Guidance on Commissioning Cancer Services

Improving Outcomes in

Head and Neck Cancers

The Manual

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Foreword

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 comorbidities 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 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’: thyroid cancer shares with penile cancer the dubious distinction of having no randomised trial evidence to guide management.

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.

Professor RA Haward, December 2003.

[1] NICE Guidance on supportive and palliative care for people with cancer – FULL REF

[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*, Vol. 95, No. 10, May 21 2003.

Acknowledgements

These will follow in the final published document.

Key Recommendations

- Services providing treatment for patients with head and neck cancers should be concentrated in centres where management is provided by a multidisciplinary team (MDT) which includes a full range of appropriate specialists.
- Each MDT should include clinical nurse specialists , who should be involved in the care of every patient and will be available to provide expert advice to other nursing staff, helping them to deal with the particular needs of this group of patients.
- Specialist services have a crucial role in assessment, support and rehabilitation, and should be available to all patients who need their input. These include speech, language and swallowing services, dentistry, nutrition, and psychological services.Co-ordinated multidisciplinary Local Support Teams should be established to provide care for patients during out-patient treatment and offer long-term support and rehabilitation after radical treatment for cancer of the upper aerodigestive tract.
- Data collection services and research into the effectiveness of treatment and rehabilitation require 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 guidance on commissioning, intended for 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 present unique problems. They 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 nature of the anatomical sites affected and the variety of professional disciplines involved in caring for patients.

There are over thirty 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 ranks as the 8th most common cancer among men and the 16th most common in women, with over 7,000 cases and 2,500 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) and the upper part of the throat (larynx and pharynx). Other UAT sites include the salivary glands, nose, sinuses and middle ear, but these cancers are relatively rare; cancer which develops 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]

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 totally unlike UAT cancers, but this site is included because the services required 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.

This Guidance does not cover cancers of the skin or brain, which are not generally included in discussions of head and neck cancers. 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*.[2]

Table 1a. Registrations, incidence, and deaths, England [3]

Cancer site	***ICD10 code***	**Number of registrations 2000**	**Incidence: crude rate per 100,000, 2000**		***ICD9 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

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

[2] Available on the NICE website (www.nice.org.uk).

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

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 [4]

Cancer site	***ICD10 code***	**Number of registrations 2000**	**Incidence: crude rate per 100,000, 2000**		***ICD9 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

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] However, there are problems with the data. For instance, sometimes statistics combine cancers of the oral cavity (mouth) with those of the pharynx (throat); cancers of the nasopharynx (the area of the pharynx above the soft palate and behind the nose), middle ear, sinuses and salivary glands may or may not be included. Similarly, cancers of the thyroid are sometimes included in the general category of head and neck cancers, sometimes not.

Over the last decade, registration rates for the most common forms of head and neck cancer - cancers of the mouth and pharynx - have been rising, particularly among younger

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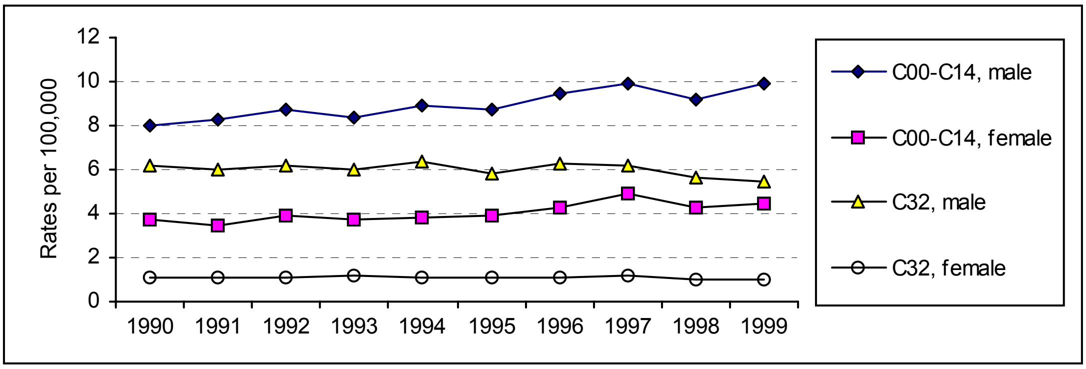
[4] Figures from the Welsh Cancer Intelligence & Surveillance Unit, Office of National Statistics (ONS).

[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**: supplement A.

people.[6] An audit in one region found an increase of nearly 40% in cases of oral cancer between 1997 and 2000.[7] This increase is counterbalanced somewhat by a decrease in incidence of cancer of the larynx (Figure 1).[8]

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



Both incidence of, and mortality from, UAT cancers are higher among disadvantaged population groups.[9] The pattern is similar to that for lung cancer, which has many of the same causes (in particular, smoking). In south-west England, the age-standardised incidence of smoking-related cancer of the head and neck in 1985-1991 was 12 cases per 100,000 among the most deprived men (Carstairs quintile 5), and five per 100,000 among the more affluent (Carstairs quintiles 1 and 2). Mortality rates follow a similar pattern. Patients with UAT cancers who live in deprived areas are more likely to die from their disease than those who live in more affluent areas (relative risk 1.25, 95% CI 1.15, 1.35).[10]

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[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] Birchall MA & Bailey D. *SWAHN II : Head and neck cancer management in the South and West of England, quantity and quality*. Cancer Intelligence Unit, Winchester. 2001.

[8] Quinn, 2001: *op.cit.*

[9] 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**: 503-8.

[10] Edwards DM, Jones J. Incidence of and survival from upper aerodigestive tract cancers in the UK; the

Most patients with UAT cancers are middle-aged or older (Figures 2a and 2b).[11]

Figure 2a. New cases of cancer of the oral cavity, by age[12]

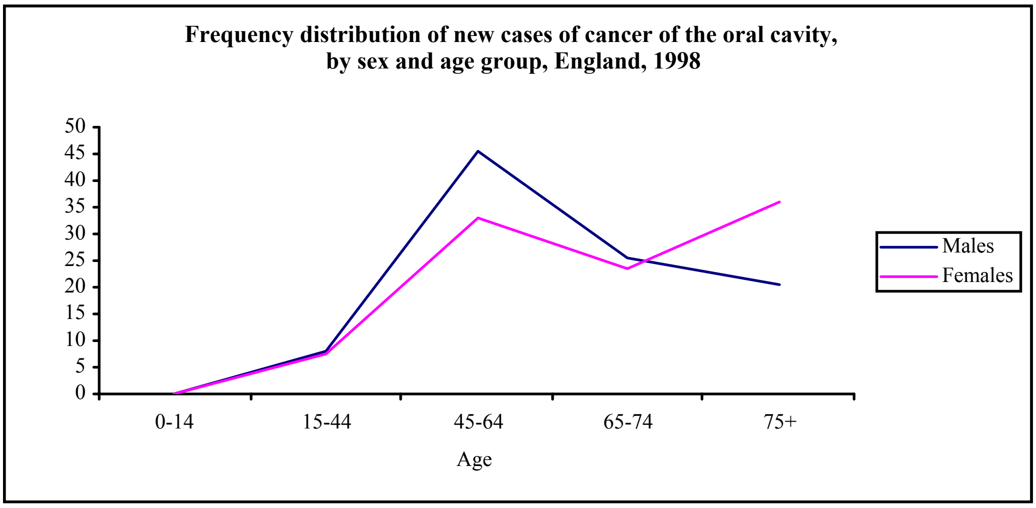

Figure 2b. New cases of cancer of the larynx, by age (males only)

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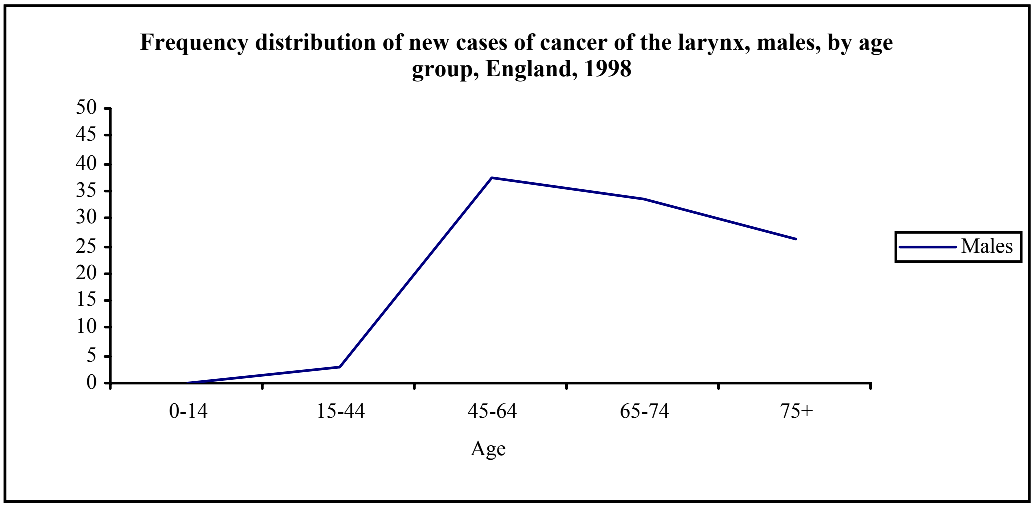
influence of deprivation. *Eur J Cancer* 1999. **35**(6): 968-72.

