Head and Neck Cancer Service Guidance
2nd consultation
18th May – 15th June 2004
National Institute for Clinical Excellence

Organisation	Comment number office use only	Document	Chapter number Or general	Line	Comments Please insert each new comment in a new row.	Developers' response Please respond to each comment
Abbott Laboratories Limited (BASF/Knoll)						This organisation was approached but did not respond.
Afiya Trust, The						This organisation was approached but did not respond.
All Wales Head and Neck Cancer Steering Group						This organisation was approached but did not respond.
Amgen UK Ltd						This organisation was approached but did not respond.
Association of British Neurologists						This organisation was approached but did not respond.
Association of British Neurologists						This organisation was approached but did not respond.
Association of Hospice and Specialist Palliative Care Social Workers						This organisation was approached but did not respond.
Association of Surgeons of Great Britain and Ireland						This organisation was approached but did not respond.
Association of the British Pharmaceuticals Industry (ABPI)						This organisation was approached but did not respond.
AstraZeneca UK Ltd						This organisation was approached but did not respond.
Aventis Pharma						This organisation was approached but did not respond.
Bard Limited						This organisation was approached but did not respond.
Barts and the London NHS Trust	1	All	General	General	My colleagues and I are grateful for the opportunity to comment on this document, coming late as we have, we hope that the comments we have made will not be ground already	No response required.

					considered and dismissed.	
Barts and the London NHS Trust	2	Full	General	General	Firstly, other than our two colleagues in Leeds, we note there are no other anaesthetists involved in this review.	No response required.
Barts and the London NHS Trust	3	Full	B/Ground	307-311	Pharyngo-laryngoscopy in OPD is invaluable when planning airway management.	This is too much detail for the Background section – this is not about service structure or where it should be provided.
Barts and the London NHS Trust	4	Full	B/Ground	337-347	Tracheostomy care is of such high priority that we feel this may merit mention here.	Not appropriate for the Background section.
Barts and the London NHS Trust	5	Full	B/Ground	387-395	We fully concur that specialised skill is essential, and that extends beyond the surgeon to the team. We have seen examples of patients labelled inoperable by anaesthetic colleagues, who would be accommodated in a more specialised area.	No response required.
Barts and the London NHS Trust	6	Full	2	88	We fully endorse the need for a special interest, or expertise in difficult airway and long reconstructive procedures.	No response required.
Barts and the London NHS Trust	7	Full	3	115-116	Patients dread anaesthesia usually for all the wrong reasons, We feel strongly patients should have access to experienced anaesthetic advice or information which is invaluable in making choices between treatment modalities.	The following sentence has been added in Topic 4 to decision-making about treatment: 'Issues about anaesthesia should be discussed with patients for whom surgery would be appropriate.'
Barts and the London NHS Trust	8	Full	3	205-208	Patients dread anaesthesia usually for all the wrong reasons, We feel strongly patients should have access to experienced anaesthetic advice or information which is invaluable in making choices between treatment modalities.	See response to point above.
Barts and the London NHS Trust	9	Full	4	36-38	We assume this would include a specialist anaesthetist? Our experience is that cardiologists and respiratory physicians lack focus when assessing fitness for a 14hr reconstruction	This issue is covered in the paragraph 'Anaesthetic assessment', in Topic 4: Pre-treatment assessment and management.
Barts and the London NHS Trust	10	Full	4	62	We are in full agreement as to the benefit of Peg tubes. It concerns us that patients undergoing peg insertion and dental extraction prior to definitive surgery may have difficult airways but are sedated and recovered in opd facilities.	The Developers are not entirely clear about the point being made. Reference is already made to the need for guidelines.
Barts and the London NHS Trust	11	Full	4	87-90	The co-morbidity demonstrated in evidence 122-126 makes it vital that pre-operative assessment should be seen as a team effort. Proper assessment of metastatic spread is important but so is cardiovascular disease which is likely to compromise flap survival	This is covered by 'assessment of the patient's general health'. Also, this is a benefit, not a recommendation.
Barts and the London NHS Trust	12	Full	5	General	We have four issues here which it may be felt are operational. We feel however that we should raise them We do not pretend to know the answers 1) We have a lot of experience of primary tumour resection	The following text has been amended/added under the heading 'Surgery':

					and reconstruction. These commando procedures are taking between 14 and 23 hrs operating time. This length of procedure raises questions of safety and continuity of care, and will fall foul of working time issues 2) Dissection versus reconstruction There is a conflict of interest that arises when the surgeon resecting a tumour over 4 – 6 hours is also faced with reconstructing a flap to fill the hole directly afterwards, particularly when the tumour is larger than expected or the surgeons repertoire of flaps is limited. It would seem that different specialities have different policies on this. 3)Intensive care We wholeheartedly agree with the concept of specialist wards for head and neck surgery. Some of our specialists surgeons insist on admission to ITU after prolonged surgery, others do not Some anaesthetists ward their patients after a long flap procedure others admit to ITU Availability of intensive care facilities are a major issue and inconsistency in this policy has been a source of great stress in our department 4) Lastly we would like to reinforce the need for specialists with experience, of whatever speciality, and the need for multidisciplinary teamworking to deliver the best clinical care.	'All surgical modalities, including laser excision and partial laryngeal excision, should be available. A range of surgeons who specialise in different aspects of the procedure should be involved in complex operations: for example, one surgeon may lead in tumour resection, whilst others concentrate on reconstruction. Microvascular expertise is essential in reconstructive surgery to minimise the risk of flap failure (failure of tissue grafts used to restore the patient's appearance and function after surgery), which is a major source of morbidity among these patients. The MDT should agree policies on admission criteria for intensive care, and adequate intensive care facilities must be available to meet anticipated need.'
Barts and the London NHS Trust	13	Full	5	381-383	Our trust has identified the need for specific tracheostomy care training for all our nursing staff. Audit work identified deaths due to poor trache care and an improvement in survival with training We also demonstrated through audit that despite a specialist head and neck/neuro ward every ward in our trust cared for at least one trache patient each year. The training was therefore made available to all staff. We feel that post operative tracheostomy care is done poorly and would benefit from the raised awareness this document should bring	The following text has been added: 'Ward staff should have specific training in looking after patients who have undergone tracheostomy. Such training should be available to staff on all wards where such patients are nursed.'

Barts and the London NHS Trust	14	Full	8	63-70	This is excellent if patients and staff are well trained and informed. In the absence of appropriate skills and training the acute airway is a source of a lot of anxiety and mayhem with the potential for distress to patents, relatives and staff.	The text has been amended as follows: 'Patients at risk of airway obstruction should be identified and ambulance personnel, GPs and carers should be informed of where such patients should be taken. They should be made aware that these patients should *not* be taken to accident and emergency departments unless no alternative is available.'
Baxter Oncology						This organisation was approached but did not respond.
Bayer PLC						This organisation was approached but did not respond.
Biolitec Pharma Ltd (formerly QuantaNova Limited)	1	All	General	General	Attached are the comments from Biolitec Pharma on the second consultation for the guidance on head and neck cancer. We noted that our comments on the first consultation were not addressed in the revised version, and wondered if there was a reason for this oversight. The use of photodynamic therapy (PDT) as a treatment option for recurrent and advanced disease is not adequately covered by the documents.	The comments on the first consultation were addressed (see response to stakeholder consultation). There is insufficient evidence to recommend the routine use of PDT in head and neck cancer. The manual covers the use of PDT in topic 7 (Follow-up and recurrent disease): 'Other forms of therapy such as photodynamic therapy and monoclonal antibody treatment should only be offered in the context of multicentre clinical trials, unless there is reliable evidence of effectiveness. Research is urgently needed, especially to evaluate newer therapeutic agents.'
Biolitec Pharma Ltd (formerly QuantaNova Limited)	2	Full	7	61	The use of PDT is only recommended in the context of multicentre clinical trials. However, Foscan-mediated PDT has been approved in the European Union for the palliative treatment of patients with advanced head and neck squamous cell carcinoma failing prior therapies and unsuitable for radiotherapy, surgery or systemic chemotherapy. The clinical effectiveness of PDT in recurrent and advanced head and neck cancer has been demonstrated in clinical trials (D'Cruz AK, et al. Head Neck 2004;26:232-240; Biel M. Proc	The references given are one published study, one conference abstract and one consensus guideline. The published study is not an RCT. This is not a suitable evidence base on which to recommend an intervention. Please refer to response to point above.

					ASCO 2003;22:503). In addition, the use of PDT for the management of low volume disease and for the palliation of end-stage disease is described in the Third Consensus Document (2002) for Effective Head and Neck Cancer Management complied by the British Association of Otolaryngologists Head and Neck Surgeons (page 78).	
Biolitec Pharma Ltd (formerly QuantaNova Limited)	3	Full	8	51	There is no reference to the use of PDT for palliation. The existing statement could be amended to read: "Surgery, radiotherapy, chemotherapy and photodynamic therapy can all be used for palliation, and all treatments should be available".	The following has been added: 'Other forms of therapy should only be offered in the context of multicentre clinical trials, unless there is reliable evidence of effectiveness.'
Biolitec Pharma Ltd (formerly QuantaNova Limited)	4	Public		45	There is no reference to the use of PDT in the treatment of head and neck cancer. **A statement could be added to show that additional treatment modalities, such as PDT, are available.**	New text proposed under more research should be done section (in light of the above text) - 'Involvement in clinical trials using treatments such as photodynamic therapy or monoclonal antibody treatment may be discussed with patients.'
Boehringer Ingelheim Ltd						This organisation was approached but did not respond.
Brighton & Sussex University Hospitals Trust						This organisation was approached but did not respond.
British Association for Counselling and Psychotherapy	1	Full	1	104 – 107	We are disappointed that NICE decided to remove all reference to primary care staff taking advantage of opportunities to encourage patients to reduce their risk of developing cancer by overcoming addiction, and referring them onto appropriate counselling/addiction services or patient support groups where appropriate. Patients with persistent mouth or throat problems who are also addicted to drugs or alcohol may benefit from psychotherapeutic intervention to understand the potential risk of associated cancer development and to address their addiction problems.	The sentence: 'They should offer help with overcoming addiction, including referral to appropriate services' has been added to the text under Prevention.
British Association for Counselling and Psychotherapy	2	Full	3 (2)	224	The sentence 'notably the clinical psychologist and liaison psychiatrist' should be re-written 'notably, the clinical psychologist, counsellor and liaison psychiatrist', in line with the extended team member list on pages 44-45 (line 100). All	The current research evidence does not support the inclusion of a counsellor.

					three disciplines offer effective psychological interventions.	
British Association for Counselling and Psychotherapy	2	Full	3	224	The sentence 'notably the clinical psychologist and liaison psychiatrist' should be re-written 'notably, the clinical psychologist, counsellor and liaison psychiatrist', in line with the extended team member list on pages 44-45 (line 100). All three disciplines offer effective psychological interventions.	The current research evidence does not support the inclusion of a counsellor.
British Association for Counselling and Psychotherapy	3	Full	4	200	The sentence 'Counselling can also be helpful for carers' is missing from the second draft. This may have been omitted by accident. If deliberate, we would ask that you reconsider the decision as carers are often an overlooked, yet invaluable support for patients and in times of stress may themselves benefit from counselling.	The study described here did not report the results of carers' views on counselling. Although the authors concluded that counselling can be helpful for carers, there are no results to support this conclusion. Therefore the statement has been deleted. Details of the study are in the Research Evidence (Hull 1994).
British Association for Counselling and Psychotherapy	4	Full	6	77	Despite the fact that psychological service support is 'adequately covered' elsewhere in the manual, we believe that this line should include the term 'counsellor' as a local support team member, alongside psycho-oncology, liaison psychiatry or clinical psychological services. This would also ensure consistency within the manual (see page 45 line 100)	This has been added.
British Association for Counselling and Psychotherapy	5	Full	6	102	The sentence 'Social skills training and cognitive behavioural therapy should be available…' should be re-written 'Social skills training, counselling and cognitive behavioural therapy should be available….' This is internally consistent with the suggested MDT Extended Team member's list (see page 44-45) and with the range of services these special groups of patients need.	Few counsellors are trained to deal with this specific problem.
British Association for Counselling and Psychotherapy	6	Full	Appendix 4		The term Counselling is used throughout the Manual, but is not defined in the appendix. We believe its inclusion would reduce some of the confusion that surrounds elements within the talking therapy field. We would suggest the following: Counselling is a generic term used to describe a broad range of 'talking therapy' interventions delivered by qualified	The purpose of the Glossary is to define words or phrases that are unfamiliar to a lay audience. In the Developers' view, 'counselling' is generally understood. No amendment proposed.

					counsellors, who work within a diverse range of settings. Counselling is a systematic process which gives individuals an opportunity to explore, discover and clarify ways of living more resourcefully, with a greater sense of well being. Counselling may be concerned with addressing and resolving specific problems, making decisions, coping with crises, working through conflict or improving relationships with others. Additional information about counselling is drawn from the NICE guideline for the Management of Depression (p.122), which states: Counselling involves active listening, where the client can explore various aspects of their life and feelings, talking about them freely and openly in a way that is rarely possible with friends or family. Bottled up feelings such as anger, anxiety, grief and embarrassment can become very intense and counselling offers an opportunity to explore them with a possibility of making them easier to understand.	
British Association for Counselling and Psychotherapy	7	Full	Appendix 4		'Cognitive and behavioural intervention' is widely used by many practitioners within the talking therapy field, including counsellors and psychotherapists. We would therefore recommend that the words, 'often delivered by psychologists' be removed.	Amendment accepted.
British Association for Counselling and Psychotherapy	8	IFP		108-109	We would suggest this sentence is reconsidered to say: The involvement of <u>psychotherapeutic</u> services is especially important, because patients <u>can often develop</u> psychological problems, which may be worsened by the effects of treatment. 'Psychotherapeutic' because it encompasses the full range of talking therapy disciplines, including psychiatry and psychology, and 'can often develop psychological problems' because the current phasing implies that patients will automatically have psychological problems as a result of their cancer.	Comments noted : see below.

British Association for Counselling and Psychotherapy	9	IFP		149	The term 'psychological services' should be replaced with the term 'psychotherapeutic services' for the reasons mentioned above.	Comments noted. 'Psychological, psychiatric and counselling' used as examples for ease of understanding.
British Association for Counselling and Psychotherapy	10	IFP		203	We would recommend that this sentence be changed to read: To improve services, more information is needed about the effects of treatment and care of patients with head and neck cancers. 'Effects' of treatment because 'effectiveness' implies that only good results occur, which is not always the case.	Changes made.
British Association for Counselling and Psychotherapy	11	IFP		208	For the same reasons noted above, this sentence should be changed to read: More research is urgently needed on the effects of assessments, treatment, aftercare services and rehabilitation.	Changes made.
British Association of Endocrine Surgeons	1	All	General	General	The draft is an improvement on the first and builds on the appreciation that thyroid and aerodigestive malignancies are different diseases with different behaviours dealt with by different teams.	No response required.
British Association of Endocrine Surgeons	2	Full	General	General	We welcome the clear statement that Thyroid malignancy should be dealt with by Thyroid MDTs and the understanding that such teams will also be dealing with non-malignant but often more complex diseases which are equally life threatening. As what you have chosen to call "thyroid cancer MDTs" will also deal with, adrenal and other non head and neck malignancies as well as complex non malignant disease, the term "Endocrine MDT" is our preferred term and is a concept which we will continue to promulgate.	The Guidance clearly acknowledges that under these recommendations MDTs dealing with thyroid cancer take two main forms, depending on whether the local service is built around an endocrine or head and neck model. In either case the role they fulfil is that of the thyroid cancer MDT. In practice some teams may prefer to call themselves by other names e.g. thyroid MDT.
British Association of Endocrine Surgeons	3	All	General	General	We are still concerned at the low level of Endocrine Surgical input into the document. The text reveals a lack of familiarity with thyroid disease and we note only four names in your list of referees who might be considered Endocrine surgeons. Of these Professor Farndon has, sadly, been dead for several years and Mr. Dudley is retired. Comments are appended below to identify by line some of the errors of clinical fact in	The referees listed are those who were consulted on the original proposals, following the Proposal Generating Event in February 2001. As is usual practice, all those involved in the enterprise are listed; inevitably, it is a somewhat historical document.

					the text.	
British Association of Endocrine Surgeons	4	Full	General	General	Our Executive committee are very concerned that there is no specific mention of Medullary Thyroid Cancer in the text. Our own national peer audit shows that this malignancy tends to be under-treated by surgeons who are not from specialist centres and we believe all cases of Medullary carcinoma MUST be referred to specialist centres. They should NOT be referred to head and neck teams as they may have other endocrine abnormalities and adrenal malignancy, they require formal genetic assessment and where familial cases are identified prophylactic surgery is required in childhood. A change of practice in this specific malignancy may well produce health and survival gains numerically greater than improvement in the care of the more common but usually survivable differentiated tumours.	The guidance clearly recommends that thyroid cancers should be dealt with by a specialist MDT for this disease, serving a substantial population. This is not a clinical guideline and the precise arrangements for sub-types of thyroid cancer come within the remit of this MDT.
British Association of Endocrine Surgeons	5	Full	General	General	In view of the impending release of guidelines on the management of endocrine tumours in childhood it would seem appropriate to make a comment on their management.	Children's cancers are excluded from the scope of this Guidance.
British Association of Endocrine Surgeons	6	Full	B/Ground	397	The moves to specialisation in endocrine surgery have been continuing for 20 years though more slowly in the UK than elsewhere in Europe. We hope this document will help to speed up the process.	No response required.
British Association of Endocrine Surgeons	7	Full	B/Ground	428-439	We are disappointed that you have not included reference to the BAES national peer review audit, now in its fifth year. The delayed analysis document of the first 18 months of data (1,622 operations) is now complete and has gone to the publishers. We would be happy to send you a pre-publication text if you wish. Several of the lessons apparent from the audit have already informed changes in the national guidelines due for republication in August (which incidentally indicate that all thyroid malignancy should be considered at a thyroid MDM) Draft on www.baes.info	The draft referred to is not available on the website. Also, this is too much detail for the Background section.
British Association of Endocrine Surgeons	8	Full	1	77	Suggest you delete "(goitre)" which in current clinical parlance is a swelling of all or most of the thyroid, distinguishing it from a solitary or dominant nodule.	Agreed. This has been deleted.
British Association of Endocrine Surgeons	9	Full	1	115	WRONG! Thyroid cancer presents as a solitary nodule or as a "dominant" nodule in a multinodular goitre. It is now regarded as prudent to ignore the thyroid function in the context of excluding malignancy. A solitary nodule is potentially malignant regardless of the thyroid status and ALL solitary	The text has been re-worded as follows: 'Patients with thyroid cancer usually present with a solitary nodule in the thyroid gland or a dominant nodule in a multi-nodular goitre. Amongst such patients, the incidence of

					nodules should be referred to a thyroid specialist. Those who have criteria suspicious for malignancy should be referred to a rapid access Thyroid clinic. We would consider it totally inappropriate to separate off a subgroup to be sent to a " head and neck" clinic or a " neck lumps" clinic unless that is the routine path for thyroid referrals in that geographic area.	malignancy is approximately 10%. All patients with solitary nodules should be referred to a clinic that deals with patients who may have cancer, which may be a thyroid clinic or a neck lump clinic, depending on local arrangements. If the nodule is increasing in size, urgent referral is necessary (see above).'
British Association of Endocrine Surgeons	10	Full	2	105	We note again that it would be more constructive to refer to these MDTs as THYROID MDTs or ENDOCRINE MDTs.	See response to 2nd point above.
British Association of Endocrine Surgeons	11	Full	2	332	Re. your comment on inadequate treatment in specialist centres. You really have an obligation to reference this sort of statement except in so far as some patients with any disease will be inappropriately treated in any specialist centre you study.	This statement has now been deleted.
British Association of Endocrine Surgeons	12	Full	2	442	Though we support the thrust of the argument here this section represents inappropriate selection of data simply to support the argument and detractors could quote British and Australian studies that find that surgical complications are NOT necessarily related to volume in thyroidectomy. The BAES audit also shows this. If you wish quote this US paper you ought to add its reference.	The US study is referenced in the Research Evidence document.
British Association of Endocrine Surgeons	13	Full	2	410	and elsewhere. Whilst accepting the NYCRIS data is probably very good there is no evidence that it is typical for the nation as a whole and there ought to be a disclaimer added to this effect. (also p 95 L347)	The claim is not made that this is typical – if this situation applies anywhere (as in the NYCRIS area) then steps must be taken to improve it.
British Association of Endocrine Surgeons	14	Full	3	65	WRONG!. As above. All solitary thyroid nodules must have an FNAC done REGARDLESS of thyroid status. If you have evidence to the contrary we would be interested to see it. Core biopsies of the thyroid are not generally done; firstly because they are considered dangerous and secondly because they are (as the paper you quote shows) not much better at reaching a diagnosis particularly in the difficult area of follicular lesions because sampling errors occur.	This has already been answered in earlier sections, and is felt to be too clinically detailed for service guidance. It is agreed that core biopsy of the thyroid is not generally done, and whilst all solitary thyroid nodules should have an FNAC regardless of thyroid status at presentation, it should generally not be done in the hyperthyroid state because it leads to false positive results. Patients who do have hyperthyroidism should be rendered euthyroid before the FNAC is performed.
British Association of Endocrine Surgeons	15	Research	133	147	As above. (WRONG!. As above. All solitary thyroid nodules must have	See response to point above.

