feel it is important that individuals have the opportunity to discuss their condition or treatment with someone outside of the NHS structure especially as patients are now expected to be more involved in decision making about treatment. The time available for consultations with health professionals is limited and there can be a great deal of information to absorb, individuals often feel that they were unable to ‘take everything in’. For example Breast Cancer Care’s helpline gives people the opportunity to discuss their treatment options, go over what they have been told and formulate questions in preparation for their consultations with health professionals to ensure they make the best use of time. The helpline is anonymous and this can encourage people to ask what they consider ‘silly’ but important</p>	<p>This has been addressed in comments relating to the inclusion of both voluntary and self-help organisations.</p>

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		questions.	
Breast Cancer Care		The guidance recommends that patients and carers should be facilitated to be involved in decision making where this is desired. The guidance should consider that a patient's choice of whether to be involved in decision making will be affected by how well they understand the information they have been given about treatment. Patient involvement may therefore be affected by whether or not the health professional advising them is a good communicator. It is also important to recognise that patients can be further empowered and supported to take decisions through organisations like Breast Cancer Care. For many callers the Breast Cancer Care helpline offers an opportunity to discuss their condition and treatment options with someone who is informed and supportive – but who is also not directly involved in providing clinical treatment. Our experience at Breast Cancer Care is that people are increasingly faced with difficult and complex decisions and greatly value the opportunity to be able to speak to someone who can help them take decisions that are right for them. We believe that the contribution and value of services like those provided by Breast Cancer Care should be formally recognised as an integral part of the support provided to people affected by cancer.	This is covered in the information section and the 'face to face communication' section of the Guidance.
Breast Cancer Care		The guidance suggests that all health and social care professionals should be able to judge whether they have sufficient knowledge and skills to communicate with individual patients. We feel good communication skills are hard to achieve and it is very difficult for people to judge their own level of communication skills. Experienced staff may feel that because they have worked in the area for a long time they are experienced at communicating, but this is not always the case. We believe the only way to monitor communications skills is to	This is covered in some depth in the face to face communication section of the Guidance.

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		<p>regularly review and monitor patient satisfaction with professional's communication skills. All levels of staff involved in the cancer journey should be monitored from consultants to GPs to nurses to radiotherapists.</p> <p>Good communication is complex but key to patient satisfaction. We believe improvements in communications skills should be a key priority and a timeline and targets are needed for training on this area as well as procedures for monitoring and assessing staff.</p>	<p>See comments regarding standards and peer review.</p>
Breast Cancer Care	Information	<p>The guidance states that there should be a locally agreed selection of information products for patients. Breast Cancer Care proposes that the guidance should recommend that patients, carers and voluntary groups are involved in the decision making process about what information products are available both in relation to the kind of information required and how that information can be best presented. At Breast Cancer Care we also know that there are real gaps in information. For example there is very little good quality information available that deals with secondary breast cancer. As a result of talking to people affected by breast cancer, Breast Cancer Care recently published a booklet on living with secondary breast cancer.</p>	<p>This is covered in the section relating to information provision and also the section on user involvement.</p>
Breast Cancer Care		<p>The guidance recommends that patients be offered assistance to help them understand information products and come to terms with the emotional impact of the information. This is an excellent recommendation - although we are concerned about how this is to be resourced within cancer units. We would also strongly recommend that units ensure patients are aware of voluntary organisations that can provide assistance in understanding information through initiatives such as helplines.</p>	<p>Please see comments above.</p>
Breast Cancer		<p>The voluntary sector has a wealth of experience in producing</p>	<p>See comments above.</p>

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Care		written information for patients. The sector is knowledgeable about the type of information patients are looking for and publications have often been produced in response to an identified need. Breast Cancer Care produces about 50 different booklets and factsheets and sends out between 40-50,000 copies of these a month which are distributed to health professionals and individuals and we are involved with the Coalition for Cancer Information. The guidance suggests that the 'Coalition for Cancer Information' should oversee the commissioning, design, quality assurance and compilation of a comprehensive range of information products for people with cancer. We feel it is important that the guidance recommends that patients, carers and voluntary sectors be involved in this process. We also feel it is important that work is not duplicated and where good information leaflets already exist and are produced by the voluntary sector these should be used and promoted rather than writing new material.	
Breast Cancer Care	5.18	The guidance discusses (5.18) the development of policies at a local level to decide which information materials should be routinely offered at various stages in the cancer journey. When networks or provider organisations are creating these policies they should seek advice from patients, carers and voluntary organisations.	See above.
Breast Cancer Care	5.33	In section 5.33 the guidance acknowledges that health and social care professionals will need support to meet the information needs of patients and carers. The guidance should recommend that health professionals liase with the voluntary sector for this support, especially as this sector has an enormous amount of expertise in producing patient information. The guidance states that promoting access to information is a	See above.

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		prime concern and highlights the importance of cancer helplines and cancer information centres in providing access to information. Many of the best cancer information services and helplines are run by voluntary organisations, the guidance does not say this and we feel it is important that this is acknowledged particularly as the guidance is for service commissioners.	
Breast Cancer Care		Access to good information is crucial because it empowers patients and enables them to make informed choices about their treatment and care. We would like to see a timeline and targets for improving information given to patients. We are aware from recent surveys that access to written information is very variable throughout the UK. Recent work carried out on breast cancer services by the Dr Foster organisation found wide variations in performance in hospitals in relation to the provision of written information about breast cancer. The best hospitals provide up to 75 per cent of patients with information about their condition while a large number only provide 40-50 per cent of patients with written information. This situation needs to be improved to 100% as quickly as possible.	Please see earlier comments relating to standards and peer review.
Breast Cancer Care	Psychological support services 6.6	Section 6.6 discusses which organisations provide psychological support services. It does not explicitly mention the voluntary sector and only refers to 'non- professional' support groups and services offered by the statutory services. The voluntary sector should be mentioned in this paragraph as they provide a wide range of support services including helplines, support groups, and counselling. As this document is for commissioners it is important to highlight provision of services from the voluntary sector. It should be stressed that the voluntary sector is integral to the provision of psychological support services.	See comments above regarding this section and others.
Breast Cancer	6.9	Section 6.9 discusses points in the patient pathway that can be	This has been acknowledged in the Guidance -

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Care		particularly difficult. From our experience at Breast Cancer Care we are aware that many individuals actually experience psychological problems and distress after they have finished treatment and have left the patient pathway. It is often when people return to 'normal life' that they become depressed, when the reality of what they have been through hits them and they have to adjust to living with breast cancer and the fear it may return. We would like to see this time acknowledged in the guidance. Breast cancer care runs courses on 'Living with Breast Cancer' courses and 'healthy living days'. These courses focus on the practical and emotional elements of living with breast cancer, and enable people with breast cancer to come together, share their experiences and support one another.	and in the revised section on psychological support and also in the rehabilitation service section.
Breast Cancer Care		Patients are to be assessed for psychological problems at key points in the patient journey and if necessary referred to psychological services. While this system will pick up many of the individuals experiencing psychological problems it is unlikely to identify all. Emotions can change rapidly during the cancer journey, at the time of psychological assessment the patient may be coping fine but this could change soon afterwards. It should be recognised that patients can identify their own psychological problems and they should be informed about the wide range of support services that are available to them so that they can access these when they need them.	This has been acknowledged in the revised psychological services section.
Breast Cancer Care		The guidance states that staff providing psychological care should be adequately trained but it does not quantify what this means in terms of accreditation or how the care provided will be reviewed and monitored.	Specific qualifications are not identified – but the skills and expertise of the practitioners working at each level are identified.
Breast Cancer Care	6.16	In section 6.16 the guidance recommends that commissioners and cancer networks should ensure that all patients have access to an appropriate level of psychological support by	Please see earlier comments regarding the inclusion of voluntary and self-help organisations.