[11] 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).

[12] Source: National Cancer Intelligence Centre, Office for National Statistics.



Thyroid cancer incidence has an entirely different pattern (Figure 2c). It is more common in women, among whom new cases peak between the ages of 30 and 50; the rate falls in middle age, peaking again in those aged 70-74. In men, incidence rises to a peak in the 45-49 age-group, and then to a second maximum at 65-74 years.[13] Thyroid cancer is considerably more common among young people (particularly young women) than other head and neck cancers.[14]

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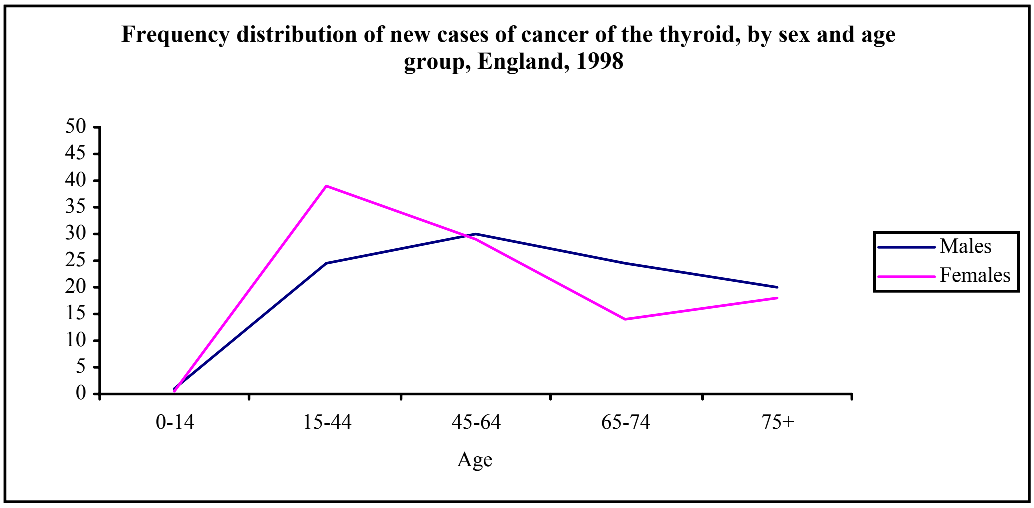
[13] Quinn, *op. cit.,* Appendix B4.

[14] Office of National Statistics, Cancer Registrations Series MB1, 2002.

Figure 2c. New cases of cancer of the thyroid, by age



Survival rates

Survival rates differ markedly according the site and stage of the cancer, but data from the Eurocare 3 study shows that rates in both England and Wales are broadly similar to the European average (Table 2).[15] 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 Britain inappropriate. Where there are high coverage rates (for example in Scandinavia), survival rates for UAT cancers are similar to those in England.

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[15] Eurocare III, data not yet published.

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

	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 of unreliable data. Austria, for example, appears to have spectacular survival rates for salivary gland cancers – but only six cases are included. 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 are somewhat larger and probably sufficient to make comparisons between selected countries. 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%.

The prognosis for individual patients depends heavily on the stage of the disease, which is described 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). Figures for stage at diagnosis and survival rates for the South and West of England are given in Table 3, below. The relationship between the stage classification used here and TNM stage for each cancer site is given in the document from which the figures were derived.[16]

Table 3. Cancer stage and survival in the South and West of England, 1999-2000[17]

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	89.7%	34	21	6	13	12
II	71.8%	27	16	13	17	8
III	57.6%	17	15	22	7	8
IV	48.6%	15	34	50	28	47
unknown	69.8%	7	11	9	35	25

Research in Scotland suggests that one-year survival has changed little over twenty-five years and survival rates at five years have declined.[18] One recent report has argued that survival rates for patients undergoing treatment have not changed for the last two decades. This is partly because many patients are already debilitated at the time of diagnosis; most are long-term smokers and may suffer from other conditions associated with smoking, such as cardiovascular disease and lung cancer.[19]

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

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

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

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

The case for change in NHS services for patients with UAT cancers thus has less to do with survival rates than with other aspects of outcome, particularly quality of life for survivors. In the case of thyroid cancer, however, it appears that long-term survival rates in England are inferior to those in comparable countries.

Specific Cancers

Cancer of the oral cavity

Oral cavity cancer includes cancer of the lip, tongue, gum, floor of the mouth and palate. Of these, cancer of the floor of the mouth and tongue are the most common in both men and women. Oral cancer has the highest incidence of the head and neck cancers, with about 2240 new cases each year in England; 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).[20]

Roughly 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. Approximately 10-30% 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.[21]

The symptoms of oral cavity cancer are most commonly a sore or lump on the lip or in the mouth, but may include pain 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. Difficulty in speaking or swallowing may also be a symptom. Some of these lesions may be pre-malignant, and can be picked up by a doctor or dentist.

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

[21] Cancer Research Campaign. *Cancer Statistics: Oral – UK*. July 2000.

Overall, the incidence of oral cancer is relatively low in England and Wales compared to many other countries. There are higher rates among people from a South Asian (Indian sub-continent) background, mirroring the high incidence in India, Pakistan and Bangladesh.[22,23]

Public awareness of oral cancer is low. Where people have heard of such cancer, they are more aware of the role of smoking than of other risk behaviours.[24] This lack of awareness may reflect the relative rarity of this form of cancer, particularly among young people.

Cancer of the larynx

Cancer of the larynx (voice box) is the second most common form of head and neck cancer, with over 1900 new cases each year (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).

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 early symptoms such as hoarseness.[25]

Virtually all cancer of the larynx is squamous cell carcinoma. The most common symptom is hoarseness; other symptoms may include pain on swallowing or problems with swallowing (dysphagia). There can also be a lump on the neck, sore throat or ear ache, or a persistent cough.

Cancer of the pharynx

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[22] 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**: 1312-19.

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

[24] Warnakulasuriya KA *et al.* An alarming lack of public awareness towards oral cancer. *Br Dent J* 1999. **187**(6): 319-22.

[25] *Check reference*

Cancer of the pharynx (throat) is less common (Table 1). There are three principal locations for cancer within the pharynx: 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. 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, over three quarters of whom are male. Five year survival rates are relatively poor, at about 40% for cancer of the oropharynx and 20% for the hypopharynx.[26]

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 can be either squamous carcinoma, or of nasopharyngeal type, which 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, dysphagia and otalgia 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. Cancer of the nasopharynx is particularly common among people of Southern Chinese origin.[27]

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 goitre (a swelling in the neck

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[26] Eurocare III, data not yet published.

[27] Warnakulasuriya KA, 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.

due to enlargement of the thyroid gland); cancer is found in about 10% of such cases. Other symptoms are rare, but include swollen glands in the neck (cervical lymphadenopathy), hoarseness, difficulty in breathing or swallowing, and discomfort in the neck.

The commonest type of thyroid cancer is described as “differentiated”; this accounts for 90% of cases. Differentiated thyroid cancer is made up of papillary (80%) and follicular (10%) adenocarcinoma, both of which develop in cells that produce thyroid hormones. Papillary cancer tends to grow slowly and is not regarded as being highly malignant. Differentiated thyroid cancers are usually treated with surgery, which can be supplemented with radioiodine ablation. Survival rates are excellent.

Other types of thyroid cancer include medullary cancer (5% of cases), 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 not covered by the above. Taken together, these add up to a further 1350 cases in England and Wales among people aged 15 and over, or 17% of all head and neck cancers.[28] Of these, the most common are cancers of the salivary glands and cancers of the nasal cavity, middle ear and accessory

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[28] National Cancer Intelligence Centre, Office for National Statistics and Welsh Cancer Intelligence & Surveillance Unit

sinuses (Table 1). This diverse group also includes cancers of the facial bones, peripheral nerves, connective and soft tissues, and various glands.

Skull base cancers are included among head and neck cancers, but cancers that involve the skull usually originate in soft tissue. Treatment for these cancers is 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.[29]

Cigarette smoking is associated with increased risk of all of the more common forms of UAT cancer; the risk among cigarette smokers may be ten or more times that for non-smokers. Pipe or cigar smoking is associated with an even higher excess risk of oral cancer.[30] 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.[31,32]

The intensity of tobacco use increases risk, while ceasing to smoke for ten years or more reduces it to virtually equal to non-smokers. There is also evidence that the heavier the smoking prior to diagnosis, the more likely people with cancer of the oral cavity, larynx or

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[29] Blot WJ, McLaughlin JK, Winn DM. *et al.* Smoking and drinking in relation to oral and pharyngeal cancer. *Cancer Res* 1988. **48**:3282-87.

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

[31] 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**: 1312-19.

