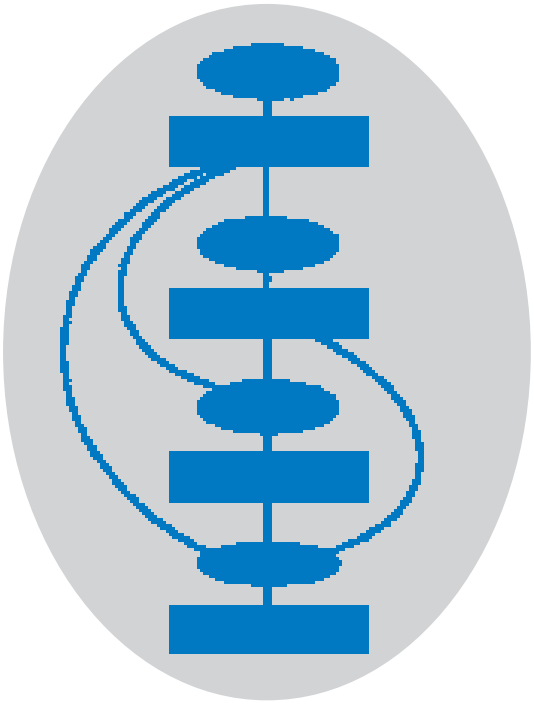
NHS

National Institute for Clinical Excellence

Guidance on Cancer Services

Improving Outcomes in Head and Neck Cancers

The Manual



Improving Outcomes in Head and Neck Cancers
Cancer service guidance supports the implementation of *The NHS Cancer Plan* for England,[1] and the NHS Plan for Wales *Improving Health in Wales.*[2] The service guidance programme was initiated in 1995 to follow on from the Calman-Hine Report, *A Policy Framework for Commissioning Cancer Services.*[3] The focus of the cancer service guidance is to guide the commissioning of services and is therefore different from clinical practice guidelines. Health services in England and Wales have organisational arrangements in place for securing improvements in cancer services and those responsible for their operation should take this guidance into account when planning, commissioning and organising services for cancer patients. The recommendations in the guidance concentrate on aspects of services that are likely to have significant impact on health outcomes. Both the objectives and resource implications of implementing the recommendations are considered. This guidance can be used to identify gaps in local provision and to check the appropriateness of existing services.

References

1. Department of Health (2001) *The NHS Cancer Plan.* Available from: www.dh.gov.uk

2. National Assembly for Wales (2001) *Improving Health in Wales: A Plan for the NHS and its Partners.* Available from: www.wales.gov.uk/healthplanonline/health_plan/content/nhsplan-e.pdf

3. *A Policy Framework for Commissioning Cancer Services*: *A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales* (1995). Available from: www.dh.gov.uk

This guidance is written in the following context:
This Guidance is a part of the Institute's inherited work programme. It was commissioned by the Department of Health before the Institute was formed in April 1999. The developers have worked with the Institute to ensure that the guidance has been subjected to validation and consultation with stakeholders. The reccommendations are based on the research evidence that addresses clinical effectiveness and service delivery. while cost impact has been calculated for the main reccommendations, formal cost-effectiveness studies have not been performed.

National Institute for Clinical Excellence

MidCity Place
71 High Holborn
London
WC1V 6NA

Web: www.nice.org.uk

ISBN: 1-84257-812-X

Copies of this document can be obtained from the NHS Response Line by telephoning 0870 1555 455 and quoting reference N0758. Bilingual information for the public has been published, reference N0745, and a CD with all documentation including the research evidence on which the guidance is based is also available, reference N0759.

Published by the National Institute for Clinical Excellence
November 2004

© National Institute for Clinical Excellence, November 2004. All rights reserved. This material may be freely reproduced for educational and not-for-profit purposes within the NHS. No reproduction by or for commercial organisations is permitted without the express written permission of the Institute.

Guidance on Cancer Services

Improving Outcomes in Head and Neck Cancers

The Manual

Contents

Foreword 3

Acknowledgements – the improving outcomes guidance.....6

Key recommendations.....8

Background.....9

The topic areas

1. Referral 28

2. Structure of services 38

3. Initial investigation and diagnosis 57

4. Pre-treatment assessment and management 66

5. Primary treatment 76

6. After-care and rehabilitation 92

7. Follow-up and recurrent disease.....101

8. Palliative interventions and care.....107

Appendices

1. Economic implications of the guidance.....112

2. How this guidance manual was produced 116

3. People and organisations involved in production of the guidance.....118

4. Glossary of terms.....142

5. Abbreviations 155

Foreword

Professor R A Haward,
Chairman, National Cancer Guidance Steering Group

Head and neck cancer is not a single entity; this is a group that includes many different types of disease, most of which are uncommon and some, rare. The services necessary to care for people with these diseases are, with a few important exceptions, broadly similar in scope and in the expertise required. We have therefore approached this guidance topic by focussing on common themes wherever possible, rather than accentuating differences.

Treatment for most forms of head and neck cancer has permanent effects on organs essential for normal human activities like breathing, speaking, eating and drinking. Consequently, patients facing therapies of all kinds require expert support before, during and after their treatment. Many need rehabilitation over a sustained period, and despite the best care, some people experience long-term problems which necessitate continued access to services.

People who present with cancers of the upper aerodigestive tract (the majority of head and neck cancers) can have important underlying health problems, reflecting high-risk behaviour such as heavy smoking and alcohol consumption. The resulting co-morbidities complicate management, as fitness to undergo therapy can be a key issue in determining the options for treatment. Those providing services are often faced by patients with multiple health and social care needs. Whilst this generalisation inevitably oversimplifies the range of patients who require head and neck cancer services (and their circumstances), it highlights the fact that some patients, at least, are ill-equipped at the outset to cope with the burdens of treatment.

In most head and neck cancers, early stage at presentation permits a positive outlook, and outcomes are frequently good. Late stage at presentation, on the other hand, is not uncommon; and treatment in such circumstances can be complex to deliver and very demanding for the patient. Treatment can have long-term adverse effects on the patient's subsequent quality of life, and these outcomes are therefore crucial.

For these reasons, the recommendations in this guidance highlight support and rehabilitation aspects of services. Whilst we have presented these within the context already set by the National Institute for Clinical Excellence (NICE) guidance on supportive and palliative care,[1] many issues encountered in head and neck cancer are site-specific, reflecting the particular problems experienced by these patients and those caring for them.

An unusual feature of head and neck cancer services is the number of surgical disciplines routinely involved. Otolaryngologists, maxillofacial surgeons, plastic and reconstructive surgeons, endocrine surgeons, and general surgeons with special interests, all regularly operate on some patients. Others, such as neurosurgeons, are also involved from time to time. Members of any or most of these disciplines carry out some types of operation, and results may well be equivalent in good hands. We have responded to this heterogeneity by adopting 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 have also recognised another important trend in complex surgery. This is the increasing involvement of several surgeons, working together during the course of operations and sharing the operative tasks. Such arrangements may be concurrent or sequential and are a consequence of the length of some operations and the range of expertise required. This has implications for safe and effective surgical practice and clinical organisation.

The question of centralisation inevitably arises because many types of head and neck cancer are rare and the main treatment options are radiotherapy (mainly concentrated in Cancer Centres already) and surgery. In an editorial in the Journal of the National Cancer Institute, Smith *et al.* describe evidence from 123 of 128 studies published at that time (2003) which show a "volume–quality" relationship in outcomes of cancer treatment.[2] They emphasise that this evidence is consistent for cancer services as a whole, and note that the magnitude of benefit of treatment by high-volume providers can be striking. However, we have found little specific evidence from studies of head and neck cancer treatment to guide our recommendations. Indeed, the evidence picture overall is thin.

We have reacted pragmatically to this situation, recognising two competing influences on service organisation.

The first is pressure to concentrate services because of the low incidence of cases, their variety and complexity, and the wide range of expertise necessary to support good, safe, and comprehensive services.

The second counterbalances the first, in that many of these patients are poorly placed to travel. Ideally, diagnosis, management and subsequent support should be provided locally.

We have tried to balance these issues in formulating recommendations and have left some flexibility for implementation so that the level of local skills and interests can influence some aspects of the service pattern. There are not sufficient skilled people available to deliver these services everywhere, even if that were desirable and affordable.

It is with great sadness that I record that Peter Madeley, one of two cancer patients on our editorial group, died at the end of September 2004 after the guidance was completed, but before it could be published. He had a short final illness following a second malignancy, having already coped with the consequences of laryngeal cancer.

Like many cancer patients who contribute to this kind of work, Peter was wholeheartedly committed to making sure we listened to him, so that the patients' perspective was reflected in the final document. He pursued this mission with persistence, warmth, good humour, and obvious insight into the difficulties facing those with head and neck cancer. These qualities led to his increasing involvement in representing cancer patients in his home area of Hull, regionally, and nationally through other work with NICE.

References

1. National Institute for Clinical Excellence. *Improving Supportive and Palliative Care for Adults with Cancer.* London: NICE, 2004.

2 Smith TL, Hillner BE, Bear HD. Taking action on the volume–quality relationship: How long can we hide our heads in the colostomy bag? *Journal of the National Cancer Institute* 2003;**95**(10):695-697.

Acknowledgements – the improving outcomes guidance

Since this project began in the summer of 1995, we have produced service guidance for the great majority of types of cancer (87% of incident cancers excluding non-melanoma skin). This guidance deals with the eighth new topic to be covered; there have also been two updates.

There was no prior working model for service guidance, so we had to devise one to include both the development methodology and a suitable format in which to present the recommendations and results of evidence reviews to the NHS. This work was conducted at a hectic pace and the first completed guidance was published within a year.

This early phase drew heavily on specialist expertise in evidence based guideline development from David Eddy (USA), Joan Austoker and Trevor Sheldon. Clinical and professional support was also essential. While it is always difficult to single out individuals, the particular contributions to the methodology and process made by Robert Mansel, Gill Oliver, Jack Hardcastle, Jane Barrett, John Sloane, Mark Baker, Mike Richards and Sue Atkinson must be highlighted, all of whom found themselves in unfamiliar territory.

Once the methodology had been outlined, breast cancer was the prototype which would prove to be a sound model for all titles in the series. Many leading figures in breast cancer were unwitting guinea pigs at the first ever 'proposal generating event', accepting that role with good grace. The evidence review team for breast cancer came from the Mario Negri Institute, Milan, headed by Alessandro Liberati and Roberto Grilli, working with Trevor Sheldon (who was then at the NHS Centre for Reviews and Dissemination (CRD), in York). They established the pattern for all subsequent evidence reviews.

Many people have been closely involved from the beginning (or soon thereafter), and deserve particular recognition.

- The team in Leeds has been the centre of organisation and communication. Elsie Johnston and Val Saunders have shouldered considerable burdens of administration and project management, which expanded as the project became part of the National Institute for Clinical Excellence (NICE).

- At York, Jos Kleijnen and his team at CRD have provided crucial support for the project, given the centrality and scale of the evidence reviews. Alison Eastwood has co-ordinated most evidence-review work and managed links to the editorial process.

- Once cost impact economic analysis was included, we had support from the School of Health and Related Research (ScHARR) at Sheffield University, initially from Alan Brennan and latterly from Sue Ward.

- I have personally enjoyed unstinting support from Jane Barrett and Mike Richards throughout this project - as co-facilitators in proposal generating events and in all the editorial board meetings, particularly at those times when things were difficult.

- Pride of place goes to our writer, Arabella Melville, who drafted all ten manuals, often under considerable pressure. Despite the inadequacies of expert opinion and research evidence, her writing skills resulted in guidance which is clear, coherent and accessible.

Although the guidance only latterly came under the NICE umbrella, and did not entirely fit their system, we have enjoyed support and help in completing the work programme, particularly from Peter Littlejohns, Gill Leng, Nancy Turnbull and Nicole Elliott.

The project is also indebted to large numbers of people who were involved once their particular field became a guidance topic, including clinicians from a range of professions and disciplines, managers, public health specialists and cancer patients.

Finally, recognition is due to Sir Kenneth Calman, who saw that site-specific cancer guidance would add value to his and Dame Deirdre Hine's initiative in cancer policy.

Bob Haward

Key recommendations

- Services for patients with head and neck cancers should be commissioned at the Cancer Network level. Over the next few years, assessment and treatment services should become increasingly concentrated in Cancer Centres serving populations of over a million patients.

- Multi-disciplinary teams (MDTs) with a wide range of specialists will be central to the service, each managing at least 100 new cases of upper aerodigestive tract cancer per annum. They will be responsible for assessment, treatment planning and management of every patient. Specialised teams will deal with patients with thyroid cancer, and with those with rare or particularly challenging conditions such as salivary gland and skull base tumours.

- Arrangements for referral at each stage of the patient's cancer journey should be streamlined. Diagnostic clinics should be established for patients with neck lumps.

- A wide range of support services should be provided. Clinical nurse specialists, speech and language therapists, dietitians and restorative dentists play crucial roles but a variety of other therapists are also required, from the pre-treatment assessment period until rehabilitation is complete.

- Co-ordinated local support teams should be established to provide long-term support and rehabilitation for patients in the community. These teams will work closely with every level of the service, from primary care teams to the specialist MDT.

- MDTs should take responsibility for ensuring that accurate and complete data on disease stage, management and outcomes are recorded. Information collection and audit are crucial to improving services and must be adequately supported.

- Research into the effectiveness of management – including assessment, treatment, delivery of services and rehabilitation – urgently requires development and expansion. Multi-centre clinical trials should be encouraged and supported.

Background

This guidance manual deals with services for adult patients with cancers of the head and neck. It is intended to inform commissioning and provision of cancer services by people from both clinical and non-clinical communities; it is *not* clinical guidance and does not include the level of detail that would be required to inform decision-making about specific treatments for individual patients. The *Background* section is designed primarily to orientate non-specialist readers to broad issues peculiar to this group of cancers. It provides general information on the nature of these diseases, incidence and survival rates, treatment and rehabilitation, epidemiology, risk factors, and prevention.

Head and neck cancers can have devastating effects on the lives of patients; the treatment can be disfiguring and often makes normal speech and eating impossible. For health services, head and neck cancers present particular challenges because of the complexity of the anatomical structures and functions affected, the variety of professional disciplines involved in caring for patients, and the relatively sparse geographical distribution of patients requiring specialised forms of therapy or support.

There are over 30 specific sites (ICD10 codes) in this group and cancer of each particular site is relatively uncommon (Tables 1a and 1b). However, the group as a whole accounts for over 8,000 cases and 2,700 deaths per year in England and Wales.

The majority of these cancers arise from the surface layers of the upper aerodigestive tract (UAT): the mouth, lip and tongue (oral cavity), the upper part of the throat and respiratory system (pharynx), and the voice-box (larynx). Other UAT sites include the salivary glands, nose, sinuses and middle ear, but these cancers are relatively rare; cancer which originates in the nerves and bone of the head and neck is even rarer. These low incidence rates impede efforts both to build good databases and to carry out clinical trials of sufficient size to produce reliable information on the effectiveness of different types of treatment.[1]

[1] Johnson NW, Warnakulasuriya KAAS. Epidemiology and aetiology of oral cancer in the United Kingdom. *Comm Dental Health* 1993;**10**(suppl 1):13-29.

The guidance also deals with cancer of the thyroid, a gland in the neck which produces hormones that regulate metabolism. Like cancers of other sites in the head and neck, it is quite rare. In most other respects, thyroid cancers are unlike UAT cancers, but the services required for patients overlap. In the text below, the term "UAT cancer" refers to the majority of cancers in this group; "head and neck cancer" will be used when all, including thyroid cancer, are being discussed.

Table 1a. Registrations, incidence, and deaths, England[2]

Cancer site	ICD 10 code	No of registrations 2000	Incidence: crude rate per 100,000 2000		ICD 9 code	Deaths 2000	Mortality: crude rate per 100,000 2000	
			Men	Women			Men	Women
Mouth, lip & oral cavity	*C00-06*	2329	5.9	3.7	*140-141, 143-145*	782	1.8	1.3
Salivary glands	*C07-8*	422	1.0	0.8	*142*	138	0.3	0.2
Pharynx (throat)	*C09-14*	1339	4.0	1.6	*146-149*	617	1.7	0.8
Nasal cavity, ear & sinuses	*C30-31*	352	0.8	0.6	*160*	110	0.3	0.2
Larynx (voice-box)	*C32*	1903	6.6	1.3	*161*	655	2.1	0.5
Thyroid	*C73*	1131	1.3	3.3	*193*	251	0.3	0.7

Table 1b. Registrations, incidence, and deaths, Wales[3]

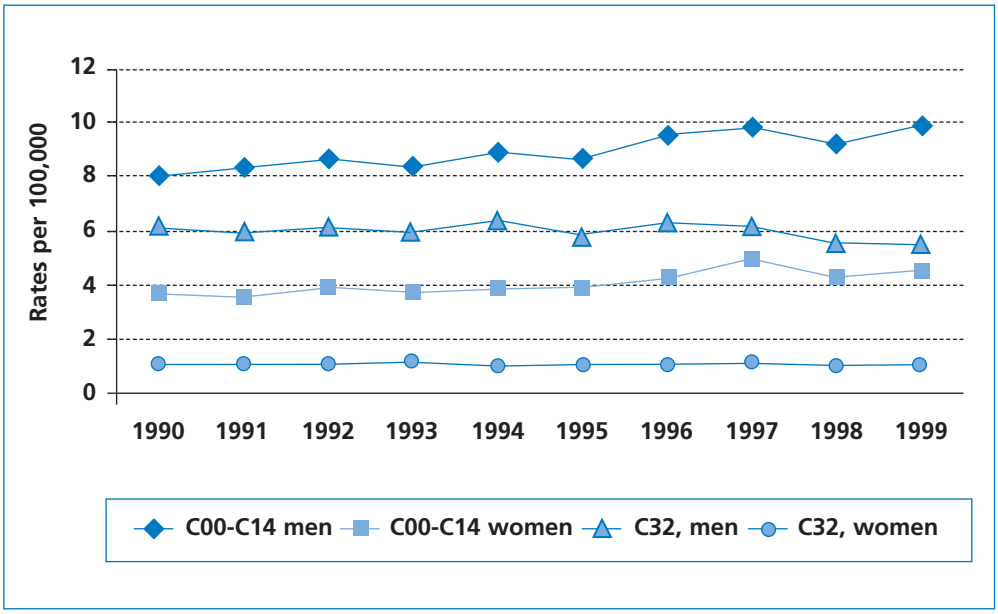
Cancer site	ICD 10 code	No of registrations 2000	Incidence: crude rate per 100,000 2000		ICD 9 code	Deaths 2000	Mortality: crude rate per 100,000 2000	
			Men	Women			Men	Women
Mouth, lip & oral cavity	*C00-06*	166	7.1	4.4	*140-141, 143-145*	45	1.8	1.3
Salivary glands	*C07-8*	47	1.6	1.6	*142*	8	0.3	0.3
Pharynx (throat)	*C09-14*	90	4.7	1.6	*146-149*	43	1.9	1.1
Nasal cavity, ear & sinuses	*C30-31*	21	0.9	0.5	*160*	7	0.4	0.1
Larynx (voice-box)	*C32*	147	9.0	1.4	*161*	54	3.0	0.8
Thyroid	*C73*	57	1.3	2.6	*193*	8	0.1	0.4

[2] Figures from the Office for National Statistics (ONS).
[3] Figures from the Welsh Cancer Intelligence & Surveillance Unit, Office for National Statistics (ONS).

This guidance does not cover cancers of the skin or brain. Lymphomas, which often produce lumps in the neck which must be differentiated from head and neck cancers, are discussed in *Improving Outcomes in Haematological Cancers*.[4]

There are marked regional variations in the incidence of head and neck cancers, with rates ranging from roughly 8 per 100,000 in the Thames and Oxford regions to 13-15 per 100,000 in Wales and in the North Western region.[5] Registration rates for two of the three most common forms of head and neck cancer - cancers of the mouth and pharynx - have risen by over 20% over the last three decades, particularly among people under the age of 65.[6] This increase continued over the 1990s, but is counterbalanced somewhat by a recent decrease in incidence of cancer of the larynx (Figure 1).

Figure 1. Age-standardised incidence rates for cancers of the mouth and pharynx (C00-C14) and larynx (C32), 1990-1999, England and Wales[7]



[4] Available on the NICE website <www.nice.org.uk>.

[5] Consensus Group of Practising Clinicians. Practice care guidance for clinicians participating in the management of head and neck patients in the UK. *Eur J Surg Oncol* 2001;**27**(suppl A):S4.

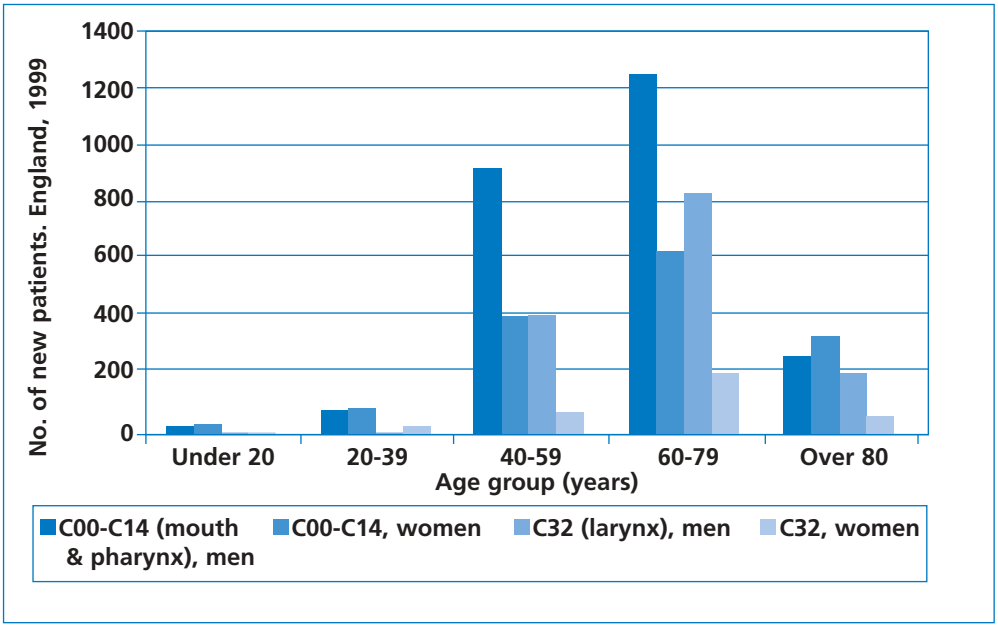
[6] Quinn MJ, Babb P, Brock A, Kirby L, Jones J. *Cancer Trends in England and Wales 1950-1999. Studies on Medical and Population Subjects no.66.* London: The Stationery Office, 2001.

[7] See Quinn MJ, Babb P, *et al*, reference 6 above

Both incidence of, and mortality from, UAT cancers are higher among disadvantaged population groups.[8] The pattern is similar to that for lung cancer, which has many of the same causes (in particular, smoking). Smoking-related cancer of the head and neck is more than twice as common among the most deprived men (Carstairs quintile 5), as in the more affluent (Carstairs quintiles 1 and 2). Moreover, patients with these cancers who live in deprived areas are more likely to die from their disease.[9]

Most patients with UAT cancers are middle-aged or older (Figure 2a).

Figure 2a. Age distribution of patients with new diagnoses of UAT cancers (C00-C14 and C32)[10]



Thyroid cancer incidence has an entirely different pattern. It is more common in women, among whom new cases peak between the ages of 30 and 54; the rate falls in middle age (from 4.4 to 2.9 per 100,000 among those aged 50-54 and 55-59, respectively), rising to a second peak in women over the age of 70 years. In men, the incidence is low, but reaches its maximum in later life.[11] Thyroid cancer is considerably more common among young women than other head and neck cancers. The age distribution of new cases is shown in Figure 2b, below; note that because the numbers are much smaller

---

[8] Thorne P, Etherington D, Birchall MA. Head and neck cancer in South West England: influence of socio-economic status on incidence and second primary tumours. *Eur J Surg Oncol* 1997;**23**:503-508.

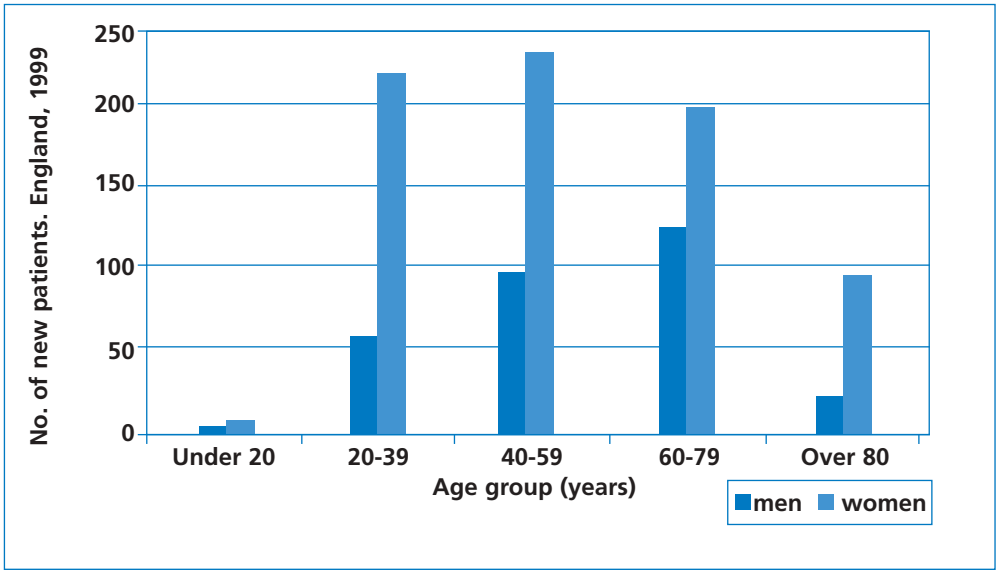
[9] Edwards DM, Jones J. Incidence of and survival from upper aerodigestive tract cancers in the UK; the influence of deprivation. *Eur J Cancer* 1999;**35**(6):968-972.

[10] See National Statistics, Registrations of Cancer Diagnosed in 1999, England, Series MB1 no. 30, Table 1; available on the National Statistics website <www.statistics.gov.uk>.

[11] Quinn MJ, Babb P, Brock A, Kirby L, Jones J. *Cancer Trends in England and Wales 1950-1999. Studies on Medical and Population Subjects no.66.* London: The Stationery Office, 2001, Appendix B4.

than in Figure 2a (above), the scale of the value (X) axis is different; also note that the age-bands in this diagram are such that it does not show the dip in incidence among middle-aged women.

Figure 2b. Age distribution of patients with new diagnoses of thyroid cancer (C73)[12]



Thyroid cancer in England and Wales has not been linked with social deprivation.

Survival rates

Survival rates differ markedly according to the site and stage of the cancer. Data from the Eurocare 3 study shows that England and Wales are broadly similar to the European average.[13] Table 2 shows figures for survival rates for the most common forms of UAT cancer (mouth, pharynx and larynx) and for thyroid cancers, in England, Wales and Europe as a whole.

There appear to be quite wide differences in outcomes within mainland Europe, so whilst survival rates in England and Wales may be as good as the European average, or even above it, some countries seem to do consistently better, whilst others – particularly those in Eastern Europe – are considerably worse. However, the data may not be entirely reliable. For half of the countries included in the Eurocare 3 study, fewer than 15% of cases of head and neck cancer were included and the total numbers are sometimes very small. This allows considerable scope for error. The coverage rates for France, Germany, the Netherlands and Spain were 4%, 2%, 6% and 6% respectively, making comparisons between these countries and

[12] See National Statistics, Registrations of Cancer Diagnosed in 1999, England, Series MB1 no. 30, Table 1; available on the National Statistics website <www.statistics.gov.uk>.
[13] Eurocare-3, data not yet published.

Britain inappropriate. Where there are high coverage rates (for example in Scandinavia), survival rates for UAT cancers are similar to those in England and Wales, with 50% and 100% coverage respectively.

Table 2. Five-year age-standardised relative survival rates (with 95% confidence intervals), for patients diagnosed with head and neck cancers, 1990-1994[14]

	Oral cavity and pharynx (141, 143-148)		Larynx (161)		Thyroid (193)	
	Men	Women	Men	Women	Men	Women
England	42.1 (40.5-43.7)	52.3 (50.2-54.6)	67.1 (65.4-68.9)	60.9 (57.4-64.6)	71.4 (67.9-75.0)	79.1 (77.3-80.8)
Wales	40.2 (35.5-45.6)	54.6 (47.8-62.4)	67.4 (62.4-72.8)	50.4 (40.8-62.3)	80.1 (68.3-93.9)	79.1 (72.9-85.8)
Europe	33.1 (31.7-34.7)	50.8 (48.4-53.5)	62.3 (60.7-63.8)	60.4 (56.3-64.8)	72.4 (68.2-76.9)	82.0 (80.5-83.5)

Focussing on rarer forms of cancer exacerbates problems with unreliable data. Austria, for example, appears to have spectacular survival rates for salivary gland cancers – but only six cases are included (8% coverage). England, with 50% coverage, contributes more cases of salivary gland cancer to the database than any other country, with outcomes very close to the European average; age-standardised five-year survival rates for both sexes combined are close to 57% in England and Wales, compared with 60% for Europe, with overlapping confidence limits.

There are similar problems with European outcomes data for thyroid cancer, although the numbers reported by some countries are probably sufficiently reliable to make comparisons between them. Five-year relative survival rates in Norway, Finland and Sweden, which all have 100% coverage of cases in the Eurocare 3 database, are around 85% - significantly better than in England, with 59% coverage and about 77% of patients surviving. For Europe as a whole, the five-year survival rate is 80%.

[14] Eurocare-3, data not yet published.

As with any type of cancer, the prognosis for individual patients depends heavily on the stage of the disease. This can be described most precisely in terms of the size of the initial tumour (T), the extent of lymph node involvement (N), and the presence or absence of metastatic spread (M). The system used by many in the UK is simpler, ranging from Stage I (early disease) to IV (metastatic). Figures for stage at diagnosis and survival rates for the South and West of England are given in Table 3, below. The relationship between this system used here and TNM stage for each cancer site is complex, but details are given in the document from which these figures were derived.[15]

Table 3. Cancer stage and survival in the South and West of England, 1999-2000[16]

Stage	Two-year survival crude rate (all sites)	Cancer site (% of cases at each stage at diagnosis)				
		Larynx n=190	Oral n=241	Pharynx n=161	Salivary gland n=56	Other n=79
I early disease	89.7%	34	21	6	13	12
II locally advanced	71.8%	27	16	13	17	8
III tumour in lymph nodes	57.6%	17	15	22	7	8
IV metastatic	48.6%	15	34	50	28	47
unknown	69.8%	7	11	9	35	25

A study of patients treated for cancers of the tongue or floor of the mouth in Scotland found that just over half of the patients had relatively small tumours (T_1 and T_2); these patients survived for about twice as long as those with large tumours (T_3 and T_4), after adjusting for other factors known to affect survival.[17]

[15] South West Cancer Intelligence Service, *Second Head and Neck Audit Report* (*SWAHNII*), 2001.

[16] Table derived from data published in South West Cancer Intelligence Service, *Second Head and Neck Audit Report* (*SWAHNII*), 2001, Tables 3.11 and 8.2.

[17] Robertson AG, Robertson C, Soutar DS, Burns H, *et al.* Treatment of oral cancer: the need for defined protocols and specialist centres. Variations in the treatment of oral cancer. *Clinical Oncology* 2001;**13**:409-415.

Head and neck cancers are unusual in that there appears to have been little, if any, improvement in survival rates over recent decades.[18,19] This may be due, at least in part, to the fact that most patients are long-term smokers, who tend to have a range of other health problems such as cardiovascular disease.[20] However, since a wide variety of factors – both social and medical – influence survival, it is not possible to determine which have had the greatest impact.

It is not clear whether survival rates for patients with UAT cancers could be substantially improved by changes in NHS services. However, quality of life for survivors could undoubtedly be enhanced by optimum treatment and the provision of adequate support and rehabilitation services (see *Services for patients with head and neck cancer,* below). In the case of thyroid cancer, by contrast, it appears that long-term survival rates in England are inferior to those in comparable countries, and it is therefore reasonable to conclude that there is room for improvement.

Specific cancers

Mouth, lip and oral cavity (oral cancer)

Oral cancer has the highest incidence of the head and neck cancers, and like other cancers of the upper aerodigestive tract and respiratory system, it is more common in men than in women (Table 1). Five-year survival rates are over 80% for people with early stage, localised disease, and over 40% for whose disease has spread to the neck, but below 20% for those who have distant metastatic disease (spread to other parts of the body).[21]

Approximately 90% of oral cancers are squamous cell carcinomas, arising from the lining of the mouth, most often the tongue and the floor of the mouth. It has been estimated that between 10 and 30% of patients with primary oral cancer develop second primary UAT tumours; these patients also have higher rates of lung and bladder cancer than the general population.[22]

---

[18] Soutar D, Robertson G. Head and neck cancers. In *Cancer Scenarios: an aid to planning cancer services in Scotland in the next decade.* Edinburgh: The Scottish Executive, 2001.