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		setting up a network wide psychological support service. The service will provide a comprehensive range of interventions to match level of support to patient need. We would like the guidance to recommend that voluntary sector services are an integral part of this network wide support service. Patient representatives should also be involved to advise on services needed.	
Breast Cancer Care	6.18	The voluntary sector is not mentioned in the five level model (6.18) of psychological assessment and support services. Services provided by this sector need to be more explicitly highlighted in the document.	This has been amended.
Breast Cancer Care	6.42	The guidance development has identified evidence that healthcare professional's current abilities to detect the psychological needs of people with breast cancer are limited and that training needs to be provided on psychological assessment (6.42). We believe it is essential that this situation is improved as soon as possible and would like to see timelines and targets for training. Structures should also be put in place to monitor and review staffs recognition of psychological distress and their ability to recognise when to refer on.	See earlier comments regarding standards and peer review process.
Breast Cancer Care		The guidance should recommend that procedures are put in place to regularly update NHS staff on support services available both within the statutory voluntary sectors.	This would be a part of the updating of the local service directories.
Breast Cancer Care		Capacity of psychological support services is a major issue and recommendations for this area cannot be implemented unless there are increases in staff to provide the necessary psychological services and support. It is essential that networks and service providers undertake a needs assessment in terms of number of psychiatrists and psychologists needed to support patients with cancer. We are aware that some individuals are being told that there is a waiting time of over a year for an	This is acknowledged in the economic review – and is not only an issue for those providing psychological support.

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		<p>appointment with a psychiatrist.</p> <p>Also see Joint response at end of table.</p>	
Bristol Cancer Help Centre		<p>Thank you for including us as stakeholders in this work. We have pleasure in making some comments on Part A, although we are mindful of the fact that at this stage there is only a limited opportunity for alteration. However, we would like to make a few constructive comments.</p>	<p>Thank you for your comments.</p>
Bristol Cancer Help Centre	The Evidence Review	<p>I note that you base the draft guidelines on evidence graded according to the Evidence Grades which are customarily used to establish best practice in health care interventions with the Randomised Controlled Trial (RCT) considered as the 'gold standard'. Whilst fully supporting the fact that practice should be supported by best evidence, based on sound research, we are also aware that in the case of complex interventions, such as those concerned with supportive and palliative care, the RCT is considered by many reputable experts to be an unsatisfactory tool. The nature of the methodology produces misleading results that fail to pick up important issues as the social and organisational contexts of the intervention, the skills of individual practitioners, and the benefits of the intervention for subgroups of needy individuals. An example of this would be exploring best ways of providing support for people with cancer in areas of high health need. Such issues may well need a more participative approach to evaluation. There is a body of knowledge around the evaluation of complex interventions, such as those concerned with health promotion, and the development of best practice in health promotion, which could perhaps be drawn on. I recognise that, at this stage, it is necessary to go along with the approach you have adopted, but would it be possible to have a paragraph or two in the final document which</p>	<p>The Evidence Review Team have included a chapter in the research manual which is a reflection on the nature of research in supportive and palliative care in cancer. This has picked up on these issues.</p>

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		acknowledges the difficulties, and perhaps guides people to this different paradigm of participative research? I could supply you with references if necessary.	
Bristol Cancer Help Centre		A second point regarding the literature review, is that by definition it is reviewing only things that have been experimentally designed. Much supportive and palliative care is relatively undeveloped, let alone well evaluated, so the information gleaned from a historical review of the evidence must be limited at best. The guidelines quotes the national survey of cancer patients, but people don't always ask for things they don't know about, and hence the potential benefits of things like creative arts, or even basic elements such as exercise and nutrition, may be overlooked.	<p>The scope of the guidance is very inclusive. This counts for the topic areas, which are considered as well as for the kind of evidence that is taken into account. There are 11 topic areas included covering a wide variety of issues pertaining to cancer care. The research evidence that has been reviewed for this guidance is not only from studies with an experimental design. In areas where this kind of evidence is lacking other sources were consulted and appraised.</p> <p>Creative arts were experimented with in the context of spiritual support or occupational therapy. We also have evidence of rehabilitative programmes testing physical exercise for patients during chemotherapy, or dietician counselling for example.</p>
Bristol Cancer Help Centre	Defining Supportive and Palliative care	The document acknowledges the difference between supportive and palliative care through definitions suggested by the WHO (palliative care) and the National Council for Hospice and Specialist Palliative Care Services (supportive care). The disadvantage of inviting the latter organisation to suggest the definition, is that they do come from a palliative care and disease management perspective, rather than one which is more broadly health promoting. Could there perhaps be a sentence inserted to indicate that supportive care could be interpreted more widely and that this will be addressed in Part B? It is to be hoped that as the second stage of the guidelines	The combining of the two parts of the Guidance should have identified the broader perspective of what supportive care is. The scope of the Guidance cannot go beyond NHS commissioned services. The role of the voluntary and self-help sectors has been strengthened throughout the document.

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		<p>is developed, a broader perspective on supportive care and rehabilitation will be incorporated. Apart from areas such as counselling, complementary therapies and nutritional advice, supportive care could include the following:</p> <ul style="list-style-type: none"> • helping people access support from facilities and organisations within their local communities (e.g. leisure centres, creative arts, music etc); • support from the workplace to promote healthy work environments • improved working practices such as increased use of part-time hours for people for whom return to full-time work is not advised; • and help with financial planning and lifestyle review. <p>Section 2 does explore these issues, but very much from a professional, medical and nursing perspective. It feels that a much wider range of agencies, and significantly more collaborative working, will be required to make supportive care a dynamic reality.</p>	
Bristol Cancer Help Centre	The language of 'patients' and 'carers'.	<p>This may seem a small point, but the document throughout refers to 'patients' and 'carers'. Our research on the support needs of people with cancer and their supporters ¹ suggest that people generally prefer not to be designated always as 'patients', which places them firmly within the medical paradigm. Given that 'supportive care' may be provided, off and on, for people for many years, perhaps using 'people with cancer' might be a better form of language. Similarly, people who live with people with cancer may be 'supporting' them, rather than necessarily 'caring for' them. I would like to think that the issue</p>	<p>The point is understood and acknowledged – but the Guidance in this form is primarily written for commissioners of services – the Public Version written for the public will be able to acknowledge this.</p>

¹ Tritter et al *'Meeting the needs of people with cancer and their supporters for support and self-management'* Bristol Cancer Help Centre 1999

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		of language and how it is used could be more fully addressed in the initial sections where the definitions are being discussed. It is alluded to in Section 2.9 on page 11.	
Bristol Cancer Help Centre		In addition, our research showed, and our experience bears out, that people need supportive care long before they need palliative care, and that they hold back from accessing support precisely because they do not want to see themselves as needing a service they associate with dying. Without in any way seeking to belittle the important care given by colleagues within palliative care, we feel that it is vital that the voices of people with cancer are heard in this respect. It is essential that we devise a language which fits their needs, rather than ascribe labels which are useful for professional identity, but unhelpful for people with cancer.	See comment above.
Bristol Cancer Help Centre	Issues of assessment.	The issue of ‘assessment’ comes up a great deal in the document, and this is usually in the context of people with cancer ‘being assessed’ by professionals in order to identify their eligibility for a variety of supportive and palliative care services. A helpful addition would be some discussion of how people with cancer can be helped to assess their own needs, and to decide what is helpful for them from a ‘menu’ of local resources. It may seem pedantic, and it may be the way it is written, but there is a very real sense of the person with cancer being passed from professional to professional without having much of a ‘say’ in the process. This might be well-co-ordinated care, but it is prone to problems when being implemented, and it hardly promotes empowerment and choice. The literature suggests that regaining control and self empowerment are important adjuncts of good rehabilitation and recovery. If greater emphasis were placed on good systems within the primary care setting, such as ‘patient-held’ records, and cancer	This is acknowledged in the combined document – and the recommendation for local service directories to be made available to patients and their carers. The point is also identified throughout the Guidance – and in the psychological service section and the rehabilitation sections specifically.