		Evidence			an FNAC done REGARDLESS of thyroid status. If you have evidence to the contrary we would be interested to see it. Core biopsies of the thyroid are not generally done; firstly because they are considered dangerous and secondly because they are (as the paper you quote shows) not much better at reaching a diagnosis particularly in the difficult area of follicular lesions because sampling errors occur.)	
British Association of Endocrine Surgeons	16	All	General	General	There are other criticisms of detail but so long as the management of thyroid malignancy continues to be considered separately from aerodigestive malignancy the general thrust of the proposals are acceptable and could improve outcomes for thyroid cancer patients. (If the very significant funding required is made available and if there is sufficient control exerted to make sure the recommendations are implemented).	Thank you for your comments.
British Oncology Pharmacy Association					The British Oncology Pharmacy Association does not wish to submit any further comments on this guidance.	Thank you.
British Society for Oral and Maxillofacial Pathology						This organisation was approached but did not respond.
British Association for Parenteral & Enteral Nutrition (BAPEN)	1				BAPEN has no further comments on the head and neck guidelines but were disappointed that our earlier simple suggestions (attached) were ignored.	We have responded to all the points received.
British Association for Parenteral & Enteral Nutrition (BAPEN)	2			General	Thank you for the opportunity to examine these draft guidelines in relation to nutrition support.	Thank you.
British Association for Parenteral & Enteral Nutrition (BAPEN)	3		4	P69.	We were delighted to see that nutritional assessment was included along with evidence to suggest that appropriate help may be beneficial	No response required.
British Association for Parenteral & Enteral Nutrition (BAPEN)	4			P 27	The need for the occasional use of artificial nutritional support via enteral tube, gastrostomy or occasionally PN should be mentioned	Too much detail for the Background section.
British Association for Parenteral & Enteral Nutrition (BAPEN)	5		2	P44	Although a suitably experienced dietitian is includede in the MDT, we feel that on occasions access to a nutrition support team skilled in providing safe parenteral nutrition for potentially extended periods should be mentioned. There may also be the need for gastrostomy placement either by gastroenterologists or radiologists.	We believe that all these points are already adequately dealt with.
British Association for						This organisation was approached but did

the Study of Community Dentistry (BASCD)						not respond.
British Association of Art Therapists						This organisation was approached but did not respond.
British Association of Endocrine Surgeons						This organisation was approached but did not respond.
British Association of Head and Neck Nurses						This organisation was approached but did not respond.
British Association of Head and Neck Oncology Nurses (BAHNON)	1	Full	2	168-169	The model of the CNS seeing all patients irrespective of need is not a good model, nor does it reflect guidance from the UKCC, RCN, DoH, or Macmillan Cancer Relief on the role of the CNS. I think that it is very important that a suitably qualified nurse assesses all patients, but this nurse does not need to be a CNS. The guidance should perhaps be saying that there should be a suitably qualified generic cancer nursing workforce in all clinics and wards where these patients are cared for so that fundamental standards of care can be met at all stages of the patient's pathway. The CNS should lead the development of pathways, guidelines, protocols and education to ensure that patients receive a high standard of nursing care at all times. The CNS should have clear referral criteria so that the medical and nursing teams ensure that all patients who have complex needs are referred to the CNS for expert specialist support. The CNS will facilitate good teamworking to ensure that this happens. This will ensure that there is a sustainable workforce available at all times to patients, providing the high standard of the fundamental care that patients need. It will also ensure that there are always nursing staff who are being developed and gaining experience, in order to build a healthy resource of skilled nurses for the future. I would go as far as surmising that the models of nursing care being encouraged in this and previous cancer guidance documents have had a very detrimental effect on the provision of a generic skilled nursing workforce, especially in outpatient settings. They have been very insular, and encouraged a reliance on the site specific CNS to fill various gaps in the service, which has led to concealment and ignoring of issues	The numbers of new head and neck cancer patients are not large and unmanageable – a typical MDT serving around a million population will discuss just two or three new patients on average each week. The needs of these patients are very variable in terms of the nature of their disease, the therapeutic options likely to be relevant, the implications for the patient of these choices, and the starting position of the individual patient. The interplay of these issues is more than usually complicated in head and neck cancer, and is best assessed by the most expert nurse i.e. the CNS. She is then able to contribute effectively in the MDT and in helping patients with the difficult treatment choices that face them (based on first hand knowledge of the patients). This input is important in helping shape subsequent decisions on management. It is clear from our own commissioned work (NCA) and from Macmillan amongst others that patients value access to the CNS very highly and believe it to be crucial to their welfare. Thus, although we have modified the text on the CNS significantly to further reflect these comments and the stress they place

					of under resourcing in the generic workforce. This means that we no longer have a good base of generic nurses providing fundamental care and being developed, and also that we have created very unhealthy working practices for CNSs. It also means that we do not have a sustainable service for patients. Therefore I would suggest replacing this text with something along the lines of – Providers should ensure that there is a good base of skilled cancer nurses in clinics and departments to ensure that patients' fundamental needs are met at all stages of the pathway. Care pathways and guidelines should be in place to ensure that all patients are assessed and supported by a qualified skilled nurse. All patients with complex needs are referred to the CNS for expert assessment and support prior to decisions about management being made (NB It may be most appropriate for the CNS to meet the patient AFTER the MDT meeting, when the team has discussed the various options. The CNS can then talk through these options with the patient.) The CNS will provide expert support to the patient on decisions about treatment, working closely with other team members.	on the importance of the development and professional leadership roles, and the variable level of input required by individual patients, we retain the vital 'failsafe' requirement for all patients to see the CNS in the initial period. We have increased the time window within which the CNS should see patients for the first time to help the practical arrangements. We have also emphasised in a number of areas the CNS role in 'ensuring' rather than personally 'doing' in order to show that the role is a complex mix of personal contributions and wider responsibilities. Some of these comments emphasise the roles of CNSs in developing and supporting the wider nursing workforce, a position which is clearly accepted in this Guidance. However, the comments are expressed as if the explicit role of the CNS in seeing patients before and during the early decision making process was in some senses an alternative to the objective of developing and supporting a broadly based skilled nursing workforce. This perspective is not accepted, and the developers consider that both objectives are important. Some general comments on the way nursing as a whole is structured and managed go beyond the scope of this Guidance. The specific suggestion of clear referral criteria to the CNS must be viewed with a degree of caution as they could act as a barrier to easy patient access to the CNS.

						These comments, as others on this topic, appear motivated at least in part by an unstated concern that there will not be appropriate developments in CNS staffing (and in other key supportive staff such as SALTs) as a result of this Guidance. As the cost impact work makes clear this is the crucial area for investment to remedy widespread weaknesses in current services. CNS numbers are very low at present and change in this is vital. Developments in these areas are expected to take time, but will show real benefits in the quality of life outcomes for these patients. Given that this enhancement to services occurs over time - as it has following previous documents, then the CNS role set out is both realistic and sustainable.
British Association of Head and Neck Oncology Nurses (BAHNON)	2	Full	2	470	I would suggest instead of this outcome measurement – Evidence that the department is staffed adequately to ensure that all patients have been assessed by a suitably skilled qualified nurse, and that those with complex needs are seen by a CNS And Evidence that every patient is given contact numbers for members of the team - the department nursing team, the consultant's secretary, the CNS, SLT etc as appropriate(then if the named nurse/CNS is on leave, there will always be someone to speak to)	See earlier comments - The performance bullet points have been revised to reflect the drafting changes in the document. CNS staffing levels should permit year round continuity of staffing – at least in the normal working day.
British Association of Head and Neck Oncology Nurses (BAHNON)	3	Full	4	16 - 18	These first 2 sentences are not good! I would suggest instead – A skilled qualified member of the nursing team should perform a comprehensive assessment of the patient/family's needs. If complex needs are identified, the nurse will refer on to the CNS. Care pathways and referral criteria will ensure that patients are referred for expert support appropriately. It is estimated that approximately 75% of patients will require expert CNS input.	See response to 1st point.
British Association of	4	Full	2	165	I am puzzled by the focus on postoperative here, many	The text now reads: 'Post treatment period'.

Head and Neck Oncology Nurses (BAHNON)					patients have non surgical treatment and require the same level of support. Additionally, the preoperative period is perhaps even more essential for helping patients to understand the impact of interventions, to gain truly informed consent	
British Association of Head and Neck Oncology Nurses (BAHNON)	5	Economic	Appendix 1	Page 123	Sentence 2 reads "At present many CNSs are over-stretched, having to cover other nursing work". I do not understand what "other nursing work" refers to and this may be an inaccurate statement. I think may be best to leave it at "over-stretched." (Unless you want to add - not having an adequate generic nursing team to work with, and in some cases, performing inappropriate tasks such as data collection and administrative work).	Amendment agreed.
British Association of Head and Neck Oncology Nurses (BAHNON)	6	Economic	Appendix 1	Page 124	Sentence 1 would be better phrased – The role of the nurse practitioner has been proposed in this guidance to act as a support to the CNS. It is not being widened.	The text in the Manual now reads: 'Senior nurse who can provide advanced skills for the management of stomas (tracheostomies and gastrostomies), nasogastric tubes and tracheo-oesophageal valves. This nurse should work alongside the CNS, SLT and dietitian,', and therefore reference to nurse practitioner has been removed from the economic review.
British Association of Head and Neck Oncology Nurses (BAHNON)	7	Full	General	General	I think that the philosophy behind the guidance of all patients receiving a high standard of nursing support is absolutely correct. However, the model that is being put forward is flawed. I think it results from a misconception of the CNS role, and of the work that nurses, and cancer nurses in particular, do. People with cancer need nursing support; nurses provide a unique fundamental mixture of emotional, physical and psychosocial support to all cancer patients. All nurses are trained to do this. CNSs have developed a high level of expertise in their chosen field, but should be providing this higher level of expertise in a focused way, working alongside a team of nurses who can provide the fundamental care. A central facet of the CNS role is to educate and develop the generic nursing team. If the generic nursing teams are adequately resourced and trained, then patients will be satisfied with the support given. Patient dissatisfaction arises when there is a lack of this resource, and gaps are apparent. Cancer guidance needs to ensure that the generic nursing	Although we have modified the text on the CNS significantly to reflect all the comments received from the profession, including the stress placed on the importance of the development and professional leadership roles, and the variable level of input required by individual patients, we retain the vital 'failsafe' requirement for all patients to see the CNS in the initial period. It is clear from our own commissioned work (NCA) and from Macmillan among others that patients value access to the CNS very highly and believe it to be crucial to their welfare.

					workforce is provided for all cancer patients across the board. It is neither common sense nor sustainable practice for large pieces of the patient pathway to be filled by site specific CNSs alone.	The cost impact work makes clear that this is a key area for investment, to remedy widespread weaknesses in current services.
British Association of Head and Neck Oncologists	1	Full	general		We endorse the view that "the key issue in assembling specialist services for head and neck cancer patients is that those involved should have the necessary training, skills, experience and expertise. It is this rather than the specialty as such, that influences outcomes." We support the concept of "increasing involvement of several surgeons working together during the course of operations and sharing operative tasks". We would add such teams may be made up of individuals from the same specialty or may come from a variety of specialities. Members of The British Association of Oral and Maxillofacial surgeons have a database of approximately eight thousand patients treated more or less in a similar fashion i.e. initial radical surgery with micro vascular reconstruction and followed by radiotherapy as indicated by the definitive histology. We have no evidence that volume operators have better outcomes as opposed to those who are low volume providers. What is striking however that the general adoption of the above treatment regimes has improved disease specific survival rates for Oral and Oropharyngeal cancer for all stages from approximately 40% to 65% or more.	No response required. Agreed. No response required. Population based data are generally more accurate than clinical databases in determining trends in survival. Data from the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS) showing 5-year survival as five year moving averages for Lip, Oral cavity and Pharynx demonstrate a slow improvement from rates of 42% to 44% in the 1980s, to over 48% in the most recent periods with full follow-up. It is difficult to reconcile this with the high rates described, but case selection is likely to be a factor. However, there are no currently published national statistics to refer to for recent time periods.
British Association of Oral and Maxillofacial Surgeons	2	Full		Pg 7	Dietician is mis-spelt page 7	The accepted spelling of this word is 'dietitian', according to the British Association of Dietetics. While there are two alternative spellings in the dictionary, we have therefore settled on this spelling, and

						its usage is consistent throughout the document.
British Association of Oral and Maxillofacial Surgeons	3	Full	general		We are supportive of the primacy of the MDT in deciding treatment modalities, data collection of disease incidence, management and outcomes. It is essential that appropriate emphasis be given to necessity of providing funding to properly support the MDT. We also endorse the view that the Head and Neck MDT has responsibility for skull base tumours and Thyroid Cancer.	Support to MDTs is recommended and included in the cost impact study.
British Association of Oral and Maxillofacial Surgeons	4	Full	Back-ground	124	Page 16 We are unable to agree with the statement Page 16 (124). A paper presented by Mr. Magennis at the Annual Scientific meeting of the Association in 2002 clearly showed that disease specific survival for Oral and Oropharyngeal cancer has increased by approximately 30% in the last fifteen years in the United Kingdom.	Population based data are generally more accurate than clinical databases in determining trends in survival. Data from the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS) showing 5-year survival as five year moving averages for Lip, Oral cavity and Pharynx demonstrate a slow improvement from rates of 42% to 44% in the 1980s, to over 48% in the most recent periods with full follow-up. It is difficult to reconcile this with the high rates described, but case selection is likely to be a factor. However, there are no currently published national statistics to refer to for recent time periods.
British Association of Oral and Maxillofacial Surgeons	5	Full	Back-ground	178-179	Page 18 statement (178-179). We cannot agree with this statement.	It is not possible to respond to this comment without an explanation of the basis of the disagreement.
British Association of Oral and Maxillofacial Surgeons	6	Full	2	154-159	Page 47 We support the view expressed in 154—159. Organisation of MDT meetings. It is the view of the specialty that for those clinicians involved in the MDT, formal recognition of that commitment is incorporated into the clinician's job plan.	This is an issue pertinent to all core team members, and is covered in the paragraph following the team list.
British Association of Oral and Maxillofacial Surgeons	7	Full	2	324-329	Page 53—(324---329.) We strongly support the views expressed in this paragraph and in the following paragraph (330—335).	No response required.
British Association of	8	Full	2	449—	Page 58 (449—454)It is the belief of the specialty that	The guidance is based on evidence, not

Oral and Maxillofacial Surgeons				454	treatment practices for salivary gland cancers have now become concentrated in the hands of true specialists in this area of head & neck practice. The study referred to is completely out of date and does not reflect modern management.	beliefs; please supply evidence.
British Association of Oral and Maxillofacial Surgeons	9	Full	3	22—26	Page 61 (22—26) Such activity is laudable but may be impracticable due to the pressures of the service.	Hence the need for this service guidance, which describes the service that should be provided.
British Association of Oral and Maxillofacial Surgeons	10	Full	3	43—49	Page 62 (43—49) BAOMS would prefer if the wording was as follows " Designated Head & Neck Surgeons, Oncologists, Haematologists, Cytologists and Radiologists should cooperate to ensure that an appropriate diagnostic work up is provided for patients with neck lumps.	No reason has been given for this comment, and this was not the view of the Editorial Board.
British Association of Oral and Maxillofacial Surgeons	11	Full	5		Page 83 We support the concepts espoused in this section, in particular it is essential that surgeons who wish to continue Head & Neck Oncological practice away from the Head & Neck Cancer Centre, must personally attend the MDT to discuss their patients, to ensure that the treatment provided is both apposite and appropriate.	No response required.
British Association of Oral Surgeons	1	Full	general	General	Our Association agrees in principle with the overall thrust of this document. It is well written accurate and long overdue.	Thank you for this acknowledgement.
British Association of Oral Surgeons	2	Full	2	78	We would hope that fully trained and experienced oral surgeons would be involved in the extended MDT. They would be involved in getting the patient 'dentally fit' usually by undertaking dental extractions etc. many H&N patients have gross dental neglect and need their mouths cleared of infected teeth and roots.	A restorative dentist is in the core team and other specialist surgeons in the extended team.
British Association of Oral Surgeons	3	Full	4	52	An oral surgeon will need to see the patient regarding dental extractions that may need to be done under general anaesthesia within a hospital setting. It is imperative that experienced oral surgeons treat patients for dental extractions after radiotherapy.	A sentence has now been inserted under Dental Assessment which reads, "Those who require dental extractions under general anaesthesia should see an oral surgeon.' The 'specialist restorative dentist' is referenced in Topic 6. Also, following text added: 'Patients who need dental extractions after treatment should be referred to an oral surgeon.'

British Association of Oral Surgeons	4	Full	3	27 - 107	Many patients with malignant oral ulcers are sent to an ordinary DGH Oral Surgery department for biopsy and diagnosis. This biopsy is often/usually done by a junior member of staff. When the diagnosis is made the patient will be informed of the diagnosis and then sent to the regional H&N Unit for treatment. It is most likely that the patient will be told the diagnosis at a 'local' DGH not at the regional unit. Training on 'Breaking Bad News' should therefore be carried out very widely indeed especially at local DGHs	Agreed. This point is now covered in the wording.
British Association of Otolaryngologists, Head & Neck Surgeons						This organisation was approached but did not respond.
British Association of Plastic 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	1	Full	general	General	This document will be the basis of service guidance for all specialities working in head and neck oncology and peer review for cancer services nationally. It is crucial that this document clearly outlines the identified need of specific specialities consistently in each section and emphasises the collaborative approach for the management of patients by core members of the team, that have varied and wide ranging roles / responsibilities that are shared equally between professional groups like the CNS, SLT and Specialist Dietitian. Currently this document fails to acknowledge the clinical specialist dietitian on the same wavelength as the CNS and SLT. There is a clear imbalance throughout the document and this will have huge consequences on the impact required for the implications in service delivery for dietitians working in head and neck oncology and patient management. Some of the amendments suggested by the British Dietetic Association in first consultation have been included with regard to the dietitian's role in assessment of nutritional status and advice during treatment. However, this is only part of their role and there is much needed information / emphasis to be included within this document. There are specifics that are	There is a balance to strike about the level of detail appropriate for inclusion in this Service Guidance. We have indicated broadly the nature and range of contributions from different professionals and how they meet the needs of patients. Thus although we have broadly tried to reflect the concerns fed though to us from the professional interests involved, it has not been possible, or appropriate, to include all the fine detail requested. A large number of small changes have been made to the text, to avoid suggesting that any particular discipline is more important than another. The CNS does, however, have a key role.

					not included or mentioned briefly, but with an imbalance on emphasis compared to other professional groups. This following are some examples of how the clinical specialist dietitian has not been acknowledged throughout the document: • Role as patient advocate with regard to information giving; counselling; clinical expertise and knowledge to facilitate decision making regarding treatment options at all stages during the patient pathway; social and psychological support where appropriate for patients and carers • Key member of the MDT that should be involved in the decision making of the patients treatment plan ▪ Education and training to advance skills and knowledge of MDT members regarding nutrition, swallowing and feeding tube care / management	
British Dietetic Association	2	Full	General	General	Please refer to correspondence that has been submitted by the British Dietetic Association (February 2004 and July 04)	We have responded to all comments received.
British Dietetic Association	3	Full	General	General	There have been specific comparisons made with the CNS and SLT throughout this comments response. This has been done to demonstrate the impact of these 3 professional groups 'together' and not independently (unless appropriate) or excluding the clinical specialist dietitian with regard to their collaborative approach for patient care and as part of the MDT for head and neck patients.	There is no suggestion at any point that the dietitian should be excluded from the discussion.
British Dietetic Association	4	Full	General	General	Reference to the dietitian is inconsistent within this document (dedicated dietitian, oncology dietitian, State registered dietitian). Professor Haward clearly states in the forward '…specialist services for head and neck cancer patients is that those involved should have the necessary training skills, experience and expertise….' Reference to the dietitian needs to be Clinical Specialist Dietitian. This is supported by the NICE Guidance on supportive and palliative care guidelines/ British Dietetic Association definitions for grading dietitians.	Where there were inconsistencies, these have now been addressed. Reference is made to 'dietitian' throughout. This is consistent with the terminology in 'Improving Supportive and Palliative Care for Adults with Cancer'. We are describing the expertise required, not a particular role. The nature of the dietitian is specified in the MDT.
British Dietetic Association	5	Full	General	General	There is evidence available that has not been included in this document for issues relating to nutrition. (Some examples: Prophylactic PEG placement / Patient satisfaction for Dietetic Intervention / Pre-operative nutrition support and impact on post operative complications / emotional and functional	The research undertaken was based on the questions raised at the original Proposal Generating Event. This issue (the role of the dietitian in general) was not identified as one of the research questions in the

					outcomes / diagnosis and treatment of cancer cachexia) We appreciate that no further evidence can be submitted but could this be reconsidered. Please contact to discuss further – This document should be the 'gold standard' and therefore appropriate and relevant evidence should be included.	process. Many of the nutrition issues identified have, however, been covered, including prophylactic PEG placement. Cachexia is a generic issue, not specific to this group of cancers. Please see the research evidence document for full details of the research evidence used.
British Dietetic Association	6	Full	General	General	It is acknowledged that health professionals could be male or female, therefore sentences referring to health professionals should say them or they rather than he (she)	Them and they are plural – this would therefore be inappropriate. No change proposed.
British Dietetic Association	7	Full	General	General	Reference to puree diets should read texture modified as not all patients require puree diets and the correct terminology is 'texture modified' which then refers to soft/moist or liquid diets.	Agreed. Text amended.
British Dietetic Association	8	Full	General	General	Please refer to: First round consultation (NICE response)– Stakeholder comments, Number 43, 57, 69, 114 The 'resource implications' for each section is dependant on the analysis of the potential economic impact of the guidance. I am in communication with Sue Ward from Sheffield University and will feed back directly to her regarding the implications for nutrition and dietetic services.	No response required.
British Dietetic Association	9	Full	General	General	Please refer to correspondence that has been submitted by the British Dietetic Association (February 2004 and July 04)	The Developers believe that they have responded to all the points made.
British Dietetic Association	10	Full	Forward	Pg 3, Paragraph 3	'fitness to undergo therapies…' the word 'fitness' should be defined and read as 'physical, social and psychological status to undergo therapies'	The Developers do not believe that this would improve the text. No amendment proposed.
British Dietetic Association	11	Full	Forward	Pg 4, Paragraph 1 +2	Paragraph 2 clearly defines the medical specialities. Paragraph 1 acknowledges the support and rehabilitation services but does not clearly define the specialities (Specialist Dietitian, CNS and SLT). This information should be consistent in the context of this document. As the increasing and significant need for AHPs and specific support services need to be made explicit.	This level of detail is inappropriate for the Foreword.
British Dietetic Association	12	Full	Key Recc	Pg 7 Bullet pt 4	'Dietitian' should read as 'Clinical Specialist Dietitian'. Justification for this is given in the general comments section. Assumptions from this paragraph could be made and interpreted as the specialist services only being required until the period of rehabilitation is complete. In order to achieve 'outcomes' continuous and appropriate assessment / monitoring is required throughout the patient pathway.	See response to the 4th point above.