[19] Quinn MJ, Babb P, Brock A, Kirby L, Jones J. *Cancer Trends in England and Wales 1950-1999. Studies on Medical and Population Subjects no.66.* London: The Stationery Office, 2001.

[20] British Association of Otorhinolaryngologists – Head and Neck Surgeons. *Effective Head and Neck Cancer Management: Second Consensus Document.* London: Royal College of Surgeons, 2000.

[21] Worrall SF. Oral cancer – an overview. Unpublished paper 2001. Posted on internet site: <www.baoms.org.uk/info/cancer/oral.pdf>.

[22] Cancer Research Campaign. *Cancer Statistics: Oral – UK.* London: CRC, 2000.

The most common symptom of oral cavity cancer is a persistent sore or lump on the lip or in the mouth, but there may also be pain and/or a lump in the neck. Other symptoms are a white or red patch on the gums, tongue or lining of the mouth, and unusual bleeding, pain or numbness in the mouth. Only a minority patients with oral lesions will have cancer, however. Some patients have difficulty in speaking or swallowing.

Overall, the incidence of oral cancer is relatively low in England and Wales compared to many other countries. The rates are higher among people from a South Asian (Indian sub-continent) background, mirroring the high incidence in India, Pakistan and Bangladesh. Ethnic immigrants from the Indian sub-continent are more than twice as likely to die from oral cancer than natives of England and Wales.[23,24]

Public awareness of oral cancer is low, probably because of its relative rarity. Those who have heard of it are more likely to be aware of the role of smoking than of other risk behaviours.[25]

Cancer of the larynx

Cancer of the larynx (voice box) is the second most common form of head and neck cancer, (Table 1). It is the 14th most common cancer in males, but is much rarer among women. Survival rates are better than for oral or pharyngeal cancer, with nearly two-thirds of patients surviving for five years (Table 2).

Virtually all cancer of the larynx is squamous cell carcinoma. Within the larynx, the glottis (the area containing the vocal cords) is most frequently affected. Glottic cancer has the most favourable prognosis of all forms of laryngeal cancer, as people tend to seek medical advice for chronic hoarseness, which is the most common early symptom.[26] Other symptoms of laryngeal cancer may include pain or problems with swallowing (dysphagia). There can also be a lump in the neck, sore throat, earache, or a persistent cough.

---

[23] Swerdlow AJ, Marmot MG, *et al.* Cancer mortality in Indian and British ethnic immigrants from the Indian subcontinent to England and Wales. *Br J Cancer* 1995;**72**:1312-1319.

[24] Parkin DM, Pisani P, Ferlay J. Estimates of the worldwide incidence of 25 major cancers in 1990. *Int J Cancer* 1999;**80**:827-841.

[25] Warnakulasuriya KAAS, *et al.* An alarming lack of public awareness towards oral cancer. *Br Dent J* 1999;**187**(6):319-322.

[26] Scott N, Gould A, Brewster D. Laryngeal cancer in Scotland, 1960-1994: Trends in incidence, geographical distribution and survival. *Health Bulletin* 1998;**56**:749-756.

Cancer of the pharynx

Cancer of the pharynx (throat) is less common (Table 1). It occurs in three principal locations: the oropharynx, which includes the under surface of the soft palate, the base of the tongue and the tonsils, the hypopharynx (bottom part of the throat) and the nasopharynx (behind the nose). The most common site of cancer within the pharynx is the tonsil but even this is fairly rare, with just over 400 new cases per year in England. Five-year survival rates are relatively poor, at about 40% for cancer of the oropharynx and 20% for the hypopharynx.[27]

Cancers of the oropharynx and hypopharynx are, like oral cancer and cancer of the larynx, usually squamous cell carcinomas which originate in the epithelial cells that line the throat. Cancer of the nasopharynx has a different aetiology and natural history.

The symptoms of cancer of the pharynx differ according to the type. For oropharynx, common symptoms are a persistent sore throat, a lump in the mouth or throat, and otalgia (pain in the ear). For hypopharynx, problems with swallowing and ear pain are common symptoms and hoarseness is not uncommon. Nasopharynx cancer is most likely to cause a lump in the neck, but may also cause nasal obstruction, deafness and post-nasal discharge.

The geographical incidence of pharyngeal cancer (aside from nasopharynx) is similar to that of oral cancers. It is relatively low in England and Wales, but higher among those with a South Asian background; among immigrants from the Indian sub-continent, the risk of death from cancer of the pharynx is five times that of British natives.[28] Cancer of the nasopharynx is particularly common among people of Southern Chinese origin.[29]

Thyroid cancer

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.

---

[27] Eurocare-3, data not yet published.

[28] Swerdlow AJ, Marmot MG, *et al.* Cancer mortality in Indian and British ethnic immigrants from the Indian subcontinent to England and Wales. *Br J Cancer* 1995;**72**:1312-1319.

[29] Warnakulasuriya KAAS, Johnson NW, *et al.* Cancer of mouth, pharynx and nasopharynx in Asian and Chinese immigrants resident in Thames regions. *Oral Oncol* 1999;**35**:471-475.

The commonest type of thyroid cancer is described as "differentiated"; this accounts for 90% of cases. This is sub-divided into two forms: papillary and follicular adenocarcinoma, which account for 80% and 10% of cases, respectively. Both develop in cells that produce thyroid hormones, but papillary cancer tends to grow slowly and is usually curable. Differentiated thyroid cancers are usually treated with surgery, which can be supplemented with radioiodine ablation. Survival rates are excellent.

Five per cent of patients have medullary cancer, which is sometimes familial and can be associated with other endocrine malignancies. Again, treatment is with surgery, but this disease is more difficult to control because it tends to be more invasive and cannot be treated with radioiodine.

Finally, there are two rare types which occur in the elderly. About 1% of patients have lymphoma of the thyroid, which presents as a rapidly expanding mass and is usually diagnosed on the basis of the patient's history, together with a tissue diagnosis. Many of these patients can be cured. In contrast, the outlook is poor for the 3% of patients who have anaplastic thyroid cancer, which presents in a similar way and must be differentiated from lymphoma with a biopsy.

Other cancers of the head and neck

There are a wide range of other cancers of the head and neck which are not described above. Taken together, these are responsible for 17% of cases of head and neck cancer. All are relatively rare, the least rare being cancers of the salivary glands and cancers of the nasal cavity, middle ear and accessory sinuses (Table 1). This diverse group also includes cancers and sarcomas of the facial bones, peripheral nerves, connective and soft tissues, and various glands.

Skull base cancers are included among head and neck cancers, but tumours that originate in the skull are very rare; most cancers that invade the skull originate in soft tissue. Treatment for these patients can be particularly challenging.

Risk factors and prevention

Cancers of the upper aerodigestive tract (mouth, pharynx, and larynx)

Most UAT cancers are triggered by alcohol and tobacco, which together probably account for three-quarters of cases.[30] Cigarette smoking is associated with increased risk of all of the more common forms of UAT cancer; the risk among cigarette smokers may be 10 or more times that for non-smokers. Pipe or cigar smoking is associated with an even higher excess risk of oral cancer.[31] Chewing tobacco – with or without areca (betel) nut – is strongly linked with oral and pharyngeal cancer, as well as to some extent with cancer of the larynx and the thyroid.[32,33]

More intense use of tobacco increases risk, while ceasing to smoke for 10 years or more reduces it to virtually equal to that among non-smokers. The heavier the smoking prior to diagnosis, the more likely people with cancer of the oral cavity, larynx or pharynx are to develop second primaries, i.e. tumours which did not develop from the first one. The same pattern is found among people who continue to smoke after diagnosis.[34]

High alcohol consumption and smoking have synergistic or multiplicative effects on the risk of head and neck cancer. For heavy drinkers who are also heavy smokers, the risk of oral cancer is over 35 times that for those who neither smoke nor drink, and a similar pattern is found with cancer of the larynx.[35,36] Alcohol consumption is a particularly important risk factor for cancers of the mouth and pharynx, and to a lesser degree, for cancer of the larynx. Consuming 100g of alcohol or more per day (about 12 units – six pints of beer or 12 measures of wine or spirits) multiplies the risk of developing oral cancer at least six-fold, after adjustment for tobacco use; the more alcohol consumed, the greater the risk.[37]

---

[30] Blot WJ, McLaughlin JK, Winn DM, *et al*. Smoking and drinking in relation to oral and pharyngeal cancer. *Cancer Res* 1988;**48**:3282-3287.

[31] La Vecchia C, Tavani A, Franceschi S, Levi F, *et al*. Epidemiology and prevention of oral cancer. *Oral Oncology* 1997;**33**:302-312.

[32] Swerdlow AJ, Marmot MG, *et al*. Cancer mortality in Indian and British ethnic immigrants from the Indian subcontinent to England and Wales. *Br J Cancer* 1995;**72**:1312-1319.

[33] Johnson NW, Warnakulasuriya KAAS. Epidemiology and aetiology of oral cancer in the United Kingdom. *Comm Dental Health* 1993;**10**(suppl 1):13-29.

[34] Wynder EL, Dodo H, *et al*. Epidemiologic investigation of multiple primary cancer of the upper alimentary and respiratory tracts: a retrospective study. *Cancer* 1969; **24**(4):730-739.

[35] Blot WJ, McLaughlin JK, Winn DM, *et al*. Smoking and drinking in relation to oral and pharyngeal cancer. *Cancer Res* 1988;**48**:3282-3287.

[36] Talamini R, Bosetti C, La Vecchia C, *et al*. Combined effect of tobacco and alcohol on laryngeal cancer risk: a case-control study. *Cancer Causes and Control* 2002;**13**:957-964.

[37] Bagnardi V, Blangiardo M, La Vecchia C, Corrao G. A meta-analysis of alcohol drinking and cancer risk. *Br J Cancer* 2001;**85**:1700-1705.

Diet also affects the risk of cancers of the oral cavity, pharynx and larynx; as with many other forms of cancer, frequent consumption of fruit and vegetables is associated with reduced risk. Poor diet is often associated with heavy smoking and alcohol use, and the malnutrition which can result exacerbates the risk of cancer. Eating Cantonese-style salted fish increases risk – which may account for high levels of particular forms of head and neck cancer found among some Chinese ethnic groups.[38,39]

Given the importance of tobacco, alcohol and diet as risk factors for many forms of head and neck cancer, it is clear that they are largely preventable. Smoking and alcohol cessation and reduction programmes are important, as is the promotion of healthy eating. Effective interventions for reducing smoking are described in the guidance document on lung cancer in this series (*Improving Outcomes in Lung Cancer: The Manual).*[40] A recent literature review found evidence that oral cavity cancer in young people (aged under 40) may not be associated with these traditional origins, and suggested that genetic disposition may play a role, but further research is needed.[41]

Occupational exposure to asbestos, formaldehyde, nickel, isopropyl alcohol and sulphuric acid mist have been linked with laryngeal cancer. Exposure to diesel fumes is also associated with increased risk.[42] It is not possible to quantify precisely the importance of these factors in the population as a whole, but they are likely to be responsible for far fewer cases than smoking and alcohol consumption. Oral cancer has also been linked with environmental and occupational factors, but when smoking and alcohol use are taken into account, most of these associations disappear. Exposure to formaldehyde is an exception; indeed, there is accumulating evidence that this is an independent risk factor for cancers of the mouth and pharynx.[43]

---

[38] Potter JD (Chair). *Food, nutrition and the prevention of cancer: a global perspective*. Washington, DC: World Cancer Research Fund/American Institute for Cancer Research, 1997.

[39] Esteve J, Riboli E, *et al.* Diet and cancers of the larynx and hypopharynx: the IARC multi-center study in Southwestern Europe. *Cancer Causes and Control* 1996;**7**:240-252.

[40] Available on the Department of Health website <www.dh.gov.uk>.

[41] Llewellyn CD, Johnson NW, Warnakulasuriya KAAS. Risk factors for squamous cell carcinoma of the oral cavity in young people – a comprehensive literature review. *Oral Oncol* 2001;**37**:401-418.

[42] Muscat J, Wynder E. Tobacco, alcohol, asbestos and occupational risk factors for laryngeal cancer. *Cancer* 1992;**69**:2244-2251.

[43] Merletti F, Boffetta P, Ferro G, Pisano P, Terracini B. Occupation and cancer of the oral cavity or oropharynx in Turin, Italy. *Scand J Work Environ Health* 1991;**17**:248-254.

Infection by particular types of virus, notably human papillomavirus (HPV) – which is known to cause cervical cancer – is implicated in the development of some cancers of the oral cavity, pharynx and larynx.[44] The authors of an ongoing systematic review estimate that HPV could be involved in 30-40% of cases of oropharyngeal cancer in western countries.[45] Patients with cancer of the tonsil are particularly likely to show signs of previous HPV infection.[46] HPV positive tumours have a better prognosis than those associated with smoking and alcohol.

Thyroid cancer

A history of radiation exposure to the neck area is associated with increased risk of thyroid cancer, often after a delay of well over a decade; some cases can be traced to radiation treatment in childhood. Both deficiency and excess dietary iodine are associated with increased risk.[47] Other predisposing factors include prolonged stimulation with thyroid stimulating hormone (which can be due to chronic iodine deficiency), chronic lymphocytic thyroiditis (lymphoma), and genetic factors (linked with medullary thyroid cancer). Women are more than twice as likely as men to develop thyroid cancer.

Diagnosis, treatment and rehabilitation

Identification of patients and diagnosis

There is no national screening programme for any form of head and neck cancer and it is unlikely that such a programme will be established in the near future. Reasons for this include the following: first, although screening has been considered for oral cancer, this is relatively rare so the pick-up rate would be very low. Second, the natural history of these cancers is poorly understood. Finally - and crucially - there is no evidence to show that such screening would be beneficial for the population as a whole. More research is needed, particularly on screening members of high risk groups and opportunistic screening.

---

[44] Hobbs C, Birchall M. Human papillomavirus infection in the etiology of laryngeal carcinoma. *Current Opinion in Otolaryngology and Head and Neck Surgery* 2004;**12**:88-92.

[45] Hobbs C, personal communication, 2004.

[46] Gillison BL, Koch WM, Capone RB, Spafford M, *et al.* Evidence for a causal association between human papillomavirus and a subset of head and neck cancers. *J Nat Can Inst* 2000;**92**:709-718.

[47] Potter JD (Chair) *Food, nutrition and the prevention of cancer: a global perspective.* Washington, DC: World Cancer Research Fund/American Institute for Cancer Research, 1997.

Because head and neck cancer is relatively rare, the average GP would expect to see a new case only every six years; an otolaryngologist (ear, nose and throat (ENT) specialist) or maxillofacial surgeon working in a district general hospital would expect to see one case every six weeks. Some forms of oral cancer may be initially diagnosed by dentists, who are trained to carry out a comprehensive examination of all areas of oral mucosa (gum and interior of the mouth) when patients attend for dental care. Pharmacists may also be able to alert customers to the need for investigation, for example if they frequently buy treatments for mouth ulcers or are hoarse for a month or more.

Initial investigation is usually by close inspection of the affected area. When the lesion is inaccessible, endoscopy (pharyngolaryngoscopy) – usually using a fibre-optic device inserted into the pharynx and/or larynx – is essential. A definite diagnosis of cancer requires the removal of a small quantity of tissue for microscopic examination, using biopsy when the lesion is on the lining of the mouth or airway, or fine needle aspiration (FNAC) for neck lumps.

If cancer is found, various forms of imaging may be used to stage the disease: that is, to discover the size and extent of the primary tumour and to find out if it has spread to nearby lymph nodes or to more distant sites (metastases). In practice, staging at the time of initial assessment may not be accurate and the speed at which any particular tumour may grow is not known, so predicting prognosis is difficult. Also, the patient's general health has a marked effect on survival.

Primary treatment

Most head and neck cancers are treated with surgery or radiotherapy or a combination of both. Chemotherapy alone is rarely appropriate for these forms of cancer, but chemotherapeutic agents are sometimes used to enhance the effects of radiotherapy; this is known as chemoradiation. Plastic or reconstructive surgery and specialised dentistry are often needed. Patients need considerable help and support with nutrition and communication, both during and after primary treatment.

People who have been treated for UAT cancers remain at high risk, both of developing recurrent disease and of new cancers in the head and neck region and other parts of the body such as the lungs. Careful follow-up and systems for rapid referral for specialist assessment and treatment are therefore essential.

Thyroid cancers are usually treated by surgical removal of the thyroid gland. Radioiodine treatment, which requires special protected rooms, may be used to destroy residual disease. Endocrinologists play important roles in the management of patients treated for thyroid cancer, who require thyroid hormone replacement therapy and monitoring for the rest of their lives. The cancer can recur many years after primary treatment, but most patients will remain free from it.

Rehabilitation, support and palliative care

Living with the effects of head and neck cancer can be difficult for both patients and carers. Radiotherapy can be debilitating, with many persistent side-effects, and people can have difficulties with speaking, chewing and swallowing, which can add to problems with nutrition. Those who have undergone laryngectomy (surgical removal of the larynx) must permanently cope with breathing through an opening in the neck (stoma) and with dealing with any secretions coughed out through the stoma, as the airway is completely separated from the gullet (pharynx and oesophagus). These patients need to learn to communicate in a new way. Those who undergo oral and facial surgery may face difficulties with eating, drinking and talking, and may have to learn to live with facial disfigurement. Such patients need specialised support from a variety of therapists, particularly specialist nurses, speech and language therapists, and dietitians.

The importance of psychosocial support is amplified by the nature of the patients who are most likely to develop UAT cancer. A significant proportion are heavy users of tobacco and alcohol, which can reflect pre-existing difficulties with social integration and means that they are likely to need continuing help to achieve lasting abstinence. Depression is relatively common in these patients. In addition, most are elderly and many have to cope with socio-economic deprivation. These features act together to increase the need for effective support in the community after definitive treatment. The primary care team plays a crucial role in providing such support, but input from health care and other professionals with specialised knowledge of the problems faced by these patients is also required.

Palliative care aims to maintain patients' comfort and dignity, and again primary care teams will play a important role in providing such care. Whilst all professionals working with patients may address palliative care needs, palliative care specialists, working in hospitals, hospice or the community, are likely to be required to support patients with advanced disease.

As many as half of all patients with UAT cancers are likely to die of the disease eventually, and most will require palliative interventions; however, most of those treated for thyroid cancer enjoy good long-term health. For patients with late stage disease, good nursing care and palliative measures such as pain control and interventions to help them eat and breathe are crucial; however, those who are expected to live for a significant period may benefit from palliative surgery, radiotherapy or chemotherapy.

Services for patients with head and neck cancer

One of the striking characteristics of head and neck cancer services is the range of clinicians involved in its treatment and care, together with a variety of different patient pathways and experiences. This is partly because "head and neck" is a catch-all category and not a single cancer, and a variety of organs and functions are involved.

Some aspects of services for patients with head and neck cancer are less well developed than for other cancers. For example, a recent national study found that slightly less than half of hospitals/Trusts had multi-disciplinary teams (MDTs) for head and neck cancer, compared to much higher proportions for more common types of cancer (over 80% in the case of breast cancer).[48] Some Trusts have multi-disciplinary clinics, held jointly by oncologists and surgeons, but few have formal head and neck cancer MDTs which meet regularly and fulfil the criteria for MDT working which are now well established for the management of patients with breast cancer.

NHS provision for these patients is not consistent: it varies from place to place and has been changing over recent years with the re-organisation of services for other forms of cancer. In some areas, patient management is now concentrated in hospitals which offer a range of specialised services; in others, such specialisation has not been achieved; yet others are in a transitional phase.

Many patients receive treatment at several hospitals, and this has been linked with poor co-ordination of care at many stages of the patient's cancer journey.[49] A large number of consultants are involved, most of whom do not specialise in head and neck cancer. A major audit, carried out in 1999/2000, revealed that the majority of patients in the South and West were treated by consultants who carried out 10 or fewer procedures for head and neck cancer in a year.[50] This must be a matter for concern because variety and complexity of surgical interventions required by such patients means that specialised skill is essential to achieve optimum results, both in terms of disease control and satisfactory cosmetic and functional outcomes.

---

[48] Commission for Health Improvement/Audit Commission. *NHS Cancer care in England and Wales*. London: Department of Health, 2001.

[49] Edwards, D. *Face to Face: Patient, family and professional perspectives of head and neck cancer care*. London: King's Fund, 1997.

[50] South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001.

Thyroid cancer has traditionally been treated by general surgeons, although there have been recent moves towards increased specialisation. Audit data from the Northern and Yorkshire Cancer Registry area (1998-9) shows that over a third of patients were treated by surgeons who dealt with two or fewer cases per year.[51] A study from Birmingham revealed that a substantial proportion of patients in that area did not receive adequate treatment, but that this was less likely to occur when patients were managed by a multi-disciplinary team of specialists.[52]

Two-fifths or less of hospitals/Trusts had agreed guidelines for the treatment of head and neck cancer in 2000. This was below the average for all cancers, although by no means the worst. Perhaps more significantly, one-third of hospitals/Trusts surveyed had no designated lead clinician for head and neck cancer and three-quarters had no lead nurse.[53]

Information, support, and sensitive communication are crucial for patients and carers from the time of diagnosis. After treatment, rehabilitation services become particularly important, both before and after discharge from hospital. There appears to be considerable regional variability in provision of these aspects of care; some patients report having very little support, others praise the wide-ranging services provided by their head and neck cancer team. Speech and language therapists (SLTs) and specialist nurses (CNSs) are particularly appreciated.[54] A substantial proportion of patients who would benefit from the help of SLTs, CNSs and dietitians do not have access to them.[55] There is consistent evidence that, at present, many patients' rehabilitation needs are not met in a co-ordinated way; and those who do have access to some forms of help may not be offered sufficiently specialised care to deal with the difficulties they face.

Different aspects of NHS provision are described in more detail in later sections of this manual, but readers should be aware that some of the information given may not accurately reflect the current situation. Without an up-to-date nationwide audit, it is not possible to present a reliable snapshot of current services for patients with head and neck cancer.

---

[51] Northern and Yorkshire Cancer Registry and Information Service (NYCRIS), unpublished data, 2003.

[52] Kumar H, Daykin J, Holder R, Watkinson JC, Sheppard MC, Franklyn JA. An audit of management of differentiated thyroid cancer in specialist and non-specialist clinic settings. *Clinical Endocrinology* 2001;**54**:719-723.

[53] Commission for Health Improvement/Audit Commission. *NHS Cancer care in England and Wales*. London: Department of Health, 2001.

[54] The National Cancer Alliance (NCA) report on patients' views specifically mentions appreciation of support from CNSs and SLTs. This is also evident from Edwards, D. *Face to Face: Patient, family and professional perspectives of head and neck cancer care.* London: King's Fund, 1997. Problems with diet and eating are frequently mentioned by patients, but dietitians were so rarely involved in their management that there was little opportunity for appreciation of their role.

[55] South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001.

The British Association of Otorhinolaryngologists – Head and Neck Surgeons (BAOHNS) set out standards for the treatment and care of patients with head and neck cancer in 1998. These were updated in 2000 and substantially expanded in a new publication in 2003.[56] However, there is relatively little research into the effectiveness of treatment for head and neck cancers, compared with breast or colorectal cancer.[57]

The British Association of Head and Neck Oncologists (BAHNO) has begun a process of nationwide audit, supported by the National Clinical Audit Support Programme (NCASP).[58] This project, known by the acronym DAHNO (data for head and neck oncology), will substantially improve the data available on outcomes of treatment in the NHS. Towards the end of the discussion of each topic area of this manual, a Measurement section (D) is included to guide audit. This is intended to identify ways in which Cancer Networks, MDTs and Trusts can measure the impact of service development, and to highlight areas of particular concern. The variety of issues that could be included is almost infinite and a wide range of additional issues could be monitored, some of which will have particular relevance to specific population groups or areas. Audit activity of this sort is valuable and the necessarily limited list given should not be regarded as complete.

---

[56] British Association of Otorhinolaryngologists – Head and Neck Surgeons. *Effective Head and Neck Cancer Management: Third Consensus Document*. London: Royal College of Surgeons, 2003.

[57] Savage J, Birchall M. Distribution of head and neck cancer in the UK. *Lancet* 2001;**257**:9272.

[58] Available on the NHS Information Authority website <www.nhsia.nhs.uk/ncasp/pages/audit_topics/cancer.asp>

Referral

1

A. Recommendations

Diagnosis and assessment of patients with possible head and neck cancers requires a sequence of activities which take place at different levels of the service. When patients first present to their GPs with symptoms, it is usually not obvious that the patient has cancer. Most will first be referred to a local hospital, ear, nose and throat (ENT) or maxillofacial clinic, where cancer will be found or strongly suspected in a small minority of cases. These patients require onward referral for further assessment, normally in a Tertiary Centre. This sequence is described in more detail below, and in Topic 3, *Initial investigation and diagnosis*.

Networks should decide which hospitals will provide diagnostic services for patients with symptoms that might be due to head and neck cancers. Hospitals which do not have the capacity to provide the type of service specified in this manual should have mechanisms for onward referral to Trusts where appropriate expertise is available. There should be specific referral routes for patients with persistent hoarseness, neck lumps or thyroid nodules. These arrangements should be clear, agreed within each Network by all Trusts that are likely to deal with these patients, and should be disseminated to GPs, specialists in medicine for the elderly, dentists, and any other professional groups which are likely to encounter such patients. Development of systems for rapid referral of patients with suspected cancer should take account of the short timescales that will become mandatory in the near future, when the government introduces referral-to-treatment targets.

Every district general hospital (DGH) or Cancer Unit which provides diagnostic services for symptoms which could be due to head and neck cancer should identify two or more designated clinicians who will take personal responsibility for the following aspects of the service at the hospital at which they are based:

- There should be systems in place which ensure that any patient who might have head and neck cancer is dealt with promptly and appropriately.

- All clinicians working in the hospital – in particular, those who work in ENT and maxillofacial clinics – who are likely to discover new patients with head and neck cancers should be able to contact one of the designated clinicians without delay. Any patient with a suspicious lesion should be seen by a designated clinician.

- When biopsy of a suspicious lesion is appropriate, a designated clinician should arrange for this to be done promptly.

- Designated clinicians should refer patients who are strongly suspected to have cancer on to appropriate assessment clinics at Cancer Centres (see Topic 2, *Structure of services* and Topic 3, *Initial investigation and diagnosis*).

Designated head and neck cancer clinicians and clinicians in ENT, maxillofacial and oral medicine clinics should be in regular contact with each other. It is not necessary for local hospitals to establish formal multi-disciplinary (MDT) structures to deal with people with head and neck cancer, but designated clinicians should have formal links with the MDT(s) to which they refer patients.

Urgent referral

Patients who meet the Department of Health's criteria for urgent (two-week) referral should either be referred directly to the designated lead head and neck clinician at a local DGH which provides such services, or to a rapid-access neck lump assessment clinic (described below). The guidelines for urgent referral in England are given below.[59] Revised guidelines are expected in 2005.

Urgent referral guidelines (England)

- Hoarseness persisting for more than six weeks.

- Ulceration of oral mucosa persisting for more than three weeks.

- Oral swellings persisting for more than three weeks.

- All red or red and white patches of the oral mucosa.

- Dysphagia persisting for more than three weeks.

- Unilateral nasal obstruction, particularly when associated with purulent discharge.

- Unexplained tooth mobility not associated with periodontal disease.

[59] Department of Health. *Referral Guidelines for Suspected Cancer*. Available on the Department of Health website <www.dh.gov.uk>. (Updated guidelines are due for publication in March 2005.)

- Unresolving neck masses for more than three weeks.
- Cranial neuropathies.
- Orbital masses.

The level of suspicion is further increased if the patient is a heavy smoker or heavy alcohol drinker and is aged over 45 years and male. Other forms of tobacco use and/or chewing betel (areca nut), gutkha, or paan should also arouse suspicion.

In Wales, the urgency of any referral is assessed by the hospital specialist to whom the referral is made; it is therefore crucial both that referral letters include sufficient information to allow judgements about the risk of cancer to be made, and that patients who may have cancer (i.e. those who meet the urgent referral criteria given above) are referred specifically to a designated head and neck clinician.

Patients with non-thyroid neck lumps

Patients who present with masses in areas of the neck other than the thyroid, whose symptoms persist despite treatment with antibiotics and in whom infectious mononucleosis has been excluded, should be referred to rapid-access lump clinics for investigation. Networks which do not have lump clinics should establish them at selected hospitals (see Topic 3, *Initial investigation and diagnosis*).

Patients found to have cancer should be referred without delay to the appropriate MDT. Pre-booking systems should be established for results clinics at which each patient with a diagnosis of cancer can be seen by a senior member of the MDT which deals with that type of cancer, and where support is available from a clinical nurse specialist.[60]

Thyroid cancer

Patients with thyroid cancer are likely to present with a lump in the neck, usually with no other symptoms or signs. Local triage is important; this should be formally organised and audited. Urgent referral is necessary for the following groups of adult patients:[61]

- Those with solitary thyroid nodules that are increasing in size;
- Patients with thyroid lumps, who have family histories of thyroid cancer or who have had neck irradiation;
- Thyroid lumps in patients over the age of 65;

---

[60] National Institute for Clinical Excellence. *Improving Outcomes in Haematological Cancers*. Available on the NICE website <www.nice.org.uk>.

[61] Indications in this list are derived from guidelines published by the British Thyroid Association and Royal College of Physicians in *Guidelines for the management of thyroid cancer in adults*. Royal College of Physicians of London, 2002.

- Patients with unexplained hoarseness or voice changes associated with a goitre;
- Cervical lymphadenopathy;
- Stridor (a harsh sound when the patient draws breath: this is a late presenting sign and patients should be seen immediately).

Routine referrals

Upper aerodigestive tract (UAT) cancer

The majority of patients found to have cancer enter the system by routine referral, normally to ENT or maxillofacial out-patient departments in local hospitals; some are identified in oral medicine departments of dental hospitals. These patients have a wide range of mouth or upper airway symptoms. However, very few of those with such symptoms have cancer; indeed, the average GP is likely to encounter only one case of head and neck cancer every six years. Most of those who do have cancer will have one or more of the symptoms listed above; many will also have some degree of persistent pain.

The most common presenting symptoms of cancer are also common symptoms of infection. The crucial difference is that symptoms due to cancer tend to persist, and not resolve with conservative treatment; so patients who fail to improve should be referred. GPs, practice nurses and dentists should check patients' mouths for lesions that could be due to cancer or pre-malignant conditions (e.g. red or white patches) when suitable opportunities arise.

Health professionals should be aware of risk factors for head and neck cancers (see *Background*) and should be particularly alert to the possibility of cancer in patients in higher-risk groups, such as heavy smokers and drinkers who develop persistent mouth or throat problems.

Referral forms should be developed by hospitals which offer diagnostic services, with tick-boxes or similar features which define the patient's symptoms and can be used to identify the specialist by whom they should be seen initially (for example, chronically hoarse patients might be referred to an ENT clinic, and those with oral symptoms to a maxillofacial specialist). There should be a central point in the hospital to which these forms are sent, where appropriate action will be taken; the number for this service should be clearly marked on the form.

Thyroid lumps

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).

GPs should request thyroid function tests for all patients with goitre. Patients with abnormal thyroid function test results (hyper- or hypothyroidism) are unlikely to have cancer and should not be referred to the head and neck cancer service, but they may need to be referred to an endocrinologist. Those with goitre and normal thyroid function should be given routine referrals either to a thyroid clinic or a neck lump clinic, unless they fulfil any of the criteria for urgent referral listed previously.

Prevention

Commissioners should continue to develop services to help people to overcome behaviours that increase risk of head and neck cancers, particularly smoking and heavy drinking (see *Background*). Services to help people to overcome addiction to substances such as betel should be provided in areas with significant Asian populations. Such services should be specifically designed to meet the needs of these ethnic groups.

Staff working in any part of the NHS, particularly those in primary care, should take advantage of any opportunities for counselling patients who smoke, chew betel or tobacco or are believed to drink heavily. They should offer help with overcoming addiction, including referral to appropriate services.

B. Anticipated benefits

Greater awareness of head and neck cancers among health professionals, especially in patients whose lifestyles put them at relatively high risk, could lead to more appropriate referral and earlier detection of cancer. As with other forms of cancer, outcomes are better for patients whose disease is diagnosed and treated early.

C. Evidence

Note: the reliability and quality of evidence supporting the recommendations is graded A, B or C, where A is evidence based on one or more randomised controlled trials. The grading taxonomy is explained in Appendix 2. A detailed and fully referenced summary of the evidence is given in the *Review of Research Evidence* that accompanies this manual.

Tumour stage, nodal status and survival

Two observational studies provide evidence that patients whose cancers are detected later require more extensive treatment and experience poorer outcomes.