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		registers at GP practice level, (which the guidelines refer to in 3.21) then people could be helped within their usual healthcare setting, and linked to local resources within their local lay community. However, the guidelines as currently configured place more emphasis on hospital teams than they do with other areas, where people with cancer may, in fact, spend more time.	
Bristol Cancer Help Centre	Information for people with cancer	A point to be considered in this section is to give more emphasis on the provision of supportive information for when people have finished treatment (at least for the time being). Our research and experience suggests that people find this a particularly stressful time when they no longer have regular access to their hospital staff, with whom they may have formed supportive relationships. It is at this point that supportive complementary therapies, and advice on nutrition, rest and exercise can be especially helpful. It may be that these are not formally provided within the NHS, but there may well be local resources which people can use, if they are given the correct information. Good links with primary care combined with local information can be particularly helpful at this stage as we noted in the above paragraph. Finally, it is important to stress that healthcare professionals may need to work creatively and flexibly within their local area to meet the specific information needs of 'hard to reach' groups.	This is covered in the revised sections on co-ordination and information, and also in the rehabilitation services section.
Bristol Cancer Help Centre		One final detail re this section – on page 31, the box is incorrectly labelled as 3.1 – it should be Box 5.1.	Thank you.
Bristol Cancer Help Centre	Psychological support services	This section seemed to indicate that there is considerable unmet need for psychological support, but is rather narrow in its approach to helping such potentially large numbers of people. Perhaps this can be addressed in Part B, but it is certainly an area where facilitating access to complementary therapies and self-help techniques, to say nothing of links to a broad range of	The psychological services section has been revised – and has acknowledged this point.

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		community resources could be helpful. Perhaps a sentence or two could be included to this effect. In addition, it concerns us that with current staffing levels, those healthcare professionals at the front-line may lack the time to adequately counsel people who may just need a bit more time, rather than more specialist interventions.	
Bristol Cancer Help Centre		<p>In conclusion, we recognise that it has been an enormous task to draw together such a disparate range of topics and issues that should be included within Supportive and Palliative Care. However, some aspects of the guidelines are problematic, and the evidence base is rather medically orientated and may not have picked up some potentially valuable areas of support. We hope that some of the suggestions we have made are helpful. They are certainly intended to be so. A particular area of concern seems to us to be that without stressing the links to agencies outside the NHS, whether they be local, social or voluntary sector resources, the guidelines may appear to already over-loaded staff to be difficult to implement.</p> <p>We look forward to being able to be more actively involved in the development of Part B of the Guidelines for Supportive and Palliative Care and to the development of models of best practice in this important area.</p>	See comments above regarding inclusion of voluntary and self-help organisations.
British Association for Counselling and Psychotherapy		This organisation was approached but did not respond.	
British Association for Nursing in Cardiac Care		This organisation was approached but did not respond.	
British Association		This organisation was approached but did not respond.	

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for Parenteral & Enteral Nutrition (BAPEN)			
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 Committee for Standards in Haematology		This organisation was approached but did not respond.	
British Dietetic Association		Thank you for giving us the opportunity to comment on the above treatment guideline. We welcome that the majority of the comments made by our reviewers at the first consultation stage have been responded to and, that we also have the opportunity to contribute to Part B. Our only comment would be to re-iterate the two points raised by our reviewers on the first consultation that have not been included in the second consultation document.	Noted – thank you.
British Dietetic Association	Background	We feel that the results of the patient questionnaire need to be widely disseminated both to specialised services and to health professionals in general General palliative services Access to paper medical notes out of hours can be problematic. IT investment is needed to facilitate records. Shared notes (by all professionals involved) and patient held records should be explored.	Comment noted. This point is acknowledged in the section on co-ordination.
British Dietetic	2.18	In addition, there is a minor typographical error ‘soles’ instead of	Thank you!

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Association		'roles' in section 2.18.	
British Geriatrics Society-Special Interest Group in Diabetes		This organisation was approached but did not respond.	
British Liver Trust		This organisation was approached but did not respond.	
British Lung Foundation		This organisation was approached but did not respond.	
British Medical Association		No comment	
British National Formulary (BNF)		This organisation was approached but did not respond.	
British Oncology Pharmacy Association		This organisation was approached but did not respond.	
British Psychological Society, The		This organisation was approached but did not respond.	
British Psychosocial Oncology Society		<p>BPOS warmly commends the publication of the draft Strategy as we share many of its aspirations. The fact that psychosocial aspects of cancer are receiving such recognition in the shape of formal guidelines attests to the importance of this area in the total care of people living with cancer.</p> <p>We have not chosen to provide a detailed response to the document as many of our members will be responding individually or through other mechanisms or have contributed to the document at various stages of its development. We would, however make two broad general points for consideration.</p>	Thank you for your comments.
British Psychosocial		This country lags behind many of our European and transatlantic colleagues in the matter of training in psychosocial	The Guidance does not identify specific qualifications for practitioners at the levels of care

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Oncology Society		oncology, both for those for whom it is a prime function as well as for those who contribute as a part of their practice. Being a multi-professional group we are in a good position to encourage and (hopefully) develop training in this area. We would welcome a strengthening of the Guidance in this matter and a strong statement regarding the need for specialists to develop further training in this area. This would allow for the development of properly accredited training courses and would enhance quality of service delivery.	identified – but does identify the skills and expertise expected of those practitioners.
British Psychosocial Oncology Society		<p>Second, we feel that more could be made of preventative models and ideas. The document concentrates on what happens when people become distressed. There is surely a case to be made for reducing the possibility of the distress arising in the first place. Whilst some of that is systemic in nature, the aim of psychosocial care is not simply to be reactive but also to advise on the psychosocial impact of the systems through which people pass.</p> <p>We would, of course, be happy to amplify on these or any other issues.</p>	The psychological service section has been revised taking this point into account.
British Society of Rehabilitation Medicine		This organisation was approached but did not respond.	
Cancer Black Care		This organisation was approached but did not respond.	
Cancer Research UK		This organisation was approached but did not respond.	
Cancer Services Co-ordinating Group		Thank you for inviting the CSCG to provide comment and feedback as part of the second draft consultation of the Supportive and Palliative Care Cancer Service Guidance. I have set out below some general remarks followed by more specific comments.	Thank you.

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Cancer Services Co-ordinating Group	1.22	To date NHS Wales has not adopted the English Workforce Development Confederations system as referred to in paragraph 1.22. Wales has a Workforce Development Steering Group which is responsible for the commissioning of NHS education and training for all staff. It is also responsible for taking forward job re-design and new ways of working, the 'renewal agenda'. The Workforce Development Steering Group is chaired by the Director of the NHS in Wales. Membership is drawn from all sectors including NHS Trusts, Local Health boards, the independent sector, the voluntary sector, the trade unions and social services.	Text altered.
Cancer Services Co-ordinating Group		It should be noted that a draft Welsh Assembly Government document entitled 'A Strategic Direction for Palliative Care Services in Wales' was recently consulted on across Wales. It has the stated aim 'to provide a strategic framework which will provide a blueprint for consistently high quality palliative care services that are available uniformly across Wales'. I did not find a reference to this draft document in the NICE draft guidance and wonder whether you have seen a copy. As these two documents may be published at the same time it would seem sensible to cross reference.	Copy obtained and referenced within Guidance.
Cancer Services Co-ordinating Group	Page 61	Given that some Specialist Palliative Care Teams may only have one nurse specialist, Palliative Care Teams may not be able to respond after receiving every assessment made (page 61) whether it is deemed for further action or not. Furthermore clarification is required regarding what teams do with this information and who assesses their performance.	This will be linked with to the locally determined eligibility criteria and the development of local assessment tools to best determine when such a referral should take place.
Cancer Services Co-ordinating Group	1.3 / 1.4 / 2.35	Limited resources were recently provided to set up a 'user and carer project' jointly run between Macmillan Cancer Relief and the South West Wales Cancer Network.	Thank you for this information.
Cancer Services	1.4	In Wales a draft specialist palliative care cancer data set has	Thank you.