					The sentence '…until rehabilitation is complete' should read as '…..from the pre-treatment assessment period and thereafter at every stage of the patient pathway.'	
British Dietetic Association	13	Full	Background	58 / 59	This sentence needs to be finished	Amendment made.
British Dietetic Association	14	Full	Background	144	The word 'roughly' should be changed to 'approximately'	Agreed. Amendment made.
British Dietetic Association	15	Full	Background	145	'approximately' should be changed to 'It is estimated between 10 – 30%….'	Agreed. Amendment made.
British Dietetic Association	16	Full	Background	171	The sentence should read as '…...sore throat, ear ache or persistent cough.'	Agreed. Amendment made.
British Dietetic Association	17	Full	Background	152 and 170 and 185	Please refer to: First round consultation (NICE response)– Stakeholder comments, Number 17,18,19 Cancer cachexia is a symptom and is implicated in the demise of 30 – 50 % of all cancer patients with a solid tumour. Weight loss is a consequence of chewing and swallowing problems and this needs to be highlighted in the context of this section because it adds to the underlying cachexia and other symptoms to impact on outcomes. The sentence should read as: 152: '…have difficulty in speaking or swallowing resulting in weight loss' 170: '….pain or problems with swallowing (dysphagia) resulting in weight loss' 185: '..problems with swallowing resulting in weight loss an ear….' Supporting evidence available on request.	Please see response to point 5. We are detailing specific symptoms of these cancers. Many cancers cause weight loss.
British Dietetic Association	18	Full	Background	226	This appears to be a random statement – is there a more appropriate place for this sentence	The statement refers to the previous sentence in the same paragraph.
British Dietetic Association	19	Full	Background	251	Please refer to: First round consultation (NICE response)– Stakeholder comments, Number 25 'Frequent consumption….' Is not explicit and there is sufficient evidence to justify the rationale for including specific recommendations as previously mentioned. This sentence should read as '….5 portions of fruit and vegetables is associated….'	The research is based on more rather than less frequent consumption, not 5 portions (which is a Government recommendation).
British Dietetic Association	20	Full	Background	252	Please refer to : first round consultation (NICE response) – Stakeholder comments, Number 21	This interpretation is not accepted. No amendment proposed.

					The sentence 'Poor diet…exacerbates the risk of cancer.' Implies that malnutrition increases the risk of cancer, this is not correct and should read as 'Poor diet is often linked with heavy smoking and alcohol use, leading to malnutrition and its associated complications impacting on quality of life and survival.'	
British Dietetic Association	21	Full	Background	257	Preventative measures should be taken with regard to diet and therefore the sentence should read as '…are important and health promotion strategies should be encouraged for healthy eating in the appropriate care setting'	The phrase 'as is the promotion of healthy eating' has been added.
British Dietetic Association	22	Full	Background	270	This sentence should be referenced	Reference now added.
British Dietetic Association	23	Full	Background	316	A supporting statement should be included in the sentence '…..general health has a marked effect on survival and therefore early referral at the point of diagnosis to the appropriate support services should be encouraged' This is recommended by other national documents such as BAO - HNS	This is a description of the disease – not about services.
British Dietetic Association	24	Full	Background	323	The sentence should read '…..support with nutrition and communication, before, during and after primary treatment. This should be available from the clinical specialist dietitian and speech and language therapist.' The benefit of 'effective' nutrition support during and after treatment is very much dependant on early intervention 'before' treatment starts. Supportive evidence in available on request.	Not appropriate for the Background section.
British Dietetic Association	25	Full	Background	337-339	The sentence should read as 'Radiotherapy or surgery can be debilitating…….which can add to problems with maintaining adequate nutritional status.'	The typo has been amended but no other amendment is required.
British Dietetic Association	26	Full	Background	343	The sentence should read as '…patients need to learn to communicate in a new way and adapt to certain dietary changes' The consequences of a laryngectomy focus on the communication aspect in this document, however there are certain dietary changes those patients need to adapt to. This is associated with the surgical reconstruction that results in the patient needing to have a little and often approach, include soft / moist /high fibre foods and make physical changes to the way they have their meals. This is supported by the National	This point is already covered. No change proposed.

					Association of Laryngectomy Club written information for patients and further information is available on request.	
British Dietetic Association	27	Full	Background	345 – 347	The sentence 'Such patients……' needs to be re-worded. At present it outlines what the speech therapist does but does not outline what the CNS and dietitian do and this should be consistent within each section of the document. The sentence should read as 'Such patients…..particularly speech and language therapists, clinical specialist dietitians and specialist nurses. These services provide expert assistance with nutrition, swallowing, communication and breathing issues'.	On reflection, it was felt that this was too much detail for the Background section, and the text about the SLT has been deleted.
British Dietetic Association	28	Full	Background	365 – 367	Please refer to : first round consultation (NICE response) – Stakeholder comments, Number 24 The sentence should read as '….good nursing care and appropriate input from members of the MDT to discuss palliative measures such as pain control and interventions to support their nutrition and breathing are crucial…'' The late stage of a patient's disease incorporates a full discussion with members of the MDT to incorporate their specific roles to make appropriate recommendations.	Too much detail for the Background section – the issues are covered in the appropriate section.
British Dietetic Association	29	Full	Background	390	Typo… 199/2000 should be 1999/2000	Amendment made.
British Dietetic Association	30	Full	Background	412	Dietitians were very much recognised as an identified need in the audit report but there was limited access. In the context of this document we need to highlight this deficiency and therefore the sentence should read as 'Speech and language……from the help they can provide do not have access to them. This included clinical specialist dietitians'	Dietitians have been added to the list.
British Dietetic Association	31	Full	1	75	Overall, Clinical nurse specialists will only see patients with a confirmed diagnosis and therefore this sentence is misleading. Patients that present in the urgent referral setting may present with weight loss / dysphagia / hoarseness and referred to the Dietitian or SLT. This sentence should read as '……and where support is available from an appropriate member of the MDT'.	But the text refers to patients with a confirmed cancer diagnosis – the point being made is not clear.
British Dietetic Association	32	Full	1	132	See comments for line 257. This sentence should read as '…and offer help with overcoming addiction and improving dietary habits.'	This paragraph is about addiction, not diet. Amendment not accepted.
British Dietetic Association	33	Full	1	253	This sentence should read as '……referral forms for all members of the MDT'	This point has now been deleted; the whole system is referenced in the first point under structure.

British Dietetic Association	35	Full	2	66	Refer to rationale in general comment section. This bullet point should read as 'Clinical Specialist Head and Neck Oncology Dietitian, with the expertise and experience to assess, identify, evaluate and monitor the ongoing nutritional needs of the patients'. This is to ensure consistency with other national documents when describing the grade of dietitian required to work with this patient group.	The specialism issue is dealt with in the preamble to the list. All the issues listed here are dealt with in the explanatory paragraph about the dietitian, further on in the section.
British Dietetic Association	36	Full	2	73	Does the sentence '….not be a clinical nurse specialist, since this….' need to be included in the context of the document given there is a section on the role of the CNS.	This may seem prescriptive, but was included because historically CNSs took this role, and it is felt important to emphasise that this should not be their role.
British Dietetic Association	37	Full	2	89	The dietitian is also a key professional that other professionals/patients should be able to consult with regarding the suitability and method of gastrostomy placement and overall management of feeding tubes. Also the nutrition nurse/CNS). The sentence should read as 'Gastroenterologists…..surgeons and other health professionals with expertise in gastrostomy….'	'And other health professionals' has been added.
British Dietetic Association	38	Full	2	78	Physiotherapist and Occupational Therapist.	Agreed. OT now added.
British Dietetic Association	39	Full	2	113	The dietitian is not mentioned on the list of Thyroid cancer MDT members and should be included.	This is a more general point, also relating to other professionals. Accordingly, the following sentence has been added: 'Individual members of the Head and Neck Cancer core or extended teams may be required to participate in the management of some patients with thyroid cancer.'
British Dietetic Association	40	Full	2	197	Please refer to : first round consultation (NICE response) – Stakeholder comments, Number 35; This response – general comment The title should read as 'Clinical Specialist Dietitian'.	See response to 4th point above.
British Dietetic Association	41	Full	2	198 – 204	Please refer to : first round consultation (NICE response) – Stakeholder comments, Number 35; Structure of services, line 232, 291 -297 Thank you for including a section on the dietitian as requested in the first consultation but this paragraph only describes the role of the dietitian with regard to assessment of patients and does not clarify their wide ranging role in line with other professionals groups. The clinical specialist dietitian does not	These points are reasonable, although the extent of change required to take them on board seems overstated. Some relevant changes have been made to the text. As the guidance already recognises this is an important issue for some patients and this is a resource that is necessary for services and within the MDT. However it is not appropriate for the guidance to address

					work 'co-operatively' with the SLT and CNS, we work in 'collaboration with each other'. This implies an imbalance with other professional groups who are considered a 'core' member of the MDT and is inconsisitent with other sections of the document and does not have the impact required for the implications in service delivery for dietitians. It is crucial that the following is included in this section to outline the roles and responsibilities within the team and there is not too much detail for this section in comparison to text included by the CNS, SLT. This paragraph should read as: 'The clinical specialist dietitians, like the SLT and CNS have a variety of roles and responsibilities at every stage of the patient's pathway and as a core member of the MDT should take a leading role for matters relating to nutrition. Their expertise, knowledge and skills are crucial to assess the patient's nutritional needs and evaluate how different treatments will impact on a patient's nutritional status, taking actions to correct nutritional deficiencies. They are key to recommending the most appropriate short/ long term nutritional interventions and provide support to patients/carers regarding nutritional issues. This includes dietary modifications, tube feeding and how to overcome psychological barriers relating to oral and artificial feeding at each stage of their care. They may educate patients/carers regarding tube care and should share equal responsibility for the decision making and management of nutrition, swallowing and treatment planning with other members of the MDT. The dietitian as part of the MDT contributes nutritional expertise in developing protocols and policy relating to nutrition and provides information, expert opinion or advice on current thinking, evidence based and best practice in nutrition. They are key to providing education and training to all members of the MDT within the network both in the acute and primary setting on matters relating to nutrition in Head and Neck Oncology.' There is sufficient evidence to support this text. BAO-HNS / NICE-supportive and palliative care guideline / refer to Section 2 232-234, 291 - 297	concepts of professional parity or esteem on the basis of 'column inches'. The draft as revised does reflect the important messages for commissioners and cancer networks about the dietetic inputs required. A large number of small changes have been made to the text to avoid the suggestion that any particular discipline is more important than another. For example, the use of the word 'co-operatively' seems to have been interpreted as suggesting that one group is subordinate to another. This was not the intention and in order to remove ambiguity on this point, the wording has been changed to read as follows: 'and there should be mutual co-operation between dietitians, SLTs and CNSs'. Collaboration has a slightly different meaning which we believe is less close to that intended. The rest of this paragraph has been re-drafted to take account of points raised as follows: 'The dietitian should be involved in pre-treatment assessment, taking action both to correct patients' pre-existing nutritional deficiencies before treatment begins, to maintain their nutritional status during treatment. The dietitian can play an important role throughout the patient's cancer journey, providing support and advice for those who require tube feeding, and helping patients to cope with the after-effects of treatment. Dietitians should also be involved in providing education on nutritional issues for other professionals who work with these patients.'

British Dietetic Association	43	Full	2	222	The sentence should read 'there should be close liaison between all MDT members'.	'All' has been added.
British Dietetic Association	44	Full	2	232	Dietitian should be amended to read as 'Clinical Specialist Dietitian'.	This point is made again and again. See response to 4th point above.
British Dietetic Association	45		2	309 – 318	This paragraph provides a severe imbalance for the clinical specialist dietitian compared to the CNS and SLT with regard to their value and relationship with the patient, decision making as part of the MDT, role as patient's advocate with their preferences and circumstances etc. This paragraph implies that the CNS and SLT are the key members of the 'core' MDT for non medical staff. As mentioned previously and with justification, this is inaccurate and will have huge consequences for service provision and patient care if the role/responsibilities of the dietitian are not made explicit / consistent with the CNS/SLT within this document where appropriate. The dietitian is hugely appreciated but severely under resourced. We have an equal role compared to SLT and CNS in reducing anxiety, QOL, hospital admissions, length of stay, post operative complications etc (all consequences of malnutrition). It is imperative that this is made explicit alongside the CNS and SLT with equal emphasis and not in isolation. Relevant justification with rationale has been given throughout and the paragraph should read: 'Patients …….speech and language therapists and clinical specialist dietitians value it greatly……access to a CNS, SLT and Clinical specialist dietitian when ….CNSs, SLT and Clinical specialist dietitians and other non medical staff…'	These comments are predicated on assumptions of professional equity and parity, which are outside the remit of this Guidance to address. The roles of the disciplines described in head and neck cancer are not the same and do not, and need not, duplicate in the sense of being interchangeable in many of the areas described. Whilst it is accepted that all these disciplines contribute to the support to patients and sometimes their carers, the role of the CNS lies at the heart of continuing coordination and support to a greater degree than the other two disciplines. This is supported in the comments from patient groups and research on patient views which makes it clear that they look to the CNS primarily.
British Dietetic Association	46	Full	2	319 – 323	This paragraph is extremely relevant and should not be excluded but could this be incorporated into the above paragraph (line 309 –318) as per the ammended text?	A considerable number of textual amendments have been made, but not all specific suggestions accepted. See response to previous points.
British Dietetic Association	47	Full	2	460	Specialist dietitian should read as 'Clinical Specialist Dietitian'.	See response to 4th point above.
British Dietetic Association	48	Full	2	479	Please refer to : first round consultation (NICE response) – Stakeholder comments, Number 43	This issue is covered in the Economic Review.

British Dietetic Association	49	Full	3	83	This sentence should read ' …named nurse or member of the MDT. This nurse …..contact numbers for the team to the patient….' At time the issues raised by the patient or carer is related to issues that are more appropriate for another member of the team to discuss. In this situation it is the responsibility of the CNS /delegated nurse to acknowledge their own boundaries and liaise with the relevant person on the team.	There has been considerable re-drafting to the text – see responses to previous points.
British Dietetic Association	50	Full	3	128	The sentence should read as 'There should…facilitated by a CNS, SLT or specialist Dietitian, to ensure….' This is most definitely a shared responsibility amongst these team members and justification for this is outlined in the document. However, this needs to be consistent in each section and currently it provides an imbalance for the dietitian in comparison to the CNS /SLT and this is a shared /equal role between these professional groups. Examples are of people who have had a gastrostomy, total glossectomy, laryngectomy etc.	See responses to other points. The text has been generally checked and reviewed for balance and consistency.
British Dietetic Association	51	Full	3	212	Please refer to : first round consultation (NICE response) – Stakeholder comments, Number 50, 51, 52, 53 An overview of some of the findings of the NCA / Face to Face report is given. You have justified not including comment 50 because it is a 'summary of key evidence' yet have acknowledged the Speech therapist and CNS in this section of the document. Either the sentence needs to read 'Speech therapists, specialised nurses and clinical specialist dietitians are particularly appreciated…provide. Additionally, patients highlighted access and expertise for support services was limited' or the sentence should be removed, as it is inconsistent with the NCA findings and there is an imbalance amongst these professional groups.	This comment is not supported by the contents of either report. There is no mention of appreciation of dietitians – just of common problems with food. Amendment not accepted.
British Dietetic Association	52	Full	3	226	Please refer to : first round consultation (NICE response) – Stakeholder comments, Number 54 This sentence should read as ' Integrated care pathways to include written protocols and guidelines, agreed by all head and neck cancer MDT's…..'	Not accepted. This section is about diagnosis only.
British Dietetic Association	53	Full	4	14	Please refer to : first round consultation (NICE response) – Stakeholder comments, Number 59 The agreed revised text from the first consultation is only partially included '…. and recommend the most appropriate	This was the initial re-drafted sentence. In the event, some wording was moved to the section on 'Preparation for treatment effects, etc.'

					short and long term nutritional interventions and support during treatment' is not included A further amendment to this sentence should be: 'Following nutritional screening, the nutritional status of the patient should be assessed by the clinical specialist dietitian who can initiate action to correct deficiencies, and recommend the most appropriate short and long term nutritional interventions and give support during and following treatment. Majority of hospitals now have screening tools in place following the Kings Fund Report. Therefore patients would be screened to highlight those patients that would benefit from a specialist dietetic assessment and should be referenced in the text.	A further amendment now reads: 'The dietitian and SLT should work closely together, sharing responsibility for explaining nutritional and swallowing issues to the patient and ensuring that he or she is prepared for any short-or long-term interventions that may be required, before treatment begins.' This would be the role of local protocols/ guidelines, already referenced in the text.
British Dietetic Association	54		4	37 –38	Does the sentence need to include the text '…including a clinical nurse specialist who knows the patient, should be present.' The paragraph has already mentioned ''all relevant clinical specialists' and further describes the MDT in line 43 – 44. This could imply that other specialists 'do not know the patient' which is incorrect and suggests an imbalance amongst professional groups such as dietitian, SLT. This sentence should read 'including the clinical nurse specialist, dietitian and SLT….' or be removed.	See earlier responses about textual balance.
British Dietetic Association	55	Full	4	43	Dietitian should be replaced with 'Clinical specialist dietitian'	See response to 4th point above.
British Dietetic Association	56	Full	4	44 - 44	Excellent paragraph!	Thank you.
British Dietetic Association	57	Full	4	66	The word "(PEG)" needs to be removed as it implies that all gastrostomies are PEGs, which is not the case. Gastrostomy is the generic term. A patient may have a PEG (percutaneous endoscopic gastrostomy) or a PRG (percutaneous radiological gastrostomy) or in rare cases a surgically-placed gastrostomy.	The sentence now reads: 'There should be specific guidelines on the use, placement and management of gastrostomy (usually PEG) tubes.'
British Dietetic Association	58	Full	4	68	Dietitian needs to be replaced with 'clinical specialist dietitian'	See response to 4th point above.
British Dietetic Association	59	Full	4	72	This paragragh should be re-worded to read as 'The clinical specialist dietitian and SLT should work together, sharing responsibility for explaining nutrition and swallowing issues to the patient and ensuring that he or she is prepared for any	See previous comments about text balance. 'And swallowing' has been added to this sentence.

					interventions that may be required before treatment begins. The SLT should give recommendations for safe oral nutrition and textures and the clinical specialist dietitian should give specific advice on dietary modification and assess the need for artificial feeding to maintain adequate nutrition during treatment and thereafter.' The current paragraph implies that both the Dietitian and SLT give specific advice about nutritional issues, and this is better described as nutrition and swallowing. It is the SLT's role to assess if the patient is safe to take oral nutrition and make recommendations regarding safe textures. It is the dietitians role to assess the need for artificial feeding / prophylactic gastrostomy placement and give individualised dietary advice to maintain nutritional status throughout the patient pathway. This reflects and justifies the recommended text.	
British Dietetic Association	60	Full	4	94	Dietitian should read as 'Clinical Specialist Dietitian'	See response to 4th point above.
British Dietetic Association	61	Full	4	91 - 98	Excellent paragraph	Thank you.
British Dietetic Association	62	Full	4	102	Please refer to : first round consultation (NICE response) – Stakeholder comments, Number 65 I acknowledge your comments, but the following are not only anticipated benefits but evidence based with regard to appropriate and timely nutrition support: ▪ Correct nutritional deficiencies and prevent weight loss ▪ Improve patients' nutritional status to allow them to receive more intensive treatment ▪ Minimise the risks of malnutrition-related morbidity and mortality ▪ Reduce the risk of developing post operative complications ▪ Prevent treatment interruptions and possible hospitalisation ▪ Maximise patient motivation to improve overall quality of life The following is recommended: 'prepared' should be changed to 'nourished' and the sentence	We appreciate that these are benefits, but would stand by our previous response.

					should read as '….will be better nourished to tolerate treatment and reduce the likelihood of admissions to hospital for feeding related complications.' References available on request	
British Dietetic Association	63	Full	4	143 – 152	This study also showed a significant difference in the supplemented group with regard the emotional and functional outcomes for QOL.	The study described here did not assess emotional and functional outcomes (see the Research Evidence for details of the study).
British Dietetic Association	64	Full	4	237	Please refer to: first round consultation (NICE response) – Stakeholder comments, Number 66, 67, 68,69 Additional points that should be included for the measurement section Availability of ring fenced time in surgery and endoscopy with a secondary service available in radiology for placement of gastrostomy tubes.	This would be covered in the point about 'network-wide guidelines'; no amendment.
British Dietetic Association	65	Full	4	246	Additional bullets to be included: • Evidence for waiting times for gastrostomy placement in surgery, endoscopy and radiology • Evidence of audit for measurable nutritional outcomes • Evidence of audit for QOL issues relating to alternative feeding methods	The following bullet point has been amended: 'Evidence that every patient's nutritional status and needs are assessed by a dietitian member of the MDT before treatment begins, and that any necessary pre-treatment interventions are provided without delay.' This is not pre-treatment assessment. This is not pre-treatment assessment.
British Dietetic Association	66	Full	4	254	This bullet point should read as: 'Evidence that every patient who presents, or is at risk of malnutrition and whose treatment is expected to effect nutrition and swallowing is assessed by the clinical specialist Dietitian before treatment begins'	See response to point above.
British Dietetic Association	67	Full	4	257	'dietitians' should be changed to 'clinical specialist dietitian'	See response to 4th point above.
British Dietetic Association	68	Full	4	259	Additional bullets to be included: • Audit of minor and major complications with different methods of placing feeding tubes • Audit of network-wide guidelines on the nutritional management of patients	Too clinical for this context. Not an outcome.