One, an audit of 206 patients with oral cancer from Scotland, gives details of associations between tumour stage, lymph node involvement, treatment and survival. This study found that patients who presented with Stage I disease had significantly longer disease-free periods after treatment, and significantly higher survival rates, than those with more advanced tumours. About half the total group had relatively small, early tumours (T_1 and T_2); these patients survived for about twice as long as those with more extensive disease.(B)

A study from Brazil investigated delays in the referral process and relationships between disease stage, treatment costs and hospital stay. The majority of delays (58%) were due to patients delaying consultation with health professionals. However, health professionals were responsible for some or all of the delay in almost a quarter of cases. Patients who reported symptoms promptly were approximately half as likely to present with late stage disease. There was a dramatic increase in hospital costs with more advanced disease. For example, duration of treatment (which is a major component of cost) for oral carcinomas ranged from a mean of nine days for Stage I disease (T_1, node negative) to 91 days for Stage III disease ($T_{1/2}$, node positive, or T_3).(B)

Effectiveness of strategies to improve early detection of head and neck cancer

No evidence was found on the effectiveness of raising awareness of head and neck cancer among members of groups at relatively high risk. There is limited evidence suggesting that educational interventions can increase awareness among health professionals, but whether this affects their practice has not been established.

A brief, multi-component educational intervention designed to teach health care professionals about the oral sites at risk, etiological factors and early signs and symptoms of oral and pharyngeal cancers, and screening techniques, was assessed in a US study. The authors concluded that this type of intervention could increase some health

care professionals' knowledge. However, knowledge levels among the dentists and nurses in the study did not change and no patient outcomes were measured.(B)

A UK study of the feasibility of systematic examination of the oral mucosa by dentists concluded that this could be carried out as part of routine dental inspection. One carcinoma, which presented as an ulcer in the mouth, was discovered in the group of 1,947 people screened. The participants in this study were employees of a limited company; it was not carried out in the context of an NHS dental practice.(B)

Delays in access to diagnosis and treatment in the NHS

The first source of delay in access to treatment is the delay between patients' awareness of symptoms of their cancer and visiting their GP, which is usually about two to three months but can be years.[62] There is no clear-cut relationship between delay in referral and survival, since patients with more acute symptoms are less likely to delay and are more likely to be referred by their GPs within two weeks; consequently, those who are referred quickly tend to have later stage disease and poorer survival rates.[63]

Since 2001, the Department of Health has required that patients referred urgently for possible cancer be seen by a specialist within two weeks. For England as a whole in the last quarter of 2002, 99% of patients with potential head and neck cancer whose referral was received within 24 hours, and 90.5% of those whose referral took longer, were seen within this period.[64]

The appointment with a specialist is only the first step in the assessment process and waiting time figures do not indicate time to confirmed diagnosis or treatment, nor the time that patients who are not referred under the two-week guidelines may wait. There are no national data on these delays, but audit data for 1996-7 and 1999-2000 in the South and West have been published (SWAHNI and SWAHNII).[65] These audits show that the median time between GP referral to first out-patient visit was 14 days or less for patients with oral and pharyngeal cancers, but patients with cancers of the larynx or salivary glands waited a median of about seven days longer. A further 18, 20 or 30 days, respectively, elapsed before assessment at a joint clinic. The longest delays were between initial assessment and treatment.

---

[62] South West Cancer Intelligence Service, *Head and Neck Audit Report* (*SWAHNI*), 1997.
[63] South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001.
[64] See <www.dh.gov.uk>.
[65] South West Cancer Intelligence Service, *Head and Neck Audit Report* (*SWAHNI*), 1997 and *Second Head and Neck Audit Report* (*SWAHNII*), 2001.

In 1997, the median waiting times for patients with oral cancer were 40 days between GP referral and surgery, and 53 days to radiotherapy; very little of this time was taken in testing procedures. SWAHNII shows that three years later, delays had increased by about a week. The range of waiting times was large, with delays between first out-patient appointment and assessment at a joint head and neck clinic ranging from less than a week to more than 19 months (median 18 days).

A similar pattern of waiting times can be seen for patients with cancer of the larynx, pharynx, and other sites. Median waiting times (for example, 47 days from GP referral to surgery and 85 days to radiotherapy for patients with larynx cancer in 2000) obscure the wide variation between patients. Some waited a year after their first out-patient appointment before radiotherapy began, though the maximum delay before surgery was less (82 days).

There are also no national data on the stage at which head and neck cancer is diagnosed, although there is some information on the size and stage of tumours at this point. Figures from the SWAHNII audit are given in Table 3, *Background*. Data collected by the Mersey Region Maxillofacial Unit, based on nearly 700 patients with cancer of the oral cavity and oropharynx, show that three-quarters of the cancers were classified as T_2 (two to four centimetres diameter, usually Stage II-III) or more at the point of diagnosis. Over a quarter were classified as T_4 (Stage IV, invading adjacent structures). Similar findings were reported from Leeds, where roughly one-quarter of head and neck cancers fell into each tumour size category (T_1-T_4). There was no clear association between the nature of the symptoms and the urgency with which they were viewed by patients.[66]

Specific referral routes

Persistent hoarseness

Two studies described rapid-access clinics for patients with husky or hoarse voices. One included 271 patients who were referred to an "immediate access" clinic where the average waiting time was three weeks. 39 (14%) of these patients had suspicious lesions; cancer was diagnosed in 11 cases. The second study was an audit of 34 patients, of whom 94% were seen within five working days. 85% of referrals were judged appropriate. One case of cancer was reported.(B)

[66] Amir Z, Kwan SYL, Landes D, Feber T, Williams SA. Diagnostic delays in head and neck cancers. *EJC* 1999;**8**:198-203.

Neck lump clinics

One study compared two cohorts of 50 patients each, referred to a "lump and bump" clinic before and after implementation of the two-week wait initiative. In a brief report, the authors state that the introduction of this initiative was associated with an increase in the mean time between referral and clinic appointment from 14 to 25 days, and a fall in the pick-up rate for malignancy from 14% to 4%. They do not report on other changes in policy or practice over the same period, which might have contributed to these results.(B)

An audit and re-audit of a "one-stop" head and neck lump clinic where staff were able to carry out fine needle aspiration cytology (FNAC), found that over two-thirds of 245 patients required only one visit to the clinic. During the first six months, the mean time from referral to clinic appointment was 17 days; at re-audit, it was 21 days. Patients waited, on average, about an hour to be seen at the clinic. 12% of patients presented with malignant disease affecting the lymph nodes or salivary glands. The level of accuracy of FNAC in this clinic was 94%.(B)

The authors of this study made the following recommendations, based on their experience:

1. Allocation of dedicated clinic time;

2. GPs should have access to the fax number of the clinic;

3. A senior member of the surgical staff should assess each patient;

4. A cytopathologist should be based in the clinic to perform and interpret FNAC specimens;

5. FNAC accuracy of cytopathologists should be known before clinic starts;

6. Continuing re-evaluation of the strategy.

An earlier (1998) report describes another direct referral clinic for patients with neck masses. It was staffed by a consultant otorhinolaryngologist and a consultant radiologist, who carried out ultrasound assessment with FNAC when appropriate. Of the first 100 patients seen within the clinic's first year of operation, 46 patients were referred with enlarged lymph nodes; 10 of these (22%) had squamous cell carcinomas and three (7%) had lymphoma. 21 patients had thyroid swellings, of whom five subsequently underwent surgery; four had cancer. 17 patients had salivary gland lumps, of which two were malignant.(B)

D. Measurement

Structure

- Defined systems for routine and urgent referral as outlined, disseminated to all relevant health professionals in the Network.
- Availability of neck lump clinics.

Process

- Evidence that patients are referred on to MDTs without delay.
- Audit of delay between initial referral by GP and confirmation of diagnosis.

Outcome

- Stage at diagnosis.

E. Resource implications

The only aspect of these recommendations which is expected to have significant cost implications is the establishment of rapid-access neck lump clinics with on-site cytological expertise. Many hospitals already have lump clinics, but few are able to offer a one-step service with FNAC. It is estimated that the annual cost of providing this service would be £20,000 per clinic; assuming that the average Network would have three such clinics, the cost for all 37 Networks in England and Wales would be £2.2 million per annum.

Structure of services

A. Recommendations

2

Optimum management of patients with head and neck cancers requires the active involvement of experts from a particularly wide variety of fields. Services for these patients should be planned and commissioned at Network level. Each Network should review the range of professionals, services and specialist resources available and smaller Networks should consider co-operating with neighbouring Networks to develop joint services.

Management by multi-disciplinary teams (MDTs)

All patients with head and neck cancers (including thyroid cancer) should be managed by appropriate MDTs, constituted as specified below. Each Network should ensure that a comprehensive range of professionals is available for all the MDTs in the area it covers, and organise the service so that every patient can be managed by a full MDT. These MDTs should deal with minimum of 100 new cases of upper aerodigestive tract (UAT) cancer per annum (excluding glandular tumours), which implies a population base of over a million; most will be based in Tertiary Centres which have radiotherapy facilities. Some Networks in sparsely populated areas may, however, elect to develop teams for smaller numbers. Where more than one Trust provides services in close geographical proximity (for example, where two Trusts operate in a single conurbation), Networks should consolidate services under a single MDT.[67]

Networks should identify specific head and neck cancer MDTs which will provide treatment for patients with cancer in rare sites and patients whose cancers present especially challenging problems: in particular, salivary gland tumours and those that involve the base of the skull. These teams are likely to be located in large Centres which have access to a wider range of resources. Sarcomas presenting as head and neck cancer should be managed jointly with the sarcoma MDT. All cases should be discussed together by appropriate

[67] BAHNO guidelines recommend that MDTs should deal with a minimum of 80 new cases per year. This is regarded as a conservative figure which might be appropriate for MDTs serving sparsely populated areas. (British Association of Head and Neck Oncologists, Practice care guidance for clinicians participating in the management of head and neck cancer patients in the UK. *Eur J Surg Oncol* 2001;**27**(suppl A):S4.)

members of the respective MDTs prior to decisions about management and again when definitive histology is available. All suspected sarcomas should be reviewed by the specialist sarcoma pathologist on the sarcoma MDT.[68]

Members of the head and neck cancer core MDT

The concept of MDT management is well established in head and neck cancer, but it has proved difficult to achieve the necessary level of expertise in all the disciplines involved in a single hospital. MDT management involves more than establishment of joint or multi-disciplinary clinics; it requires formal team membership and regular meetings, which all members are expected to attend. In practice, this means that each MDT member should be present at a majority of meetings.

Whilst it is not necessary for every head and neck cancer MDT to include all types of specialist, it is important that all the skills required to deal with the range of patients treated by each MDT are available among its members. All members should specialise in head and neck cancer, and every clinical specialty should be represented at each meeting: cover should always be available when specific MDT members cannot be present. A clinical nurse specialist (CNS) should be present at every MDT meeting. Teleconferencing may be used to ensure access to particular specialists.

Every MDT should include an identified lead clinician. Each MDT should specify the range of cancers with which it deals; for example, some will manage patients with thyroid cancer (see *Thyroid cancer MDTs*, below), and will therefore include the specific members required for that work; others will not. Members required for an MDT responsible for the management of UAT cancers are listed below. Where the role specified is new to this document, or deviates from that generally available at present, it is described in more detail below. It is recognised that some time will be required for staff training before some of these role specifications can be fully implemented.

- Surgeons: each MDT should include three or more designated surgeons, who are likely to be ear, nose and throat (ENT), maxillofacial, or plastic surgeons. It is important that each MDT includes, or has access to, surgeons who are proficient in reconstruction, including microvascular techniques. This document will refer to all surgeons in the MDT as surgical specialists, whatever their individual background or specialty. Each surgeon in the MDT should normally dedicate half of his or her time to head and neck cancer.

[68] National Institute for Clinical Excellence guidance on sarcoma is due for publication in October 2005.

- Clinical oncologists: each MDT should, if possible, include two clinical oncologists, one of whom should always be present at meetings.
- Restorative dentist.
- Pathologists with expertise in both histopathology and cytopathology, who participate in external quality assurance (EQA) schemes.
- Radiologist.
- Clinical nurse specialists (CNSs).
- Speech and language therapist.
- Senior nursing staff from the head and neck ward.
- Palliative care specialist (doctor or nurse), who should work with palliative care services in the community.
- Dietitian.
- Team secretary who will provide clerical support for the MDT, recording all decisions made by the team and communicating appropriate information promptly to all those (such as GPs) who may require it.
- Data manager, who will ensure that the MDT has all relevant details for each meeting, record details of care plans, and to ensure that data are available for other purposes, such as clinical audit.
- MDT co-ordinator, who should take responsibility for organising MDT meetings (see below). The co-ordinator may also take the role of team secretary and/or data manager, but should not be a clinical nurse specialist, since this is not an appropriate use of the CNS's skill or time.

The core team should normally meet weekly, since weekly MDT meetings will be essential to meet *Cancer Plan* waiting time targets. Sessional commitments should be formally agreed for all MDT members in their job planning process.

Extended team members

These individuals are required for some patients but need not attend all MDT meetings. The extended team should be made up of designated professionals who have an interest in head and neck cancer and experience of dealing with these patients, and who will make themselves available whenever their expertise is needed. MDTs that provide treatment for patients with particular problems, such as tumours involving the skull, are likely to need a wider range of specialists at the majority of meetings. The involvement of psychiatric and psychological services is particularly important, since many patients have pre-existing psychological problems which may be exacerbated by the consequences of treatment.

- Other specialist surgeons.
- Anaesthetist with a special interest in head and neck cancer.
- Gastroenterologists, radiologists, surgeons, and other health professionals with expertise in gastrostomy creation, feeding tube placement and support for patients who require tube feeding.
- Ophthalmologist.
- Pain management specialist.
- Nuclear medicine specialist.
- Therapeutic radiographer.
- Maxillofacial/dental technician.
- Dental hygienist.
- Social worker.
- Benefits advisor.
- Liaison psychiatrist.
- Clinical psychologist.
- Counsellor.
- Physiotherapist.
- Occupational therapist.

Thyroid cancer MDTs

All patients with thyroid cancer, including those whose cancer is discovered during surgery for apparently benign disease, should be referred for management by thyroid cancer MDTs. These teams may take one of two alternative forms, being either:

1. Designated head and neck cancer teams, joined by experts in endocrinology for the relevant part of the MDT meeting; or

2. Specialised endocrine oncology teams.

Since thyroid cancer is a relatively rare condition, with an incidence rate of roughly two patients per 100,000 population per year, these MDTs will also only be required in large Centres (those which serve populations in excess of a million). Thyroid cancer MDTs may manage patients with both malignant and non-malignant disease.

Members of the thyroid cancer MDT

- Endocrinologist.
- Surgeon who specialises in thyroid/endocrine oncology.
- Oncologist.
- Radiologist.
- Nuclear medicine specialist.
- Specialist pathologists (both histopathology and cytopathology).
- Clinical nurse specialist (who may be a head and neck cancer CNS).
- Secretarial and support staff, as above.

One or more members of the team must be trained and certificated to give radioiodine.

Thyroid cancer MDT meetings should be organised in whatever way is most convenient for the members. Thyroid cancer MDT meetings may, for example, follow head and neck cancer MDT meetings, to allow best use of time for those involved in both areas and for those who are involved only in one of these areas. Alternatively, the thyroid cancer MDT might hold entirely separate meetings. 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.

Responsibilities of MDTs

The management of every new patient should be discussed by an appropriate head and neck or thyroid cancer MDT. The MDT should take overall responsibility for assessment, treatment planning and management of all patients throughout the course of their disease and rehabilitation, and for supporting, advising and educating professionals who provide services for these patients outside the Centre. Head and neck cancer patients usually require long-term help, much of which is likely to be provided by Cancer Units; experts from the MDT should therefore offer an outreach service, liaising with those who have less specialised expertise to ensure that a high level of care is provided for patients in the periphery.

When new cases are diagnosed, referring surgeons should be invited to join the MDT to discuss the management of their patients. Pathologists throughout the Network should ensure that diagnostic biopsy or cytology samples that show head and neck cancer have been reviewed by a pathologist who attends the MDT. Similarly, any radiologist who recognises head and neck cancer when viewing results of imaging should draw the case to the attention of a radiologist who is a member of the relevant MDT.

The MDT should take responsibility for deciding what form of treatment should be offered, where the proposed treatment should be carried out, and by whom. Surgery should normally be carried out by surgeons who are members of the MDT in a hospital with a specialised head and neck ward where patients can be nursed after the operation. Treatment may be provided for patients with small, localised UAT tumours by surgeons with appropriate skills in peripheral hospitals, if these surgeons are full members of the MDT and the MDT considers this to be appropriate. Such treatment should be consistent with the treatment plan developed by the MDT.

Roles specific to head and neck cancer MDTs

The clinical nurse specialist (CNS)

Clinical nurse specialists play key roles in MDTs, and at least one CNS should be present at every MDT meeting. The role of the CNS includes both psychosocial support and co-ordination of care for patients, but the level of involvement with individual patients will vary according to their requirements. Although all patients should be offered the opportunity to see a CNS before final decisions are made about the management of their disease, patients who are relatively fit, free from significant psychological or physical problems, and have early tumours for which treatment is straightforward, may require only a short interview with the CNS.

A named head and neck cancer CNS should be available for every patient who needs the multi-faceted support and expertise she (or he[69]) can provide, throughout the course of the disease. The CNS should be informed about each new patient when a definitive diagnosis is made, although she may delegate specific tasks, such as provision of support at the time the patient is given the diagnosis, to other named nurses. Patients and carers should be given contact details for their CNS or named nurse, so that they can get in touch if they have questions about their condition, or if they need help to cope with their disease or its consequences.

The CNS requires highly developed communication and psychosocial skills, so that she can recognise patients' non-clinical needs as well as problems directly associated with their cancer or treatment. She should be closely involved in ensuring that patients and their families understand the nature and potential impacts of the interventions that may be required, and be available to provide expert help when required with managing the practical, social and psychological consequences of treatment. This type of help may be necessary during the post-treatment period and for a considerable time after discharge from hospital (see Topic 6, *After-care and rehabilitation*).

The CNS should take a leading role in ensuring that appropriate care is provided for patients, working in a flexible way with other professionals across institutional boundaries and in the community. The provision of education and support for other members of the nursing team is an important facet of this role. The CNS should be available to help and advise nurses working in ENT, head and neck and maxillofacial departments and primary health care teams, and to facilitate the development of the skills required to care for patients whose needs may be unique to head and neck cancer. Other professionals should be able to consult the CNS for expert advice on issues such as managing patients with tracheostomies, gastrostomies, prostheses, or difficult wounds.

CNSs should also work closely with other groups, including patient self-help groups, and with other members of specialist and extended teams, both in the Centre and the periphery. They should identify patients who might benefit from referral to other professionals (for example, a clinical psychologist, liaison psychiatrist, social worker, or benefits advisor) and be able to arrange access to services such as social skills training. They should be involved in co-ordinating care for individual patients, but should not be expected to take on the administrative burden of co-ordinating MDT meetings.

[69] In the text below, the pronoun "she" may be used for convenience to refer to the CNS or other nurse; it is acknowledged that the nurse may be male.

The speech and language therapist (SLT)

Speech and language therapists, like CNSs, have wide-ranging roles in supporting patients with head and neck cancer. Their expertise is essential for helping patients whose cancer or treatment causes problems with communication or swallowing, but they also provide psychosocial support and information for patients and carers. SLTs should contribute to MDT discussions on treatment planning. 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. An SLT with specialist expertise should be available to work with such patients and their carers for substantial periods of time. (See Topic 6, *After-care and rehabilitation.*)

Dietitian

Dietitians with specific expertise in dealing with head and neck cancer patients should be available for all those who may require their help, and there should be mutual co-operation between dietitians, SLTs and CNSs. The dietitian should be involved in pre-treatment assessment, taking action both to correct patients' pre-existing nutritional deficiencies before treatment begins, and 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.

Access to specific services

Dental services

The MDT should be responsible for ensuring that specialised dentistry is available for all patients who require it. Expert dental assessment and treatment is important both before and after treatment, especially when radiotherapy is being considered.

Many of these patients have complex needs that cannot be adequately met by primary care dental services. A consultant with experience in maxillofacial prosthetics and implantology is required to manage patients who need oral rehabilitation. This consultant should co-ordinate the dental care of patients after treatment by liaison with primary care dental practitioners.

Nuclear medicine

Nuclear medicine is central to imaging and radionuclide therapy for patients with thyroid cancer.

Psychological services

Because of the location of the cancer and the effects of treatment on social interaction, patients with head and neck cancer are at particular risk of psychological problems, particularly social anxiety and depression. Dependence on alcohol and nicotine is also more common than in most other patient groups. Psychological interventions can therefore be important in the management of these patients.

There should be close liaison between all MDT members – particularly the CNS – and psychological support services. Members of the core or extended teams with expertise in these areas (notably the clinical psychologist and liaison psychiatrist) should be available to assess patients' psychological needs and provide or arrange appropriate therapy when required.

How the teams function

Each MDT should have an administrative head (the lead clinician) who should work closely with the co-ordinator, but a democratic ethos should be encouraged during meetings. It is important that all clinical members of the MDT should play active parts in discussing treatment plans, since each can offer a distinctive and valuable perspective; the participation of CNSs, SLTs, dietitians, and other allied health professionals should be regarded as essential to the function of the team. MDTs should consider taking training in effective team-work.

At any one time, a named member of the team should be the principal clinician to whom the patient relates. It is important that such arrangements should be explicit and properly understood by patients and their GPs, who should be given information about all the members of the team involved in their management.

The team should be responsible for planning care in a seamless way so that each patient receives prompt and appropriate care throughout the process of diagnosis and treatment, until the patient is released from follow-up or dies. One member of the team (normally the team co-ordinator) must have a system for tracking all patients throughout their illness and ensuring that the relevant notes are available wherever and whenever they are required.

Organisation of MDT meetings

Meetings should be arranged in sessional time by the team co-ordinator. The co-ordinator should work with members of the MDT to ensure that all the following patients are identified for discussion at the meeting, and their case notes, along with diagnostic, staging, and pathology information, are available for consideration at the meeting.

- Every patient with a new diagnosis of cancer in any head and neck site with which the MDT deals. The MDT co-ordinator should work with pathologists and radiologists to ensure that all such cases are identified.

- All patients who have undergone initial surgery. Detailed review of pathology after surgery is important to inform decisions about further treatment and has prognostic value.

- All patients with newly identified recurrent or metastatic disease.

- Any other patient whose management is thought by any member of the MDT to require discussion.

All information and facilities necessary for effective team functioning and clinical decision-making should be available at each meeting. Team members should be adequately prepared for the meeting, so that they can discuss each case without delay; such preparation and attendance at meetings should be recognised as important clinical commitments and time should be allocated accordingly. In addition to the basic physical facilities such as adequate room and table space, there must be appropriate equipment to allow the whole group to study radiographic and pathology images together, using a microscope and data projector/monitor. Videoconferencing facilities may be necessary to allow all MDT members to contribute to the discussion.

Each MDT should have adequate systems for recording decisions made at meetings and ensuring that appropriate action is taken to carry out these decisions. Information and decisions about individual patients should be recorded on an appropriate pro-forma; ideally, this should be available on a laptop computer so that it can be used during MDT meetings.

The administrative head of the MDT, working with meeting support staff, should take responsibility for ensuring that treatment plans and other items of information relevant to specific patients are sent to their GPs and referring hospitals as quickly as possible.

Audit, clinical trials, and other issues of relevance to the Trust or Network should also be discussed at MDT meetings. Each MDT should have audit support staff who work with the data manager.

There should be an operational policy meeting at least once a year at which the head and neck cancer team discusses and reviews its policies. This meeting should be organised around an open agenda to which all members of the team may contribute.

Achieving consistency within Networks

Network-wide guidelines should be agreed, with joint protocols for clinical management, referral and audit. Information about each patient should be recorded in the database produced for the ongoing nationwide audit known as DAHNO (see *Background*, page 27). There should also be Network-wide audit, not only of clinical issues and outcomes, but also of patients' and carers' experience of the service. Information derived from audit should be used to identify and reduce variations within Networks.

B. Anticipated benefits

Genuinely multi-disciplinary working and combined decision-making benefits patients by increasing the probability that the interventions offered will be those that are most appropriate for them. MDTs whose members can offer the full range of necessary skills, and who have access to a greater variety of facilities, are more likely to provide effective, efficient and comprehensive services for their patients. MDT meetings ensure that each patient is considered from a range of viewpoints by people with different areas of specialisation, who can pool their expertise and learn from one another.

Clinicians with experience of sharing difficult problems in the supportive environment of an MDT meeting report that they find it very helpful. Inclusion of palliative care specialists in the MDT benefits patients, ensuring that palliative care needs are recognised and met early; it also brings a palliative care perspective to the meeting, which may help other clinicians to deal with the emotionally draining effects of managing patients whose condition deteriorates despite their efforts.

Management by a efficiently co-ordinated MDT, which has adequate secretarial support and data management, will improve communication and co-ordination throughout the service. This will tend to prevent duplication of work and help to ensure that all those involved in dealing with patients have the information they require to carry out their roles effectively.

Patients who receive support from CNSs and SLTs value it greatly. Increasing the number of these professionals so that all patients with head and neck cancer have access to a CNS and/or an SLT when they require it, is likely to reduce anxiety among patients and carers, enhance their quality of life, and could reduce post-treatment hospital admissions by ensuring that problems are dealt with promptly and appropriately. CNSs, SLTs and other nursing and allied health professionals can play crucial roles in MDT meetings, both in discussion of management strategies for individual patients, and by contributing to wider strategic planning and policy-making. Because of the nature of their relationship with patients, they can often bring a richer understanding of patients' preferences, social situation, cognitive and coping skills, to the decision-making process.

Involvement of specialist dietitians in the MDT can improve outcomes by enhancing awareness of the importance of nutritional issues and the provision of appropriately prepared food among care providers, and by improving the nutritional status of individual patients through appropriate interventions. This both helps patients to cope with their treatment and its aftermath, and reduces the risk of complications.

Increased concentration of work in hands of fewer specialists tends to enhance expertise among those who see more patients. This is likely to improve outcomes in all groups of patients, but particularly in those with more challenging or rarer forms of head and neck cancer, such as salivary gland and thyroid tumours. Accurate staging of the tumour is more likely at bigger Centres where clinicians are more specialised; this is essential for treatment planning.

At present, the service for patients with thyroid cancer is particularly fragmented. Many are managed by general surgeons who do not have a special interest in thyroid cancer. Consolidation of services in the hands of experts will increase the probability that every patient receives appropriate treatment.

Low levels of activity make meaningful audit of outcomes impossible. This, too, is likely to improve when the management of all cases of head and neck cancer is concentrated in the hands of appropriately constituted MDTs working in larger Centres.

C. Evidence

Note: the reliability and quality of evidence supporting the recommendations is graded A, B or C, where A is evidence based on one or more randomised controlled trials. The grading taxonomy is explained in Appendix 2. A detailed and fully referenced summary of the evidence is given in the R*eview of Research Evidence* that accompanies this manual.

The situation in the NHS

UAT cancers

At present, many patients are treated at several hospitals, by a range of specialists, and there is considerable anecdotal evidence of problems with communication between professionals and, consequently, with co-ordination of care. The author of a detailed study of the experiences of patients treated for head and neck cancer comments that, "Lack of co-ordination was a theme which emerged again and again at different stages of the cancer journey."[70] Co-ordination and communication problems caused considerable frustration, both to patients and clinicians.

[70] Edwards D. *Face to Face: Patient, family and professional perspectives of head and neck cancer care.* London: King's Fund, 1997, p23.

Professionals spoke of the value of teamwork. All participated in joint clinics, although the composition of these varied. Surgeons and oncologists reported that planning treatment in joint clinics with colleagues from different disciplines kept them up-to-date, made sure that they considered all options for treatment, and provided them with support and a chance to discuss their difficult cases. The concept of the team spoken about by the professionals in the study had moved away from separate cure and care teams, to one team which included all professionals, the patient and the family. The role of the surgeon within the team had also changed. "It used to be thought that the Captain (surgeon) knows it all and can fly the whole plane and all its contents and crew out of danger. And they have very sensibly abandoned that idea years ago and it's a team that flies the aircraft, taking due recognition of everybody's contribution… We are not there to cut out a tumour we are there to provide a route of survival for a person."[71]

On average, five consultants are involved in the diagnosis of head and neck cancer; a recent survey by the Royal College of Surgeons of England found that the range was from two to 14. Around half of the hospitals that treat patients with head and neck cancer hold joint clinics, with an average of 24 patients seen in each clinic (range: 4-60).[72]

Of the 18 Trusts included in the nine-Network CHI/Audit Commission survey (2000/2001), just under half held regular MDT meetings to plan the management of patients with head and neck cancer, usually during lunch time. Six Trusts provided information on the frequency of MDT meetings; in three, the team met weekly; other teams met fortnightly or monthly. Of the head and neck cancer MDTs that met regularly, 30% kept minutes of their meetings. Two endocrine cancer MDTs met regularly; neither kept minutes.[73]

In the South and West Region, it was decided that 95% of all new head and neck cancer patients should be seen in a combined clinic prior to treatment. In 1997, no Trust achieved this level; indeed, in 16 of the 22 Trusts, fewer than 60% of patients were seen in a multi-disciplinary clinic before treatment began. However, in each of the four Trusts which treated the largest numbers of patients (50-65 per Trust), about two-thirds of patients did receive multi-disciplinary assessment. Overall, 46% of patients were seen in combined clinics.[74] The SWAHNII audit revealed that this situation had changed substantially by 1999/2000, when 74% of patients were seen in combined head and neck clinics.[75]

---

[71] Edwards D. *Face to Face: Patient, family and professional perspectives of head and neck cancer care*. London: King's Fund, 1997, p19.

[72] Birchall M, Brown PM, Browne J. The organisation of head and neck oncology services in the UK: The Royal College of Surgeons of England and British Association of Head and Neck Oncologists' preliminary multi-disciplinary head and neck oncology audit. *Ann R Coll Surg Engl* 2003;**85**(3):154-157.

[73] Commission for Health Improvement/Audit Commission. *NHS Cancer Care in England and Wales*. London: Department of Health, 2001.

[74] South West Cancer Intelligence Service, *Head and Neck Audit Report (SWAHNI)*, 1997.

[75] South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001.

This increase in multi-disciplinary assessment was associated with a simultaneous increase in the proportion of patients who are referred to larger Centres for treatment, described in the SWAHNII report as "creeping centralisation". This was not a uniform change; two Networks have concentrated almost all treatment in two hospitals each, whilst three others showed little sign of centralising care for head and neck cancer. There has been very little transfer of resources, so centralisation has resulted in increased waiting times for treatment at hospitals which receive larger numbers of patients – a problem exacerbated by the increasing incidence of these cancers.

The majority of surgeons who treated these patients each carried out four or fewer operations for head and neck cancer in the year of the SWAHNII audit. Of 61 surgical consultants involved in the treatment of head and neck cancer, 10 dealt with more than 10 cases during that year, treating a total of 163 cases between them. 181 patients were treated by 51 consultants who each carried out 10 or fewer procedures; 15 of these treated only one patient. Surgical consultants gave opinions on surgery for a further 294 patients at joint head and neck clinics, 76 at ENT clinics, and nine at maxillofacial clinics.

There was more evidence of specialisation among the 19 oncologists included in the SWAHNII audit. 89% of patients who received radiotherapy were treated by nine oncologists, each of whom saw more than 20 cases in the year. The remaining 10 oncologists treated an average of five patients each.

Only 40% of Trusts/hospitals had a CNS for head and neck cancer in 2000/2001.[76]

Thyroid cancer

In the Northern and Yorkshire Cancer Registry (NYCRIS) area in 1998-9, patients with thyroid cancer were most likely to be treated by general surgeons working outside MDTs. 59% of patients were treated by surgeons who dealt with fewer than 10 cases in the two-year period studied (i.e. an average of five or fewer cases per year); and in over a third of cases, treatment was given by surgeons whose case-load averaged two or fewer per year. Audit based on questionnaires, with a response rate of 60%, revealed that half of the consultants who performed surgery for thyroid cancer worked in MDTs; of those who did not, 62% met regularly with oncologists and 81% discussed the diagnosis with a pathologist or imaging specialist. Only 56% of MDTs which managed thyroid cancer patients discussed every case. 44% of these MDTs also dealt with other endocrine cancers, 22% were head and neck cancer teams, whilst 31% did not specify any other cancers in their remit.[77]

---

[76] Commission for Health Improvement/Audit Commission. *NHS Cancer Care in England and Wales*. London: Department of Health, 2001.

[77] Northern and Yorkshire Cancer Registry and Information Service (NYCRIS), unpublished data, 2003.

Salivary gland tumours

A study from the West Midlands Cancer Registry of treatment received by 196 patients with parotid pleomorphic adenomas (benign parotid gland tumours) between 1977 and 1986 found that 62% of patients were treated by general surgeons, 14% by ENT surgeons and 8% by plastic or dental surgeons. Each consultant carried out a median of two operations during this period – an average of one every five years. ENT surgeons were significantly more likely to perform adequate surgery than others, whilst patients treated by general surgeons were more likely to receive radiotherapy (which is usually inappropriate for this type of tumour).[78]

Individual members of the MDT

Research evidence was found on the contributions of some members of the MDT (SLTs, dietitians, CNSs, social workers, and restorative dentists) to outcomes for patients with head and neck cancers. These studies did not, however, deal specifically with their roles in the context of MDT management.