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Co-ordinating Group		been produced.	
Cancer Services Co-ordinating Group	1.22	'local health boards' should read 'Local Health Boards (LHBs)' throughout the document	Text altered
Cancer Services Co-ordinating Group	1.24	This paragraph should also refer to LHBs in Wales.	Text altered
Cancer Services Co-ordinating Group	2.33	This should read 'less than half of health authorities in England <i>and Wales</i> involved in the CHI/audit commission survey in 2000...'	Text altered
Cancer Services Co-ordinating Group	3.7	...and the Welsh Association of Hospice Specialist Palliative Care	Not included – need confirmation from CSCG regarding status of this body.
Cancer Services Co-ordinating Group	3.31	Please also include the Wales Cancer Trials Network (WCTN)	Text altered to include.
Cancer Services Co-ordinating Group	5.16	The CSCG Communications Working Group was closed some time ago. Therefore the final sentence should be deleted.	Text altered – but waiting for confirmation as to whom may have taken over this role in Wales.
Cancer Services Co-ordinating Group	7.3	Does this paragraph refer to England only? Do you require data if available for Wales?	Information requested from Wales.
Cancer Services Co-ordinating Group	7.5	Are these data in the public domain? The recently published Peer Review of Cancer Services in England did not include reference to Palliative Care Services.	Peer review did include a review of hospital based palliative care services. The data is in the public domain.
Cancer Services Co-ordinating Group	8.4	Do you require information regarding education and training initiatives in Wales?	Information requested.
Cancer Services	8.8	We are currently clarifying whether the Good Practice Guide	Update on this would be useful – information

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Co-ordinating Group		also applies to Welsh Practitioners and Health Bodies.	requested.
Cancer Services Co-ordinating Group	8.24	We are currently clarifying the position regarding 24h district nursing agreements in Wales.	Update on this would be useful – information requested.
Cancer Services Co-ordinating Group	8.35	Community nurse training was only made available in England.	Noted – text altered.
Cancer Services Co-ordinating Group	Page 82	Professor Roisin Pill is based at the 'Llanaderyn Health Centre, Cardiff'.	Noted – text altered.
Cancer Services Co-ordinating Group		<p>Feedback on the draft document has been generally positive and overall it should provide a solid platform to support cancer services in Wales and England, building on areas already functioning well. However it should be noted that implementation of any future guidance will not be straightforward given the acute pressures currently on the palliative care service particularly in terms of an overall shortage of palliative care consultants in Wales. The Guidance will also have quite significant resource implications associated with it which will need to be fully costed.</p> <p>If you should require further information or clarification on any of the above points please do not hesitate to contact me at the CSCG office.</p>	An economic review is included in the version of the Guidance going out for consultation in July/August 2003.
CancerBacup		See Joint response at end of table	
Chartered Society of Physiotherapy		The development of service configuration guidance on supportive and palliative care for patients with cancer is very welcome, and we congratulate the authors on the omprehensive work undertaken.	

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		We are pleased to see that some of the comments we made at the first consultation have been accepted. However, some haven't and we repeat them here and ask the Guideline Development Group to seriously consider their incorporation.	
Chartered Society of Physiotherapy	7.23, 7.30	We reiterate our previous comment that the suggested minimalist team can barely be described as specialist with this limited range of expertise. This very minimalist description is in danger of encouraging commissioners to fund inadequate teams	The role of the Allied Health Care professionals is expanded in the section on rehabilitative services which was not included in Part A of the Guidance.
Chartered Society of Physiotherapy	7.24 and 7.31	Again we repeat our comment that it needs to be clear that the expertise of a specialist palliative care allied health professional (AHP) is more than the general expertise of an AHP.	Please refer to the new section on rehabilitative services.
Chartered Society of Physiotherapy	7.30	Chronic oedema is frequently a distressing symptom of advanced cancer. In-patient specialist palliative care services should have access to a lymphoedema specialist (who may also be a specialist nurse, specialist physiotherapist or specialist occupational therapist). There is no mention of lymphoedema management in this document. All cancer patients who are at risk of developing this distressing condition should have access to a health-care professional with specialised training in this area.	Please refer to the new section on rehabilitative services – lymphoedema therapists and the management of lymphoedema are included in this section.
Clinical Psychologists in Oncology and Palliative Care group		May I start by offering my congratulations to the Editorial Group for the excellence of the revised document? There are many paragraphs that were music to my ears - thank you. In terms of additional comments, I have some suggestions about wording changes and a couple of general comments for the Group's consideration.	Thank you for your comments.
Clinical Psychologists in Oncology and	6.1 line 3	Suggest 'as well as' rather than 'or'.	Section re-drafted.

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Palliative Care group			
Clinical Psychologists in Oncology and Palliative Care group	6.9	Suggest that [under bullet point 1] that the end of treatment is included as a critical point.	Section re-drafted.
Clinical Psychologists in Oncology and Palliative Care group	6.11 line 1	The wording almost sounds as if self-help is the recommendation here. I wonder whether a phrase such as 'Some patients and carers will find their own ways of dealing with distress (and health care professionals can encourage and support them in this), some will have levels of distress which require speedy referral to service'	Section re-drafted taking this comment into account.
Clinical Psychologists in Oncology and Palliative Care group	6.16	The implication of this paragraph is that the network is the preferred organisational structure for psychosocial services. I'm not sure whether this is what is meant. In practical terms, the services are likely to be based in Cancer Centres/Units with good links to primary care and the local voluntary organisations. It would be difficult, for example, to have a single service for all of West Yorkshire, but it might be possible to build up a federation of services throughout the network.	The Network is seen as the common denominator for the organisation of services based on a geographical model. This will include primary and secondary care services within this area together with voluntary and self-help services.
Clinical Psychologists in Oncology and Palliative Care group	Appendix 5	I seem to have lost my doctorate between Appendix 4 and Appendix 5. Also, as I am now in Leeds, I think that my workplace in this Appendix should be Leeds Teaching Hospitals Trust.	Text altered – many apologies!
Clinical Psychologists in Oncology and Palliative Care group	General	There are two general points I would make, one a re-iteration of one I made previously. This refers to survival. As more people survive and live with the aftermath of cancer, so their needs become more pressing. Many patients talk of the transition out of active treatment and into survivorship (as opposed to into	Psychological services section re-drafted taking these comments into account.

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		<p>palliative or terminal care) as being one of the most psychologically demanding times and one when the amount of support is diminishing (patients often talk of feeling abandoned). I believe that we have a particular role in helping people through this period both individually and systemically. In this latter regard, the links between Centres/Units and primary care will need careful development. For the former, I believe that treatment centres should allocate some resource to this process. I personally take this seriously enough to be suggesting that the majority of my clinical time is spent at this stage of the patient pathway. I would suggest that a paragraph is added to the effect that: 'At the end of treatment, patients often feel isolated and abandoned and services that they have valued are no longer available to them. Psychosocial services should look towards providing care and support over this period, ensuring that appropriate links are made with community services, both statutory and voluntary.</p>	
<p>Clinical Psychologists in Oncology and Palliative Care group</p>	<p>General</p>	<p>The second general point refers to specialisation. There are many of us now working in this area who wish to set up further training for our colleagues both in terms of ensuring that those who work in the area for the majority of their time are properly trained and that those who may have deal with people with cancer in the community have some basic skills and knowledge. So, for example, the group of clinical psychologists in oncology and palliative care is looking towards developing a syllabus which would lead to some sort of accredited training. We feel this essential for all sorts of reasons, including recruitment and clinical governance. It would certainly help the development of these skills (for all the groups involved) if a key document such as this were to encourage the development of accredited specialist training.</p>	<p>The Guidance does not identify specific qualifications for practitioners at the levels of care identified – but does identify the competencies expected of those practitioners. It is considered that anything further would be beyond the scope of the Guidance.</p>

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		I hope that these comments are helpful.	Thank you.
Cochrane Pain, Palliative Care and Supportive Care Group		This organisation was approached but did not respond.	
College of Occupational Therapists		This organisation was approached but did not respond.	
Department of Health and Welsh Assembly Government		<p>Thank you for the opportunity to comment on the second draft of the head injury in children and adults guideline. This letter reflects the views of the Department of Health and the Welsh Assembly Government.</p> <p>We are considering whether the Supportive and Palliative Care Guideline may be considered as universal guideline for all conditions and may have some further comments on this matter. We will inform you of these in due course.</p>	Thank you.
Department of Health and Welsh Assembly Government	Paragraph 3.10 Page 23	Please would you consider adding a last bullet point of “from an early stage”?	Text altered.
Department of Health and Welsh Assembly Government	Page 24	Would it be possible to make some reference to information being available in appropriate languages in this chapter? Chapters 4 and 5 refer to this matter and we are content with the approach taken there.	Text altered.
Department of Health and Welsh Assembly Government	Paragraph 3.14	<p>This paragraph mentions recording findings from assessments. It would be helpful if the report could suggest that where possible services use the data definitions being developed as part of the cancer dataset programme - see http://www.nhsia.nhs.uk/phsmi/datasets</p>	Text altered.