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

pharynx are to develop second primary tumours, i.e. which did not develop from the first one. The same pattern is found among people who continue to smoke after diagnosis.[33]

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.[34] 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 multiplies the risk of developing oral cancer at least six-fold, after adjustment for tobacco use.[35]

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 reduces risk. 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.[36,37]

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 cessation and reduction programmes are important. Effective interventions for reducing smoking are described in the guidance document on lung cancer in this series (*Improving Outcomes in Lung Cancer: The Manual)*.[38] A recent literature review found evidence that oral cavity cancer in young people (aged under 40) may not be associated with these traditional

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[33] 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): 730-39.

[34] Blot WJ, McLaughlin JK, Winn DM. *et al.* Smoking and drinking in relation to oral and pharyngeal cancer. *Cancer Res* 1988. **48**:3282-87.

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

[36] 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.

[37] 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**: 240-52.

[38] Available on the Department of Health website (doh.gov.uk)

origins, and suggested that genetic disposition may play a role, but further research is needed.[39]

Occupational exposure to asbestos, formaldehyde, nickel, isopropyl alcohol or sulphuric acid mist have been shown to be risk factors for laryngeal cancer, but the influence of these factors is small in relation to smoking and alcohol consumption.[40]

Some forms of virus infection, including infection with *Herpes simplex* (HSV), Epstein-Barr virus and human papillomavirus (HPV), are associated with cancers of the oral cavity, pharynx and larynx.[41]

Thyroid cancer

A history of x-ray exposure is associated with the development 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 of dietary iodine are associated with increased risk.[42] 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

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[39] 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**: 401-18.

[40] *check reference*

[41] Rees L, Birchall M *et al*. A systematic review of case control studies of human papillomavirus (HPV) infection in squamous cell carcinoma of the larynx. Draft paper. [contact martin.birchall@bristol.ac.uk for publication details]

[42] 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.

Identification of patients and diagnosis

There is no national screening programme for any form of head and neck cancer. A national advisory group set up to examine whether population screening should be introduced concluded that it would be neither appropriate nor cost-effective, as it would attract the worried well rather than the heavy smokers and drinkers who are more likely to have such cancer.

Because head and neck cancer is relatively rare, the average GP would expect to see a new case only every six years; a district general otolaryngologist (ENT) or maxillofacial surgeon 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) at regular intervals 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) – the insertion of a fibre-optic device into the pharynx and larynd – is usually necessary. A definite diagnosis of cancer requires the removal of a small quantity of tissue from the lesion for microscopic examination, using fine needle aspiration (FNAC) or biopsy.

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). Pathological stage, which is more precise than clinical stage, can be assessed by a pathologist using excised tissue when patients are treated by surgery.

In practice, predicting prognosis is difficult, as staging is often unreliable (particularly if patients are treated with radiotherapy) and the speed at which any particular tumour may grow is not known. 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 chemo-radiation. The majority of head and neck cancer patients are referred to and treated by otolaryngologists or maxillofacial surgeons, together with oncologists. Plastic or reconstructive surgery and specialised dentistry may also be needed.

Thyroid cancers have traditionally been treated by general surgeons or surgical oncologists with an interest in breast disease, although there have been recent moves towards more specialised treatment. Endocrinologists also play important roles in both diagnosis and management.

Rehabilitation, support and palliative care

Living with the effects of head and neck cancer can be difficult. Radiotherapy can be debilitating, with many persistent side-effects, and people can have difficulties with speaking, chewing and swallowing. Those who have undergone laryngectomy (surgical removal of the larynx or voice box) 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 talk 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 speech and language therapists and dieticians.

Palliative care aims to maintain patients' comfort and dignity. All professionals working with patients may address palliative care needs, but palliative care specialists, working in hospitals, hospice or the community, are likely to be required, particularly to support patients with advanced disease. Interventions such as radiotherapy and chemotherapy may be used with palliative intent when curative treatment is not feasible.

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.

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 multidisciplinary teams (MDTs) for head and neck cancer, compared to much higher proportions for more common types of cancer (over 80 per cent in the case of breast cancer).[43] Two-fifths or less of hospitals/trusts had agreed guidelines for its treatment by surgery, chemotherapy or radiotherapy in 2000. This was below the average for all cancers, although by no means the worst. Perhaps more significantly, one third of hospitals/trusts had no designated lead clinician for head and neck cancer and three quarters had no lead nurse.[44]

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.

Different aspects of NHS provision are described 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 a nationwide audit, it is not possible to present a reliable snapshot of current services for patients with head and neck cancer.

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

[44] *Ibid.*

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.[45] However, there is relatively little research into the effectiveness of treatment for head and neck cancers, compared with breast or colorectal cancer.[46] The British Association of Head and Neck Oncologists (BAHNO) has developed a national minimum dataset for head and neck cancer, the use of which should substantially improve the data available for research purposes.[47] A recent survey found that just over half (56%) of all teams were collecting this information.[48] Participation in clinical trials in head and neck cancer has traditionally been poor..

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

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

[47] British Association of Head and Neck Oncologists. *National Minimum and Advisory Head and Neck Cancer Data sets.* BAHNO, 1999.

[48] Browne J, Birchall M, Browne P. The Royal College of Surgeons of England Multidisciplinary Head and Neck Oncology Audits: Preliminary results of the first audit. *Clinical Oncology 2001*

1. Referral

A. Recommendations

Networks should decide which hospitals will provide a diagnostic service for patients with symptoms that might be due to head and neck cancers. Some smaller hospitals will not have the capacity to provide the type of service specified in this Manual; these should have mechanisms for onward referral to Trusts where appropriate expertise is available. There should be specific referral routes for patients with neck lumps and 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 designate a lead clinician. A second clinician should be nominated to take this role when the lead clinician is absent.

These lead clinicians should take personal responsibility for the following aspects of the diagnostic 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.
- Clinicians who are likely to discover new patients with head and neck cancers – in particular, those who work in ENT and maxillofacial clinics – should be able to contact the lead clinician (or the person nominated as their cover) without delay. The

lead clinician (or cover) should aim to see personally any patient found to have a suspicious lesion.

- When biopsy of a suspicious lesion is appropriate, the lead clinician (or cover) should arrange for this to be done promptly.
- The lead clinician (or cover) should refer patients on to appropriate assessment clinics at Cancer Centres (see Topics 2 and 3).

Head and neck cancer lead clinicians and clinicians in ENT and maxillofacial clinics should be in regular contact with each other. It is not necessary, however, for local hospitals to establish formal MDT structures to deal with head and neck cancer.

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.[49] Revised guidelines are expected in 2005. 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 these urgent referral criteria) are referred specifically to the head and neck lead clinician.

Urgent Referral Guidelines (England)

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

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[49] Department of Health. *Referral Guidelines for Suspected Cancer.* Available on

- 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.
- 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 pan should also arouse suspicion.

Patients with neck lumps

Patients who present with masses in the neck should be referred to rapid-access lump clinics for investigation, where such clinics are available. Networks which do not have lump clinics should consider establishing them at selected hospitals. These clinics should be run by clinicians with specific expertise in this area, and there should be an on-site cytologist with skill in fine needle aspiration cytology (FNAC).

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.[50]

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http://www.doh.gov.uk/pub/docs/doh/guidelines.pdf

[50] National Institute for Clinical Excellence. *Improving outcomes in haematological cancers.* Available on the NICE website (www.nice.org.uk).

Thyroid cancer

Patients with thyroid cancer are likely to present with a lump in the neck (goitre), 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:[51]

- 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;
- Patients with unexplained hoarseness or voice changes associated with a goitre;
- Cervical lymphadenopathy;
- Stridor (this is a late presenting sign and patients should be seen immediately).

Routine referrals

UAT cancer

The majority of patients found to have cancer enter the system by routine referral, normally to ENT or maxillofacial outpatient departments in local 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

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[51] 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.

resolve with conservative treatment; so patients who fail to improve should be referred. Both GPs 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 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. Networks should continue to develop services to help people to overcome behaviours that expose them to increased risk of head and neck cancers (see Background); these should include services for people from ethnic minorities who are addicted to substances such as betel. Primary care staff should take advantage of any opportunities for counselling patients, explain that they can reduce the risk of cancer by quitting, and offer help with overcoming addiction.

Referral forms should be developed by hospitals which offer diagnostic services, with tick-boxes or similar features which define the patients' 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 cancer

Patients with thyroid cancer usually present with a palpable solitary nodule in a goitre. Amongst such patients, the incidence of malignancy is approximately 10%.

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 be referred to an endocrinologist. Those with 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.

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 (see below).

Evidence

Tumour stage, nodal status and survival

A study of 206 patients with oral cancer from Scotland gives details of associations between tumour stage, lymph node involvement, treatment and survival.[52] The table below gives some illustrative figures taken from this paper.

Tumour details	Proportion of patients	Overall survival hazard ratio (95% CI)
T_1	21.4%	1.00
T_2	32.0%	1.40 (0.83 to 2.37)
T_3	17.0%	2.27 (1.28 to 4.03)
T_4	29.6%	2.41 (1.38 to 4.21)
Node negative	51.5%	1.00
Node positive	48.5%	1.46 (0.98 to 2.16)

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[52] 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.

It is clear that patients with relatively small, early tumours (T_1 and T_2) survive significantly longer than those with more extensive disease. However, almost half of the total group had relatively advanced tumours at the time of diagnosis; these require more demanding treatment which is less likely to be successful.