British Dietetic Association	69	Full	4	262	Please refer to: first round consultation (NICE response) – Stakeholder comments, 69 Please refer to general comment:	The cost impact work makes clear the need for investment to remedy widespread weaknesses in current services. Developments in these areas are expected to take time, but will show real benefits in the quality of life outcomes for these patients.
British Dietetic Association	70	Full	5	14	Please refer to: first round consultation (NICE response) – Stakeholder comments, 71 The dietitian is also a core member of the team and has the experience, clinical expertise, knowledge and skills for the patients to discuss their concerns with following information regarding treatment plans. We have a key role in developing clear, up to date and practical information for patients on relevant aspects of diet, alternative feeding and other aspects related to nutrition that other members of the team could only support. The sentence '……information with their SLT, CNS, or other appropriate member of the team.' currently implies an imbalance amongst the professional groups that patients work extremely close with and should read as 'information with their SLT, CNS, clinical specialist dietitian or other appropriate member of the team..' as the dietitian is key to the decision making process as mentioned in other sections of the document but this needs to be consistent throughout.	The dietitian has now been included.
British Dietetic Association	71	Full	5	41	'Partial laryngeal excision' is a specific surgical approach. Is this relevant to mention as it would come under the umbrella of 'laser excision'	No amendment proposed.
British Dietetic Association	72	Full	5	59 - 62	This paragraph needs to be re-worded as follows: 'There should be a clinical specialist dietitian available on wards where all patients who need it will receive the specialist support and advice they need to optimise their nutritional status and correct nutrient deficiencies and minimise the risk post operative complications. Ongoing training and education for nursing, medical and other health professionals on nutritional aspects should be programmed. The specialist dietitian, ward nurses and SLTs should work with catering services to ensure the provision of appropriate texture modified diets to meet the patients individual requirements in line with national guidelines for texture modified diets. This needs to be built into the contract specification for external	Too much detail. All the relevant points are included in the existing paragraph.

					catering providers.' Throughout the document there appears to be no acknowledgment for the role of the dietitian with education and training etc. There are national guidelines that The British Dietetic Association and The Royal College of Speech Therapy have developed for dysphagia management and it is imperative that head and neck units are / should be working towards implementing these guidelines with external catering services for the provision of appropriate texture modified diets for head and neck patients. This is justification for including the above text.	
British Dietetic Association	73	Full	5	93	The sentence '….advice from their CNS and other appropriate specialists (…) should read as '…advice from all appropriate specialists, such as CNS, Clinical Specialist Dietitian, SLT and Physiotherapist……'	The list has now been removed.
British Dietetic Association	74	Full	5	103 – 104	Many of the issues that are required for patients having radiotherapy are multidisciplinary – pain control, psychosocial issues, dysphagia, weight loss, texture modification etc and these clinics should be supported by the relevant members of the MDT (Specialist dietitian, CNS, SLT, radiographers etc). Many departments have a support clinic as described above and the benefit to the patient is multifactorial with regard to improving outcomes – compliance / tolerance to treatment / QOL / reduced admission to hospital etc. It is imperative that this document does not give the impression that the dietitian does not have a role in education and support for other staff as it currently does. The dietitian is responsible for developing clear, up to date and practical information for patients /carers on relevant aspects of diet, alternative feeding and other aspects related to nutrition. The role and presence of a dietitian in such a clinic has been audited and shown to be highly effective, including the reasons mentioned above. The text should read as follows: '…support clinics, staffed by radiographers, cancer nurses, CNS, Clinical specialist dietitians and SLT. There should be the provision of education and support for both staff and patients working in the clinic from the CNS, clinical specialist	The dietitian has been added here.

					dietitian and SLT or other appropriate members of the team'	
British Dietetic Association	75	Full	5	105	'specialist oncology dietitian' should be changed to 'clinical specialist dietitian' and the sentence should read 'All patients…' (this is supported by national guidelines, BAO-HNS'.	See response to point 4.
British Dietetic Association	76		5	110 – 115	The text does not read appropriately and should read as: 'Large numbers of head and neck patients require nasogastric and gastrostomy tube feeding in the short and/or long term respectively, as an integral part of their nutritional management. The clinical specialist dietitian is key to assess the need for tube feeding and provide on going support and education before, during and after the period of treatment to cope with feeding issues, tube care and maintain their nutritional status (see Topic 4, Pre-treatment assessment and management. Patients and their carers should be given guidance on texture modified diets, nutritional supplement and tube feeding if required before discharge from hospital. Cancer networks should have in place a co-ordinated service to ensure careful patient selection and appropriate gastrostomy placement. Local services should have adequate provisions for replacing tubes when necessary.' Nasogastric tube feeding should only be used for up to 4 weeks. If alternative feeding is envisaged for greater than 4 weeks then gastrostomy placement is indicated.(This is evidence-based practice in this population group – reference available on request). Puree meals are not the only dietary requirements of the patient.	Too much detail for service guidance. Some minor amendments have been made to the text, e.g: 'They need support from dietitians with expertise in managing these interventions before, during and after the period of treatment, to cope with feeding problems and maintain their nutritional status.'
British Dietetic Association	77	Full	5	159	This should read as '…..specialist staff, such as SLTs, clinical specialist dietitians, CNS and….'	The text has now been amended to: 'The involvement of a wide range of specialist staff and adequate support services for patients.'
British Dietetic Association	78	Full	5	162	The sentence should read as '….with nutrition, swallowing…..' ie; the word eating should be removed	This amendment is not accepted.
British Dietetic Association	79	Full	5	182	The text regarding weight loss in this population group needs to be referenced – available on request	The reference has been added.
British Dietetic Association	80		5	305 – 309	Please refer to: First round consultation (NICE response) – Stakeholder comments, 50,51,52; This comments response -Initial Investigation and diagnosis, line 212; Primary Treatment, line 59:	This section is reporting the evidence, not drawing conclusions.

					This paragraph should be supported with a sentence to highlight the identified need by patients (as in the NCA report) for access to a clinical specialist dietitian for dietary advice and the rationale for external catering services that can provide texture modified diets in line with national standards. The sentence should read: '…..not to be interested. This reflects the patients needs for access to clinical specialist dietitians and availability of texture modified diets that meet national guidelines in hospital.'	
British Dietetic Association	81	Full	5	362	'Suitably specialised and experienced head and neck dietitian' should read as '…access to a CNS, clinical specialist dietitian with the expertise for all issues relating to nutritional management' The word 'suitable' is open to interpretation.	The wording has been adjusted, as follows: 'Availability of support for patients undergoing treatment, including access to a CNS, a dietitian with expertise in head and neck cancers, …'
British Dietetic Association	82	Full	5	365	This sentence reads better as 'Facilities for a range of enteral feeding tubes (including…..'	Amendment agreed.
British Dietetic Association	83	Full	5	384 – 386	Refer to this comments response - Primary treatment, 103 – 104 As mentioned it is imperative that this document does not give the impression that Dietitians are not involved or responsible for education and training and this section should acknowledge this either independently and read as: 'Provision of regular training and education of all members of the multidisciplinary team by the clinical specialist dietitian on all aspects of nutrition in order to ensure consistent information is given to patients, and to ensure team members are aware of current advances and changes in practice. This is required at all levels, from pre and post-graduate training, through to induction sessions for new members of staff' or as a joint MDT approach and read as: 'Provision of ongoing rolling raining programmes for and by all members of the MDT'.	The text has been amended to be more generic, as follows: 'Provision of ongoing rolling training programmes for nurses, medical staff, and allied health professionals, in dealing with common problems associated with tracheostomy, surgical voice restoration, and effects of treatment on breathing, swallowing and nutrition.'
British Dietetic Association	84	Full	5	422	Patients could have there tubes in situ before, during and after treatment for months / years and therefore the sentence should read as 'Audit of tube feeding placement and complications.'	This has been added to the outcome measures in Topic 6, Aftercare and Rehabilitation.
British Dietetic Association	85	Full	6	6	Could the text '…..often through the stomach wall' be omitted, not sure of the rationale for inclusion.	Agreed. Amendment made.
British Dietetic	86	Full	6	44 –50	Is this a core role for the CNS ? The individual member of the	Yes, it is a core role (described in Topic 2).

Association					MDT should be responsible for ensuring that they are working closely with their own peers in the community to provide a seamless service and networking to build collaborative links between the Cancer centre, cancer unit and primary care. This needs to be an integrated core responsibility and should be evident by the production of integrated care pathways for each network.	
British Dietetic Association	87	Full	6	59	The sentence should read as '…...management of valves and stomas including gastrostomy sites….' The word gastrostomy site needs to be emphasised because without this clarification the word 'stoma' will only be interpreted as 'neck stoma'	Agreed. Amendment made.
British Dietetic Association	88	Full	6	69	'Dietitian' should be amended to read as 'clinical specialist dietitian' Because of the complex and extensive needs of this population group it is essential that local teams have experienced dietitians with the expertise for managing the variety of nutritional issues. Also, there is an increase in the number of head and neck patients with ng / gastrostomy tubes in the community (BAHNS report 2002), and the patients should be given the same level of support for managing artificial feeding and ongoing support during the rehabilitation period. It is acknowledged that local support team members will not have the same wte specialist dietitians but they should have the experience and a similar level of expertise.	See response to 4th point above. Text has been added as follows: 'Dietitian; where this is not a dietitian with specialised knowledge of the head and neck cancer, there should be close liaison between the dietitian in the community and her counterpart in the MDT who has been working with the patient'
British Dietetic Association	89	Full	6	73	It is imperative that this document does not exclude the dietitian's role and responsibilities with regard to education and training. The dietitian is also a key professional that other professionals should be able to consult regarding the management of gastrostomies. Many dietitians have the clinical skills and expertise for being consulted regarding the management of stomas and therefore can offer advanced skills. The sentence should read as '……work alongside the CNS, SLT and Clinical specialist dietitian…..'	Dietitian has been added.
British Dietetic Association	90	Full	6	95	Refer to this comments response – After care and rehabilitation, line 69 It is imperative and a national requirement due to the structure of services for nutrition and dietetics, as well as the identified needs of this population group and the proposed impact of NICE guidance, that the dietitian in the primary care setting should be a clinical specialist dietitian. They should be	See response to point above.

					dedicated to head and neck and should work with patients for oral rehabilitation, tube feeding and tube care. They should have close links with their peers working in cancer centres / units. The paragraph should read as: 'The dietitian in the local support team should be an experienced dietitian with the appropriate skills and knowledge of working with head and neck patients. They should have access to specialist dietitians at cancer centres/units for ongoing support, education and training needs. Additionally, all patients with severe weight loss, malnutrition, feeding tubes and eating and drinking problems should have access to an experienced dietitian for advice on texture modification, food preparation and tube feeding / care to maintain the patients nutritional status.'	
British Dietetic Association	91	Full	6	121 – 126	The principles of this paragraph in essence could be applied to other members of the MDT such as dietetics and speech therapy. The paragraph could include 'The ability to specialise in head and neck oncology is currently limited in the uk. The creation of clinical specialist dietitians with specific roles and responsibilities as outlined within this document provides a number of opportunities to attract and retain high calibre dietetic staff.'	While the developers do not disagree with this point, the purpose of the paragraph is generally to highlight the benefits of working together.
British Dietetic Association	92	Full	6	127 – 128	Please refer to: first round consultation (NICE response) – Stakeholder comments 103 Apologies for not being explicit with my comments during the first consultation - In summary this was describing the process for oral rehabilitation and how this is achieved. A sentence at the end of the paragraph should be included '…and quality of life. Close working between the clinical specialist dietitians and speech therapists in the cancer centre and local support team is crucial to recommend safe swallowing techniques and monitor oral intake to prevent compromising the nutritional status of the patient.'	This is a section on benefits, not on what should be done and how to achieve it.
British Dietetic Association	93	Full	6	227	Access to local services should be available to support patient being weaned from tube feeding to oral nutrition. The sentence should read as ' …….who rely on tube feeding and / or require oral rehabilitation'.	Agreed. Amendment made.
British Dietetic Association	94	Full	7	16	How is the word 'functional' interpreted?. Each specialist may see this as something different. For example to a dietitian it means 'eating and drinking' but a surgeon or SLT may	Rehabilitation is a different issue; it is expected that the different specialties will pick up different types of problems.

					interpret this as something different. Does the sentence need to read as '…for rehabilitation, functional or psychological problems'	
British Dietetic Association	95	Full	7	51 - 52	Please refer to: First round consultation (NICE response) – Stakeholder comments, 71 This response - Primary treatment, line 14 As previously highlighted in the above comments, in addition to references from other national guidelines BAO-HNS. The dietitian is also a core member of the team and has the experience, clinical expertise, knowledge and skills to assess patient's needs and contribute to decision making about management. The sentence only acknowledges the SLT and CNS and should read as '….the CNS, SLT and clinical specialist dietitian should also……' This information is mentioned in other sections of the document but needs to be consistent throughout and currently implies an imbalance amongst the professional groups that patients work extremely close with and does not acknowledge the dietitian on an equal measure to the CNS and SLT.	Dietitian has been added.
British Dietetic Association	96	Full	7	68	This should read as '….high level of support before, during and after treatment to deal with problems with nutrition…….'	'Nutrition' has been added.
British Dietetic Association	97	Full	8	32 –38	Please refer to: First round consultation (NICE response) – Stakeholder comments, 71 This response - Primary treatment, 14; Follow up and recurrent disease, 51-51 This gives an imbalance to the access required for patients and the expertise of the dietitian in this sentence. Although the document and this response clearly highlights the need. The sentence should read as ' ….such as speech and language therapists, clinical specialist dietitians and head and neck cancer CNSs……' The sentence on line 36 – 38 should read as '……ongoing assessment by a specialist SLT and clinical specialist dietitian, who can provide support and advice on communication, nutrition and swallowing.	Dietitian added.
British Dietetic Association	98	Full	8	80	Please refer to: first round consultation (NICE response) – Stakeholder comments, 94 Unclear as to what 'principles of management for airway obstruction' are being referred to in the context of this section	The principles of management are those referred to, i.e. most patients, etc.

					that are similar to 'management of swallowing.' This section should refer to 'nutrition and swallowing' as these are 2 independent issues. Nutrition for palliative interventions and care will have a lot of similarities with the nutrition offered to patients having active oncological interventions. However, the goal of treatment will be aimed at maintaining or improving QOL. Patients may well require more support when they are faced with the reality that their disease is no longer responding to curative treatment or that they are going to deteriorate progressively. The combined effect of dysphagia (resulting in weight loss) and cachexia (tumour induced metabolic changes) leads to malnutrition and its associated complications. Nutrition support is imperative as an integral part of a palliative care package for overall management of nutrition and swallowing at this stage. The clinical specialist dietitian should discuss these options with the patients / carers and facilitate the decision making process alongside other members of the team. Supportive nutrition (good communication and symptom control is the right of every individual and the duty of every professional (BAO-HNS)' The text should read as 'Patient's ability to consume oral intake can be severely restricted or eliminated due to the progressive nature of the disease causing swallowing difficulties. This can lead to malnutrition and its associated consequences and be further exacerbated by tumour induced metabolic changes (cancer cachexia). The dietitian should discuss the options for supportive nutrition and facilitate the decision making process for appropriate nutritional management with other members of the MDT. Interventions such as nasogastric and gastrostomy placement should be carefully considered for symptom control and fully discussed with the patient / carers regarding ethical and legal aspects.'	It is felt that this level of detail is not appropriate. One of its purposes is to reduce inappropriate interventions for dying patients.
British Dietetic Association	99	Full	8	88	Please refer to: First round consultation (NICE response) – Stakeholder comments, 71 This comments response -Primary treatment, line 14; Follow up and recurrent disease, 51-51; Palliative interventions and	Dietitian has been added.

					care, 32 -38 For reasons already mentioned throughout this response and to achieve consistency throughout this document. The sentence should read as '….Ongoing contact with a SLT and/or CNS and/or clinical specialist dietitian and palliative care……'	
British Dietetic Association	100	Full	Appendix 1	Page 124, Paragraph 3	Dietitians should be referred to as 'clinical specialist dietitian' The paragraph should be re-worded to read as: 'There is lack of dedicated clinical specialist dietitians working in head and neck oncology at cancer centres / units and primary care. It is crucial for those patients who are nutritionally screened at risk of malnutrition to be assessed by a specialist dietitian to carry out the roles and responsibilities at each stage of the patients pathway and as a core member of the MDT that are outlined in the service guidance document. (This includes education, training, audit and research). Discussions with clinical specialist dietitians around the country….3 and 4 WTE clinical specialist dietitians……'	Reference is made to 'dietitian' throughout the manual, and the supporting documents. This is consistent with the terminology in 'Improving Supportive and Palliative Care for Adults with Cancer'. The nature of the dietitian is specified in the MDT.
British Dietetic Association	101	Information for the public	Information for the public	185 – 190	Please refer to this response – Structure of services 198 –204 This section should read as 'Nutrition and Dietetic Services – The Clinical Specialist Dietitian The text should be re-written and be a summary of the recommended text in 'structure of services 198 - 204	Heading of section changed to Nutrition and dietetic services. Text amended to reflect manual – '…dietitians with specific expertise in dealing with head and neck cancer..'
British Medical Association						This organisation was approached but did not respond.
British National Formulary (BNF)						This organisation was approached but did not respond.
British Nuclear Medicine Society	1	Full	General	General	Perhaps some reference should be made to the 2002 RCP/BTA guidelines on the management of thyroid cancer when discussing management and follow-up.	Reference is not routinely made in the Manual to clinical guidelines; this is service guidance. These clinical guidelines would not have met the inclusion criteria for the Research Evidence due to the lack of methodological detail.
British Nuclear Medicine Society	2				There is no mention of PET in the diagnostic measurement section although CT, MRI and specialist ultrasound are mentioned. Is this intentional or has a mistake been made? We think PET should appear in this section.	PET is only recommended for suspected recurrent disease, so it is not appropriate to include it here.
British Nuclear Medicine Society						This organisation was approached but did not respond.
British Oncology					The British Oncology Pharmacy Association does not wish to	Thank you.

Pharmacy Association					submit any further comments on this guidance.	
British Psychological Society, The						This organisation was approached but did not respond.
British Society of Oral Medicine						This organisation was approached but did not respond.
British Thyroid Foundation		All	General	General	Nowhere mentions the problems that many patients experience when having to have a whole body scan after ablation due to stopping taking thyroxine and how patients can be helped through this often traumatic time with the use of recombinant human TSH. Studies have demonstrated successful radioiodine ablation using rhTSH, the results being comparable to those with thyroid hormone withdrawal. Further references in addition to those previously supplied are provided below: Toft A, Beckett G **"Use of recombinant thyrotropin"** The Lancet 2002; 359:1874-1875 Mazzaferri E, Robbins R, Spencer C, Braverman L, Pacini F, Wartofsky L, Haugen B, Sherman S, Cooper D, Braunstein G, Lee S, Davies T, Arafah B, Ladenson P, Pinchera A **A Consensus Report of the Role of Serum Thyroglobulin as a Monitoring Method for Low-Risk Patients with Papillary Thyroid Carcinoma** J Clin Endocrinol Metab 2003; 88 (4): 1433-1441 Schlumberger M, Berg G, Cohen O, Duntas L, Jamar F, Jarzab B, Limbert E, Lind P, Pacini F, Reiners C, Franco F, Toft A, Wiersinga W **Follow-up of low-risk patients with differentiated thyroid carcinoma: a European perspective** European Journal of Endocrinology 2004; 150: 105-112	This level of clinical detail is not appropriate to service guidance.
British Thyroid Foundation		Full	Foreward	Page 5	The statement “thyroid cancer shares with penile cancer the dubious distinction of having no randomised trial evidence” is	This point has been accepted and the comment removed.