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Department of Health and Welsh Assembly Government	Paragraph 3.22	You may want to refer readers to the NHS Information Authority work to support the development of practice-based registers in primary care for a range of patient groups including those with cancer. See http://www.nhsia.nhs.uk/phsmi/datasets/pages/pbrs.asp	Text altered.
Department of Health and Welsh Assembly Government	Paragraph 3.27	The route to achieving its recommendations should include the implementation of Information for Health and Information for Social Care.	Text altered to refer to this.
Department of Health and Welsh Assembly Government	Environmental issues	<p>We believe that the environment in which care is provided is important. The environment can help patients feel safe or unsafe, welcome or unwelcome, calm or stressed, supported or abandoned, private or exposed. We believe that people responsible for the environment of care should be included in “multiprofessional care”.</p> <p>Although the document addresses general palliative care provided within a community setting, increasingly older people die in Care Homes. We believe greater emphasis should be made on ensuring access to palliative care services for Care Homes.</p>	<p>Comment noted – and acknowledged in the sections on psychological services and face to face communication.</p> <p>Comment noted – and care homes identified wherever appropriate throughout the Guidance.</p>
Department of Health and Welsh Assembly Government	Patient experience	You may wish to note that the Department of Health, as part of its programme of work in the context of the “patient experience” agenda, has developed a toolkit to make it easier for the NHS to produce good quality patient information. The toolkit consists of guidance for written patient information and a series of templates to accompany the guidance. It has been put together with the Patient Information Forum, a national group representing people working in the field of patient information in the NHS and the voluntary sector, the Royal National Institute for the Blind and the Plain English Campaign. The toolkit will be	Comment noted and references included.

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		<p>available shortly.</p> <p>The Centre for Health Information Quality/Help for Health Trust is currently working on a range of quality skills and toolkits work for the Department and their web site offers some practical tips to writing and assessing quality information (www.hfht.org/chiq). You might wish to consider referring to this information.</p> <p>DISCERN (website www.discern.org.uk/) is an instrument, or tool, which has been designed to help users of consumer health information judge the quality of written information about treatment choices. This project was funded by the NHS Executive South East regional office. Please would you consider making reference to this, should you feel it is appropriate?</p>	
Department of Health and Welsh Assembly Government	Paragraph 5.22	Would it be possible to include NHS Direct as well as NHS Direct Online for people who do not have access to the Internet?	This point specifically refers to access to web-based information.
Department of Health and Welsh Assembly Government	<i>Mental Health</i> Chapter 6	It would be very helpful in this section to have a reference to the very useful work, such as that undertaken at Great Ormond Street Hospital, for families with children dying of cancer. There is good evidence that this is helpful for families and for children themselves. Would it be possible for you to consider this?	It is considered that this is outside the scope of the Guidance.
Department of Health and Welsh Assembly Government		Please would you consider including some relevant literature references in this section (or references to the assessment report) so that your recommendations are more transparent? For example, there are a number of systematic reviews, (such as Barswick, A et al 2002 reported in EBMH vol 5 - a review of psycho-educational interventions to reduce depressive symptoms in cancer showing these are effective. Additionally,	All the supporting evidence and references for each section are to be found in the Evidence Manual. These specific references have been passed to the Evidence Review Team

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		Greer, S et al 1994 in `Psychosocial processes and health' Steptoe A and Wardle J Cambridge University Press – this was a large prospective study of women with breast cancer showing a strong relationship between coping style and survival.	
Department of Health and Welsh Assembly Government		Please would you consider mentioning the role of mental health nurses in primary care, acute hospital liaison and Community Mental Health Trusts in this section as all of them would be able to contribute advice to colleagues as well as specific interventions?	The psychological services section has been re-drafted and this comment taken into account.
Department of Health and Welsh Assembly Government	Page 44 Level 3	Please would you consider adding “Clinical Nurse specialists could also potentially be trained and supported to deliver such interventions as an integral part of their practice”?	Text altered to include this.
Department of Health and Welsh Assembly Government	Paragraph 6.23 Page 45	You state in the last line “treat a variety of mental health problems.” Please would you consider changing this to “alleviate psychological distress.” Our rationale being that this is the first and only mention of ‘mental health problems’ and therefore might be changed to be consistent with the rest of the chapter.	Comment noted – but decision made not to alter text.
Department of Health and Welsh Assembly Government	Paragraph 6.26	We remain uncertain about your definition of "emergency psychological care" and recommend this should be defined more carefully to cover issues of access by patient, regardless of their primary diagnosis, to the range of mental health provision. We are concerned that this recommendation may be unworkable as it stands and therefore perhaps you might consider inserting "psychiatric and/or" before psychological in the last line.	Comment noted – text altered.
Department of Health and Welsh Assembly	Paragraph 6.26 - 6.31 Page 46	Please would it be possible to highlight the importance of developing local partnerships, plans and expectations around access to secondary & tertiary services especially Crisis or	Comment noted – reference made to role of local mental health teams.

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Organisation/Individual name	Section Number	Comment	Response/Changes made by Guideline developers
Government		Emergency services.	
Department of Health and Welsh Assembly Government	Paragraph 6.34	We are unsure what this exactly means. We believe screening should be happening at level 0 & 1 and level 2 is developing further expertise and being able to deliver specific interventions. Would it be possible to clarify this?	The psychological services section has been re-drafted and this comment taken into account. Screening is specifically identified at level 2.
Department of Health and Welsh Assembly Government	Page 49 - D.4 Training and Support	Please would you consider adding the word Supervision to the title as in "Training, Support and Supervision?"	Text altered.
Department of Health and Welsh Assembly Government	Chapter 7 & 8 Workforce development 8.35 - 8.37	Please would you consider making reference in these paragraphs that palliative care providers might wish to work together with workforce development confederations and PCTs to ensure that training needs for staff are identified?	Text altered.
Department of Health and Welsh Assembly Government	Paragraph 8.24	Please would you consider making reference within these paragraphs that palliative care providers might wish to work together with workforce development confederations and PCTs to ensure that training needs for staff are identified? The NAW are concerned that the draft guidance reads as if it is an England only document. Please would you consider making the following changes:-	See above.
Department of Health and Welsh Assembly Government	Paragraph 8.24 Page 62	This section refers to PCTs and should refer to "Trusts" in Wales, as Wales do not have PCTs. Please would it be possible to clarify this matter?	Changes introduced throughout document – detailed review of nomenclature to take place with representatives of the Government for Wales.
Department of Health and Welsh Assembly Government	Paragraph 8.7 Page 59	This section refers to NHS Direct taking over Out of Hours services triage by 2004 which is in England only whilst no deadline has been set for Wales. Please could you clarify this?	Waiting for comment from Wales to clarify this.
Department of	Paragraph 8.8	Would it be possible to make reference to WHC(2002)86	Document obtained – decision made by Guidance

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Health and Welsh Assembly Government		"Palliative Care and Out of Hours Access to Essential Drugs", issued on 23 July 2002 in this section?	Development Team not to include as specific references.
Eisai Limited		This organisation was approached but did not respond.	
Elan Pharmaceuticals Ltd		This organisation was approached but did not respond.	
Faculty of Dental Surgery		<p>Despite my expressing concern about the lack of reference in this guideline concerning the oral health care needs of the patient in Palliative Care there continues to be no reference to this in this 2nd consultation document.</p> <p>Patients with cancer whether oral cancer, cancer of the head and neck or those with haematological cancers and particularly those in terminal care often experience problems specifically related to their oral care . These issues - often associated with oral pain, cleansing and oral functional issues can become some of the most important factors in that patients' quality of life during their last days - I would be pleased to provide you with references again if that would be helpful - but my previous data has obviously been completely disregarded.</p> <p>I will be raising this issue at the next NICE Partners Council meeting because I am certain there will be other groups for whom information is similarly disregarded.</p>	The scope of the Supportive and Palliative Care Guidance does not include detailed recommendations regarding oral health needs.
Faculty of Public Health Medicine		This organisation was approached but did not respond.	
Foundation for Integrated Health		This organisation was approached but did not respond.	
General Medical Council		This organisation was approached but did not respond.	