Specialist nursing

No comparative studies of specialist nursing were found. The only study included in the review was a comparison between the cost of staying in a theoretical hospital-based skilled nursing facility and the costs of an acute ward. This suggests that substantial savings might be made by making skilled nursing and specialist input available outside acute wards.

Speech and language therapist

Three studies were found which investigated the opinions of patients who had undergone laryngectomy. All suggested that patients feel that they benefit from opportunities to see SLTs, both before and after surgery.(B) However, these studies were neither well designed nor well reported, and they described the experiences of patients outside the UK some decades ago.

Dietitian

Two studies suggest that early involvement of a dietitian or nutritionist can improve outcomes in patients with head and neck cancers.

In a randomised controlled trial (RCT) investigating the effectiveness of supplementation for malnourished patients undergoing treatment for head and neck cancer, all the patients were assessed by a dietitian. Malnourished patients who received supplements had better outcomes than malnourished patients who did not.(A) However, the study was designed primarily to assess the effectiveness of supplementation, not the role of the dietitian.

---

[78] Parry J, Wilson S, Cummins C, Redman V, Woodman C. A review of parotid pleomorphic adenomas in the West Midlands Region 1977-1986. *Clinical Oncology* 1993;**5**:147-149.

In a study in which patients whose diets were managed by nutritionists were compared with historical controls in whose management nutritionists had not been involved, the group managed by nutritionists (most of whom were given gastrostomy (PEG) tubes) lost significantly less weight and were less likely to require hospital admission for dehydration.(B)

Social worker

A questionnaire study of laryngectomy patients in the US revealed that they were unaware that social workers could provide emotional support and psychological counselling. Most thought social workers could only offer help with filling forms and claiming benefits.(B) It is not clear whether any findings from this study can be generalised to patients in the UK in the 21st Century.

Restorative dentist

The only reports pertinent to this issue were case studies, describing a total of five patients. One concluded that it is important that health workers in all levels of care work together for efficient and effective delivery of care. The other showed that a maxillofacial prosthodontist can alert the MDT to the development of second malignancies.

Patient volumes, specialisation and MDT management

A study of outcomes in 206 patients with oral cancer in the west of Scotland found that those treated by a specialist team (n=124) were less likely to have recurrent disease and survived for significantly longer than patients managed in less specialised Units (82 patients treated in 13 Units by 24 surgeons). The hazard ratio for recurrence, calculated by a multivariate analysis that included disease stage, sex, age and deprivation, in patients treated in smaller Units was 1.43 (95% CI: 1.02 to 2.02); for death, it was 1.48 (95% CI: 1.06 to 2.06). This difference disappeared when treatment strategy was accounted for, which suggests that concentration of services in one hospital has allowed the MDT to develop considerable experience in delivering individually-designed treatments. These treatment strategies seem to be more effective than those designed by clinicians who see fewer patients.(B)

This is the only study identified which links patient outcomes with throughput and specialisation in UAT cancer. There is, however, consistent evidence of volume-quality relationships in cancer treatment generally, particularly when management is more complex. This evidence has been summarised in previous publications in this series, for example *Improving Outcomes in Colorectal Cancer.*[79]

[79] National Institute for Clinical Excellence. *Improving Outcomes in Colorectal Cancers: Manual Update.* London: NICE, 2004. Available on the NICE website <www.nice.org.uk>.

A study of treatment for thyroid cancer in 205 patients from England found consistent and significant differences between the adequacy of management by a multi-disciplinary team of specialists and that provided by other clinicians. The MDT was much less likely to carry out inadequate surgery, more likely to give radioiodine treatment when indicated, and more likely both to monitor thyroglobulin and deal appropriately with high thyroglobulin levels.(B) All these have previously been shown to be independent predictors of long-term survival.[80]

A report from the US, based on data from 5,860 patients, suggests that surgeons who carry out thyroidectomy (for benign or malignant disease) relatively frequently achieve lower complication rates than those who do so rarely. Among patients treated by surgeons who carried out the fewest thyroidectomies (one to nine during the six-year study period), the complication rate was 16%, compared with 4% among those whose surgeons carried out 100 or more such procedures over the same time. The authors conclude that individual surgeon experience is significantly associated with complication rates and length of stay in hospital.(B)

What little research evidence is available on the views of clinicians who treat patients with head and neck cancer suggests that they value multi-disciplinary teamwork, and that MDTs treating patients with challenging tumours can achieve impressive outcomes. Surgeons and oncologists in a focus group study reported that planning treatment with colleagues from different disciplines ensured that all treatment options were considered.(B)

Patients and their relatives support the establishment of specialised Centres to treat head and neck cancers. Focus group studies show that they feel strongly that these cancers should be managed on a dedicated ward or ward area where specialised nursing is available.(B)

D. Measurement

Structure

- Evidence that each Network has an appropriate range of MDTs, constituted as recommended.

- Availability of sufficient numbers of CNSs, dietitians and SLTs to handle the wide-ranging roles described in this manual.

[80] Mazzaferri EL, Kloos RT. Current approaches to primary therapy for papillary and follicular thyroid cancer. *JCEM* 2001;**86**(4):1447-1463.

- Access to specialist training in the needs of patients with head and neck cancer for general dietitians, nurses who may wish to become head and neck cancer CNSs, and less specialised SLTs.

- Appropriate staff and structures in place for recording accurate and complete data on disease stage, management and outcomes.

Process

- Evidence that every patient is discussed by a suitable MDT at the first opportunity after initial diagnosis and assessment, and when recurrent disease is identified.

- Evidence that each MDT works with written protocols for disease management.

- Evidence that operational arrangements are in place to ensure joint management of head and neck sarcomas with the sarcoma MDT.

- Evidence that every patient is offered the opportunity to be interviewed by a CNS before final decisions are made about treatment.

- Evidence that every patient is given a contact telephone number for a CNS or support nurse who can deal with questions about their disease and management.

- Evidence that a CNS is present at every MDT meeting.

- Evidence of participation by individual specialists in MDT meetings.

Outcome

- Survey of patients' views on availability and quality of information.

E. Resource implications

Many more dedicated staff (both medical and non-medical) will be required to create full head and neck cancer MDTs with adequate support staff in every Network. The requirement that these teams meet in sessional time (rather than at lunch time, which is common practice in hospitals where established head and neck cancer MDTs currently exist) will generate additional costs.

The cost estimates for running MDTs are principally based on staff time requirements. The analysis assumes that one head and neck cancer MDT will meet weekly in each Network, discussing UAT and thyroid cancers for three hours and one hour, respectively. Based on these assumptions, the estimated annual cost of running each MDT would be just over £85,000, an increase of £76,000 over current costs. Extrapolating these figures to the whole of England and Wales gives an additional cost of £2.7 million. These costs exclude staff travel and videoconferencing. Costs may be slightly higher if the thyroid and UAT cancer MDTs meet separately, since some members will attend both meetings.

The frequency of meetings and the number of MDTs have significant impacts on costs. If meetings are held fortnightly rather than weekly, the estimated additional cost falls to £1.2 million. If the number of MDTs is assumed to be 52 rather than 37 (one per million population, rather than one per Network), meeting weekly, the cost rises to £4.3 million.

There will be significant staffing issues. Few Trusts have adequate numbers of head and neck cancer CNSs to fulfil the role described in the guidance; few MDTs currently include specialist dentists; and there are shortages in most parts of England and Wales of other crucial members, such as radiologists, pathologists, oncologists, dietitians, SLTs, and palliative care specialists. This has obvious implications for training provision. Furthermore, only about one-third of MDTs have administrative support. It is estimated that providing such support for every MDT will require an additional £0.5 million.

The anticipated costs of employing sufficient numbers of additional CNSs, SLTs, dietitians and other staff, to meet the recommendations of the guidance as a whole, are summarised in section E *Resource implications* of Topic 6, *After-care and rehabilitation.*

Initial investigation and diagnosis

A. Recommendations

Clinicians from all relevant multi-disciplinary teams (MDTs) within each Network should work together to develop locally-agreed protocols which specify appropriate investigations for each type of presentation of possible head and neck cancer; these should include specific guidelines for investigation and diagnosis of each form of head or neck cancer, including thyroid cancer. The desired model of diagnostic services is described below, and commissioners should work towards this. However, it is recognised that it will take some time before adequate numbers of appropriately trained staff are available to implement these recommendations fully. Interim arrangements should, as far as possible, be consistent with this model.

Networks should ensure that expertise in the necessary diagnostic skills – including fine needle aspiration cytology (FNAC) and cytopathology – is available, and that there are effective fast-track routes to appropriate expertise. Networks should monitor the quality of cytopathology services and arrange for training to be provided where the necessary skills are not available.

Initial investigations and diagnosis

At each local hospital which offers a diagnostic service for head and neck cancers, patients with symptoms that could be due to cancer should be seen by designated clinicians (see Topic 1, *Referral*). Adequate cover arrangements must be made to ensure rapid access to diagnostic services for high-risk patients when crucial staff members are absent.

A definite diagnosis requires microscopic examination of tissue by a pathologist with appropriate skills; both cytopathology and histopathology are important. Any pathologist who identifies a case of head or neck cancer should report the findings to the referring consultant and ensure that the patient is discussed at the next MDT meeting. The referring consultant should ensure that the patient's GP is informed within 24 hours.

Cancers of the upper aerodigestive tract (UAT)

Most of these are squamous cell carcinomas, tumours which develop from the surface layers of the mouth and airways; they can often be recognised by direct inspection or endoscopy. A head and neck clinician working in a district general hospital (DGH) who makes a presumptive diagnosis of UAT cancer should refer the patient immediately to the relevant MDT (see Topic 2, *Structure of services*), along with the evidence on which the diagnosis was based – for example, a report that a lesion that appears to be a tumour was seen by endoscopy.

An initial biopsy may be taken by a designated clinician at the DGH, but where there is little doubt about the diagnosis, onward referral should not await pathology results. Access to magnetic resonance imaging (MRI) or computed tomography (CT) imaging is necessary before biopsy for some patients. Surgeons and other clinicians who have a particular interest in head and neck cancer may, if they wish, join the MDT for meetings at which patients they referred are discussed. Patients with neck lumps which persist for more than three weeks despite treatment, or with suspected salivary gland tumours, should be referred to specialist lump clinics for investigation. These lump clinics should be broadly similar to one-stop breast diagnosis clinics, but organised collaboratively by haematology, ear, nose and throat (ENT), and services for head and neck cancer.

Designated ENT specialists, head and neck surgeons, oncologists, haematologists, cytologists and radiologists should co-operate to ensure that an appropriate diagnostic work-up is provided for patients with neck lumps. Patients found or suspected to have cancer should be referred without delay to the appropriate MDT. There should be pre-booking systems for appointments at results clinics at which each patient with a diagnosis of cancer would be seen by a senior member of the MDT which deals with that type of cancer, and where support would be available from a clinical nurse specialist (CNS).

Any patient with an isolated neck lump should first be examined by flexible endoscopy. There should be an experienced on-site cytologist who can provide FNAC in the clinic to determine the nature of the lump; however, this may take some time to achieve and interim arrangements may be necessary. Ultrasound guidance is a useful adjunct to either FNAC or needle core biopsy and its use is expected to increase. No patient should undergo surgical excision or core biopsy of an enlarged lymph node without preliminary discussion with a haematologist or oncologist.

A high level of expertise is required to achieve a precise and reliable diagnosis in salivary gland tumours, and all those who carry out this work should regularly update their skills.

Thyroid cancer

Lumps in the thyroid gland are fairly common and most of these patients do not have cancer. Triage is therefore important at DGH level. Each DGH should have at least two designated surgeons or endocrinologists who deal with such patients. Only surgeons who have a special interest and training in thyroid surgery should operate on patients with goitre.

All patients who present with thyroid nodules should have tests of thyroid function. When overt thyroid dysfunction has been excluded, FNAC should be performed. The diagnosis of cancer is made by a pathologist, on the basis of material obtained by FNAC, core or open biopsy. FNAC can also be used to investigate suspicious lymph nodes.

When thyroid cancer is strongly suspected or confirmed, the patient should be referred to an MDT which deals with thyroid cancer (Topic 3, *Structure of services*). Pathologists throughout the Network should ensure that diagnostic biopsy samples that show thyroid cancer are reviewed by a pathologist with a particular interest in thyroid disease who attends MDT meetings.

Informing patients

Patients should be encouraged to bring a carer, relative or friend to the appointment at which they are to be told that they have cancer. The initial diagnosis may be given by a designated clinician at a DGH before onward referral; all such clinicians should have training in breaking bad news.[81]

The diagnosis and its implications should be discussed with the patient by a senior member of a head and neck cancer MDT, in a quiet, private room with no distractions. Each patient should be supported both during and after this consultation by a suitably trained nurse. The CNS should be informed about each new patient when a definitive diagnosis is made and may provide direct emotional support at this time; alternatively, she (or he[82]) may delegate provision of such support to another named nurse. This nurse should give a contact telephone number to the patient and remain available to answer questions and provide advice, information and support for both patients and carers.

---

[81] National Institute for Clinical Excellence. *Improving Supportive and Palliative Care for Adults with Cancer*. London: NICE, 2004.

[82] In the text below, the pronoun "she" may be used for convenience to refer to the CNS or other nurse; it is acknowledged that the nurse may be male.

All members of the head and neck cancer MDT, and particularly senior clinicians who may break the news to patients that they have cancer, should have training in communication skills and should follow the 'Breaking Bad News' guidelines. They need to be aware that patients are likely to remember very clearly the way the news was given, but may not remember details of the information. Patients should be given copies of letters to their GPs about their diagnosis, and MDTs should consider offering patients audiotapes of crucial consultations, so that they can consider the information in their own time.

All patients should be given as much information as they want about their cancer and any proposed interventions. Those who give this information must be sensitive to individual patients' concerns, preconceptions, preferences and reactions; they should be aware both that patients need time to absorb all the relevant information and that they are likely to have additional questions after the consultation. Patients should be encouraged to make lists of their questions prior to appointments, and to take pen and paper so that they can make notes.

With the exception of the small proportion who make it clear that they do not want such details, patients should be given realistic and accurate information, in language they can be expected to understand, about all aspects of treatment options appropriate for that individual. Information should be provided in the form that best fits the patient's needs; it should be available in written, verbal and alternative forms. Videotapes about head and neck cancer treatment, rehabilitation and outcomes – ideally those made by patient groups – should be offered to new patients for whom they would be appropriate.

Information for patients and carers should normally cover the following issues:

- Any pre-treatment interventions that may be required;
- The likely nature, timing and duration of the forms of treatment that are likely to be recommended (as far as this can be judged);
- A realistic assessment of anticipated outcome: in particular, the probability that initial treatment will eradicate the tumour or that more than one form of treatment may be required;
- Short- and long-term adverse effects of different types of intervention;
- Support services, including patient support groups;
- Rehabilitation;

- Other treatment-related issues which may be relevant to the patient and his or her particular form of cancer;
- Members of the MDT responsible for the patient;
- Contact details (including telephone number) for the CNS and/or other named nurse who will take responsibility for providing support and information;
- The hospital(s) where interventions are to be provided. This should include information about car parking, access, visiting arrangements and other practical details relevant to patients and carers.

After patients have been given information, they should be asked if there is anything else they want to know. Patients should be given adequate time to reflect and get answers to their questions before any decisions are made about treatment, and if necessary should be given extra time for appointments so that they can discuss their concerns more fully.

There should be a defined mechanism, facilitated by a CNS or speech and language therapist (SLT), to ensure that patients who are likely to be offered radical treatment are given the option of introduction to others who have been through similar experiences and who are able to offer support to newly-diagnosed patients. Training (for example, 'Cancer Voices' training provided by Macmillan Cancer Relief) should be arranged for these patient visitors.

B. Anticipated benefits

The benefits of giving patients adequate information, breaking bad news sensitively, and providing support at the crucial time of diagnosis, are well documented. These issues are discussed both in previous documents in this series and in *Improving Supportive and Palliative Care for Adults with Cancer* (National Institute for Clinical Excellence, 2004).

Meeting people who are coping well with their situation is particularly helpful for patients who have to come to terms with the prospect of radical treatment.

C. Evidence

Note: the reliability and quality of evidence supporting the recommendations is graded A, B or C, where A is evidence based on one or more randomised controlled trials. The grading taxonomy is explained in Appendix 2. A detailed and fully referenced summary of the evidence is given in the *Review of Research Evidence* that accompanies this manual.

Diagnostic value of FNAC and core biopsy in thyroid cancer

In an Italian study, both FNAC and core biopsy were performed on patients diagnosed with thyroid nodules by ultrasound scanning. 32 of the patients had core biopsies, of which 13 were insufficient for diagnosis. Tissue samples were examined by experienced pathologists. The results suggest that both methods may permit accurate diagnosis, but whilst FNAC produced sufficient material in all cases, core biopsy was frequently inadequate. However, this study had serious methodological flaws.(B)

Other studies on FNAC for initial diagnosis of neck lumps are summarised in the evidence section of Topic 1, *Referral*.

Effectiveness of written information for patients with head and neck cancers

Studies from Canada and the UK suggest that written information can be helpful for patients, and that patients recall more information when they receive it in this form. A Canadian randomised controlled trial (RCT) assessed the effects of educational pamphlets for patients explaining risks associated with surgery to remove the thyroid or parotid gland. The results demonstrated that those patients who received written information recalled significantly more than those to whom potential complications were only explained orally. Other outcomes, such as anxiety, were not measured.(A)

A pilot study of an information booklet about head and neck surgery, carried out in Northern Ireland, concluded that considerable time and effort is required to produce accurate, comprehensible and attractive written information for patients. All respondents found the booklet informative, all were satisfied or very satisfied with the overall content, and 93% of patients and relatives found the pictures helpful. 7% of patients and relatives, and 10% of health professionals, rated the booklet as frightening.(B)

A wide-ranging support strategy developed for patients undergoing laryngectomy in England included a comprehensive information pack with material on topics ranging from the procedure itself to support groups and financial benefits. The information pack was used by a CNS to explain the operation and its consequences to patients and their families. 85% of patients who were given the pack felt that they

had been given as much information and support as they needed on diagnosis, compared with 59% of those who were not. Of the three patients (15%) who had had the information pack yet did not feel they had enough information, one had required emergency surgery which did not allow time for provision of the usual level of support, and another had received more radical surgery than had been anticipated.(B)

A booklet about facial cancer, developed in the UK, was judged more helpful when it focussed on coping strategies which stressed active self-management by the patient, rather than medical issues.(B)

Patients' experience of NHS services

The National Cancer Alliance (NCA) survey of head and neck cancer patients' experience, carried out to inform the guidance,[83] revealed that some consultants were reluctant to provide the information that patients wanted. This tended to heighten anxiety. Respondents generally expressed a need to be kept informed; those who had little support or information described a stressful period before treatment, when they felt isolated and fearful. All felt that written information and ready access to support, for example from specialist nurses and counsellors, was needed at this stage.

The moment when patients are told they have cancer is often recalled vividly. The way the diagnosis is given and the availability of information and support at this point is of the utmost importance to patients. When this crucial turning point was well managed, patients tended to have more confidence in the treatment they were offered. There are examples in the NCA report of insensitive communication of the diagnosis – in one case, by a registrar on a hospital ward – and the distress that resulted for both patients and their partners.

An earlier study of patients' experience of head and neck cancer *(Face to Face*[84]) discusses psychological issues surrounding the diagnosis and confronting the prospect of radical treatment in some detail. The author states emphatically that, "Information and choice were two of the strongest themes to emerge from the patient, carer and professional focus groups" (p.31). Meeting patients' needs for information so that they can participate in decisions about care is a strategy for empowerment for people with cancer and the teams which support them. The information should be designed to meet patients' needs: people with cancer are more concerned to know about the potential effects of treatment on their lives – for example, whether they will be able to eat or speak, the amount of scarring that is likely to result, and how treatment could affect their ability to have children – than technical details.

---

[83] National Cancer Alliance. *Patients' views of head and neck cancer services and developing national guidance.* Oxford: NCA, 2002.

[84] Edwards, D. *Face to Face: Patient, family and professional perspectives of head and neck cancer care.* London: King's Fund, 1997.

Both the NCA report and *Face to Face* note that many patients do not receive information about patient support groups or services. The experience of wishing there was somebody to talk to, somebody who could answer questions, was a common one. Speech and language therapists and specialist nurses are particularly appreciated, both for their willingness to provide clear information and the support they provide.

D. Measurement

Structure

- Written protocols, agreed by all head and neck cancer MDTs in the Network, which specify investigations for each type of presentation of possible head and neck cancer.
- Specific guidelines for investigation and diagnosis of each form of head or neck cancer, including thyroid cancer.
- Availability of rapid-access FNAC services for patients with neck lumps or suspected salivary gland tumours.
- Network-wide systems for monitoring the quality of cytopathology services.
- Availability of appropriate facilities and staff for discussing the diagnosis with each new patient.
- Availability of written information for patients about their cancer, proposed interventions, members of the MDT and their roles, and hospital and support services.

Process

- Evidence that biopsy samples from possible cancers are sent to a designated pathologist with expertise in identification of head and neck cancer.
- Audit of accuracy of FNAC.
- Audit of delay between initial investigation and definitive diagnosis.
- Evidence that all clinicians who inform patients of a cancer diagnosis receive training in breaking bad news.

Outcome

- Surveys of patients' views of the way the diagnosis was given.

E. Resource implications

The recommendations on diagnosis are not expected to generate significant additional costs apart from cytology services in neck lump clinics, which are covered in Topic 1, *Referral*.

Pre-treatment assessment and management

A. Recommendations

Initial assessment

Careful assessment of each patient's clinical, nutritional and psychological state is crucial to inform treatment planning. Multi-disciplinary teams (MDTs) should therefore establish multi-disciplinary pre-admission clinics at which all aspects of the case can be considered by appropriate specialists, and members of the MDT can discuss the way forward with individual patients and their carers.

The patient's presenting symptoms should be assessed. Members of the MDT – in particular, the palliative care specialist and the speech and language therapist (SLT) - should become involved in the immediate management of those whose symptoms are difficult to control. Co-morbidity, performance status, psychological state, and alcohol dependence should also be assessed early, using validated techniques. The nutritional status of the patient should be assessed by a dietitian who can initiate immediate action to remedy any deficiencies.

A clinical nurse specialist (CNS) should ensure that all patients and carers receive appropriate support and information, that their non-medical needs are assessed, and that there is effective liaison between hospital staff, primary care teams and other agencies such as social services.

Patients who are dependent on smoking, drinking, or other addictive substances associated with increased risk of head and neck cancer, should be offered interventions and support to help them quit. Every unit which provides diagnostic services for head and neck cancer should follow documented guidelines on alcohol dependency assessment and management. Initial interventions should be offered without delay and patients with addiction problems should also be referred to local smoking cessation services, alcohol dependency or addiction services, as appropriate.

Imaging

All patients with upper aerodigestive tract (UAT) cancers should have chest X-rays. Other forms of imaging are necessary to assess the stage and spread of the tumour, and specialist ultrasound, computed tomography (CT) and magnetic reasonance imaging (MRI) should be available. If imaging shows possible tumour invasion of the skull, the patient should be referred to an MDT which has specific expertise in treating this type of problem. Positron emission tomography (PET) imaging should be used, if available, when it is important to differentiate between benign and malignant lung nodules. It is anticipated that the role of PET will increase over the course of the next decade.

Decision-making about treatment

Suggestions about treatment strategies for individual patients should be made and developed in the context of MDT meetings at which all relevant clinical specialists, including a CNS who knows the patient, should be present. As it is often unclear which treatment approach would optimise both survival time and quality of life, decisions on treatment plans cannot be made by the MDT in isolation; they require informed discussion between patients and the specialists who would be involved in their treatment and rehabilitation.

Appropriate members of the MDT, usually a surgeon, oncologist, CNS, dietitian and SLT, should discuss possible treatment options with the patient. Patients should be offered full information about all potential treatment options and their anticipated effects, so that those who wish to contribute to decision-making are able to do so. Issues about anaesthesia should be discussed with patients for whom surgery would be appropriate. The discussion should be carried out in a sensitive way, in a series of meetings if necessary, so that patients do not feel intimidated or overwhelmed by professionals. (See Topic 3, *Initial investigation and diagnosis.*) The patients should be given adequate time to consider the MDT's proposals and raise any concerns before the final plan is agreed.

Dental assessment

Patients whose treatment will affect the mouth or jaw should be examined by a specialist dentist and any dental problems should be identified and treated before cancer treatment begins. Those who require dental extractions under general anaesthesia should see an oral surgeon. Patients who are to have radiotherapy should be treated without delay, to allow time for healing. A dental hygienist should work with these patients to achieve high standards of oral hygiene, to reduce problems after treatment. Patients' dental prostheses should be assessed, along with the denture-bearing ridges, to check that the prosthesis is both comfortable and effective. Those who are to undergo surgery to the jawbone should be assessed by the restorative dentist who works with the surgeon in the MDT.

Preparation for treatment effects on speech, nutrition and swallowing

Both surgery and radiotherapy can cause difficulties with speech, eating and swallowing. There should be written protocols and guidelines, agreed by all head and neck cancer MDTs in the Network, for the nutritional management of patients who are to undergo these types of treatment. There should be specific guidelines on the use, placement and management of gastrostomy (usually PEG) tubes.

When it has been decided that a patient is to have treatment that will affect eating or swallowing, the surgeon and/or oncologist, dietitian, CNS and SLT should discuss the method of feeding that will be used. The primary care team should be informed well in advance about patients who may be tube-fed for more than a month, so that preparations can be made for the patient to be supported at home.

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. Patients and carers should be given specific advice on food preparation, and diet to maintain adequate nutrition during out-patient treatment and after discharge from hospital.

Patients whose treatment is likely to affect their ability to communicate should meet the SLT before treatment begins. The SLT should explain rehabilitation strategies to the patient and carer, describing how she (or he[85]) will work with the patient to make the most of his or her potential for recovery of speech, voice and swallowing.

Anaesthetic assessment

Patients who are to undergo surgery which will involve the airways should be assessed by a specialist anaesthetist who works regularly with surgeons in the MDT.

B. Anticipated benefits

Appropriate treatment of cancer depends crucially on accurate assessment of both the tumour and the patient's general health. Assessment of patients with head and neck cancers by specialists in this field is likely to be more accurate than that by professionals with less specific expertise, who may miss metastatic disease and therefore under-stage the cancer.

[85] In the text below, the pronoun "she" is used for convenience to refer to the SLT, although it is recognised that the SLT may be male.

A holistic and well-organised approach to assessment is essential to ensure appropriate management for individual patients. Involving specialists from a range of disciplines – including head and neck cancer CNSs, SLTs, dietitians, dentists and others – at an early stage allows all aspects of the patient's condition and situation to be considered in decision-making, and provides opportunities for early interventions to deal with problems that need to be resolved before cancer treatment can begin. It also helps patients and carers to understand more fully what treatment and rehabilitation are likely to involve, and allows them to get to know the MDT members who will play important parts in their subsequent care.

The nutritional status of patients with head and neck cancer is often poor; early nutritional assessment allows this problem to be addressed and promotes provision of appropriate pre-treatment nutritional interventions, so that these patients will be better prepared for treatment and better able to tolerate it.

Psychological problems are also more common in these patients than in the general population, and the effects of treatment on social relationships can magnify pre-existing problems; it is therefore important that these patients' psychological needs are recognised and - as far as possible - met, from the beginning of the process. Alcohol and nicotine dependence are common; recognising and dealing promptly with such addiction can both prevent acute withdrawal problems when patients undergo treatment, and improve longer term outcomes.

Appropriate dental treatment and good oral hygiene, both before treatment begins and throughout the post-treatment period, helps to reduce the risk of infection in the mouth and minimise problems such as necrosis in the jawbone after radiotherapy. This improves the probability that patients will retain their natural teeth.

C. Evidence

Note: the reliability and quality of evidence supporting the recommendations is graded A, B or C, where A is evidence based on one or more randomised controlled trials. The grading taxonomy is explained in Appendix 2. A detailed and fully referenced summary of the evidence is given in the *Review of Research Evidence* that accompanies this manual.

Prevalence of co-morbidity

A study carried out in a large US hospital found that 21% of 341 patients with head and neck cancer had moderate or severe co-morbidity (other illness, such as respiratory or cardiovascular conditions) – a rate significantly exceeded only by patients with lung cancer, and similar to that for patients with colorectal cancer. Death-rates among these patients were markedly higher than among those with less co-morbidity.[86]

Up to 40% of patients with head and neck cancers are found to be clinically depressed, both at the time of diagnosis and for many years after treatment. This is a higher rate of depression than among patients with other common cancers, and it is associated with increased risk of suicide.

No evidence was found on the use of specific instruments for assessment of co-morbidity in patients with head and neck cancer.

Effectiveness of imaging to assess chest involvement

Two studies compared the effectiveness of X-rays with CT for screening patients with head and neck cancers for tumours in the chest. Both found that CT was significantly more sensitive, but the specificity of X-ray imaging was somewhat higher. Although X-ray screening may fail to identify a substantial proportion of patients with chest involvement, the diagnosis is likely to be accurate when X-ray images do reveal tumour in the lungs.(B)

Nutritional assessment

Two small studies describe the effectiveness of assessment of patients by dietitians before radiotherapy. Both found that insertion of a gastrostomy tube before radiotherapy could prevent weight loss in vulnerable patients. One found that dehydration-related hospital admissions were reduced from 18% to zero, even though patients who received gastrostomy feeding were those judged to be at greater risk of poor diet or dehydration. The other was an observational study of 100 in-patients in the UK who were assessed as being at risk; 68% received nasogastric feeding (which is uncomfortable and only suitable for short-term use) and 32% had a gastrostomy. Patients who were fed through nasogastric tubes did not go home until they could eat and drink unaided, but patients on gastrostomy feeding were able to go home or to a nursing home earlier, despite the fact that, as a group, they tended to have more serious long-term problems.(B)

[86] Piccirillo JF. Importance of comorbidity in head and neck cancer. *Laryngoscope* 2000;**110**:593-602.

A small randomised trial found that pre-operative nutritional supplements for malnourished patients undergoing surgery for head and neck cancer was associated with a lower rate of complications and less time spent in hospital. 59% of the 61 patients studied were judged to be malnourished and were given nutritional counselling. The supplemented group (n=19) were also given specific recommendations or a nutritional supplement, and contacted as necessary by the dietitian during the pre-admission period to encourage compliance. Appropriate nutritional support was provided in the post-operative period for all patients. The authors report that 59% of the malnourished, unsupplemented group suffered complications, compared with 32% of both the nutritionally healthy and the supplemented groups.[87](A)

Dental assessment

The evidence review shows that a high proportion of patients have very poorly maintained teeth and many require extensive dental treatment before radiotherapy. One study from the Mersey region of England reports on case notes for 1719 patients treated with radiotherapy for head and neck cancers between 1987 and 1990. 250 new patients had dental assessments before treatment in 1990; 65% had not seen a dentist for over three years and their teeth were in a very poor state. 68% required extractions. 21% had full dentures which were over five years old and generally unsatisfactory.(B)

Reports from Canada and the US also reveal high rates of dental caries in patients who had radiotherapy for head and neck cancers. Of those with teeth at the time of assessment, two-thirds or more required extractions; in one group, only 5% had good teeth. One study found that 84% of patients had oral complications after radical radiotherapy; most had severe xerostomia (dry mouth). Despite the provision of dental treatment before radiotherapy, 7% developed rampant caries and 7% had increased difficulty with dentures.(B)

One study reported on the effectiveness of dental care (careful examination, oral hygiene, atraumatic extractions and use of topical fluoride) before radiotherapy in 528 patients, 65% of whom had UAT cancers. In the majority, dental health was preserved after radiotherapy; 3% of patients, most of whom had failed to comply with the recommended dental programme, developed radiation-related caries.(B)

[87] This study is discussed in the context of Topic 2, *Structure of services*, in the *Review of Research Evidence*.

Decision-making about treatment

Research based on focus groups in south east England revealed that most patients want to be involved in decision-making about their treatment. In general, younger patients wanted more involvement, whereas some older patients felt that it made no difference as doctors would do as they wanted anyway. Some people were given choices in their treatment, but did not have enough information on which to base a choice. Most patients wanted to make a joint decision with the advice of their clinician and have their views taken into account.(B)

Clinicians acknowledged considerable uncertainty about optimum treatment in particular cases, but opinions differed about how much choice patients should be given. Many felt that patients should be involved in choices about rehabilitation and palliative care but the choice of primary treatment should be made by the consultant. Everyone agreed that the patient should have a veto on their treatment but few clinicians presented a range of options with their relative merits, either because of time constraints or for philosophical reasons. "Very often what we do is to make a decision and test with the patient whether that decision is completely unacceptable, which is probably paternalistic. It may be the wrong way round but I suspect that's what we do."[88](B)

Psychological interventions

All the studies included in the review of research evidence on psychological interventions for patients were small and had serious methodological flaws. Nevertheless, the evidence they provide is consistent in suggesting that such interventions can be beneficial.