					untrue. Published trials include Creutzig 1987, Johansen 1991, Bal 1996, Sirisalipoch 2004 and most recently Bal 2004: Bal, C, Kumar A, Pant G: "Radioiodine Dose for Remnant Ablation in Differentiated Thyroid carcinoma: A Randomized Clinical Trial in 509 Patients", The Journal of Clinical Endocrinology & Metabolism 2004; 89 (4): 1666-1673.	
British Thyroid Foundation		Full	Background	Line 195	The statement "it usually presents as a solitary nodule in a goitre" is untrue. The majority of tumours are papillary which present either as a solitary nodule without a goitre or with a lymph node enlargement in the neck. It is therefore also untrue in line 197 to state that presentation with "swollen glands in the neck" is rare.	This comment is largely accepted and text revised as below: 'Thyroid cancer, although relatively rare, is most likely to develop in women of reproductive age. It usually presents as a solitary nodule in a patient with normal thyroid hormone levels; cancer is found in about 10% of such cases. Other symptoms are uncommon, but include swollen glands in the neck (cervical lymphadenopathy), hoarseness, difficulty in breathing or swallowing, and discomfort in the neck.'
British Thyroid Foundation		Full	Background	Line 197	It is also untrue to state that presentation with "swollen glands in the neck" is rare.	See above revision.
British Thyroid Foundation		Full	Background	Line 204	It is misleading to suggest that papillary cancer "is not regarded as being highly malignant" as it can be lethal! A better phrase might be "is usually curable with adequate treatment".	Accepted. The phrase 'usually curable' has been inserted.
British Thyroid Foundation		Full	1	116	The statement "usually present with a palpable solitary nodule in a goitre" is untrue.	Agreed. The text now reads:'Patients with thyroid cancer usually present with a solitary nodule in the thyroid gland'
British Thyroid Foundation		Full	General	General	Throughout the Guidance thyroid cancer is included in an extremely fractionated manner, being accorded a paragraph or two every few pages. This is ideal in the overall context of head and neck cancer. However, the majority of thyroid cancers are seen by other disciplines including endocrine surgeons, clinical oncologists, endocrinologists, and nuclear medicine physicians. Although editorially convenient, the document is not fit for the purpose for the majority of healthcare works involved in thyroid cancer.	The coverage is appropriate for service guidance and the main sections on the MDT, for example, are clearly set out and presented.
British Thyroid Foundation	1	public	page 4	105/110	Totally agree with these lines as quite often these issues are not dealt with in relation to thyroid cancer	Thank you for your comments.
British Thyroid Foundation	2	public	page 6	145	Specialist services - could this include information on patient support groups and expert patients? For example information	NICE policy is not to include references to individual patient support groups. 'Other

					could be included about the British Thyroid Foundation in relation to thyroid cancer.	local patients willing to provide support' has now been added to the local support team section.
British Thyroid Foundation	3	full	1	134/136	From the patient perspective this statement is highly desirable to raise awareness of the current situation and the need for improvement to bring England into line with the rest of Europe as a minimum standard	No response required.
British Thyroid Foundation	4	full	3	74/133	Excellent	Thank you.
British Thyroid Foundation	5	full	3	116	Support services – suggest this include patient support groups	Agreed; this has been added.
British Thyroid Foundation	6	all	general	General	In relation to thyroid cancer, overall the guidelines have been welcomed by the British Thyroid Foundation and received excellent feedback from those with experience of thyroid cancer. However, nowhere mentions the problems that many patients experience when having to have a whole body scan after ablation due to stopping taking thyroxine and how patients can be helped through this often traumatic time with the use of rhTSH. Studies have demonstrated successful radioiodine ablation using rhTSH, the results being comparable to those with thyroid hormone withdrawal: 1) J Nucl Med. 2002 Nov;43(11):1482-8. A retrospective review of the effectiveness of recombinant human TSH as a preparation for radioiodine thyroid remnant ablation. Robbins RJ, Larson SM, Sinha N, Shaha A, Divgi C, Pentlow KS, Ghossein R, Tuttle RM. 2) Clin Endocrinol Metab. 2003 Sep;88(9):4110-5. Related Articles, Links **Radioiodine treatment with 30 mCi after recombinant human thyrotropin** stimulation in thyroid cancer: effectiveness for postsurgical remnants ablation and possible role of iodine content in L-thyroxine in the outcome of ablation. Barbaro D, Boni G, Meucci G, Simi U, Lapi P, Orsini P, Pasquini C, Piazza, Caciagli M, Mariani G.	This level of clinical detail is not appropriate to service guidance.
BUPA						This organisation was approached but did

						not respond.
Cambridge Laboratories		Full	B/Ground	5 – 7	We acknowledge that this is not clinical guidance and it is not designed to inform on specific treatments, however, there are instances where such treatments are mentioned as on page 91 (line 269-281). We agree with the inclusion of the specific treatments, however, we strongly believe that treatment options have not been fully dealt with and should include both prophylactic and acute options, as significant numbers of patients experience oral mucositis following head & neck treatment. This is re-iterated in section 7: Follow-up & recurrent disease, lines 34-36, where you state the adverse effects of radiotherapy "are common and usually treatable," however, there is no mention of treatment of oral mucositis once it presents. We also refer back to the feedback given to our first draft, comment 15, where you say that with respect to oral mucositis, you wish to emphasise "the importance of treating it." We will refer back to these points in the relevant sections of the draft guidance.	See comments in relevant sections.
Cambridge Laboratories		Full	B/Ground	11-12	This recognises the devastating impact of head and neck cancer on patient's quality of life. Patients are often traumatised and depressed following treatment and routines such as good oral hygiene are less of a priority.	This point is not appropriate for the Background section.
Cambridge Laboratories		Full	B/Ground	138-147	Within head & neck cancer, oral cancer has the highest incidence. These patients will have radiotherapy (and possibly chemotherapy) as part of their treatment. These patients will experience oral mucositis[1] and most probably difficulties in eating and swallowing. We feel it is important to address this issue of the aftermath of radio/chemotherapy more fully, in the section on oral mucositis beginning on page 91 – at present it only deals with prophylaxis of oral mucositis, with no mention of acute management of the condition which affects the vast majority of patients post treatment.	This degree of detail is not appropriate for the Background section, nor for service guidance (as opposed to clinical guidelines).
Cambridge		Full	B/Ground	298-	GPs rarely see a new case; however, they do need to manage	This is too much detail for the Background

[1] Sonis ST, Eilers JP, Epstein JB et al. Validation of a new scoring system for the assessment of clinical trial research of oral mucositis induced by radiation or chemotherapy. Cancer 1999; 85 (10): 2103-2113

Laboratories				299	patients when they return to primary care post treatment. This is when patients need support, particularly if they having difficulties eating. This can affect them psychologically and impact on their nutritional status. The latter could also impact on their treatment regimen. Oral mucositis can present several days after their cancer treatments and is an area of management that GPs and other members of the MDT need to be aware.	section.
Cambridge Laboratories		Full	B/Ground	319-324	This emphasises the point made earlier referring to lines 138-147. The key line (line 323-324) being "Patients need considerable help and support with nutrition and communication, both during and after primary treatment." Within head & neck cancer, oral cancer has the highest incidence. These patients will have radiotherapy (and possibly chemotherapy) as part of their treatment. These patients will experience oral mucositis[1] and most probably difficulties in eating and swallowing. We feel it is important to address this issue of the aftermath of radio/chemotherapy more fully, in the section on oral mucositis beginning on page 91 – at present it only deals with prophylaxis of oral mucositis, with no mention of acute management of the condition which affects the vast majority of patients post treatment.	More detail would not be appropriate for the Background section.
Cambridge Laboratories		Full	B/Ground	337-339	Please refer to comments above relating to lines 319-324	See previous comments on level of detail, etc.
Cambridge Laboratories		Full	B/Ground	348-368	This recognises the devastating impact of head and neck cancer on patient's quality of life. Patients are often traumatised and depressed following treatment and routines such as good oral hygiene are less of a priority. The point is well made on trying to preserve the patient's dignity and comfort in the palliative care setting, helping them to eat being important for the patient and their loved ones.	No response required.
Cambridge Laboratories		Full	B/Ggroun d	369	In the previous draft we made the comment that current service provision is highly variable and principally focused on cancer treatment, not necessarily on services during and post treatment. We acknowledge the significant amendments made from the first draft.	No response required.
Cambridge Laboratories		Full	2	Genera l	The structure and content of this section is much improved. Key individuals for managing the after care of patients especially with respect to eating and maintaining nutritional	This is not relevant to the section on Structure of Services.

				62 64 66 92 95	status (as well as oral hygiene) are: Clinical Nurse Specialist (CNS) Palliative Care specialist Dietitian Pain management specialist Dental hygienist This goes back to the issue that within head & neck cancer, oral cancer has the highest incidence. These patients will have radiotherapy (and possibly chemotherapy) as part of their treatment. These patients will experience oral mucositis[1] and most probably difficulties in eating and swallowing. Once again, we feel it is important to address this issue of the aftermath of radio/chemotherapy more fully, in the section on oral mucositis beginning on page 91 – at present it only deals with prophylaxis of oral mucositis, with no mention of acute management of the condition which affects the vast majority of patients post treatment. The individuals highlighted above are key for service provision with respect to maintaining a healthy nutritional status for the patient.	
Cambridge Laboratories		Full	2	152-185	We acknowledge the significant change to the role of the CNS made since the first draft.	No response required.
Cambridge Laboratories		Full	2	165-167	In providing this crucial element of care post treatment, the CNS should be able to recommend simple medications and devices (i.e. oral bio-adherent gels such as Gelclair) to manage oral pain.	This is too much detail for service guidance.
Cambridge Laboratories		Full	2	201-203 319-323	Similarly for dieticians, they should be able to recommend simple medications and devices (i.e. oral bio-adherent gels such as Gelclair) to manage oral pain.	This is too much detail for service guidance.
Cambridge Laboratories		Full	3	94-95	Patients should also be informed on consequences of any intervention i.e. oral mucositis if the likelihood of occurrence is high.	Not appropriate at this point – this is about initial diagnosis.
Cambridge Laboratories		Full	3	115	Addresses the above point in a separate section	This comment is not clear.
Cambridge Laboratories		Full	4	14-15	The dietician can also manage the expectation of adverse effects such as pain associated with eating, swallowing as a	This is about assessment.

					result of treatment.	
Cambridge Laboratories		Full	4	67-76	These are welcome new comments to manage the nutritional status of the patient and difficulties with eating and swallowing.	No response required.
Cambridge Laboratories		Full	4	100-103	To add to preparing the patient pre-treatment, it allows patients to identify potential adverse effects at an early stage i.e. the pain associated with eating or oral mucositis.	Not relevant at this point.
Cambridge Laboratories		Full	4	242	We welcome the addition of guidelines on nutritional management of patients.	No response required.
Cambridge Laboratories		Full	5	59-62	We welcome comments on the provision of quality food for these patients. We would emphasise that strategies need to be in place to allow them to eat food especially if they are experiencing adverse effects such as oral mucositis.	No response required.
Cambridge Laboratories		Full	5	72-76	The point of continuity of treatment is well made. Oral Mucositis is a common cause of interruption/dose reduction. Treatment delays and interruptions are likely to have a clinical impact on that patients' treatment plan. The NCI estimate that "A significant number of patients develop mucositis to such severity as to require modification in their overall medical management"[2]. According to the National Institutes of Health (NIH), a 'significant number' of patients develop mucositis of such severity that their medical management is changed[1].	This issue is adequately dealt with in the last paragraph of the section.
Cambridge Laboratories		Full	5	85-86	The amendment to the first draft to add " appropriate palliative measures should be taken to minimise problems with the lining of the mouth" is appropriate recognising that significant numbers of patients are likely to be afflicted with this issue.	Agreed. See above.
Cambridge Laboratories		Full	5	93-95	These are welcome additions to the 1st draft	The wording is now generic.
Cambridge		Full	5	101-	These are welcome additions to the 1st draft, and recognise	No response required.

[2] National Cancer Institute Monograph 9, 1990
[3] Lavertu P, Adelstein DJ, Saxton JP, et al. Aggressive Concurrent Chemoradiotherapy for Squamous Cell Head and Neck Cancer Arch Otolaryngol Head Neck Surg. 1999;125:142-148

Laboratories				109	the particular needs of patients undergoing radiotherapy, particularly post treatment when late effects present, such as difficulties with eating due to the pain associated with oral mucositis and ulceration.	
Cambridge Laboratories		Full	5	189-192	Makes a valid point in that even in relatively well controlled conditions (i.e. RCTs) the treatment course time is significantly affected (approximately 25% cases), this number could be much higher in the real world setting.	No response required.
Cambridge Laboratories		Full	5	265-274	This section on prophylaxis of oral mucositis has been modified and generalised, with the conclusion that "these prophylactic interventions could prevent mucositis." Within head & neck cancer, oral cancer has the highest incidence. These patients will have radiotherapy (and possibly chemotherapy) as part of their treatment. These patients will experience oral mucositis[1] and most probably difficulties in eating and swallowing. We feel it is important to address this issue of the aftermath of radio/chemotherapy more fully, in this section on oral mucositis beginning on page 91 – at present it only deals with prophylaxis of oral mucositis, with no mention of acute management of the condition which affects the vast majority of patients post treatment, giving them a great deal of pain, difficulties in eating, significant impact on their quality of lives, and potentially interrupting their treatment course. We would propose an additional section on "Acute Management of Oral Mucositis" with information along the lines of the following: Ionising radiation to the oral cavity for head and neck cancers is a common cause of damage to the oral mucosa. When the treatment field includes the oral mucosa, the patient will almost certainly experience oral mucositis[1]. Patients receiving concomitant chemotherapy are likely to progress to a more severe grade – as many as 88% of patients may experience grades 3 or 4 mucositis with particularly aggressive therapy[3]. Symptoms start 1-2 weeks after the first dose of radiation, and continue for 1-3 weeks after the last dose if there are no complicating factors. Patients with the most severe mucositis	Too much detail for service guidance.

					will often be given enteral nutrition. In addition to medications needed to address oral infections, the management of pain caused by oral mucositis is essential. Bio-adherent gels (i.e. Gelclair) are being increasingly employed to manage the pain associated with oral mucositis. The physical barrier over the surface of the oral mucosa that is formed by the bio-adherent gel shields receptors from over stimulation. In this way Gelclair can reduce the pain of oral mucositis and can also enable patients to eat and drink more easily while they have the condition. CNS have found this device (Gelclair) particularly useful to enable patients to eat and maintain their nutritional status following ulceration in the mouth and mucositis. (B). The additional benefit is that patients can remain at home if they are being treated on an outpatient basis.	
Cambridge Laboratories		Full	5	275-281	This is a new section and specifically mentions precise therapies. (Please note that oral mucositis is different from xerostomia and should receive mention separately as it is so impactful on patient quality of life and nutritional status).	
Cambridge Laboratories		Full	5	279	Additional over the counter products should include “bio-adherent gels”, this is more specific than just “gels”.	General wording has been amended; this is too much clinical detail.
Cambridge Laboratories		Full	5	400	Taking into account the need to treat mucositis when it does occur, this process should read “Use of prophylactic / acute measures to prevent / treat mucositis in patients treated with radiotherapy or chemotherapy”.	This now reads: 'Use of measures to prevent and treat mucositis'.
Cambridge Laboratories		Full	6	5,	Highlights the need for these patients to be informed and provided management strategies for eating difficulties, oral hygiene, and oral pain management.	Agreed. No amendment proposed.
Cambridge Laboratories		Full	6	24-25	Highlights the need for these patients to be informed and provided management strategies for eating difficulties, oral hygiene, and oral pain management.	Agreed. No amendment required.
Cambridge Laboratories		Full	6	General	This is a modified section which is welcomed and emphasises the special needs of these patients.	No response required.
Cambridge Laboratories		Full	6	25	Point of clarification, are the needs of the group mentioned in the text covered or not covered in the referenced document?	It means that they are not covered (see text).
Cambridge		Full	6	58	Highlights the need for these patients to be informed and	No response required.

Laboratories					provided management strategies for eating difficulties, oral hygiene, and oral pain management.	
Cambridge Laboratories		Full	6	95-99	Highlights the need for these patients to be informed and provided management strategies for eating difficulties, oral hygiene, and oral pain management.	No response required.
Cambridge Laboratories		Full	7	14-15	Proactive management of potential adverse and late effects of treatment as an aim is welcomed. This is also the first time that "delayed effects" is mentioned and perhaps it's a terminology that needs to be used in other parts of this document to highlight areas such as oral mucositis.	Not accepted. This is about follow-up, and therefore it is appropriate to introduce it here.
Cambridge Laboratories		Full	7	34-36	As the adverse effects of radiotherapy "are common and usually treatable" it makes sense to include the treatment section highlighted above in Primary Treatment (See comment above relating to lines 265-274).	The wording has been changed to'should be treated'.
Cancer Research UK	1	All	General	General	Overall, we are impressed by the commitment and application that has been shown in compiling this appraisal. It represents an important shift in care for head and neck cancer, and if this guidance is properly implemented it should provide the UK with services at the forefront of those in most other western countries, including the USA.	No response required.
Cancer Research UK	2	Full Guidance	1	3 – 41	In most cases, performance of an MRI scan prior to biopsy provides more accurate information than that performed following surgery. This is because distortion of tissues by the biopsy may lead to overstaging of the tumour. Wherever possible, biopsy should also be preceded by digital photography. Where lesions require endoscopy, photographs should ideally be taken from two views: top down and at 70-90 degrees using appropriate telescopes.	See response to comment below.
Cancer Research UK	3	Full Guidance	3	34	Similarly as above, when an initial biopsy is taken on suspicion of UAT cancer, performance of an MRI scan and digital photography prior to biopsy is important.	This issue comes from only one source. While prior MRI scanning and photography may be desirable in some cases, as is being suggested, it is neither practical nor necessary to do it in all circumstances. The issue is too clinically detailed to cover in those recommendations and the review identified no evidence that MRI is specifically necessary. However additional text has been added to recognise the facilities that need to be

						potentially available as follows: Topic 3 page 62 line 35 – New sentence inserted after …..Await pathology results: 'Access to MRI or CT imaging is necessary before biopsy for some patients.'
Cancer Research UK	4	Full Guidance	2	11 – 21	The 1 million population recommended for a multidisciplinary team (MTD) is, in our estimation, too small a population. This 1 million figure implies there should be approximately 60 MTD centres in the country. However at present there are not enough true specialists to support this number of MTD centres. Existing centres, such as Liverpool, currently comfortably see far more than the recommended 100 cases per annum (Liverpool is now seeing 450 new cases per annum and the new UCL unit will see about 500.) It also seems excessive that in sparsely populated areas MTDs should be developed for smaller populations. Whichever part of the country a patient comes from, they should be treated by their nearest experienced clinical team.	The 1 million is a minimum, as are the case numbers. Each network (34 only in England) will consider the local issues and plan for their service. The likely number of MDTs therefore will be between 34 and the combined population of England and Wales in millions (less than 60 million).
Cancer Research UK	5	Full Guidance	2	64	The importance of the input of the palliative care physician to advanced disease decision-making should be highlighted. There is currently a shortage of palliative care physicians, and their input is especially valuable in head and neck cancer.	It is believed that their importance is already implicit in the text.
Cancer Research UK	6	Full Guidance	2	138 – 143	We applaud the sentiment in this paragraph that pathology and radiology review by specialists in head and neck cancer is fundamental. We would also ask that this specialist review should be extended to cytology.	Agreed. Addition made.
Cancer Research UK	7	Full Guidance	7	127	In many cases of recurrent disease, PET scanning can make a big difference to decision making. In the US, all patients (new or recurrent) now get PET scans. In addition to being effective in assessing the cancers listed, PET scanning is also invaluable in assessment of recurrent salivary (e.g. adenoid cystic) cancer.	The following text has been added: 'It is envisaged, as this modality becomes more available to MDTs, that greater use will be made of PET (and PET/CT and PET/MRI) in staging and recurrent disease.'
Cancer Research UK	8	Full Guidance	5	144	This paragraph on research and service development should be more strongly worded. By the time a trial has been accepted by the NCRI for its portfolio it has undergone the most rigorous assessment. Thus all networks should be encouraged to participate in NCRI trials, except where they do not have specific facilities for doing so. Networks should not turn down trials which they are equipped to undertake.	All networks cannot support trials in all topics. However, A sentence has been inserted, as follows: 'Each Cancer Research Network should regularly review the addition of studies of rarer tumours (such as head and neck cancers) to its portfolio, and ensure that these trials are

						considered by the Network's site-specific group.'
Cancer Research UK	9	Full Guidance	Appendix 1	All	The economic analysis is thoroughly welcomed. However, this does not seem to include the cost of increased training and appointment of medical staff in the areas of radiotherapy and oncology, palliative care, pathology and radiology. The economic analysis should take in to account the costs of recruiting and training for both existing, vacant posts, especially for consultants in pathology, but also for any additional staff required to meet the recommendations within this guidance.	Reference is made in the economic review to the fact that training costs have been omitted.
Cancer services collaborative improvement partnership	1	Full	general	General	Thank you for the opportunity to comment on this guidance which will undoubtedly benefit patients and ensure that they all receive the choice and support needed. The Cancer Services Collaborative 'Improvement partnership' (CSC'IP') has recently commenced work with Head and Neck Cancers and the guidance will undoubtedly influence the service redesign work required in this area. The comments below have been sought from the CSC'IP' National Advisory group for Head and Neck Cancer which covers most of the specialties involved, in fact the core MDT membership. We will be undertaking some work on the patient pathway to ensure that the combination of clinical interventions required and visits and time for the patients to reflect, meet with other patients, CNS, SLT, dietitians etc that for the more complex patient pathways the waiting times targets in the NHS Cancer Plan are achievable.	No response required.
Cancer services collaborative improvement partnership	2	Full	general	General	Overall this guidance will benefit patients and assist networks to provide services required. The forward would benefit from emphasising the importance of the multidisciplinary team and the holistic approach for this patient group so that all readers are aware from the beginning of the document that these elements are central to the service required.	The Developers believe that this approach is already clear from the current wording of the document; no response required.
Cancer services collaborative improvement partnership	3	Full	general	General	**Dietetic services**. Comments from first draft have generally been taken on board however there is still a lack of clarification of the dietitians role and a lack of understanding of the experience required to manage head and neck patients. It would be useful if the terminology about to be adopted with Agenda for Change were used which relates to a dietitian	We are describing the expertise required, not a particular role. The nature of the dietitian is specified in the MDT. Where there were inconsistencies, these have now been addressed. Reference is made to 'dietitian' throughout. This is consistent with

					reuired at this level as a Clinical Specialist, currently the guidance refers to dedicated and specialist.	the terminology in 'Improving Supportive and Palliative Care for Adults with Cancer'.
Cancer services collaborative improvement partnership	4	Full	general	General	**Speech and Language Therapy.** Comments from the first draft have generally been taken on board. However still some concerns about lack of emphasis of the specialist skills required and a slight missed opportunity re true MDT working as it concentrates on specialities rather than skills required. Concerns also over the lack of Quality of Life measurements generally in the document.	Reference is made in the document to the skills required; also, the role is described in the MDT. There is a balance to strike about the level of detail appropriate for inclusion in this Service Guidance. Thus although we have broadly tried to reflect the concerns fed though to us from the professional interests involved, it has not been possible, or appropriate, to include all the fine detail requested.
Cancer services collaborative improvement partnership	5	Full	general	General	**CNS.** Concerns that the role is too descriptive.	There has been considerable re-drafting of the text relating both to the CNS and other professional groups in the light of all the comments received.
Cancer services collaborative improvement partnership	6	Full	1	101	There is eveidenc to show that practice nurses can be trained are well placed and to check patients' mouths and should be added along with GPs and dentists.	Agreed. This addition has been made.
Cancer services collaborative improvement partnership	7	Full	2	19	Combining of more than one MDT in a single conurbation will cause problems for some networks where each MDT may reach the 1 million or close to figure. It may be helpful to networks to give clearer guidance on this.	Networks have to decide for themselves how this will work.
Cancer services collaborative improvement partnership	8	Full	2	165	The emphasis on this aspect of support is welcomed however it would be more appropriate to read '**post treatment period**' rather than post operative period. Patients undergoing other forms of treatment require the support as much as surgical patients.	Agreed. Amendment made (both to the Manual and the Research Evidence).
Cancer services collaborative improvement partnership	9	Full	2	205	Rather than reading 'the MDT should be responsible' a better reflection of reality would be to read '**the MDT should be supported in ensuring** that specialised dentistry is available….'	Not accepted. The responsibility rests with the MDT.
Cancer services collaborative improvement partnership	10	Full	5	67	There is no mention of the use of hyperbaric oxygen in the radiotherapy section.	The role of hyperbaric oxygen was not a question addressed by the Editorial Board.
Cancer services	11	Full	8	63 –	In some hospitals it has been deemed appropriate to direct	The text has been amended as follows:

collaborative improvement partnership				68, 104 105	patients with airway obstruction to accident and emergency rather than the ward and this can work well. The key element should be a clear agreed and documented process for where patients should be directed and that all concerned are aware of this process. With anticipated staffing such juniors on ward will not be proficient with management and there may not be appropriate equipment available.	'Patients at risk of airway obstruction should be identified and ambulance personnel, GPs and carers should be informed of where such patients should be taken. They should be made aware that these patients should *not* be taken to accident and emergency departments unless no alternative is available.'
Cancer services collaborative improvement partnership	12	Full	General	General	We would suggest this document be revised. I would also suggest a comment that this IOG should be reviewed and revised after 24 months – Sept 2006. This will allow for reassurance with the stakeholders that comments and suggestions will be listened to and taken on board.	This is outside the Developer's remit. NICE should be approached about its planned timescale for updating the guidance.
Cancer services collaborative improvement partnership	13	Full	General	General	We are concerned that ophthalmology patients have been missed. Could they be included in any future revision of the document or are there plans to include them in any other guidance?	Again, this query should be directed to NICE.
Cancer Services Co-ordinating Group						This organisation was approached but did not respond.
Cancer Voices						This organisation was approached but did not respond.
CancerBACUP						This organisation was approached but did not respond.
Cephalon UK Ltd						This organisation was approached but did not respond.
Changing Faces						This organisation was approached but did not respond.
Chartered Society of Physiotherapy	1	Full	General	General	This document largely omits the role of physiotherapy. Physiotherapists contribute to post-surgical and post-radiotherapy in providing immediate and long term care; this includes respiratory interventions, facilitating return to usual activities, increasing physical activity and stamina, confidence, and providing support to family and carers. The catch-all to refer commissioners to the NICE Supportive and Palliative Care document is too broad and vague, as is noted in section 6, line 25-26.	The Developers believe that the role of physiotherapy has been adequately addressed. It is documented as part of the extended MDT and the local support team. Its generic role is covered by cross-reference to 'Improving Palliative and Supportive Care for Adults with Cancer'.
Chartered Society of Physiotherapy	2	Full	1	346-7	Rehabilitation, support and palliative care	This is information in the Background section, not a recommendation.