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GlaxoSmithKline UK		This organisation was approached but did not respond.	
GlaxoSmithKline UK - Supp & Pall care		This organisation was approached but did not respond.	
Haven Trust, The		This organisation was approached but did not respond.	
Health Technology Board of Scotland		This organisation was approached but did not respond.	
Help Adolescents with Cancer		This organisation was approached but did not respond.	
Help the Hospices		See Joint response at end of table	
International Myeloma Foundation (UK)		This organisation was approached but did not respond.	
Janssen-Cilag Ltd		No comment	
Joint Committee on Palliative Medicine		This organisation was approached but did not respond.	
Macmillan Cancer Relief	General	<p>Thank you for inviting Macmillan Cancer Relief to comment on the second draft of Part A of the Supportive and Palliative Care Guidelines.</p> <p>We welcome the opportunity to comment on these Guidelines. You have asked us to comment specifically at this stage on how well our comments on the first draft (submitted in August 2002) have been reflected in the second dated September 2002. Macmillan Cancer Relief is also a co-signatory to a letter from 9 charities detailing common concerns.</p> <p>Many of our original comments have been reflected in the new draft. In particular, we note that new text has been written on</p>	Thank you.

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		<p>psychological distress and self-help reflecting the patient's normal support networks. However, we are concerned that the changes have not been made consistently throughout the document, and in many areas the original recommendations in each section need to be amended to be consistent with the emphasis in the new text.</p> <p>In our response we outline a number of key areas of concern in relation to the structure, the tendency for the Guidelines still to be over-professionalised, and the need for a more integrated focus on patients' and carers' needs. We also draw attention to the short timescale used for consultation, which is in breach of the Cabinet Office 'Code of practice on written consultation' and the Compact Agreement.</p> <p>We look forward to being involved in further stages of drafting this document.</p>	<p>Concerns regarding the timescale have been drawn to the attention of NICE and an additional time period has been allowed or the first consultation period during July and August 2003. This is not an issue that the developers of the Guidance can comment on further.</p>
Macmillan Cancer Relief	Executive Summary	<p>Macmillan welcomes the fact that many of our original comments submitted in August have been reflected in the new draft dated September 2002. In particular, we note that new text has been written on psychological distress and self-help reflecting the patient's normal support networks. However, we are concerned that the changes have not been made consistently throughout the document, and in many areas the original recommendations in each section need to be amended to be consistent with the emphasis in the new text.</p> <p>For example, we remain concerned that user involvement and joint decision-making with users is still not reflected as an underpinning philosophy throughout the guidance, even though attempts have been made to give this a higher priority in certain sections. We recommend that NICE ensures greater and more</p>	<p>Please refer to the new section on user involvement, which was not included in the consultation of Part A topics.</p>

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		consistent emphasis is given to this throughout the document <i>(Reiterated in joint letter signed by 8 other charities, dated 22 October 2002).</i>	
Macmillan Cancer Relief		We recommend that users be fully involved in the development, drafting and consultation of future sections, in line with the recommendations made by Jane Bradburn in her interim report to the Editorial Board on user involvement dated September 2002.	This has been actioned.
Macmillan Cancer Relief		We continue to be concerned that areas of the Guidelines are still over-professionalised. For example, there is too much emphasis in the information section on health care professionals acting as gate-keepers to information. Similarly, while we welcome the new category in the psychological support section on normal support networks, we still feel that the remainder of the section is over-medicalised.	Please see revised sections on psychological services, user involvement, and services for families and carers. This point has been taken into account specifically in these sections and throughout the Guidance.
Macmillan Cancer Relief		We are concerned that the document is still lengthy and repetitive. We recommend that the Editorial Board edits the final version considerably and amalgamates sections. For example, we recommend amalgamating the three sections, 'Face-to-face communication', 'Information' and 'Psychological support' to reflect the interdependency if these. We also recommend that carers' needs be considered alongside patients' needs rather than in a separate section because there is considerable overlap.	The Guidance has been edited since these comments were made – however – the Guidance Development Team have made the decision to retain the separate sections – whilst referring to other relevant sections where appropriate.
Macmillan Cancer Relief		We are concerned overall about whether additional funding will be provided to implement the changes recommended in the Guidelines, in particular for Cancer Networks. Macmillan recommends that the Editorial Board, working with the Department of Health, also clarifies who will be responsible for enforcing the Guidelines and what authority they will have <i>(reiterated in joint letter from by 8 other charities).</i>	This is outside the scope of the Guidance.

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Macmillan Cancer Relief		The timescale for consulting on drafts is very short, i.e. 4 weeks only. We are particularly concerned about this when Parts A and B are brought together in May 2003 because it is critical that the guidance addresses users' needs holistically. Consultation with a group whose health is by definition unpredictable has to take longer. We therefore recommend that NICE extends the consultation period for stakeholders, at least in line with the Compact Code of Good Practice, which states that voluntary organisations should be allowed 12 weeks to reply to written policy consultations (<i>reiterated in joint letter from by 8 other charities</i>).	Please see comment above. This is an issue for NICE to consider but the Guidance developers.
Macmillan Cancer Relief	Evidence Base	In our previous response to the first draft of the Guidelines, we drew attention to the fact that limited use had been made of patient-led research, qualitative studies, user experience and professional consensus as sources of evidence. We are pleased to see in this second draft that the table showing the scope of evidence included (Table 1.1) has been changed to give greater weight to observational studies and professional consensus. Similarly, we welcome the statement in the document that RCTs should be regarded as no more valuable a source of evidence than observational studies or professional consensus.	Thank you.
Macmillan Cancer Relief	Guidelines Development Process	We are pleased to see that the contribution of the user involvement focus group, commissioned from Macmillan Cancer Relief by Kings College London to support the development of these guidelines, is now acknowledged in Appendix 3. We strongly endorse the recommendations in the interim report dated 20 September 2002 to NICE on user involvement and hope that the level of user involvement will be greater and more effective in influencing the document during future stages of drafting.	Actioned.

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Macmillan Cancer Relief	Structure And Purpose Of Document 3.1 structure	We continue to be concerned about the arbitrary division in the document – between Parts A and B and splitting users' needs into 10 domains, rather than considering them holistically as patients and carers want. We recommend that when Parts A and B are brought together, user's needs as defined in section 2.22 are considered holistically, making use of the commissioned user-involvement focus group. We also recommend that the consultation period for stakeholders be extended, at least in line with the Compact Code of Good Practice which states that voluntary organisations should be allowed 12 weeks to reply to written policy consultations. Consultation with a group whose health is by definition unpredictable takes time.	The Guidance is now being developed as a whole document rather than in the two separate sections. There is a specific section on user involvement and user needs are identified throughout the Guidance. Please see comment above regarding timescales for consultation.
Macmillan Cancer Relief	Structure	We recommend that the Editorial Board amalgamates the three sections, 'Face-to-face communication', 'Information' and 'Psychological support': patients want to have information communicated to them in a supportive way. The current divisions are arbitrary and do not take account of the fact that information, communication and support are a continuum. Amalgamating the three sections would also cut down some of the unnecessary repetition.	Comment noted – but decision made not to amalgamate the sections. It is believed that each has merits as stand alone sections reflecting specific aspects of care and service delivery. Cross-references have been provided where links need to be made between sections.
Macmillan Cancer Relief		We recommend that it would be more logical in the structure for the 'Generalist Pall Care Services' section to come before the 'Specialist Pall Care Services' section because this is more logical.	Order altered.
Macmillan Cancer Relief		We remain concerned that there are insufficient references to carers' needs in Part A. We understand that this will be addressed in Part B; however, the issues for patients and carers are not necessarily that different. There is considerable overlap between the two, for example in information needs and psychological support. This issue highlights the difficulties of	This has been addressed with the combination of the two parts – and a specific section entitled 'Services for Carers and Families, including Bereavement Care'.