A study from Brazil investigated relationships between disease stage, treatment costs and hospital stay. This demonstrated 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 9 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

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, as well as 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.

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.[53] 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.[54]

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.[55]

But this appointment is only the first step in the process and does 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).[56] These audits show that the median time between GP referral to first outpatient 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 7 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.

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 delays had grown about a week longer three years later. The range of waiting times was large, with delays between first outpatient

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

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

[55] See www.doh.gov.uk/cancerwaits

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

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 outpatient 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, but some information on the size and stage of tumours at this point is available. 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 T2 (two to four centimetres diameter, usually stage II-III) or more at the point of diagnosis. Over a quarter were classified as T4 (stage IV, invading adjacent structures). A recent study, based on smaller numbers, found that roughly one quarter of head and neck cancers fell into each category T1-T4. There was no clear association between the nature of the symptoms and the urgency with which they were viewed by patients.[57]

Neck lump clinics

One report from an NHS hospital (published in 1998) describes a 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 fine needle aspiration cytology (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 3 (7%) had lymphoma. 21 patients had thyroid

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[57]

swellings, of whom five subsequently underwent surgery. 18 patients had salivary gland lumps, of which three were malignant. (B)

A second report, again from a clinic based in the otolaryngology department of a UK teaching hospital, on a one-stop clinic staffed by a senior specialist registratrar and senior cytopathologists who were able to carry out FNAC and provide rapid reports on their findings. During the first six months, the mean time from referral to clinic appointment was 17 days and PATIENTS waited, on average, a total of 65 minutes (including time awaiting the initial FNAC report). 54% of patients were discharged after a single visit; the remainder were referred for surgery, radiological investigation, or further clinical review. 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%, in those patients in whom the initial information from FNAC was predictive of malignancy. (B)

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

1. Allocation of dedicated clinic time;
2. GPs should have access to fax number of the clinic;
3. A senior member of the surgical staff access 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.

A second audit from the same clinic reported that the mean waiting time between referral and consultation had increased from 17 to 21 days, despite the availability of a fax number for direct referrals. FNAC was carried out on 76% of neck lumps.

An earlier (1985) report from a neck lump clinic in the UK gave information on the consistency between FNAC findings and the results of biopsy. The results are not clearly described but suggest that overall, at least three quarters of malignancies were quickly and correctly diagnosed by FNAC.

D. Measurement

Structure

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

- Evidence that systematic delays in diagnosis do not occur.
- Stage at diagnosis.

E. Resource Implications

2. Structure of services

A. Recommendations

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 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 Multidisciplinary Teams

All patients with head and neck cancers (including thyroid cancer) should be managed by appropriate multidisciplinary teams (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 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. Networks in sparsely populated areas may elect to develop teams for smaller numbers; but 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.[58]

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[58] 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 such as parts of Wales. (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. European Journal of Surgical Oncology, 2001, 27, Supplement A, pS4).

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.

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 three forms:

1. Designated head and neck cancer teams, who are joined by experts in endocrinology for part of the head and neck cancer MDT meeting; or
2. Specialised endocrine oncology teams; or
3. Endocrinology teams which manage both benign and malignant disorders of the thyroid.

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 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 head and neck cancer 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. 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. Every speciality should be represented at each meeting: cover should always be available when specific MDT members cannot be present. Teleconferencing may be used to ensure access to particular specialists.

Members of the core team should aim to attend all meetings; in practice, this means that they will be present at a majority of meetings. All should specialise in head and neck cancer.

- 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 speciality. Each surgeon in the MDT should normally dedicate at least half of his or her time to head and neck cancer.
- Radiotherapists (clinical oncologists): each MDT should, if possible, include two clinical oncologists, one of whom should always be present at meetings.
- Specialist restorative dentist
- Specialist pathologists, with expertise in both histopathology and cytopathology
- Radiologist with expertise in head and neck cancer.
- Speech and language therapist with expertise in rehabilitation of patients who have undergone treatment for head and neck cancer (See Topic 7, After-care and Rehabilitation)
- Clinical nurse specialists (CNSs). This role is discussed below.
- 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 with a specialist interest in patients with head and neck cancer.

- 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.

- 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.

The core team should meet weekly or fortnightly, depending on availability of members and case-load. 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.

- Neurosurgeon

- Surgical specialist with expertise in microvascular techniques

- Ophthalmologist

- Pain management specialist

- Prosthetic services

- Dental hygienist
- Social worker
- Benefits advisor
- Liaison psychiatrist
- Clinical psychologist
- Bereavement counsellor
- Physiotherapist

Members of the thyroid cancer MDT

- Endocrinologist.
- Surgeon who specialises in thyroid/endocrine oncology.
- Oncologist.
- Radiologist
- Nuclear medicine physician, if available.
- 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 should be trained and licensed to give radioiodine.

Thyroid cancer MDT meetings should be organised in whatever way is most convenient for the members. Thyroid 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.

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 both for 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, liasing 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 samples that show head and neck cancer have been reviewed by a pathologist who attends the 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. Major surgery should 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 the MDT responsible for their management considers this to be appropriate. Such treatment should be consistent with the treatment plan developed by the MDT.

The Clinical Nurse Specialist (CNS)

A named head and neck cancer clinical nurse specialist (CNS) should be available to support every patient, throughout the course of the disease. Patients and carers should be given contact details for their CNS at the time of diagnosis, 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 (or he[59]) can recognise patients' non-clinical needs as well as problems directly associated with their cancer or treatment. She should be closely involved in helping patients and their families to understand the nature and potential impacts of the interventions that may be required, and provide expert help when required with managing the practical, social and psychological consequences of treatment. This type of help is essential during the post-operative period and may be necessary for a considerable time after discharge from hospital (see Topic 7, After-care, rehabilitation and follow-up).

CNSs 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, CNSs can often bring a richer understanding of patients' preferences, cognitive and coping skills, and a more detailed knowledge of their social situation, to the decision-making process.

The CNS should take a leading role in providing care 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 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, speech and language therapists (see below), 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,

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[59] 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.

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.

The Speech and language therapist (SALT)

Speech therapy for people who have been treated for head and neck cancer demands a high level of expertise over a substantial period of time – often a year, sometimes even longer. The SALT should discuss the planned treatment and rehabilitation with the patient before treatment begins, and should be responsible both for assessment of speech and swallowing and for helping patients to deal with problems with eating, drinking and face-to-face communication.

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, since many of these patients have complex needs (such as restorative dentistry and prostheses) that cannot be adequately met by community dental services.

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 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 cognitive-behavioural and other forms of 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 clinical nurse specialists and members of professions allied to medicine 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 that copies of 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 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. There should 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 multidisciplinary working and combined decision-making - currently rare in head and neck cancer in the UK - 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 is not only beneficial for patients, ensuring that palliative care needs are recognised and met early, but can reduce the emotionally draining effects on other clinicians of dealing with 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 Clinical Nurse Specialists value it greatly. Increasing the number of such nurses so that all patients with head and neck cancer have access to a CNS 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. The CNS often has a better insight into social and psychological issues which are important to patients than other members of the MDT, because patients will talk more frankly with nurses than with doctors or surgeons. Input to MDT discussion from a CNS who knows the patient improves the probability that decisions about management will take full account of the patient's wider situation and concerns.

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; even in "specialist centres", some patients do not receive adequate treatment. This may explain why long-term survival rates are poorer in England than in Scandinavia (see Background). 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

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."[60] Co-ordination and communication problems caused considerable frustration, both to patients and clinicians.

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."[61]

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

[61] *Ibid*, p19.

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 fourteen. Around half of the hospitals that treat patients with head and neck hold joint clinics, with an average of 24 patients seen in each clinic (range: 4-60).[62]

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.[63]

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 multidisciplinary 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 multidisciplinary assessment. Overall, 46% of patients were seen in combined clinics.[64] 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.[65]

This increase in multidisciplinary 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

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[62] Browne J, Birchall M & Brown P. The Royal College of Surgeons of England Multidisciplinary Head & Neck Oncology Audits: Preliminary Results of the First Audit. *Clinical Oncology* 2002 xx

[63] Commission for Health Improvement/Audit Commission. *NHS Cancer Care in England and Wales.* London: CHI/AC. 2001.

[64] South and West Regional Cancer Organisation Head and Neck Tumour Panel, *South and West Head and Neck Audit Report (SWAHNI),* South and West Cancer Intelligence Unit, Winchester, 1999.

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

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 the hospitals which receive larger numbers of patients – a problem exacerbated by the increasing incidence of these cancers. Radiotherapy, radiology and histopathology services are under particular pressure.

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, ten dealt with more than ten cases during that year, treating a total of 163 cases between them. 181 patients were treated by 51 consultants who each carried out ten 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 ten oncologists treated an average of five patients each.

Only 40 per cent of trusts/hospitals had a specialist nurse (CNS) for head and neck cancer in 2000/2001.[66]

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 ten 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.