					We are pleased to see reference made to some allied health professionals in this section, however as it is written it will not help ensure the correct commissioning of some services. For example, while it does say 'Such patients need specialised support from a variety of therapists' (line 345), commissioners will read the next line 'particularly speech and language therapists, who provide expert assistance with swallowing, communication and breathing problems, specialist nurses, and dietitians' (346-347). This raises the real likelihood that other services, such as radiography, occupational therapy, physiotherapy will not be commissioned.	
Chartered Society of Physiotherapy	3	Full	2	78-110	Extended Team We are extremely concerned that commissioners do not understand the subtlety of clinical variation expressed in this section, and will not commission sufficient services to permit physiotherapists (and the other proposed extended team members) to 'make themselves available whenever their expertise is needed' (line 82). This section has the potential to therefore weaken services rather than improving them. This document is intended for those commissioning services, and therefore it would be clearer to describe one large 'team' rather than devising an artificial divide. Perhaps it would be helpful to further elucidate on specific circumstances when members of the 'extended' team may participate? For example, for physiotherapists, it could say, 'Physiotherapists should be involved pre-operatively for assessment and education with patients, and post-intervention for respiratory management, such as difficulty expectorating excess secretions and tracheostomy, postural care, reduced physical activity and stamina following radical surgery, and reduced range of neck and shoulder movement and muscle	This would simply not be practical, and would be likely to waste the time of many busy professionals.

					activity.'	
Chartered Society of Physiotherapy	4		2	152, 186, 192, et al	Why include some job descriptions for these professionals and not all the members of the core, and extended team? This goes directly against the philosophy of NICE and the Government's modernisation plans that interventions need not be delivered by roles on an historical professional basis, but that they should be delivered by the professionals best able to deliver them.	Please see explanatory sentence in the preceding paragraph in the text on this rationale.
Chartered Society of Physiotherapy	5		2	231-233	We agree and therefore do not understand why 'other allied health professionals' are omitted from the core team.	It is not appropriate for them to be at every single meeting – hence their inclusion in the extended team.
Chartered Society of Physiotherapy	6		2	314	Would it be more inclusive to say 'Nursing and allied health professional staff play crucial roles…'	Agreed. Amendment made.
Chartered Society of Physiotherapy	7		2	458-465	This exemplifies our concern that commissioners will not ensure the full range of services are provided while the emphasis is placed on CNSs, dieticians and SLTs.	The emphaseis is placed on these, as they are key members of the MDT.
Chartered Society of Physiotherapy	8		6	105	We are pleased to see recognition of the role of the physiotherapist here. However, the description merely reflects 'shoulder syndrome' and not the range of current service provision or desired service provision. The physiotherapist would provide assistance in developing a programme to increase the patient's stamina, physical activity, and confidence. Reduction or loss of all three may be due to ongoing respiratory problems or because of the nature and extent of the surgery. Physiotherapy will also be directed at alleviating reduced range of movement and specific muscle action in the face, neck or shoulder.	Agreed. The text has been amended.
CHI						This organisation was approached but did not respond.
College of Occupational Therapists	1	Full	2	78-101	It is essential that *Occupational Therapist* is added to the extended MDT. The reasons for referral to OT as a member of the extended head and neck MDT are as follows:	Agreed. Addition made.

					▪ To facilitate safe, effective discharge through assessment in conjunction with the multidisciplinary team. ▪ If the client has new visual loss or impairment ▪ If the client is experiencing difficulties with fatigue, productivity or leisure ▪ If the client has cognitive/perceptual difficulties and or memory problems ▪ The client's condition is deteriorating effecting their functional ability or independence ▪ There is concern regarding the client's safety and ability to manage within their home environment. Occupational therapists carry out the following interventions with head and neck clients: • The use of functional activities for the treatment of physical, psychological and emotional difficulties • Energy conservation/goal setting • Facilitating psychological adjustment to loss of function • Retraining of cognitive/perceptual dysfunction. Also teaching of coping strategies. • Relaxation training and stress management • Retraining in personal/domestic activities of daily living • Home assessment and/or referral to social services for:- o Provision of equipment to enable optimum independence o Care packages • Support and education for carers of aspects of function, eg hoisting and transfer techniques • Assessment for wheelchairs, pressure relief and seating needs. The College therefore recommends that *Occupational Therapist* is included as members of the extended MDT to enable these interventions to occur in a timely manner.	
College of Occupational Therapists	2	Full	2	231-233	We agree that SLTs and dietitians are essential to the function of the team, but if "other allied health professionals should be regarded as essential to the function of the team" we do not	It is not appropriate for them to be at every single meeting – hence their inclusion in the extended team.

					understand why they are omitted from the MDT?	
Department of Health	1	Table of responses from NICE to DH comments	No. 15		In reply to point 15, we believe that the Editorial Board may not have given sufficient cognisance to the DH 'Hospital at Night ' recommendations. It appears they are seeking to enforce a 24/7 resident middle grade / consultant rota in ENT onto hospitals in circumstance where the consequences have not been fully thought through.	The wording now reads: 'Hospitals which deal with patients with head and neck cancers should have systems in place to ensure that patients who may develop acute airway obstruction can be admitted directly to a ward where staff have the expertise required to deal with the problem. Patients at risk of airway obstruction should be identified and ambulance personnel, GPs and carers should be informed of where such patients should be taken. They should be made aware that these patients should *not* be taken to accident and emergency departments unless no alternative is available. Specific training in care for patients with end tracheostomies (neck breathers) should be provided for staff who are likely to deal with these patients.' The guidance is seeking to ensure that optimal arrangements are in place to manage these patients. Implications for the service of their implementation are the responsibility of the cancer networks.'
Department of Health	2	Table of responses from NICE to DH comments	No. 15		The right hand column states 'This point was extensively discussed by the Editorial Board, and this was not their view' – We would be grateful for further information as to the reasons why this was not their view. In the same section, which reply are they referring to when it states 'see above?' If this is in relation to this not being the view of the Editorial Board comment, again we would be grateful for further information as to the reasons why this was not their view.	Because management of airway obstruction is complex, and requires specific training and expertise (see wording above). See response above.
Department of Health	3	Full guidance 2nd	8	67-68	Please would you consider amending to read 'should not routinely be taken to A&E departments', as we believe that this is a very prescriptive statement at odds with the 'should	The text has been amended as follows: 'Patients at risk of airway obstruction should be identified and ambulance personnel,

		draft			have' and 'can' that were previously amended (lines 64 & 65).	GPs and carers should be informed of where such patients should be taken. They should be made aware that these patients should *not* be taken to accident and emergency departments unless no alternative is available.'
Department of Health	4	Full guidance 2nd draft	8	63 Management of airway obstruction	In addition to the comments made during the first consultation, and the response to the developers comments, this recommendation still causes us some concern, because in our view: • If patients go to a ward they may not have adequate resuscitation facilities or systems to get immediate attention. • Although many hospitals do not have specialist head and neck units, if it is a life threatening condition then it is suggested that the ambulance crew should probably take the patient to the nearest A&E that has anaesthetic / intensive care team on site. • We suggest that a patient with acute airway obstruction may require immediate resuscitation and that therefore it is suggested that such patients are managed as a resuscitation call.	• This only applies where the appropriate facilities are available at the hospital. • This was not the view of the Ed Board, because of the potential impact of inappropriate treatment on a patient's QOL. • The text has been amended as follows: 'Patients at risk of airway obstruction should be identified and ambulance personnel, GPs and carers should be informed of where such patients should be taken. They should be made aware that these patients should *not* be taken to accident and emergency departments unless no alternative is available.'
Eisai Limited						This organisation was approached but did not respond.
Eli Lilly and Company Ltd						This organisation was approached but did not respond.
Faculty of Dental Surgery	1	Full	general		This group welcomes the recognition that dental and oral care for this group of patients is an essential part of their assessment, treatment and aftercare. The dental team should be involved as soon as the diagnosis has been made. We agree that the presence of the consultant in restorative dentistry with a special interest in oncology at the MDT is essential. The supporting dental team should include a dental hygienist, maxillofacial or dental technician and dental nurse. This team would liaise with the patient's dentist and other MDT members. The inclusion of a specialist restorative dentist as a member of the core team as listed on page 43 is welcomed. The inclusion	No response required.

					of a dental hygienist as an extended team member is important (page 45) but on page 44 where ''prosthetic services'' is listed, perhaps this should be changed to maxillofacial/dental technician.for consistency. In addition to pre-operative and peri-operative care, oral rehabilitation following treatment should be a major priority to help patients improve mastication, speech, appearance and for an improved quality of life.	This is the term used in the current draft. This point is already covered in the text.
Faculty of Dental Surgery	2	Full	2		Dental services (page 48) ''The MDT should be responsible for ensuring that specialised dentistry is available for all patients who require it. Expert dental assessment is important both before and after treatment especially when radiotherapy is being contemplated. Many of these patients have complex needs. A consultant with experience in maxillofacial prosthodontics and implantology is required to manage patients who need complex oral rehabilitation within the secondary care sector. In addition the consultant should also co-ordinate the dental care of patients following treatment by liaison with primary care dental practitioners who will be able to provide appropriate treatment and maintenance for many oncology patients.	These issues are dealt with in later sections of the document (Pre-treatment assessment and Aftercare and rehabilitation).
Faculty of Dental Surgery	3	Full	2		Section 2B, anticipated benefits We suggest including the following comment (page 52) A pre-treatment dental assessment and appropriate dental treatment will help prevent future problems such as osteoradionecrosis which is often precipitated by the necessity to extract diseased teeth following radiotherapy.	This is dealt with later on in the manual (Topic 4, Pre-treatment and assessment)
Faculty of Dental Surgery	4	Full	2		Section 2C, evidence (page 54) Currently, there are many H&N cancer centres which have no input from a consultant in restorative dentistry with a special interest in oncology. The larger regional centres have dedicated dental oncology consultants but there are only about 15 of these posts in England and Wales.	No response required.
Faculty of Dental Surgery	5	Full	2		Section 2E, resource implications (page 59) More consultant in restorative dentistry (oncology) posts will be needed to reach the objective of one in every MDT.	Generically, this point is already covered.
Faculty of Dental Surgery	6	Full	4		Section 4, Dental assessment (page 70) We suggest adding the following: Appropriate planning should be undertaken in the light of the	This is too detailed for service guidance.

					patient's presenting disease and the likely effects which oncology treatment will have upon their ability to maintain a functioning dentition. The planned surgical procedure should be discussed with the restorative specialist to help decide; * which teeth should be retained/removed * with maxillary resections, the decision to close surgically or obturate the defect * the need for surgical/temporary prosthesis * Involvement of the restorative specialist during surgery.	
Faculty of Dental Surgery	7	Full	8		Section 8A, Local Support Team Members (page 105) We suggest the following be added: The local support team members should liaise with the patient's dental practitioner with regard to ongoing care. If specialist oral rehabilitation is indicated, then the consultant in restorative dentistry would take the lead in this.	This reference is not clear. (Not this section, not this page). Oral rehabilitation is already covered in Topic 6, After-care and rehabilitation.
Faculty of Dental Surgery	8	Full	8		Section 8C Restorative Dentistry (page 110) This just deals with studies on osseo-integrated implants. The experience of this group is that oral rehabilitation using osseo-intergrated implants can be of great benefit in improving appearance, speech, mastication and general quality of life, but there are also other prostheses which do not rely on dental implants for retention, such as maxillary obturators which are indispensable for some patients. There are other questions for which evidence should be sought such as: * The decision to close a maxillary defect surgically or obturate the defect with a prosthesis *The best oral care to avoid and treat radiation caries *Whether implant retained prostheses should be fixed or removable The first sentence of the paragraph on page 110 could read "A number of small studies of the outcome of dental and facial bone restoration using prostheses retained by osseo-integrated implants show that these are effective for many patients and are often the only way of rehabilitating the patient".	These were the questions felt to be important by the Editorial Board. Evidence on other questions has not been sought.
Faculty of Dental Surgery	9	Full	general		I hope you will consider this group's comments favourably. We wish to be involved in any future deliberations regarding the management of head and neck cancer patients and I enclose our contact details.	No response required.

Faculty of Public Health						This organisation was approached but did not respond.
General Medical Council						This organisation was approached but did not respond.
Help Adolescents with Cancer						This organisation was approached but did not respond.
Help the Hospices						This organisation was approached but did not respond.
Institute of Physics and Engineering in Medicine						This organisation was approached but did not respond.
Intensive Care Society						This organisation was approached but did not respond.
Isle of Wight NHS Trust						This organisation was approached but did not respond.
Joint Committee on Palliative Medicine						This organisation was approached but did not respond.
Let's Face It						This organisation was approached but did not respond.
Link Pharmaceuticals						This organisation was approached but did not respond.
Luton and Dunstable Hospital NHS Trust	1	Full	General	General	Overall we consider that this guidance will be very helpful to clinicians and MDTs in developing best practice for the management of Head & Neck Cancers	No response required.
Luton and Dunstable Hospital NHS Trust	2	Full	General	General	The guidance recommends specialised teams for the management of thyroid, salivary and skull base tumours. Whilst we agree in principle, it should be noted that salivary tumours are not always diagnosed pre-operatively and the existing surgical team may perform surgery.	This issue is dealt with in the surgery section of Topic 5.
Luton and Dunstable Hospital NHS Trust	3	Full	General	General	Whilst we agree with guidance recommendations that MDTs are responsible for ensuring accurate and complete data recording, this requires adequate resources to be identified/made available to support this.	The following point has been added to the Measurement section under Structure: 'Appropriate staff and structures in place for recording accurate and complete data on disease stage, management and outcomes'. The Economic Review covers the cost implications of resourcing Data Managers.
Luton and Dunstable Hospital NHS Trust	4	Full	General	General	We agree with guidance recommendations that a wide range of support services should be provided, but it should include that restorative dentists and clinical psychologists are in short supply nationally.	This point is not within the remit of the guidance.

Luton and Dunstable Hospital NHS Trust	5	Full	Chapt.8	32 - 45	Recommend that this section also raises the importance of having a Palliative Care Consultant as part of the MDT. We see that their role would be dedicated to Head and Neck Cancer patients.	The Palliative Care Consultant is included in the core team (see Topic 2, Structure of services).
Macmillan Cancer Relief	1	Full			Thank you for your invitation to respond to the second draft of the guidance for head and neck cancers. We were pleased to see that many of the points we made in response to the first draft of the Guidance were approved by the developers and have been incorporated into this second draft. We therefore feel it unnecessary to make further comments on the latest version. However, we are aware that there are issues relating to the CNS role, which we recognise as being especially contentious, and on which we would like to comment. In response to the first consultation, we suggested that not all patients would wish to be referred to a specialist Head and Neck CNS, but expressed our desire that all patients should have access to one. Recognising that there were strong views held on both sides of the argument that all head and neck cancer patients should be referred to a specialist CNS, we undertook a brief consultation on this point with a number of such patients with whom we are in contact. The results of this 'mini-consultation' suggested that it is certainly helpful for patients to have access to a Specialist Nurse in view of the very specialised nature of many head and neck cancers, and in particular the side-effects of these conditions or their treatment, especially in the early stages of a diagnosis and treatment. Patients who have to deal with, for example, facial disfigurement and/or loss of verbal communication in addition to the cancer diagnosis value the specialist head and neck nurse very highly in order to improve their quality of life. It was therefore perceived that generalist nurses can contribute a great deal to the care of head and neck cancer patients, but that access to specialist advice and guidance was essential for both generalist nurses and patients. It would seem that much of the care needs of these patients can be met in a variety of ways, and that it is not therefore necessary for specialist nurses to see every patient. Need will vary very much according to the wishes of individual patients and what	Although we have modified the text on the CNS significantly to reflect all the comments received from the profession, including the stress placed on the importance of the development and professional leadership roles, and the variable level of input required by individual patients, we retain the vital 'failsafe' requirement for all patients to see the CNS in the initial period. It is clear from our own commissioned work (NCA) and from Macmillan among others that patients value access to the CNS very highly and believe it to be crucial to their welfare.

					opportunities exist to have their specific concerns addressed and needs met. However, we would certainly wish to see access to specialist advice for patients, their families and for those caring for them (including healthcare professionals) when they require it. Such a model would ensure that specialist skills are spread further through the nursing workforce and that pressure is eased on the limited number of specialist nurses. We hope you find these comments helpful, and should be pleased to provide further information if required. We look forward to the next stage of the study.	
Medicines and Healthcare Products Regulatory Agency (MHRA)						This organisation was approached but did not respond.
Merck Pharmaceuticals						This organisation was approached but did not respond.
National Association of Laryngectomee Clubs						This organisation was approached but did not respond.
National Cancer Alliance						This organisation was approached but did not respond.
National Cancer Network Lead Clinicians Group	1	Full	general		General - there is still some disappointment over the pace of change and the feeling that a lack of resource and oversensitivity to self-identified special interests has exerted too much influence on the speed (or lack of it) of centralisation of the surgery. To both recognise and support the continuation of surgery outwith specialist centres is a departure from earlier surgical guidance documents and may present difficulties in implementation on a wider canvas than just head and neck.	The point is that there are very limited and defined circumstances in which surgery may be supported outside specialist centres. The guidance makes clear where those limited circumstances apply.
National Cancer Network Lead Clinicians Group	2	Full	3		page 62. We remain unconvinced that so much emphasis should be given to FNAC rather than core biopsy. The latter is better for addressing the diagnostic pathway overlap with haematology and a much more reliable way of securing a histological diagnosis without excision.	This comment serves to highlight the limited evidence base for any decisions. What is practicable at a particular site depends on the cytopathological and clinical expertise and facilities being present. FNA in a well-organised setting is rapid and reliable which is the basis for the way the guidance is set out. However, the technique of choice (FNA

						versus core biopsy) will depend on the clinical situation and the suspected diagnosis (as well as on clinical skills). This issue is almost getting into clinical guidelines mode, and it is reasonable for Service Guidance to avoid taking an absolute view on which modality to use in a given situation.
National Cancer Network Lead Clinicians Group	3	Full	3		page 63. We are not sure that discussion with a haematologist or oncologist should take temporal precedence over a full examination of the aero-digestive tract and the obtaining of material for a histological diagnosis.	Agreed. The text has been amended to 'core biopsy'.
National Cancer Research Institute (NCRI)						This organisation was approached but did not respond.
National Council for Disabled People, Black, Minority and Ethnic Community (Equalities)						This organisation was approached but did not respond.
National Council for Hospice and Specialist Palliative Care Services						This organisation was approached but did not respond.
National Nurses Nutrition Group						This organisation was approached but did not respond.
National Public Health Service						This organisation was approached but did not respond.
NCC Cancer Mr Rob Grimer/Dr Joe Kearney – Lead Clinician and Chair of the Sarcoma GDG	1	Full	General	General	At a recent meeting of the sarcoma GDG, which is developing NICE guidance on improving outcomes in sarcoma, the issue of head and neck sarcoma (including skull based tumours) was raised. The Group felt it important that this population of patients should not be overlooked but were unsure as to whether they were being considered as part of the head and neck service guidance. The sarcoma GDG would be very grateful for feedback on this issue and details of any relevant references which have been located on the subject. In particular the GDG were anxious that the appropriate referral routes and channels of communication between the	Soft tissue sarcomas are rare. When they arise it would be expected that head and neck surgeons would discuss them with the oncologists from the sarcoma team. If they need resecting, then pragmatically it would be a joint ENT/OMFS/Plastics team that resect and reconstruct with oncological management by the specialist sarcoma oncologists. [Note: This issue has been put to the team dealing with the sarcoma guidance. Subject

					head and neck and sarcoma MDT's were specified in the head and neck service guidance.	to any comments they wish to make this will be included in a brief mention in this guidance.]
NHS Information Authority (DAHNO Project)	1	Full	General	General	We welcome the greater emphasis on data collection and the need to resource that, throughout the guidance.	No response required.
NHS Information Authority (DAHNO Project)	2	Full	7	Key recommendations	We welcome the statement that "Information and audit are crucial to improving services and should be adequately supported".	No response required.
NHS Information Authority (DAHNO Project)	3	Full	29	428-432	We welcome the updating of this section to reflect advances in national clinical audit for head and neck since the original BAHNO initiatives.	No response required.
NHS Information Authority (DAHNO Project)	4	Full	43	70	We welcome the recommendation that the team should have a data manager, but the role of the data manager should be further explained, i.e., the role of the data manager is to: • ensure that the MDT has all relevant details for the MDT meeting • to record details of the care plan • to ensure that data is available for other purposes, such as clinical audit	Agreed. A synopsis of the role has now been included.
NHS Information Authority (DAHNO Project)	5	Full	51	258 – 277	We welcome the description of information and facilities necessary to support MDT meetings.	No response required.
NHS Information Authority (DAHNO Project)	6	Full	52	283 – 285	We welcome the recommendation that "Information about each patient should be recorded in the database produced by BAHNO, as part of the ongoing audit known as DAHNO". Please note, however, that the "see background" note directs readers to an incorrect page (33) the correct page is 29 Please also note that NCASP produced the database technical infrastructure. BAHNO has contributed to the development of the database.	Text amended.
NHS Information Authority (DAHNO Project)	7	Full	121	Appendix 1	We welcome the costing of an MDT co-coordinator/data manager for each MDT. It should be spelt out however, how many teams in the country it is envisaged there will be, so that the reader can assess the assumptions upon which the calculations were made.	Now that the assumptions regarding MDT provision have been finalised, this is inluded in the text.
NHS Information Authority (DAHNO	8	General	General		The DAHNO project team, which includes representatives from the Healthcare Commission, the Department of Health,	NICE stakeholders are not listed within the final guidance document. The Developers