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		commenting confidently on a document which is incomplete and fragmented.	
Macmillan Cancer Relief	Purpose of document	We note that attempts have been made to clarify the links between the Guidelines and other policy documents in the Introduction section. However, there are still no references to the Expert Patients Programme, and it is not clear what the status is of Supportive Care Networks in Government policy (paragraph 3.8, page 22). It is also not clear whether or not this document is intended for England only or England and Wales, particularly as the Welsh Assembly has recently issued its own preliminary guidelines on palliative care.	<p>The reference to the Expert Patient Programme is now included.</p> <p>The Guidance has been developed working on the basis that supportive and palliative care networks work alongside and in conjunction with the Cancer Networks – as defined by the Department of Health.</p> <p>The document is for England and Wales as defined in the scope.</p>
Macmillan Cancer Relief		We welcome the increased clarity about the role of Cancer Networks as the lead on these Guidelines and in particular, the reference to PCO Cancer Leads. However, the references to Strategic Health Authorities and Boards are confusing and it is not clear what relationship there will be with PCTs.	The draft referred to was written at the time of considerable change in NHS organisation and structures. These are now clarified and the text altered throughout the Guidance to reflect the current understanding of roles, responsibilities and functions.
Macmillan Cancer Relief		We are concerned overall about whether additional funding will be provided to implement the changes recommended in the Guidelines, in particular for Cancer Networks who do not actually have the money to deliver the recommendations. Macmillan recommends that the Editorial Board clarifies who will be responsible for enforcing the Guidelines and what authority they will have.	This is outside the scope of the Guidance and the Guidance Development Team.
Macmillan Cancer Relief	Editorial issues	We expressed concern in our previous response about the length and repetition in the document. To our disappointment, the document now appears to be even longer and more unwieldy. Significant work is required if the guidelines are to become a useful tool for service commissioners, or indeed if a	<p>Please see comment above regarding length and the need for stand-alone sections.</p> <p>Considerable efforts have been put into editing and refining sections of the text where considered</p>

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		<p>patient guide is to be produced. We urge NICE to consider how the document is to be used on the ground. Certainly a professional edit will be essential at the point at which Parts A and B are brought together. Much of the “Background” section could be put into an appendix, for example, and care needs to be taken that the text within each subsection of the document is consistent with the given ABC(123) structure.</p> <p>The language in the document also remains inconsistent. There appears to be confusion in the definitions between supportive and palliative care and the definitions given do not link in with the descriptions of what patients want. We recommend that the Editorial Board clarifies the differences between the two aspects of care: clinical aspects of palliative care, and supportive care – which must support patients throughout their clinical pathway.</p>	<p>appropriate.</p> <p>The production of the Guidance as one complete document should have demonstrated the clear differences between supportive and palliative care. The sections on general and specialist palliative care have also been revised.</p>
Macmillan Cancer Relief	Fundamental Principles / Assumptions	We are pleased to see that the model in Figure 2.2 has been redrawn. We welcome the recognition that patients and carers play a central role in decisions about their own care and we also welcome the comments in this section about the importance of user empowerment as a key principle underpinning good supportive and palliative care.	Thank you for your comments
Macmillan Cancer Relief	Fundamental Principles / Assumptions	In our previous response to the first draft, we were pleased to see the reference to patient’s inner resources in the Introduction section. However, this reference appears now to have been taken out!	This was removed after comments from other reviewers. However, this remains acknowledged in the co-ordination of care section and throughout the document.
Macmillan Cancer Relief	Fundamental Principles / Assumptions	We welcome the fact that there is much more emphasis throughout the document on self-help groups. However, we would like to see more references to self-care/management and more explicit recommendations relating to the role of health care professionals in facilitating this. For example, the document refers to self-care and problem solving skills as relevant on p38	This point is now included specifically in the section on user involvement and also in sections such as psychological care and rehabilitation.

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		in the Information section, but there are no recommendations to support this in the rest of the section.	
Macmillan Cancer Relief	Fundamental Principles / Assumptions	We welcome the new objective in the “Face-to-face Communication” section which discusses the need for decisions to be made in partnership with patients. This is a fundamental point, and it needs to be reflected more strongly throughout the document.	This has been done in the new draft.
Macmillan Cancer Relief	5.1 Coordination of Care	We welcome the new mention of a key worker/named contact to facilitate coordination of care. We remain concerned about the excessive emphasis on formal assessment in this section, rather than ongoing informal assessment. We recommend that the Editorial Board gives greater weight to the importance of asking patients and carers how they are feeling, as they are often the best assessors of their own needs.	Text altered to take account of this point.
Macmillan Cancer Relief	5.2 Face-to-face Communication	We welcome the fact that the recommendations reflect the fact that patients differ in their desire to be involved in decision-making. While the introduction in this section reflects well the need for health care professionals to ask patients what they know, we recommend that greater emphasis be given to patients’ own knowledge about their illness and the need to draw this out during consultation. We would also like to see greater emphasis given to listening and responding are also an important part of communication – communication is a two-way process and is more than just ‘giving out information’.	Text altered to take account of this point. Text altered to take account of this point.
Macmillan Cancer Relief	5.3 Information	We are pleased to see the importance of support, as well as information reflected in this section. Similarly we welcome the	

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		<p>new sections advising on the need for flexibility in responding to patients' needs, and particularly the reference to the fact that most professionals underestimate patients' desire for information.</p> <p>We recommend that greater emphasis be given to the role of information in helping patients to decide for themselves what care options are most appropriate to them.</p> <p>We feel that there remains too much emphasis in this section on the role of health care professionals as gatekeepers to information. This is impractical to implement without a huge investment in resources, but is also unnecessary. There are a variety of sources of information, from voluntary sector providers to electronic media and patients should be encouraged to seek these out for themselves. The role of the health care professional is more as a navigator than a gatekeeper.</p> <p>We also feel that there is too much emphasis on written material, rather than other means of communicating information. We recommend that the Editorial Board clarifies whether the recommendations here apply only to written information materials or whether they refer to information in general.</p> <p>We welcome the new improved evidence section. However, the recommendations need to reflect the new improved evidence section, as well as the new emphasis on support.</p>	<p>Text altered to take account of these points.</p> <p>The Guidance Development Team considers that this is covered in the text – no change made.</p> <p>Evidence précis have been revised for each of the sections.</p>
Macmillan Cancer Relief	5.4 Psychological Support	We welcome the greater emphasis on self-help and support in this section, particularly the addition of a separate category (level 0) in the model for assessment and support, which states that some psychological distress is normal and discusses the role of informal support structures. Similarly, we welcome the validation that non-professional support is equally as important as professional support.	This section has been extensively re-written with input from the Macmillan User Involvement Adviser who is on the Editorial Board.

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		<p>However, the rest of this section remains relatively unchanged. It is important to note that around 80% of people who receive a diagnosis of cancer experience a normal adjustment process, with 10% requiring some assistance and another 10% some form of psychological help. We recommend that the section be redrafted to emphasise more strongly that the majority of cancer information and support staff can provide non specialist support, help and care, which is more than adequate to meet the needs of patients and their carers.</p>	
Macmillan Cancer Relief	5.5 Specialist Palliative Care Services	<p>We welcome the reference to the benefits of day therapy and respite services in this section, which is important to both patients and their carers. Also see Joint response at end of table</p>	Noted.
Marie Curie Cancer Care		See Joint response at end of table	
Merck Pharmaceuticals		This organisation was approached but did not respond.	
Napp Pharmaceuticals		This organisation was approached but did not respond.	
National Cancer Alliance		See Joint response at end of table	
National Council for Hospice and Specialist Palliative Care Services		This organisation was approached but did not respond.	
Northern Cancer Network - 2		This organisation was approached but did not respond.	
Ortho Biotech		In our response to the first draft guidelines (attached) we expressed:	