A small (n=36) controlled study suggests that imagery-hypnosis before surgery for cancer may be capable of improving outcomes, but – possibly because of the sample size – only one of the reported comparisons showed a statistically significant effect. The mean post-operative hospitalisation period in the intervention group was 8.7 days, significantly shorter than in controls, for whom it was 13.9 days.(B)

Another study reported that counselling, hypnosis and relaxation training could benefit both patients and carers. However, the author only reported opinions volunteered by patients; had all patients been asked to give their opinions, the findings might have been different.(B)

A study from Sweden of group cognitive-behavioural therapy which began at the time of diagnosis and continued at increasing intervals for a year, reported that patients who participated in psychological therapy showed greater improvements in most areas of functioning than controls who only completed the questionnaires. The intervention led to improved emotional and social functioning, and better quality of life.(B)

---

[88] Edwards, D. *Face to Face: Patient, family and professional perspectives of head and neck cancer care*. London: King's Fund, 1997, p42.

A focus group study with patients in England found that many felt that counselling did not help; this was usually because the counsellors had not listened to them but rather, tried to find solutions to their problems. In contrast, when people – who were not necessarily trained in counselling – took time to listen, they were able to help them come to terms with what they were going through.(B)

Patient visitor and peer support schemes

Peer support is important for patients, and structured patient visitor schemes make this form of support more readily available. Five studies (one of various forms of head and neck cancer, four of laryngectomy patients) provide consistent evidence that introducing patients who are about to undergo treatment to people who have been through it can benefit both groups. Such visitors bring hope, understanding and encouragement, and can give patients a goal at which to aim. Sometimes contact is maintained for many years. However, patients should be consulted on the timing of the first visit.(B)

A questionnaire study from the UK which evaluated a structured laryngectomy friendship scheme found that it was very effective. The scheme increased the proportion of patients offered the opportunity to meet trained ex-patients who could provide support, and increased the level of satisfaction patients felt with their visitor.(B)

Smoking cessation programmes

A randomised controlled trial (RCT) comparing a smoking cessation programme with "usual care" for patients with newly diagnosed head and neck cancer failed to show any difference in outcomes between the groups. Both approaches were, however, effective. At the beginning of the study, 88% of patients were current smokers; after one year, 70% were continuous abstainers.(A)

Practice in the NHS

Assessment by dietitian and access to SLT

The SWAHNII audit revealed that overall, fewer than half of all patients with newly diagnosed UAT cancers in the South and West in 1999-2000 saw a dietitian (34%, 46% and 37% for cancers of the larynx, oral cavity and other sites, respectively).[89] The locally agreed standard against which this may be judged was that 95% should have such an assessment. There was very marked variability between areas; for example, in the Dorset Cancer Network, no patients with larynx cancer saw a dietitian, in contrast to the "Three Counties", where 92% did. It may not be a coincidence that Dorset dealt with much smaller numbers of these patients than any other Network in the audit.

[89] South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001.

The local standard called for all of those who were to have surgery to the larynx, hypopharynx or posterior third of the tongue to see an SLT. In fact, the regional averages were 80%, 72% and 32%, respectively. Dorset's single case saw an SLT, so Dorset achieved perfect compliance with this standard.

Imaging

Although the agreed standard in the region covered by the SWAHNII audit was that all patients with head and neck cancers should have chest X-rays before treatment, a third did not. Patients who did have chest X-rays had significantly higher survival rates. The authors speculate that this might be because Trusts which routinely used X-rays might have more rigorous pre-treatment assessment protocols and provide more appropriate management.

D. Measurement

Structure

- Availability of all imaging modalities necessary to assess the stage and spread of the tumour, including specialist ultrasound, CT and MRI.
- Availability of specialised dental services for all patients who are likely to receive treatment that could affect the jaw or teeth.
- Network-wide guidelines on nutritional management of patients.
- Network-wide guidelines on the use, placement and management of gastrostomy tubes.
- Availability of time and clinic space in out-patient settings for each member of the MDT to talk with patients and carers.

Process

- Evidence that patients who are dependent on alcohol, nicotine or other drugs receive care plans which address their needs for counselling and/or cognitive-behaviour therapy to help them to overcome their dependency before definitive treatment begins.
- Evidence that every patient with UAT cancer has a chest X-ray or CT scan of the chest.
- Evidence that every patient whose treatment is expected to affect eating, swallowing or breathing is assessed by an SLT member of the MDT before treatment begins.

- 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.

- Evidence that patients whose treatment is likely to involve the jaw are referred to appropriate members of the MDT, such as dental specialists, dietitians and SLTs.

- Evidence that patients' psychological state has been assessed and that any needs identified are addressed.

- Evidence that patients' dental health needs are addressed before radiotherapy.

Outcome

- Audit of dental health of patients before and after definitive treatment.

E. Resource implications

There is a general shortage of specialised staff in most of the disciplines that should be involved in pre-treatment assessment of patients with head and neck cancers. This problem is briefly discussed in the context of Topic 2, *Structure of services*. The anticipated costs of employing sufficient numbers of additional CNSs, SLTs, dietitians and other staff, to meet the recommendations of the guidance as a whole, are summarised in section E *Resource implications* of Topic 6, *After-care and rehabilitation*.

Primary treatment

A. Recommendations

Information for patients

All patients who are to undergo treatment for any form of head and neck cancer should have been given opportunities to discuss information about the potential effects of that treatment with members of the multi-disciplinary team (MDT) beforehand, so that they know what to expect. They should have clear and accessible information in written form, describing the potential risks of treatment as well as its anticipated benefits, in a language they understand. Such information provided should cover the procedure itself, anticipated time-scales, and short- and long-term effects of treatment. Patients should be encouraged to talk through any issues that may concern them after studying this information with their speech and language therapist (SLT), clinical nurse specialist (CNS), dietitian, or other appropriate member of the team. When primary treatment is complete, each patient should be offered a candid assessment of its success and given the opportunity to discuss any further interventions that are being considered.

Videotapes are available on laryngectomy; these should be given to patients who are to have this operation.

Cancers of the upper aerodigestive tract (UAT)

Availability of treatment and support

Either radiotherapy or surgery may be appropriate as primary treatment; some patients will require both. Head and neck cancer teams within each Network should agree guidelines for the treatment of each form of cancer within this group. Treatment given should be audited against these guidelines. MDTs should be able to offer all treatment modalities considered standard practice in the UK to the particular types of patients they treat. Those that are unable to offer forms of treatment that might be appropriate for specific patients should refer these patients to teams which have access to a wider range of facilities.

Surgery

It is anticipated that all surgery for head and neck cancer will be centralised within the next decade. During this period, however, minor surgery to remove early tumours may be carried out by nominated surgical specialists in district general hospitals (DGHs). This is only appropriate if these surgeons are active members of the head and neck cancer MDT and can provide adequate post-operative support, after-care and rehabilitation for their patients. In each case, treatment must be planned by the MDT in a formal MDT meeting at which pathological and imaging data are discussed.

Patients who require radical surgery should be managed by the MDT in a Cancer Centre, and the operation should be carried out by surgeons who are members of the MDT. Care for such patients should, if possible, be provided in a specialised head and neck cancer ward. When surgical case-loads are concentrated in this way, commissioners should take responsibility for ensuring that Centres that receive increased numbers of patients receive sufficient funds to cover the costs of an expanded service.

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.

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.

There should be 24-hour access to emergency surgery to reverse flap failure.

Surgical voice restoration should be available for patients who undergo laryngectomy, normally at the time of primary surgery. This service should be adequately supported, with specialist SLT support on wards, appropriate rehabilitation services and equipment (see Topic 6, *After-care and rehabilitation*). The specialist SLT should train nurses and medical staff to carry out basic troubleshooting for these patients, so that they are able to deal with common problems such as leaking or blocked voice prostheses and breathing and swallowing problems that may occur out of hours. Ongoing rolling training programmes should be planned to allow for staff rotation and changes.

Surgery for suspicious or malignant salivary gland tumours, or those which involve the skull, should be carried out only by surgeons with specific expertise in this work after discussion by an appropriate MDT (see Topic 2, *Structure of services*). When salivary gland cancer is discovered unexpectedly after initial surgery for what was believed to be a benign condition, the patient should be referred immediately to a head and neck cancer MDT which specialises in salivary gland cancers.

There should be specialist dietetic support on wards where patients with head and neck cancer are nursed. The dietitian, ward nurses and specialist support staff should work with catering services to ensure that high quality food is provided in a form that meets the individual's requirements.

Histopathologists should report on surgical specimens using dataset proformas developed by the Royal College of Pathologists, and if possible, photograph specimens for discussion by the MDT. Pathology departments which deal with head and neck cancers should participate in external quality assurance (EQA) schemes.

Radiotherapy

Access to modern radiotherapy facilities, including 3D conformal treatment where appropriate, should be available. 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.

Many patients are treated with radiotherapy alone, but those with more advanced disease may require both radiotherapy and surgery or chemoradiation. The interval between surgery and radiotherapy should be as short as possible, ideally less than six weeks. Radiotherapy departments should make every effort to ensure that each patient receives a complete and unbroken course of the prescribed treatment; gaps in treatment must be avoided if at all possible. If radiotherapy is interrupted, the schedule should be altered to minimise the effects of the interruption, as recommended by the Royal College of Radiologists' guidelines.[90]

Each Network should make arrangements for provision of brachytherapy (radiotherapy delivered directly to the tumour, inside the body) for selected patients. Brachytherapy need not be provided in every Network, but where it is not available, there should be specific agreements for referral between Networks.

---

[90] Board of the Faculty of Clinical Oncology, The Royal College of Radiologists. *Guidelines for the management of an unscheduled interruption or prolongation of a radical course of radiotherapy*. London: Royal College of Radiologists, 2002. Available on <www.rcr.ac.uk>.

Synchronous chemoradiation or altered fractionation regimens should also be available for selected patients. These more intensive forms of treatment are appropriate for patients with advanced disease who are fit enough to cope with their adverse effects.

The importance of mouth care and oral hygiene during and after treatment should be emphasised to patients. Appropriate palliative measures should be taken to minimise problems with the lining of the mouth. Patients who need dental extractions after treatment should be referred to an oral surgeon.

Support for patients undergoing radical therapy

Treatment for head and neck cancers can cause problems with eating, swallowing, breathing, speech and voice. Specific support and appropriate interventions should be provided for all patients, both during and after treatment. Patients should be educated about adverse effects of treatment before it begins, so that they know what problems may be anticipated, when they are likely to occur, how to minimise their impact, and how long they may be expected to last. They should have access to help and advice from all appropriate specialists when required, throughout the period of treatment and rehabilitation.

Hospital staff, particularly ward staff, should be alert to these patients' psychosocial needs and should take appropriate action to meet such needs as far as this is possible. Staff must be aware of the importance to patients of maintaining their dignity despite the disfiguring effects of surgery. Some patients do not wish to be seen by members of the public and should be given privacy, if this is what they prefer, during ward visiting times.

Patients treated with radiotherapy need access to support over a protracted period, both in their homes and in the radiotherapy Centre. 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. Patients should have access to a dietitian and an SLT within the radiotherapy Centre, who should liaise closely with their counterparts in the patient's local support team (see Topic 6, *After-care and rehabilitation*). Patients and their carers should be given a telephone number for a radiotherapy helpline so that they have access to advice at weekends.

Many patients rely on gastrostomy or nasogastric tube feeding, at least in the short term. 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 (see Topic 4, *Pre-treatment assessment and management*). The Cancer Network should ensure that there are adequate facilities for placement of gastrostomy tubes and local services which can replace feeding tubes when necessary.

Patients and their carers should be given guidance on the preparation of suitable food before discharge from hospital.

Other treatment modalities
These are discussed in the context of recurrent disease (see Topic 7, *Follow-up and recurrent disease*).

Treatment for thyroid cancer

The thyroid cancer MDT should discuss pathology, imaging and endocrinology results for every new patient, and decisions about overall management should be made by the MDT to which patients are referred after initial diagnosis. Multi-disciplinary management, which involves endocrinology, oncology, and usually, nuclear medicine, is essential. Clinicians from local hospitals should be invited to join MDT discussions about the patients they refer.

Most patients require total thyroidectomy – removal of the whole thyroid gland. This is normally a fairly straightforward procedure in expert hands, but less expert surgery is more likely to result in complications. If the referring surgeon has an appropriate level of expertise in this procedure, he or she can be invited to work with the surgical specialist in the MDT; or, if the MDT so decides, the patient may undergo surgery in the local Cancer Unit.

Further treatment, such as ablation of residual thyroid tissue using radioactive iodine or external beam radiotherapy (used for locally advanced disease, residual disease after surgery, and some rare forms of thyroid cancer), is likely to require expertise and facilities which are only available in a limited number of hospital sites, mainly Cancer Centres. These include special rooms for patients undergoing radioiodine treatment, to prevent the spread of radioactivity into the wider environment.

All patients who have undergone thyroidectomy or thyroid ablation therapy will need supplements of thyroid hormones for the rest of their lives. Calcium supplementation may also be required. All those who have been treated for thyroid cancer require regular long-term monitoring by members of the thyroid cancer MDT.

Research and service development

Because head and neck cancers are relatively rare, collaborative research is essential to improve the effectiveness of treatment and care management. Head and neck cancer MDTs should be actively involved in relevant studies within the National Cancer Research Network (NCRN) portfolio. 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 Centres should consider developing academic links to facilitate basic research into these forms of cancer.

Cancer Centres should be committed to ongoing service development through the assessment of new diagnostic technology and new methods of treatment and support for patients. Commissioners should ensure that such development is possible through the provision of in-house facilities or links with appropriate organisations.

B. Anticipated benefits

Adequate and appropriate treatment for all patients can be expected to improve both short- and long-term outcomes. Timely involvement of surgeons with microvascular expertise can prevent the failure of complex reconstructions to restore patients' appearance and function after radical surgery.

The involvement of a wide range of specialist staff and adequate support services for patients who undergo radical treatment, can be very important to patients' quality of life. Such staff have the necessary expertise to deal with the many difficulties patients face, with eating, swallowing, breathing, communication and prostheses, and can help other ward and oncology staff to manage some of these problems.

C. Evidence

Note: the reliability and quality of evidence supporting the recommendations is graded A, B or C, where A is evidence based on one or more randomised controlled trials. The grading taxonomy is explained in Appendix 2. A detailed and fully referenced summary of the evidence is given in the *Review of Research Evidence* that accompanies this manual.

UAT cancers

Choice of treatment modality

The optimum form of primary treatment for patients with UAT cancers depend on two crucial issues: whether the tumour is sufficiently localised to permit complete resection, and the general fitness of the patient. Other important issues are the probability of long-term disease control and the anticipated impact of the treatment on the patient's quality of life.

In some cases, either radiotherapy or surgery may be appropriate. Regrettably, there appears to be very little reliable research evidence on which a decision between these forms of treatment can be based. One systematic review was identified, of randomised controlled trials (RCTs) comparing radiotherapy with surgery for early glottic laryngeal cancer (the most common form of cancer in the larynx); but only one poorly-described study met the inclusion criteria for the review.

This study reported disease-free survival rates for 205 patients with early stage (T_1 and T_2) tumours, 76 of whom were allocated to surgery. No information was given on the baseline characteristics of patients in each group, neither was there any explanation for the imbalance in the numbers in the treatment arms, so it is possible that there was bias in the allocation of patients to different forms of treatment. The results showed slightly higher rates of recurrence among patients treated with radiotherapy, but none of the differences between groups was statistically significant except for five-year disease-free survival rates in patients with T_2 tumours (60% and 79% after radiotherapy and surgery, respectively). In this sub-group, the difference only achieved statistical significance (p=0.036) with a one-sided test – which could be regarded as inherently biased. No information was given on other outcomes that are important to patients, such as their ability to speak and swallow.(A)

There are considerably more studies assessing the effectiveness of chemotherapy in combination with other forms of radical treatment. In head and neck cancer, most such studies compare radiotherapy with chemoradiation.

Five systematic reviews were identified which investigated the value of adding chemotherapy to radiotherapy (with or without surgery). Taken together, these show that concomitant chemoradiation can significantly increase survival time and reduce recurrence in the head and neck area, particularly in patients with locally advanced disease. Some studies suggest that platinum-based chemotherapy is particularly effective, although the evidence on specific agents is not entirely consistent. Chemoradiation does, however, produce more severe acute adverse effects than radiotherapy alone, and the long-term adverse effects of radiation are also increased. Indeed, some authors argue that the effects of chemoradiation are basically the same as those of a higher dose of radiotherapy. Because of the severity of the adverse effects, chemoradiation is not generally considered appropriate for less fit patients, those with metastatic disease, or patients with early tumours (which generally respond well to less toxic treatment); such patients are usually excluded from these trials.(A)

There is little evidence to suggest that chemotherapy improves disease control or survival when given before or after other forms of treatment for larynx cancer, rather than concurrently. A small study found reduced pain and improved mental health in patients who had neo-adjuvant chemotherapy, but the evidence base overall is unconvincing.(A)

A review of trials of chemotherapy given in addition to radiotherapy for locally advanced nasopharyngeal cancer found that concurrent chemotherapy offers significant survival benefits over radiotherapy alone (OR for overall survival 0.42, 95% CI: 0.23 to 0.76), but at the cost of increased acute and late radiation morbidity. Neo-adjuvant chemotherapy appears to improve disease-free survival rates (OR 0.77, 95% CI: 0.59 to 0.99), but not overall survival.

Radiotherapy: dose intensity, treatment time and the effects of delay

There is consistent evidence that minimising treatment time can be crucial to the success of radiotherapy for head and neck cancers. Awareness of the importance of overall treatment time has increased over recent decades and conventional radiotherapy schedules used in RCTs have been intensified by 4-5 Gy; this corresponds to an increase of over 10% in the probability of local tumour control.(A) However, even in RCTs, compliance with the prescribed schedule can be relatively poor. For more than a quarter of patients included in major trials, the time taken to complete treatment exceeded that prescribed by more than five days.(B)

Retrospective analysis of data for patients treated with conventional radiotherapy for cancer of the larynx shows that gaps in the treatment schedule or increases in treatment times can reduce the disease-free period. An increase of five days reduces local control rates from 80% to 77% at two years. Among a cohort of patients treated in Glasgow, the disease-free period decreased significantly with increasing gaps ($p=0.0002$). Calculations using data derived from RCTs of different fractionation schedules suggest that an additional 0.8 Gyd^{-1} is required to counteract each day added to the intended treatment time.(B)

Further evidence relating outcomes to the length of time taken to complete radiotherapy treatment was reported in a study which found that patients whose treatment was completed in less than 48 days (median duration 45 days) had a 60% chance of survival at two years, compared with 54% survival among those whose treatment took 49 days or more (median 50 days). After adjustment for risk factors, this translates to a non-significant benefit of 3% for those whose treatment was completed more quickly.(B) A study of split course radiotherapy, used for patients with more advanced tumours, found that prolonged overall treatment time was associated with worse loco-regional control and disease-free survival. Multivariate analysis suggests that each day of interruption of treatment increased the hazard rate by 3.3% for loco-regional failure and 2.9% for disease-free survival, but these figures may not be reliable.(B)

Audit data shows that interruptions in radiotherapy for head and neck cancer are common. In the UK in 2000, treatment for 37% of patients was prolonged for two days or more. The most important cause of interrupted treatment was machine downtime, either planned servicing or to deal with machine breakdown. In 14% of cases, treatment was interrupted because of adverse reactions to radiotherapy.[91]

Delays in initiating radiotherapy can also reduce the effectiveness of the treatment. Although the evidence is not entirely clear, it appears that longer delays entail greater hazard; in every study where significant associations have been found between delayed treatment and poorer disease control and/or reduced long-term survival, the period involved is over 30 days. Similar effects of delay are found in studies of primary radiotherapy and of post-operative radiotherapy.(B)

It has been suggested that radiotherapy given several times a day (hyperfractionated or accelerated radiotherapy), instead of the conventional single dose each weekday, might improve loco-regional control and survival in patients with locally advanced head and neck cancers. The results of one meta-analysis suggest that this might be the case, with quoted hazard ratios for death and loco-regional failure of 0.78 and 0.76, but methodological problems in trials and shortage of statistical detail mean that no definite conclusions can be drawn.

This potential benefit is balanced by more severe acute adverse effects. One study suggested that patients had greater problems with eating and speech a year after accelerated radiotherapy, but gave no details. A Texan study reported significant improvements in some aspects of quality of life after accelerated radiotherapy, but significantly more pain at day 21. In this study, the two-year loco-regional control rate was 54% for accelerated radiotherapy and 46% for conventional treatment (p=0.045), but survival differences did not reach statistical significance.(A)

Prophylaxis for oral mucositis

A wide range of interventions can be used to reduce oral mucositis in patients undergoing radiotherapy. A Cochrane review of randomised trials of prophylactic agents for oral mucositis in patients with a variety of forms of cancer, treated with radiotherapy or chemotherapy, included 52 studies (n=3,594). The most effective intervention appears to be ice chips, with an odds ratio of 0.42 (95% CI: 0.19 to 0.93). Other interventions, including GM-CSF, antibiotic paste or pastilles and hydrolytic enzymes, can also reduce the severity of the problem. Since this review included a variety of types of cancer, the findings may not apply equally to all.(A)

---

[91] Board of the Faculty of Clinical Oncology, The Royal College of Radiologists. *Guidelines for the management of an unscheduled interruption or prolongation of a radical course of radiotherapy, Appendix A*. London: Royal College of Radiologists, 2002. Available on <www.rcr.ac.uk>.

A second review focussed on patients receiving radiotherapy for head and neck cancers. This also found that prophylactic interventions could prevent mucositis; meta-analysis of five studies of antibiotics produced a pooled odds ratio of 0.47 (95% CI: 0.25 to 0.92).(A)

A systematic review of amifostine for prevention of mucositis in patients with head and neck cancers found that it was beneficial for those who underwent chemoradiation, but pooled results for patients receiving a variety of treatments did not show any significant reduction in mucositis overall. Nevertheless, patients treated with amifostine had significantly better quality of life scores in the year after treatment.(A)

Interventions for treatment-related xerostomia (dry mouth)
A variety of types of intervention can relieve the symptoms of treatment-related xerostomia, including pilocarpine and amifostine. Pilocarpine is only effective for patients with adequate pre-treatment salivary function.(A) None of these interventions cause serious adverse effects.(A)

Nutritional support and dietary supervision
A prospective study involving 69 patients undergoing combined-modality treatment (surgery plus radiotherapy) for oral cancers demonstrated that increasing supervision by a dedicated head and neck team dietitian and changing the protocol for referral to the dietitian reduced the incidence of severe weight loss during and after treatment. The average weight loss before the protocol change was 9.83%, compared with 6.6% afterwards ($p<0.05$).[92](B)

Relaxation therapy for patients undergoing radiotherapy
A non-randomised study found that anxiety levels were consistently lower among patients who received music therapy, aromatherapy, or guided imagery during radiotherapy than among controls. This was a very small study which showed no clinically significant difference in the effectiveness of these forms of intervention. The authors state that music therapy and aromatherapy can be easily delivered in the clinical environment, but guided imagery is more problematic.[93](B)

[92] Dawson ER, Morley SE, Robertson AG, Soutar DS. Increasing dietary supervision can reduce weight loss in oral cancer patients. *Nutrition and Cancer* 2001;**41**:70-74.

[93] This study is summarised under Topic 4, *Pre-treatment assessment and management* in the *Review of Research Evidence*, under *Availability of psychosocial care*. It is included here because the patients were undergoing radiotherapy at the time of the intervention.

Practice in the NHS

Patients' views on hospital services

Focus group interviews with patients and relatives in south east England revealed concern about hospital accommodation, information about side-effects, choice, support services and the impact of treatment. Patients who were happiest with their accommodation were those who were nursed in side rooms and those who were on cancer wards. Many who had been in wards with patients having different procedures felt that the nursing staff did not know enough about their condition, and that being on a non-cancer ward reduced mutual support. Patients and relatives understood that their cancers were rare and supported the concept of specialist Centres with expertise in head and neck cancer.(B)

The National Cancer Alliance (NCA) report commissioned to inform this guidance manual raised specific concerns about hospital food. All the patients felt that this was a very important aspect of care and for most, it was not well provided. Several reported that their eating difficulties were compounded by poor quality or unsuitable food.[94]

Two recent audits from the South and West of England, SWAHNI and SWAHNII,[95] give figures on the proportion of new patients who receive each major treatment modality, broken down by cancer site and stage. These show that, despite the size of the population base (6.5 million), the number of patients in each sub-group is often quite small.

SWAHNII shows that in 1999/2000, the majority of patients with cancers of the pharynx and larynx received radiotherapy only, but many of those with advanced or metastatic disease had both radiotherapy and surgery. The combination of radiotherapy and chemotherapy was most often used for patients with Stage IV oral or pharyngeal cancer. Surgery alone was the most common form of treatment for patients with early oral cancers.

Within each cancer site/stage sub-group, there was considerable variability in the form of treatment used. The authors comment that "This reflects continuing uncertainty and lack of clear evidence-based guidelines for most tumours," and point out the need for research and audit.[96] Nevertheless, the overall figure of 65.7% survival at two years compares favourably with comparable data from other countries.

---

[94] National Cancer Alliance. *Patients' views of head and neck cancer services and developing national guidance.* Oxford: NCA, 2002.

[95] South West Cancer Intelligence Service, *Head and Neck Audit Report,* 1997 and *Second Head and Neck Audit Report*, 2001.

[96] South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001, p51.

Comparison of the two SWAHN audits shows that waiting times for radiotherapy have worsened, and cite lack of resources as the most probable reason for this. However, CHI/Audit Commission figures suggest that there is great variability between radiotherapy Centres in the number of patients treated in relation to facilities, suggesting that the way these are managed and used may also be important.[97]

A survey of lead head and neck pathologists, surgeons and oncologists in the UK, carried out in 2001, revealed that whilst most were aware of the Royal College of Pathology minimum datasets, only 20% of pathologists produced reports in this form, probably because many laboratory IT systems did not enable them to do this easily. In general, the data items that are easiest to record were reported most consistently. Departments with higher workloads (>1 major resection each fortnight) tended to record a wider range of data items than those with lower workloads.[98]

Thyroid cancer

There is some information from recent audits on treatment given in hospitals in England to patients with thyroid cancer. One of these was based on retrospective analysis of clinic data, laboratory and other records in Birmingham. The authors reported that a substantial proportion of patients did not receive what is judged by professional consensus to be adequate treatment. In almost one-fifth of cases, surgery was inadequate; more than one-fifth had biochemical evidence for inadequate thyroxine treatment; and 11.7% of patients in the cohort for whom radioiodine ablation was indicated did not receive it. Potential adverse effects of surgery – such as vocal cord palsy – were often not recorded.[99](B)

A recent audit by the Northern and Yorkshire Cancer Registry (NYCRIS) also found deficiencies in the service. The data were derived from questionnaires, but since the overall response rate was only 60%, the figures can only be regarded as suggestive. Nevertheless, they give cause for concern. For example, they reveal that for more than half of the patients, there is no documented evidence that information was given on the risks of treatment; and only 19% of MDTs and 29% of consultants working outside MDTs gave written information to patients.[100]

[97] Commission for Health Improvement/Audit Commission. *NHS Cancer Care in England and Wales*. London: Department of Health, 2001.
[98] Helliwell T. Minimum pathology dataset for head and neck cancer. *ENT News and Views* 2003;**12**:54-55.
[99] This study is also discussed in Topic 2, *Structure of services*.
[100] Northern and Yorkshire Cancer Registry and Information Service (NYCRIS). *Management of thyroid cancer in the Northern and Yorkshire Region 1998-1999*. Leeds: NYCRIS, 2004.

D. Measurement

Structure

- Agreed guidelines, consistent throughout the Network, describing appropriate treatment of each form of cancer within this group.

- Evidence that patients are given accessible written information about their treatment, which covers risks and timescales, as well as anticipated benefits.

- Availability of support for patients undergoing treatment, including access to a CNS, a dietitian with expertise in head and neck cancers, and an SLT with specialist experience in all forms of speech and voice rehabilitation and management of swallowing and eating difficulties.

- Facilities for insertion and management of a range of enteral feeding tubes (including nasogastric tubes and gastrostomy), with adequate support for patients based in hospital and the community who require these forms of feeding.

- Availability of all surgical modalities (including laser) to each MDT.

- Availability of appropriate rehabilitation for laryngectomees, including primary surgical voice restoration.

- Availability of adequate facilities within each Network for modern radiotherapy, including 3D conformal treatment. This should include modern linear accelerators, mould room facilities and treatment planning systems, together with adequate personnel such as radiographers and physicists.

- Arrangements for provision of brachytherapy for selected patients.

- Facilities for provision of chemoradiation or altered fractionation radiotherapy.

- Availability of suitably protected rooms for radioiodine treatment.

- 24-hour availability of facilities and staff with appropriate expertise to provide emergency treatment of flap failure.

- Availability of specialised wards for patients undergoing surgery.

- Availability of advice and support at all times (including weekends and outside normal working hours) for patients with breathing or swallowing problems caused by treatment or who have problems associated with surgical voice restoration.

- 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.

- Contract specification for external catering providers, such that the dietary needs of patients with head and neck cancers are met.

- Agreed guidelines, accepted throughout the Network, designed to encourage recruitment to clinical trials.

- Evidence of links to Cancer Research Network to facilitate research and development.

Process

- Audit of congruence between treatment given and Network guidelines.

- Evidence that patients have been given written information describing the procedures they undergo, and that this information covers risks as well as anticipated benefits.

- Audit of adequacy of surgery.

- Audit of free flap failure rate.

- Audit of delays or gaps in prescribed courses of radiotherapy, and their causes.

- Audit of delays between surgery and post-operative radiotherapy.

- Use of measures to prevent and treat mucositis.

- Evidence that appropriate care and rehabilitation is provided for patients who undergo temporary or permanent tracheostomy.

- Evidence that surgical voice restoration, and access to appropriate equipment and rehabilitation, is provided for all patients who would be expected to benefit from it.

- Audit against national guidelines of catering service provision for texture modified diets.

Outcome

- Five-year survival rates for all patients, with information on cancer grade and stage, co-morbidity, age and other features of case-mix, and primary treatment.
- Audit of failure rates in the neck, osteonecrosis, and surgical mortality.
- Audit of late complications of radiotherapy.
- Audit of functional outcomes of surgery.
- Proportion of patients undergoing laryngectomy who receive surgical voice restoration.
- Audit of vocal cord palsy, long-term hypoparathyroidism, and other complications of thyroid surgery.
- Patients' satisfaction with practical, psychosocial and dietetic support during treatment and the recovery period.
- Patients' satisfaction with food provided in hospital.
- Audit of feeding-related complications during treatment period.
- Proportion of patients recruited to clinical trials.

E. Resource implications

Additional resources will be required for Cancer Centres, which will treat larger numbers of patients with head and neck cancer. The costs involved depend on what proportion of operations are carried out in the Centre: that is, whether all surgery is centralised, or only radical surgery (including neck dissection).

The economic analysis is based on detailed figures from two Networks, Four Counties (Oxford) and North Trent. The actual costs for each Network will vary widely, because of the variation in centralisation that currently exists. It is estimated that the cost for England and Wales as a whole would be £5.1 million if only radical procedures were undertaken in Cancer Centres, and £7.4 million if all head and neck cancer surgery were centralised. Other issues to be considered are the staffing implications of complete centralisation, and the distances that patients and professionals would have to travel in thinly-populated areas.

The recommendations on treatment suggest that about 525 patients who currently receive radiotherapy alone should be offered chemoradiation. Assuming that around half of this group would be treated as in-patients and the other half as out-patients, the total additional cost is estimated to be about £850,000 for England and Wales as a whole.

The cost of purchasing new radiotherapy equipment has not been assessed in the economic analysis, since this is covered by other initiatives, in particular the *NHS Cancer Plan*.

After-care and rehabilitation

Patients treated for head and neck cancer: a group with special needs

Patients who have been treated for cancers of the upper aerodigestive tract (UAT) (other than thyroid cancer) can be left with major dysfunction. Most have problems with eating and drinking and a substantial proportion have to cope with tube feeding. Although such problems may resolve after recovery from treatment, they may continue throughout the patient's remaining lifetime. These patients often live alone and need a high level of supportive care.

Patients who undergo laryngectomy, or other surgery which results in diversion of the trachea (the airway in the throat) through an opening in the neck (end tracheostomy), have both to cope with the stoma and learn a new way of speaking; these patients require ongoing specialist help, which may be needed for a year or more. Some patients use a valve inserted between the trachea and the oesophagus (surgical voice restoration); others learn oesophageal speech; some need special equipment such as an electronic larynx.