Project)					the NHS Information Authority, BAHNO, the English cancer registries and the Royal College of Surgeons would wish to be noted as consultees for this guidance in the final draft.	did not explicitly consult DAHNO; as with many other stakeholders, their comments have contributed to the final version of the text.
NHS Information Authority (DAHNO Project)	9	Full	General	General	We welcome the greater emphasis on data collection and the need to resource that, throughout the guidance	No response required.
NHS Information Authority (PHSMI Programme)						This organisation was approached but did not respond.
NHS Quality Improvement Scotland						This organisation was approached but did not respond.
Norfolk and Norwich University Hospital NHS Trust						This organisation was approached but did not respond.
Novartis Consumer Health (Novartis Medical Nutrition)						This organisation was approached but did not respond.
Ortho Biotech						This organisation was approached but did not respond.
Prodigy						This organisation was approached but did not respond.
Royal College of Anaesthetists						This organisation was approached but did not respond.
Royal College of General Practitioners						This organisation was approached but did not respond.
Royal College of General Practitioners Wales						This organisation was approached but did not respond.
Royal College of Nursing (RCN)	1	All	General	General	There is a distinct lack of references incorporated through out this piece of work. Whilst studies and meta-analysis are referred to they are not referenced.	The RCN is invited to refer to the Research Evidence document, fully referenced, which was available for the web consultation. Inevitably, limited reference is made to it in the Guidance document itself; its role is to provide all supporting evidence.
Royal College of Nursing (RCN)	2	Full	6	70	The role of the ENT/maxillofacial nurse practitioner described is currently what is expected of any specialist/senior nurse on a head and neck ward so that 7-day cover is already provided. This role should be the role of ward nurses and of OPD nurses	The text now reads: 'Senior nurse who can provide advanced skills for the management of stomas (tracheostomies and gastrostomies),

					rather than creating another role as this will lead to deskilling of ward and OPD nursing staff. The local team described does not currently include any ward staff who are the key to the patient's initial recovery after surgery and who co-ordinate discharge planning and head and neck OPD nursing staff continue that role after discharge. The local support team should therefore be including specialist head and neck ward & OPD nurses.	nasogastric tubes and tracheo-oesophageal valves. This nurse should work alongside the CNS, SLT and dietitian, …'
Royal College of Paediatrics and Child Health						This organisation was approached but did not respond.
Royal College of Pathologists					The Royal College of Pathologists consider that the alterations in the second draft appear to have covered previous comments.	Thank you.
Royal College of Physicians of London	1	All	General	General	Although there may be more than one surgical site for Head and Neck in a network there does need to be a unified multi-disciplinary team or at least regular meetings between everyone who treats head and neck cancer in a network.	The point about network working is already adequately covered – reference is made to network-wide guidelines and audit. Local arrangements are to be agreed and implemented by the network.
Royal College of Physicians of London	2	All	General	General	Complex patients eg those receiving multi modality treatment, chem, radiation +/- surgery perhaps should be treated at the one site in the network. There is a safety issue here and also patients can then get used to the Head and Neck team that is delivering all their modalities of treatment.	The Developers believe that this point is adequately covered in the text the way it is currently drafted.
Royal College of Physicians of London	3	All	General	General	There needs to be a lot more emphasis on research in Head and Neck cancer because research into this area is really very lacking, particularly in the UK, and this document is an opportunity to try and encourage networks to get a research base.	The importance of research is acknowledged – see the key recommendations and the Foreword.
Royal College of Physicians of London	4	full	1.	57 and 58	We question the rationale of referring patients with "cranial neuropathies" or "orbital masses" to a Head and Neck clinician, unless there is a high clinical suspicion of head and neck cancer. A very small proportion of cranial neuropathies end up being cancer related. Patients with cranial neuropathies should be referred to a neurologist and ? orbital masses probably to an ophthalmologist otherwise the Head and Neck clinician will see too much MS, stroke, shingles and Graves disease.	This text is taken verbatim from the DoH Urgent Referral Guidelines (England). (These are currently being revised – refer to NICE for details.)
Royal College of	5	full	2.	122	A minor correction should be made to this line. The term for	Agreed. Amendment made.

Physicians of London					the document required to authorise the use of Radioiodine is called an ARSAC certificate not a licence so presumably the line should read ..... and certificated to give.	
Royal College of Physicians of London	6	full	4.	238-9	PET scanning is referred to under both the initial diagnosis and staging section and the follow up section. We would agree that it has a role in both. However, lines 238-239 make no reference to PET although CT and MRI are mentioned and specialist ultrasound. Is this intentional or simply an oversight? We believe PET scanning should be referred to here as well as the similar section on follow up where indeed it does appear.	The text refers to PET scanning 'if available', hence its non-appearance in the Measurement section.
Royal College of Physicians of London	7	full	7.	72	We accept that these are service not clinical guidelines but still think that some reference to the 2002 Royal College of Physicians/British Thyroid Association guidelines on the management of thyroid cancer would have been appropriate when discussing management and follow up.	Generic reference is made to the need for protocols and guidelines. Many specific guidelines provide no evidence base.
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 Speech and Language Therapists	1	All	general	General	Overall this version of the document provides much more balanced information which includes all members of the MDT with more equal weighting. Most of our concerns regarding the description of the role of speech and language therapy (SLT) have been amended accordingly. We have made comment on chapters that are most relevant to our profession. The comments highlight the points that we feel most strongly in agreement or disagreement with. Any information or chapter not commented on, is by no means a representation of what we feel is any less important and should therefore remain in this document.	No response required.
Royal College of Speech and Language Therapists	2	All	general	General	There continues to be a lack of reference to measuring quality of life (QOL) pre and post treatment throughout the document – there is only 1 mention in follow-up. This is very disappointing given all the evidence on this topic which was presented at Harrogate. There is a huge evidence base for using QOL measures to inform patients & target interventions appropriately.	Measurement of QOL should be an integral part of the approach to patient management, as described in the guidance.
Royal College of Speech and	3	Full	Key Recs.	Key recs.	The key recommendations have changed significantly from the last version, which we welcome. There is a much firmer	Thank you for this acknowledgement. No response required.

Language Therapists					commitment to delivery of care in centres; equal weight given to key members of the multi-disciplinary team (MDT) - including SLT; and higher priority given to the local support team and research.	
Royal College of Speech and Language Therapists	4	Full	Background	308	Whilst we acknowledge there is a balance to be struck with detail, we still consider it important to include stroboscopy here: We suggest: "…is essential, and stroboscopic examination of the larynx is useful".	Too much detail for the Background section.
Royal College of Speech and Language Therapists	5	Full	Background	336-357	Our comments re: patients/carers/financial needs have been included but not sexual problems. The latter should be mentioned in the guidance.	This is a generic issue – not appropriate to include here.
Royal College of Speech and Language Therapists	6	Full	Background	439	We reiterate our suggestion to include reference to the laryngectomy/surgical voice restoration (SVR) dataset here.	The DAHNO dataset is referenced. Is this an additional dataset?
Royal College of Speech and Language Therapists	7	Full	1A	12-22	Re-organisation of services is to be a network responsibility but there are still no recommendations on how services should be re-configured i.e. what about hospitals that do have the capacity to provide an equivalent service to a nearby centre? There needs to be consultation with all trusts at present delivering a Head and Neck service. Will there be a bidding process between trusts?	The guidance provides a framework – local circumstances within the cancer network will dictate service provision.
Royal College of Speech and Language Therapists	8	Full	2A	61	Remove "dedicated'" and replace with: "Speech and language therapist with specialist expertise".	'Dedicated' has been removed. Specialism applies to all team members.
Royal College of Speech and Language Therapists	9	Full	2A	72-74	We question why these comments are inserted here. These are utilisation issues which should be resolved locally, not national guidelines.	This may seem prescriptive, but was included because historically CNSs took this role, and it is felt important to emphasise that this should not be their role.
Royal College of Speech and Language Therapists	10	Full	2A	152	The members of the MDT should be discussed in the order that they are listed on pages 42-43 in order to maintain consistency within the document.	The order has been altered to maintain consistency within the document.
Royal College of Speech and Language Therapists	11	Full	2A	160, 170 and 179 – 185	The comments in this section do not apply purely to the CNS role – but also to other MDT members. We suggest that there could be a general comment about these issues at the beginning of this section and then shorter, more equal, paragraphs about each specific profession.	This is accepted, and there has been some redrafting of the text.
Royal College of Speech and Language Therapists	12	Full	2A	187 – 196	This section is much improved, however please amend the following: a) The SLT is responsible for the assessment of….(remove the phrase "share responsibility").	The text has been re-drafted to take account of comment (a). It is accepted that this aspect of assessment should be the responsibility of the SLT, but other aspects

					b) Remove "dedicated'" and replace with: "Speech and language therapist with specialist expertise". This section should also include reference to the 'considerable time after discharge' as with CNS – (or this could go in the general comment at the beginning, as recommended above). It also needs to include the provision of support and information for carers– much of what the SLT does involves supporting and informing the carers and family members.	of the role described are likely to be shared. The sentence now reads as follows: 'They should take responsibility for assessment of communication and swallowing before treatment, and share responsibility with other MDT members for discussing the potential impact of proposed treatments on the patient and helping patients who have problems with eating, drinking or communication during and after treatment.' The text has been altered as suggested in (b). A clause has been added to include the role of the SLT in providing information and supporting carers; this part of the text now reads as follows: 'they also provide psychosocial support and information for patients and carers'.
Royal College of Speech and Language Therapists	13	Full	2A	274	"As quickly as possible" needs quantifying.	It is difficult to be more prescriptive. Local targets should be set.
Royal College of Speech and Language Therapists	14	Full	2B	309	We welcome inclusion of SLT in this topic.	No response required.
Royal College of Speech and Language Therapists	15	Full	2B	319-323	We also welcome the inclusion of dietitian here.	No response required.
Royal College of Speech and Language Therapists	16	Full	2D	460 – 462	We welcome this action.	No response required.
Royal College of Speech and Language Therapists	17	Full	2D	463 – 465	This is an ambiguous sentence (it reads as if nurses might wish to become SLTs!). Rephrase to: "…general dietitians, SLTs who wish to specialise and nurses who may wish to become…"	Not accepted. No change required.
Royal College of Speech and Language Therapists	18	Full	2D	472	How will participation be measured?	This must be locally agreed.

Royal College of Speech and Language Therapists	19	Full	3	128	We welcome the inclusion of SLT here.	No response required.
Royal College of Speech and Language Therapists	20	Full	4	General	Very impressed with the chapter's focus on holistic management and team-decision with regard to treatment decisions .	No response required.
Royal College of Speech and Language Therapists	21	Full	4A	11 - 12	"SLT involved in management of those whose symptoms are difficult to control" - It is not clear what this means. The SLT will see all patients. We strongly agree that SLT be called in immediately.	This is about the immediate management of presenting symptoms, if necessary.
Royal College of Speech and Language Therapists	22	Full	4A	62-80	We welcome the inclusion of SLT here. We agree strongly with this paragraph, however we would suggest aiming for protocols and guidelines that are agreed at a national level (by professional bodies) rather than at network level, particularly with regards to guidelines for use, placement and management of PEG tubes.	The guidance does not imply that the guidelines would be local. National, evidence-based guidelines are clearly desirable.
Royal College of Speech and Language Therapists	23	Full	4A	67	Recommendation should include assessment of swallowing (as well as methods of feeding). Assessment comes first.	This is part of assessing presenting symptoms (see Initial Assessment); effects on swallowing post-surgery are also covered.
Royal College of Speech and Language Therapists	24	Full	4A	77	Delete "their SLT" replace with "the SLT".	Agreed. Amendment made.
Royal College of Speech and Language Therapists	25	Full	4A	79	Suggest s/he rather than footnotes throughout.	Not accepted. This would make smooth reading of the text more difficult.
Royal College of Speech and Language Therapists	26	Full	4A	79-80	Replace "to make the most of" with "to optimise".	Not accepted. This is not the same meaning.
Royal College of Speech and Language Therapists	27	Full	4B	100-103 & 111-112	We strongly agree with these recommendations	Thank you.
Royal College of Speech and Language Therapists	28	Full	4B	106	Include: "…psychological needs are recognised and mental health status is measured"	This is the benefits section. Why is it a benefit to measure mental health status? There have been some minor amendments to the text, including the following addition to the Process points of the Measurement section: 'Evidence that patients' psychological state

						has been assessed and that any needs identified are addressed'.
Royal College of Speech and Language Therapists	29	Full	4C	225 and 226/7	Amend to: Speech and language therapist	Amendment made.
Royal College of Speech and Language Therapists	30	Full	4D	242 and 243	We agree but would prefer national guidelines to overcome inconsistencies between networks	But there have to be local agreements. It is assumed that networks would make use of any existing, good quality, evidence based national guidelines.
Royal College of Speech and Language Therapists	31	Full	4D	251	We welcome this measurement	No response required.
Royal College of Speech and Language Therapists	32	Full	4D	252+254	Amend to read specialist instead of 'specialised'	The wording has now been changed.
Royal College of Speech and Language Therapists	33	Full	4D	256	We welcome this measurement	No response required.
Royal College of Speech and Language Therapists	34	Full	5A	11-12	While we agree that videos should be available, we do not feel that it is appropriate for **every** laryngectomy patient to be given a video to watch. Instead we feel that **every** patient be seen by a specialist SLT to discuss the surgery and the impact of this on speech and swallowing and that the videos only be given when the team feels it appropriate to do so.	The text provides for every patient to be given the opportunity to see the video; it is not prescriptive that every patient *should* see it. No change proposed.
Royal College of Speech and Language Therapists	35	Full	5A 5 5	14	We welcome this recommendation.	No response required.
Royal College of Speech and Language Therapists	36	Full	5A 5 5	46	This sentence should read "Primary surgical voice restoration…" as stated in our submission for the previous draft as this should be the gold standard. It is not acceptable to only offer secondary SVR. All patients should be given this option at time of laryngectomy surgery - they do not have to have it. Please amend.	Accepted. Text revised as follows: 'Surgical voice restoration should be available for patients who undergo laryngectomy, normally at the time of primary surgery.'
Royal College of Speech and Language Therapists	37	Full	5A 5 5	50	Suggest removal of the word 'inhaled' as that would be a medical emergency and not for nurses to deal with. Replace with "blocked".	Agreed. Amendment made.
Royal College of Speech and Language Therapists	38	Full	5A 5 5	88-95	We strongly agree, all too often patients are referred too late and miss out on the specialist support that they require.	No response required.

Royal College of Speech and Language Therapists	39	Full	5A 5 5	98	Typo:'s' missed off "patients".	Amendment made.
Royal College of Speech and Language Therapists	40	Full	5A 5 5	87-109	We welcome these comments re: the role of SLT.	No response required.
Royal College of Speech and Language Therapists	41	Full	5B	159-163	We welcome these comments re: the role of SLT and the inclusion of quality of life.	No response required.
Royal College of Speech and Language Therapists	42	Full	5D	369	"Including primary SVR if appropriate" - remove "if appropriate" (see earlier comment re: primary SVR).	Amendment made.
Royal College of Speech and Language Therapists	43	Full	5D	381-385 and 402-405	We welcome these recommendations.	No response required.
Royal College of Speech and Language Therapists	44	Full	5D	404+ 416	Primary SVR.	See response to point 36 above.
Royal College of Speech and Language Therapists	45	Full	5D	406	We welcome this measure, but include QOL evidence.	The relevance to the line quoted is not understood.
Royal College of Speech and Language Therapists	46	Full	5D	415-423	We welcome these additions. Add QOL to outcome measurement.	QOL is more relevant to topic 6: Aftercare and Rehabilitation.
Royal College of Speech and Language Therapists	47	Full	6A	5-6	Add communication here.	This is already covered in a later paragraph.
Royal College of Speech and Language Therapists	48	Full	6A	13	We feel that the statement '… which may be needed for a year or more' is too specific and could be misleading. We suggest that it should be left, as "these *patients require ongoing specialist help".*	This is intended to give commisioners some idea of what the likely timescale might be. No amendment proposed.
Royal College of Speech and Language Therapists	49	Full	6A	14	The valve is inserted between trachea and oesophagus not pharynx – hence tracheo-oesophageal puncture.	Amendment made.
Royal College of Speech and Language Therapists	44	Full	6A	14-15	Amend to: "Others use oesophageal voice".	Amendment made.
Royal College of	45	Full	6A	17	Not just surgery to tongue and mouth – other sites and	The wording has been amended to:

Speech and Language Therapists					treatment can cause speech and eating problems	'Other forms of treatment, such as surgery to the tongue and mouth'.
Royal College of Speech and Language Therapists	46	Full	6A	70	We agree with the concept that ENT/OMFS nurse practitioners can provide advanced skills for the management of tracheo-oesophageal valves. However this role should only be one of troubleshooting rather than complete management of valves. Complete management of valves (particularly valve changes etc…) should only be carried out by those nurses who have been deemed competent by specialist SLTs or CNSs.	The text now reads: 'Senior nurse who can provide advanced skills for the management of stomas (tracheostomies and gastrostomies), nasogastric tubes and tracheo-oesophageal valves. This nurse should work alongside the CNS, SLT and dietitian, …'
Royal College of Speech and Language Therapists	47	Full	6A	88 - 90	Amend: "A full range of assessment, techniques…." "SVR preferred" now deleted, please reinsert as before, followed by, "but patient choice paramount" Amend: …electronic larynx and other equipment..	This is about the local team and rehabilitation, after the decisions have been made. No amendment proposed.
Royal College of Speech and Language Therapists	48	Full	6C	136 – 142	Why include reference given caveat?	Because of the explanation given in the text after the caveat!
Royal College of Speech and Language Therapists	49	Full	6C	154-162	We are still concerned the references re: laryngectomy and SVR and other methods of voice are not the most appropriate or up to date ones. We submitted some more up to date and relevant ones in the comments for the last draft and these have not been incorporated. Please include.	We can only reiterate our previous response, i.e: The issue of the effectiveness of SVR was not one of the research questions. The Editorial Board considered it to be the 'gold standard'.
Royal College of Speech and Language Therapists	50	Full	6C	205, 219 and 265	Speech and language therapist.	Amendment made.
Royal College of Speech and Language Therapists	51	Full	7	General	We agree with all concepts discussed within this chapter .	No response required.
Royal College of Speech and Language Therapists	52	Full	8A	32 and 37	We welcome the inclusion of SLT here.	No response required.
Royal College of Speech and Language Therapists	53	Full	8A	51-54	We strongly agree - palliative intervention should only be offered if the patient's quality of life can be improved .	No response required.
Royal College of Speech and Language Therapists	54	Full	Appendix 1	Page 124	All SLTs working in head and neck should have received post-graduate training.	Thank you for your comment.