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		<p>The relevance of including in the supportive care guidance a section on symptom control and side effects associated with chemotherapy, and include within this service configuration issues with regard to chemotherapy induced anaemia and fatigue.</p> <p>The urgent need for the DoH and NICE to rapidly commission the production of supporting clinical guidance on best treatment and care practices in cancer that will directly improve the quality of life of patients with cancer. These are needed to complement the service delivery guidance but would focus on the clinical evidence for best supportive care treatments, including management of chemotherapy related side effects such as anaemia/fatigue.</p>	<p>The Supportive and Palliative Care Guidance provides a service configuration model – and is not a clinical guideline. References to specific treatments will not be included in the Guidance.</p> <p>This point is outside the scope of the Guidance.</p>
Ortho Biotech		<p>Our key follow-up comments on draft 2 are:</p> <p>It appears minimal attention has been given in the second draft part A to service issues for the provision of information, communication and care co-ordination relating to the side effects of chemotherapy. In both the manual and evidence documents there was no mention of cancer related fatigue or anaemia.</p> <p>At a minimum we would have expected cancer related fatigue to be included as a symptom in the definition of patient and carer outcome measures used on page 7 of the Research Evidence Manual (we commented on this in our response to the first draft).</p>	<p>Please see comment above regarding inclusion of information regarding treatments or side effects.</p>
Ortho Biotech	Page 18	<p>On page 18, section 2.30 (“Communication”) of the Manual it was stated that 29% of patients in the national survey of cancer</p>	<p>This point is covered in the sections on information and face to face communication.</p>

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		patients did not completely understand the discussions of the possible side effects of their treatment. We feel that it would enhance the clarity of the guidance to stress the need for clear communication and information on the side effects of treatment (and who is best placed to provide that communication), and to specify what these side effects are.	
Ortho Biotech		Details are provided in the manual of the process by which topic proposals for the guidance were selected, including a 2 day residential event, although no timelines are specified. We feel the dates of the key events should be published. It may be that at the time topics were being selected issues such as cancer related fatigue were not sufficiently prominent in the minds of the experts. However, increasing professional attention has been given to issues around symptom management in recent times including in the USA in July 2002 a National Institutes of Health State of the Science Conference Statement on pain, depression and fatigue Symptom Management in Cancer ¹ . Hence, we feel the process of guidance development should be sufficiently flexible to encompass new topics as required during the course of guidance development.	Please see comment above regarding the inclusion of treatment specific information – text not altered.
Ortho Biotech		<p>We recognize the importance of clear guidelines for the improvement of cancer service delivery which improve patients well being and we hope it is possible to consider our comments. We would also like to stress the urgent need for NICE to press on with the production of clinical guidelines which incorporate evidence for best treatment and care practice in symptom management and treatment side effects such as cancer related anaemia and fatigue.</p> <p>We are happy to discuss any of our comments/views in more detail with either the Guidance Development Group or NICE.</p>	This comment related to NICE and not to the Guidance developers.

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		National Institutes of Health State-of the-Science Conference Statement. Symptom Management in Cancer: Pain, Depression and Fatigue, Draft Statement, July 15-17, 2002	
Pharmacia Limited		Thank you for sharing the second draft of the above guidance with us. We have no significant comments to feedback. However, you may be interested in a number of minor typo's that have been identified below;	
Pharmacia Limited	page 13 – 2.18	“soles” should be “roles”	Thank you for these!
Pharmacia Limited	page 43 – 6.18 (fourth line)	“self help and” is repeated	
Pharmacia Limited	page 43 – Table 6.1	“self help” repeated under ‘level 0, Interventions’.	
Prodigy		This organisation was approached but did not respond.	
Prostate Cancer Charity, The		You emailed in the middle of a final gallop through the document. We have nothing more to add and feel that most of our original comments have been incorporated satisfactorily. The tone of the document has been majorly revised and it reads much more as if it's a genuine attempt to bring patients to the centre of it all. So that's a 'well done'. Also See Joint response at end of table	Thank you.
Relatives and Residents Association		This organisation was approached but did not respond.	
Royal College of General Practitioners		This organisation was approached but did not respond.	
Royal College of Nursing		This organisation was approached but did not respond.	

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Royal College of Nursing – Palliative Nursing Group		This organisation was approached but did not respond.	
Royal College of Paediatrics and Child Health		This organisation was approached but did not respond.	
Royal College of Physicians		This organisation was approached but did not respond.	
Royal College of Psychiatrists		This organisation was approached but did not respond.	
Royal College of Radiologists		This organisation was approached but did not respond.	
Royal College of Surgeons of England		This organisation was approached but did not respond.	
Royal Pharmaceutical Society of Great Britain		This organisation was approached but did not respond.	
Sargent Cancer Care for Children		This organisation was approached but did not respond.	
Scottish Intercollegiate Guidelines Network (SIGN)		This organisation was approached but did not respond.	
Society and College of Radiographers		This organisation was approached but did not respond.	
Sue Ryder Care		This organisation was approached but did not respond.	

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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 Myeloma Forum		This organisation was approached but did not respond.	
UK Pain Society		This organisation was approached but did not respond.	
Joint response: National Cancer Alliance The Prostate cancer charity Help the Hospices Breakthrough Breast cancer Breast cancer care Cancer Bacup Marie Curie cancer care The National Council for Hospices and Specialist Palliative care services Macmillan cancer relief		As organisations reflecting the views and priorities of users of supportive and palliative care services, we are pleased to see that a number of our concerns have been reflected in the 2 nd draft of Part A, dated September 2002. However, we still share three key areas of concern:	Thank you for your comments.
Joint response:		The timescale for consulting on drafts is very short, i.e. 4 weeks	Concerns regarding the timescale have been

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Organisation/Individual name	Section Number	Comment	Response/Changes made by Guideline developers
<p>National Cancer Alliance The Prostate cancer charity Help the Hospices Breakthrough Breast cancer Breast cancer care Cancer Bacup Marie Curie cancer care The National Council for Hospices and Specialist Palliative care services Macmillan cancer relief</p>		<p>only, in breach of the Cabinet Office ‘Code of practice on written consultation’. We are particularly concerned about the short consultation period when Parts A and B are brought together in May 2003 because it is critical that the guidance looks at users’ needs holistically. Consultation with a group whose health is by definition unpredictable has to take longer. We therefore recommend that NICE extends the consultation period for stakeholders, at least in line with the Compact Code of Good Practice, which states that voluntary organisations should be allowed 12 weeks to reply to written policy consultations. We also request that NICE highlight revisions in the document during successive drafting phases to enable stakeholders to comment on changes more easily.</p>	<p>drawn to the attention of NICE and an additional time period has been allowed or the first consultation period during July and August 2003. This is not an issue that the developers of the Guidance can comment on further.</p>
<p>Joint response: National Cancer Alliance The Prostate cancer charity Help the Hospices Breakthrough Breast cancer Breast cancer care Cancer Bacup Marie Curie cancer care</p>		<p>We remain concerned that user involvement and joint decision-making with users are still not reflected as an underpinning philosophy throughout the guidance, even though attempts have been made to give these higher priority. We recommend that the Editorial Board ensures greater and more consistent emphasis is given to this throughout the document, and users are fully involved in the development, drafting and consultation of future sections.</p>	<p>Please refer to the new section on user involvement, which was not included in the consultation of Part A topics. References to user involvement at both a strategic level and a personal level are included throughout the document.</p> <p>Three user representatives are members of the Editorial Board and their input has been invaluable throughout the process. The User Reference Group has also provided invaluable input.</p>

**Supportive and Palliative Care 1st Consultation – Stakeholder comments
date**

National Institute for Clinical Excellence

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The National Council for Hospices and Specialist Palliative care services Macmillan cancer relief			
Joint response: National Cancer Alliance The Prostate cancer charity Help the Hospices Breakthrough Breast cancer Breast cancer care Cancer Bacup Marie Curie cancer care The National Council for Hospices and Specialist Palliative care services Macmillan cancer relief		We are concerned that many of the document's recommendations will be impractical to implement owing to a lack of resources. Additional resources will be needed to ensure that the recommendations on information provision and other services are fully implemented by cancer networks. We recommend that NICE and/or the Department of Health clarifies how the guidance should be implemented on the ground and what resources would be needed to support this. We are also concerned that the document is still lengthy and repetitive and recommend that the Editorial Board edits the final version considerably so that it is workable and useable. 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.	This point is outside the scope of the Guidance. However, the economic review is now complete and will be a part of the July/August 2003 consultation exercise. Considerable efforts have been put into editing and refining sections of the text where considered appropriate.