Other forms of treatment, such as surgery to the tongue and mouth, can also cause long-term problems with both speech and eating, and these patients need considerable help with communication and nutrition. Not surprisingly, problems with communication and changed facial appearance can lead to psychosocial difficulties.

These patients may also have to cope with a variety of other problems; many are too disabled to return to work. Some patients have neck and shoulder problems, or problems with hearing and balance. A substantial proportion suffer from fatigue. Dental problems, dry mouth, and damage to the lining of the mouth and tongue are common, especially after radiotherapy. The particular needs of this group of patients are not covered in *Improving Supportive and Palliative Care for Adults with Cancer* (National Institute for Clinical Excellence, 2004).

There is consistent evidence that, at present, the needs of patients who have been treated for head and neck cancer are often not adequately met. A new model for provision of support and rehabilitation services is therefore required.

A. Recommendations

Structure of services

The structure of support and rehabilitation services for patients who have been treated for head and neck cancers should be reviewed at Cancer Network level, to ensure that sufficient numbers of appropriately-trained staff are available wherever they are required. The roles and responsibilities of staff involved in providing support for patients should be clarified, and effective systems established for communication and information-sharing between them.

Every Cancer Unit or Cancer Centre which deals with patients with head and neck cancer should establish a local support team (described below), which will provide services within a defined geographical area. This is a flexible, locally-based team; it is not anticipated that it would have regular formal meetings, although individual members should meet frequently on an informal basis. Local support team members may be shared between Units, or work on an outreach basis. They may also contribute to continuing assessment in an out-patient setting.

Each local support team should have access to the expertise required to manage the after-care and rehabilitation needs of all of its patients, working closely with Cancer Centre staff and primary health care teams to provide seamless care. Skilled care should thus be available locally, throughout the Network. The clinical nurse specialist (CNS) should take responsibility for ensuring that these levels of service work together, for advising health care staff working in the community, and arranging training for such staff when required. (See discussion of the role of the CNS in Topic 2, *Structure of services*.)

The multi-disciplinary team (MDT) at the Cancer Centre should establish criteria to be met before patients are discharged from hospital. These criteria should include a written rehabilitation plan, drawn up by MDT members in collaboration with the patient, his or her carers, and the member of the local support team who will take formal responsibility for co-ordinating the care provided by the team for that patient. This individual should be the member of the local support team whose skills are best fitted to meeting the patient's needs, who will then act as the patient's point of contact with the team.

Patients and their carers should be taught about wound, mouth and dental care, and management of valves and stomas (including gastrostomy sites), and should be given contact numbers for members of the local support team who will help with any problems they may encounter. The local support team should ensure that every patient has access to regular dental care from dentists who are able to deal with the problems that can develop after treatment for head and neck cancer. Routine care may be provided at the primary care level if suitable dentists are available, but arrangements should be made for

patients who require specialist care to be treated by restorative dentists in a district general hospital (DGH) or dental hospital.

Local support team members

- Clinical nurse specialist (CNS).
- Speech and language therapist (SLT).
- Dietitian; where this is not a dietitian with specialised knowledge of 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.
- 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 help to teach local hospital and community nursing teams, thus creating a sustainable and robust seven day service for patients who require help.
- Dental hygienist, who should liaise with the patient's dentist.
- Psycho-oncology, liaison psychiatry, clinical psychology and/or counselling services.
- Local patients who are willing to provide 'buddy' support and help with group rehabilitation sessions.
- Physiotherapist.
- Occupational therapist.
- Social worker.

The local support team should aim to ensure that the long-term needs of patients and carers are met. Patients may be discharged from care at a mutually agreed point, but should be able to re-access the service if they feel they need further help. Some patients may never be discharged from this service.

An SLT who specialises in head and neck cancer should be available to work with every patient whose primary treatment disrupts the ability to speak, eat or swallow. A full range of techniques, products and facilities should be available for swallowing and voice rehabilitation, and electronic larynx equipment should be provided for those who need it. If the specialist SLT in the MDT delegates rehabilitation work to an SLT working in the community, the specialist SLT should remain available to provide expert advice (for example on managing problems with tracheo-oesophageal valves) and to assist the community SLT in meeting the specific needs of these patients.

The role of the dietitian in the local support team will be to work with other members of the team to provide ongoing advice and assistance for patients and carers. Patients who are discharged with feeding tubes in place are particularly likely to require such help, but all those with eating difficulties, or who have suffered severe weight loss, should have access to advice on diet and food preparation.

Social skills training and cognitive-behavioural therapy should be available for patients who have problems with social anxiety after treatment. Patients with communication problems, and those who are left disfigured, are particularly likely to need this type of support. Patient support groups can play important roles in helping newly-discharged patients to cope with social situations.

Many patients - particularly those who have had radical treatment to the neck, who may develop shoulder problems - will require ongoing physiotherapy. These patients are also likely to require the help of occupational therapists.

Oral rehabilitation should be provided by the specialist restorative dentist (see Topic 2, *Structure of services*) for all patients who require it. This dentist should co-ordinate continuing dental care for these patients and take responsibility for long-term liaison with other dentists who may treat them.

B. Anticipated benefits

At present, what support is available tends to be fragmented, and patients in some areas find it difficult to get the help they need. Establishing co-ordinated support teams should ensure that each patient gets specific assistance with his or her particular problems and that work is not duplicated. The involvement of a wide range of professionals should provide patients and carers with support in all areas of daily life which can be affected by head and neck cancer treatment, from wound care to eating, communication, and practical matters such as maintaining cleanliness at home.

A range of benefits can be anticipated if members of maxillofacial and ear, nose and throat (ENT) department nursing teams spend time working alongside head and neck cancer specialist nurses. Patients would never be left without a service, and the skills of local nurses would be enhanced. This would tend to reduce staff turnover by making the nurse's job more interesting, and could facilitate recruitment for CNS posts in the future. Currently, there is a dearth of suitable applicants for these posts.

Expert oral rehabilitation after treatment can be crucial to the patient's mastication, speech, facial appearance and quality of life.

C. Evidence

Note: the reliability and quality of evidence supporting the recommendations is graded A, B or C, where A is evidence based on one or more randomised controlled trials. The grading taxonomy is explained in Appendix 2. A detailed and fully referenced summary of the evidence is given in the *Review of Research Evidence* that accompanies this manual.

Rehabilitation services

None of the 12 studies of rehabilitation services included in the evidence review were carried out in the UK, so they do not reflect service provision in the NHS. However, the research does suggest that speech, language and swallowing therapy is important to the rehabilitation of patients treated for head and neck cancer, and that it appears to be more effective if it is initiated early.(B)

These studies document the prevalence, magnitude and range of disabilities experienced by patients who have been treated for cancers of the head and neck, and the length of time required for rehabilitation. Particular problems were reported with physical appearance, speech, chewing, swallowing, and cranial motor nerve deficits.

A study from Slovenia highlights the importance of individually planned rehabilitation. Patients with problems that make rehabilitation more difficult – such as hearing impairment, previous neurological, pulmonary and gastroenterological disease – can be identified before treatment. These patients require intensive help from a range of professionals.(B)

Swallowing rehabilitation for patients dependent on tube feeding after treatment for head and neck cancer usually takes about three months, according to a Dutch study. About 20% of patients needed help for six months or more, and 11% did not respond to therapy.(B)

A recent US survey of members of a laryngectomy patient association indicated that 27% used oesophageal speech and 21% used tracheo-oesophageal speech; 89% of these patients were satisfied with their means of communication. Satisfaction levels were lower, at 62%, among the 48% who used an electrolarynx. However, the duration of therapy for most patients, at three months or less, was shorter than is usual in the NHS. An older study, also from the US, reported that speech therapy after laryngectomy took an average of five months in patients assessed before surgery, and three months for those reviewed after surgery. 26% of prospectively studied patients used oesophageal speech as the dominant mode of communication, 34% the electrolarynx, and 34% communicated by writing. 45% were considered not to be successfully rehabilitated.(B)

One small study reported on the role of art therapy, which the authors felt could be particularly valuable for patients with communication problems. This was a descriptive study with no objective outcome measures.

Restorative dentistry

A number of small studies of the outcome of dental and facial bone restoration using prostheses retained by osseointegrated implants show that these are effective for many patients. The proportion of implants reported lost over five years varies widely between studies, from 22% to 79% in patients who have been treated with radiotherapy; loss rates are below 20% in patients who have not been irradiated. The probability of success appears to be higher when hyperbaric oxygen is given with radiotherapy and when reconstruction involves the use of grafted bone.(B)

Patient support and education groups

There is evidence – albeit based on surveys and focus groups rather than trials – which suggests that patients derive a variety of benefits from membership of support groups. There are well-established support groups in the UK for patients who have facial disfigurement, for laryngectomees, and for those with dental problems. Details for these can be found on the NHS Direct website (www.nhsdirect.nhs.uk) and should be available from members of local support teams.

Patients who were members of support groups, interviewed for a British study of head and neck cancer care, felt that these provided a lifeline. They described the relief of meeting someone who understood what they had been going through and valued access to a person at the other end of the telephone if they needed to talk. Many patients had not heard about support groups, and said they would have liked to have known about them even if they decided not to attend meetings.(B)

A Norwegian study suggests that active membership of a local branch of the Norwegian Society for Laryngectomees, which all patients scheduled for laryngectomy are invited to join, is associated with better quality of life.(B)

The fear that patients might panic or become depressed by listening to other people's problems in a support group for patients with head and neck cancer, was found to be unjustified. Participation in this group, which was run by psychotherapists and mainly attended by hospital in-patients, was said to be associated with improved independence and self-care; however, no objective data were reported.

Two studies described education groups for patients with head and neck cancers; one met monthly, whilst the other lasted for a week and involved patients whose cancer had been diagnosed a year earlier. Both reported a variety of positive outcomes. The monthly group produced better understanding of the cancer, reduced patients' sense of isolation, and led to better co-operation with giving up smoking and drinking alcohol. The one-week group led to improved functioning and reduced problems with symptoms. (B)

Patient-held records

A study from the Netherlands concluded that a patient-held record (log-book) for patients who had been treated for head and neck cancers contributed to harmonising hospital and home-based care and produced psychological benefits for patients. A large majority of those who returned the questionnaire evaluating the log-book said they had read all of it, and that it clarified things for them, decreasing fear, tension, depression and uncertainty.

94% of patients shared the log-book with professionals involved in their care; SLTs and ENT physicians were particularly likely to write comments in it. Professionals in the control group, treating patients at a different hospital, reported regular breakdowns in communication, particularly in relation to information given to patients by other team members.(B)

Current services in the NHS

The SWAHNII audit revealed that 80%, 72% and 32% of patients who had surgery to the larynx, hypopharynx and posterior third of tongue, respectively, saw an SLT. Overall, just 48 of 75 patients – 64% – saw an SLT, despite an agreed standard throughout the region covered by the audit that all should do so.[101]

D. Measurement

Structure

- Availability of local support teams throughout the Network, constituted as described above.
- Systems for provision of specialised advice and assistance at any time for patients in the community who rely on tube feeding and/or who require oral rehabilitation.
- Streamlined systems to facilitate access to funding for communication aids and equipment for individual patients.

[101] South West Cancer Intelligence Service, *Second Head and Neck Audit Report (SWAHNII)*, 2001, p18.

Process

- Evidence that support is available from a local support team for every patient after radical treatment for UAT cancer.
- Evidence that patients receive the communication aids or equipment they require within one month of radical treatment.
- Evidence of co-ordination of ongoing dental care by a specialist dentist for patients whose treatment affects the mouth or jawbone.

Outcome

- Patients' and carers' experience of local support services.
- Audit of feeding-related problems, including complications of tube feeding.

E. Resource implications

Support services for patients who have been treated for head and neck cancer are generally poor, so the resource implications of establishing integrated local support teams will be substantial. The number of members required by each Network, and the amount of time they are likely to have to commit to these patients, was calculated as part of the analysis of the economic implications of the guidance, and this information is given in Appendix 1.

The figures given here include not only the cost of provision of local support teams, but also the costs for the other aspects of the roles of these professionals described in this manual. These include support for patients from the time of initial assessment, and in some cases from the time of diagnosis. The CNS, SLT and dietitian, in particular, play important roles in the MDT throughout the assessment, decision-making and treatment process, and will remain involved in caring for some patients for a substantial period after treatment. In addition, some of these individuals – particularly the CNS – have important roles in providing education, training and advice for local hospital and community nurses, and in co-ordination of care for patients (see Topic 2, *Structure of services*; also Topic 4, *Pre-treatment assessment and management*, and Topic 5, *Primary treatment*).

The number of professionals required to provide adequate rehabilitation and support services (the local support team) was calculated using published data and consultation with relevant experts, on the basis of the description of their roles given in the manual. It was estimated that a typical Network, with a population of 1.5 million, would require between 4.25 and 6.5 such teams. The number of professionals already available to fill these roles is not, however, precisely known (although it is clear that there is a serious shortfall of suitably trained individuals), so the number of new posts required is uncertain.

The cost of providing sufficient numbers of CNSs, SLTs, dietitians, senior nurses and other staff required for these teams, plus all the other aspects of patient-centred care described in the manual (other than in-patient nursing care), is likely to be of the order of £24.9 million. Within this figure the cost of the local support teams themselves is expected to be between £7.5 million and £14.7 million.

It is likely that the implementation of these recommendations – in particular, provision of better co-ordinated care and improved support for patients – will lead to some long-term cost savings, through reduced duplication of effort and reduced re-admission to hospital for previously-treated patients. However, the scale of such potential savings is not known and therefore could not be taken into account in the economic analysis.

Follow-up and recurrent disease

A. Recommendations

Clinical follow-up

Upper aerodigestive tract (UAT) cancers
Regular clinical follow-up is important for patients who have been treated for head and neck cancer. Multi-disciplinary teams (MDTs) within each Network should develop locally-agreed guidelines for follow-up. Follow-up clinics may be located in local hospitals, but all patients should be seen by professionals who have expertise in head and neck cancer. Follow-up can be shared by the Centre and the periphery; for example, by alternating appointments in specialist and local clinics.

The main aims of follow-up include:

- Identification of recurrent tumour or new primary disease;
- Provision of help for patients suffering from complications and side-effects of treatment (including delayed effects);
- Identification of patients who need additional help with, or treatment for, functional or psychosocial problems.

Regular examination of the neck is particularly important during the first two years after treatment, when 90% of recurrences develop. The majority of recurrences can be picked up by experienced clinicians, and salvage treatment can be curative when recurrence is identified early. The period between routine follow-up appointments can be increased with each year after treatment. Patients can be discharged from routine follow-up after five years, but should retain contact details for the MDT, so that those who require long-term specialist help have continuing access to it, and all patients have a route back to the MDT if new problems develop.

Follow-up clinics should use regular quality of life screening (assessed with validated tools designed for this patient population), to identify other problems that may require intervention, including complications of treatment. The DAHNO dataset, which should be completed for every patient with head and neck cancer (see *Background*, page 27) includes the Eastern Co-operative Oncology Group (ECOG) scale of performance status, to be recorded at one year after treatment.

Any patients who continue to smoke or drink alcohol should be encouraged to take up interventions to help them quit. Those who have given up smoking and drinking should have access to ongoing support to help them avoid relapse.

Follow-up after radiotherapy should include assessment of dental health, the lining of the mouth and salivation, since adverse effects in these areas are common and should be treated. Specialist restorative dentistry and prosthodontic expertise should be available.

Management of patients with recurrent disease

Local recurrence, or development of new primary tumours, is particularly common in patients who have been treated for cancer in the upper aerodigestive tract. These patients are at risk not only of cancer in the head and neck region (recurrences and second primaries), but also of developing cancer in other parts of the body, particularly the lungs or oesophagus.

Most patients with recurrent disease are identified in follow-up clinics, although some present with new symptoms between follow-up appointments. All should be seen by members of an appropriate specialist MDT. Patients who develop problems associated with their disease, or their doctors, families or other carers, should be able to ring the head and neck cancer clinic to ask for an urgent appointment.

All patients who are suspected to have recurrent disease or second primary cancers need full assessment and imaging, but previous treatment can make interpretation of images particularly difficult. Positron emission tomography (PET) scanning should be available if needed to assess suspected recurrent disease, especially in patients who have previously had radiotherapy. It is envisaged that greater use will be made of PET (and PET/computed tomography (CT) and PET/magnetic resonance imaging (MRI)) in staging and assessing recurrent disease, as this modality becomes more available to MDTs.

The clinical nurse specialist (CNS), dietitian and speech and language therapist (SLT) should also meet and assess each patient so that they are able to contribute to decision-making about management.

Each case should be discussed in an MDT meeting at which all diagnostic information is available for scrutiny. The patient's views, overall state of health and other psychosocial issues should be carefully considered when decisions are made about the most appropriate treatment strategy.

Treatment for recurrent disease may involve surgery and/or radiotherapy (sometimes brachytherapy) and palliative care. Chemotherapy or chemoradiation is increasingly used, but reliable evidence of effectiveness is lacking and there is uncertainty about the overall impact on quality of life. Other forms of therapy such as photodynamic therapy and monoclonal antibody treatment should only be offered in the context of multi-centre clinical trials, unless there is reliable evidence of effectiveness. Research is urgently needed, especially to evaluate newer therapeutic agents. Where salvage therapy requires expertise not available to a particular MDT, it may be appropriate to refer the patient to an MDT which has that expertise.

Patients who undergo treatment for recurrent disease are likely to need a high level of support, both during and after treatment, to deal with problems with swallowing, breathing, nutrition and communication. Their anticipated requirements should be assessed as for new patients (see Topic 4, *Pre-treatment assessment and management*), and dealt with as described in Topic 5, *Primary treatment*.

Thyroid cancer

Patients treated for thyroid cancer need life-long surveillance to identify recurrence and maintain appropriate levels of thyroid hormones. They should be seen at least once a year by a member of a thyroid cancer MDT in a follow-up clinic. Thyroid hormones and serum calcium should be monitored regularly. Thyroglobulin should be monitored in patients with differentiated thyroid cancer, and calcitonin in those with medullary cancer.

Up to 30% of patients who have been treated for thyroid cancer may develop recurrence, sometimes many years after initial treatment. Many of these patients can be treated, and often cured, with further surgery and radioiodine. External beam radiotherapy may be used in addition to other forms of treatment. All such patients should be assessed and restaged, and their further management discussed by the thyroid cancer MDT.

B. Anticipated benefits

Patients who have been treated for head and neck cancer remain at high risk of developing both recurrent and second primary cancers in the head and neck region, and cancers in other parts of the body, usually the lungs. These are most likely to occur within five years of initial treatment. Regular specialist follow-up in the first few years after treatment maximises the chances of identifying these at an early stage, when treatment is most likely to be effective.

Recurrent disease is often treatable, though more challenging than treatment for primary disease. Access to appropriate specialist MDTs will ensure that patients receive the expert help they need. Availability of a high level of diagnostic expertise and specialist imaging will enhance the probability that appropriate treatment is provided. The CNS's contribution to decisions about whether radical treatment, palliative chemotherapy or supportive care would be most appropriate for individual patients can be particularly valuable.

C. Evidence

Note: the reliability and quality of evidence supporting the recommendations is graded A, B or C, where A is evidence based on one or more randomised controlled trials. The grading taxonomy is explained in Appendix 2. A detailed and fully referenced summary of the evidence is given in the *Review of Research Evidence* that accompanies this manual.

Clinical follow-up: incidence of recurrent disease and additional primary tumours

UAT cancers

A study from France found that 30-50% of patients had local or regional recurrences within five years of initial treatment for head and neck cancer, and that the risk of developing a second cancer (most often in the head and neck, oesophagus or lung) among these patients is 10 to 30 times that in the general population. Continued smoking and drinking after initial treatment are both associated with significant increases in risk, but patients who do not smoke and drink at the time of initial treatment are at low risk of developing second primaries.[102] Other studies (tabulated in this paper) suggest, however, that the incidence of second primaries reported in this study might be unusually high, and the recurrence rate is generally accepted to be about 3% per year.(C)

Thyroid cancer

In a cohort of 1,528 patients treated for differentiated thyroid cancer in the US, the recurrence rate over 40 years was about 35%. The rate of recurrence declined over time; two-thirds occurred during the first decade after initial therapy. 68% of recurrences were local, whilst 32% were distant metastases, mostly in the lungs. Among adult patients, recurrence rates and the risk of cancer death are highest in those who are over the age of 60 at the time of initial therapy. Recurrences in younger patients were more often curable, particularly when detected at an early stage.[103]

---

[102] Schwartz LH, Ozzahin M, Zhang CN, Tonboul E, *et al.* Synchronous and metachronous head and neck carcinomas. *Cancer* 1994;**74**(7):1933-1938.

[103] Mazzaferri EL, Kloos RT. Current approaches to primary therapy for papillary and follicular thyroid cancer. *JCEM* 2001;**86**(4):1447-1463.

Effectiveness of alternative follow-up strategies

Although many different follow-up strategies are used for patients who have undergone treatment for head and neck cancers, there appears to be no evidence on their effectiveness. Neither was any research evidence identified on the most appropriate location of follow-up clinics or the level of specialisation required.

Diagnosis of recurrent disease

Imaging

A study that compared CT with MRI found that both these forms of imaging detected about half of all cases of tumour recurrence. MRI was more effective for distinguishing recurrence from post-radiation changes, with an accuracy levels of 73-78%, compared with 64% for CT. A second study reported higher levels of accuracy for both methods, but again found MRI to be superior to CT.(B)

Three studies included comparisons between CT and PET for patients with suspected recurrence; one also assessed Colour-Doppler Echography (CDE). All reported that PET was more accurate than CT or CDE. No direct comparisons were found between PET and MRI, but the sensitivity figures reported for PET are higher than those in studies of MRI. One study which compared PET with ultrasound found the former to be considerably more accurate (86% versus 64%).(B)

Research studies on the effectiveness of PET scanning have been reviewed by the Intercollegiate Standing Committee on Nuclear Medicine.[104] This committee concluded that PET scanning can be useful for identifying tumour recurrence in patients previously treated for carcinoma of the oropharynx and larynx, and for assessment of tumour recurrence in medullary carcinoma of the thyroid.(C) There is more reliable evidence for the value of PET scanning for assessment of patients with suspected recurrent thyroid cancer, negative iodine scans and elevated thyroglobulin.(B) Although PET imaging is available in the UK, at the time of writing (2004), facilities are limited and geographically uneven.

[104] The Intercollegiate Standing Committee on Nuclear Medicine. *Positron emission tomography: A strategy for provision in the UK*. London: Royal College of Physicians of London, 2003. Available at <www.rcplondon.ac.uk/pubs/wp_pet.pdf>.

D. Measurement

Structure

- Network-wide guidelines for long-term follow-up of patients treated for each type of head and neck cancer.
- Availability of PET scanning for patients with suspected recurrent disease, when clinical doubt remains after other forms of imaging.

Process

- Evidence that all patients with suspected recurrent disease are seen promptly by members of the appropriate MDT.
- Evidence that patients' quality of life is adequately assessed and that patients receive help with functional or psychosocial problems when required.
- Audit of monitoring of thyroid hormones, serum calcium, and thyroglobulin/calcitonin in patients who have been treated for thyroid cancer, and action taken when blood levels of any of these are not within specified limits.

Outcome

- Proportion of patients continuing to use alcohol or cigarettes.
- Patients' quality of life.
- Survival rates in patients with recurrent disease.

E. Resource implications

The model of follow-up described here does not deviate substantially from that which is provided in most Centres; additional costs, if any, are not expected to be significant.

Palliative interventions and care

The supportive and palliative care guidance, *Improving Supportive and Palliative Care for Adults with Cancer*, published by The National Institute for Clinical Excellence (NICE) in March 2004, provides generic recommendations in the following topic areas:

1. Co-ordination of care.
2. User involvement in planning, delivering and evaluating services.
3. Face-to-face communication.
4. Information.
5. Psychological support services.
6. Social support services.
7. Spiritual support services.
8. General palliative care services, incorporating care of dying patients.
9. Specialist palliative care services.
10. Rehabilitation services.
11. Complementary therapy services.
12. Services for families and carers, incorporating bereavement care.
13. Research in supportive and palliative care: current evidence and recommendations for direction and design of future research.

The recommendations below are intended to complement the generic guidance, highlighting specific issues of particular relevance to patients with head and neck cancers. It is acknowledged that primary health care teams play crucial roles in the provision of palliative care services; however, this manual does not deal with this issue, since the role of primary care is discussed in *Improving Supportive and Palliative Care for Adults with Cancer* (NICE, 2004).

A. Recommendations

Patients' needs for palliative interventions and care should be considered by all members of the multi-disciplinary team (MDT) and discussed at MDT meetings. Patients may suffer from pain from the time of diagnosis, after initial treatment and at later stages of their cancer journey, and pain control specialists should be involved in their management.

Patients should have access to help from a range of professionals, such as speech and language therapists (SLTs), dietitians and head and neck cancer clinical nurse specialists (CNSs), who have specific expertise in managing the range of problems that they may face. These should be members of either head and neck cancer MDTs (see Topic 2, *Structure of services*) or local support teams (Topic 6, *After-care and rehabilitation*). Patients with progressive disease should have ongoing assessment by a specialist SLT and a dietitian, who can provide support and advice on communication, swallowing and nutrition.

Possibly as many as half of all patients who develop head and neck cancers eventually die of the disease and will require palliative interventions. Many experience moderate to severe pain, which should be regularly assessed and treated in accordance with the World Health Organisation (WHO) analgesic ladder. In most cases, the cause of death is tumour in the head and neck. Terminal care for these patients can be very difficult. Choking or bleeding to death is particularly feared (although death is more likely to result from infection), and patients, carers and health care staff who care for them are likely to require considerable practical, psychological and spiritual support.

Although hospices may be able to provide the support patients need, some patients will have problems that mandate their return to hospital. General wards in some local hospitals may be unable to offer adequate care and these patients will need to be transferred to a ward which can provide privacy, palliative care expertise, and airway management. Staff in local hospitals should be able to access to expert advice and guidance from specialists based in the Cancer Centre.

Surgery, radiotherapy and chemotherapy can all be used for palliation, and all three treatment modalities should be available. Other forms of therapy should only be offered in the context of multi-centre clinical trials, unless there is reliable evidence of effectiveness. Decisions about whether to offer major palliative interventions should be made by the full MDT, and the quality of the patient's remaining life should be the first consideration. Some palliative procedures – for example, surgery to control tumour in the neck – may be appropriate for selected patients, but major resections have the potential to cause great morbidity and distress at the end of life and should be avoided.

Few patients require palliative care for metastatic thyroid cancer, since the disease can usually be cured. However, external beam radiotherapy and orthopaedic interventions should be available to treat bone metastases.

Patients should always be given full information about the expected effects of palliative interventions. Care should be taken when such treatment is proposed to ensure that patients and carers understand that palliative treatment does not offer the prospect of cure: that the intention is to achieve improved quality of life, and potential benefits must be carefully balanced against adverse effects.

Management of airway obstruction

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.

Patients with airway obstruction can be cared for in hospices, local hospitals or at home, by local teams supported by the specialist MDT. Some may wish to return to the Cancer Centre with which they are familiar, whilst others prefer to receive palliative care at home. Each patient should be considered as an individual and should, as far as possible, be allowed to choose where to go for terminal care. In making decisions about management of airway obstruction, it is important to differentiate between patients who are believed to have a significant period to live and those who are in the terminal phase of the disease. Most patients do not require surgery (tracheostomy), but do need careful nursing and palliative measures to minimise distress.

Nutritional support

The principles of management for patients whose tumour interferes with swallowing are similar to those for patients with airway obstruction (see above). A dietitian should discuss nutritional support with the patient.

B. Anticipated benefits

Continued involvement by specialist members of the MDT will permit optimum management of symptoms and problems caused by advancing tumour. Ongoing contact with a palliative care specialist, SLT, CNS and/or dietitian, will help patients make informed choices about their care, as well as ensuring that they receive continuing support. This is likely to reduce stress for carers and help to alleviate fear about the manner of impending death.

C. Evidence

Note: the reliability and quality of evidence supporting the recommendations is graded A, B or C, where A is evidence based on one or more randomised controlled trials. The grading taxonomy is explained in Appendix 2. A detailed and fully referenced summary of the evidence is given in the *Review of Research Evidence* that accompanies this manual.

One randomised controlled trial (RCT) was identified which compared radiotherapy alone with chemoradiation, using bleomycin and mitomycin C, for previously untreated patients with inoperable head and neck cancers. 92% of patients included were reported to have Stage IV disease, but those with distant metastases were excluded from the trial. The outcomes, assessed after two months, varied according to the site of the cancer. Among patients with oropharyngeal cancer (two-thirds of the group), 66% were assessed as disease-free after chemoradiation, compared with none of those treated with radiotherapy alone. By contrast, there was no evidence of any benefit of chemotherapy for patients with cancers in other sites. Chemoradiation was associated with a significantly higher rate of severe mucositis than radiotherapy alone.(A)

Regular analgesia, given in accordance with the WHO pain control ladder, can reduce the pain suffered by most terminally ill head and neck cancer patients to acceptable levels. A study of the effectiveness of a pain control service for patients receiving palliative care in Israel found that the pain intensity score (on a scale with a maximum of 10) fell from a mean of 4.7 before analgesic therapy to 1.9 after therapy.(B)

D. Measurement

Structure

- Evidence of systems to ensure that patients with anticipated acute airway obstruction can be admitted directly to a ward where staff have the necessary expertise.

Process

- Evidence that patients are able to choose where to spend their last weeks of life.
- Death rates within three months of palliative surgery.

Outcome

- Bereaved carers' views of appropriateness of services for dying patients.

E. Resource implications

The recommendations on palliative interventions are not expected to have significant resource implications.

Appendix 1

Economic implications of the guidance

A1

Summary

An economic modelling exercise was carried out to estimate the cost implications for England and Wales of implementation of the main recommendations of this guidance.

The major impacts on costs fall in five broad areas. A summary of these costs is given below.

Cost Summary

(All costs in £ million per year)

Lump clinics		**£ 2.2**
Multi-disciplinary teams (MDTs)		
Additional costs of staff time for MDT meetings		**£ 2.7**
Low scenario	£ 2.2	
High scenario	£ 3.9	
Centralisation of surgery		**£ 5.1**
Chemoradiation		**£ 0.9**
Patient–centred care, including local support teams		**£ 24.9**
Clinical nurse specialists	£ 5.5	
Speech and language therapists	£ 8.1	
Dietitians	£ 5.3	
Senior nurses	£ 1.4	
Other Staff	£ 4.6	
Total		**£ 35.8**

Rapid-access lump clinics

The guidance recommends the establishment of rapid-access lump clinics for patients presenting to their GP with a lump in the neck. Although such clinics exist in the majority of hospitals which deal with head and neck cancer patients, the majority do not have on-site cytological support, which is recommended in the guidance. It has been assumed that such clinics will be run on a weekly basis, and require six hours in total (four hours clinic time, plus two hours administration). Coupled with the need for each clinic to have support from a biomedical scientist, the annual cost impact is estimated to be £2.2 million per annum.

Multi-disciplinary teams (MDTs)

MDT working allows patients to benefit from the expertise of a range of specialists for their diagnosis and treatment, and helps ensure that that care is given according to recognised guidelines. Head and neck cancer MDTs are already well established in many Trusts, although thyroid cancer MDTs are generally less well developed.

In order that MDTs can function in accordance with the guidance, additional time for meetings will be required and more staff will need to be involved. Many MDTs currently suffer from lack of administrative and data management support. The cost of additional staff time for MDT meetings (including ensuring that all MDTs have a co-ordinator/data manager) is estimated to be an additional £ 2.7 million per annum.

Centralisation of surgery

Two scenarios have been assessed in carrying out the economic review of the centralisation of head and neck cancer surgery. Firstly, that under the guidance, all "radical" surgery would be carried out in Cancer Centres and secondly that all surgery would be transferred to Centres. Data from two sources were used in the analysis, reflecting the uncertainty in the cost of transferring surgery from Units to Centres. Using NHS Reference Cost data, the expected costs across the whole of England and Wales under the scenario of centralising radical surgery would be around £5.1 million (the whole of this cost would be attributable to the Centres), compared with around £7.4 million under the alternative scenario of centralising all surgery. These costs include the cost of the surgical procedure, in addition to the cost of any in-patient stay required. Cancer Centres are also likely to incur costs through the need for ward space. The cost of new build has not been taken into account. The cost at individual Network level will vary depending on the degree to which centralisation has already taken place, and the population base of the Cancer Network.

Chemoradiation

The guidance is expected to lead to an increase in the proportion of head and neck cancer patients who are treated with chemoradiation. Through discussions with a number of clinical oncologists, it has been assumed that, of the patients being treated with radiotherapy, 30% of these will be treated with chemoradiation in the future, compared with 20% currently. The costs associated with this include the cost of the chemotherapy drugs, plus the costs associated with patient care, which vary depending on whether patients are treated on an in-patient or an out-patient basis. It is estimated that this change would lead to an annual additional cost of £0.85 million across the whole of England and Wales (assuming that 50% of patients are treated on an in-patient basis and 50% on an out-patient basis).