Royal College of Speech and Language Therapists	55	Evidence	186	159	Needs and/or between art therapist & SLT.	The text has been amended (the reference to the art therapist has been deleted, as the statement relates to lack of detail about the SLT intervention).
Royal College of Speech and Language Therapists	56	Evidence	201		Latest Perry paper 2003 is more relevant rather than 2000 one.	The Perry 2003 paper is a further analysis of results presented in the Perry 2000 paper, which is included in the Research Evidence. The 2003 article was published subsequent to the literature searches that were undertaken for the systematic review.
Royal College of Speech and Language Therapists	57	Evidence	306	1st //	Remove face-to-face communication.	The text has been amended.
Royal College of Speech and Language Therapists	58	Evidence	306	Guidance a)	Expertise in rehabilitation of patients with H&N cancer (i.e. not just those who have undergone treatment).	The text has been amended.
Royal College of Speech and Language Therapists	59	Evidence	306	Guidance c)	Patients should have access to a SLT before, during and after RT. Evidence shows that SLT provided during radiotherapy improves swallowing outcomes (particularly range of movement exercises) - Pauloski et al.	Point (c) has been amended to include this evidence.
Royal College of Speech and Language Therapists	60	Evidence	307		A full range of support and equipment should be available for on-going assessment and treatment of functional voice and swallowing rehabilitation.	The wording has been changed to reflect this.
Royal College of Speech and Language Therapists	61	Evidence	308	2nd //	Speech & Language Therapist.	Amendment made, and the text is now consistent.
Royal College of Speech and Language Therapists	62	Evidence	309		We welcome the inclusion of research in SLT role.	No response required.
Royal College of Speech and Language Therapists	63	Evidence	309 + 344		Re: role of SLT in support team. Generally it is the case that local teams could not take on the long-term rehabilitation of patients for the reasons stated. It may be that patients would be better served by increasing numbers of staff in centres & providing an outreach service, as many are doing already. Currently, there are insufficient numbers of SLTs in H & N to do both. Another important consideration is that SLT rehabilitation is not delivered in isolation & needs the MDT liaison & support provided by the team at the centre.	The guidance states that any Centre or Unit that deals with patients with head and neck cancer should have its own team, and so this would not be an out-reach service. It is expected that the members of the local support team at each hospital would meet informally, and so the rehabilitation would not be done in isolation.
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.
Scarborough and North East Yorkshire Health Care NHS Trust						This organisation was approached but did not respond.
Scottish Intercollegiate Guidelines Network (SIGN)						This organisation was approached but did not respond.
Sheffield Teaching Hospitals NHS Trust	1	Full	2	168-169	The model of the CNS seeing all patients irrespective of need is not a good model, nor does it reflect guidance from the UKCC, RCN, DoH, or Macmillan Cancer Relief on the role of the CNS. I think that it is very important that a suitably qualified nurse assesses all patients, but this nurse does not need to be a CNS. The CNS should lead the development of pathways, guidelines, protocols and education to ensure that patients receive a high standard of nursing care at all times. The CNS should be involved in the education and development of suitably qualified staff to ensure a competent workforce is available within the clinics and on the wards. This will ensure a continuity of care and not the dependence on one person. The CNS should have clear referral criteria so that the medical and nursing teams ensure that all patients who have complex needs are referred to the CNS for expert specialist support. The CNS will facilitate good teamworking to ensure that this happens. It will also ensure that there are always nursing staff who are being developed and gaining experience, in order to build a healthy resource of skilled nurses for the future. It would be more appropriate to ensure an adequate skill mix of staff is provided in order to provide and support a good service. Which would hopefully ensure guidelines and pathways are followed and that patients are supported through all the stages of their cancer journey by suitably qualified staff.	The numbers of new head and neck cancer patients are not large and unmanageable – a typical MDT serving around a million population will discuss just two or three new patients on average each week. The needs of these patients are very variable in terms of the nature of their disease, the therapeutic options likely to be relevant, the implications for the patient of these choices, and the starting position of the individual patient. The interplay of these issues is more than usually complicated in head and neck cancer, and is best assessed by the most expert nurse ie the CNS. She is then able to contribute effectively in the MDT and in helping patients with the difficult treatment choices that face them (based on first hand knowledge of the patients). This input is important in helping shape subsequent decisions on management. It is clear from our own commissioned work (NCA) and from Macmillan amongst others that patients value access to the CNS very highly and believe it to be crucial to their welfare. Thus, although we have modified the text

						on the CNS significantly to further reflect these comments and the stress they place on the importance of the development and professional leadership roles, and the variable level of input required by individual patients, we retain the vital 'failsafe' requirement for all patients to see the CNS in the initial period. We have increased the time window within which the CNS should see patients for the first time to help the practical arrangements. We have also emhasised in a number of areas the CNS role in 'ensuring' rather than personally 'doing' in order to show that the role is a complex mix of personal contributions and wider responsibilities. Some of these comments emphasise the roles of CNS's in developing and supporting the wider nursing workforce, a position which is clearly accepted in this Guidance. However the comments are expressed as if the explicit role of the CNS in seeing patients before and during the early decision making process was in some senses an alternative to the objective of developing and supporting a broadly based skilled nursing workforce. This perspective is not accepted, and the developers consider that both objectives are important. Some general comments on the way nursing as a whole is structured and managed go beyond the scope of this Guidance. The specific suggestion of clear referral criteria to the CNS must be viewed with a degree of caution as they could act as a

						barrier to easy patient access to the CNS. These comments, as others on this topic, appear motivated at least in part by an unstated concern that there will not be approriate developments in CNS staffing (and in other key supportive staff such as SALTs) as a result of this Guidance. As the cost impact work makes clear this is the crucial area for investment to remedy widespread weaknesses in current services. CNS numbers are very low at present and change in this is vital. Developments in these areas are expected to take time, but will show real benefits in the quality of life outcomes for these patients. Given that this enhancement to services occurs over time – as it has following previous documents, then the CNS role set out is both realistic and sustainable.
Sheffield Teaching Hospitals NHS Trust	2	Full	2	470	I would suggest instead of this outcome measurement – Evidence that the department is staffed adequately to ensure that all patients have been assessed by a suitably skilled qualified nurse, and that those with complex needs are seen by a CNS and Evidence that every patient is given contact numbers for members of the team – the department nursing team, the consultant's secretary, the CNS, SLT etc as appropriate. If the CNS is on holiday or not available there is someone else the patient can speak to who will be able to help and for whom the patient can seek the appropriate advice/answer.	See earlier comments - The performance bullet points have been revised to reflect the drafting changes in the document. CNS staffing levels should permit year round continuity of staffing – at least in the normal working day.
Sheffield Teaching Hospitals NHS Trust	3	Full	4	16-18	It may be appropriate that a suitably qualified member of the nursing team performs an assessment of the needs of the patient. If complex needs are identified the patient can then be referred to the CNS. Pathways of care will ensure this is carried out.	See response to 1st point above.
Sheffield Teaching Hospitals NHS Trust	4	Full	2	165	Many patients treatment involves not having surgery and the support they require is just as great as patients undergoing surgery. In order for us to ensure they have chosen the	The text now reads: 'Post treatment period'.

					correct treatment choice for themselves we have to fully ensure that they have understood the implications and effects.	
Sheffield Teaching Hospitals NHS Trust	5	Economic	Appendix 1	Page 124	Sentence 1 would be better phrased – The role of the nurse practitioner has been proposed in this guidance to act as a support to the CNS. It is not being widened.	The text in the Manual now reads: 'Senior nurse who can provide advanced skills for the management of stomas (tracheostomies and gastrostomies), nasogastric tubes and tracheo-oesophageal valves. This nurse should work alongside the CNS, SLT and dietitian,', and therefore reference to nurse practitioner has been removed from the economic review.
Sheffield Teaching Hospitals NHS Trust	6	Full	General	General	I think that the philosophy behind the guidance of all patients receiving a high standard of nursing support is absolutely correct. The problem is that the role of the CNS is not accurate. The CNS cannot do everything neither does he/she want to. There are excellent nurses working with cancer patients who do a fantastic job, these people need to be encouraged and built upon. All nurses provide support in its various forms to patients, it is part of their every day job. The nurses need to recognise when expert help is needed and to refer to the CNS at that time. The CNS should work as part of the time not in isolation. A central role of the CNS is about education and sharing good practice. Patient dissatisfaction occurs through lack of knowledge, lack of continuity and lack of resources. Cancer guidance needs to ensure the generic workforce is also accounted for. Part of the CNS specialist role is that of a co-ordinator she can only do this if she/he works as a team member and has suitably qualified staff within that team.	Although we have modified the text on the CNS significantly to reflect all the comments received from the profession, including the stress placed on the importance of the development and professional leadership roles, and the variable level of input required by individual patients, we retain the vital 'failsafe' requirement for all patients to see the CNS in the initial period. It is clear from our own commissioned work (NCA) and from Macmillan among others that patients value access to the CNS very highly and believe it to be crucial to their welfare.
Society and College of Radiographers	1	Full	General		The Society and College of Radiographers welcomes the opportunity to respond to the second round consultation however is very disappointed that the guidance pays little if any attention to the significant contribution made by therapeutic radiographers to the care pathway for head and neck cancer patients. We are particularly disappointed as one audience for this document is commissioners and are therefore concerned that when commissioning new services the need for therapeutic radiographers input will be overlooked.	In Topic 5, Primary Treatment, the following text has been added in the Radiotherapy section: 'Therapeutic radiographers, based in such facilities, will play crucial roles in planning and providing radiotherapy, and supporting patients with head and neck cancers throughout the process of radiotherapy.'
Society and College	2	Full	General		In terms of actual numbers of patients for a catchments	See response to 1st point above.

of Radiographers					population of approximately 1.5million we would expect to treat around 200 H&N patients per annum with radiotherapy, of whom approximately 75% would have Radical/Curative treatment (the rest would be palliative shorter/simpler treatments). We acknowledge that there are some variations across the country related to ethnicity e.g. Ca Nasopharynx in Indo-chinese populations) and alcohol etc. (please see below). All therapeutic radiographers will be involved to a greater or lesser degree in planning, treating and offering care and support to Head & Neck patients. As noted within the consultation document these are a particularly challenging group of patients both from a technical radiotherapy and a psychosocial support point of view for the following reasons: Almost all radical treatments will require the construction of individualised immobilisation devices (therapeutic radiographers do this in many departments) A high proportion of patients will have multiphase, multimodality (photons and electrons) requiring planning expertise and very intensive treatment verification procedures before and during treatment (again mostly carried out by therapeutic radiographers) Because the treatments are aggressive then so, often, are the side effects. Radiographers will offer advice and support before, during and after treatment courses and will refer on to other members of the multi-professional team e.g. Dieticians, Speech & Language Therapists, Clinical Psychologists etc. as required. As there are strong epidemiological links with alcohol and tobacco abuse and therefore an often-low "compliance" with regular attendance for treatment over a 5 - 6 week period. Therapeutic radiographers use their enhanced communication skills to enable their patients to complete the course of treatment. Regular attendance for this group of patients is particularly important since most are classified Category 1 (i.e. local control of tumours is likely to be compromised if there is prolongation of treatment course)	
Society and College	3	Full	General		We are also conscious of the impact that this and other similar	This is a generic point. Specific economic

of Radiographers					guidance documents placing extra burdens diagnostic services and would like to suggest that in future consultation focus groups an appropriate diagnostic radiography services manager is involved ensuring a whole systems approach. We would be very happy to nominate if required.	issues identified during the development of the guidance are addressed; the guidance cannot tackle all generic resource issues.
Society and College of Radiographers	4	Full	B/Ground	390	Omission should be 1999/2000	Amendment made.
Society and College of Radiographers	5	Full	2	31	Emphasise MDT also requires formal team membership, leadership and regular meetings and active participation by all attendees.	This is discussed later in the section.
Society and College of Radiographers	6	Full	2	56	(Extra line after 56) Optional: there may also be a specialist head and neck cancer therapeutic radiographer on the MDT (position exists at Addenbrookes Hospital and at Belvoir Park Hospital where the therapeutic radiographer has facilitated improved communication between the Surgical and Oncology teams leading to enhanced multidisciplinary work).	The therapeutic radiographer has been added to the extended team.
Society and College of Radiographers	7	Full	2	78	Add in if not within main MDT: a position for the Specialist Therapeutic Radiographer. (Therapeutic Radiographers see patients often for up to 7 weeks treatment on a daily basis it is therefore vital that information relating to the patients condition is relayed to the MDT. Therapeutic Radiographers responsibilities include obviously delivering the RT but also • Constructing immobilisations shells (frightening experience in itself for the patient and may be difficult if the patients condition has not been considered before booking) • Daily assessment of wellbeing of patient prior to delivering RT • Referring for extra appointments if and when required • Communicating vital information to the MDT • Radiographers also require knowledge from discussions held at the MDT/Extended MDT meetings to enhance patient care.	The therapuetic radiographer is now included as an extended team member.
Society and College of Radiographers	8	Full	2	128	The guidance states that one of the responsibilities of the MDT is “management of all patients throughout the course of their disease” we would argue that Therapeutic Radiographers also require the exposure to the MDT/?extended MDT to develop their own expertise further and to develop the expertise of others within the MDT with regard to the specifics of the Radiotherapy Planning and Delivery processes. (E.g.	The therapuetic radiographer has been added to the extended team.

					head and neck therapeutic radiographer). Benefits Seamless care for the patient. Provide appropriate and specific guidelines for that patient during the RT process taking into account discussions held at the MDT/Extended MDT meetings.	
Society and College of Radiographers	9	Full	2	233	Other AHP's surely there is a role in mentioning Therapeutic Radiographers: Radiographers are key to the treatment process. Low exposure of the profession and low recognition contribute to radiographers morale… too often the work of the therapeutic radiographer is unrecognised and whilst we do recognise that this document is not about promoting professional groups we believe this does effect retention and recruitment to this important professional group and hence this has an effect on patient throughput ultimately.	The therapeutic radiographer has been added to the extended team.
Society and College of Radiographers	10	Full	5	68	Add after modern "networked" (the complexity of treatment demands that planning and treatment units are networked to enable automatic transfer of data).	This is a practical, local issue. 'Modern' is a requirement.
Society and College of Radiographers	11	Full	5	87	Support for patients undergoing radical radiotherapy	This section includes other treatment modalities than radiotherapy.
Society and College of Radiographers	12	Full	5	91	Patients should be educated about adverse effects of treatment, by Clinical Oncologists and Therapeutic Radiographers.	This section is not just about radiotherapy.
Society and College of Radiographers	13	Full	5	95-96	Liaison between therapeutic radiographers, CNS and the ward is a key aspect of patient care.	Liaison is covered elsewhere.
Society and College of Radiographers	14	Full	5	103	Registered title is now therapeutic radiographer and this should be used instead of the title therapy radiographer.	Amendment made.
Society and College of Radiographers	15	Full	5	104	Education and support should be multidirectional i.e. the therapeutic radiographer has extensive knowledge about the RT process and less re Surgery therefore the Therapeutic Radiographer can educate other including the CNS and Cancer Nurses re effects from RT.	The text now reads as follows: 'Radiotherapy departments should have radiotherapy support clinics, staffed by cancer nurses and therapeutic radiographers who share knowledge with head and neck cancer CNSs, dietitians and SLTs.'
Society and College of Radiographers	16	Full	5	373-374	Availability of adequate networked facilities.	Too much detail.
Society and College of Radiographers	17	Full	5	384	Add AHP's to list please.	Agreed. This has been added.
Society and College	18	Full	6	66	Local Support Team some trusts may employ a therapeutic	This is about Aftercare – not relevant to this

of Radiographers					radiographer to be part of this important team.	section.
Society and College of Radiographers	19	Full	6	124-125	Inclusion of the Therapeutic Radiographer here could also aid recruitment to key posts.	Thank you for your comment.
Society for Endocrinology	1	Full	1	67	'Patients with neck lumps' should read 'Patients with non-thyroid neck lumps'. It only becomes clear later that this section is not relevant to thyroid patients.	Agreed. Amendment made.
Society for Endocrinology	2	Full	1	115	Heading should read 'Thyroid Lumps', not 'Thyroid Cancer'.	Agreed. Amendment made.
Society for Endocrinology	3	Full	1	116	Should read 'Patients with thyroid cancer typically present with a clinically solitary thyroid nodule'.	The text has been re-worded as follows: 'Patients with thyroid cancer usually present with a solitary nodule in the thyroid gland or a dominant nodule in a multi-nodular goitre. Amongst such patients, the incidence of malignancy is approximately 10%. All patients with solitary nodules should be referred to a clinic that deals with patients who may have cancer, which may be a thyroid clinic or a neck lump clinic, depending on local arrangements. If the nodule is increasing in size, urgent referral is necessary (see above).
Society for Endocrinology	4	Full		117	A new sentence is needed following line 117: '…..is approximately 10%. Thyroid cancer may also be present in patients with multinodular or diffuse goitre'.	See response to point above.
Society for Endocrinology	5	Full	3	61	It is unlikely that all DGHs will have at least 2 designated surgeons or endocrinologists with a specialist thyroid interest	Whilst its unlikely that all DGHs will have more than one endocrinologist with a specialist thyroid interest, the majority of DGHs will be performing up to 50 thyroidectomies a year and most will have at least one other surgeon (general and/or ENT Surgeon) contributing to this surgery. It is therefore not unreasonable to expect that most DGHs will have at least two designated surgeons involved.
Society for Endocrinology	6	Full	7	74	Should read 'They should be seen at least once a year by a member'.	Agreed. Amendment made.
Society of British Neurological Surgeons						This organisation was approached but did not respond.
Teenage Cancer						This organisation was approached but did

Trust, The						not respond.
Tenovus Cancer Information Centre						This organisation was approached but did not respond.
The Royal Society of Medicine						This organisation was approached but did not respond.
Trent Strategic Health Authority						This organisation was approached but did not respond.
UK Pain Society						This organisation was approached but did not respond.
Ulster Community and Hospital Trust	1	Full guidance	B/Ground	356 – 357	This paragraphs needs to include – Specialist practitioners such as the clinical nurse specialist should be available to act as a resource for the primary care team and where necessary facilitate care of the patient in conjunction with the primary care team.	[General point – while these comments from Ulster are welcomed, it should be noted that this guidance is for England and Wales only.] These are not recommendations – this is the Background section.
Ulster Community and Hospital Trust	2	Full guidance	2	73 – 74	Agree very much with this statement.	No response required.
Ulster Community and Hospital Trust	3	Full guidance	2	153 – 159	I feel that this is a good model of practice where a head and neck clinical nurse specialist is ***available*** to support each patients, throughout the course of the disease.. again I agree that the CNS should be informed when each new patient is given a definite diagnosis, however, he or she may delegate provision of support to a suitably qualified nurse. Again newly diagnosed patients should be given contact details for their CNS. The CNS should lead the development of pathways, guidelines, protocols and education to ensure that patients receive a high standard of nursing care at all times. The CNS should have clear referral criteria so that the medical and nursing teams ensure that all patients who have complex needs are referred to the CNS for expert specialist support. The CNS will facilitate good teamworking to ensure that this happens. This will ensure that there is a sustainable workforce available at all times to patients, providing the high standard of the fundamental care that patients need. It will also ensure that there are always nursing staff who are being developed and gaining experience, in order to build a healthy resource of skilled nurses for the future.	These comments are generally supportive and tend to paraphrase issues recommended in the Guidance. No new issues are raised and there is no specific disagreement with the current text. The specific suggestion of clear referral criteria to the CNS must be viewed with a degree of caution as they could act as a barrier to easy patient access to the CNS.
Ulster Community	4	Full	2	165 -	I am somewhat bewildered by the focus on postoperative	The text now reads: 'Post treatment period'.

and Hospital Trust		guidance		166	management here. Many patients have non surgical intervention as their primary treatment or as an adjuvant and require the same level of support. In addition, the preoperative period is perhaps even more essential for helping patients to understand the impact of interventions, to gain truly informed consent.	
Ulster Community and Hospital Trust	5	Full guidance	2	168 – 169	I feel this paragraph should be reworded to …All patients with complex needs are referred to the CNS for expert assessment and support prior to decisions about their management being made.	The concept of triage and selective referral at this early stage is not felt to be appropriate.
Ulster Community and Hospital Trust	6	Full guidance	2	470	Should be reworded to.. Evidence that all newly diagnosed patients and their carer has been assessed by a CNS or a suitably skilled, qualified nurse. Evidence that every patient is given contact numbers for members of the team - the department nursing team, the consultant's secretary, the CNS, SLT etc as appropriate(then if the named nurse/CNS is on leave, there will always be someone to speak to).	See earlier comments - The performance bullet points have been revised to reflect the drafting changes in the document. CNS staffing levels should permit year round continuity of staffing – at least in the normal working day.
Ulster Community and Hospital Trust	7	Economics	Appendix 1	Page 123	Sentence 2 reads "At present many CNSs are over-stretched, having to cover other nursing work". I do not understand what "other nursing work" refers to and this may be an inaccurate statement. I think may be best to leave it at "over-stretched." (Unless you want to add - not having an adequate generic nursing team to work with, and in some cases, performing inappropriate tasks such as data collection and administrative work. Adequate funding should be available for personnel to undertake administrative work, data collection and assistance with audit).	Amendment agreed.
Ulster Community and Hospital Trust	8	Full guidance	4	66	Include the word long-term management…this is often a necessary and somewhat uncoordinated part of care.	'Management' does not imply short term; no amendment proposed.
Ulster Community and Hospital Trust	9	Full guidance	5	184	Evidence of availability of advice and support for patients and their carers at weekends who are having problems related to their radiotherapy treatment.	Line 184 is the heading 'radiotherapy'; what is the point being made?
Ulster Community and Hospital Trust	10	Full guidance	6	102	Should include patients who are having psychosocial problems such as depression, anxiety, difficulties socialising due to alteration in appearance or communicating, or related functional disabilities.	This point is already adequately covered. No amendment proposed.
Walton Centre for Neurology and						This organisation was approached but did not respond.

Neurosurgery NHS Trust						
Welsh Assembly Government	1	Full	2	235	Clarification of principle clinician – any Member of the MDT or doctor member?	The text is already clear on this point – a clinician member of the MDT, hence principal clinician.
Welsh Assembly Government	2	Full	2	470	This says every patient interviewed by CNS when line 152 states delegated named nurse.	This has been revised to reflect the changes to the CNS section.
Welsh Assembly Government	3	Full	4	185	"be" missed out. Should read "treatment should be made".	Amendment made.
Wessex Cancer Trust						This organisation was approached but did not respond.
Wyeth Laboratories						This organisation was approached but did not respond.