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[66] Commission for Health Improvement/Audit Commission. *NHS Cancer Care in England and Wales.*

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.[67]

Research evidence on 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=144) were less likely to have recurrent disease and survived for significantly longer than patients managed in less specialised units (63 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). Concentration of patients in the plastic surgery unit at one hospital has allowed the combined team to develop considerable experience in delivering individually-designed treatments, which seem to be more effective than treatment plans 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.*

In a study of three hospitals treating head and neck cancer in the Midwest of the USA two hospitals had specialist dental outpatient clinics the other did not. 104 patients received

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London: CHI/AC. 2001.

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

radical treatment (mainly radiotherapy or radiotherapy and surgery) at the three hospitals. Although dental consultation rates were not significantly different, oral complication rates were markedly higher in the hospital without a specialist dental clinic. (B)

A study of treatment for thyroid cancer from England found significant differences between the adequacy of management by a multidisciplinary team of specialists (134 patients) and that provided by other clinicians (71 patients). The former group was much less likely to carry out inadequate surgery (11% versus 37% of cases, $p<0.001$), more likely to give radioiodine treatment when indicated ($p=0.002$), and more likely both to monitor thyroglobulin[68] and deal appropriately with high thyroglobulin levels ($p=0.006$). (B) All these have previously been shown to be independent predictors of long-term survival,[69] but death and tumour recurrence were not measured in this study because of the indolence of the disease and its low mortality rate.

A report from the US suggests that surgeons who carry out thyroidectomy (for benign or malignant disease) relatively frequently achieve lower complication rates than those who do so rarely. Surgeons were allocated to one of four categories, according to the number of thyroidectomies carried out between 1991 and 1996. Patients treated by surgeons in the lowest volume group (1-9 procedures) suffered consistently higher complication rates than those treated in the highest volume group (>100 procedures: an average of over 20 per year). This difference was particularly marked for total thyroidectomy (usually appropriate for thyroid cancer), with a 16% complication rate for the low-volume group, compared with 4% for the high-volume group. The authors conclude that individual surgeon experience is significantly associated with complication rates and length of stay in hospital. (B)

A study from the West Midlands Cancer Registry of treatment received by patients with parotid cancer between 1977 and 1986 found that management varied with surgical

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[68] High serum thyroglobulin levels can indicate residual or recurrent thyroid cancer.

[69] Mazzaferri EL, Kloos RT. Current approaches to primary therapy for papillary and follicular thyroid cancer. Journal of Clinical Endocrinology and Metabolism, 2001;86(4):1447-1463.

specialty. 62% of 196 patients were treated by general surgeons, 14% by ENT surgeons and 8% by plastic or dental surgeons. ENT surgeons were significantly more likely to remove the parotid gland than others, whilst patients treated by general surgeons were more likely to receive radiotherapy. (B)

D. Measurement

Structure

- Evidence that each Network has an appropriate range of MDTs, constituted as recommended.
- Availability of sufficient numbers of Clinical Nurse Specialists to handle the wide-ranging role described in this Manual.

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 every patient is interviewed by a CNS and given her contact telephone number.
- 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 CNSs are required and resources will be needed for their training and employment. (Further information to be added when available.)

3. Initial investigation and diagnosis

A. Recommendations

Clinicians from all relevant 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.

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.

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 who have a special interest in these forms of malignancy. These clinicians should carry out initial investigations and refer patients who appear to have cancer to appropriate specialist MDTs (described in Topic 2, Structure of services) for assessment. 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

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 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 the lead clinician at the DGH, but where there is little doubt about the diagnosis, onward referral should not await pathology results. 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 or suspected salivary gland tumours may require FNAC. This is only likely to be available in specialist lump clinics, to which such patients should be referred for investigation. A high level of expertise is required to achieve a precise and reliable diagnosis in salivary gland cancer, and 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.

Thyroid cancer may be suspected on the basis of ultrasound examination of the thyroid by an appropriately-trained professional. Any patient with a suspicious goitre should have thyroid function tests and FNAC. 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

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 during and after this consultation by a Clinical Nurse Specialist (CNS). 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.

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. 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. MDTs should consider offering patients an audiotape 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.

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 that might be appropriate. Information should be provided in both written and verbal forms. It 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;
- 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;
- The hospital(s) where interventions are provided.

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.

There should be a defined mechanism, facilitated by a CNS or speech and language therapist, to ensure that patients who are likely to be offered radical treatment which would affect their ability to speak are introduced to others who have been through similar treatment, learnt to speak again, and who have been trained (by a CNS, speech and language therapist or psychologist) in supporting newly-diagnosed patients. 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 surgery. Whenever possible, videotapes – ideally those made by patient groups – should be given to new patients.

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 the supportive and palliative care guidance.

C. Evidence

Diagnostic value of FNAC and core biopsy in thyroid cancer

In an Italian study, both FNAC and core biopsy were performed on 136 patients diagnosed with thyroid nodules by ultrasound scanning. 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 did not. 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

A booklet about facial cancer, developed by psychologists 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.

A Canadian study 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. (B)

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)

Psychosocial issues

A review of the literature on psychosocial aspects of head and neck cancer surgery suggests that patients at high risk of psychological problems should be identified early, and that psychological preparation for surgery is important to facilitate coping after the operation.

Patients' experience of NHS services

The National Cancer Alliance (NCA) survey of head and neck cancer patients' experience, carried out to inform the guidance,[70] 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*[71]*)* 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.

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

[71] 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 therapists and specialist nurses are particularly appreciated, both for their willingness to provide clear information and the support they provide.

When clinicians introduce past patients to patients about to undergo treatment, this has been found to benefit both. The other person can provide understanding and encouragement and give the person undergoing treatment hope and something to aim for. In some cases people maintain contact for many years. (B)

A questionnaire study evaluating a structured laryngectomy friendship scheme found that it was very effective. Many patients felt that peer support was important, and the scheme increased the proportion of patients offered the opportunity to meet trained ex-patients who could provide support. (B)

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, 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.

Outcome

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

E. Resource Implications

4. Pre-treatment assessment and management

A. Recommendations

Patient assessment

Careful assessment of each patient's medical, nutritional and psychological state is crucial to inform treatment planning. Co-morbidity, performance status, and alcohol dependence should be assessed early, using validated techniques. The nutritional status of the patient should be assessed by a dietician who can initiate action to remedy deficiencies.

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. Brief interventions should be offered at the point of diagnosis, and patients with addiction problems should be referred to local smoking cessation services, alcohol dependency or addiction services, as appropriate.

Imaging

All patients with UAT cancers should have chest x-rays. Other forms of imaging are necessary to assess the stage and spread of the tumour; specialist ultrasound, CT and MRI should be available. PET imaging should be used, if available, when it is important to differentiate between benign and malignant lung nodules. 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.

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 clinical nurse specialist 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 surgeons, oncologists, clinical nurse specialists, and speech and language therapists, 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. 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 2, Diagnosis and Assessment.) 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 have a thorough dental examination and any dental problems should be identified before treatment. In patients who use removable dental prostheses, these should be assessed, along with the denture-bearing ridges, to ensure that the prosthesis is both comfortable and effective.

Dental problems in patients who are to have radiotherapy should be treated without delay, to permit sufficient time for healing before radiotherapy. A dental hygienist should work with these patients to achieve high standards of oral hygiene, to reduce problems after treatment.

Preparation for treatment effects on speech and swallowing

Both surgery and radiotherapy cause difficulties with speech and swallowing. A dietician should discuss nutritional problems during radiotherapy and in the period after treatment, and ensure that the patient is prepared for interventions that may be required beforehand. She should explain about any planned procedures – for example, feeding through a nasogastric tube or by percutaneous gastrostomy (PEG) – and advise the patient and carers on modifications to food preparation and diet to maintain adequate nutrition during outpatient treatment.

Patients who are to undergo radical treatment which is likely to affect their speech or ability to swallow should be referred to a speech and language therapist (SALT) before such treatment begins. The SALT should explain rehabilitation strategies with the patient and carers, and describe how she will work with the patient to restore speech.

Anaesthetic assessment

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

A holistic approach to assessment is essential to ensure appropriate management for individual patients. Alcohol and nicotine dependence are common; recognising and dealing promptly with such addiction can prevent acute withdrawal problems when patients undergo treatment. 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.

Good dental health and oral hygiene, both before treatment begins and throughout the post-treatment period, helps to reduce the risk of infection in the mouth and minimise dental problems associated with treatment. This improves the probability that patients will retain their natural teeth.

C. Evidence

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.[72]

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.

Effectiveness of imaging

Two small studies evaluated the value of chest X-rays and CT scans in the assessment of patients with squamous carcinomas of the head and neck. One reported that three of 44 patients had synchronous tumours in the lung, all of which were detected by CT scan, but

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

only one by chest X-ray (plain radiograph), and concluded that CT scanning was more sensitive than X-ray. The other study included 25 patients with Stage III or Stage IV tumours; 20% had positive chest findings, all of which were detected by chest X ray. The authors concluded that routine CT scanning is not justified. Neither study can be regarded as reliable because both have serious methodological flaws.