Patient-centred care and local support teams

Clinical nurse specialists (CNSs)

The guidance emphasises the central role that CNSs should take in providing care for patients. At present, many CNSs are over-stretched, leading to an inadequate consultation time with each patient. Some Units providing care and treatment for head and neck cancers do not currently have a full-time CNS. The requirement within the guidance that every patient should be offered the opportunity to be seen by the CNS before a treatment decision is made is not current practice and implementation of this recommendation is expected to increase the workload of CNSs.

An order of magnitude estimate of the additional number of nurses required was made, based on feedback from the recent Cancer Services Collaborative questionnaire and discussions with a number of CNSs regarding future roles and the level of input required. The preliminary estimate for the cost impact of providing additional CNSs is £5.5 million per annum (for an additional 173 whole time equivalent (WTE) posts). This corresponds to an additional 4.7 WTE posts in a typical Network of 1.5 million people.

Speech and language therapists (SLTs)

An SLT who specialises in head and neck cancer should be available to work with every patient whose primary treatment disrupts the ability to speak, eat or swallow. The guidance will increase the workload for SLTs, particularly within Cancer Centres. Additional posts or part-time posts may be required to allow the duties of existing SLTs to be expanded to a greater volume of patients and to allow cover for attendance at clinics and MDT meetings, as well as training, holidays, sickness etc. The cost implications are expected to be around £8.1 million per annum (for an additional 196 WTE posts). This corresponds to an additional 5.3 WTE posts per Network.

Dietitians
Dedicated dietitians play an important role throughout the patient's cancer journey, providing nutritional support, advice on tube feeding and coping with the after-effects of treatment. Discussions with dietitians around the country have confirmed that current levels of input are low and vary considerably between hospitals. Calculations indicate that a typical Cancer Network of 1.5 million may require an additional 4.7 WTE posts. The majority of these would be based at the Centre, with a smaller service at the Units, and for the local support team role. In total this corresponds to an additional 173 WTE dietitian posts in England and Wales, resulting in an estimated total cost impact of around £5.3 million per annum.

Senior nurses
The role of the senior nurse is to act as a support to the CNS, being primarily involved in providing long-term support for patients with head and neck cancer. Calculations indicate that an additional 56 WTE posts may be required, at a cost of £1.4 million per annum.

Local support teams
The provision of additional staff for post-treatment patient support teams is expected to have significant cost implications. Each hospital which deals with patients with head and neck cancer should establish such a team, and given the current low provision of many of the roles required in the team, this will necessitate the recruitment of a large number of staff.

The role of CNSs, SLTs, dietitians and senior nurses within local support teams is included within the total costs given above for these staff. The local support team element of their role is estimated to be £6.5 million out of the total of £20.3 million. The estimated additional annual cost impact of the remaining team members is £4.6 million.

Appendix 2

How this guidance manual was produced

A2

The manuals in this series are intended to guide health organisations (Strategic Health Authorities, Primary Care Trusts, Cancer Networks and Trusts), their managers and lead clinicians in improving the effectiveness and efficiency of services for patients with cancer. The information and recommendations in the manual are based on systematic reviews of the best available evidence on diagnosis, treatment and service delivery. This evidence is assessed by experts and the recommendations are the product of extensive discussion with leading clinical specialists. The production process is described briefly below; more detail is available in earlier guidance manuals in the series.

The production process begins with a two-day residential event where proposals for improving services for patients with cancer of a specific site (or sites) are generated. A large group of relevant health care professionals, people with personal experience of the particular type of cancer being considered, health care commissioners and academics from around the country, meet to put forward structured proposals based on their experience and knowledge of the research literature. All proposals share a common structure and are intended to improve outcomes for patients. These proposals are then sent to referees, including clinicians, academics, representatives of health authorities, the Department of Health, patient organisations, and relevant charities, many of whom make detailed comments and suggestions. They are also reviewed as part of the process of the National Institute for Clinical Excellence (NICE) and form the basis of the scope of the guidance. Systematic reviews of the research literature, designed to evaluate the proposals, are then carried out or commissioned by the Centre for Reviews and Dissemination (CRD) at the University of York.

This process culminates in the production of two large sources of information, one with a practical or operational focus, and the other containing detailed research evidence on effectiveness. The guidance draws on both these sources, with added input from commissioners, patients, and experts in the particular fields. The writing of the guidance manual is overseen by an editorial group chaired by Professor Bob Haward, accountable to the National Cancer Guidance Steering Group. The writing is undertaken by Dr Arabella Melville, in conjunction with CRD.

Complementary research, designed to quantify the potential cost of major changes in services, is carried out by the School of Health and Related Research at the University of Sheffield. This work involves literature searching, interviews with clinicians and managers, and analyses of costs.

The production of this guidance was funded by the National Institute for Clinical Excellence (NICE), and it has been subject to the full NICE consultation process.

Evidence grading

The reliability and quality of evidence which supports the recommendations in the guidance manual is graded throughout the document. The grades are as follows:

A. Evidence derived from randomised controlled trials or systematic reviews of randomised trials.

B. Evidence from non-randomised controlled trials or observational studies.

C. Professional consensus.

The quality of research evidence forms a continuum and there is overlap between these categories. Most of the published research on cancer focuses on clinical evaluations of treatment; little direct research has been carried out on the organisation and delivery of services, issues on which randomised controlled trials (categorised here as the highest quality evidence) may not be feasible. Research designs which might be regarded as of relatively poor quality for evaluating a clinical intervention may therefore be the most reliable available for assessing the organisational issues.

The systematic reviews used to inform the manual are summarised in the document *Improving Outcomes in Head and Neck Cancers: The Research Evidence*. This document includes details of all the studies to which the manual refers. It is available on the CD-ROM provided with this manual, and is also available in printed format as a CRD report (email: crdpub@york.ac.uk, Tel: 01904-433648).

Appendix 3

People and organisations involved in production of the guidance

A3

3.1 National Cancer Guidance Steering Group

3.2 Participants in the proposal generating event

3.3 People/organisations invited to comment on original proposals

3.4 Researchers carrying out literature reviews and complementary work

3.5 Members of focus groups

Guidance synthesis and writing

Ms A Eastwood	Senior Research Fellow, Centre for Reviews and Dissemination, University of York
Professor J Kleijnen	Director, Centre for Reviews and Dissemination, University of York
Dr A Melville	Writer

assisted by members of the National Cancer Guidance Steering Group, together with:

Professor M R Baker	Director/Lead Clinician, Yorkshire Cancer Network, Leeds
Mr G J Cox	Consultant Head and Neck Surgeon, Radcliffe Infirmary, Oxford
Ms T Feber	Macmillan Nurse Specialist, Yorkshire Centre for Clinical Oncology, Leeds
Dr C Gaffney	Consultant Clinical Oncologist, Velindre Hospital, Cardiff
Dr G Harding	GP/Medical Director, St John's Hospice, Doncaster

Dr T Helliwell	Consultant Histopathologist, University of Liverpool
Ms J Machin	Speech and Language Therapist, Surrey
Mr P Madeley	Patient, Cottingham, East Yorkshire
Dr J Olliff	Consultant Radiologist, Queen Elizabeth Hospital, Birmingham
Dr N Slevin	Consultant Clinical Oncologist, Christie Hospital, Manchester
Mr D S Soutar	Consultant Plastic Surgeon, Canniesburn Hospital, Glasgow
Mr E D Vaughan	Consultant Maxillofacial Surgeon, University Hospital Aintree, Liverpool
Mr J C Watkinson	Consultant Otolaryngologist/Head & Neck Surgeon, Queen Elizabeth Hospital, Birmingham
Mr P Williams	Patient, Amersham, Bucks.

People/organisations invited to comment on drafts of the guidance

National Cancer Guidance Steering Group
Focus Groups
Various professional organisations
Department of Health
NICE Stakeholders; the drafts were subject to the full NICE consultation process

NICE Guideline Review Panel

Dr G Archard
Mr M Emberton
Dr J Hyslop (Chair)
Mr S Karp
Dr D Sommerville

Economic reviews

School of Health and Related Research, University of Sheffield

Project support

The Northern and Yorkshire Cancer Registry and Information Service

Appendix 3.1

Membership of the National Cancer Guidance Steering Group

A3

(This Group, originally established to oversee production of the 'Improving Outcomes' programme, also managed its transition to the NICE programme.)

Chairman

Professor R A Haward	Professor of Cancer Studies, University of Leeds

Vice Chairman

Professor M Richards	Sainsbury Professor of Palliative Medicine, St Thomas' Hospital, London and National Cancer Director

Members

Dr J Barrett	Consultant Clinical Oncologist and Clinical Director, Four Counties Cancer Network
Mrs G Batt	Section Head, Cancer Policy Team, Department of Health, Wellington House
Mr A Brennan	Director of Operational Research, School of Health and Related Research, University of Sheffield
Ms A Eastwood	Senior Research Fellow, Centre for Reviews and Dissemination, York
Dr J Hanson	Cancer Services Project Co-ordinator, Welsh Office
Dr G Harding	GP and Medical Director, St John's Hospice, Doncaster
Professor J Kleijnen	Director, Centre for Reviews & Dissemination, University of York
Professor P Littlejohns	Clinical Director, National Institute for Clinical Excellence

Professor R E Mansel	Chairman, Division of Surgery, University of Wales College of Medicine, Cardiff
Dame G Oliver	Director of Service Development, Macmillan Cancer Relief
Mrs V Saunders	Manager, Northern and Yorkshire Cancer Registry and Information Service
Dr J Verne	Consultant in Public Health Medicine/Director, South West Public Health Observatory

Appendix 3.2

Participants in the head and neck cancers proposal generating event

A3

Mr W Archer	Patient, Pontefract
Professor M R Baker	Director/Lead Clinician, Yorkshire Cancer Network
Mr A Batchelor	Consultant Plastic Surgeon, St James's University Hospital, Leeds
Mr M Birchall	Reader in Head and Neck Surgery, Southmead Hospital, Bristol
Dr E Bradbury	Health Psychologist, The Alexandra Hospital, Cheadle
Mr J Brown	Consultant Oral and Maxillofacial Surgeon, University Hospital Aintree, Liverpool
Mr G Buckley	Consultant Head and Neck Surgeon, The General Infirmary at Leeds
Dr S Closs	Consultant in Palliative Medicine, Ty Olwen Palliative Care Service, Morriston Hospital, Swansea
Mr C Collins	Patient, Batley
Mr N E Dudley	Consultant Surgeon, The John Radcliffe Hospital, Oxford
Mr L Durham	Consultant ENT Surgeon, Rotherham General Hospital
Mrs V Durkin	Patient, Dewsbury
Dr D Edwards	Director of Public Health, North Liverpool PCT
Ms C Faulkner	Macmillan Head and Neck Clinical Nurse Specialist, Morriston Hospital, Swansea
Ms T Feber	Macmillan Head and Neck Specialist Nurse, Cookridge Hospital, Leeds
Dr J Glaholm	Consultant Clinical Oncologist, Queen Elizabeth Hospital, Birmingham
Dr J Halpin	Lead Clinician, Mount Vernon Cancer Network
Dr C L Harmer	Consultant Clinical Oncologist, The Royal Marsden Hospital, London

Dr T R Helliwell	Reader and Consultant in Pathology, University of Liverpool
Dr J M Henk	Consultant Clinical Oncologist, The Royal Marsden Hospital, London
Ms M Henriques-Dillon	Head and Neck Specialist Nurse, New Cross Hospital, Wolverhampton
Ms S Hunton	Director, Bradford Cancer Support Centre
Professor N W Johnson	Professor of Oral Medicine and Pathology, Guy's, King's and St Thomas' Dental Institute
Dr R J Johnson	Consultant in Diagnostic Radiology, Christie Hospital, Manchester
Ms G Jones	Macmillan Head and Neck Clinical Nurse Specialist, Royal Berkshire Hospital, Reading
Dr J Kabala	Consultant Radiologist, Bristol Royal Infirmary
Ms A Kelly	Speech and Language Therapist, The Royal National Throat, Nose and Ear Hospital, London
Dr C G Kelly	Consultant Clinical Oncologist, Newcastle General Hospital, Newcastle upon Tyne
Miss J Lees	Cancer Services Manager, Greenwich District Hospital, London
Mr A G Leonard	Consultant Plastic Surgeon, The Ulster Hospital, Belfast
Professor A McGregor	Professor of Reconstructive Surgery, Welsh Regional Burns and Plastic Surgery Unit, Morriston Hospital, Swansea
Mr K MacKenzie	Consultant ENT Surgeon, Glasgow Royal Infirmary
Professor K MacLennan	Professor of Cytopathology and Histopathology, St James's University Hospital, Leeds
Ms H McNair	Superintendent Radiographer, The Royal Marsden Hospital, Surrey
Mr P Madeley	Patient, Cottingham
Mr I Martin	Consultant and Senior Lecturer in Oral and Maxillofacial Surgery, Sunderland Royal Hospital
Dr D Morgan	Consultant Clinical Oncologist, Nottingham City Hospital
Dr R Neal	GP, University of Wales College of Medicine, Wrexham
Dr P Norris	GP, Kingston upon Thames
Ms K Radford	Speech and Language Therapist, Birmingham City Hospital
Dr M Robinson	Consultant Clinical Oncologist, Weston Park Hospital, Sheffield

Mr S Rogers	Consultant Oral and Maxillofacial Surgeon, University Hospital Aintree, Liverpool
Mrs L Rushworth	Patient, Bradford
Dr D Salvage	Consultant Radiologist, Hull Royal Infirmary
Professor C Scully	Dean and Director of Studies and Research, Eastman Dental Institute for Oral Healthcare Sciences, University College London
Ms C Shaw	Chief Dietitian, The Royal Marsden Hospital, London
Dr M J Shaw	Consultant in Restorative Dentistry, Birmingham Dental Hospital and School
Mrs I Theabould	Patient, Bradford
Mr N Towler	Patient, Thirsk
Dr B Walker	GP, Seascale
Dr S Warnakulasuriya	Reader and Honorary Consultant in Oral Medicine, King's Dental Institute, London
Mrs E Waters	Chief Oncology Dietitian, Clatterbridge Centre for Oncology, Merseyside
Mr J C Watkinson	Consultant Otolaryngologist/Head and Neck Surgeon, The Queen Elizabeth Hospital, Birmingham
Ms W White	Macmillan Head and Neck Clinical Nurse Specialist, Queen Alexandra Hospital, Portsmouth
Professor J Wilkinson	Professor of Public Health, North East Public Health Observatory
Professor S Williams	Professor of Dental Public Health, The Oral Health and Ethnicity Unit, The Leeds Dental Institute
Ms H Woods	Speech and Language Therapist, Christie Hospital, Manchester
Mr G Zaki	Consultant Oral and Maxillofacial Surgeon, Queen Alexandra Hospital, Portsmouth
Dr I Zammit-Maempel	Consultant Radiologist, Freeman Hospital, Newcastle upon Tyne

Facilitated by:

Dr J Barrett	Consultant Clinical Oncologist and Clinical Director, Four Counties Cancer Network
Professor R A Haward	Professor of Cancer Studies, University of Leeds

Appendix 3.3

Referees of the head and neck cancers proposals

The guidance was subject to the NICE consultation process (see website www.nice.org.uk for details).

The individuals listed below were also invited by the Developer to act as referees of whom 39% responded.

Ms S Acreman	Dietitian, Velindre Hospital, Cardiff
Dr S Adam	National Cancer Taskforce Member
Ms V Adophy	Macmillan Neuro-oncology Clinical Nurse Specialist, Kings College Hospital, London
Ms I Aggus	Administrator, British Psychological Society
Mr A Ali	Consultant in Restorative Dentistry, Glasgow Dental Hospital and School
Ms C Allam	Quality Development Officer, The Ulster Hospital, Belfast
Mr C J Allan	Consultant in Restorative Dentistry, Dundee Dental Hospital and School
Ms J Anderson	National Cancer Implementation Group Member
Mr R Anderson	Economic Adviser, Department of Health
Dr P Anslow	Consultant Neuroradiologist, Radcliffe Infirmary, Oxford
Ms J Appleton	Speech and Language Therapist, Charing Cross Hospital, London
Mr G Arnold	National Cancer Taskforce Member
Dr D Ash	Consultant Clinical Oncologist, Cookridge Hospital, Leeds
Mr B M W Bailey	Consultant Oral and Maxillofacial Surgeon, Queen Mary's University Hospital, London
Mr J Bannister	Lead Clinician, Barnsley District General Hospital
Ms R Bardell	Macmillan Head and Neck Clinical Nurse Specialist, Queen's Medical Centre, Nottingham
Mr A Bardsley	Consultant Plastic and Reconstructive Surgeon, West Norwich Hospital

Dr J Barrett	Consultant Clinical Oncologist and Clinical Director, Four Counties Cancer Network
Ms S Bayes	Cancer Strategy Co-ordinator, Department of Health
Dr A Benghiat	Lead Clinician, Leicestershire Cancer Services Network, Leicester Royal Infirmary
Professor I C Benington	Professor of Dental Prosthetics, Queen's University, Belfast
Ms H Bevan	National Cancer Implementation Group Member
Dr J Bibby	National Cancer Taskforce Member
Mr K A Bishop	Consultant in Restorative Dentistry, Morriston Hospital, Swansea
Dr D Black	GP, Sherwood, Nottingham
Dr P Blain	National Cancer Implementation Group Member
Ms A Bolton	Macmillan Head and Neck Clinical Nurse Specialist, Freeman Hospital, Newcastle upon Tyne
Mr P Bradley	Consultant Otolaryngologist, University Hospital, Nottingham
Mr T Bradnam	Macmillan Head and Neck Clinical Nurse Specialist, West Norwich Hospital
Dr C Brammer	Consultant Clinical Oncologist, New Cross Hospital, Wolverhampton
Ms J Bray	Chair, HIV and AIDS Oncology Palliative Care Education, College of Occupational Therapists
Mr A Brennan	Director of Operational Research, School of Health and Related Research, University of Sheffield
Dr J E Bridger	Consultant Pathologist, New Cross Hospital, Wolverhampton
Ms S Bright	Quality Assurance Officer, Royal College of Speech and Language Therapists
Mr A M S Brown	Consultant Maxillofacial Surgeon, The Queen Elizabeth Hospital, Birmingham
Mr J Brown	Consultant Oral and Maxillofacial Surgeon, University Hospital Aintree, Liverpool
Mr M J K M Brown	Consultant ENT Surgeon, Royal Gwent Hospital, Newport
Dr C Bunch	Medical Director, The John Radcliffe Hospital, Oxford
Ms L Burgess	Macmillan Head and Neck Clinical Nurse Specialist, The Queen Elizabeth Hospital, Birmingham
Mr S Burgess	Consultant Obstetrician and Gynaecologist, King George Hospital, Essex

Ms A Burke	Senior Policy Officer, Association of Community Health Councils for England and Wales
Dr A Byrne	Consultant in Palliative Medicine, Holme Tower Marie Curie Centre, Penarth
Professor W Caan	Professor of Public Health, Essex Public Health Network
Ms T Caffrey	Macmillan Head and Neck Clinical Nurse Specialist, The Queen Elizabeth Hospital, Birmingham
Dr B M Carrington	Consultant Radiologist, Christie Hospital, Manchester
Ms C Chard	Head of Hospital Business, ASTA Medica Ltd
Professor K K Cheng	Professor of Epidemiology, University of Birmingham
Mr D Cheshire	Consultant in Restorative Dentistry, St Richard's Hospital, Chichester
Ms T Chittenden	Physiotherapist, The Royal Marsden Hospital, London
Ms B Clark	Nursing Teacher of ENT, Queens Medical Centre, Nottingham
Dr N Clarke	Outcomes and Effectiveness Section Head, Department of Health
Mr C Collins	Chairman, Clinical Effectiveness Committee, Royal College of Surgeons of England
Ms J Connelly	Director, Cancer Action Team, St Thomas' Hospital, London
Ms M Constable	Clinical Audit Co-ordinator, Ida Darwin Hospital, Cambridge
Ms J Cooper	Treasurer, HIV and AIDS Oncology Palliative Care Education, College of Occupational Therapists
Dr B Cottier	National Cancer Implementation Group Member
Mr A J Cowles	General Secretary, Royal College of Radiologists
Mr G J Cox	Consultant Head and Neck Surgeon, Radcliffe Infirmary, Oxford
Dr I Cox	GP, Birmingham
Dr A Crellin	Consultant Clinical Oncologist, Cookridge Hospital, Leeds
Ms D Crowther	Chief Executive, Wirral Holistic Care Services
Mr R Cullen	Consultant ENT/Head and Neck Surgeon, New Cross Hospital, Wolverhampton
Mr A Culline	President, National Association of Laryngectomee Clubs

Mr P Darragh	National Cancer Implementation Group Member
Professor L Davies	National Cancer Taskforce Member
Mr S Day	National Cancer Taskforce Member
Mr R F Deans	Consultant in Restorative Dentistry, Glenfield Hospital, Leicester
Mr M Donachie	Consultant in Restorative Dentistry, Aberdeen Royal Infirmary
Mr A Duckworth	Business Development Manager, Britannia Pharmaceuticals Ltd
Mr N E Dudley	Consultant Surgeon, The John Radcliffe Hospital, Oxford
Mrs V Durkin	Patient, Dewsbury
Ms A Eastwood	Senior Research Fellow, Centre for Reviews and Dissemination, York
Dr J E Ellershaw	Medical Director, Liverpool Marie Curie Centre
Dr D Empey	Medical Director, St Bartholomew's Hospital, London
Dr R Errington	Consultant Clinical Oncologist, Clatterbridge Centre for Oncology, Merseyside
Mr B Evans	Consultant Maxillofacial Surgeon, Southampton General Hospital
Ms E Evans	Speech and Language Therapist, Singleton Hospital, Swansea
Mr M J Fardy	Consultant Oral and Maxillofacial Surgeon, University Dental Hospital, Cardiff
Professor J Farndon	Professor of Surgery, Bristol Royal Infirmary
Professor A Faulkner	Professor of Communication in Health Care, Cheshire
Ms C Faulkner	Macmillan Head and Neck Clinical Nurse Specialist, Morriston Hospital, Swansea
Ms T Feber	Macmillan Head and Neck Specialist Nurse, Cookridge Hospital, Leeds
Ms K Fell	National Cancer Taskforce Member
Ms J Fenelon	National Cancer Implementation Group Member
Dr J Ferguson	Clinical Director, South East London Strategic Health Authority
Mr C P Fielder	Consultant Otolaryngologist, Singleton Hospital, Swansea
Mr J Fielding	Cancer Director, The Queen Elizabeth Hospital, Birmingham
Dr R Fitzgerald	Consultant Radiologist, New Cross Hospital, Wolverhampton
Ms A Fletcher	National Cancer Taskforce Member
Mr I T H Foo	Consultant Plastic Surgeon, Bradford Royal Infirmary

Dr K Forbes	Consultant in Palliative Medicine, Bristol Haematology and Oncology Centre
Dr A Ford	GP, Nottingham
Ms E Foulds	Lecturer in Cancer Care, Centre for Cancer and Palliative Care Studies, Surrey
Professor J Franklyn	Professor of Medicine, The Queen Elizabeth Hospital, Birmingham
Mrs J Fraser	Researcher for the National Association of Laryngectomee Clubs
Ms A Frater	National Cancer Implementation Group Member
Dr D Freake	National Cancer Taskforce Member
Professor J Friend	National Cancer Taskforce Member
Dr J Galloway	GP, Kings Lynn
Dr S George	Senior Lecturer in Public Health Medicine, Health Care Research Unit, Southampton
Professor D E Gibbons	Specialty Adviser in Dental Public Health, Royal College of Surgeons of England
Mr G Gilmour	Consultant in Restorative Dentistry, Mayday University Hospital, Croydon
Dr S Golding	Consultant Radiologist, The John Radcliffe Hospital, Oxford
Professor A H Goldstone	Director of Services, The North London Cancer Network
Mr T Goodacre	Consultant Plastic Surgeon, Radcliffe Infirmary, Oxford
Dr K Goodchild	Consultant Clinical Oncologist, Mount Vernon Hospital, Middlesex
Mr D Gordon	Consultant Plastic Surgeon, The Ulster Hospital, Belfast
Dr M E Gore	Consultant Cancer Physician, The Royal Marsden Hospital, London
Mr R Goss	Director, Patient Concern
Mr B Gowland	National Cancer Implementation Group Member
Mr G Greenwood	Chief Executive, Clatterbridge Centre for Oncology, Merseyside
Professor S Griffiths	National Cancer Taskforce Member
Mr D Guerrero	Neuro-oncology Clinical Nurse Specialist, The Royal Marsden Hospital, Surrey
Mr P Guest	Consultant Maxillofacial Surgeon, Bristol Dental Hospital and School
Ms H Gwynn	National Cancer Taskforce Member
Professor R R Hall	Director of Cancer Services, Northern Cancer Network, Newcastle upon Tyne
Dr J Halpin	Lead Clinician, Mount Vernon Cancer Network
Professor C Ham	National Cancer Taskforce Member
Dr R Hamilton	National Cancer Taskforce Member

Mr R Hammond	Professional Adviser, Chartered Society of Physiotherapists
Ms C Hampton	Macmillan Head and Neck Clinical Nurse Specialist, Royal South Hants Hospital, Southampton
Mr K Hancock	Consultant in Plastic Surgery, Whiston Hospital, Merseyside
Ms C Hannah	National Cancer Taskforce Member
Dr J Hanson	Cancer Services Project Co-ordinator, Welsh Office
Dr G Harding	GP and Medical Director, St John's Hospice, Doncaster
Dr C L Harmer	Consultant Clinical Oncologist, The Royal Marsden Hospital, London
Mr I Harris	Consultant in Restorative Dentistry, Charles Clifford Dental Hospital, Sheffield
Dr C Harrison	National Cancer Implementation Group Member
Dr G Harvey	Director, Quality Improvement Programme, Royal College of Nursing
Dr P Harvey	Consultant Clinical Psychologist, The Queen Elizabeth Hospital, Birmingham
Mr J P Hayter	Consultant Oral and Maxillofacial Surgeon, Leicester Royal Infirmary
Dr J Heathcote	GP, Bromley
Dr T R Helliwell	Reader and Consultant in Pathology, University of Liverpool
Dr V Hempsall	Cancer Lead, Dorset and Somerset Strategic Health Authority
Dr J M Henk	Consultant Clinical Oncologist, The Royal Marsden Hospital, London
Ms M Henriques-Dillon	Head and Neck Specialist Nurse, New Cross Hospital, Wolverhampton
Ms J Hewett	Macmillan Head and Neck Cancer Clinical Nurse Specialist, Torbay Hospital, Torquay
Dr F Hicks	Consultant in Palliative Medicine, St James's University Hospital, Leeds
Dr N Hicks	Consultant in Public Health Medicine, East Hampshire PCT
Professor I Higginson	Professor of Palliative Care and Policy, Guy's, King's and St Thomas' School of Medicine, London
Dr R Hillier	Consultant Physician in Palliative Medicine, Countess Mountbatten House, Southampton
Mr C Hilton	Consultant Cardiothoracic Surgeon, The Freeman Hospital, Newcastle upon Tyne
Professor J A Hobkirk	Professor of Prosthetic Dentistry, Eastman Dental Institute for Oral Health Care Sciences, London

Mr P Hodgkinson	Consultant Plastic Surgeon, Royal Victoria Infirmary, Newcastle upon Tyne
Mr P A Hooper	Managing Director, Eisai Ltd
Dr G Houghton	GP, Birmingham
Mr D Howard	Deputy Director, Institute of Otolaryngology, The Royal National Throat, Nose and Ear Hospital, London
Mr A Hudson	Past General Secretary, British Institute of Radiology
Ms V Hughes	Clinical Guidelines and Pathway Co-ordinator, Nottingham City Hospital
Ms N Hunter	Macmillan Head and Neck Clinical Nurse Specialist, South Cleveland Hospital, Middlesbrough
Ms S Hunton	Director, Bradford Cancer Support Centre
Dr D J Husband	Consultant Clinical Oncologist, Clatterbridge Centre for Oncology, Merseyside
Mr I Hutchison	Consultant Oral and Maxillofacial Surgeon, The Royal London Hospital
Dr S Ibbotson	National Cancer Implementation Group Member
Dr I Ilott	Group Head Research and Development, College of Occupational Therapists
Ms M Jackson	Speech and Language Therapist, Canniesburn Hospital, Glasgow
Dr A Jeynes	Medical Director, Wyeth Laboratories
Professor N W Johnson	Professor of Oral Medicine and Pathology, Guy's, King's and St Thomas' Dental Institute, London
Dr R J Johnson	Consultant in Diagnostic Radiology, Christie Hospital, Manchester
Dr I Johnston	Medical Director, University Hospital, Nottingham
Ms A Jones	Macmillan Head and Neck Clinical Nurse Specialist, Cumberland Infirmary, Carlisle
Professor A S Jones	Professor of Otolaryngology/Head and Neck Surgery, University of Liverpool
Ms G Jones	Macmillan Head and Neck Clinical Nurse Specialist, Royal Berkshire Hospital, Reading
Ms E Jordan	Physiotherapist, Christie Hospital, Manchester
Dr E Jorge	Former Director of Public Health, Portsmouth and South East Hampshire Health Authority
Dr J Kearney	Director of Public Health, Dacorum PCT
Mr M Kelleher	Consultant in Restorative Dentistry, Guy's, King's and St Thomas' Dental Institute, London

Ms A Kelly	Speech and Language Therapist, The Royal National Throat, Nose and Ear Hospital, London
Dr C G Kelly	Consultant Clinical Oncologist, Newcastle General Hospital, Newcastle upon Tyne
Dr S Kelly	GP, Chichester, West Sussex
Professor P Kendall-Taylor	Professor of Endocrinology, Royal Victoria Infirmary, Newcastle upon Tyne
Mr C Kerawala	Consultant Oral and Maxillofacial Surgeon, North Hampshire Hospital, Basingstoke
Professor D Kerr	Professor of Clinical Oncology, University of Birmingham
Mr P A King	Consultant in Restorative Dentistry, Bristol Dental Hospital and School
Dr S Kite	Consultant in Palliative Medicine, The General Infirmary at Leeds
Professor J Kleijnen	Director, Centre for Reviews and Dissemination, York
Dr Mr Lakhani	Chairman of Communications and Publishing Network, Royal College of GPs
Dr R Lane	Consultant in Palliative Medicine, Dewsbury and District Hospital
Ms S Lane	Macmillan Palliative Care Nurse Specialist, University Hospital Aintree, Liverpool
Professor J D Langdon	Professor of Oral and Maxillofacial Surgery, Guy's, King's and St Thomas' School of Medicine, London
Mr S Langton	Consultant Oral and Maxillofacial Surgeon, Blackburn Royal Infirmary
Mr K M Lavery	Consultant Oral and Maxillofacial Surgeon, Queen Victoria Hospital, East Grinstead
Dr A W Lee	GP, Scunthorpe
Dr C Lemon	Consultant Clinical Oncologist, Mount Vernon Hospital, Middlesex
Dr S Levy	GP, Stockport
Dr H G Lewis-Jones	Consultant Radiologist, University Hospital Aintree, Liverpool
Professor P Littlejohns	Clinical Director, National Institute for Clinical Excellence
Professor J Lowry	Lead Adviser, Faculty of Dental Surgery, The Royal College of Surgeons of England
Mr A McCombe	Consultant ENT Surgeon/Head and Neck Surgeon, Frimley Park Hospital, Surrey
Ms S McCormack	Speech and Language Therapist, North Manchester General Hospital
Professor D G MacDonald	Professor of Oral Pathology, Glasgow Dental Hospital and School
Professor M McGurk	Professor of Oral and Maxillofacial Surgery, Guy's Hospital, London

Ms F Mackay	Macmillan Head and Neck Clinical Nurse Specialist, Royal United Hospital, Bath
Mrs E A McLaughlin	Consultant in Restorative Dentistry, Birmingham Dental Hospital and School
Mr N R McLean	Consultant Head and Neck/Plastic and Reconstructive Surgeon, Royal Victoria Infirmary, Newcastle upon Tyne
Dr J McNeill	National Cancer Taskforce Member
Dr J Maher	Consultant Clinical Oncologist, Mount Vernon Hospital, Middlesex
Sister K Mais	Head and Neck Specialist Nurse, Christie Hospital, Manchester
Dr U K Mallick	Consultant Clinical Oncologist, Newcastle General Hospital, Newcastle upon Tyne
Dr I Manifold	Medical Director, Weston Park Hospital, Sheffield
Professor R E Mansel	Chairman, Division of Surgery, University of Wales College of Medicine, Cardiff
Mr I Mark	Consultant Urologist, Lincoln County Hospital
Mrs R Miles	Chair, National Cancer Alliance
Professor D H Miller	Honorary Secretary, Association of British Neurologists
Dr M Minton	Consultant in Palliative Medicine, The Churchill Hospital, Oxford
Ms M Monteith	National Cancer Implementation Group Member
Ms C Moore	Policy Officer, CancerBacup
Dr D Morgan	Consultant Clinical Oncologist, Nottingham City Hospital
Ms D Morgan	National Cancer Taskforce Member
Dr D Munday	National Cancer Taskforce Member
Dr S Munday	Director of Public Health, South Warwickshire PCT
Ms K Murphy	Director of Communications, The Patients Association
Mr D Murray	Past President, British Association of Plastic Surgeons
Ms Z Neary	Macmillan Head and Neck Clinical Nurse Specialist, The Queen Elizabeth Hospital, Birmingham
Ms J Nedin	Chief Dietitian, Singleton Hospital, Swansea
Dr G Newman	Consultant Clinical Oncologist, Royal Sussex County Hospital
Mr N Niran	Consultant Plastic and Reconstructive Surgeon, Broomfield Hospital, Essex
Mr T Nisbet	Consultant in Restorative Dentistry, Wrexham Maelor Hospital