Nutritional assessment

Two small studies describe the effectiveness of assessment of patients before radiotherapy by dieticians. Both found that insertion of a PEG before radiotherapy could prevent weight loss in vulnerable patients. One found that dehydration-related hospital admissions were significantly reduced by PEG, from 18% to zero, even though patients who received PEGs 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 PEG inserted. Patients who were fed through nasogastric tubes did not go home until they could eat and drink unaided, but patients on PEG feeding were able to go home or to a nursing home earlier, with the PEG still in place, despite the fact that, as a group, they tended to have more serious long-term problems. (B)

A small randomised trial found that preoperative nutritional supplements for malnourished patients undergoing surgery for head and neck cancer was associated with a lower rate of complications and less time in hospital. 59% of the 61 patients studied were judged to be malnourished, defined as meeting at least one of three criteria: 1) body weight of 80% of standard weight for height and reports impaired food intake; 2) loss of 5% or more of usual body weight over 1 month; 3) subnormal values for three or more nutritionally relevant laboratory parameters. 10-21 days before hospital admission, all 36 malnourished patients received nutritional counselling and suggestions on ways to cope with eating problems. The supplemented group (n=19) were also given specific recommendations on meeting their individual nutrient requirements or a nutritional supplement, and contacted as necessary by the dietician 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. (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 was identified from the Mersey region of England; this reports on case notes for 1719 patients treated with radiotherapy for head and neck cancers between 1987 and 1990. Only 13% of these records gave information on dental condition and treatment. 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)

Decision-making about treatment

Research based on focus groups in South East England revealed that more patients wanted to be involved in decisions about their treatment than actually were. 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.

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 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."[73]

Psychological interventions

A small study suggests that imagery-hypnosis before surgery for cancer may be capable of improving outcomes. The post-operative hospitalisation period in the intervention group (n=15) was significantly shorter than in controls (n=21), with a mean of 8.7 days compared with 13.9 days ($p<0.05$). (B) The authors suggest that a randomised trial of this type of intervention would be worthwhile.

An observational study of counselling by a trained psychotherapist suggests that this type of intervention can help to reduce fear and improve confidence before treatment for head and neck cancer. Counselling, hypnosis and relaxation training appear to improve both quality of care and quality of life for patients. Counselling can also be helpful for carers. (B)

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

A pilot study of group psychological therapy reported that patients who participated more than once in the group (eight of 25 patients invited) had worse scores on validated quality of life measures at the beginning of the study than controls. At follow-up after a year, those who participated in psychological therapy showed greater improvements in most areas of functioning than controls who only completed the questionnaires. The greatest benefits of the intervention were in emotional and social functioning, and in global quality of life. Most participants valued the group, particularly the opportunity it gave to talk with other patients about their feelings and reactions to their disease. (B)

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)

Preparation for laryngectomy

The authors of a Swiss study of patients who had undergone laryngectomy concluded that preparation of patients and their relatives for the operation and its consequences should be the task of an interdisciplinary team which includes another laryngectomee. Many of these interviewees suggested that speech training should be conducted by laryngectomees. (B)

Two studies from the US reported that patients felt that they would have benefited from talking with a speech pathologist and a successfully rehabilitated laryngectomee before surgery. (A)

Practice in the NHS

Assessment by dietician and access to SALT

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 dietician (34%, 46%

and 37% for cancers of the larynx, oral cavity and other sites, respectively).[74] 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 dietician, 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.

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 a speech therapist. In fact, the regional averages were 80%, 72% and 32%, respectively. Dorset's single case saw a speech therapist, 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.

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

- Availability of specialised dental services for all patients who are likely to receive treatment that could affect the jaw or teeth.

Process

- Evidence that patients who are dependent on alcohol, nicotine or other drugs receive counselling and/or cognitive-behaviour therapy to help them to quit before definitive treatment begins.
- Evidence that every patient with UAT cancer has a chest X-ray or CT of chest.
- Evidence that patients whose treatment is likely to involve the jaw are referred to appropriate dental specialists.

Outcome

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

E. Resource Implications

5. 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 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. High-quality videotapes are available on laryngectomy; these should be given to patients who are to have this operation. Patients should be encouraged to talk through any issues that may concern them after studying this information with their SALT or CNS. 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.

Cancers of the Upper Aerodigestive Tract

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

In some cases, minor surgery to remove early (T_1) tumours may be carried out by nominated local surgical specialists in District General Hospitals. This is only appropriate with specific agreement of the head and neck cancer MDT, after full discussion of pathological and imaging data in the context of a formal MDT meeting.

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; however, this may prove difficult in centres which deal with fewer than four cases per week. When surgical case-loads are concentrated in this way, Networks should take responsibility for ensuring that centres that receive additional patients receive sufficient funds to cover the costs of providing an expanded service.

All surgical modalities, including laser excision and partial laryngeal excision, should be available. 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. There should be 24 hour access to emergency surgery to reverse flap failure.

Surgical voice restoration should be available for patients who undergo laryngectomy.

Surgery for 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 3). 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.

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 quality assessment (EQA) schemes.

Radiotherapy

Access to modern radiotherapy facilities, including 3D conformal treatment where appropriate, should be available. 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.[75]

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.

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.

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[75] 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.

The importance of mouth care and oral hygiene during and after treatment should be emphasised to patients. Ice chips should be provided to reduce the severity of oral mucositis (sore mouth) in patients who undergo chemotherapy. Topical treatment with antibiotic paste or pastilles should be considered for patients with mucositis associated with radiotherapy.

Support for patients undergoing radiotherapy

Radiotherapy for head and neck cancers can cause problems with eating, swallowing, breathing and speech, and specific support should be provided for these patients, both during and after treatment. Patients should be educated about adverse effects of radiotherapy before treatment 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.

Radiotherapy departments should have radiotherapy support clinics, staffed by cancer nurses and/or therapy radiographers who receive education and support from head and neck cancer CNSs. Patients should have access to a specialist oncology dietitian and speech therapist within the radiotherapy centre, who should liaise with local support teams (see Topic 8, After care and rehabilitation), and should be given a telephone number for a radiotherapy helpline so that they have access to advice at weekends.

Many patients rely on gastrostomy (PEG) or nasogastric tube feeding, at least in the short term. They need help to cope with feeding problems and maintain their nutritional status. The cancer network should ensure that there are adequate facilities for placement of PEG tubes and local services which can replace nasogastric tubes when necessary.

Other treatment modalities

Other forms of therapy such as photodynamic therapy and monoclonal antibody treatment should only be offered in the context of multicentre clinical trials, unless there is reliable evidence of effectiveness.

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. Multidisciplinary 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 can cause complications such as voice change, permanent hypoparathyroidism and a poor scar. 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 Cancer Centres.

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 NRCN portfolio. 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.

C. Evidence

UAT cancers

Choice of treatment modality

A systematic review comparing the effectiveness of open surgery or endolaryngeal excision (with or without laser) and radiotherapy for early glottic laryngeal cancer found no reliable evidence from randomised controlled trials (RCTs) to guide treatment choice. One poorly-designed comparative study was found, with 76 patients allocated to surgery and 129 to radiotherapy. This reported five year survival rates in patients with T1 and T2 tumours of 92% and 89%, respectively, after radiotherapy, compared with 100% and 97% after surgery. These differences are not statistically significant. No information was given on side effects, quality of life, voice outcomes or cost. (B)

Surgery

Major centres report success rates in excess of 95% for complex reconstructions after radical surgery in patients with head and neck cancers.[76] Cigarette smoking and weight loss of more than 10% before surgery are associated with higher rates of major complications.

Radiotherapy

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

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[76] See, for example, Haughey BH, Wilson E, Kluwe L, Piccirillo J, et al. Free flap reconstruction of the head and neck: analysis of 241 cases. Otolaryngology – Head & Neck Surgery, 2001;125(1):10-7.

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 assessed before treatment, 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 interruption of therapy and 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. (B) These figures may not, however, be reliable because of methodological flaws in the study.

A retrospective study looking for evidence of a relationship between delay in initiating radiotherapy for early larynx cancer and recurrence found none. Longer treatment times were, however, significantly associated with relapse. (B)

Audit data shows that interruptions in radiotherapy for head and neck cancer are not uncommon. 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 servicing – either planned or to deal with breakdown. In 14% of cases, treatment was interrupted because of adverse reactions to radiotherapy.[77]

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.

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[77] 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.

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 Canadian review of a Texan study which examined quality of life outcomes 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)

Chemoradiation and chemotherapy

Three meta-analyses of randomised controlled trials comparing radiotherapy alone with radiotherapy and concomitant chemotherapy (chemoradiation) have concluded that chemoradiation produces significantly higher survival rates in head and neck cancer. One, based on individual data for 3,727 patients in 26 trials, found a hazard ratio for death of 0.90 (95% CI, 0.85 to 0.94, $p<0.0001$), which corresponds to an absolute survival benefit of 4% at two and five years. The authors conclude that this is not sufficient to justify routine use of chemoradiation. Chemotherapy was only beneficial when it was given over the same time-period as radiotherapy. (A)

The second meta-analysis reported consistent benefits across ten trials of platinum-based chemoradiation for locally advanced head and neck cancer (1,514 patients), with a pooled risk difference of 12% ($p<0.0001$). Sub-group comparisons show that treatment based on mitomycin C (522 patients) is also effective, with a survival benefit of 14% ($p=0.032$). An earlier meta-analysis produced similar results, with a reported pooled difference in risk of death of 12% (95% CI, 5.0 to 19.0) (A)

A review focussing on adverse effects of treatment found that chemoradiation is considerably more toxic than radiotherapy alone. The pooled odds ratio for acute mucosal morbidity was 2.86 (95% CI, 2.15, 3.81); for late morbidity (bone and soft tissue necrosis and fibrosis), it was 1.82 (95% CI, 1.02, 3.26). However, it appears that the aggravation of adverse effects may be less severe with platinum-based regimens and mitomycin C than with other agents, particularly bleomycin. The authors suggest that the effect of chemotherapy is akin to that of a higher dose of radiotherapy, and it is not clear whether chemotherapy improves the therapeutic ratio. (A)

Neoadjuvant chemotherapy – chemotherapy given before local treatment with surgery, radiotherapy or both – does not improve survival in patients with locally advanced head and neck cancer. Meta-analysis of individual patient data from 31trials (5,269 patients) produced a hazard ratio (HR) of 0.95 (95% CI, 0.88 to 1.01, p=0.10). Pooling data from three trials (602 patients) which compared larynx preservation with surgery (with or without neoadjuvant chemotherapy) showed a non-significant benefit for surgery (HR 1.19, 95% CI, 0.97 to 1.46; p=0.10). (A)

Prophylaxis for oral mucositis

A Cochrane review of randomised trials of prophylactic agents for oral mucositis in patients treated with radiotherapy or chemotherapy included 52 studies (n=3,594). Of the 21 interventions assessed, the following were found to be the most effective: Ice chips (odds ratio 0.42, 95% CI, 0.19 to 0.93); with a baseline incidence of 60%, the number of patients that needed to be treated to prevent one case (NNT) was 5. GM-CSF was associated with a relative risk (RR) of developing mucositis of 0.51 (95% CI, 0.29 to 0.91), NNT= 5/2; the RR for antibiotic paste or pastille using PTA (Polymyxin E, Tobramycin and Amphotericin B) was 0.87 (95% CI, 0.79 to 0.97), NNT 13. Hydrolytic enzymes reduced the severity of the problem (RR 0.49, 95% CI, 0.30 to 0.81). This review included a variety of types of cancer and treatments and the benefits may not be the same for all. (A)

A second review, focussing on patients receiving radiotherapy for head and neck cancers, included 15 RCTs, of which 13 were included in a meta-analysis. Prophylactic interventions were found to be effective, with a pooled odds ratio of 0.64 (95% CI, 0.46 to 0.88, p<0.01). However, the odds ratio from meta-analysis of the better quality studies was lower and non-significant. Five studies of antibiotics produced a pooled odds ratio of

0.47 (95% CI, 0.25 to 0.92). (A). The authors concluded that narrow-spectrum antibiotic pastilles should be given to patients with mucositis.

Nutritional support and dietary supervision

A before-and-after study involving 69 patients undergoing treatment for oral cancers demonstrated that increasing dietary supervision and changing the dietary protocol reduced the incidence of severe weight loss after treatment. This improvement was particularly marked in patients who underwent combined modality treatment (surgery plus radiotherapy). The average weight loss before the protocol change was 9.83%, compared with 6.6% afterwards ($p<0.05$).

Relaxation therapy for patients undergoing radiotherapy

A small, non-randomised study found that anxiety levels were consistently lower among patients who received one of three interventions to reduce anxiety during radiotherapy than among controls. Music therapy, aromatherapy, and guided imagery all produced similar benefits; no clinically significant difference was observed between their effects. The authors state that music therapy and aromatherapy can be easily delivered in the clinical environment, but guided imagery is more problematic. (B)

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)

Current practice in the NHS

Two recent audits from the South and West of England, SWAHNI and SWAHNII,[78] 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.[79] Nevertheless, the overall figure of 65.7% survival at two years compares favourably with comparable data from other countries.

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 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.[80]

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

[79] *Ibid,* p51.

[80] Commission for Health Improvement/Audit Commission. *NHS Cancer Care in England and Wales.* London: CHI/AC. 2001.

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.[81]

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.

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.[82]

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[81] Helliwell T. Minimum pathology dataset for head and neck cancer. ENT News and Views, 2003;12:54-55.

[82] The full reference for this report will be available in time for publication of this Manual.

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, suitably specialised and experienced dietician, and a speech, language and swallowing therapist.

- Facilities for enteral feeding (by nasograstric tube or percutaneous gastrostomy), with adequate support for patients who require these forms of feeding.

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

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

- Availability of adequate facilities within each Network for modern radiotherapy, including 3-D 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.

- 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) for patients with breathing or swallowing problems caused by treatment.

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

- Evidence of links to academic departments 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 prophylactic measures to prevent mucositis in patients treated with radiotherapy or chemotherapy.

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

- Evidence of initiatives to attract both external grant funding and local support for research and development.

Outcome

- 5-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 vocal cord palsy, long-term hypoparathyroidism, and other complications of thyroid surgery.
- 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. Availability of specialised wards… etc *(These issues will be covered by the ScHARR economic review.)*

6. Recurrent and advanced disease

A. Recommendations

Most patients with recurrent disease are identified in follow-up clinics (see Topic 8), although some present with new symptoms between follow-up appointments. All should be seen by members of an appropriate specialist MDT.

UAT cancers

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. There should be systems for rapid access to the MDT for patients who may have recurrent tumours, since curative treatment may still be possible. 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 these patients need full assessment and imaging, but previous treatment can make interpretation of images particularly difficult. PET scanning should be available if needed, to assess suspected recurrent disease, especially in patients who have previously had radiotherapy. Each case should be discussed in an MDT meeting at which all diagnostic information is available for scrutiny.

Treatment for recurrent disease may involve surgery and/or radiotherapy (sometimes brachytherapy) and palliative care. Chemotherapy or chemoradiation may be appropriate for some patients. 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.

Thyroid 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, plus or minus external beam radiotherapy. All should be assessed, restaged, and their further management discussed by the thyroid cancer MDT.

B. Anticipated benefits

C. Evidence

Incidence of recurrence

UAT cancers

A study of 851 patients treated for head and neck cancers in France reported that 40% of patients developed a second primary cancer within five years. The authors of this study state that 30-50% of patients have local or regional recurrences and 20-30% have distant metastases (clearly, some patients must fall into more than one of these groups). Continued smoking and drinking after initial treatment are associated with significant increases in risk.[83]

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[83] Schwartz LH, Ozzahin M, Zhang CN, Tonboul E, et al. Synchronous and metachronous head and neck carcinomas. *Cancer*,1994;74(7):1933-8.

Thyroid cancers

In a cohort of 1,528 patients treated for differentiated thyroid cancer in the US, the recurrence rate over 40 years was about 35%, two thirds occurring during the first decade after initial therapy. 68% of recurrences were local, whilst 32% were distant metastases, mostly in the lungs. Recurrences in younger patients were more often curable, particularly when detected at an early stage.[84]

Diagnosis of recurrent disease

PET scanning

Research studies on the effectiveness of PET scanning have been reviewed by the Intercollegiate Standing Committee on Nuclear Medicine.[85] 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, facilities are limited and geographically uneven (early 2004).

D. Measurement

Structure

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[84] Mazzaferri EL, Kloos RT. Current approaches to primary therapy for papillary and follicular thyroid cancer. Journal of Clinical Endocrinology and Metabolism, 2001;86(4):1447-1463.

[85] 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 on www.rcplondon.ac.uk/pubs/wp_pet.pdf.

- 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.

Outcome

- Survival rates in patients with recurrent disease.

E. Resource Implications

7. Palliative interventions and care

The Supportive and Palliative Care Guidance, to be published by NICE in early 2004, will provide 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 this generic guidance, highlighting specific issues of relevance to patients with head and neck cancers.

A. Recommendations

Palliative care should be available for all patients. Some suffer from pain after initial treatment and pain control specialists should be involved in their management.

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 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, and patients, carers and health care staff who deal with them are likely to require considerable practical, psychological and spiritual support.

Although hospices may be able to provide the support these patients need, some will have problems that mandate their return to hospital. General wards in some local hospitals may be unable to offer adequate care for these patients; in others, staff may require 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. 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.

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 with acute airway obstruction are admitted directly to a ward where staff have the expertise required to deal with the problem. Ambulance personnel, GPs and carers should be made aware that these patients must *not* be taken to accident and emergency departments. Specific training in care for patients with end trachostomies (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 for dying patients

The principles of management for patients whose tumour interferes with swallowing are the same as those for patients with airway obstruction. For those who are in the terminal phase of the disease, palliative care is very important but new surgical interventions such as gastrostomy are rarely appropriate.

B. Anticipated benefits

Optimum management of symptoms and problems caused by advancing tumour; reduced stress for carers; alleviating fear about the manner of death.

C. Evidence

D. Measurement

Structure

- Evidence of systems to ensure that patients with acute airway obstruction are 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.

- Audit of tracheostomy and gastrostomy rates in patients with advanced cancer.

- Death rates within three months of palliative surgery.