Ms T Norman	National Cancer Implementation Group Member
Professor D Nutbeam	National Cancer Taskforce Member
Dame G Oliver	Director of Service Development, Macmillan Cancer Relief
Dr J F C Olliff	Consultant Radiologist, The Queen Elizabeth Hospital, Birmingham
Mr A Orlando	Consultant Plastic Surgeon, Frenchay Hospital, Bristol
Dr V Pace	Consultant in Palliative Medicine, St Christopher's Hospice, London
Mr A Parker	Consultant Otolaryngologist, Royal Hallamshire Hospital, Sheffield
Dr M Parmar	Head, Cancer Division, MRC Trials Unit, Cambridge
Mr M Patel	Consultant Oral and Maxillofacial Surgeon, University Hospital of South Manchester
Dr I C M Paterson	Consultant Clinical Oncologist, Velindre Hospital, Cardiff
Dr S Pearson	Director of Clinical Strategy, Gloucestershire Hospitals NHS Trust
Ms J Penny	National Cancer Implementation Group Member
Mr A G B Perks	Consultant Plastic Surgeon, Nottingham City Hospital
Dr T Phillips	Director, Development Strategy and Planning, Scotia Pharmaceuticals
Dr A Pickup	Head of Medical Affairs, Merck Pharmaceuticals
Ms S Pinder	National Cancer Implementation Group Member
Dr F A Pitt	Consultant in Public Health Medicine, North Sheffield PCT
Mrs E Porterfield	National Cancer Implementation Group Member
Ms E Potter	Macmillan Head and Neck Clinical Nurse Specialist, Southmead Hospital, Bristol
Mr D Pruce	Audit Development Fellow, Royal Pharmaceutical Society of Great Britain
Dr E Pugh	Medical Director, Butterwick Hospice, Stockton-on-Tees
Ms K Radford	Speech and Language Therapist, Birmingham City Hospital
Ms N Rae	Macmillan Head and Neck Clinical Nurse Specialist, Mount Vernon Hospital, Middlesex
Dr S Ramakrishnan	Lead Clinician, Weston Park Hospital, Sheffield
Mr C Randall	Consultant ENT Surgeon, Southampton General Hospital

Ms V Reed	General Secretary, National Association of Laryngectomee Clubs
Mr B I Rees	Consultant General Surgeon, University Hospital of Wales, Cardiff
Professor M Richards	Sainsbury Professor of Palliative Medicine, St Thomas' Hospital, London and National Cancer Director
Ms M Rigge	Director, College of Health
Dr J Rippin	Senior Lecturer in Oral Pathology, University of Birmingham
Ms F Robinson	Speech and Language Therapist, University Hospital, Nottingham
Dr M Robinson	Consultant Clinical Oncologist, Weston Park Hospital, Sheffield
Mr A K Robson	Consultant Otolaryngologist, Cumberland Infirmary, Carlisle
Ms M Roche	National Cancer Implementation Group Member
Ms W Rockett	Macmillan Head and Neck Clinical Nurse Specialist, The Queen Elizabeth Hospital, Birmingham
Mr H Rogers	Director of Elective Services, West Middlesex University Hospital
Ms R Ruban	Lead Cancer Nurse, George Eliot Hospital, Coventry
Ms J Rule	Chief Executive, CancerBACUP
Dr N Rumsey	Reader in Psychology, The Centre for Appearance and Disfigurement Research, University of the West of England, Bristol
Dr D Russell	Medical Director General Practice, Tower Hamlets PCT
Ms J Ryles	Macmillan Head and Neck Clinical Nurse Specialist, Doncaster Royal Infirmary
Dr D R Salvage	Consultant Radiologist, Hull Royal Infirmary
Professor R Sanders	Director of Research, The RAFT Institute of Plastic Surgery, Mount Vernon Hospital, Middlesex
Mr R Sanderson	Consultant Otolaryngologist, St John's Hospital, West Lothian
Professor M I Saunders	Professor of Clinical Oncology, Mount Vernon Hospital, Middlesex
Dr L Savy	Consultant Radiologist, The Royal National Throat, Nose and Ear Hospital, London
Dr E A Scott	Implementation Director, NHS Modernisation Agency
Mr E Seal	Clinical Director, Bexley and Greenwich Community Dental Services

Mr A Searle	Consultant Plastic and Reconstructive Surgeon, The Royal Marsden Hospital, London
Ms C Semple	Macmillan Head and Neck Clinical Nurse Specialist, The Ulster Hospital, Belfast
Dr M J Shaw	Consultant in Restorative Dentistry, Birmingham Dental Hospital and School
Ms T Shaw	Cancer Centre Project Manager, Leicester Cancer Centre
Dr J Sheffield	National Cancer Taskforce Member
Ms V Shepherd	Macmillan Head and Neck Nurse Specialist, Derbyshire Royal Infirmary
Professor M Sheppard	Professor of Medicine, The Queen Elizabeth Hospital, Birmingham
Ms H Shirley-Quirk	National Cancer Taskforce Member
Mr R T J Shortridge	Consultant ENT Surgeon, New Cross Hospital, Wolverhampton
Professor D Silk	Professor of Gastroenterology, Central Middlesex Hospital, London
Dr K Simpson	Consultant Anaesthetist, St James's University Hospital, Leeds
Dr P Simpson	President, Royal College of Anaesthetists
Dr R H W Simpson	Consultant Histopathologist, Area Department of Pathology, Exeter
Dr C Sinnott	Consultant and Senior Lecturer in Palliative Medicine, St Thomas' Hospital, London
Dr N J Slevin	Consultant Clinical Oncologist, Christie Hospital, Manchester
Mr J Smallwood	Consultant Surgeon, Southampton General Hospital
Mr C Smee	Chief Economic Adviser, Department of Health
Mr B J Smith	Consultant in Restorative Dentistry, Guy's, King's and St Thomas' Dental Institute, London
Mr I M Smith	Consultant ENT Surgeon, Royal Cornwall Hospital, Truro
Dr M Smith	Lead Cancer Clinician/Associate Medical Director, Heatherwood and Wexham Park Hospitals
Mr N Smith	Clinical Services Director, Head and Neck, Southampton General Hospital
Mr R Smith	Consultant Plastic Surgeon, Queen Victoria Hospital, East Grinstead
Ms M Smithson	Macmillan Head and Neck Specialist Nurse, Blackburn Royal Infirmary
Dr M Soljak	Consultant in Public Health Medicine, North West London Strategic Health Authority

Dr A Sorman	Senior Government and National Health Policy Manager, Aventis Pharma
Mr D Soutar	Consultant Plastic Surgeon, Canniesburn Hospital, Glasgow
Professor P Speight	Professor of Oral and Maxillofacial Pathology, University of Sheffield
Dr J Spiby	Consultant in Environmental Public Health, Chemical Incident Response Service, London
Ms W Stanton	Radiographer, Christie Hospital, Manchester
Dr N Stuart	Consultant Medical Oncologist, Ysbyty Gwynedd
Dr N Summerton	Clinical Senior Lecturer in Primary Care, University of Hull
Dr N Sykes	Consultant in Palliative Medicine, St Christopher's Hospice, London
Dr R P Symonds	Consultant Clinical Oncologist, Leicester Royal Infirmary
Dr A Tandon	Consultant in Palliative Medicine, Prince Charles Hospital, Mid Glamorgan
Dr G Tanner	GP, Bridgwater, Somerset
Mr H Taylor	National Cancer Taskforce Member
Mr R M Terry	Consultant ENT Surgeon, Princess Royal University Hospital, Orpington
Mr D Thomas	Consultant in Dental Public Health, Cherwell Vale PCT, Oxford
Mrs H Thornton	Chair, Consumers' Advisory Group for Clinical Trials
Dr R Tiner	Medical Director, Association of the British Pharmaceuticals Industry
Dr J Tobias	Consultant Clinical Oncologist, The Middlesex Hospital, London
Dr I Trotman	Consultant in Palliative Medicine, Mount Vernon Hospital, Middlesex
Mr A Turner	National Cancer Implementation Group Member
Dr P Twentyman	Secretary, United Kingdom Co-ordinating Committee on Cancer Research
Mr A G Vaughan	Consultant in Restorative Dentistry, Derriford Hospital, Plymouth
Mr E D Vaughan	Consultant Oral and Maxillofacial Surgeon, University Hospital Aintree, Liverpool
Dr J Verne	Consultant in Public Health Medicine/Director, South West Public Health Observatory
Dr C Waine	Former Director of Health Programmes and Primary Care Development, Sunderland Health Authority
Dr R Walker	Director, Tenovus Cancer Information Centre

Professor A W G Walls	Professor of Restorative Dentistry, The Dental School, Newcastle upon Tyne
Dr J D Walter	Consultant in Restorative Dentistry, Guy's, King's and St Thomas' Dental Institute, London
Ms E Walters	Senior Dietitian for Cancer Care, Royal Southampton Hospital
Mr A Wardle	National Cancer Taskforce Member
Dr V Warren	Consultant in Public Health Medicine, BUPA
Professor J Wass	Professor of Endocrinology, Radcliffe Infirmary, Oxford
Mrs E Waters	Chief Oncology Dietitian, Clatterbridge Centre for Oncology, Merseyside
Mr J C Watkinson	Consultant Otolaryngologist/Head and Neck Surgeon, The Queen Elizabeth Hospital, Birmingham
Mr J D Watson	Consultant Plastic Surgeon, St John's Hospital, West Lothian
Dr P Watson	Medical Director, Essex Strategic Health Authority
Dr B Wee	Consultant and Senior Lecturer in Palliative Medicine, Countess Mountbatten House, Southampton
Professor A Weetman	Professor of Endocrinology, Northern General Hospital, Sheffield
Mr A Welch	Consultant Otolaryngologist/Head and Neck Surgeon, Freeman Hospital, Newcastle upon Tyne
Mr R Welfare	Clinical Director, Eastman Dental Hospital, London
Ms Z Whale	Lecturer, Macmillan Education Institute, Cardiff
Mr N Whear	Consultant Maxillofacial Surgeon, New Cross Hospital, Wolverhampton
Dr C White	CRC Research Fellow in Psychosocial Oncology, Gartnavel General Hospital, Glasgow
Ms I White	National Cancer Taskforce Member
Ms W White	Macmillan Head and Neck Clinical Nurse Specialist, Queen Alexandra Hospital, Portsmouth
Mr R G Wight	Consultant ENT Surgeon, North Riding Infirmary, Middlesbrough
Mr J Williams	Consultant Maxillofacial Surgeon, St Richard's Hospital, Chichester
Mr P Williamson	Consultant Otolaryngologist, St George's Hospital, London
Ms C Wilson	Head and Neck Radiographer, Addenbrooke's Hospital, Cambridge

Professor J Wilson	Professor of Otolaryngology, Freeman Hospital, Newcastle upon Tyne
Dr C Withey	Clinical Casemix Consultant, NHS Information Authority
Dr C Wolfe	Reader in Public Health Medicine, Guy's, King's and St Thomas' School of Medicine
Mr K Woods	Radiographer, Clatterbridge Centre for Oncology, Merseyside
Mr R T M Woodwards	Consultant Oral and Maxillofacial Surgeon, North Manchester General Hospital
Mrs L Wright	National Programme Manager, Cancer Services Collaborative
Ms A Young	Lead Cancer Nurse, The Queen Elizabeth Hospital, Birmingham

Department of Health and Welsh Assembly representatives

Appendix 3.4

Researchers carrying out literature reviews and complementary work

A3

Overall co-ordinators

Ms A Eastwood	Centre for Reviews and Dissemination,
Professor J Kleijnen	University of York

i) Literature reviews

Miss R Collins	Centre for Reviews and Dissemination,
Mr A Flynn	University of York

Ms L Mather, Centre for Reviews and Dissemination undertook the literature searches for the review work.

Additional assistance in the review process was provided by Dr K Soares-Weiser, Visiting Fellow, UK Cochrane Centre, and Dr S Hempel and Dr G Norman, Centre for Reviews and Dissemination.

ii) Patient views of head and neck cancer services

Ms R Miles	National Cancer Alliance, Oxford
Ms C Smith	

iii) Economic review

Mr S Eggington	School of Health and Related Research,
Ms S Ward	University of Sheffield

Appendix 3.5

Focus Groups: Membership

Professor M R Baker	Director/Lead Clinician, Yorkshire Cancer Network
Dr S Balmer	Director of Public Health, Leeds North East PCT
Dr A Benghiat	Lead Clinician, Leicestershire Cancer Services Network, Leicester Royal Infirmary
Dr C Bentley	Director of Public Health & Clinical Engagement, South Yorkshire Health Authority
Ms M Davison	Director, Northern Cancer Network, Freeman Hospital
Dr P Elton	Director of Public Health, Bury PCT
Dr J Halpin	Lead Clinician, Mount Vernon Cancer Network
Ms C Heneghan	Professional Executive Cancer Lead, Central Liverpool PCT
Mr D Heron	North Wales Cancer Network Manager
Mr L Hughes	Chief Executive, East Leeds PCT
Dr J Kearney	Director of Public Health, Dacorum PCT
Mr M Lyles	Cancer Lead, Bradford City PCT
Dr M Marshall	Cancer Lead, Middlesbrough PCT
Dr C Richards	Primary Care Cancer Lead, Brookvale Practice Health Centre

Facilitated by:

Ms S O'Toole	Consultant in Health Policy and Management

Supported by:

Mrs V Saunders	Manager, Northern and Yorkshire Cancer Registry and Information Service

Appendix 4

Glossary of terms

3D conformal radiotherapy
Conformal *radiotherapy* aims to reduce the amount of normal tissue that is irradiated by shaping the X-ray beam more precisely. The beam can be altered by placing metal blocks in its path or by using a device called a multi-leaf collimator. This consists of a number of layers of metal sheets which are attached to the *radiotherapy* machine; each layer can be adjusted to alter the shape and intensity of the beam.

Adenocarcinoma
Adenocarcinomas are cancerous growths of glandular tissue.

Aetiology
The origins or causes of disease.

Altered fractionation regimens
See *hyperfractionated radiotherapy*.

Amifostine
A drug used to protect against acute and late *xerostomia* in head and neck cancer in association with *radiotherapy*.

Anaplastic thyroid cancer
See *thyroid cancer*.

Areca or betel nut
Fruit of the tropical palm Areca catechu. It forms the basis of a number of chewed products and is commonly mixed with slaked lime and a variety of other ingredients and flavourings according to local practices; tobacco may also be added. In *paan* small pieces of areca nut are mixed with lime and wrapped in a betel leaf (leaf of the betel vine); tobacco may also be added.

Atraumatic extraction
Removal of (in this case) teeth with the minimum amount of trauma.

Audit
A method by which those involved in providing services assess the quality of care. Results of a process or intervention are assessed, compared with a pre-existing standard, changed where necessary, then reassessed.

Betel nut
See *Areca nut*.

Biochemical evidence
Evidence produced as a result of chemical reactions in the body.

Biopsy
Removal of a sample of tissue or cells from the body to assist in diagnosis of a disease.

Brachytherapy
Radiotherapy delivered within an organ.

Calcitonin
A hormone that tends to lower the level of calcium in the blood.

Cancer Networks
The organisational model for cancer services to implement the *NHS Cancer Plan*, bringing together health service commissioners and providers, the voluntary sector and local authorities. There are currently 34 Cancer Networks covering between 600,000 and 3 million population, (two-thirds serve a population of between one and two million people).

Cancer Research Network
Part of the National Cancer Research Network and closely linked to the 34 Cancer Service Networks in England.

Cardiovascular
Having to do with the heart and blood vessels.

Cervical lymphadenopathy
Disease or swelling of the *lymph nodes* in the neck.

Chemoradiation
Treatment that combines *chemotherapy* and *radiotherapy*.

Chemotherapy
The use of drugs that kill cancer cells, or prevent or slow their growth.

Chronic lymphocytic thyroiditis
Slowly developing and generally painless enlargement of the *thyroid* which frequently results in lowered *thyroid* function.

Clinical oncologist
A doctor who specialises in the treatment of cancer patients, particularly through the use of *radiotherapy*, but may also use *chemotherapy*.

Cognitive and behavioural interventions
Types of therapy usually based on talking and practising specific types of voluntary activity. This group of interventions can include, for example, relaxation training, counselling, and psychological approaches to pain control.

Colostomy
A procedure to create an opening of the colon onto the front of the abdomen. The opening is called a *stoma.* A bag is worn over the *stoma* to collect the stools.

Community
Non-hospital based services.

Computed tomography (CT)
An X-ray imaging technique.

Cranial neuropathies
Functional disturbances or changes in the nervous system of the cranium (skull).

Cytologist
A person who specialises in the study of the appearance of individual cells under a microscope.

Cytology
The study of the appearance of individual cells under a microscope.

Cytopathologist
A person who specialises in diagnosis through detecting and identifying disease in individual cells.

Cytopathology
A branch of pathology that deals with disease at the cellular level.

Dysphagia
Difficulty with swallowing.

Electrolarynx
A battery operated device which may be used to help *laryngectomees* speak.

Endocrine
Having to do with glandular tissues that secrete hormones directly into the bloodstream.

Endocrinologist
A doctor who specialises in treating diseases of the *endocrine* system.

Endoscope
A tubular device with a light at the end that transmits images to aid diagnosis or therapy. It may also be used to take samples of tissues *(biopsy).*

Endoscopy
Examination of the interior of the body using an *endoscope.*

End tracheostomy
See *tracheostomy.*

Enteral feeding
Feeding by tube. See *nasogastric tube* and *percutaneous gastrostomy feeding.*

Epidemiology
The study of populations in order to determine the frequency and distribution of disease and measure risks.

Epithelial cells
Cells which form a membrane-like tissue that lines internal and external surfaces of the body including organs, vessels and other small cavities.

Fine needle aspiration cytology (FNAC)
A fine needle is inserted into tissue to withdraw cells which are then examined for the presence of cancer cells.

Flap
A tissue graft. A reconstructive technique where areas of fat, muscle or skin are moved from one area of the body to another.

Follicular thyroid cancer
See *thyroid cancer.*

Gastroenterological
Having to do with the digestive system, including the liver.

Gastrostomy
The surgical creation of an opening through the abdominal wall into the stomach in order to insert a tube through which liquid food can be administered. See *percutaneous gastrostomy feeding.*

Glottis
The middle part of the *larynx* where the *vocal cords* are situated.

Goitre
An enlargement of the *thyroid* gland that is commonly visible as a swelling at the front of the neck.

Grade
Degree of malignancy of a tumour, usually judged from its histological features.

Gutkha
A form of chewing tobacco.

Histopathologist
A person who specialises in the diagnosis of disease through study of the microscopic structure of tissue.

Histopathology
The study of microscopic changes in diseased tissues.

Hospice
A place or service that provides specialist *palliative care* for patients with progressive, advanced disease.

Human papillomavirus
A virus that causes warts and is often associated with some types of cancer.

Hydrolytic enzymes
Enzymes which speed up the breakdown of substances into simpler compounds through reaction with water molecules.

Hyperbaric oxygen
A procedure where oxygen is given in a pressurised chamber. This allows larger amounts of oxygen to be given than would otherwise be possible. The higher level of oxygen in the tissues provides a better healing environment and can also lead to the growth of new blood vessels in areas where they have been damaged by, for example, *radiotherapy*.

Hyperfractionated or accelerated radiotherapy
Radiotherapy is usually given over an extended period and the dose given per day is known as a fraction. Hyperfractionated or accelerated radiotherapy is where more than one fraction is given per day.

Hyperthyroidism
This is a condition where the *thyroid* is overactive. This may cause loss of weight, a rapid heart action, anxiety, overactivity and increased appetite.

Hypoparathyroidism
A condition where abnormally low levels of parathyroid hormones are produced. This may be due to inadvertent damage or removal of the parathyroid glands during *thyroidectomy*. A common symptom is low *serum calcium*.

Hypopharynx
The lower part of the *pharynx* which opens into the *larynx* and *oesophagus*.

Hypothyroidism
Deficiency of *thyroxine* which causes obesity, lethargy and a coarse skin.

Infectious mononucleosis
An infection caused by the Epstein-Barr virus, also called glandular fever. An acute viral infection that can cause high fever, sore throat and swollen *lymph nodes*, particularly in the neck.

Laryngectomee
A person who has had their *larynx* removed.

Laryngectomy
Surgical removal of the *larynx*. A partial laryngectomy is where only part of the *larynx* is removed.

Larynx (voice box)
The larynx is a small organ situated in the front part of the neck and attached to the windpipe. It is larger in men, where it is commonly known as the Adams apple. It allows the air breathed in through the nose and mouth to reach the lungs, acts as a valve which closes to prevent food and drink entering the windpipe when swallowing and it contains the *vocal cords*.

Laser excision
The use of a laser to remove tissue.

Local recurrence
Recurrence of disease at the site of the original tumour following initial potentially curative treatment.

Lymph nodes
Small organs which act as filters in the lymphatic system.

Lymphoma
Cancer of the lymphatic system. There are two main types of lymphoma - Hodgkin's disease and Non-Hodgkin's lymphoma.

Lymphoma of the thyroid
Lymphoma of the *thyroid* gland starts in the lymph tissue of the *thyroid*. When it occurs there is usually evidence of *chronic lymphocytic thyroiditis*.

Magnetic resonance imaging (MRI)
A non-invasive method of imaging which allows the form and metabolism of tissues and organs to be visualised (also known as nuclear magnetic resonance).

Maxillofacial
Having to do with the jaws and face.

Medullary thyroid cancer
See *thyroid cancer*.

Meta-analysis
The statistical analysis of the results of a collection of individual studies to synthesise their findings.

Metachronous
Occurring at different times.

Metastases - metastatic disease
Spread of cancer away from the primary site.

Microvascular
Having to do with very small blood vessels.

Monoclonal antibody treatment
Antibodies produced in the laboratory from a single copy of a human antibody that can target specific cancer cells wherever they may be in the body.

Mucositis
See *oral mucositis*

Nasal cavity
The passageway just behind the nose through which air passes on the way to the throat during breathing.

Nasogastric tube
A thin tube passed via the nose into the stomach down which liquid food is passed.

Nasopharynx
The upper part of the *pharynx* behind the nose.

Neo-adjuvant treatment
Treatment given before the main treatment.

Neurological
Having to do with the nervous system.

Oesophageal speech
Following a *laryngectomy* the ability to speak in the normal way is lost. There are several methods available to help *laryngectomy* patients produce sound and learn to speak again. The commonest is a technique known as oesophageal speech. Air is swallowed and forced into the *oesophagus* by locking the tongue to the roof of the mouth. As the air is expelled, it vibrates the walls of the *oesophagus* which creates a low-pitched sound which can be formed into words.

Oesophagus
The gullet.

Oncologist
A doctor who specialises in treating cancer.

Oncology
The study of the biology and physical and chemical features of cancers. Also the study of the causes and treatment of cancers.

Ophthalmologist
A person who specialises in the structure, functions, and diseases of the eye.

Oral
Having to do with the mouth.

Oral cavity
The mouth. This includes the front two-thirds of the tongue, the upper and lower gums, the lining of the inside of the cheeks and lips, the bottom of the mouth under the tongue, the bony top of the mouth (hard *palate*) and the small area behind the wisdom teeth.

Oral mucosa
The mucous lining of the mouth.

Oral mucositis
Inflammation of the mucous membranes in the mouth (sore mouth).

Orbit
The bony cavity which contains the eyeball.

Oropharynx
The middle part of the *pharynx*.

Osseointegrated implants
Surgical implants which become integrated into the surrounding bone.

Osteonecrosis
The death of an area of bone caused by poor blood supply.

Otalgia
Earache.

Otolaryngologist or otorhinolaryngologist
A doctor who specialises in treating diseases of the ear, nose and throat.

Paan
Also known as pan or pahn. See *Areca nut*.

Palate
The roof of the mouth. The bony portion at the front of the mouth is known as the hard palate and the fleshy portion at the back is known as the soft palate.

Palliative
Anything which serves to alleviate symptoms due to the underlying cancer but is not expected to cure it.

Palliative care
Active, holistic care of patients with advanced, progressive illness which may no longer be curable. The aim is to achieve the best *quality of life* for patients and their families. Many aspects of palliative care are also applicable in earlier stages of the cancer journey in association with other treatments.

Papillary thyroid cancer
See *thyroid cancer.*

Parotid gland
One of the *salivary glands* situated just in front of the ear.

Partial laryngeal excision
An operation where only part of the *larynx* is removed. See *laryngectomy.*

Percutaneous gastrostomy (PEG) feeding
Feeding by a tube which is passed through the wall of the abdomen directly into the stomach.

Periodontal disease
A general term for diseases of the gums, teeth and underlying bone.

Pharynx (pharyngeal)
The passage which starts behind the nose and goes down the neck to the *larynx* and *oesophagus*. Commonly known as the throat. The top section of the pharynx is known as the *nasopharynx,* the middle section as the *oropharynx* and the lower section as the *hypopharynx.*

Photodynamic therapy
A procedure where laser light, in combination with light-sensitising drugs, is used to kill cancer cells.

Pilocarpine
A drug which stimulates the *salivary glands* to produce more saliva.

Positron emission tomography (PET)
An imaging method which reveals the level of metabolic activity of different tissues.

Prophylaxis
An intervention used to prevent an unwanted outcome.

Prosthesis
An artificial device used to replace a missing part of the body.

Prosthodontist
A specialist in replacing missing teeth. A prosthodontist is required for the specifically difficult cases of full dentures and complex rehabilitation of even partial replacements.

Protocol
A policy or strategy which defines appropriate action.

Psychosocial
Concerned with psychological influence on social behaviour.

Pulmonary
Having to do with the lungs.

Purulent
Containing, consisting of, or being pus.

Quality of life
The individual's overall appraisal of his/her situation and subjective sense of well-being.

Radical treatment
Treatment given with curative, rather than *palliative* intent.

Radioiodine
A radioactive substance which is concentrated in thyroid tissue, and may be used for the treatment of *thyroid* cancer as a form of internal *radiotherapy*.

Radioiodine ablation
Treatment with *radioiodine* to destroy any *thyroid* tissue remaining after surgery.

Radiologist
A doctor who specialises in imaging.

Radionuclide therapy
Treatment using radioactive isotopes in order to target tumour cells. *See radioiodine.*

Radiotherapy
The use of radiation, usually X-rays or gamma rays, to kill cancer cells.

Randomised controlled trial (RCT)
A type of experiment which is used to compare the effectiveness of different treatments. The crucial feature of this form of trial is that patients are assigned at random to groups which receive the interventions being assessed or control treatments. RCTs offer the most reliable (i.e. least biased) form of evidence on effectiveness.

Recurrence
The return of cancer. See *local recurrence*.

Resection
The surgical removal of all or part of an organ.

Salivary glands
Glands situated near to and opening into the mouth which produce saliva to aid the initial process of digestion.

Sensitivity
Proportion of people with disease who have a positive test result.

Serum calcium
Level of calcium in the blood.

Sinuses
Small hollow spaces in the skull around the nose. The sinuses are lined with cells that make mucus which keeps the nose from drying out. They are also spaces through which the voice can echo to make sounds when a person talks or sings.

Specificity
Proportion of people without disease who have a negative test result.

Squamous cell carcinoma
A common type of cancer which originates in superficial layers of tissue (squamous epithelium).

Staging
The allocation of categories defined by internationally agreed criteria. Staging helps determine treatment and indicates prognosis. The TNM staging classification system is based on the depth of tumour invasion (T), lymph node involvement (N) and metastatic spread (M).

Stoma
A surgically created opening (see *tracheostomy).*

Stridor
A harsh vibrating sound heard during breathing caused by obstruction of the air passage.

Supportive care
Care that helps the patient and their family and carers to cope with cancer and its treatment throughout the cancer journey, and in the case of the family and carers, into bereavement. It aims to help the patient maximise the benefits of treatment and provide the best possible *quality of life.*

Synchronous
At the same time.

Thyroglobulin
A protein made by the normal *thyroid* gland. However, thyroglobulin can also be produced by papillary or follicular *thyroid cancer* cells. If high levels of serum thyroglobulin (thyroglobulin in the blood) are found following *thyroidectomy* and *thyroid ablation therapy,* this may indicate residual or recurrent *thyroid cancer.*

Thyroid
A small butterfly shaped gland situated in the front of the neck just below the *larynx*. Its chief function is to produce the hormones which control the body's rate of metabolism.

Thyroid ablation therapy
Treatment to destroy *thyroid* tissue. See *radioiodine ablation.*

Thyroid cancer
There are four main types of cancer of the *thyroid*. Papillary cancer is the most common and develops in cells that produce *thyroid* hormones containing iodine; it most commonly affects women of child-bearing age and tends to grow slowly. Follicular cancer also develops in cells that produce iodine containing hormones, but is much less common and tends to occur in older people. Medullary cancer is rare and develops in cells that produce the hormone *calcitonin*; it is known to run in families. The rarest thyroid cancer is anaplastic cancer which tends to affect older people and can be confused with thyroid *lymphoma;* it grows rapidly and can be difficult to treat.

Thyroidectomy
Surgical removal of the *thyroid* gland. A partial thyroidectomy is where only part of the *thyroid* is removed.

Thyroxine
The main active ingredient of the hormone produced by the *thyroid* gland. This hormone is one of the most important in the body and controls the rate of metabolism. The body needs a regular supply of iodine to produce thyroxine.

Tonsils
Masses of lymphoid tissue that lie on each side of the back of the throat.

Trachea
The windpipe.

Tracheo-oesophageal valve
A valve which fits in the surgically created opening between the *trachea* and *oesophagus* preventing food from entering the *trachea*.

Tracheostomy
A surgically created opening in the lower part of the neck which allows air to be breathed in following a *laryngectomy* or other type of surgery where it was necessary to divert the *trachea*.

Trusts
In the context of this guidance, Trusts are organisations responsible for managing and/or delivering health services. There are a variety of Trusts, the two most common being Primary Care Trusts (PCTs) and NHS Trusts. PCTs are local organisations responsible for managing health services in a given local area. NHS Trusts manage hospitals, but can also provide services in the *community*.

Ultrasound
High-frequency sound waves used to create images of structures and organs within the body.

Upper aerodigestive tract
The mouth, lip and tongue *(oral cavity)* and the upper part of the throat *(larynx* and *pharynx)*.

Vocal cord palsy
Paralysis of the *vocal cords*.

Vocal cords
Two vocal cords are contained within the *larynx*, which vibrate together when air is passed over them to produce the sound to be turned into speech.

Xerostomia
Deficiency of saliva - dry mouth.

Appendix 5

Abbreviations

AC	Audit Commission
BAHNO	British Association of Head and Neck Oncologists
BAOHNS	British Association of Otorhinolaryngologists and Head and Neck Surgeons
CDE	Colour-Doppler echography
CHI	Commission for Health Improvement
CI	Confidence interval
CNS	Clinical nurse specialist
CT	Computed tomography
DAHNO	Data for head and neck oncology
DGH	District general hospital
ECOG	Eastern Co-operative Oncology Group
ENT	Ear, nose and throat
EQA	External quality assurance
FNAC	Fine needle aspiration cytology
GM-CSF	Granulocyte macrophage colony stimulating factor
Gy	Gray (unit of absorbed dose of radiation)
HPV	Human papilloma virus or human papillovirus
IARC	International Agency for Research on Cancer
ICD	International classification of disease
IT	Information technology
MDT	Multi-disciplinary team
MRC	Medical Research Council
MRI	Magnetic resonance imaging
NCA	National Cancer Alliance
NCASP	National Clinical Audit Support Programme
NCRN	National Cancer Research Network
NICE	National Institute for Clinical Excellence
NYCRIS	Northern and Yorkshire Cancer Registry and Information Service
ONS	Office for National Statistics
OR	Odds ratio
PEG	Percutaneous gastrostomy

PET	Positron emission tomography
RCT	Randomised controlled trial
SLT	Speech and language therapist
SWAHNI	South and West Head and Neck Audit Report
SWAHNII	Second South and West Head and Neck Audit Report
T	Tumour
TNM	Tumour invasion, lymph node involvement and metastatic spread
UAT	Upper aerodigestive tract
WHO	World Health Organisation
WTE	Whole time equivalent