Outcome

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

E. Resource Implications

8. After-care, rehabilitation and follow-up

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

Patients who have been treated for cancers of the upper aerodigestive tract (other than thyroid cancer) can be left with major dysfunction. Most are likely to have problems with eating and drinking, at least in the short term, and a substantial proportion of these have to cope with tube feeding (usually PEG feeding) while they recover from treatment. 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; this may require specialist help for a year or more. Some patients use a valve inserted between the trachea and the pharynx (surgical voice restoration); others learn to speak using the oesophagus; some need special equipment such as an electronic larynx. Surgery to the tongue and mouth can also cause long-term problems with both speech and eating. Not surprisingly, problems with communication and changed facial appearance often lead to psychosocial difficulties.

These patients may also have to cope with a variety of other problems. Dental problems, dry mouth, and damage to the lining of the mouth and tongue are common, especially after radiotherapy. Some patients have neck and shoulder problems, or problems with hearing and balance. Many are unable to return to work because of their disabilities. The particular needs of this group of patients are not covered in the Supportive and Palliative Care Guidance.

There is consistent evidence that, at present, these patients' needs are often not 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.

Each Local Support Team should have access to the expertise required to manage the aftercare and rehabilitation needs of all of its patients, working closely with Cancer Centre staff and Primary Care Teams to provide seamless care. Skilled care should thus be available locally, throughout the Network.

The 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 a 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 most appropriate member of the Local Support Team to meet the patient's needs, and 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, valves and stomas, and should be given contact numbers for members of the Local Support Team who will help with any problems they may encounter.

Local Support Team Members

- Clinical nurse specialist (CNS)
- Speech and language therapist (SALT)
- Dietician
- ENT/maxillofacial nurse practitioner, based in ENT and Maxillofacial outpatient departments, who can provide advanced skills for the management of stomas (tracheostomies and gastrostomies), nasogastric tubes and tracheoesophegal valves. This nurse practitioner will work alongside the clinical nurse specialist, and help to teach local hospital and community nursing teams, thus creating a sustainable and robust 7 day service for patients who require help.
- Dental hygienist
- Psycho-oncology, liaison psychiatry or clinical psychology 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 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.

A speech and language therapist (SALT) 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 functional voice rehabilitation; surgical voice restoration is preferred, but electronic larynx equipment should be provided for those who need it. If the specialist SALT in the MDT delegates rehabilitation work to a SALT working in the community, the specialist SALT should remain available to provide expert advice and to assist the community SALT in meeting the specific needs of these patients.

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.

Clinical follow-up

Upper aerodigestive tract cancer

Regular clinical follow-up is important for patients who have been treated for head and neck cancer. 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:

1. Identification of recurrent tumour or new primary disease.
2. Provision of help for patients suffering from side-effects of treatment (particularly delayed effects of radiotherapy).
3. Identification of patients who need additional help with 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.

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. 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 usually treatable. Specialist restorative dentistry and prosthodontic expertise should be available. A trial of pilocarpine should be offered to patients with persistent xerostomia (dry mouth) after radiotherapy who had normal salivary function before treatment.

Patients can be discharged from routine follow-up after five years, but should retain contact details for their CNS and SALT, 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.

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 once a year by a member of a thyroid cancer MDT in a follow up clinic. Thyroid hormones, serum calcium, thyroglobulin and calcitonin should be monitored regularly.

B. Anticipated benefits

At present, what support is available tends to be fragmented, and patients 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.

A range of benefits can be anticipated if members of maxillofacial and ENT department nursing teams spend time working alongside head and neck 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 nurse practitioner and CNS posts in the future. Currently, there is a dearth of suitable applicants for these posts.

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 in the lungs. 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.

C. Evidence

Rehabilitation services

The evidence review includes various studies of rehabilitation from the United States, many of which were carried out two or more decades ago. It is often not clear that the results are useful to inform service provision in the NHS in the 21st Century. However, these studies document the prevalence and magnitude of disability experienced by patients who have undergone treatment for cancer of the head and neck. Particular problems were reported with physical appearance, speech, chewing, swallowing, and cranial motor nerve deficits.

A recent study from Slovenia highlights the importance of individually planned rehabilitation and intensive help from a range of professionals after treatment. (B)

A study of the effectiveness of speech and swallowing therapy with range of motion (ROM) exercises for patients who underwent surgery for oral or oropharyngeal cancer suggested that these exercises can improve outcomes when they are started early after surgery. Statistically significant differences were found in global swallowing measures in those who received instruction in ROM exercises, compared with those who did not. (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, although about 20% need help for six months or more and some patients (9 of a group of 82) did not respond to therapy. Patients with transport problems fared better than those with aspiration. (B)

A recent US study indicated that 27% of patients used oesophageal speech, 21% used tracheosophageal speech, and 48% used an electrolarynx. 89% of patients in the two former groups were satisfied with their means of communication, but satisfaction levels were lower (62%) among those who used the electrolarynx. 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.

90% of a group of Swiss patients who had undergone laryngectomy received speech therapy to learn oesophagal speech. The average duration was three months, within which time half of these patients learnt to communicate using speech. 20% took 4-6 months and 15% required longer. Half of the group used the oesophageal voice as their principle means of communication. Early speech therapy was regarded as a factor of great importance in learning to produce a voice after surgery.

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.

Restorative dentistry

A number of small studies of the outcome of dental and facial bone restoration using osseointegrated implants show that these are effective for many patients, despite radiation damage to the jawbone. The proportion of implants reported lost over five years varies between studies, from 22% to 79% in patients who have been treated with radiotherapy. One study suggests that hyperbaric oxygen may improve osseointegration in irradiated patients, but no reliable evidence on this was identified. The probability of success appears to be higher when reconstruction is carried out more than four months after implantation. Loss rates are below 20% in patients who have not been irradiated. Some studies report high levels of patient satisfaction with implants but this has not been systematically measured; most studies report implant survival rates but give no information on patients' experience. (B)

Effectiveness of treatment for persistent xerostomia

Two systematic reviews of randomised controlled trials show that pilocarpine can be effective for patients with xerostomia after radical radiotherapy to the head and neck. These suggest that overall symptoms of xerostomia, oral dryness and the need for salivary substitutes can be significantly reduced. Adverse events are dose-related; increased sweating, for example, occurs in about a quarter of those taking 5mg three times daily, and in twice as many taking twice this dose. No severe or life-threatening events were reported in any study. One review concluded that the optimum dose is 5mg three times a day, but it is not clear whether systemic or topical pilocarpine is more effective. (A)

A small case-series study assessing the effectiveness of over-the-counter agents (Biotene mouthwash, toothpaste, chewing gum and toothbrushes, and Oralbalance gel) suggests that these products may help to relieve symptoms of post-radiation xerostomia. (B)

Patient support groups

There are well-established support groups 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 (http://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 study of a support group for people who undergo laryngectomy in Norway suggests that active membership of a local branch of the Norwegian Society for Laryngectomies, 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.

Patient-held records

A study from the Netherlands evaluated the effectiveness of a patient-held record (log-book) for patients who had been treated for head and neck cancers. There was a control group: patients without cancer, treated at a different hospital. Regrettably, it is doubtful that this was an appropriate control.

91% of the 60 patients who returned the questionnaire evaluating the log-book said they had read all of it; 91% had given it to their partner to read and 94% had given it to a professional involved in their care. 47% reported making entries in the book, usually using it as a diary. The most used sections were those explaining what cancer is and social nursing provision. 88% said the book clarified things for them.

Of the health professionals, speech therapists and ENT physicians were most likely to add comments. In 59% of cases, information on medication was included. 63% of health professionals felt it contributed to harmonising care; 27% reported knowing better to whom to refer patients and 48% reported that they referred more patients. 77% found it beneficial for aligning hospital and home-based care. Professionals in the control group reported no formal method for sharing information and regular breakdowns in communication, particularly in relation to information given to patients by other team members.

The authors concluded that patients given a log-book had more and clearer information than patients who did not have one. The benefits associated with this information and improved communication included decreased fear, tension, depression and uncertainty. (B)

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.[86] 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.[87]

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 a speech therapist. Overall, just 48 of 75 these patients – 64% – saw a SALT, despite an agreed standard throughout the region covered by the audit that all should do so.[88]

D. Measurement

Structure

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[86] Schwartz LH, Ozzahin M, Zhang CN, Tonboul E, et al. Synchronous and metachronous head and neck carcinomas. *Cancer*,1994;74(7):1933-8.

[87] Mazzaferri EL, Kloos RT. Current approaches to primary therapy for papillary and follicular thyroid cancer. Journal of Clinical Endocrinology and Metabolism, 2001;86(4):1447-1463.

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

- Network-wide guidelines for long-term follow-up of patients treated for each type of head and neck cancer.
- Availability of Local Support Teams throughout the Network, constituted as described above.

Process

- Evidence that support is available from a Local Support Team for every patient after radical treatment for UAT cancer.
- Audit of monitoring of thyroid hormones, serum calcium, thyroglobulin and 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' and carers' experience of local support services.

E. Resource Implications

Additional resources will be necessary in most Networks to provide adequate local support services for patients who have been treated for head and neck cancer.